

Needs of Family Members of People with Aphasia in Early Acute Care

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Background

Family members should be included at all stages of aphasia rehabilitation including receiving information and training to support communication (Hebert et al. 2015; Winstein et al. 2016; Simmons-Mackie et al. 2017). However, services for family tend to be minimal (Halle, Le Dorze & Mingant, 2014; Levack et al. 2009). Anecdotal evidence suggests that this situation is particularly apparent in the early acute phase of hospitalization.

Aims

The overall goal of this project was to develop a practical program to address information and training needs for families during the early acute stage of hospitalization.

The immediate aim of this study was to identify parameters requiring change in this setting based on family member experiences and collect concrete information to assist in creating relevant resources.

Methods

The early acute care project took an Integrated Knowledge Translation (IKT) approach, designed to promote health care change.

The present study is the first phase of this project and entailed qualitative research to gather information from family members (n=15) regarding early acute experiences, needs, and potential resources (addressing IKT stages of defining problems and identifying knowledge and behavior parameters).

Data collection methods included focus groups (n=8) and an open-ended written survey (n=15).

Qualitative thematic analysis of the data was conducted (Braun & Clark, 2006) and findings were audited to ensure analytical rigor.

Integrated Knowledge Translation Stages

Clearly defining the problem(s)

Identifying knowledge & behavior change parameters

Adapting change to the context

Assessing barriers to knowledge use

Creating resources for implementation

Implementing the changes in line with quality improvement (QI) principles

Key stakeholders involved throughout the process

Findings

"There's nothing for the family"

Family members felt alone on a traumatic journey and had to find information themselves (e.g. searching online without guidance).

"So #1, get the [aphasia] diagnosis early on"

None of the family members in the focus groups heard the word "aphasia" until after discharge from acute care.

"They did not give me any information about it [how to communicate]"

No information was provided to the families about how to communicate with the person with aphasia.

**"They did not really communicate with him"
"Staff would...not even bother with him"**

Families reported poor staff understanding of aphasia, lack of attention & time, and failure to use communication support.

"Only the speech pathologist mentioned this and she was rarely there when I could be present"

Families felt that ALL staff should be knowledgeable and responsible for helping family members understand aphasia and communication support.

"They do not want to give you hope"

Future options and hope for the future were not provided; families wanted more support & hope.

Discussion

Our findings showed there were very negative evaluations of services in acute care as they relate to aphasia and communication.

- Families' needs for information about aphasia and how to communicate with the person with aphasia (PWA) were unmet.
- Staff members were not able to communicate with the PWA or with the family.
- Staff members did not provide the hope and support that families wanted.

Best practice recommendations could address all concerns expressed in the study. However, guidelines regarding inclusion of families and patients and training of all team members in supported conversation were not implemented in acute care settings. (Hebert et al., 2016).

These findings suggest an urgent need for the implementation of acute care services that are aligned with best practice guidelines, especially as they relate to aphasia assessment, early SLP involvement, and family information needs about aphasia and training in communication. Staff members also need specialized communication skills for interacting with people with aphasia, which could favorably impact their interactions with family members.

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