

COMPUTER-ASSISTED COMMUNICATION WITH PERSONS EXPERIENCING EXPRESSIVE APHASIA – CAREGIVER PERSPECTIVE

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Purpose: To describe the communication experience of primary caregivers for persons experiencing aphasia who were enrolled in a study to examine the feasibility of learning and using computer generated speech to assist in every day communication.

Method: A modified grounded theory approach (Taylor & Bogdan, 1983) was used to elicit stories about the caregiver's experiences communicating with their care recipient. 10 subjects who were the primary family (n=7) or professional (n=3) caregivers for persons who were actively engaged in speech therapy following a cerebrovascular injury leading to some degree of expressive aphasia. Subjects were interviewed for 1-1.5 hours at three time points: prior to introduction of computer assisted speech to care recipient, after the computer had been programmed for content tailored to the care recipient and the caregiver had been taught how to modify the program, and after the care recipient had been using the computer for 2-4weeks. Each interview was audio and videotaped, and transcribed verbatim. The transcription was then checked against the audio-tape. QSR- NUDIST was used to manage the data. Data that described the communication experiences were coded by theme. Similar themes were categorized into broader topical areas. An audit trail of coding decisions was maintained. Credibility was addressed by having 2 investigators independently code the the data, discuss coding categories, and develop consensus on labels for categories, and placement of data in categories. Categories were examined across the three study time points. Similarities and differences across time were examined.

Findings: Communication strategies developed and used by caregivers were clearly articulated by all caregivers at the beginning of the study. Most subjects described a strong investment in the usefulness of these methods and reported difficulty embracing the idea of trying a new method. Even those subjects who vocalized that existing strategies did not work enough of the time, expressed hesitancy about using the computer. Some described the use of computer assisted speech as a "crutch" and were afraid that the care recipient would lose ground with other speech methods. Differences were noted between family and professional caregivers. Major categories describing the communication experience included: Routine CareStrategies, Insider Meaning, Emotional Meaning, and One-Sided Meaning.

Discussion: These data have demonstrated the complexity and challenge of communication for caregivers of persons experiencing expressive aphasia and support the need for further examination of communication between caregivers and care recipients who have diminished capacity for communication.

