

“Well, You Are the One Who Decides”

Attempting Shared Decision Making at the End of Aphasia Therapy

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Clinical borderlands manifest themselves through encounters between people deemed to be in need of health care and health care providers (Mattingly, 2010). This article addresses the problem of inherent asymmetry in the clinical discourse between clinical providers, such as speech–language pathologists (SLPs), and persons with aphasia. Speech–language pathologists, communicating as experts, tend to dominate the discourse regarding the course of treatment, particularly with clients with aphasia who may lack the necessary communicative skills to participate in decision making. Such patterns of communication were apparent in a study reported here that involved thematic analysis of the views of 12 SLPs regarding involving people with aphasia in shared decision making and in analysis of 33 video recordings of these 12 SLPs and 28 people with aphasia during clinical interactions. Although the SLPs stated that they wanted to involve their clients in decision making and took steps to do so, the discourse sample analysis revealed that the SLPs controlled the interaction through their initiations, topic selection, and presentation of limited choices. Alternatives for supporting greater decision-making participation among people with aphasia with their clinicians are discussed. **Key words:** *aphasia therapy interaction, client involvement, conversation, shared decision making*

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A VALUE supporting the goal of shared decision making by health care providers and health care recipients is well integrated in health care service documents that address work with specific populations, including guidelines for working with people who have had a stroke (e.g., Heart & Stroke Foundation, 2013; Ministry of Prevention and Health, 2013). The goal to involve patients or clients in shared decision making also has gained foothold in the principles of a widespread attempt to deliver evidence-based practice worldwide and across professions. In definitions of evidence-based practice, clinical expertise and client perspectives are to be taken into consideration equally with external scientific evidence when deciding on treatment methods (Sackett, Straus, Richardson, Rosenberg, & Haynes, 2000). The importance of such an integrated approach creates the need to investigate client involvement in different health-related contexts such as aphasia

therapy. Client involvement and shared decision making generally occur in communicative interactions between participants and may use both spoken and nonverbal means. Communication for the purpose of decision making is therefore an inherent and focal part of client involvement in aphasia therapy, but it has rarely been investigated (Dieppe, Rafferty, & Kitson, 2002).

Some research has shown that people with aphasia want to be involved in decisions about their health and rehabilitation after stroke (Berg, Askim, Balandin, Armstrong, & Rise, 2017; Hersh, Worrall, Howe, Sherratt, & Davidson, 2012; Nordehn, Meredith, & Bye, 2006; Worrall et al., 2011). Speech-language pathologists (SLPs) also express a desire and willingness to involve people who have aphasia in decision making (Bellon-Harn, Azios, Dockens, & Manchiaiah, 2017; Berg, Rise, Balandin, Armstrong, & Askim, 2016; Isaksen, 2014). Many of these studies are based on interviews that have focused on goal setting in aphasia therapy (e.g., Berg et al., 2016; Berg et al., 2017; Hersh et al., 2012; Worrall et al., 2011). However, decision making takes place at other crucial transition times throughout aphasia therapy and not just during goal-setting sessions (Berg et al., 2017; Isaksen, 2014).

The current study was designed to fill a gap in the research about how shared decision making and other joint activities take place in the clinical discourse between SLPs and people with aphasia. It also was designed to ask questions about how people with aphasia might discuss and make decisions about their therapy. Specifically, this study aimed to provide insight into decision-making processes toward the end of aphasia therapy, at which point decisions about further treatment or termination of treatment are made. The specific purposes of this study were to (1) describe the presence and process of decision making as a part of the clinical discourse between SLPs and people with aphasia; (2) describe SLPs' views on involvement of people with aphasia in decision making; (3) analyze discourse patterns between SLPs and people with aphasia,

given their uneven knowledge and communication skills as a means of shedding light on the challenges of the cultural borderland of clinical discourse; and (4) explore possible ways and times to increase shared decision making, such as in the outcome evaluation when treatment decisions are made regarding next steps.

Such interactions—revolving around transition—bring into focus the significance of clinical discourse as means to negotiate cultures of identity and reveal the nuances of clinical discourse practices, the outcomes of which are often taken for granted.

THE CULTURAL BORDERLAND OF DECISION MAKING IN CLINICAL DISCOURSE

Rosaldo (1989) defined cultural borderlands as “busy intersections” that occur on the boundaries of recognized cultural units (p. 28). Institutional culture can be defined as, for example, “common ideas, values, and standards that permeate the everyday lives of its members, and that are perpetuated by institutional indoctrination, actions, and leadership” (Simone, 2009, p. 5). However, members of any institutional culture can challenge a seemingly well-defined culture through their actions, which can make it relevant to talk of a cultural borderland. Clinical discourse between SLPs and their clients with aphasia may be a cultural borderland manifested through encounters between the land of the help seekers and the professional health care providers (e.g., SLPs; Mattingly, 2010). This manifestation involves an inherent asymmetry where professional experts are expected to make diagnoses and determine courses of treatment for laypersons (in this case, people with aphasia), who do not share a similar body of knowledge. However, the SLPs do not inhabit the lifeworld of the individuals they are assessing and seeking to treat—a lifeworld that has the potential to influence the course of diagnosis and treatment (Mishler, 1984). This study aims to examine the nature of specific institutional discourse between people with aphasia

and their SLPs with the purpose of seeking alternatives to situating clinical discourse in cultural borderlands.

