

Research Article

Asking the Stakeholders: Perspectives of Individuals With Aphasia, Their Family Members, and Physicians Regarding Communication in Medical Interactions

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Purpose: The purpose of this study was to explore the experiences of patients with aphasia, their family members, and physicians related to communication during medical interactions.

Method: Face-to-face, semistructured interviews were conducted with 18 participants—6 patients with aphasia, 6 family members involved in patient care, and 6 practicing physicians. A qualitative description approach was used to collect and summarize narratives from participants' perspectives and experiences. Participants were asked about experiences with communication during medical interactions in which the family member accompanied the patient. Interviews were audio- and/or video-recorded, transcribed, and then coded to identify main themes.

Results: Patients and family members generally described their communication experiences as positive, yet all

participants discussed challenges and frustrations.

Three themes emerged: (a) patients and family members work as a team, (b) patients and family members want physicians to “just try” to communicate with the patient, and (c) physicians want to interact with patients but may not know how.

Conclusions: Participants discussed the need for successful accommodation, or changing how one communicates, to help facilitate the patients' increased understanding and ability to express themselves. Over- and underaccommodation with communication were commonly reported as problems. Speech-language pathologists have a role to play in helping to improve communication during medical interactions. Implications for current speech-language pathologist practice and future directions of research are discussed.

Individuals with communication disorders form a vulnerable patient population in receiving health care services (Nordehn, Meredith, & Bye, 2006). The presence of communication disorders has been linked to higher rates of medical errors (Bartlett, Blais, Tamblyn, Clermont, & MacGibbon, 2008), reduced accessibility to health care (Ziviani, Lennox, Allison, Lyons, & Del Mar, 2004), and decreased satisfaction with services provided when compared with the general patient population (Hoffman et al., 2005). Because communication is the “medium” through which health care is provided (Lipkin, 2010, p. 3), patients with communication disorders routinely experience

diminished autonomy in making health-related decisions as well as decreased opportunities to participate in shared decision making about their care (Murphy, 2006; Pound, Duchan, Penman, Hewitt, & Parr, 2007).

Many aspects of medical interactions can be daunting for patients with communication disorders (McCooey, Toffolo, & Code, 2000; O'Halloran, Hickson, & Worrall, 2008). For example, although talking on the telephone is often one of the most disliked and anxiety-provoking tasks for these patients, the phone is typically the only way to schedule an appointment or to ask questions related to care when patients are not face-to-face with their health care providers (Baylor, Burns, Eadie, Britton, & Yorkston, 2011). In addition, written materials utilized in health care (e.g., consent forms, billing forms, patient education materials) are often too complex for many patients with language disorders, such as aphasia or cognitive-communication disorders (Hoffmann & Worrall, 2004; Rose, Worrall, & McKenna, 2003). Even navigating through medical facilities

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can create problems for patients who are unable to understand the signage they encounter.

Despite numerous barriers in telephone and written communication, face-to-face interactions with physicians often create the most significant obstacles for patients with communication disorders in accessing quality health care and taking part in their own health decisions (Murphy, 2006; Pound et al., 2007). Physicians are taught to follow protocols involving a series of tasks, such as establishing rapport, setting an agenda for the interaction, exploring the patient's symptoms, developing a diagnosis, establishing a plan of care, and concluding the interaction (Brown, Bylund, Eddington, Gueguen, & Kissane, 2010). Accomplishing these objectives of the medical encounter is more difficult with patients with communication disorders, especially given the limited time that is typically allotted for most medical appointments (Ziviani et al., 2004). In addition, lack of familiarity with communicatively vulnerable patients and limited training in communicating with patients with any type of disability can negatively affect patient-provider communication. Further, physicians have reported receiving limited training in communicating with patients with any type of disability (Duggan, Bradshaw, Carroll, Rattigan, & Altman, 2009), including communication disorders. Conversational analyses of encounters between patients with communication disorders and nurses have demonstrated the limited opportunities that patients with communication disorders often have for communication in medical encounters (Gordon, Ellis-Hill, & Ashburn, 2009). Health care providers interacting with patients with communication disorders tend to use close-ended questions, limited turn-taking, and other conversational devices that constrain opportunities for patients to exert control over the medical interaction.

Patients with communication disorders often have another person (typically a family member) accompany them to medical visits to mitigate some of these communication obstacles. Yet, the presence of a third person creates a communication triad that can potentially change these conversational dynamics (Karnieli-Miller, Werner, Neufeld-Kroszynski, & Eidelman, 2012; Laidsaar-Powell et al., 2013; Murphy, 2006; Sakai & Carpenter, 2011; Tates & Meeuwesen, 2001). Physicians, nurses, and other medical staff acknowledge relying heavily on family members or other caregivers to communicate for the patient, but the patients with communication disorders do not necessarily want to relegate communication to their family members (Murphy, 2006).

Emerging research suggests that family members or other unpaid caregivers may either help facilitate communication between patients and health care providers, interfere with this process, or both (Hemsley & Balandin, 2004; Hemsley, Balandin, & Togher, 2007, 2008b, 2008c; Karnieli-Miller et al., 2012; Laidsaar-Powell et al., 2013; Sakai & Carpenter, 2011). As such, the roles this additional person plays during triadic medical interactions are not fully defined (Cordella, 2011), which might be related to competing interests on the part of all stakeholders. For

example, people with aphasia must deal with the conflict between often needing communication support to participate in activities yet wanting to be independent, whereas family members are caught between wanting to promote that independence yet feeling the need to protect the patient (Gillespie, Murphy, & Place, 2010). Logically, physicians may face similar conflicts between their desire to support patient autonomy in medical visits versus the practicality of needing to exchange information in a clear, precise, and efficient manner.

Many unanswered questions remain about the process of communication during these interactions. What do these stakeholders say about patient-provider communication when patients struggle to communicate? What barriers exist, and how can they be overcome? How does the addition of a third person into medical interactions affect communication between patients and physicians, and what role does (or should) this person play in the medical interaction? As speech-language pathologists (SLPs) who specialize in improving the effectiveness of communication, how can we potentially help increase the access these patients have to quality health care services?

The current study builds on prior research to address some of these questions. The goal of this study was to better understand the process of communication during a range of medical visits from perspectives of individuals with communication disorders, their family members, and physicians. Specifically, we were interested in learning about the roles each stakeholder plays in communication during medical interactions, the restrictions to participation in medical encounters that individuals with communication disorders experience when communication breaks down, and the types of accommodations that have been successful in repairing these breakdowns. This research may assist SLPs and other health care providers to improve the effectiveness of communication during these interactions and to identify key areas in which to focus future research.

Method

Face-to-face, semistructured, qualitative interviews were conducted. A qualitative description approach (Sandelowski, 2010) was used to collect and summarize narratives from participants' perspectives and experiences. All study procedures were approved by the University of Washington (UW) Institutional Review Board.

Participants

Participants represented a convenience sample of individuals with communication disorders (hence referred to as *patients*),¹ family members involved in their care, and physicians from the Pacific Northwest. Patients were

¹Although referring to individuals with communication disorders as *patients* is not ideal, it serves to distinguish them from other participant groups in the study and reflects the relationship or role of these individuals in the medical interaction.

recruited from the UW Speech and Hearing Clinic and the UW Aphasia Registry and Repository, and they were asked to nominate a family member to participate with them. Physicians were either nominated by patient and family member participants, or they were recruited through the four hospitals within the affiliated medical centers associated with the UW School of Medicine.

Inclusion criteria for patients were (a) a diagnosed acquired neurological communication disorder, including one or more of the following: expressive and/or receptive aphasia, apraxia of speech, or dysarthria; (b) the capability of answering interview questions with or without assistance from the licensed SLP conducting the interviews, and without assistance from their family members (to be interviewed independently during the study); and (c) at least 18 years of age. Patients were excluded from the study if they attended medical visits without a family member or if they were unable to answer interview questions despite receiving assistance from their family member or a licensed SLP.

