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Observational Outcome Measures to Evaluate Assistive Technology Use by People with Dementia - Report Series # 12

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Observational Outcome Measures to Evaluate Assistive Technology Use by People with Dementia

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About SERC (Sheridan Elder Research Centre)

Through applied research the Sheridan Elder Research Centre (SERC) will identify, develop, test and support implementation of innovative strategies that improve the quality of life for older adults and their families.

- 1. Wherever possible, older adults participate in the identification of research questions and contribute to the development of research projects at SERC.
- 2. We conduct applied research from a psychosocial perspective which builds on the strengths of older adults.
- 3. Our research is intended to directly benefit older adults and their families in their everyday lives. The process of knowledge translation takes our research findings from lab to life.
- 4. SERC affiliated researchers disseminate research findings to a range of stakeholders through the SERC Research Report Series, research forums, educational events and other means.
- 5. A multigenerational approach is implicit, and frequently explicit, in our research.
- 6. To the extent possible our research is linked to and complements academic programs at the Sheridan College Institute of Technology and Advanced Learning.

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This report describes a digital video-audio behavioural observation methodology for use in a naturalistic setting to evaluate communication rehabilitation interventions for older adults with dementia. Behavioural observation via recorded video-audio offers a number of advantages over other data collection methodologies, which can be subject to a number of biases and limitations, some of which are discussed. In this study, high quality digital audio-video recordings were collected on participants attending a respite care day program. Recording equipment was inconspicuously placed, and measurement occurred either during normal day-to-day activities or during more directed activities (e.g., playing bingo). The recordings can be used to document the occurrence of behaviours and paired behaviours of interest over extended periods of time or selected samples of interest can be downloaded for detailed analysis including lag-sequential analyses. It was found that behavioural observation can complement traditional objective measures of impairment and subjective questionnaire measures, in accordance with the World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (2001).

1. Purpose

Disease co-occurrence can interact to make a pair of diseases more disabling than either one would be alone, and this may be the relationship between dementia of the Alzheimer's type and hearing impairment associated with aging. Unmanaged hearing loss will most likely interrupt the processing of spoken messages regardless of other pre- or co-occurring conditions. Therefore, one must consider hearing management in the patient with hearing loss and dementia of the Alzheimer's type. Interestingly, hearing impairment that co-occurs with dementia of the Alzheimer's type may be particularly problematic as there is some data indicating overlapping communication difficulties (e.g., asking for repetition, searching, forgetting) that may be caused by Alzheimer's disease (AD), hearing loss, or a combination of these conditions (e.g., Peters, Potter, & Scholer, 1988).

Currently, about 1 in 10 Canadians between 75 and 84 years and 1 in 3 over the age of 85 years suffer from dementia and by 2031 over 750,000 will be affected (Canadian Study of Health and Aging, CMAJ, 1994). The prevalence of clinically significant auditory deficits is markedly higher. Hearing loss is the third most prevalent chronic disability among older adults, exceeded only by arthritis and hypertension (e.g., Binnie, 1994; Haber, 1994). Age-related hearing loss (presbycusis) progresses over time until there are measurable and clinically significant changes in threshold sensitivity. As many as half of adults aged 75 to 79 years have some degree of audiometrically measurable threshold hearing loss (Willott, 1991). Thus, it should come as no surprise that many individuals with dementia also suffer from hearing impairment. Palmer *et al.* (1999) note that hearing deficits may be the most frequently unrecognized condition in patients with dementia of the Alzheimer's type because patients either communicate adequately in quiet or the impairment is masked by other behavioural symptoms of dementia of the Alzheimer's type.

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Although patients with AD have been considered difficult to test, previous research has demonstrated that it is possible to conduct reliable and valid hearing assessments. For example, Uhlmann, Rees, Psaty, and Duckhert (1989) used an audiometric screening of 40 dB HL with 34 demented and non-demented individuals and found they could produce reliable hearing thresholds. Also, Palmer *et al.* (1999) conducted standard audiometric assessments of 8 persons with AD without notable difficulty. If difficulty is encountered during the assessment procedure, Durrant, Gilmartin, Holand, Kamerer, and Newall (1991) recommend re-instruction, encouragement, and gentle prodding.

Management of hearing impairment can be conceptualized by the CARE model (Goldstein & Stephens, 1981), a model designed to help those with hearing loss achieve better communication and which appears prominently in the World Health Organization's (2000) terminology. These include (1) Counseling and psychosocial aspects, (2) Audibility or amplification aspects, (3) Remediation of communication activity, and (4) Environmental coordination/participation improvement. Although there is empirical support for the use of various aspects of the CARE model with "normal" individuals, there is a paucity of empirical support related to the management of hearing loss in this population.

The objective of the current research is the development of a naturalistic observation methodology for use in planning and evaluating communication rehabilitation interventions for older adults with dementia of the Alzheimer's type. Behavioural observation offers a number of advantages over other assessment methodologies, which can be subject to a number of biases and limitations, some of which are discussed later. The development of the methodology will include (1) optimizing the use of unobtrusive state-of-the-art digital audio-video recording technology, (2) creating procedures for transcribing and coding recordings of everyday communication behaviours, and (3) establishing behavioural measures to characterize baseline (pretreatment) performance and outcomes due to interventions.