The clinical discourse in a traditional setting such as aphasia therapy may be characterized as institutional or clinical interaction, particularly when it fails to take into consideration the lifeworld experiences of the participants (e.g., Horton, 2007; Lindsay & Wilkinson, 1999). Clinical discourse often differs in systematic ways from everyday conversations with, for example, peers, because it is situated in a context defined by certain structures and premises (Wilkinson, 2004). The interaction between the participants is oriented to this specific institutional context, but it also may rely on interactional practices and resources from everyday communication (Hutchby & Woofitt, 2008). Drew and Heritage (1992) have accentuated features that distinguish institutional interaction from everyday interaction, drawing on results from analyzing communication between dyads such as patient–doctor and defendant–judge pairs.

One difference is that institutional interaction involves the participants in goal-oriented behavior relevant to the specific institutions. An example is, what is performed in the office of the SLP with the person with aphasia is recognized or acknowledged as a component of speech and language therapy (e.g., assessment, treatment, consulting sessions) by the participants. Another feature is the involvement of constraints on contributions in the given context. For example, the institutional categories in which a person with aphasia and SLP interact often invoke specific interactional actions such as the SLP leading the clinical interaction, because that is to be expected from both the SLP and the person with aphasia (Drew & Heritage, 1992).

INVOLVEMENT OF PEOPLE WITH APHASIA

Social inclusion and increased participation often are targeted outcomes of aphasia therapy and may be a goal of services for people with disabilities in general (Howe &

O'Halloran, 2017b). An increasing amount of aphasia therapy research focuses on how environmental barriers can be identified and broken down for people with aphasia to facilitate increased participation in work, leisure activities, and family life (cf. the topical issue on *Environmental Factors in Life Participation, Approaches in Aphasia* in this journal, [Howe & O'Halloran, 2017a]). However, the nature of the barriers for exclusion faced in the clinical encounter of aphasia therapy per se remains unclear. Increased involvement of people with aphasia in decision making regarding their aphasia therapy means that SLPs might need to relinquish some professional autonomy to make shared decisions with their clients. Worrall et al. (2010) wrote that most approaches to aphasia therapy to date have focused on the perspectives of the SLP rather than those most affected by clinical decisions—that is, persons with aphasia and their significant others. However, as more recent trends such as client centeredness and a holistic view on rehabilitation (e.g., as outlined in The International Classification of Functioning, Disability and Health [World Health Organization, 2001]) take effect, the role of the professional has undergone some change and may no longer be viewed as the expert, whose pronouncements are not to be questioned (Davidson & Worrall, 2017; Grenness, Hickson, Laplante-Lévesque, & Davidson, 2014; Pound, 2011). Moreover, the relationship between SLP, person with aphasia, and possibly, significant others has been proven to be of utmost importance for the success of therapy (Simmons-Mackie & Damico, 2011; Worrall et al., 2010).

In its improved form, this is not just a relationship in which the SLP brings in professional knowledge and therapy skills but a genuine relationship, with mutual respect for and interest in each other being essential (Worrall et al., 2010). It requires the SLP to take risks in establishing his or her relationship with the person with aphasia compared with the former concept of being an expert professional who has the final word (O'Halloran, Hersh, Laplante-Lévesque, & Worrall 2010). Failing

to treat clients as equals or not taking their contributions seriously can impose a disabled identity onto the client, which is the opposite of what most clinicians say they want (Downs, 2011; Rasmussen, 2013). Imposing a disabled identity is a way of maintaining the boundaries of "difference" and "otherness" (Bhabha, 1994, p. 12), which characterize cultural borderlands and are not conducive to positive therapeutic interactions. Also, Mattingly (2010) wrote about otherness or the risk of turning others into *Others* in the cultural borderland. *Others* with capital *O* are described as someone being different in a way that causes distancing. In an aphasia therapy context, the participants—due to orientation toward cultural identities as professional and patient—could, in enhancement of these roles, end up marginalizing each other and risk failing to establish a genuine relationship.

Studies in aphasia and stroke rehabilitation have pointed to impaired communication in aphasia as a substantial hindrance for involvement, but researchers have not investigated whether this is the case and if so, what the challenges are (e.g., Berg et al., 2016; Leach, Cornwell, Fleming, & Haines, 2010; Nordehn et al., 2006). Impaired communication can be a hindrance to involvement risking to marginalize people with aphasia at important transition points in their engagement in therapy such as planning and review or discharge phases. These transition points can be considered borderland activities, where the culture of the world of aphasia meets the often-dominant culture of SLP practice. Examining talk-in-interaction can reveal some of these practices because the primary medium for client involvement and shared decision making is face-to-face interactions between SLP and people with aphasia, involving both verbal and nonverbal communication. Interaction, referred to as the *main ingredient* in health care (Roter & Hall, 1993), is therefore how involvement as shared decision making occurs. If people with aphasia are to be actively distanced from "otherness," shared decision making as interactionally achieved must be examined in the context of clinical

discourse within a framework that is poised to recognize features of cultural borderlands that traditionally have characterized such interactions.

METHODS

This study was inspired by two different qualitative paradigms: (1) *phenomenology*, which involved descriptions of a culture of involvement of people with aphasia from the perspectives of SLPs (Geertz, 1973) and (2) *ethnomethodology*, which involved analysis of video files of naturally occurring interactions between SLPs and people with aphasia in the context of clinical decision making during outcome evaluation sessions (Garfinkel, 1974). Both paradigms are concerned with presenting the participants' perspectives through either their reported experiences or their interactional actions. The study was carried out as a sequential mixed-methods study (Morse & Niehaus, 2009a; 2009b), using thematic content analysis of the qualitative interviews with the SLPs (Braun & Clarke, 2006) and conversation analysis of video-recorded outcome evaluations between the same SLPs and their clients with aphasia (Heritage, 1984; Hutchby & Woofitt, 2008).