Family members were immediate family members nominated by a patient (i.e., spouse, partner, adult child) who had attended at least one physician appointment with the patient in the 6 months prior to study participation. The inclusion criterion for physicians was that they had a recent clinical experience involving patients with communication disorders. Specifically, they needed to have had face-to-face contact with either the nominating patients or a minimum of two other patients diagnosed with acquired neurological communication disorders (listed in the inclusion criteria for patients) within 6 months prior to participating in the study. Physicians from all medical specialties were eligible for this study.

Data Collection

Data were collected during face-to-face, semistructured qualitative interviews, during which participants were asked to describe their experiences and perspectives. All interviews were conducted by licensed SLPs (the first, second, and fifth authors) with experience in qualitative interviewing methods. Interviews involving patients were video-recorded to capture both verbal and nonverbal communication. All other interviews with family members and physicians were audio-recorded. Field notes were also taken by the researchers to capture information deemed to be salient or unique (i.e., concepts that participants emphasized as important, or memorable quotations they said) and were summarized by the researchers after each interview.

Patient and Family Member Interviews

Patients and family members took part in two interviews: The first one was done with both people to obtain a joint perspective, and the second one was done with each individual to allow him or her to independently contribute his or her view. During the initial interview, patients and family members were interviewed jointly by the first author

and one of two other members of the research team, and they were asked to share their experiences and perspectives together regarding communication during medical interactions with physicians. Given the anticipated challenges of interviewing individuals with aphasia, the joint interviews provided the opportunity for all of the patients to obtain assistance in sharing information about their experiences from someone who had been in the medical appointments with them and could therefore provide additional information when needed, as well as allow the patients to monitor and modify information the family member provided so that the viewpoints of both the patient and their family member could be explored and compared. The joint interviews also allowed for researchers to observe how the pairs communicated with one another and with the researchers during the interview process. Follow-up individual interviews were scheduled 1–2 weeks later, after the initial interview was transcribed and discussed by the research team. As part of the second interview, the researchers shared their impressions from the initial interview with participants and asked them to confirm or edit the content, elaborate on or alter what they had previously said, and share any information they perhaps may not have been comfortable sharing in the joint interview. During the second interview, patients were interviewed by the first author, and family members were interviewed separately by one of the other researchers.

Examples of interview questions for patients and family members interviews included “What is it like talking with your doctor(s)?” and “If you have trouble communicating with doctors, what do you do (if anything)?” Each interview lasted between 30 and 75 min, with breaks as needed. Patients and family members were interviewed at the UW Speech and Hearing Clinic or in their homes, according to their preference.

The interview protocol included modifications to provide communication support for the people with aphasia on the basis of prior qualitative research (Luck & Rose, 2007). The modifications were of four types: (a) acknowledgment that communication may be difficult and the interviewer can help; (b) interviewer clarification of the patients’ responses by interpreting words, vocalizations, gestures, and other communication attempts for the person with aphasia to confirm or refute; (c) allowing ample time to respond, paraphrasing, and using multimodal communication such as writing key words, drawing, and gestures as some examples; and (d) providing interviewer-generated ideas to which the patients could respond.

Physician Interviews

Physicians took part in a single, 20–30-min individual interview conducted by the first author at the medical facility where they worked. Examples of interview questions for physicians included “Tell me about your experiences communicating with patients with communication difficulties,” and “Are there any changes in your clinical practice that would help you talk with patients with communication difficulties?” The UW Institutional Review Board was

concerned with having physicians speak about specific patients, including those patients who nominated them for the study, to protect the confidentiality of the patient-provider relationship. Therefore, all questions for the physician participants in this study asked about patients in general, rather than detailed examples of interactions with the enrolled patient participants.

Demographic Information

Patient demographic information included age, sex, as well as medical diagnosis associated with their communication disorder (i.e., stroke), communication disorder diagnosis, and time since onset of their disorder. Demographic information collected from family members included their age, sex, relationship to the patient, how often they provide routine care (i.e., bathing, dressing, and cooking) for the patients, and how often they accompany the patients to medical visits with physicians. Demographic information collected from physicians included their sex, number of years in practice, medical specialty, the average number of patients with communication disorders they interact with each week, and whether they had received patient-provider communication training regarding those with communication disorders.

Data Analysis

The interviewers debriefed after each interview to discuss what they viewed as salient information from the interview as well as how to best describe or characterize this information. They also compared written field notes that allowed for continuity and coherence of information from the interviews.

The interviews were transcribed verbatim from audio and video recordings, including both verbal and salient nonspeech communication. Patients' verbal expression during interviews was typically characterized by incomplete utterances, revisions, sound and word substitutions, and nonword vocalizations. However, patients often supplemented their verbal communication with nonspeech behaviors to express themselves, such as facial expressions, gestures, writing, or drawing. Documenting nonverbal communication from the video recordings helped the research team better understand the patients' communication intents. The nonverbal behaviors were represented in written transcripts using parentheses. Field notes were used to supplement transcripts to make them as complete and representative of participants' responses as possible.

The interview transcripts were uploaded into Dedoose software (SocioCultural Research Consultants, 2014) for data management, coding, and analysis. Analysis involved coding for themes within and across each of the transcripts (Ayers, Kavanaugh, & Knafl, 2013). Three of the researchers (the first, second, and fifth authors) iteratively and deductively coded the transcripts by assigning key words or phrases to segments of the text that represented topics discussed by the participants. These three researchers read the first two initial joint interview transcripts

independently, and each generated tentative code terms and definitions on the basis of the transcripts. They then met to compare and reconcile their coding schemes. This process continued until the team agreed on a code dictionary that was then used as a guide to code subsequent interview transcripts. Coding of all interview transcripts was conducted by the first author, with 10% coded by one of the other authors and results compared for consistency. Any discrepancies in coding were resolved by discussion among these three coders.

The next step of analysis involved reviewing all transcript segments assigned to each code to synthesize the data into themes that summarized the common experiences and perspectives across participants, as well as differences. Qualitative analyses aim to capture the full range of ideas within themes. Themes are typically derived from the recurring topics, ideas, or concepts that a majority of participants discussed; subthemes are specific examples that may have been offered by one or more persons but raise interesting and important dimensions of the theme. For example, all patient-caregiver pairs used the pronoun "we" when describing their interactions with physicians. In addition, whereas only one patient and caregiver pair used the word "teamwork," several of these participants verbalized agreement with the researcher's use of the word "team" and "teamwork" to characterize how they interacted with physicians.

In qualitative research, trustworthiness of data can be achieved through demonstrating its credibility, confirmability, and transferability (Lincoln & Guba, 1985). Credibility of data represents the level of confidence in the authenticity of the research findings. Confirmability refers to the extent to which data reflect the perspectives of participants versus those of the researchers. Both of these can be established through triangulation of data across data sources and types and through member-checking, which involves sharing results and interpretations with research participants and asking them to provide feedback whether the data authentically represent their perspectives; this was routinely done during the interviews when interviewers would routinely restate or summarize their understanding of the participants' responses to questions, and during the second interview, which began by reviewing a summary of impressions from the first interview and field notes. In addition, after completing an initial thematic analysis from coded data, the first author provided participants with an e-mailed summary of the results for their review. Participants then had the opportunity to respond and provide feedback on this summary either by e-mail or by phone. This information was used to help shape the thematic analysis as well as to provide a potential measure of authenticity from the participants. Three participants responded (two family members and one physician), and they expressed agreement with the representation of the themes. They did not suggest any changes. Triangulation was done by comparing data within and across the interviews with the three different types of participants as well as against the researchers' field notes.

