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**Participation and Quality of Life
for Persons with Oculomotor Impairments after Acquired Brain Injury**

Sharon Gowdy Wagener

A doctoral project submitted in partial fulfillment of the requirements for the degree of
Doctor of Occupational Therapy,
St. Catherine University, St. Paul, Minnesota

May 17, 2017

Doctoral Advisor: Dr. Kate Barrett, OTD, OTR/L

Doctoral Committee Members: Dr. Kate Barrett, OTD, OTR/L

Dr. Mary Radomski, PhD, OTR/L, FAOTA

Dr. Julie Bass, PhD, OTR/L, FAOTA

**St. Catherine University
Doctor of Occupational Therapy**

Certification of Successful Doctoral Project

We, the undersigned, certify that

Sharon E. Gowdy Wagener
Student Name

has successfully completed the clinical doctoral project titled

**Participation and Quality of Life for Persons
with Oculomotor Impairments after Acquired Brain Injury**

Dr. Kate Barrett, OTD, OTR/L

Doctoral Advisor

May 17, 2017

Date

Dr. Mary Radomski, PhD, OTR/L, FAOTA

Doctoral Committee Member

May 17, 2017

Date

Dr. Julie Bass, PhD, OTR/L, FAOTA

Doctoral Committee Member

May 17, 2017

Date

Certification of Approval for Final Copy of Doctoral Project

I, the undersigned, approve the final copy of the doctoral project by

Sharon E Gowdy Wagener
Student Name

Dr. Kate Barrett, OTD, OTR/L

Doctoral Advisor

May 17, 2017

Date

Acknowledgements

This project is dedicated to the many participants and patients whose stories I have heard and of which I have been part. They have honored me with their confidences, sometimes painful. I only hope that I do them justice in representing them and may make a difference for those in the future who suffer an acquired brain injury with oculomotor impairments.

This project was wholly funded by a generous grant from the Courage Kenny Foundation.

Many thanks to ...

Dr. Kate Barrett and Dr. Mary Radomski for mentoring, editing, and guiding me through this process. You kept me focused and redirected me as needed so I kept the nuggets and did not go off on too many tangents.

Dr. Nancy Flinn who provided a sounding board as well as suggestions and encouragement throughout the project and Dr. Rob Krieger who provided the statistical expertise.

The doctoral OT faculty (especially Dr. Julie Bass who started me on the this project) and clinical mentors (Dr. Mary Radomski and Dr. Nancy Flinn) who provided the framework, resources, and questions to make this journey a reality. Nancy Hendrickson and Janet Winsand who provided technical support.

The “Vision Rehab OTs” at Abbott Northwestern Hospital and throughout the Courage Kenny system for their support and referrals.

My fellow doctoral OT students – couldn’t have done it without the inspiration and support.

Meg Boese (job share) and other colleagues at Abbott who have supported me through this.

Finally, my husband (Fred), son (Victor), parents, niece (Pippa who helped with the final edit), extended family and friends (Kimberly Alexander, Patty Martinson, and Louise Mullen and many others). Without your love, support and encouragement this would not have been possible.

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Abstract

The purpose of this project was to explore the prevalence and nature of participation and quality of life for persons with ABI-related oculomotor impairments. The specific aims were to (1) describe participation in everyday activities and social roles, and quality of life; and (2) provide preliminary recommendations for occupational therapists and health care providers on which specific participation areas to assess and identify possible tools to use.

This study used a cross sectional descriptive approach with self-report tools to measure visual symptoms, quality of life, and participation in everyday activities and social roles. Open-ended follow-up questions were also done to understand the nature of those items described as difficult. Thirty participants were interviewed.

Visual symptoms were significant for 96.7% of the participants. Quality of life scores for both physical and mental health were approximately one standard deviation below the US population norms. All categories except nutrition and personal cares were at least two standard deviations below the norms for community living adults. The everyday activities and social roles identified as very difficult for 80% or more of the participants were: recreation, education, work, house maintenance, and volunteering. Isolated tasks that were very difficult for 59% or more of participants included using a computer, communicating in a group, reading, and driving. It appears that the isolated tasks were perceived as less difficult than when put together. Narrative responses were grouped into three themes: challenges of the task and environment, self-identified personal difficulties, and changes to habits/priorities/roles. The complexity of the situation as well its dynamic nature is discussed. Recommendations are made for which activities and visual symptoms health professionals should be aware, as well as possible assessment tools to use.

Keywords: participation, quality of life, brain injury, visual perceptual

Introduction

Visual impairments that result from acquired brain injuries (ABI) are a serious health issue. About 2.8 million people suffered traumatic brain injuries (TBIs) in 2013 (Taylor, Bell, Breiding, & Xu, 2017). In addition, according to the Center for Disease Control (CDC), more than 795,000 people in the United States experience a stroke each year (CDC, 2016d). The common visual impairments due to ABI include visual field deficits, and oculomotor and binocular impairments (Kaldenburg, 2014). Occurrence of oculomotor impairments has been reported at 86.7% for and 90% for those with TBI and stroke, respectively (Ciuffreda et al., 2007).

Oculomotor refers to eye movements such as the ability to follow objects (pursuits), jump from one object to another (saccades), and fuse the gaze of both eyes together at different distances (binocular vision and vergence) (Suter & Harvey, 2011; Weisser-Pike, 2014). Often times, these patients look as if they have fully recovered without evidence of a physical impairment (e.g. hemiplegia). However, despite the invisible nature of oculomotor problems, these impairments can be particularly distressing and disabling with symptoms that include reading problems, double vision, blurred vision, balance problems, and nausea (Kaldenberg, 2014). Often patients (and sometimes providers) are unaware that these symptoms have a vision etiology (Hellerstein & Scheiman, 2011).

Since 2000 there have been significant advances in the awareness and understanding of visual impairments after ABI. This is has been due to several factors. Advances in the understanding of neuroplasticity have had an impact on the understanding of the visual system in the brain (Suter, Hellerstein, Harvey, & Gutcher, 2011). There have been a number of randomized controlled studies in vision therapy research since 2005 (Scheiman, 2011b). In

addition, the wars in Iraq and Afghanistan have resulted in over 50% of the soldiers returning home with TBI experiencing visual problems (Scheiman, 2011b). Finally, numerous research studies exploring visual impairments related to TBIs and blast injuries have been published (e.g. Brahm et al., 2009; Goodrich, Kirby, Cockerham, Ingalla, & Lew, 2007; Ciuffreda, Kapoor, & Rutner, 2007).

However, within these advances, there remains a lack of research about participation in everyday activities and social roles for those with oculomotor impairments. Research has explored the occurrence of visual symptoms associated with ABI (Brahm et al., 2009; Capó-Aponte, Urosevic, Temme, Rabett & Sanghera, 2012; Heitger et al., 2009; Rowe & VIS Group UK, 2013) and the activity of daily living limitations with visual field cuts (Warren, 2009). But no research, other than studies focused on reading, has described participation in everyday activities and social roles for this population. Therefore, the extent of the disability in these domains is unknown.