Setting

The SLP interviews were conducted in the SLPs' workplaces. The clinical discourse samples were gathered in the context of joint outcome evaluation sessions during or after outpatient aphasia therapy. The SLP, the person with aphasia, and possibly his or her significant others were present during these sessions, where an outcome evaluation took place after a period of aphasia therapy. Apart from evaluating the client's progress in therapy, a goal of the outcome evaluation sessions was deciding the next step of rehabilitation. This sometimes involved setting new goals in case of a continuation of therapy, shifting to another type of therapy, deciding termination of therapy, or identifying community activities in which the person with aphasia might participate. The sessions of outcome

evaluation lasted between a few minutes up to an hour, depending on factors such as participation of significant others or whether it was an evaluation of group therapy with all members present.

Data were collected at four public outpatient clinics in Denmark. In the Danish context, any public aphasia therapy is free of charge and is financed by the citizen's municipality under the Act on Special Education for Adults (Ministry of Education, 2015). Some municipalities have their own speech-language therapy service, whereas others contract the services from a neighboring municipality or a regional clinic, or in rare cases from a private clinic. In some places, extended therapy must be granted by an authority, whereas in other municipalities, it is clinic managers or SLPs who grant extended therapy. Three of the four participating clinics were municipality based and one was regional, but all were providing services to several municipalities.

Participants

The participants included 12 SLPs and 28 individuals with aphasia. Because an outcome evaluation session does not necessarily mean that therapy ends, some people with aphasia and some SLPs participated in more than one outcome evaluation session during therapy. Therefore, study data consisted of 33 videos, culminating in a total of 17-hr recorded data over a period of 10 months. Afterward, the 12 SLPs were revisited for an interview. All people with aphasia were receiving outpatient therapy at the time of the study, but their time postonset varied as well as aphasia types and severity. Limited data were available relative to the time postonset, aphasia type, and aphasia severity because the data for this study were collected with other purposes. Significant others, usually partners or parents, participated in 15 of the 33 recorded sessions of outcome evaluation.

Procedures

The persons with aphasia were recruited through their SLP. The study was explained through spoken and written language to all

participants prior to any observation or video recordings and before they signed informed consents. Apart from the informed consent, no ethical clearance was necessary according to Danish legislation, because no personal information was obtained and recorded. After the period of collecting video cases of outcome evaluation, the 12 SLPs were revisited to participate in semistructured interviews that lasted between 31 and 59 minutes (mean = 44; $SD = 9.4$). The interviews were conducted by the researcher and followed a semistructured interview guide with approximately 30 open-ended questions focusing on outcome evaluation and not particularly decision making or involvement, because as stated below, the interviews were initially made for another study with another scope.

Analyses

Both interviews and video cases of outcome evaluations had been analyzed prior to this study with the same two methods but different aims (see Isaksen, 2014; Isaksen & Brouwer, 2015). During data collection, client involvement and shared decision making were not a priori interest of examination, but the prominence of the topic became clear during the first round of analysis, especially with regard to the interviews (see Isaksen, 2014), although it was not thoroughly investigated until this present study. Therefore, for the current study, a secondary analysis was employed beginning with thematic analysis of the 12 SLP interviews focusing on aspects addressing involvement. All SLP interviews were transcribed verbatim by the author.

A thorough process in six phases as described in the study by Braun and Clarke (2006) was followed: (1) familiarizing oneself with the interviews, including transcription; (2) generation of initial codes/key words; (3) initial search for potential themes based on the key words (keeping in mind that one theme often covers several key words); (4) reviewing and reorganizing the themes from Phase 3 into new themes; (5) defining and naming the final themes; and (6) writing up the final findings of the analysis. Phases 2

through 5 are iterative processes, where the data are revisited with provision of new key words or merging overlapping key words and sorting the key words into themes that best reflect the reported experiences of the participants. Thematic analysis can be based on a more semantic or latent/interpretive process, however, a combined approach is often used, as was the case for this study.

The second analytic step was driven by the findings from the thematic analysis of the SLP interviews to verify the SLP's views on shared decision making and involvement expressed in the interviews. Here, the 33 video cases were reviewed for sequences or instances of involvement initiations and responses or the lack of such instances. Parts of the videos corresponding with the aims of this study and the findings from the interviews were selected for further analyses. These video clips were transcribed using the Jeffersonian transcription conventions marking features of how the interaction is carried out like longer pauses (PS) over 0.2 seconds; some nonverbal behavior marked in double brackets and reduced voice volume is marked with degree symbols around the relevant words (°words°; Jefferson, 1984). To conduct conversation analysis, the verbatim transcriptions need to be expanded with annotations describing how the interaction takes place, for example, talk in overlap, pauses, and level of loudness.

The aim was to determine whether the findings from the interview study could be seen reflected in the actual decision making recorded during the outcome evaluation. The 33 recorded cases of outcome evaluation formed the base for what in conversational analysis is called a collection of a phenomenon. It occurs across three steps: (1) location of a potentially interesting phenomenon—usually this is done with unmotivated looking, but here the interview findings motivated the search; (2) with a number of instances found the next step is to describe one of the occurrences of the phenomenon; and (3) last is a return to the data to check whether the description resonates with the other found instances. If

so, the phenomenon can be described in the same way across the instances. However, it is likely a description of a given phenomenon need to be altered or expanded in order for the data to fully represent a phenomenon. Among the identified instances are also often instances that can illustrate an odd case where the description cannot cover (Hutchby & Wooffitt, 2008).

In this study, the 33 video cases had one or more sequences of involvement of the people with aphasia, reflecting how these individuals were invited into sessions of outcome evaluation and whether they were asked for opinions and confirmation of, for example, new goals or other decisions related to their further treatment. The data, that will be describing four themes or phenomena, presented in this article are from a collection of 18 video clips ranging in length from less than a minute to more than 7 min. These clips were selected because the four main themes from the thematic analysis were either strongly reflected or the opposite. The 18 clips were analyzed by way of conversation analysis and its central principle of next-turn proof procedure, where “speakers display in their sequentially ‘next’ turns an understanding of what the ‘prior’ turn was about” (Hutchby & Wooffitt, 2008, p. 13). Conversation analysis allowed the author to observe what the SLPs did or did not do to involve the people with aphasia and to describe the function of the involving strategies or lack of strategies due to the responses of the person with aphasia.