Transferability is the extent to which the reported experiences and perspectives of participants can extend to other individuals with similar characteristics in similar situations. Researchers explored transferability by examining whether the reported communication experiences of patients, family members, and physicians in this study were similar across different participant factors. These factors included recruiting participants with a range of severity levels of communication disorders, a range of participant ages, family members with different types of relationships to patients, and physicians from different disciplines with a range of years in practice. Although the sample size in this study was relatively small, including participants representing these different factors helped to increase the likelihood of transferability of their reported experiences.

Results

Participants

Face-to-face interviews were conducted with six participants from each group. Demographic characteristics are summarized in Tables 1, 2, and 3. (Note that participants are hence referred to with a group designation of either “P” for patient, “C” for caregiver, or “D” for doctor and a number to distinguish them within each participant group. For example, P1 represents “Patient 1.”) In the patient group, five had aphasia as a result of stroke, whereas one (P4) was diagnosed with primary progressive aphasia from an unknown etiology. Most exhibited mild to moderate aphasia, with one (P5) exhibiting moderate to severe aphasia. Five had concomitant apraxia of speech, and two had short-term memory loss. All used speech as their primary method of communication during the interviews, supplemented by one or more of the following: gestures, pointing, writing, drawing, facial expressions, and unintelligible vocalizations. Among family members, five reported participating in most or all medical interactions between patients and physicians. All of the physicians reported seeing at least 1–2 patients with communication disorders in their practice per week, with half of them seeing at least four of these patients per week. Two of the six physicians (D1 and D2) were nominated by patient and family member participant pairs (D1 was nominated by P1 and C1; D2

was nominated by P3 and C3), whereas the remaining four were recruited through the UW School of Medicine and had not provided care to any patients in this study.

Themes

Three themes with corresponding subthemes emerged from the data. Because perspectives of patients and family members seemed to be distinct from those of physicians, Themes 1 and 2 represent the perspectives of patients and family members, whereas Theme 3 represents the perspectives of the physicians. Table 4 outlines these themes and subthemes that are described in detail in the following sections.

Theme 1: Patients and Family Members Are a Team

Patients and family members often discussed working together to communicate with physicians during medical interactions.

Subtheme 1.1: The team works together. The main function of the team, as described by patients and family members, was working together to help patients successfully communicate with physicians. This collaboration usually included either co-constructing messages to communicate to physicians or decoding information from physicians to help improve the patient’s comprehension or recall. When communicating information to physicians, most teams described a scenario in which the patients would attempt to communicate first, and the family members would then “jump in” (C3) to help modify or clarify the message to make it more understandable for the physicians. P3 described the team’s co-construction of information during medical interactions, stating “I think I’ll try it, and [if] there’s a problem, then she’ll do it a little bit too.” Teamwork in co-constructing messages was also demonstrated in the joint interviews, as in this example from P1 and C1:

P1: Sometimes if I don’t get it (looks at C1), you ...

C1: Get it.

P1: Team ... uh ... teamwork!

To help understand how patients, family members, and physicians communicate during medical interactions, some patients were presented with a simple diagram

Table 1. Patient (P) demographics.

P	Sex	Age (years)	Years after onset	Diagnosis	Reason unemployed	Previous occupation
P1	Female	52	3	Aphasia	Medical/communication ^a	Nurse
P2	Female	48	4	Aphasia	Medical/communication ^a	Teaching assistant
P3	Male	62	8	Aphasia	Retired	Surveyor
P4	Male	61	5	PPA	Medical/communication ^a	Salesman
P5	Male	77	10	Aphasia	Retired	Lawyer
P6	Male	57	7	Aphasia	Retired	Physician

Note. PPA = primary progressive aphasia.

^aUnemployed because of a medical condition and/or a communication disorder.

Table 2. Family member demographics.

Caregiver (C)	Sex	Age (years)	Relation to patient	Medical interactions ^a (%)	Communicates for patient ^b (%)	Routine care ^c
C1	Female	74	Mother	100	50	Rarely
C2	Male	52	Spouse	≥75	≥75	Rarely
C3	Female	59	Spouse	≥75	50	Rarely
C4	Female	60	Spouse	100	25	Often
C5	Female	74	Spouse	100	50	Regularly
C6	Male	27	Son	50	50	Rarely

^aPercentage of how often family member is present for medical interactions between patients and physicians. ^bPercentage of how often family member communicates for patient during medical interactions. ^cHow often family member provides routine physical care for patient (e.g., dressing, bathing).

(see Figure 1a) during the interviews and were asked about how communication works during these interactions. This diagram uses circles to depict a patient (P), family member (C for caregiver), and physician (D for doctor) as well as a larger circle around them to indicate the context of the interaction. The circles were drawn equidistant from one another, and bidirectional arrows were drawn between each circle to indicate the potential for communication to occur in either direction between each stakeholder in the interaction. During their individual interviews, both P3 and P5 redrew the diagram, moving the patient and family member circles closer together with the physician circle staying a longer distance away (see Figure 1b). Both patients indicated this change represented that patients and family members worked together to co-construct messages between themselves and that the messages were then relayed back and forth with physicians.

For some patients and family members, working together meant either preparing for the medical visit ahead of time or reviewing information after the medical visit was finished. Most of the patients and family members described having a conversation before the medical interaction to discuss the purpose of the appointment, the major pieces of information they wanted to communicate to the physicians (e.g., patients' current symptoms), as well as any questions that the patients (or teams) may have for the physicians. Some teams described reviewing information

after the appointment (e.g., information on diagnoses, treatment options, medications) to either improve the patient's understanding or recall of what happened or to allow the patient to ask the family member clarifying questions.

Subtheme 1.2: Patients "want to try." Patients and family members described a variety of communication roles that patients play, or want to play, in medical interactions. Most patients described their primary role during medical interactions as *reporters* of information about themselves and their symptoms to physicians. Patients also discussed being *advocates* for themselves to increase their independence during medical interactions. They wanted the opportunity to try communicating by themselves first and to have their family members help if they struggled or were unable to get their message across. P1 stated, "I want to try . . . all the time. I want my own life." Another patient (P3) said, "Well, I guess the thing . . . as much as I can for me, try to do it." To communicate for themselves, patients needed to let physicians know the best way to communicate with them. For example, C2 described how his wife (P2) often advocates for herself, stating "And she says, 'So, if you can go a bit slow that would be nicer. I may seem fine on the outside, but on the inside my mind is trying to keep up with you.'" Even when communication is difficult, patients still want to be present when their care is discussed and to be included in the decisions.

Table 3. Physician demographics.

Doctor (D)	Sex	Medical specialty	Years practicing	PCDs per week ^a	PPC training ^b
D1 ^c	Female	Neurology	20	≥4	Yes
D2 ^d	Male	Family medicine	12	1–2	Yes
D3	Female	PM&R	2	≥4	Yes
D4	Female	Neurology	24	1–2	No
D5	Female	PM&R	9	≥4	Yes
D6	Female	Palliative care	2	1–2	No

Note. PCDs = patients with communication disorders; PPC = patient–provider communication; PM&R = physical medicine and rehabilitation.

^aFrequency of PCDs seen per week by physician. ^bWhether physician has received general PPC training. ^cNominated by Patient 1 and Caregiver 1. ^dNominated by Patient 3 and Caregiver 3.

Table 4. Summary of themes and subthemes.

Theme	Subtheme
1. Patients and family members are a team.	1.1. The team works together. 1.2. Patients “want to try.” 1.3. Family members help it “go smoother.” 1.4. Teams can change. 1.5. Teams can sometimes struggle.
2. Patients and family members want physicians to “just try.”	2.1. Communicating with physicians is hard. 2.2. We feel some physicians may not know or may not try. 2.3. Poor communication can damage the relationship between the team and the physician. 2.4. How communication should be.
3. Physicians want to try but may not know how.	3.1. Effective communication is our responsibility. 3.2. Communication with patients is hard. 3.3. We rely on family members. 3.4. We are not taught how to do it.