2. Methodology

The participants attended a day program in a new facility designed for the dual purposes of providing respite care and conducting research on aging. The facility includes three large activity rooms, a greenhouse, and a kitchen with a dining area. Day program rooms are equipped with built-in digital video cameras and microphones. The cameras are high quality colour domes with 22x optical zoom that offer full pan, tilt, and zoom with 30 frame per second output, and rotate 360 degrees. The cameras are strategically placed (i.e., mounted on the ceiling) in the rooms to allow for very detailed close-ups of participants in target contexts (to capture focal behaviours). Alternatively, they can be used by operators to follow mobile subjects around a room with ease (to capture focal individual behaviours). The audio system is based on a Symetrix Symnet DSP system, a modular system that concurrently terminates and manages connections from 56 Shure MX-202/W microphones. The cameras and microphones are controlled by PC and connected to an American Dymanics Digital Video Recorder 160000 capable

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of recording 16 high resolution video channels and 1 audio channel simultaneously. The control unit can display live audio-visual signals in real-time or archive signals digitally to mass-storage computer servers capable of saving several weeks of recordings from multiple rooms. In the console, the video windows display and record all video feeds concurrently. The windows can be individually displayed at 640x480 resolution at up to 30 frames per second. The system has a 160 gigabyte hard drive for archive and retrieval of both audio and video streams. The recordings can be reviewed and selected segments stored for detailed analyses.

The recordings can be used to document the occurrence of behaviours and paired behaviours of interest over extended periods of time. Selected samples of interest can be downloaded for detailed analysis including lag-sequential analyses. First, we examined automatic recordings of daily activities to determine relevant behaviours in the repertoire of the clients with dementia participating in the regular activities of the day program. Next, we focused more closely on discourse and detailed analyses of communication behaviours during selected activities (e.g., playing bingo). We also recorded planned conversational encounters between different communication partners and individual clients. These observations were used to develop baselines against which change due to intervention can be evaluated. The first intervention will examine the use of an FM assistive listening device in small group activities with an activity leader.

Thus far, audiometric assessments have included otoscopic examinations and puretone air and bone conduction thresholds, and were collected by an audiologist. Data were collected with both a standard audiometer in a single-walled audiometric booth (located on-site) and with a portable audiometer.

3. Advantages of Behavioural Observation

The World Health Organization's (WHO) *International Classification of Functioning, Disability, and Health* (2001) has been a catalyst for the re-conceptualization of health care practices (Kiessling *et al.,* 2003; Worrall & Hickson, 2003). The WHO classification delineates that functioning with a health condition can be understood at the level of the body's *impairment* (e.g., hearing loss), at the level of the individual's ability to engage in *activity* (e.g., understand speech), and the level of *participation* in society (e.g., communicating as a spouse). These three levels are not necessarily highly correlated because the impact of impairment(s) on activity and participation can be modulated by personal and contextual factors, including social and physical environments that may be adverse or supportive.

In the biophysical tradition of health care, clinicians conduct objective tests to measure an individual's impairments in highly artificial but controlled standardized conditions. It is reasonable to assume that loss of hearing, vision, cognition, and language will have detrimental effects on communication and the ability to function in many everyday situations. Nevertheless, traditional tests of impairment are insufficient for estimating

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how a person does or could function in everyday life. Some individuals with severe impairments function well in everyday life, while others who have mild impairments experience extreme challenges. More recently, clinicians have turned to the development of questionnaires in an attempt to try to gain insight into functioning at the levels of activity and participation in everyday life. These types of subjective measures have indeed advanced our knowledge of everyday functioning. Nevertheless, clinicians remain perplexed when trying to reconcile the results of traditional clinic-based tests and the subjective reports of patients and families, and they continue to lack reliable and valid tools to evaluate everyday function in context.

The capacity to remotely record participants' focal behaviours with video and audio offers several advantages. First, it is well established that the presence of an observer can cause those being observed to alter their behaviour from that which would normally occur if the observer were not present. Although this may also be true of video-audio recording equipment, this effect is potentially minimized by the inconspicuous nature of recording equipment (e.g., video cameras covered with domes), and by the fact that video-audio recording equipment is an increasingly common feature of public spaces. A second advantage of using recorded video-audio over direct observation is that the digital recordings allow for multiple examinations of the data across time, providing the opportunity for more in-depth analysis of the focal behaviours. Further, the original data can be made available to researchers who were not present during data collection. This has the potential to increase observer reliability and validity.

4. Conclusions

We have developed a new naturalistic observation methodology to complement traditional objective measures of impairment and subjective questionnaire measures. Naturalistic observation of everyday behaviours will enable us to learn how to improve our techniques for assessing and treating problematic communication behaviours in relevant contexts. In accordance with the World Health Organization's (WHO) *International Classification of Functioning, Disability, and Health* (2001), an observational approach enables us to understand the influence of the environment on group and personal behaviours at the levels of activity and participation. By identifying and defining observable communication and associated behaviours that can be mapped to the subjective reports of family and staff, we will develop a new ecologically valid way of objectively assessing everyday communication function and measuring treatment outcomes. Our new specialized behavioural scoring system will include measures of both focal behaviours (scoring based on target behaviours of group members) and/or focal individual behaviours (scoring based on the repertoire of behaviours of an individual in the group).

Naturalistic observation methodology can be used to help establish valid ecological measures to plan and to evaluate the outcomes of interventions in terms of how communication behaviours affect activity and participation (as defined in the World Health Organization ICF, 2001).

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