The major reason for combining the methods was to compare the actual practice to what the SLPs said during their interviews to seek evidence of concordance between stated perspectives and practice. This was done during analyses of the collective data sets and not on an individual level for each SLP. However, it is important to acknowledge that “what was said” is limited to the SLPs in the study, because the participating individuals with aphasia were not interviewed by the researcher. Goffman (1989) wrote about the combination or triangulation of data and stated, “I don't give hardly any weight to what people say,

but I try to triangulate what they are saying with events” (p. 131). In this study, it serves the purpose of providing a richer account of the phenomenon of involvement in decision making in aphasia therapy from the point of view and actions of the SLPs, with the goal of facilitating a deeper understanding (Denzin, 1978; Patton, 1999). The findings were validated during data sessions (conversation analysis). Furthermore, the participating SLPs and their colleagues were involved in a process of checking and discussing main findings on the study.

Excerpts of videos and interviews were glossed into English from the original language (i.e., Danish). The original version together with the English gloss is shown in the parts presenting the conversation analysis (whereas original versions of quotes from the interviews are not presented here because of limited space). All participants’ details are anonymized. Quotations from or references to the SLPs are labelled with the abbreviation SLP followed by capital letters from A to L (not all present in this article). All participants’ details remain anonymous. Quotations from or references to the SLPs are labeled with the abbreviation SLP, followed by a number, 1 through 12 (not all present in this article). Quotations from the person with aphasia are labeled PWA and a number 1 through 28 (not all present in this article), and those from the significant others are labeled WIFE, MOM, and so forth as appropriate.

RESULTS

The findings from the two consecutive analyses of interviews and video cases, respectively, are presented and described in four themes: (1) *shared decision making is desired and attempted*; (2) *participants’ views and roles can prevent shared decision making*; (3) *shared decision making is not always necessary*; and (4) *aphasia can affect shared decision making*. The themes are illustrated below with a short description including central quotes from the thematic analysis of the interviews

and analyses of excerpts video clips that either reflect or reject topics from the interviews.

Theme 1: Shared decision making is desired and attempted

The participating SLPs all expressed intention to involve the participants with aphasia in outcome evaluation when decisions of future course or termination of therapy were to be taken. During the interviews, all SLP participants talked about listening to experiences and opinions, as well as respecting what clients and significant others had to say, indicating their view that involvement is for all parties to have their say on issues of importance to them. For example, SLP 9 said:

I would like there to be time and space for both the significant other and the client and myself to put into words how things are going. I would like the client and the significant other to feel that they have had time to say what they would like to say.

The SLPs’ stated reasons for engaging clients and significant others in decisions seemed to be centered around inherent skills and rights. For example, SLPs stated the belief that because clients are adults, they know what is best for themselves:

It is I, of course, that has the professional knowledge, but the client usually knows him/herself best: “How does this work for me?” “What therapy style do I like?” “Do I want more home exercises, do I want fewer?” “What can I handle?” (SLP 9)

In accordance with some of the benefits of client involvement shown in earlier research (Drew, Chatwin, & Collins, 2001; Hersh et al., 2012; Lawrence & Kinn, 2012; Pulvirenti, McMillan, & Lawn, 2014), four of the clinicians spoke of involvement also as a means of empowering clients or making them active in their own treatment: “You will make your client active and responsible” (SLP 10).

As shown in the remaining three themes, different factors prevent the willingness reported by the SLPs to engage people with aphasia in shared decision making. Nonetheless, the video clips are also reflecting the SLPs’ positive attitudes toward involvement.

As mentioned previously, examples of typical questions from the SLPs engaging their clients with aphasia were present in all videos including Excerpt 1 below. Excerpt 2 highlights SLPs' proposals of suggestions to the people with aphasia.

Excerpt 1

1 SLP I: men hvad tænker du så er fremtidsplanen
but what do you think is the future plan?

Excerpt 2

1 SLP L: så (0.5) ja så mit forslag er at
so yes so my suggestion is that
2 vi at at at vi starter med at holde en
we that that that we start with taking
3 pause (0.3) og ser hvad der sker
a break and see what is happening

With only one exception (see Excerpt 3), all questions about future therapy were initiated by the SLP. Only the following excerpt provides an example where a person with aphasia took the initiative to ask a question about future therapy.

Excerpt 3

1 PWA 25: jeg vil meget gerne ko komme igen
I would very much like to co come again
2 SLP L: okay ((takes up a pencil and starts to write))
3 PWA 25: ja ja (.) fordi jeg mangler al- noget altså (.)
yes yes because I need (al-)something right
4 eh jeg synes det har været meget godt i perioden
eh I think it has been very good for the time being
6 SLP L: mm ((still writing))
7 PWA 25: men har jeg nogen mulighed for det
but do I have any possibilities for that
8 SLP L: det er så det vi snakker om ((laughing))
it is what we are talking about

In this excerpt, within the opening minutes of the outcome evaluation session, the person with aphasia makes an initiative, or in conversation analytic terms, a first pair part, by stating that he would like to come back for more therapy. The minimal response "okay" he gets from the SLP in line 2 prompts him to elaborate his first statement. Again, the SLP replies with a minimal response "mm," and eventually PWA 25 asks whether his wish to continue therapy is possible. The SLP's response is not the likely preferred "yes" or alternatively a "no" but is rather a postponement of the response and is said with laughter. The re-

sponses "okay" or "mm" from the SLP to the initiation from PWA 25, and eventually the lack of reply, likely indicate that the initiation or suggestion should not come from him or maybe just not at this early point in the conversation. Despite the person with aphasia taking an interactional initiative here that could support involvement, it is treated rather as untimely by the SLP, supporting that involvement initiatives should come from, and be regulated by, the SLP.