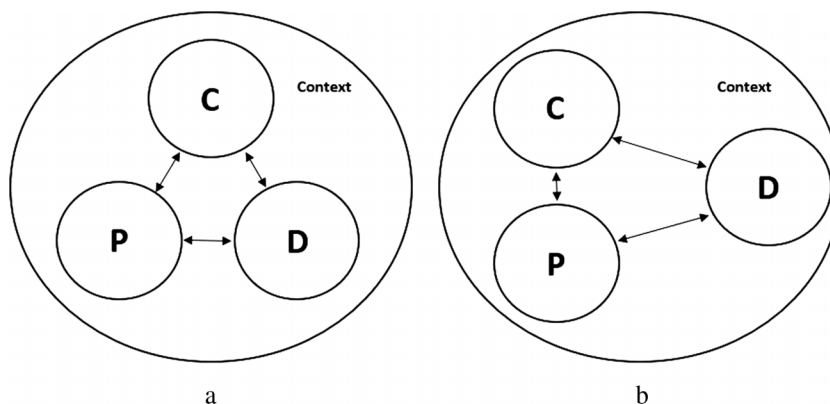
Patients and family members also described patients as *signalers* of communication during medical interactions. They often discussed situations in which the patients were struggling to communicate during medical interactions and needed help from their family members. When this occurred, they described the patients’ role as signaling the family member to “jump in” (C3) and help with the conversation. One family member (C3) stated, “If he [P3] feels like he’s not getting through, or can’t completely answer a question, he will turn to me and let me know that it’s my turn to jump in.” C1 said, “If I see her [P1] trying to say something, then I try not to fill-in. If she looks at me like, ‘What should I say?’ then I will fill-in.”

Finally, patients were described as *monitors* of communication during medical interactions. If family members needed to take over as the primary communicator during medical interactions, teams described the patients’ role as then shifting to more of a monitor of the conversation. Patients would often interject into the conversation to correct information, add additional information, or at least signal to the family members that something they said was

incorrect or incomplete. C2 stated, “I’ll try and ask a question the way I think she wants it. If that doesn’t work, I’ll look at her, and she says, ‘No. That’s not it.’”

Subtheme 1.3: Family members help it “go smoother.”
 Patients and family members also discussed a variety of roles that family members fulfilled during medical interactions. Participants described family members as advocates for the patients. This included speaking for the patients when they were unable to speak for themselves, filling in incomplete or missing information, creating opportunities for patients to communicate, and directing physicians to communicate directly with patients. Family members seemed to take on the role of advocate early in the patients’ stroke recovery, often speaking for patients when the patients had significant difficulties communicating. P2, who was struggling to communicate just after her stroke, referred to her husband (C2) as her “voice.” She had told him, “You know my likes and dislikes. I can’t articulate them to you, or to the doctor, so you’re my voice now.” As patients began recovering their communication skills and communicating more during medical interactions, family members’

Figure 1. Figure 1a is a replication of the diagram representing triadic communication during medical interactions presented to some patients during their individual interviews. Figure 1b is a replication of the diagram that P3 and P5 drew to indicate co-construction of information between patient and family member during medical interactions. C = caregiver; P = patient; D = doctor.



advocated for them by filling in any missing or incomplete information or by just physically being in the room to support patients in case they were needed. C2 characterized it as being a “safety net” for his wife (P2), meaning that she was the primary communicator during her medical interactions with physicians but that he would be there if she needed him. When describing how she advocates for her husband (P5), one family member (C5) referred to her role as “protector of the message,” taking responsibility for ensuring that physicians received the patient’s intended message. Family members also advocated for patients by directing physicians’ comments and questions to the patients during medical interactions. Family members unanimously described similar experiences, and they discussed how they have directed physicians to speak to the patients as a way to show respect to the patients and to address the patients’ needs during the interaction. One family member (C4) stated,

Well, it’s not like they [physicians] don’t talk necessarily to him, but they direct the questions to me. If that happens, I immediately say, “P4, you answer that.” And then if he stumbles, I’ll step in, but it still has to start with him.

In terms of other roles, family members described stepping in as *interpreters* for what patients were saying when physicians struggled to understand them. They also interpreted what the physicians were saying to the patients by simplifying or modifying the physicians’ messages to improve the patients’ comprehension. C2 stated, “So I try and simplify it. You know, so it’s easier.” C5 also commented, “Uh, interpreter. You know, if it gets too technical or too fast for him . . . then I will try to slow it down or simplify it, or explain it compared to something he’s familiar with.” Finally, family members also described functioning as *monitors* of the conversations between patients and physicians and helped to facilitate these interactions to improve the success of communication. Sometimes, this meant getting involved in the interaction only to help guide the conversation or keep it on topic, whereas other times it meant jumping in to take over communication for the patients to ensure the message was understood. C3 described it as being “the guide on the side,” whereas another family member (C6) described it as “steering the ship” during the medical visit. C4 stated, “Sometimes you let the person . . . um, express themselves, and sometimes you just make it . . . go smoother.”

Subtheme 1.4: Teams can change. Although family members in this study had existing relationships with patients prior to the onset of the patients’ communication difficulties, participants gave the impression that the communication team for medical interactions formed when the communication disorders began. Patients and family members also discussed how, as part of this team, their roles for communication during medical interactions have evolved over time. P2 commented that their team “formed over time” and that it took about 2 years to feel like their team was functioning optimally. C4 commented,

Well, we’ve been married for 40 years. So, and this [P4’s recovery from stroke] is a slow progression. Right? It’s not a crash course, and not a 3-hr class at the U. It’s a slow progression, and so we have constant communication.

According to the participants, several factors were responsible for the evolving communication roles. One of these factors was changes in patients’ communication skills over time. One patient (P6) referred to her communication as “dead” immediately following her stroke. C1 stated, “Sometimes she [P1] needed something, but in those early stages she couldn’t even ask.” Most patients took on more responsibility for communication during medical interactions as their communication skills improved poststroke, with family members taking more of a secondary, back-up role. One family member (C2) stated, “So, her having a stroke I’ve had to pick up things, and really help her communicate better. Now, I’m finding I just need to be there, next to her.” However, the reverse scenario was discussed by P4 and C4. Diagnosed with primary progressive aphasia in 2008, P4’s communication skills have since begun to deteriorate, and he is requiring increasing assistance from his wife, C4. Instead of their team dynamics shifting toward supporting the patient in becoming more independent with communication, C4 described taking on more responsibility for helping P4 interact with physicians during medical interactions as his communication skills have gotten worse. Both team members discussed how P4’s communication difficulties can sometimes take them by surprise, requiring the team to adjust accordingly. During their joint interview, C4 commented, “We get blindsided . . . all the time. But you know, we go, ‘What was that?’ and it will be a new step . . . new phase.”

Another variable that participants discussed causing the communication team to change is the context surrounding the medical interaction. Routine medical visits, in which the interaction between patients and physicians is often more relaxed and predictable, may facilitate more opportunities for patients to attempt to be more independent with communication. During routine medical interactions, family members seemed more willing to step back and allow patients to be the primary communicator. C4 stated, “I want to be the helper. Out of sight . . . right? As much as I can for him, and so I’ll just put the conversation back between the two of them, and I’ll just pipe up if I need to.” During medical interactions that are not routine, such as emergency room (ER) visits, family members often described taking over the lead communicator role. This was likely related to the need for accurate information to be conveyed very quickly. C3 stated, “I think when you’re dealing with ER personnel, they don’t have a whole lotta time to wait for the answers to come from him [P3].” Similarly, C5 commented, “So, they didn’t know him [P5]. They didn’t know what he was capable of. So, I pretty much had to be . . . answer everything for him. ‘Cause you know, they depend on speed, and he didn’t have time to do that.”