Previous efforts to characterize everyday functioning of persons with ABI-related oculomotor impairments are inadequate. A few studies have alluded to participation in everyday activities and social roles and quality of life for those with ABI-related oculomotor impairments. Some of these studies have looked at the differences based on visual diagnoses and symptoms in performance in everyday activities and/or quality of life (Heitger et al., 2009; Lemke, Cockerham, Glynn-Miller, Cockerham, 2013; Rowe & VIS Group UK, 2013). Other studies have explored the associations between oculomotor function/impairment, and functional outcomes and/or quality of life measures (Ali et al., 2013, Heitger et al., 2009; Lemke et al., 2013). However, there are inconsistencies between which tools are used and some limitations in the measurement tools themselves. For example, the modified Rankin Scale (MRS) and

European Quality of Life Score (EQ-5D) used by Ali et al. (2013) are very broad measurement tools and do not measure an adequate number of areas of life limitations. The MRS addresses level of disability ranging from no symptoms to dead and the EQ-5D only has 5 items including mobility, self-care, usual activities, pain and anxiety/depression. Other studies have used low vision outcome measures (e.g. Activities of Daily Living Dependent on Vision questionnaire [Rowe & VIS Group UK, 2013] and 25-item National Eye Institute Visual Functioning Questionnaire [Lemke et al., 2013]). These measures have been used in research related to other diagnoses including multiple sclerosis (Noble, Forooghian, Sproule, Westall, & O'Connor, 2006) and visual field deficits (Papageorgiou et al., 2007). However, these measures do not provide the full scope of participation areas that may be affected by oculomotor impairments.

The study of visual symptoms has been limited in the literature as well. While some studies did not appear to include a standardized assessment (Brahm et al., 2009; Rowe & VIS Group UK, 2013), others have symptom questionnaires designed for concussion symptoms, not for visual symptoms (Heitger et al., 2006; Heitger, Jones, Frampton, Ardagh, & Anderson, 2007; Heitger et al., 2009). Other studies (e.g. Capó-Aponte et al., 2012) have used the Convergence Insufficiency Symptoms Questionnaire (CISS). The CISS is an outcomes measure developed for assessing change in visual symptoms for those receiving treatment for convergence insufficiency (binocular, near vision impairments) (Rouse et al., 2004). However, the CISS does not include the full array of visual symptoms a person with ABI-related oculomotor impairments may have (e.g. blurriness with distance vision, dizziness, glare sensitivity and inability to do sustained reading). In addition, while the CISS has been used in research with the ABI population it has not been standardized for use with this population.

Vision is the most far-reaching of our sensory systems, and changes to it may interfere with a patients' ability to function in everyday life (Scheiman, 2011a). It is important for clinicians to know the symptoms of oculomotor impairments as well as the activities and roles that are most disrupted by this problem so they can direct therapy efforts where they matter most. The purpose of this study was to explore the prevalence and nature of participation difficulties and quality of life implications for a small sample of adults with ABI-related oculomotor impairments while applying a systems model approach. The specific aims were to (1) describe participation in everyday activities and social roles, and quality of life as reported by a small sample of adults with ABI-related oculomotor impairments; and (2) provide preliminary recommendations for occupational therapists and health care providers on which specific participation areas to assess and identify possible tools to use.

Review of Literature

Vision Model

It is important to have an understanding of the visual system and how it interacts with participation. The visual system itself is a complex system. The predominant model used by occupational therapists is the Hierarchy of Visual Perceptual Skills (Warren, 1993). The bottom of the hierarchy includes the foundational skills (acuity, visual field, and oculomotor control). Oculomotor control includes both monocular (fixation, pursuits, saccades) and binocular skills (convergence, divergence, and accommodation). Higher up, the model includes more complex visual processing skills in ascending order: attention, scanning, pattern recognition, visual memory, and visuocognition that eventually leads to adaptation through vision. Of note, the higher level skills are all related to cognitive functioning and how one attends, perceives, understands, and makes decisions to participate and act. Warren (1993) stresses the need to address the lower level skills prior to treating the higher level skills. The optometry profession also has models related to vision and vision rehabilitation that have similar components (Ashley, 2004, as cited by Suter et al., 2011; Scheiman, 2011a). In these models the components are more interrelated and interactive than hierarchical.

To understand how vision affects participation and quality of life a model is needed that incorporates interaction beyond the physical, cognitive and perceptual to include the environment and occupations. The systems model of motor behavior assumes that motor behavior occurs through the interaction between the person (personal characteristics), the environment (performance context), and the occupational performance tasks (Almhdawi, Mathiowetz, & Bass, 2014; Mathiowetz & Bass Haugen, 1994). The subsystems of the person include the sensorimotor, cognitive, and psychosocial systems; and the environment subsystems

include the physical, cultural, and socioeconomic systems (Almhdawi, Mathiowetz, & Bass, 2014; Mathiowetz & Bass Haugen, 1994). As the system is heterarchical, changes to any one of the subsystems of the person or environment can impact occupational performance tasks (Almhdawi, Mathiowetz, & Bass, 2014; Mathiowetz & Bass Haugen, 1994).

With oculomotor impairments after an acquired brain injury, the personal characteristic affected by the impairment is the sensorimotor system. The person may experience adverse symptoms that limit her ability to participate in occupational performance tasks. An actual task (e.g. reading or driving) may affect trigger adverse symptoms (e.g. head ache or eye strain), or it may be the physical attributes of the environment or task (e.g. glare, visually cluttered environment, or the task is located close the person and she is unable to focus both eyes on it) that lead to adverse symptoms. In this case the personal characteristics, performance context, and occupational performance tasks are interacting with each other to limit a person's ability to participate in her occupations and life roles. For the purposes of this study, the use of Warren's Hierarchy of Visual Perceptual Skills provides a basis to understand the specific oculomotor impairments as they relate to the visual system. However, the interaction of the vision system with activity participation is a heterarchical relationship between the person, tasks, and environment.

Prevalence and Symptoms of Oculomotor Impairments

Much research on visual impairments after ABI has focused on the prevalence of various visual impairments and visual symptoms. Specific to oculomotor impairments, prevalence of oculomotor dysfunction has been reported ranging from 68% to 90% of patients with TBI and stroke (Ciuffreda et al., 2007; Rowe et al., 2009). Within the literature on veterans and service members, several studies have looked at specific oculomotor problems for those with blast

related and non-blast related TBI. Convergence impairments have been reported ranging from 42.6% to 61% (Brahms et al., 2009; Capó-Aponte et al., 2012; Goodrich, Flyg, Kirby, Chang, and Martinsen, 2013), and reports of pursuit and/or saccadic impairments have ranged from 26 to 84% depending on the study (Brahms et al., 2009; Capó-Aponte et al., 2012; Goodrich et al., 2013). While percentages vary, oculomotor impairments are not uncommon for those who have experienced an ABI.

