

## **CAC 2013 Poster Presentation**

### **Title: Measuring quality of life for an economic evaluation of aphasia: First steps**

#### **Abstract**

Health economists typically use the Quality Adjusted Life Year (QALY) when conducting economic evaluations of healthcare investments. We have begun investigating methods to obtain QALYs for aphasia by developing a pictographic version of the Time Trade-Off methodology (picTTO) in an attempt to circumvent language barriers. A convenience sample of 50 adults with aphasia participated in reliability and validity testing of the picTTO. Analysis suggests that while the picTTO itself has face validity, results demonstrated poor to moderate test-retest reliability which we plan to improve by optimizing the study design.

#### **Submission**

Health economists frequently use the Quality Adjusted Life Year (QALY) to determine the impact of various health conditions on Quality of Life (QOL). The QALY is a numerical index developed for a given health condition and incorporates the idea that value of an outcome relates to both length of life and quality of life. Thus, the QALY allows one to estimate the burden or impact of a condition and estimate the value of and/or cost effectiveness of interventions. Since the QALY is composed of both length of life and QOL components, improvements in different disease areas or improvements in different areas of the same disease pathway can be compared. QALYs for a given condition are calculated based on group studies in which individuals estimate the burden of the condition. The Time Trade Off (TTO) is one of the methods for developing QALYs. The TTO requires individuals to choose between remaining in a state of poor health (e.g. current aphasic condition) or getting a “cure” for the condition in return for a shorter life expectancy (trading years lived for improved health).

Development of the QALY is important for aphasia because of the profound impact of aphasia on QOL, including social isolation, depression and diminished well-being (Astrom, Asplund, & Astrom, 1992; Cruice, Worrall, Hickson, & Murison, 2003), the limited health care resources available and the need for information on the ‘subjective’ value of aphasia intervention. Since

researchers recently identified aphasia as having the largest negative relationship to a preference-based Health Related Quality of Life (HRQOL) measure, followed by cancer, in a large Ontario study (Lam & Wodchis, 2010), development of the QALY for aphasia could provide support for aphasia intervention. However, to date, people with significant aphasia have been excluded from such investigations due to the language barriers. Although indirect methods or proxies are sometimes used in QALY studies, direct self-report by individuals who have experienced a condition provides stronger face validity. Therefore, the current project aimed to develop a communicatively accessible version of a direct method for establishing a QALY that can be used for individuals with language impairment.

## **Methodology:**

### Phase One: Development

Preliminary development of a pictographic version of the Time Trade Off method was completed on a previously funded grant and continuation of that work was done over a one-year period with input from 3 focus group sessions comprising 7 focus group participants (e.g., clients with aphasia, SLPs, staff, volunteers). The final version of the pictographic TTO (picTTO) resembles a board game. This design was intended to 'lighten' the discussion of the fact that there is currently no cure for aphasia and the hypothetical offer to 'give up' life years for a cure. By the end of this process, we were satisfied that the product had face validity in that participants with aphasia grasped the concept of giving up life years if the aphasia could 'disappear'. The poster will feature the actual pictographic version of the Time Trade-Off methodology used to make the QALY.

### Phase Two: Psychometric evaluation to determine reliability and validity

Fifty individuals with aphasia who had been attending a community aphasia program for at least six months participated in the study. Reliability was evaluated by having participants complete the picTTO on two different occasions two weeks apart. At each session, the participant was asked to estimate the time he/she would give in exchange for a cure for his/her aphasia: a) at the present time (now), and b) at the time of their stroke (before). These ratings were used to calculate QALY utility weights. A weight of 0 indicates willingness to give up all of their

remaining life years for a cure, and a value of 1 indicates that the person is unwilling to give up any life years for a cure. A 'delta' weight representing the difference between the two weights was calculated. These utility weight measures were correlated across two different administrations using Pearson's correlation and intraclass correlation coefficients to establish test-retest reliability.

### **Results and Discussion:**

Intraclass correlation coefficients (ICC) were low for the utility weights (0.00 to 0.26,  $p > 0.05$ , testing whether the ICC was different from 0). Moreover, there was low agreement between participants' willingness to trade off years of life between the test and retest administrations; this was seen for both trade off values at the "present time" and "at the time of their stroke" (multi-rater kappa: 0.20 and 0.33 respectively). However, the direction of change from 'the present time' to 'the time of the stroke' was in the expected direction (i.e., clients were willing to give up less years 'now' than 'before'). In other words, QOL had increased post-stroke.

Post hoc analyses were conducted to determine characteristics that might be related to reliability. Participants were grouped into whether the differences in test and retest scores were within +/- 5 utility points. The factor that was consistently related to decreased reliability was greater time post-onset after stroke. The mean length of time since onset of stroke was almost double among those with less reliable scores for each quantity examined (utility 'now', utility 'at the time of stroke', and the difference in utility scores). This finding is in line with qualitative interviews by the research SLP, suggesting that it may have been challenging for participants to think back to when they first had the stroke, as well as the difficulty in consistently holding 'now' and 'before' in mind at two different time periods. Qualitative analysis (in-depth interview with research SLP) highlighted the fact that reliability data might also have been affected by the fact that the questions themselves engendered much self-reflection that might have itself affected reliability scores.

### **Conclusion:**

From the start, the research team was aware of the challenges related to developing QALY scores for aphasia. This project constitutes a first step in exploring this complex topic. The major

outcome of this project to date is the development of a pictographic version of the Time Trade Off tool to develop utility weights for calculation of quality adjusted life years (QALYs) for aphasia. . The methods of administering the picTTO require alteration, possibly with the elimination of the two time periods (now and before). Future research will require tests of reliability with a simpler methodology e.g., only presenting a 'now' situation to participants. Sensitivity could be tested prospectively rather than retrospectively e.g. comparing picTTO results before and after an intervention. A small pilot survey conducted with SLP's indicates that it might be useful to consider other populations when constructing QALY'S for aphasia – these could include professionals, families and the public. If we are able to satisfactorily establish validity and reliability, the next phase involves a cross-walk to an indirect measure that will be easier for people with aphasia to use for self-report. This will circumvent the current difficulty of presenting people with aphasia the emotionally difficult choice of whether or not they would give up life years if their own aphasia could be cured.

Interest has already been expressed by some decision and policy-makers in relation to the picTTO and therefore, despite the challenges posed by this initiative, it is worthwhile for aphasia researchers to continue a research program to find a direct method to establish QALY scores for aphasia.