The complexity of information being discussed during medical interactions also seemed to create role changes for team members. Some family members described how patients were able to successfully communicate basic information related to symptoms or to answer basic physician questions, such as how the patients were doing or locations and severity levels of pain. However, as information became more complex and abstract, family members often took over as the primary communicator for the team because the level of complexity exceeded the patients' communication abilities at that time. As one family member (C3) stated, "Sometimes, it's just gotta come from me because it's too complex for whatever reason."

Subtheme 1.5: Teams can sometimes struggle. According to participants, communication between patients and family members around medical interactions does not always go smoothly. Despite having known the patients for years, some family members reported not always knowing what patients were trying to communicate to physicians during medical interactions. As one family member (C1) stated, "Sometimes it's important for her [P2] to say what she wants to say because it may not be what I am thinking." P2 attributed the source of some of the miscommunication between team members to being different people with different perspectives. She stated, "It was very, very, very hard. Because he [C2] is a different person. He is a person on his own. I am a person on my own. How will he understand what I'm trying to say?"

Another source of struggle was that sometimes during medical interactions family members would jump in to help patients before the patients needed the help, or at least before they signaled to the family members that they wanted help. According to one family member (C3),

And I was really, you know, take charge right after the stroke. And so, it took me a long time to back off . . . and where that balance is when it's good to assert myself. And occasionally I still overstep that bound, and he lets me know.

Finally, patient and family member teams may just simply disagree on which medical decision is best for the patients. At least half of the patient and family member teams described this type of disagreement. When asked how the team handles disagreements about medical decisions, one family member (C5) responded that they, "work through them until one gives in," suggesting that she and P5 do not always agree on what medical decision may be in his best interest.

Theme 2: Patients and Family Members Want Physicians to "Just Try"

Overall, patients and family members reported that most physicians did relatively well communicating with patients, and they felt that physicians were doing the best they could to provide care for the patients. However, they also described some distinct challenges and frustrations communicating with physicians, including that some physicians did not seem aware of the impact that patients'

communication disorders had on medical interactions, and some physicians appeared unwilling to adjust their communication style to meet the patients' needs.

Subtheme 2.1: Communicating with physicians is hard. Patients and family members described some of their experiences communicating with physicians as difficult. Some felt physicians should have a better idea of how to effectively communicate with patients with communication disorders. One family member (C6) talked about how it is impossible to be a good doctor if communication is not effective. He stated, "There could be the best like actual doctor in the world, but if they can't communicate with the patient then it's kind of useless."

Patients and family members seemed to readily acknowledge that a significant amount of the difficulties with communication during medical interactions stemmed from the patients' communication disorders. When asked to describe the hardest thing about talking with physicians, one patient (P6) immediately described her communication limitations, stating "um . . . [nods] . . . disaster . . . [chuckles] . . . I try to work hard, and I just can't do it." However, patients and family members also experienced communication difficulties that they felt were more the physicians' responsibility. Speed was a universal reason reported by patients and family members for communication breakdowns with physicians. They often described how the pace with which physicians conducted medical interactions was too fast, making it difficult for patients (according to C6) to "keep up." This sentiment was summarized by C1, who stated, "And they were telling her to do this and do that . . . but they talk so fast that she didn't comprehend it."

Additionally, some family members attributed communication difficulties to the lack of familiarity or history physicians had with patients—that encountering new physicians who did not know the patients could immediately cause communication challenges. C3 commented, "It was that whole piece of leaving the physician that we had been with for 25 years . . . I think we didn't realize what a challenge communication was until we had to start with somebody new." Another family member (C6) stated the following:

It's just when they're [doctors] brand new, you know? So, I guess the hardest part is just that having to like explain to them everything for the first time, every time. I don't know . . . it's really an unavoidable problem though 'cause they do need to know about what her problem is. It's just kind of tough.

Subtheme 2.2: We feel some physicians may not know or may not try. Patients and family members expressed that physicians should be aware of the ways in which communication disorders could potentially affect patients' abilities to participate in medical interactions and to be prepared and willing to change how they communicate with these patients to help make communication more successful. C6 stated, "A perfect doctor would be able to know how the person's feeling, and know how much they have to talk . . . like what they can say to them so they understand."

However, patients and family members reported that some physicians may have been unaware of the extent to which patients were struggling during medical interactions. This seemed especially true for patients who had recovered a significant amount of their communication skills poststroke. One family member (C2) commented,

One doctor said, "Oh, you [P2] seem to be fine. I know you said you had a stroke, but you seem to converse with me really fine so it didn't click with me that I needed to slow down . . . that you're still suffering with aphasia."

Patients and family members also described experiences during medical interactions in which physicians may have been aware that the patients' communication disorders were affecting their ability to participate in the interactions but did not change the way they communicated with the patients. These physicians were viewed as being less concerned with how much the patients were understanding and more concerned with keeping the interaction time to a minimum. One family member (C2) stated, "He's a young guy. He just wants to process those patients in and out." Commenting on a different physician during the same joint interview, P2 stated, "She was really . . . [makes writing motion on table] . . . doing as the book and that was it, and whether come in, do the surgery, and off you go. I didn't want that."

Other physicians were characterized as arrogant, portraying themselves in some way to be superior to patients and family members and maintaining their typical style of communication rather than being willing to adapt their communication to meet the needs of specific patients who were struggling. P4 stated,

She was trying, but she wasn't . . . it wasn't about whether I was getting it. It was about what she was telling me. "This is how I do it with all my patients. Right? And it works great. They all love me, they all come back. And, yeah, yeah, yeah . . . this patient has something I haven't heard of, but I'm gonna do the same thing because I know that it works."

Family members also felt some physicians made inaccurate assumptions about the patients' cognitive skills and ability to participate in discussions and decision making regarding the patients' care. One family member (C5) stated, "They [doctors] think that the stroke survivor has no brain. They think because they can't communicate, they don't think."

Subtheme 2.3: Poor communication can damage the relationship between the team and the physician. Communication breakdowns during medical interactions seemed to negatively affect the relationship between patient and family member teams and physicians. Frustration seemed to be a common outcome of communication breakdowns and was mentioned during interviews by most patients and family members. One patient (P1) stated, "Yes. And very fast! Like . . . it's very fast for me. Now . . . [slaps her head two times] . . . a little bit frustrated." Patients and family

members also discussed getting second opinions with other physicians or switching physicians altogether if communication did not go well. This was especially true if physicians exhibited any kind of arrogance or indifference to the patients' struggle with communication. C2 stated, "It's not worth it. This was her [P2] doctor she'd been seeing . . . and she was not too happy with her anyway. So, time to change." One patient (P2) acknowledged that some of her physicians were capable but did not seem to be the right fit to meet her needs. She stated, "They are good doctors but not good for me." Finally, patients and family members discussed a potential lack of follow-through with physicians' treatment recommendations if communication did not go well. One patient (P2) stated, "I would say three quarters of the time he was able to understand me . . . because otherwise I wouldn't have gone for my surgery, let's put it that way."

Subtheme 2.4: How communication should be. Patients and family members had clear ideas about how physicians could improve the success of communication during medical interactions involving patients with communication disorders. Respecting the patient seemed to be a central piece of advice for physicians when interacting with patients who struggle to communicate. As one patient (P4) advised physicians, "Respect the whole, whatever the whole is." One way patients and family members wanted physicians to respect patients was to look at patients and directly address them during interactions, rather than looking and speaking to family members about them. One family member (C5) stated, "You're the patient. Your appointment. They should start with the patient, look them in the eye, and ask them what the issue is." Respect also seemed to include wanting physicians to acknowledge that the patients are still capable of thinking and making health care decisions despite the presence of a communication disorder. C3 had the following comment about assumptions often made about patients with communication disorders:

I think a lot of people immediately jump to the conclusion when they hear people with speech issues, that somehow there's a cognitive deficit there too . . . you know, just 'cause they can't get the words out doesn't mean that the words aren't in there.