Making the first move, the first pair part, plays a significant role in how the clinicians make their proposal for future decision and seek acceptance. This only instance across the data set (i.e., Excerpt 3) of a person with aphasia reversing that order is turned down by his SLP.

Theme 2: Participants' views and roles can prevent shared decision making

Resistance to shared decision making from both professionals and clients is an often-mentioned barrier in other studies (e.g., Légaré, Ratté, Gravel, & Graham, 2008). Reluctance to be involved in decision making from some people with aphasia was reported by three SLPs. From their perspective, such resistance occurs when the person with aphasia either does not understand the idea of being involved or does not want to or feel able to be involved in decisions. SLP 9 said, for example, "I actually think that for many [people with aphasia] we are the ones who make the decisions." Similarly, SLP 3 said,

They [people with aphasia] would really like to have someone taking responsibility and someone that can direct them (. . .). If you have had a stroke, then you might not have the surplus energy to have an opinion about how you should do things; instead it makes them insecure.

It might seem inconsistent to talk about resistance from the participating SLPs, because they all expressed preferences for involving clients in outcome evaluation. However, a premise for involving people with aphasia directly in decision making could be considered a release of some professional

responsibility. In the aforementioned examples, there appears to be a schism between being prepared to share responsibility, thereby demonstrating views of a responsible clinician, but at the same time controlling actual clinical discussions and rationalizing being less open to considering the input of people with aphasia, which could result in a decision different than the SLP had in mind. For an SLP, it is reasonable to prepare for any contact with a person with aphasia and, in that sense, to anticipate decisions. For example, SLP 2 commented, “I think that I have a tendency to draw some conclusions before an end evaluation, because otherwise I am not able to be prepared.” Several SLPs mentioned their considerations being part of their professional responsibility. SLP 1 noted that, “I think it would be professionally irresponsible if you did not do it [consider the outcome beforehand].” The same clinician continued that she never made any decisions but just considerations, but then revised this, saying, “Well, I have made a professional estimate and that is it [pause], but that is not even true, because in some instances, I think I have actually (. . .) made a decision.” However, eight of the SLPs emphasized that reasonable or strong arguments would have to be presented by people with aphasia and their significant others to modify their considerations. For example, SLP 8 said, “When you then have this talk in the outcome evaluation, there have actually been some times when I have changed my mind a bit as opposed to what I thought beforehand. Because then you maybe have some other inputs.” Similarly, SLP 4 said, “There must be some good arguments for why they [people with aphasia] should continue [in therapy], but I can be swayed by what they say.” Such comments indicate that the professional has a particular role as the judge of whether an argument from the person with aphasia is strong enough to be taken into consideration.

The next excerpt, which is a continuation of Excerpt 2, illustrates how all participants tend to orient to the SLP’s role as the primary decision maker:

Excerpt 4

- 1 SLP L: så (0.5) ja så mit forslag er at
so yes so my suggestion is that
- 2 vi at at at vi starter med at holde en
we that that that we start with taking
- 3 pause (0.3) og ser hvad der sker
a break and see what is happening
- 4 WIFE: ‘ja’ ((nods))
yes
- 5 PS: (4.8)
- 6 SLP L: hvad siger I til det
what do you say [think] about that
- 7 PS: (2.1)
- 8 PWA 28: ja det er jo dig der bestemmer
yes well you are the one who decides
- 9 SLP L: ja:h men det er ikke så meget med at bestemme
yeah but it is not so much about deciding
- 10 det er fordi jeg vurderer hvad du får ud af det
it is because I consider what you will gain from it

The explicit suggestion from SLP 12 is not readily accepted by the client or his wife as this response could, in principle, have functioned not as an acceptance of the suggestion but merely as an acknowledgment token (Jefferson, 1983) or, maybe even disagreement as the soft-spoken response can resemble (Buttney, 1993; Isaksen & Brouwer, 2015). The SLP continues, however, by requesting their opinion of her suggestion. Again, her first pair part is followed by a long pause, before PWA 28 finally says that the SLP is the one who decides. The clinician does not deny this statement but instead gives an argument for her suggestion, underpinning her professional stance in this case. Therefore, despite calling it a suggestion, and asking the couple for their opinion, it is still understood as a decision by all parties. This example underscores the asymmetry between the involved parties due to the preference for agreement and the function of the SLP making the first pair part. Both of these discourse features pose challenges to allowing authentic involvement in decision making. Furthermore, the opposite can be seen in Excerpt 3, where a person with aphasia took the initiative.

Theme 3: Shared decision making is not always necessary

Despite SLPs’ expressed intention to involve people with aphasia in decision making

and make attempts to do so, some also commented that shared decision making is not always necessary. Consistent with this, analysis of session videos provided examples of episodes where shared decision making was not attempted. As explanation, half of the SLPs mentioned how well they typically get to know their clients, implying that the close relationships and familiarity with their clients, as well as the continuous discussions of outcomes during therapy, positioned them to see themselves as being capable of making the decisions alone. For example, SLP 5 said,

Well, I have an idea that the person with aphasia often thinks the same as me, because you have the ongoing contact where you talk about what you think (. . .). So often you have talked about therapy ending soon (. . .). You somehow know your client.