Visual symptoms have also been reported in the literature. In a review of literature exploring visual impairments after the first year of TBI the most common symptoms associated with TBI related oculomotor deficits included blurriness, reading problems, difficulty with near vision, double vision, eye strain, dizziness, and light sensitivity (Greenwald, Kapoor, & Singh, 2012). Within the literature on stroke-related visual impairments, blurred vision, diplopia, and reading difficulties were reported (Rowe & VIS Group UK, 2013).

Visual symptoms are common after ABI and may be associated with oculomotor function. The prevalence of visual symptoms has been reported higher than 75% in studies (Brahm et al., 2009; Rowe & VIS Group UK, 2013). Comparison studies between groups have shown a significant difference in symptoms assessments for those with and without TBI (Capó-Aponte et al., 2012) and between those who had recovered and not recovered after mTBI (Heitger et al., 2009). One study also found a significant moderately weak relationship between oculomotor function and the symptoms (Heitger et al., 2009). There is limited support for an association between having visual symptoms and the presence of visual impairments.

Participation for Those with Oculomotor Impairments

The literature on participation and quality of life experienced for individuals with oculomotor deficits after acquired brain injury is limited. While no systematic reviews or studies

addressed this specifically, numerous papers explored aspects of the participation and quality of life while focusing on different objectives (e.g. Ali et al., 2013; Brahm et al., 2009; Capó-Aponte et al., 2012; Ciuffreda et al., 2008; Goodrich et al., 2013; Heitger et al., 2009; Lemke et al., 2013; Rowe & VIS Group UK, 2013; Thiagarajan, Ciuffreda, Capó-Aponte, Ludlam, & Kapoor, 2014). There are three themes that that linked oculomotor problems with participation and quality of life: reading as a specific functional outcome, functional performance (activities of daily living [ADL]), and quality of life.

Reading Difficulties

Reading difficulties due to visual impairments after ABI are a common issue, and there may be a relationship between reading difficulties and oculomotor dysfunction. Reading difficulties were indicated by the below norms baseline reading rates and grade level efficiency of the adults with mild TBI (mTBI) (Thiagarajan et al., & Kapoor, 2014) and by the lower reading comprehension and reading speed for those with blast-induced TBI than those without TBI (Capó-Aponte et al., 2012). Several studies have included the prevalence of reading deficits after an ABI of more than 50% of participants (Goodrich et al., 2013; Brahm et al., 2009; Ciuffreda et al., 2008). There is weak support for a relationship between reading ability and oculomotor impairment (Thiagarajan et al., 2014; Rowe & VIS Group UK, 2013). Reading appears to be a common issue for those with oculomotor impairments. While reading is a required for most communication in school, work, and social media (e.g. emails, texting, reports, newspaper, letters, books, etc.), the research does not translate how everyday activities and social roles are experienced for individuals with reading difficulties.

Functional Outcomes/Activities of Daily Living and Quality of Life

Studies have had varied results with participation in ADLs for those with oculomotor impairments after ABI. Significant differences were found in one study for those with mTBI (Heitger et al., 2009); however, there were no differences in the ADLs in a study with stroke related visual symptoms (Rowe & VIS Group UK, 2013). These studies used different functional outcome measures: the stroke study used a low vision measure (Rowe & VIS Group UK, 2013), while the mTBI study used a tool specific for head injury (Heitger et al., 2009). Other studies have demonstrated a significant relationship between oculomotor function and functional outcomes (Heitger et al., 2009 [post-concussion syndrome after mTBI]; Ali et al., 2013 [stroke]).

Quality of life has also been explored as part of some studies addressing visual impairments. Differences in quality of life have been found between those with visual symptoms after ABI and those without (Lemke et al., 2013 [healthy sample]; Heitger et al., 2009 [those recovered after mTBI]). Research has also shown associations between quality of life measures and oculomotor function (Ali et al., 2012 [stroke]; Heitger et al., 2009 [PCS]).

Measures for Vision, Symptoms, Participation, and Quality of Life

The current literature on exploring vision and participation after ABI has limitations. As noted, much of the literature has focused on occurrence and symptoms of visual impairments. Many of the measures used are basic clinical measures of visual skills, such as acuity, visual fields, and oculomotor skills (saccades, pursuits, vergence, and binocular skills). There are a few standardized tests that look at oculomotor skills but they are normed for children (e.g. Northeastern State University College of Optometry oculomotor test [Goodrich et al., 2013]). Some studies have used computerized assessments that look at eye movements (Heitger et al., 2009; Kapoor, Ciuffreda, & Han, 2004; Szymanowicz et al., 2012; Thiagarajan & Ciuffreda, 2013; Thiagarajan & Ciuffreda, 2014; Thiagarajan et al., 2014). These assessments provide

information about how the visual system is working compared to expected skills; but does not inform how impairments impact everyday life participation.

A variety of measures have been used in the literature to characterize visual symptoms. While some studies include a standardized assessment (Brahm et al., 2009; Goodrich et al., 2013; Rowe & VIS Group UK, 2013; Rowe et al., 2008), others used symptom questionnaires designed for concussion symptoms, not for visual complaint symptoms (e.g. Rivermead Post-Concussion Symptoms Questionnaire) (Heitger et al., 2006; Heitger et al., 2007; Heitger et al., 2009). Several studies (Capó-Aponte et al., 2012; Conrad, Mitchell & Kulp, 2016; Thiagarajan & Ciuffreda, 2013; Thiagarajan & Ciuffreda, 2015; Yadav, Thiagarajan & Ciuffreda, 2014) have used the CISS, an outcomes measure developed for assessing change in visual symptoms for those receiving treatment for convergence insufficiency (i.e. binocular, near vision impairments) (Rouse et al., 2004). However, the CISS does not include the full array of visual symptoms a person with ABI-related oculomotor impairments may have (e.g. blurriness with distance vision, dizziness, glare sensitivity, and ability to do sustained reading). In addition, while the CISS has been used in research with the ABI population it has not been standardized for use with this population.

Outcomes measures of studies that have explored participation and quality of life for this population have been inconsistent and inadequate. For example the modified Rankin Scale (scored “No symptoms at all” to Dead” [The Internet Stroke Center, 2016]) and European Quality of Life Score (five items [European Research Foundation, 2017]) used by Ali et al. (2013) are very broad outcomes and do not have an adequate indication of what areas of life are limited. The Rivermead Head Injury Follow-up Questionnaire used by Heitger et al. (2009) includes ten areas of participation, but is still not inclusive enough (e.g. it does not include

reading or driving). Other studies have used low vision outcomes (e.g. Activities of Daily Living Dependent on Vision questionnaire [Rowe & VIS Group UK, 2013] and 25-item National Eye Institute Visual Functioning Questionnaire (VFQ-25) [Lemke et al., 2013]). The VFQ-25 has been used with diagnoses other than low vision, including multiple sclerosis (Noble et al., 2006) and visual field deficits (Papageorgiou et al., 2007), but do not provide the full scope of participation areas that may be affected with oculomotor impairments. Given the variety of assessments and their limitations, it is unclear which measures would best describe participation in everyday activities and social roles, and quality of life for those with ABI related oculomotor impairments.