Patients and family members also discussed their desire for physicians to try and better understand the patients' perspective—what it is like for the patients to live with communication disorders. C6 had the following perspective:

You should be able to . . . when you look at somebody who's having a really tough time, you should feel for them. You should know that there's something more behind it than them just having a problem. Like when you leave, they're still dealing with it 24 hours a day.

Patients and family members expressed a desire for physicians to be willing to take the time and learn how best to communicate with patients with communication

disorders. One family member (C2) stated, “Be patient. Get yourself educated about aphasia. And then learn . . . understand what the person you are looking after, what they can do and cannot do. And they can’t tell you. You have to watch.” C3 commented, “I think a lot of it has to do with just taking the time . . . being willing to just sit and listen, and try to figure out what’s going on.” C6 suggested that physicians actually sit in on group speech therapy sessions to learn how individuals with aphasia interact with others. He stated,

I think that they [physicians] should sit in on them [group sessions] . . . to see how the people who communicate on a daily basis deal with it [aphasia]. I think that being there and in person—actually being affected like as a person—is way more important than just getting the information in general.

Patients and family members also felt that when communication breaks down during medical interactions and the opportunity arises for physicians to implement different communication strategies, they are often unprepared to do so, and that physicians should be prepared for these situations to occur. One family member (C2) stated, “I mean, it’s not rocket science. But having them think, ‘Oh yeah. I should just pull out a piece of paper and draw this, or . . .,’” meaning that physicians should think to try different strategies to repair communication breakdowns.

Theme 3: Physicians Want to Try but May Not Know How

The third theme focuses specifically on the physicians and how they viewed interactions with patients with communication disorders and their family members.

Subtheme 3.1: Effective communication is our responsibility. Physicians unanimously stated it was part of their role as the health care provider to ensure effective communication and to repair communication breakdowns during medical interactions. One physician (D3) stated, “It rests on me to make sure that I’m facilitating communication and that information that’s being used in decision making for the patient’s care is as accurate and complete as it can be.” D2 commented,

But, I think that’s my primary job is to figure out you know, what is it they [patients] need and not just operate off my list of . . . “Well, I need to check your blood pressure, and check your cholesterol and . . .” [chuckle] . . . you know those sorts of things.

Physicians’ responsibility for ensuring effective communication during medical interactions seemed to vary depending on the physicians’ individual medical specialties. For example, one neurologist (D1) focused specifically on her responsibility for obtaining an accurate account of the patients’ medical history, stating “because in neurology, the history is everything.” Alternately, a psychiatrist (D5) seemed to focus his responsibility for communication more on developing the overall plan of care his patients would receive, stating “Really in my world, it’s [primary responsibility] addressing the rehab needs of the patient.”

Physicians also discussed the importance of trying to understand the nature of the patients’ communication disorder and how it can affect their ability to communicate during a medical interaction. One physician (D2) stated, “You need to have that sort of assessment of what the patient really . . . what are their limitations?” D1 commented, “Try to figure out what’s going on . . . and what, you know, is happening.” Some physicians described their role as more than just understanding how communication disorders can affect their patients’ participation in medical interactions; they focused on the social and emotional impact these disorders may have on their patients’ lives and truly understanding the patients’ perspectives during interactions. One physician (D4) stated, “I wanna know what they’re feeling. If they’re feeling pain or anxiety . . . you know, unfortunately most of what we do really relies on the patient’s perception of what’s going on and without that perception, we can only guess.” D2 commented, “I don’t want him to feel like he’s just a lump in the chair and I’m talking to his wife about everything.”

Subtheme 3.2: Communication with patients is hard. Physicians discussed the importance of getting the patients’ perspective during medical interactions, and they felt their patients play a large role in communicating their perspectives to physicians. However, physicians universally described the challenges associated with trying to obtain their patients’ perspectives.

Physicians seemed to characterize the role of patients with communication disorders during medical interactions as they would with any of their other patients—to provide information related to the reason for the medical visit and any symptoms they were experiencing. Additionally, D5 stated the patients’ role during a medical visit was “to decide what he or she wants to be addressed and decide what he or she wants to do with the information and advice that I offer,” implying that patients should also be included in decision making about their care, if not responsible for it. One physician (D4) characterized the patients’ role in a different way, stating the following:

Because, as you know, most of the time it’s the family member who’s giving history and telling what the issues are. I guess I try to validate the family member’s story with the patient if they can kind of affirm yes or no with their thumb up or thumb down. I try to get that information when I examine them to see if there are issues that are related to the complaints that the family member describes.

Although obtaining the patients’ perspectives seemed important, physicians were quick to characterize their experiences communicating with patients with communication disorders as challenging. One physician (D5) stated, “Well it’s definitely a challenge. And I find it can be challenging to maintain communication with the patient rather than relying on the family member to provide all the details.” D2 commented, “It’s one thing to have an interpreter for my deaf patient, but this is a different, much tougher set of patients.”

According to physicians, time was a primary reason for these interactions being so challenging. Physicians seemed to recognize that patients with communication disorders often require additional time to communicate, but they did not often have the time to afford patients this opportunity. D1 stated, "Well, it's hard because you have a limited amount of time to do things. So, I think what I tend to do is talk over patients a lot."

Physicians also struggled with helping patients find a way to reliably and consistently communicate during medical interactions. Lack of consistent, reliable communication from patients seemed to leave physicians unsure about what their patients' wants and needs were and whether their plan of care was actually addressing those wants and needs. One physician (D5) stated, "I would . . . try to communicate with the patients and then break down to yes/no and really didn't have a sense talking to the patient whether they could be reliable." As with patients and family members, struggling to help find consistent and reliable ways for patients to communicate left some physicians feeling frustrated. D5 stated, "and also hard is the patient that you just haven't found very effective strategies with. It can be pretty frustrating."

Physicians seemed to react to these communication challenges and frustrations in different ways. Some physicians said they sometimes resort to guessing or sometimes simply giving up. One physician (D4) stated, "Quite frankly, I think what happens is that you just, at some point, give up and decide you don't need all the information, and get the little bits that maybe make a difference."

Subtheme 3.3: We rely on family members. Physicians discussed often relying on the most valuable resource they had available to them when they were struggling to communicate with patients during medical interactions: the family members. Physicians discussed often relying on family members when they are unable to successfully communicate with patients during medical interactions. For some physicians, family members were a lifeline to discovering the needs of the patient. As one physician (D4) commented, "I usually step back to the most simple of questions . . . yes/no and try to validate whether those responses are actually correct. And if that breaks down, then I usually look for the family member to help me out." One physician (D1) stated, "Sometimes you just have to . . . you know, call somebody . . . people who have seen them or talk to family members . . . if you just really are not getting the information that you need." The same physician also went on to say, "You know, and without the family members, I'm kinda lost."

Physicians discussed the different roles they expect family members to fill to help improve communication with patients during medical interactions. One of the main roles that physicians described for family members was that of facilitator. They discussed how family members make communication easier during medical interactions by helping patients communicate information to physicians or by relaying information to patients that physicians are unable to successfully communicate themselves. D5 stated,

Family members are a huge support. They're a huge help to me as a provider to bring information, to provide information . . . and they often help facilitate the conversation. Because they tend to know the patient very well and tend to help support the communication if they know what strategies are effective for that patient.

Physicians also described family members as advocates for patients, as family members often know the patients well and are in a position to provide information about the patients, especially when patients are not able to communicate for themselves. Additionally, family members may help to verify information patients are communicating, or they can serve as a "memory bank" (D3) to help patients remember what was discussed during the medical interaction. Finally, physicians discussed that family members are often responsible for implementing any plans of care that stem from medical interactions. One physician (D5) commented, "They [family members] often help execute whatever the rehab plan is for that patient."