Similarly, three SLPs found that the continuous sharing of information with their clients, as well as their own meta-communication about therapy throughout the course of treatment, replaced the need for client involvement in the decision making at this potential transition point of outcome evaluation. SLP 7 noted,

I have really tried to explain a lot along the way (. . .) really explain why we should stop now. That is why it is really important to talk about, what our goals were, what has happened (. . .) and also say, "I cannot offer you anything more."

The next excerpt illustrates another situation that may not require shared decision making because the person with aphasia was already aware (and perhaps even informed) of the SLP's view that therapy was likely to terminate now:

Excerpt 5

1 SLP L: hvad så nu
 then what now
 2 PS: (5.3)
 3 SLP L: fordi faktisk så (0.5) dit forløb har været
 because actually your course has been
 4 meget meget længere end der var aftalt
 much much longer than agreed
 5 PWA 26: "ja jeg fik jo omkring tyve"
 yes I got around twenty

6 SLP L: ja
 yes
 7 PS: (1.8)
 8 SLP L: det det har været fordi at det har der været behov
 for
 it it has been because it was needed
 9 PS: (0.8)
 10 SLP L: så det er helt okay
 so that is quite okay
 11 PS: (4.7)
 12 SLP L: du vel- du ved ved næsten godt
 you vel- you know know almost
 13 hvad jeg vil sige nu gør du ikke
 what I am about to say now don't you
 14 PWA 26: ja at jeg skal stoppe ((smiling))
 yes that I must stop
 15 SLP L: jah ((laughing))
 yeah
 16 PWA 26: ja jeg ved det godt (.) ja
 yes I know yes
 17 SLP L: det har du være indstillet på
 you have been prepared for that
 18 PWA 26: "jeg ved det godt" ((looking down))
 I know

In Excerpt 5, the SLP explains why the therapy must end and the person with aphasia displays knowledge thereof. However, the long pause in line 2, together with the SLP's use of qualifiers ("actually" and "much much"), could indicate discomfort with the fact that additional therapy is not being offered. Alternatively, this could be an attempt to provide a rationale for the SLP's decision to stop therapy (Pomerantz, 1984). PWA 26 is given opportunities to respond in the long pauses in. Later, the SLP 12 asks PWA 26 for the decision she is about to give, which is subsequently spoken by PWA 26. Despite PWA 26 not being surprised that she must cease therapy, she gazed down during the interaction, which might express disappointment or disagreement together with the long pauses. During the excerpt, PWA 26 provided the prompted decision "I must stop," which might decrease the likelihood that she would or could question it. This statement conveyed her apparent acceptance of the explanation of why therapy needed to stop, provided during the excerpt and perhaps also earlier in therapy, as indicated by SLP 12's comment, can make the lack of a decision-making progress easier for the parties. However, this may not be necessarily the case as indicated by the silence and downward gaze of the client.

Excerpt 5 resembles other instances in the data set, namely, that some of the potential decisions were already made. In some instances, the payer (i.e., the client's municipality) announced prior to a course of therapy it will pay only for so many hours and additional funding of therapy is nonnegotiable. In other cases, it seemed to be the SLP's decision and not a topic for discussion. Nevertheless, the SLP in Excerpt 5 treated the decision, as if it could be discussed and negotiated. Here, the circumstances are not clear, but the comment that PWA 26 got more therapy than initially agreed upon could establish the reason for deciding to end therapy.

These examples indicate that attempts to involve people with aphasia in shared decisions are not always genuine. In some cases, that is because the decisions are made beforehand due to professional judgment or contextual limitations. Yet, the decision was still framed as if it could be discussed. Perhaps the SLP's reason for framing the decision in this manner is because he or she is pursuing agreement or acceptance of the decision presented to the person with aphasia.

Theme 4: Aphasia can affect shared decision making

In accordance with previous research (e.g., Berg et al., 2017; Leach et al., 2010), the SLP interviewees reported difficulties with involving person with aphasia because of the aphasia. SLP 6 observed, "There is hardly much interactive user involvement in it, but it is because they have difficulty expressing themselves." Similarly, difficulties in language comprehension can prevent SLPs from involving their clients. SLP 12 commented,

Well, for example, it can be really hard to evaluate with people with aphasia having difficulties in language comprehension. It is difficult, and I must evaluate without the affected being present. (...) It also happens that once in a while I must tell an affected person, 'Now I will speak to your wife, and is that okay?'"

In contrast, finding the right tools or ways to involve people with aphasia were mentioned as being important for successful decision making by four of the participants. For

example, one clinician had started using Talking Mats, a simple system of both custom- and ready-made pictures that are moved around on a mat for communicative purposes (e.g., to indicate subjects or express viewpoints; Murphy & Cameron, 2006). SLP 6 said, "I have also started using the method called Talking Mats for evaluation. And it is in fact very, very good because they [people with aphasia] have the opportunity to enter the scene."

Excerpt 6, which is a continuation of excerpt 1, shows a person with aphasia engaged in prioritizing former therapy goals in a new order for continued therapy.