Measuring Participation in Everyday Activities and Quality of Life

There are various considerations when measuring participation in everyday activities and social roles. These may include frequency, limitations, satisfaction, and level of assist (Magasi & Post, 2010; Resnik & Plow, 2009). The participation areas to be assessed may be specific or broad areas (Whiteneck, 2010). Measures may be specific to a population or setting or for more of the general population (Magasi & Post, 2010; Resnik & Plow, 2009; Whiteneck, 2010). Measures may also be self-report versus observation (Fasoli, 2014), as well as objective versus subjective (Whiteneck, 2010). Understanding participation in everyday activities and social roles for people with ABI-related oculomotor impairments requires a broad and comprehensive assessment that looks at level of difficulty to participate by self-report.

To measure and understand quality of life is challenging. Quality of life is a term often used in health care (and other disciplines) that refers to both the “negative and positive features of life” (IESE Insight, 2013, para. 5). Quality of life is multidimensional including level of independence, physical health, psychological state, employment, education, wealth, family,

social relationships, religious beliefs, housing, local services and transport, and the environment (IESE Insight, 2013). Quality of life is also “personally defined..., dynamic, and intimately related to occupations” (Radomski, 1995, p. 488). For this study, quality of life is understood as the participants’ ability to participate in everyday activities and social roles and their perceptions of their participation, or lack thereof.

Comorbidities

Given the nature of how ABI are acquired, it is important to also be aware of other impairments or changes that may occur in relation to the event. The CDC reports that TBIs and stroke may cause changes in sensation, thinking (cognition), language, and/or emotions (CDC, 2016a; CDC, 2016c). Physical challenges may include impaired balance (CDC, 2016b; American Heart Association [AHA], 2017) and fatigue (CDC, 2016b; AHA, 2016). While these challenges may be experienced by those with oculomotor impairments, they may also be experienced by those with vestibular and/or cognitive impairments. The issues are complex and it is often difficult to identify the actual root of their impairments.

Approach

This study used a cross-sectional descriptive study design.

Participants

The participants consisted of a convenience sample of 40 adult patients with oculomotor/binocular impairments after ABI who were receiving occupational therapy services at Courage Kenny Rehabilitation Institute (CKRI) outpatient regional clinics. Inclusion criteria included: documented ABI (e.g. stroke, traumatic brain injury, non-traumatic brain injury [e.g. tumor, tumor resection], concussion, post-concussion syndrome [PCS]); ABI-related oculomotor or binocular impairments identified by occupational therapy screen (see Appendix A.1 for screening sheet), including: convergence insufficiency, divergence insufficiency, impaired pursuits, and/or impaired saccades; 18 years of age or older; corrected visual acuity of 20/70 or better; and sufficient cognitive, language, and hearing capability to participate in the informed consent process and assessments as indicated by a Functional Independence Measure (FIM) score of 5 or more for the comprehension, expression, memory, and problem solving subtests (see Appendix A.2 for FIM resource provided to occupational therapists). Exclusion criteria included: visual field cut; evidence of hemi-inattention or spatial neglect; non-English speakers; and significant physical impairment that affects level of difficulty to perform basic activities of daily living or that necessitate physical assistance. Approval for the study was obtained from the Institutional Review Boards from Allina Health and St. Catherine University (see Appendices B.1, B.2 and B.3 for IRB approval letters).

Recruitment

Outpatient occupational therapists identified potential participants and determined eligibility based on inclusion/exclusion criteria (see Appendix A.1 for screening sheet), then

provided them with a flyer (see Appendix A.3 for flyer) and briefly explained the study. Verbal consent to be contacted by the researcher was obtained from those who expressed interest. The researcher called the potential subject, further explained the study and consent process, invited the subject to participate, and set up a time for a meeting (see Appendix A.4 for follow up letter to confirm meeting with participants).

Procedures

Each participant was seen for a one-time 1-2 hour meeting to complete three assessments and to collect relevant demographic data. The sessions were administered in a structured interview format. Prior to beginning the interview the consent and HIPPA forms were reviewed and consent was obtained and signed (see Appendices B.4 and B.5 for consent and HIPPA forms). Demographics collected from the participants during the assessment process and from the medical charts included: ABI diagnosis (e.g. stroke, traumatic brain injury, concussion, PCS, and non-traumatic brain injury), time since onset of ABI, visual impairment (identified by occupational therapy screen), time since occupational therapy began, number of occupational therapy appointments, age, sex, marital status, race, education, employment status, occupation/description, living alone/with someone, number of children living with them (dependents), and living situation (home ownership/renting/condo) (see Appendix C.1 for demographic data collection sheet).

Measures

The ABI Vision Questionnaire (Scheiman, 2013) (see Appendix C.2) was used to evaluate visual symptoms. This questionnaire has 23 items, the first 15 of which are based on the CISS, an outcomes measure developed for assessing change in visual symptoms for those receiving treatment for convergence insufficiency (binocular, near vision impairments) (Rouse et

al., 2004). Items are scored 0-4 with lower score representing better status. Cut-off values for the first 15 items (≥ 21) and the total score (> 32) indicate an abnormal level of visual symptoms (Rouse et al, 2004) and need for a full vision screen (Scheiman, 2013) respectively. Validity and reliability for the CISS were established on adults (Rouse et al., 2004). The remaining eight items of the questionnaire were added to assess more than just near vision visual symptoms associated with ABI. This portion of the assessment has not yet undergone validity or reliability testing (Scheiman, 2013), although it was developed specifically for ABI.

The PROMIS Global Health Scale (see Appendix C.3) was used to measure quality of life. This ten item scale was developed by the National Institute of Health in conjunction with multiple research centers. The PROMIS tools have been standardized to be used with a variety of diseases and domains and have had rigorous reliability and validity testing (Hays, Bjorner, Revicki, Spritzer, & Cella, 2009). It generates both physical and mental health scores. Most items are scored on a scale of 1-5, some are recoded, and all are converted to T-score values. Norms are based on the US general population including those with various chronic conditions (Hays et al., 2009).

The Assessment of Life Habits (LIFE-H 3.1) (see Appendix C.4) was used to assess participation in everyday activities and social roles. This assessment measures the quality of social participation for persons with disabilities (Noreau, Fougereyrollas, & Vincent, 2002). It includes 77 items that measure performance in 12 category areas, which fall under two larger areas: activities of daily living (nutrition, fitness, personal care, communication, residence, and mobility) and social roles (responsibility, interpersonal relations, community, education, employment, and recreation). The scale measures level of difficulty (no difficulty, with difficulty, accomplished by proxy, and not accomplished) and type of assistance used (no

assistance, assistive device, adaptation, and human assist). Scores are determined by difficulty level and assistance type (0-9) with lower scores representing more difficulty. In reviews of participation measures, LIFE-H has items that link to all nine Activity and Participation domains of the International Classification of Functioning, Disability, and Health (ICF) (Magasi & Post, 2010; Resnik & Plow, 2009). The tool has been used in studies for stroke (Desrosiers et al., 2005) and visual impairments, which include low vision (Desrosiers, Wanet-Defalque et al., 2009) and visual perceptual deficits (Beaudoin et al., 2013). It has reported good content validity and test-retest reliability (Magasi & Post, 2010).