Some physicians mirrored the findings discussed in Theme 1 that patients and their family members are a team. One physician (D5) referred to patients and family members as "a package deal." He discussed interactions with patients and family members in terms of their combined efforts to communicate. Other physicians seemed to consider patients and family members as separate entities, serving distinct functions for communication within a medical interaction. Whereas patients were responsible for communicating their symptoms, family members were primarily responsible for being interpreters for the patients.

Although often relying on family members to help with communication, physicians seemed to also recognize potential pitfalls of having family members communicate for patients. Specifically, they were concerned about relying on family members who may not know the patients well enough to communicate for them, or getting more of the family members' perspectives on the situation than the patients' perspectives. One physician (D2) commented, "If you have a support person who's very astute, very educated, very knowledgeable about the condition of the patient then it works great. Often you don't have that." D1 stated, "There's . . . a lot of times where they [family members] will . . . you know, fill everything in for the patients, and it's hard." One physician (D2) even discussed the potential for family members to put patients at risk and the responsibility physicians have for ensuring family members have the patients' best interests in mind:

You need somebody involved to help who's in . . . directly involved in the care of that patient and you need to be careful about who that is you know. To make sure really you're confident they're gonna operate in the best interest of that patient, because there is a huge risk of patients being taking advantage of in situations.

Subtheme 3.4: We are not taught how to do it. Although the majority of physicians reported receiving

general communication skills training during their medical education and clinical rotations, none had received training specific to facilitating communication with patients who had communication disorders. When asked how they learned to interact with these patients, physicians often discussed learning by “trial and error” (D6) during their clinical rotations. One physician (D1) stated, “I think that was through experience in watching my attendings do it.” Most physicians seemed to view this as a problem that negatively affected their current practice. They seemed to suggest that lack of formal training left them feeling deficient in specific skills they needed to successfully interact with patients with communication disorders. One physician (D2) stated the following:

I didn't learn any strategies as to how to go about dealing with these situations. It was pretty much begin to have those experiences as a resident and then step into that as a practicing physician and wing it . . . and when you hear physicians saying that “winging it” is their way of coping with it most of the time . . . It's impossible to put everything in 4 years of medical school training that we would like to put in there. But, I think you're certainly looking at a place where there's a deficit . . . certainly in my experience.

Physicians discussed the potential benefits of receiving training to improve their ability to facilitate communication with patients with communication disorders. Some even talked about specific areas of training they might find useful in their practice. D1 felt that future physicians need to have a better understanding of the basic definitions and characteristics of communication disorders, such as aphasia:

Well, I think they [medical students] definitely need to understand the different types of abnormal communication. So, I think they have to understand, what really is aphasia? You know, what does receptive aphasia look like? What does expressive aphasia look like? I think they really need to know this stuff.

Other physicians discussed the need for medical students and practicing physicians to learn and implement specific communication strategies with patients with communication disorders. One physician (D5) stated, “Some basic tools for the nonspeech pathologist would be wonderful . . . so basic tools that an MD [medical doctor] could implement in a very short time period to facilitate communication with a patient with a communication disorder would be wonderful.” D3 commented, “So it'd be nice to maybe have like one lecture that would be about that. Sort of like here's the tricks and tools and things you know that might be applicable.”

In addition to formal training during medical school, the importance of getting educated about the communication of each individual patient was raised. D1 mentioned that she would benefit from patients or family members

describing any communication strategies that have already been established and are working to help patients communicate at the start of the medical interaction itself. She stated, “That would be very helpful . . . if they came in and said, ‘You know she really doesn't do good. You have to talk really slow, or really loud, or write it down, or . . .’”

Discussion

Findings from this study both reinforce what is already known and reveal new insights about communication during medical interactions involving patients with communication disorders, family members, and physicians. Results of this study support the importance of communication as the medium through which quality health care is provided (Lipkin, 2010, p. 3). This study highlights the importance of examining the dual role of communication during medical interactions—ensuring that both the transaction of information is effective and the interaction between those involved supports patient autonomy and a positive patient–provider relationship (Burns, Baylor, Morris, McNalley, & Yorkston, 2012). Because of the many barriers to communication identified by various stakeholders, accommodations need to be made to ensure the quality of interactions between patients with communication disorders and their physicians. The need for improvements in patient–provider communication was evidenced in this study by patients reporting that they have switched providers or have not followed through with treatment recommendations because of poor communication interactions with physicians. Despite barriers, patients with communication disorders want to be involved in their health care interactions, including making decisions about their care. Results of this study also attest that physicians want to provide good care to patients with communication disorders and demonstrate respect for patient autonomy, but time pressure, lack of training, and other challenges physicians face during medical interactions involving these patients constrain them (Murphy, 2006).

The results of this study expand the insights into the complex and dynamic roles that the family member plays in an effort to make the medical interaction go smoothly (Hemsley, Balandin, & Togher, 2008a). One of the interesting findings calls into question the issue of whether the family member in the medical visit creates a true triadic communication situation or a modified dyad. The patients and family members in this study presented themselves as a team in the medical visit. The family member was not an independent or neutral third party, such as an interpreter, but a team member with the patient. As team members, the family members discussed fulfilling various roles that often change over time or in response to various situations. The family member plays the role of supporting and facilitating communication between the patients and physicians. The family member might step in to take on more of the communicative responsibility. If communication is difficult, the patient may hand off the role of providing detailed medical history information to the family member.

If the family member sees that the patient is too fatigued to continue, he or she may take on the role of question asking.

Family members also see themselves as educators. As such, they may act to reveal the competence of the patient to the physician and to inform the physician as to how best to communicate with the patient. Often this role is conducted in subtle ways. For example, if a physician asks a question directly to the family member, the family member may turn and redirect the question to the patient, thus demonstrating to the physician how to communicate directly with the patient. The family member may model communication behaviors for the physician such as asking for repetition of information or jotting down key words to support comprehension. In other cases, they may demonstrate the use of communication accommodations such as appropriate pacing and supplementation strategies. Family members may play the role of monitor, gauging whether patients can answer the questions that physicians ask, and how the questions can be modified to improve the patient's comprehension. Finally, family members see themselves as playing the role of advocate, ensuring that the patient's "voice" is heard. In this role, they may help to demonstrate the patient's competence and preferences as well as perhaps effective accommodations.

The roles played by family members are not simple or static; rather, they are described as changing depending on the context of the medical interaction. Patients often want to try to communicate with physicians themselves but are willing to accept help from family members if they are struggling. As the patients' communication skills recover or improve over time, they often want to take on more responsibility for communication and be actively involved in the interaction. Although family members recognize the importance of stepping back and allowing the patients to communicate on their own, family members are often unsure how and when to do this. Family members in this study also discussed having to step in for the patient in certain contexts. During interactions that require increased speed and accuracy of communication (e.g., ER visits) or when the complexity of information was above the patients' level of abilities, family members may take control of the interaction with physicians to ensure communication goes well.

Finally, when describing the roles that they play, family members indicated that they do not always "get it right" and that communication does not always go well. Family members can be inconsistent in interpreting the patient's perspective. They may not always know what the patient is trying to communicate, or they may provide too much assistance or "jump in" too soon and communicate for the patient when it is not necessary. They may also have ideas that differ from those of the patient as to what medical decisions might be in the patient's best interest. These experiences were consistent with the results of Laidsaar-Powell et al.'s (2013) systematic review, in which they explored triadic communication during medical interactions involving patients without communication

disorders, companions (caregivers), and physicians. In this study, researchers found that although caregivers were often perceived as helpful and that they increased patient satisfaction with communication during these interactions, the addition of a third person created some communication challenges to the interaction between patients and physicians. Specifically, the roles of companions in communication were unclear, and these individuals often seemed confused as to what their responsibilities were during the interaction.