Excerpt 6

- 1 SLP I: men hvad tænker du så er fremtidsplanen
but what do you think is the future plan
(15 seconds cut out of conversation where SLP
summarize therapy content and outcomes)
- 2 hvad skal vi så nu
what are we supposed to do now
- 3 PWA 21: "øhm" (1.7) det samme men ehh mål nummer tre skal
ehm the same but ehh goal number three must
(2.1)blive eh (.)op op hahh opdateret (2.4)
get eh up up hahh updated
- 4 så det er hovedparten
so that is the mainpart
- 5
- 6 SLP I: ah okay
- 7 PWA 21: tror jeg
I believe
- 8 SLP I: ja
yes
- 9 MUM: "opprioriteret"
greater priority
- 10 PWA 21: ja ja
yes yes
- 11 SLP I: ja (0.5) så vi forsætter med at
yes so we continue with
- 12 SLP I: [få helt styr
gaining full control
- 13 PWA 21: [men eh eh nu mål nummer to skal også være eh
but eh eh now goal number two must also be eh
- 14 SLP I: ja den bliver vi lige som nædt til at have helt styr
på
yes that we must really take control of
- 15 PWA 21: ja nemlig ja
yes exactly yes
- 16 SLP I: ja så forsætter med mål nummer to
yes so continuing with goal number two
- 17 PWA 21: "ja"
yes
- 18 SLP I: og mål nummer tre
and goal number three
- 19 PWA 21: "ja"
yes
- 20 SLP I: ja
yes
- 21 PWA 21: og så eh (.) mål nummer et skubber ehm vi lidt væk
and then eh goal number one we push ehm away a little
- 22 SLP I: ja
yes
- 23 PS: (0.4)
- 24 SLP I: det gemmer vi til senere
we save that for later

PWA 21 plays an active role in this excerpt in response to the open question from SLP 9, following a conversation about his former goals for the prior therapy course. The goals were listed on a piece of paper in front of him. PWA 21 wanted to work with the same goals but requested them to be differently prioritized for the next course of therapy. The SLP contributes to this interaction by paraphrasing his suggestions with reference to the written goals. In that sense, the SLP's input is a display of understanding but also of agreement, which contrasts most of the data, in which the SLPs either proposed suggestions or provided options in each context. This excerpt could, however, also be regarded as an example of an SLP-initiated involvement within a closed context, namely, goal setting with the same goals as the last therapy course. By posing the open question "what do you think?" the SLP opens to accommodate to the person's views, but this is potentially also an opening for disagreement. However, there is a slight change already where SLP 9 went from "you" to "we" in her question to PWA 21, indicating that this question was not open for PWA 21 to decide whatever he wanted, but that the goal setting needs to be done collaboratively.

The person with aphasia in Excerpt 6 can take part in shared decision making despite noticeable aphasia. Examples of people taking part with more impaired communication skills are also present in the video data but not presented in this article. What is of importance is that seven people with aphasia try their utmost to support communicative participation by using communication strategies including *Talking Mats*, *Supported Conversation for Adults With Aphasia*, or self-made aphasia-friendly initiatives supporting the interaction (e.g., smiley scales and other graphic illustrations; Kagan, 1998; Murphy & Cameron, 2006).

DISCUSSION

The overall findings in this study point toward the SLPs being in control of involvement and decision making, as shown in the

sequential organization of these sequences of clinical discourse, where nearly all first-pair parts from them project for second-pair parts from people with aphasia or significant others accepting the first move. Speech-language pathologist-driven decisions seem to be favored by both the SLPs and people with aphasia. Boundaries are rarely challenged as seen in Excerpt 3. This preference for SLP-made or SLP-initiated decisions is employed through the organizational structure providing an illusion of a shared decision-making process at this important transition point in aphasia therapy, the outcome evaluation, rather than being imposed deliberately or intentionally by any of the participants. In the following, three problems appearing in the aforementioned analyses, namely, *unclear context*, *preferred agreement*, and *the role of the SLP* in decision making, will be discussed and related to issue theme *clinical discourse as cultural borderlands*.

Unclear context

The examples examined within this study align with some of the prerequisites for shared decision making, which suggest that at least two people are present, they share information, and they reach an agreement (Charles, Gafni, & Whelan, 1997). However, one key prerequisite of shared decision making according to Charles et al. is that both parties take steps to participate in shared decision making. This feature is lacking in these examples. It may be that it is difficult to meet this criterion in these interactions because of the institutional context where the SLP is more likely to take interactional initiatives than the person with aphasia. People with aphasia may also be additionally challenged by their aphasia when attempting to take the initiative.

The cultural borderland is created in and through the clinical discourse, in which involvement and shared decision making become difficult because the person with aphasia neither knows nor aware of what is possible to decide, because it is not clearly presented by the SLP. In Excerpt 5, recall that

PWA 26 had received more hours of treatment than initially planned, and this was used as an argument for termination of therapy. Hence, it could not be discussed or questioned by PWA 26. Whether it was because of a lack of funding for more hours or because the SLP thought it was enough hours (or whether there was another reason) remained unclear. It should be noted that this line of argumentation about hours contrasts with how provision of therapy is described in the legislation, which specifies that aphasia therapy is to be goal-driven and not driven by a certain number of hours. Such findings point toward another unclear contextual barrier: what is up for negotiation? There is no point in negotiating whether therapy should stop or continue if, for example, the SLP or funder has already decided that therapy will stop. A greater transparency in general about the services being offered and what is up for negotiation is needed and will likely reduce the boundaries and challenges of this unclear discursive borderland activity of shared decision making.

Decisions that a person with aphasia can influence need to be clear to generate a genuine negotiation of future plans, rather than pretending that everything is possible if it is not (see Excerpt 6). If not, the cultural borderland of clinical discourse between SLPs and people with aphasia becomes an even more uncertain place than necessary. Hersh (2009) described eight reasons why discharge is difficult from the SLPs' point of view (including limitations to negotiate and discharge as an unclear phenomenon). Some of Hersh's findings are in keeping with why involvement or shared decisions are difficult as found in the current study. Clear communication of what is expected from both the SLP and people with aphasia in situations of outcome evaluation is crucial for genuine participation by all concerned.