Based on the responses to the LIFE-H, follow-up questions (see Appendix C.5) were done on items indicated as “with difficulty” to further characterize the level of difficulty (a little difficult or really difficult) and briefly discuss the nature of the most difficult items. The researcher wrote the responses on the questionnaire by item. Starting with the thirteenth interview, the researcher determined that a brief summary of the participant’s comments might be helpful both for analysis as well to ensure an accurate understanding of the interviews. Thus the interviewer started drafting a brief summary at the end of each interview and then reviewed those comments with the participant to verify the accuracy of reported challenges and issues. The first 12 interviews were reviewed later and brief summaries made based on the notes.

Analysis

The results of the assessments were entered into a spreadsheet and then analyzed using SPSS software. Descriptive statistics (frequency distributions, mean [SD], median [range]) were used to describe demographics and measurement results. Categories and specific items most frequently selected as “fairly often” and “always” on the ABI Vision Questionnaire and “very difficult” or a score of 3 or less on the LIFE-H were identified. Additionally, the number of

patients exceeding cut-off points on the ABI Vision Questionnaire of ≥ 21 on the first 15 questions or a total score of > 32 were reported. Narrative data from verbal answers to the follow up questions during the LIFE-H regarding level of difficulty and the nature of the difficulties were entered into an Excel spreadsheet. Initially the data of items identified by 50% or more of the participants as “very difficult” or having a score of 3 or less were analyzed for content to identify categories and themes. Once the primary and sub themes were identified, they were explored by item and frequency throughout the data to determine prevalence.

Outcomes

Demographics

The ABI diagnoses of the 30 participants are found in Table 1. Due to the difficulty with distinguishing between TBI, concussion, and PCS, as many participants had more than one diagnosis in the chart, these diagnoses were combined into one category. The majority of the participants ($n = 27$, 90%) fell into this diagnostic grouping. Of these, 21 (78%) had an identified concussion diagnosis in the medical record as the initial event. The precipitating events of the 27 are listed in Table 1 with the majority being motor vehicle accidents ($n = 15$, 55.6%). The mean time since the event was 17.1 months ($SD = 23.4$, Minimum = 1.6, Maximum = 111.9). Given the wide range and high variability of the time since the event, the frequency of the data is also presented in Table 1. Table 2 includes the visual impairments as identified by the occupational therapist's vision screens. All participants appeared to have convergence insufficiency. More than 60% had identified pursuits and saccades issues as well as light sensitivity. Other issues included double vision and impaired fixation.

Table 1

Acquired Brain Injury Diagnoses

Diagnosis	<i>n</i>	%
Stroke	2	6.7 ^a
NTBI (surgical)	1	3.3 ^a
TBI/PCS/Concussion	27	90.0 ^a
MVA	15	55.6 ^b
Fall	4	14.8 ^b
Assault	3	11.1 ^b
Impact	5	18.5 ^b
Time since precipitating event ^a		
> 6 months	8	26.7
7 – 12 months	7	23.3
13 – 18 months	11	36.7
19 – 24 months	2	6.7
7+ years	1	3.3

9+ years	1	3.3
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Note. ^a*n* = 30. ^b*n* = 27.

Table 2

Visual Impairments as Identified by Occupational Therapy Screen^a

Visual impairment	<i>n</i>	%
Convergence insufficiency	30	100.0
Divergence insufficiency	7	23.3
Pursuits	22	73.3
Saccades	22	73.3
Light sensitivity	18	60.0
Ambient focal	3	10.0
Other	2	6.7

Note. *N* = 30. . ^aPossible visual impairments were identified by occupational therapist screen. Not all participants had a confirming diagnosis by optometrist or ophthalmologist by the time of the interview.

The demographics of the participants are presented in Table 3 (see also Appendix D for marital status, living situation, education level, and employment area). More than half of the participants (53%) were in the 45-64 age range, and the next largest age group was ages 26-44 (37%). The majority of the participants was women (76.7%) and white (90%). In terms of marital status and living arrangements, a little more than half of participants were married, and 40% lived with a spouse/partner and children. The education level of participants varied; the largest group (43.3%) had post-graduate education. Of the 30 participants, half indicated they were unemployed. Ten were on a medical leave or disability, six had a reduction in hours worked compared to before the ABI and two had a change/loss in position and status. Overall 17 (56.7%) of the participants had a change in employment since prior to the onset of the ABI.

Table 3

Demographics of Participants

Demographic	<i>n</i>	%
Age		
18-25	1	3.3
26-44	11	36.7

45-64	16	53.3
>66	2	6.7
Sex		
Female	23	76.7
Male	7	23.3
Race		
White	27	90.0
Black/African American	2	6.7
Declined	1	3.3
Employment status		
Full-time	8	26.7
Part-time	7	23.3
Not employed	15	50.0

Note. $N = 30$.

Visual Symptoms

Table 4 summarizes the results of the ABI Vision Questionnaire assessment of vision symptoms. While the scores had wide variability, 97% of the participants scored above the cut-offs indicating a significant score for the first 15 items, and warranting a full vision screen for all items. Half or more of the participants selected “Fairly Often” or “Always” for 14 of the 23 (61%) questionnaire items as shown in Table 5.

Table 4

ABI Vision Questionnaire Results

Score	<i>M</i>	<i>SD</i>	Min-Max	<i>n</i>	%
Subtotal of 1-15 ^a	40	9.54	16-55		
Score ≥ 21				29	96.7
Total score (1-23) ^a	57	13.62	26-84		
Score > 32				29	96.7

Note. $N = 30$. ABI = Acquired Brain Injury. ^aLow scores represent fewer visual symptoms (max. subtotal score: 60; max. total score: 92, symptoms scored 0-4).

Table 5

Acquired Brain Injury Vision Questionnaire: Most Frequent Symptoms

Item	<i>n</i>	%
Do you have sensitivity to light?	25	83.3

Do your eyes feel tired when reading or doing close work?	24	80.0
Are you unable to sustain reading or close work for adequate periods?	24	80.0
Do your eyes feel uncomfortable when reading or doing close work?	22	73.3
Do you lose concentration when reading or doing close work?	22	73.3
Do you have headaches when reading or doing close work?	21	70.0
Do you have trouble remembering what you have read?	20	66.7
Do your eyes ever hurt when reading or doing close work?	20	66.7
Do you lose your place while reading or doing close work?	20	66.7
Are you bothered by movement in the surrounding environment?	19	63.3
Do you feel like you read slowly?	18	60.0
Do your eyes ever feel sore when reading or doing close work?	18	60.0
Do you have to reread the same line of words when reading?	17	56.7
Do you notice the words blurring or coming in and out of focus when reading or doing close work?	15	50.0

Note. Items determined by counting those who selected the items as Fairly Often and Always.

Quality of Life

The PROMIS Global Health Scale results are reported in Table 6. When converted to the T-score value, the average scores were approximately one standard deviation (10 points) below the general population norm (T-score of 50).