In addition to describing the many roles played by family members, this research highlights the point that physicians value communication with their patients as a critical element of their professional practice. Despite the importance of communication in providing quality health care, physicians feel unprepared to accommodate communication breakdowns during interactions with patients with communication disorders. They often discussed the frustration with wanting to help their patients but not knowing how. Some discussed "winging it" or even giving up and moving on during communication breakdowns. Physicians described having a lack of tools or strategies to fall back on to help them facilitate communication with these patients, but they expressed interest in learning better ways of communicating with their patients who struggle.

This work extends the prior work conducted by Hemsley et al. (2008a, 2008b, 2008c) with adults with cerebral palsy and complex communication needs by showing that the experiences of patients, family members, and health care providers are similar across the bodies of work. Despite the differences between complex communication needs associated with cerebral palsy and aphasia, patients in both studies expressed the need to balance the reality that they need communication support with their desire to be independent when possible and to be fully involved in the health care decision-making process (Hemsley et al., 2008c). Family members in both studies discussed the challenges of promoting the independence of the person with the communication disorder with their perceived need to protect and support that person (Hemsley et al., 2008a). Finally, the health care providers emphasized the conflict between their strong sense of responsibility to provide good care with their awareness that they were not fully prepared to care for patients with communication challenges (Hemsley et al., 2008b) and that they did not necessarily have the available resources, such as adequate time. Thus, these parallel works suggest that the roles, benefits, and challenges of the stakeholders in these medical interactions are not likely disorder-specific but may be more universal across individuals with different communication disorders, different family member roles, and different medical settings and providers. This growing evidence must reach the critical level to compel health care policy makers, administrators, and practitioners to recognize that accommodations are needed for accessible, quality health care for this patient population, and that resources need to be directed toward putting these accommodations in place.

Clinical Implications

The findings reported here have a number of clinical implications, some of which SLPs can implement immediately. SLPs are uniquely qualified to help improve communication during medical interactions involving these patients (Burns et al., 2012; Wilson-Stronks & Blackstone, 2013). They can play an important part in enhancing communication in medical interactions because they may serve as an interface between patients who struggle to communicate and their physicians. Although traditionally SLPs focus interventions on helping those with communication disorders improve their ability to interact with others (Turner & Whitworth, 2006), participation-focused treatment has recently become common place. SLPs are more often focusing interventions on creating a more “communicatively accessible environment” (Simmons-Mackie, 2013, p. 99) for patients with communication disorders. Consequently, SLPs are looking beyond the patients themselves to the environment in which they communicate. However, it is not always clear what participation-focused treatment should look like. SLPs often resort to training patients and their communication partners (e.g., family, staff) to help facilitate basic communication of the patient’s wants and needs. Perhaps instead of providing general participation-based communication training, SLPs should be shifting the focus and goals of treatment to address specific participation-based situations, such as medical interactions. For example, SLPs routinely create general support materials for their clients to help with communication in a variety of situations. Perhaps SLPs can focus on creating more tailored support materials to help their clients communicate during medical interactions with physicians and other health care providers. In addition, previous research and results of this study suggest that the “third party” in a medical interaction needs to have a solid understanding of not only the patient’s medical condition but also how the patient best communicates to provide effective support to the patient during the interaction. Medical advocates who are not family members and who may not know these patients well, such as paid caregivers, often serve as this third party in lieu of family members. Thus, it is imperative that they receive instruction and/or training to increase their awareness of how communication disorders can affect medical interactions as well as how to help facilitate communication with these patients prior to participating in medical interactions with them. SLPs can help educate and instruct these individuals to effectively support patients with communication disorders during medical interactions.

SLPs should be providing specific education to patients who struggle to communicate, their family members, and physicians to prepare them with the knowledge and tools they will need to successfully communicate during medical interactions (Yorkston, Baylor, Burns, Morris, & McNalley, 2015). SLPs can help empower patients with communication disorders to maintain their autonomy by becoming active contributors and decision makers during

medical interactions. For example, SLPs can help patients develop and communicate questions to physicians as well as advocate for themselves by communicating that they need extra time; SLPs can also help physicians simplify written health care materials to promote patients’ health literacy. SLPs can also offer these patients augmentative and alternative communication options (e.g., alphabet boards, communication notebooks) when verbal communication is not successful to help maintain their level of independence with communication during medical interactions. SLPs can train family members to optimize the roles they assume and the strategies they use to assist communication, as well as how and when to shift roles to be of most assistance. For example, SLPs may train family members to give patients an opportunity to communicate before they jump in or to monitor the conversation for specific signals from patients to indicate when they need help. SLPs can also help patients and family members understand some of the administrative constraints that physicians face, such as schedule limitations and training limitations, and how patients and their families can best help physicians communicate with patients (e.g., describe or demonstrate effective communication strategies for physicians at the start of the medical interaction).

In addition, interprofessional education is essential to positively affect communication between patients with communication disorders, family members, and physicians during medical interactions. SLPs and physicians possess knowledge that can help improve communication in these interactions. Physicians understand the systematic steps involved in medical interactions as well as the potential barriers and limitations to successful communication that these steps can create. Physicians also know the communication challenges they have experienced when patients struggle to communicate on the basis of the extent of patient-provider communication skills training they have received. SLPs understand the impact of communication disorders on medical interactions and specific strategies physicians can implement to improve communication with their patients and family members (e.g., slow down, simplify language, supplement verbal communication with visual supports). Increasing interprofessional education between SLPs and physicians can help each discipline provide the other with essential information to help improve medical interactions. SLPs and physicians can also educate health care administrators as to the supports that physicians need to care for these patients.

Future Directions

Although results of this study have provided some new insights into communication during medical interactions involving patients with communication disorders, they have also prompted additional questions to be addressed through future research. Results of the current study are limited to a single diagnostic group: aphasia. Future research in this area should focus on expanding the diversity of participants to include those with a variety of

communication disorders in differing levels of severity as well as those in the acute stages of recovery to compare their experiences and perspectives. Also, family members were recruited for this study as the “third party” involved in the medical interactions. These family members knew the patients and had preexisting relationships with them long before the patients were diagnosed with aphasia or participated in the study, and these participant pairs reported having generally successful interactions with physicians. Future research should explore both how different relationships between patients and caregivers can affect interactions with physicians as well as how team dynamics that are not generally successful can affect these interactions. Future research should also focus on better understanding the experiences of the third person in the interaction when that person is not a family member, is not as familiar with the patient, or does not have an established method of effective communication with the patient. In addition, although member-checking was performed routinely within and across participant interviews, only a few participants commented on the developed themes that were shared with all participants. This may have limited confirmability of the themes developed from the data. Finally, physician participants were interviewed only once and only for about 30 min for this study, which may have limited the opportunity to explore their perspectives in a more in-depth way. Thus, further examination of physicians’ perspectives from a wider variety of medical specialties and experience should be obtained. Although the majority of physicians in this study reported receiving some training in patient–provider communication, all reported having received no specific training related to communicating with patients who struggle to communicate. Physician perspectives should also be obtained concerning what this training should include and how it should be delivered.

Although this study was designed as a qualitative look at stakeholders’ perspectives regarding communication in medical interactions involving patients with communication disorders, future research should include recording and analyzing actual medical interactions involving patients with communication disorders, their family members, and physicians. This type of research can allow direct observation of communication during these medical interactions to better appraise and understand the dynamics of communication as it happens. Techniques such as conversational analysis have been used successfully to understand interactions between speakers with severe dysarthria and communication partners (Bloch & Wilkinson, 2009; Gordon et al., 2009). This type of research would provide more “real-world” examples of communication breakdowns and successes and may, therefore, contribute to teaching models that could be used as part of physician training. Finally, results of this study have highlighted the need for training physicians and other health care providers in facilitating improved communication with patients who have communication disorders. Future research should focus on examining the efficacy of training programs to determine whether they result in providers’ increased use of

communication-enhancing strategies when interacting with patients who struggle to communicate.

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