Agreement is preferred

Reaching agreement between the parties is, as stated previously, a part of the definition of shared decision making by Charles et al. (1997). Earlier studies show strong pref-

erences for agreement in everyday as well as institutional interactions (Isaksen & Brouwer, 2015; Pomerantz, 1984; Sacks, 1987). Hersh (2009) also implied that some issues are hard to talk about when moving toward ending therapy and might, therefore, not be addressed. Those studies, together with Stivers' (2005) description of resistance being treated as problem behavior in medical encounters, combined with findings in this study, lead to the assumption that resistance is something that is actively avoided and suppressed. For instance, in Excerpt 5, the person with aphasia might not protest against the fact that she is ending therapy, because prior to the news of therapy discharge, the SLP states that she has already received far more therapy than initially agreed on. This avoidance of resistance or disagreement seems paradoxical because it closes opportunities for genuine discussions of what is the best decision for the person with aphasia. Also in the clinical discourse as a cultural borderlands, the disagreement is diminished. This can further lead to maintenance of problematic cultural borderlands, because a clear difference between SLPs and people with aphasia remains as a consequence of silencing attempt of discussion or questioning initiated by people with aphasia as seen in Excerpt 3.

The role of the SLP in supporting shared decision making

Professional autonomy can be challenged by client-involving activities and is often mentioned as a barrier for involvement (Légaré et al., 2008). This leads to an issue worth discussing in this context, namely, aphasia, and the perceived inequality between the parties because of their diverse language skills. Hersh (2009) has found that aphasia contributes to the difficulty in shared decision making around discharge, but we know that there are many benefits of shared decision making and that people with aphasia want to be involved in therapy, goal setting, and decision making in general (Berg et al., 2016; Nordehn et al., 2006; Worrall et al., 2011).

People with aphasia in the study by Nordehn et al. (2006) suggested that sufficient time and respect, among other qualities, supported them in communicative involvement. In other areas of medical care, decision-making tools often are promoted as a good facilitator. In aphasia therapy, involvement and decision making can be supported by, for example, communicative strategies used by the conversation partner without aphasia or via the use of visual materials. However, this was not the case in any of the included excerpts. Such strategies, however, may have supported the participants with aphasia in Excerpts 4 and 5 in providing their opinions on the ending or pausing therapy. No use of any communicative support here might be due to these individuals' fairly strong spoken communication abilities but might also be a way to avoid problem behavior (e.g., protest against the decisions). Visual support and other types of tools might be supportive, but these or any other decision-making tools still require verbal communication. Most likely, conscious ways of involving people with aphasia in communication, like Talking Mats (Murphy & Cameron, 2006) or Supported Conversation for Adults with Aphasia (Kagan, 1998), would be beneficial in many complex interactions, such as shared decision making. However, facilitating communication inherently has constraints due to the reduced numbers of options the therapist provides. While provision of visual support is desirable, it may come with the associated risk of limited free responses from the person with aphasia.

Limitations of the study

The study aimed to provide insight into decision-making processes toward the end of aphasia therapy. Because of the qualitative nature of the study and a data collection made in Denmark, the generalization of the description of how decision making takes place or not as a part of the clinical discourse between SLPs and people with aphasia is limited to this specific cultural context. The cultural context including legislation can likewise also be reflected in the SLPs' views upon

involvement. The exploration of shared decision making made in and through interactions underpinned the theory of clinical discourse as cultural borderlands. Findings could be different with other participants such as people with aphasia with severely impaired language comprehension or SLPs systematically using supportive communication strategies.

This study is also limited to study shared decision making in outcome evaluation of aphasia. Therefore, the findings lack an examination of shared decision making at other time points of aphasia therapy or in other clinical contexts. Furthermore, the data collection for this study was made with another aim in mind (describing the practices of outcome evaluation in aphasia therapy), and hence this secondary analyses made in this study can be affected by that. Finally, as in any other qualitative study, there is a chance of researcher bias influencing the reported findings, but despite being analyzed the sole author of this article, the findings are discussed with and validated by fellow researchers and participating SLPs.

CONCLUDING REMARKS AND FUTURE DIRECTIONS

Involving people with aphasia in decision making is important for the 12 SLPs, who participated in this study. Throughout the video data, the SLPs provided an opportunity for people with aphasia to pose viewpoints, but all opportunities were initiated by the SLPs. When the SLPs produce the opening move in a conversation (“first pair part” according to Schegloff, 2007) there is a chance for them to prompt the specific answers by the people with aphasia in their responsive part of the interaction (second pair part). As mentioned earlier, studies have shown that agreement is preferred over disagreement (Pomerantz, 1984). This can make it awkward for the person with aphasia to disagree with the suggestion proposed by the SLP. Furthermore, the SLPs often provide options or candidate answers that are likely to either support the person with aphasia linguistically or

communicate what the person with aphasia can decide or choose between in the particular situation (Svennevig, 2012). This points toward involvement and shared decision making as an SLP-induced process (Excerpts 3, 4, and 6), where agreement or acceptance from people with aphasia is pursued rather than negotiating from unlimited free choices. Instead, client involvement can be viewed as (1) having the opportunity to accept the SLP's suggestion (Excerpts 4 and 5) or more unlikely protest against it and/or (2) choosing between given options limited by, for example, institutional context and communicative support (Excerpt 6). Such SLP-induced processes, with little scope for true involvement in decision-making practices by people with aphasia, inherently maintain the cultural borderlands of clinical discourse. A clarification

of what shared decision making or other involving attempts are and what is expected from all participants would likely help those involved to move from illusory to genuinely shared decisions.

Additional studies of how shared decision making is conducted and how it can be supported by SLPs are needed to support and expand the aforementioned findings. Furthermore, increased clinical awareness is needed of how involvement is created in and through interaction, not only at key transition points in therapy but also throughout all points in aphasia therapy. In this way, SLPs and people with can successfully navigate the often uncertain territory of clinical discourse as cultural borderland. That would enhance the activity of genuine shared decision making, where authentic engagement is key.

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