Table 6

PROMIS Global Health Scale (v. 1.1) Results

Domain	<i>M</i>	<i>SD</i>	Min-Max
Global Physical Health ^a	12.47	1.96	8-17
Global Physical Health T-score ^b	41.1	5.13	29.2-54.1
Global Mental Health ^a	10.47	2.30	6-17
Global Mental Health T-score ^c	39.8	5.63	28.4-56.0

Note. ^aHigh scores indicate better status (raw score range: 4-20). ^bHigh scores indicate better status (physical T-score range: 16.2-67.7). ^cHigh scores indicate better status (mental T-score range: 21.2-67.6).

Participation

Results of the LIFE-H are found in Table 7, including the categories and total weighted scores. Weighted scores are from 1-10 with the high scores suggesting optimal participation. The lowest scoring categories included Education ($n = 20$), Recreation, Employment, and Mobility. As each category had wide ranging items, some of which were specific tasks and others broader (e.g. Getting to your principal place of occupation and Holding a paid job), an analysis of the individual items was found to be more informative.

Table 7

Participation as Measured by Assessment of Life Habits (LIFE-H 3.1)

Categories	<i>M</i>	<i>SD</i>	Min-Max
LIFE-H: Total Weighted Score ^a	6.1	1.19	3.9-8.2
Daily Activities Domain			
Nutrition	7.3	1.46	3.9-10.0
Fitness	6.4	1.36	3.9-8.9
Personal Care	8.6	.845	6.8-9.7
Communication	6.0	1.39	3.1-8.4
Housing	6.3	1.49	3.9-9.6
Mobility	4.9	1.64	1.6-8.4
Social Roles Domain			
Responsibilities	6.7	1.55	3.2-9.3
Interpersonal Relationships	6.2	1.83	3.1-9.3
Community Life	5.7	2.12	1.9-10.0
Education ($n = 20$)	2.8	3.05	0.0-6.7
Employment	4.0	2.49	0.0-7.2
Recreation	3.2	2.46	0.0-8.4

Note. $N = 30$. Scores are based on weighted scores ranging from 1 – 10, with 10 indicating no difficulties, adaptations, assistive devices or assistance, and one indicating no participation at all.

^aTotal score excludes education as it was only applicable to 20 participants.

The LIFE-H items that 50% or more of the participants identified as very difficult, accomplished by proxy/assistance, or not accomplished are presented in Table 8. Almost half of

the items (44%) were identified this way. Some of the items were applicable to only a few participants. This included the items: participating in educational activities at a high school level ($n = 1$), seeking a job ($n = 4$), carrying out family or home-making tasks as your main occupation ($n = 5$), and choosing a home that suits your needs ($n = 7$). All but one of the participants for home maintenance and three for choosing a home indicated that these tasks were very difficult, accomplished by proxy/assistance, or not accomplished.

Table 8

LIFE-H Items Identified as Very Difficult, Accomplished by Proxy/Assistance, and Not Accomplished

Item	<i>n</i> Very difficult	<i>n</i> Who did this item	%
Participating in sporting or recreational activities	27	29	93
Undertaking vocational training	17	19	89
Holding a paid job	25	28	89
Maintaining the grounds of your home	14	16	88
Doing major household tasks	18	21	86
Maintaining your home	24	28	86
Taking part in unpaid activities (volunteering)	17	20	85
Riding a bicycle	18	22	82
Going to sporting events	20	26	77
Going to artistic or cultural events	21	28	75
Choosing a career or profession	6	8	75
Using a computer	22	30	73
Communicating with a group of people at home or in the community	21	29	72
Participating in social or community groups	13	18	72
Participating in tourist activities	18	25	72
Taking part in outdoor activities	15	22	68
Participating in artistic, cultural, or craft activities	16	24	67
Assuming your personal and familial responsibilities	20	30	67
Participating in spiritual or religious practices	13	20	65
Planning your budget and meeting your financial obligations	17	28	61
Reading and understanding written information	18	30	60
Driving a vehicle	17	29	59

Item	<i>n</i> Very difficult	<i>n</i> Who did this item	%
Choosing a home that suits your needs	4	7	57
Participating in physical activities to maintain or improve your physical fitness or health	17	30	57
Participating in relaxation, unwinding, or mental focus activities to ensure your psychological or mental well-being	14	25	56
Maintaining social relations with those around you	16	29	55
Using your neighborhood recreational services	12	22	55
Using your neighborhood businesses	16	30	53
Maintaining friendships	16	30	53
Taking care of your children	8	15	53
Getting around on slippery or uneven surfaces	15	29	52

Analysis of the follow-up questions

The analysis of the narrative data from the follow-up questions attempted to better understand how the participants experienced the difficulties with participation in relation to their visual impairments. Three themes were identified from the data: tasks and environmental challenges/supports; self-identified personal difficulties; and changes to habits, priorities, and roles.

Challenges/supports of the tasks and environment.

Participants were asked more about the specifics of which tasks were difficult and how they were difficult. The responses fit into the follow subthemes: specific activities, task requirements, physical environmental aspects, socio-economic environment, and time issues.

Specific tasks and activities.

While many of the responses about activities included naming specific activities (e.g. attending a support group; volunteering at a school; attending workshops; going to the gym; going to basketball games or swim meets; and going to movies or concerts, to name a few), the responses also included specific aspects of the activities (e.g. reading and computer use were

mentioned as challenges to employment and education activities) which are presented in Table 9. These challenging items that kept arising are from the categories of communication and mobility.

Table 9

Items Most Often Referred to as Limiting Participation in Other Items

Item	<i>n</i>	%	Items/Activities
Driving	18	60.0	Getting to and from public buildings and commercial establishments, familial responsibilities, maintaining close relationships with parents, educational opportunities, holding a paid job, and volunteering
Reading	14	46.7	Educational opportunities, participating in relaxation and unwinding, recreational activities (reading patterns and signs), taking care of health (reading medication bottles), financial management, participating in spiritual practices, and holding a paid job
Computer use	11	36.7	Interpersonal relationships (e.g. Facebook), educational opportunities, and holding a paid job
Group communication	9	30.0	Fitness activities, interpersonal relationships, community groups, and holding a paid job

Task and activity requirements.

Participants reported that cognitive and physical (including visual) demands contributed to challenges with the activities. Table 10 includes some examples of the different types of challenges. Some of the challenges were specifically identified as visual.

Table 10

Physical, Cognitive and Visual Requirements of Tasks

Requirements	<i>n</i>	%	Item/Activity	Examples
Physical	10	33.3	Home maintenance (2 items)	Bending over, standing on a chair, moving around, bending and standing, head movements, reaching up
	6	20.0	Reading	Small print, length/quantity, and density/business

Cognitive	6	20.0	Holding a paid job	“Complex info hard,” “need to multi-task and unable to,” “fast pace [with] new information,” interruptions, and “jumping from one task to another”
Visual (physical)	5	16.7	Computer use	“Back and forth,” small words, focusing, “hard to jump from screen to screen,” and eye moving
	3	10.0	Job	“Very visually demanding,”
	2	6.7	Home maintenance (2 items)	Fixating and scanning for extended time, saccades, and “everything is visually stimulating”
Visual (sensory)	12	40.0	Computer use	Computer screen/light

Physical environment.

