

## **Introduction**

Evidence-based practice recognizes “the needs, abilities, values, preferences, and interests of individuals and families to whom they provide clinical services, and integrate those factors along with best current research evidence and their clinical expertise in making clinical decisions” (American Speech-Language-Hearing Association, 2005). Identifying these factors, as a key aspect of EBP, and as it relates to people with aphasia and their families, is the focus of this paper. The aim of this study was to describe the goals of people with aphasia and their family members and to compare these to their treating speech-language pathologists’ goals.

## **Method**

### **Study Design**

A qualitative descriptive research strategy (Sandelowski, 2000) was used in the study.

### **Participants**

Fifty-one participants with aphasia were recruited through an aphasia registry and community sources in three Australian cities. Participants with aphasia (PWA) were then asked to nominate family members (FM) and their treating SLPs. One participant with global aphasia was excluded after the interview failed to obtain meaningful responses to the interview questions. Fifty people with aphasia, 49FMs, and 36 SLPs were included in this study (n= 135 in total). The PWA comprised 24 males and 26 females. The PWA had an average age of 63.9 years (32-83 years), time post-onset of 54.3 months (1-195 months), and Western Aphasia Battery Aphasia Quotient score of 69.6 (11.8-97). The FMs comprised 13 males and 36 females.

### **Data Collection**

Semi-structured in-depth interviews were conducted with the participants in their homes, place of work, or other location of their choice. The interview schedule for the PWA included the following topics: 1. Their experiences of aphasia (e.g., *Tell me about when you first had aphasia*); 2. Their rehabilitation goals and needs (e.g., *When you first had your stroke what was important to you? What were your concerns? What did you want to work on in speech therapy? What were your goals?*); 3. Their aphasia rehabilitation and service experiences (e.g., *Did you work on these areas in speech therapy? If yes, how did you work on them? If no, what did you want to work on? Did speech therapy help?*); 4. Aphasia services they would have wanted (e.g., *What other services or things did you want at that time related to your aphasia?*). These topics were repeated for specified times after their stroke (i.e., when they first went home, when they had outpatient speech therapy, later, and at the time of the interview). A similar interview schedule was used for the family members. The interview schedule for the SLPs included these topics: 1. Their experiences of providing therapy to the named person with aphasia and their family members; 2. Their goals of therapy for the person with aphasia and their family members; 3. Their perceptions of the goals of the person with aphasia and their family members; and 4. Barriers and facilitators to goal-setting.

Interviews with people with aphasia were videotaped, while interviews with family members and SLPs were audiotaped. All interviews were transcribed verbatim based on the transcription conventions of Poland (2001).

### **Analysis**

Qualitative content analysis (Graneheim & Lundman, 2004) was conducted to identify the goals and superordinate categories of goals for each participant group. Themes were then derived by identifying the meaningful essence underlying the data from the three participant groups (Graneheim & Lundman, 2004).

## **Results**

The superordinate categories of goals for each of the three participant groups are shown in Table 1. The themes underlying the data from the three participant groups centred around relationships, hope, communication and translation of identity, unmet needs, the influence of context, and the translation of goals. Each of these themes is discussed below.

**Relationships:** Many participants with aphasia and family members stressed the importance of a good relationship with their health professional, particularly their speech pathologist. Some SLPs also spoke about the importance of the relationship with their clients for goal-setting. A number of family members also talked about the impact of aphasia on their family and their relationship with the person with aphasia.

**Hope:** Several participants with aphasia and family members spoke of the importance of hope in their rehabilitation, particularly in the way that prognoses were conveyed to them and the value of a positive approach to rehabilitation by health professionals. In contrast, they spoke of the devastating effect when hope was taken away by health professionals. Although some SLPs talked about the importance of hope, others discussed the need for acceptance of the disability by the client and their family

**Communication and translation of identity:** Improving communication was, as expected, a goal of all participants. Participants with aphasia wanted to express their basic needs as well as to perform activities such as reading books and taking part in conversations with family and friends. Family members also talked about the desire to improve their communication with the person with aphasia, as well as wanting the individual to have a meaningful life. SLPs also talked about communication goals, but often used different language to describe their goals.

**Unmet needs:** Participants with aphasia focused on their requirement for information and services to meet their unmet needs. Family members also discussed unmet needs, particularly information and support, the opportunity to be involved in rehabilitation, and the need for greater recognition of the impact of aphasia on family members. SLPs also sometimes talked about services that they wished to provide, but were unable to, given their contexts and resources.

**Influence of context:** SLPs often talked about the influence of context in goal-setting, particularly the context of the workplace. Participants with aphasia and family members also expressed different goals depending on the context. For example, in the hospital, some participants with aphasia reported mainly wanting to go home.

**Translation of goals:** Some SLPs discussed the difficulties in translating goals and tensions in this process. While participants with aphasia and their family tended to identify broad goals, therapists frequently stated reported prescriptive sub-goals.

The study revealed the primary tensions in goal-setting revolved around the importance of the clinical relationship, hope, unmet needs including information, support, and family members as clients, the influence of context, and the translation of goals.

## **Discussion and conclusion**

The findings describe priorities of the primary stakeholders in aphasia rehabilitation. While communication goals were evident across all groups, emergent themes relating to "relationships and hope" illuminate ways to scaffold the process of goal setting. The combined voices of people with aphasia, family members and speech pathologists herald the emergence of an overarching philosophy for aphasia rehabilitation across the continuum of care. Thus, this research may begin to close one of the gaps (between client and clinician) in evidence based practice.

Table 1: Categories of goals

| Categories of goals for person with aphasia |                              |   | Categories of goals for family member |                        |
|---|------------------------------|---|---------------------------------------|------------------------|
| People with aphasia for themselves          | SLPs for person with aphasia | Family member for person with aphasia   | Family member for themselves          | SLPs for family member |
| Communication                               | Communication                | Communication                           | Way to communicate with individual    | Communication training |
| Information                                 | Education                    | .                                       | Information                           | Education              |
| Control and independence                    | .                            | Being independent, handling emergencies | Own space and time                    | .                      |
| Dignity and respect                         | Support                      | .                                       | Support                               | Support                |
| Return to pre-stroke life                   | Evaluation                   | .                                       | Hope                                  | .                      |
| Social, leisure and work                    | .                            | Social contact                          | .                                     | Participation          |
| Altruistic and contribution to society      | .                            | Stimulation, meaningfulness             | .                                     | .                      |
| Physical function and health                | Personal factors             | Survival                                | .                                     | .                      |
| .   | No goals set                 |   | To be included in rehabilitation      | Lack of goals, contact |

## References

- American Speech-Language-Hearing Association. (2005). Evidence-Based Practice in Communication Disorders [Position Statement]. Available from [www.asha.org/policy](http://www.asha.org/policy)
- Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, 24(2), 105-112.
- Poland, B. (2001). Transcription quality. In J. G. J. Holstein (Ed.), *Handbook of interview research: Context and method* (pp. 629-649). London: Sage Publications.
- Sandelowski, M. (2000). Whatever happened to qualitative description? . *Research in Nursing and Health*, 23(4), 334-340.
- van den Broek, M. D. (2005). Why Does Neurorehabilitation Fail? *Journal of Head Trauma Rehabilitation*, 20(5), 464-473.