

Paper

Capacity Assessment and Aphasia: Challenges in Meeting the Needs of Diverse Stakeholders

In Ontario, Canada, the Health Care Consent Act protects the rights of competent individuals to make a decision about treatment and whether to move to a long term care facility or not. If there is doubt regarding a person's ability to make a decision, then that person's capacity is evaluated. Capacity evaluation examines the ability to understand information that is relevant to the individual's medical situation and functional abilities, and to appreciate the reasonably foreseeable consequences of a decision. Following the evaluation, if the individual is found not to have the capacity to make a decision and has been given information on the appeal process, then the healthcare team may approach the individual's substitute decision maker. This course of action, if carried out conscientiously, works well in many situations. There is, nevertheless, a segment of the population for whom this process is wanting; people with aphasia.

As Speech Language Pathologists we have the skills and moral obligation to ensure that legal processes are communicatively accessible to individuals with aphasia and other communication disorders. However, this is a complex process necessitating work with diverse stakeholders including lawyers, ethicists, social workers as well as people with aphasia and speech language pathologists, all of whom have very different agendas and goals. This paper will examine some of the issues that arose in the development of the Communication Aid to Capacity Evaluation (CACE), an adaptation of the capacity evaluation to make decisions to move to long-term.

The current evaluation, 'The Capacity to Make Admission Decisions' questionnaire is highly dependent on a person's proficient use of language. It comprises five complex and lengthy questions, for example,

"How do you think admission to a nursing home or home for the aged could help you with your condition/problem?"

The linguistic structure of an open-ended question encourages the patient to generate a verbal response showing the ability to understand and appreciate. This is notoriously difficult for people with aphasia. The questionnaire provides no visual supports in the form of written material or pictures to augment comprehension, and there is no method to allow the individual to communicate a response non-verbally. Finally, capacity evaluators, predominantly social workers, report that they are not sufficiently trained in the skills to communicate with individuals with aphasia or other communication barriers (Rowland and McDonald 2008).

Three working groups were struck to develop CACE; speech language pathologists, social workers and people with aphasia. The first task for the speech language pathology group was to analyze the content of the Health Care Consent Act and current capacity evaluation tool and reduce the complexity of the language. Every sentence was put into the present tense using the active rather than passive voice. Attention was paid to the length of sentences with the goal of making them short and succinct. Vocabulary was examined ensuring that it was concrete and easy to understand and no contractions were used. Key words that carry meaning were selected and highlighted in bold font. Finally pictographs were chosen to illustrate different concepts. The pictures had to be clear, gender neutral, culturally representative and age balanced.

The most complex task was the explanation of the capacity evaluation process, which is required by law. The social work group, as evaluators, had a keen eye for the legal obligations of the Health Care Consent Act. The speech language pathologists worked hard to simplify what is meant by 'capacity'

“Capacity means that you understand your medical condition”

However, this had to be changed to comply with the Act:

“Capacity means that you have the ability to understand your medical condition.”

It is the **ability** to understand that is evaluated; a subtle difference but important nevertheless. Many of us might not understand the reasons why our electrolytes are out of balance, but we have the ability to understand that it is bad and would have an impact on our general health.

Another area of concern for the social work group surrounded the concept of “making assumptions”. Social workers are strongly encouraged in their training not to make assumptions when interacting with their patients (Rowland and McDonald 2008). The groups’ preference was to use open ended questions for example, changing the question “Do you feel safe at home?” to “How do you feel about living at home?” The speech language pathologists advocated for keeping the original format as some people with aphasia would have difficulty in answering an open ended question. However, the social workers point was well taken and strategies to make CACE more conversational rather than responsive were added to the Instructions for Administration.

The working group of people with aphasia included members with a variety of expressive and receptive aphasias. They were asked to comment on the use and clarity of language and pictures, the look of each page and the flow of the evaluation. They found choices moving from left to right easier to understand than choices moving from up to down. The group was insightful and brought up issues that the other groups missed. When evaluating the question “Do you need

to go to a Long Term Care Home?” one group member communicated she did not need to go now but might some time in the future. She was keen that this question should be posed and it was added to CACE.

The face and content validity of CACE was measured by Panel of Experts comprising 11 academics from the field of medicine, linguistics, law and social sciences. The panel was given the original capacity evaluation, sections of the Health Care Consent Act and CACE. They were then asked 7 questions and recorded their responses using a likert scale. The face and content validity was measured high (4.38/5.00). There was one area, however, that scored lower than the others;

*CACE allows the evaluator to assess whether patients **appreciate** the reasonably foreseeable consequences of their decision.*

This construct scored 3.63, midway between ‘neither agree or disagree’ and ‘agree’. This dilemma reflects the literature regarding how to assess capacity, specifically the construct “to appreciate consequences” (Karlawish 2008). Karlawish (2008) found that participants in his study scored lower when measuring ‘appreciation’ in comparison to ‘understanding information’. He also found that “appreciate” relates to the cognitive construct of ‘insight’. Impairments in insight were independent of cognition in the evaluation of capacity. In other words, if individuals scored high with cognitive testing, but insight was an issue then they more likely to be found lacking in capacity. To this end three scenarios that specifically examine ‘insight’ were added to CACE; for example, “What would you do if you fell in the bathroom?”

Without doubt speech language pathologists are well placed to advocate for people with aphasia, especially in the area of healthcare decision making. The notion that the lack of accessibility to capacity evaluation can place a person’s right to decide where to live in jeopardy is a grave ethical concern. However, it is a complex and time consuming process to make any legal process truly accessible and it cannot be achieved in isolation. Early results of the random controlled trial are showing that CACE is an effective tool to evaluate capacity, and that social workers are more confident when using this adaptation. This is in large part due to the input from a variety of different stakeholders.

References

Karlawish, J. (2008) Measuring Decision Making Capacity in Cognitively Impaired Individuals. *Neuro Signals* 16 91-98

Rowland, A. and McDonald L (2008) Evaluation of Social Work Communication Skills to Allow People with Aphasia to be part of the Decision Making Process in Healthcare. *Social Work Education the International Journal* 1-17