Participants reported that the sensory demands of the environment represented the most pressing environmental challenge to task performance. Every participant complained of at least one sensory area of challenge. Table 11 includes the descriptors and the number of participants who identified them. Notably, light, noise, and motion were all identified by more than 75% of the participants. The items most frequently identified with a physical environmental challenge were going to sporting events, gyms, and concerts; participating in spiritual activities; shopping in large stores; going to restaurants; and driving. One participant indicated that motion and movement were terrible, big crowds “make my head crazy. All the different noises and movement, [I] can’t handle it, can’t tone them out, exhausted afterwards, feel like I ran 5 miles.”

Table 11

Identified Physical Environmental Challenges

Challenges	<i>n</i>	%
Light/glare	26	86.7
Noise	25	83.3
Motion	23	76.7
People	14	46.7
Space/location/environment	11	36.7
Business/confusion/stimuli	6	20.0

Smell	2	6.7
Texture	1	3.3

Note. $N = 30$.

Socio-economic environment.

The socio-economic environment also appears to have been a factor with participation in various LIFE-H items. For the items including social interactions and relationships with family, friends and co-workers items, 12 participants (40%) reported challenges with others' inability to understand what the participant was experiencing. One stated simply, "People don't understand my disability. I explain a lot." Another said, "People have seen photos, wonder why I am not back to work when I look okay ... Some doubt. 'You look okay.'" Only four participants (13.3%) shared that some family and friends had been very supportive and understanding. As mentioned above, numerous participants were not working as they were on medical leave or disability – many of whom were following instruction from their physician ($n = 10$, 33.3%). Others indicated restrictions by their physician on fitness activities and recreational sports ($n = 6$, 20%). Financial limitations to participation were indicated by four (13.3%) participants specifically around recreational items ("loss of wages limits [participation]").

Time.

The final area of task and environmental challenges centered on time including when during the day the task was done ($n = 10$, 33.3%), the length of time the task took ($n = 3$, 10%), as well as not having enough time to do an activity ($n = 13$, 43.3%). When during the day a task was done was challenge mentioned with communicating with others, participating in a spiritual practice, and volunteering, the most frequent instance being nighttime driving difficulties. Others indicated difficulty with a set time, for example one stated "[I] find it difficult to do it at a set

time” in relation to going to church. Many indicated that they did not have enough time to do the item.

Self-Identified personal difficulties.

Participants described personal difficulties they experienced when participating in the various items. The level two categories identified included physical, cognitive, and socioemotional difficulties, and “shutting down”.

Physical difficulties.

The physical difficulties separated into two areas: adverse symptoms and difficulties. The adverse symptoms are shown in Table 12. Some participants also talked about physical symptoms after participating in an activity. For example, one talked about ice fishing, “very difficult ... okay during, but afterwards physically a wreck, head hurt, fatigue, body ached, 2 1/2 days of recovery, had a great time but paid for it.” Regarding eye discomfort/pain/fatigue, one of the participants shared about a challenging cycle related to their symptoms: “eyes go nuts ... pressure, sand paper, fatigue,” and another stated that “fatigue and eye movements ... [led to] headaches, dizziness, and nausea.” Three participants talked about their body/brain shutting down, “everything that is done [for] 5-15 minutes... [then I] move into fight or flight, hard stoppage, recovery period 2 hours.”

Table 12

Adverse Symptoms

Difficulties	<i>n</i>	%	Items/Activities
Headaches	26	86.7	Reading, computer use, writing, communication with a group, shopping, holding a job, sleep, home maintenance, fitness, driving, riding in a vehicle
Fatigue	21	70.0	Communicating with others, recreation activities, interpersonal relationships, community life (shopping, volunteering), familial responsibilities
Dizziness	10	33.3	Personal cares (shower, dressing), driving, reading,

Nausea	9	30.0	getting around, home maintenance, fitness activities, and boating
Eye discomfort/fatigue	7	23.3	Riding in a vehicle, shopping, reading, computer use, communicating in a group, recreation, writing, home maintenance, holding a paid job
			Reading, computer use, writing, recreation

The physical difficulties that participants identified are summarized in Table 13, which also includes the related activities. Fatigue appeared to be the biggest complaint. Participants also used the word “vision” to refer to a visual difficulties both in broad way (e.g. “vision not good enough to ride on lawn mower” and “it’s not right [vision]”), as well as specific issues including difficulty focusing, blurriness (“vision becomes blurry”), peripheral difficulties, and double vision. Hearing was the physical difficulty mentioned least. One participant described the challenge as “Hard to follow multiple people ... to really listen you have to hear. Brain tunes it out, multitasking.”

Table 13

Physical Difficulties with Related Activities

Difficulties	<i>n</i>	%	Activities/Items
Fatigue/energy/stamina	21	70.0	Communication (communicating with a group, reading, computer and phone use), recreation, maintaining interpersonal relationships, home maintenance, participation in community groups, assuming familial responsibilities, and holding a paid job
Balance	14	46.7	Mobility, home maintenance, recreation and fitness activities, personal cares (showers and lower body dressing), employment (standing in a classroom), and communication (talking with others)
Vision	13	43.3	Mobility (walking, driving and riding in a car), recreation and fitness, reading, home maintenance, computer use, shopping, and eating in a restaurant
Hearing	4	1.3.3	Communicating in a group

Cognitive difficulties.

Cognitive difficulties are the second subtheme of the self-identified personal difficulties. The primary issues are presented in Table 14. The items and activities for which the participants reported cognitive difficulties were broadly distributed with the exception of communication, which primarily referred to one item (communicating with others). For this study executive functioning difficulties includes multi-tasking, organization, processing, and planning. One participant summed up several of these challenges in relation to her work: “I like my job, but it’s harder – much harder. I feel like I am behind the 8 ball, because it is hard to plan. Organization is taxing, reading is hard, things don’t get in my memory, I have to ask someone.”

Table 14

Cognitive Difficulties with Related Activities

Difficulties	<i>n</i>	%	Items/Activities
Memory	19	63.3	Managing medication and medical appointments, reading, financial management, nutrition, shopping, communicating with others, familial responsibilities, and computer use
Attention/focus	18	60.0	Recreation and fitness, mobility (walking and driving), communication (with others, reading, computer use), holding a paid job, education, and community life (including shopping)
Executive functioning	17	56.7	Employment, education, home maintenance, communication (with other, reading, and computer use), and recreation
Communication	14	46.7	Communication with others

The difficulties with communication included both the comprehension and expression of oral and written communication. Participants described having difficulty processing conversations ($n = 14$, 46.7%) with slower processing, difficulty with following the train of thought, and difficulty focusing on the conversation. Expressing word difficulties ($n = 11$,

36.7%) included word finding, stutters, getting words right and increased time to talk. One participant talked about, “word finding difficulties, forget and lose [my] train of thought, (so much noise) - I can't make sense of what is said, hard, sometimes I can't figure it out.”

Emotional difficulties.

Table 15 summarizes how participants experienced emotional difficulties. Anxiety was referred to as affecting an activity (e.g. sleep and relaxation) as well as a result of socioeconomic issues (e.g. finances). Fear of falling or a re-injury was common with mobility and sporting related activities. Participants described being overwhelmed by the physical environment, “lights, sound, information, too much, overwhelming, depends on how much shopping needs to be done, the bigger the store - the harder it is.” The amount of work required by a task was also difficult: “More gets piled, the less I take care of the more anxious, overwhelming.” Powerful statements were made by several participants as they viewed changes in their self-image. One participant talked about being lazy: “[I] feel like a lazy parent.” Two other talked about the mismatch between their appearance and what was going on inside:

First impression – professional and educated; however, [I] have word finding difficulties, stringing together thoughts and organizing thoughts, feel [like I am] not communicating at level expected, feeling un-put together.

My brain is damaged - nobody gets it or cares. I look okay, I talk okay. They think I am okay. I'm not okay, I'm not who I used to be. I'm screaming inside.

Table 15

Socioemotional Difficulties

Difficulties	<i>n</i>	%	Items/Activities
Anxiety/stress/fear	21	70.0	Fitness (sleep and relaxation), financial management (medical insurance and finances), mobility (walking and driving), and recreation
Feeling overwhelmed	18	60.0	Activities in physical spaces with light, sound and movement (shopping, recreation, and fitness activities), communication with others, home

			maintenance, holding a paid job, familial responsibilities, and nutrition
Irritable/impatient/ moody/frustrated	14	46.7	Interpersonal relationships, communicating with others, reading, employment, and nutrition
Loss of motivation and interest, laziness	8	26.7	Recreation and fitness activities, interpersonal relationships, reading, financial management, personal cares, nutrition, and familial responsibilities
Self-image	4	13.3	Familial responsibilities, communication with others, and holding a paid job

Changes to habits, priorities, and roles.

Finally, participants described the changes they have made or experienced since the ABI. This includes modifications and adaptations made in order to make tasks easier, the losses experienced, and the methods used to manage daily life.

Modifications and adaptations.

Many participants talked about modifying tasks and/or environments in order to participate or be more successful with the tasks, summarized in Table 16. A few participants offered examples of why the modifications were made. Regarding walking, one person stated: “‘I am a mess,’ if I am moving and a car is moving, I have to stop, unable to judge distance and direction.” Another stated for driving, “Hard driving in any light or bad weather and snow, night time harder.” One shared when riding in a car, “because vision can be messed up, decreased depth perception, PTSD, have knitting, distract, prefer to sit in back seat and look down, cars whizzing by, sound, movement.”

Table 16

Modification and Adaptations

Item	<i>n</i>	%	Modifications and adaptations
Communication Computer and phone use	26	86.7	Enlarging font, using filters/decreasing screen brightness, taking breaks, using voice recognition,

Reading	20	66.7	and assistance Rereading, taking breaks, slowing down, using rulers and blocks, enlarging font, and use of prisms in glasses
Communicating with a group	12	40.0	Asking others to repeat or clarify, taking notes, increasing level of concentration, taking to only one person at a time, taking breaks, and quiet environment
Home Maintenance	10	33.3	Splitting the tasks (“divide and conquer”), shorten time with rest breaks, and assistance
Mobility			
Walking	17	56.7	Cautious, slower, check for traffic more, pay more attention, and assistance
Riding in a car	13	43.3	Closing the eyes, not paying attention to outside the car, looking at something inside the car, sitting in the front or back, and focusing on one thing ahead
Driving	7	23.3	Cautious and more aware; sunglasses; driving for shorter periods of time; and avoiding driving at night time, in busy traffic, and in inclement weather.

The modifications used with the activities/items of the familial responsibilities, community life, education, and employment categories were similar to the communication and home maintenance modifications described in Table 16. In particular participants described modifications to shopping, including shopping on-line, limiting time, shopping at non-busy times, using a list, and having assistance. As one participant stated, “Have to make lists. Go to grocery store and leave, don’t want to look or browse, amount of aisles – a lot to look at, florescent lights.” For interpersonal relationships, rather than going out or meeting in person, some participants talked on the phone more and used Facebook to connect. The recreation items had minimal modifications as often the activity was not accomplished. This leads to the losses, the next subtheme.

Losses and negative consequences.

Participants described losses related to ways in which tasks are performed or whether they are performed at all. The most commonly changed or not done items were mentioned in the categories of communication, interpersonal relationships, home maintenance, familial responsibilities, financial management, employment, community life (including social groups and spiritual practices), and recreation. Table 17 shows some examples of loss by activity/item.

Table 17

Losses and Negative Consequences

Item	<i>n</i>	%	Changes	Examples
Communicating with others	7	23.3	Avoiding, faking	"Faking it." "I avoid it as much as possible"
Interpersonal relationships ^a	11	36.7	Doing less, quiet environment, avoiding, isolating	"Not planning as much, less frequent reaching out, others organize." "Easier to go home and be in quiet setting." "Don't go out anywhere, talk on phone only." "Tend to close self off, been very private, don't have to deal with emotional reactions." "It's a disaster, can't make connections, hard to relate to each other." "Not being able to read people anymore (attitudes). I just don't deal with them, limit time and conversations [or] stay away."
Home maintenance	11	36.7	Lower standards, behind, not done	"Not caught up." "Somethings don't get done." "It is not done to my satisfaction." "My house is not like I'd like it to be."
Financial management and employment	7	23.3	Decline in level of performance, mistakes	"Not enough productive time ... more than 30 hours worked time to achieve less than 10 productive hours." "[I] have had scary things happen" "Very visually demanding. Have to be a lot more focused and recheck everything. I go over everything, working reduced hours. Unable to chit chat, have to focus on work, frustrating. Make mistakes easily. Things that were 2nd nature are a lot harder. I never realized how much I did. Now I realize this is a seriously visually demanding job. You take it for granted."

Social groups	8	26.7	Not doing,	“Dropped out of community, do it at home,
Spiritual practices	7	23.3	changing it	would have better life balance.”
Recreation	27	90.0	Change in activity, how it is done, or preferred activity not done ($n = 20$)	“I was a reader before, school came easy before.” “I was very active: back packing, hiking, biking, water boarding.” “Love of my life (history, sites, museums), have not been able to do, too much, stamina [and] financial.” “Can't do any of it, light, travel - disorienting, wiped out, discombobulated.”

Note. ^aIncludes maintaining relationships with friends and those around you (neighbors, co-workers, fellow students)

A big change and loss was related to loss of roles. While only a few ($n = 7$, 23.3%) articulated this, what they shared is powerful. One participant whose primary role was home making said, “I feel as if everything I did for my family has been taken away.” A grandparent shared changes with a grandchild, “I don't want to fall again, don't take a chance, I would love to get out with grandsons.” A mother whose play time with her child has changed, “[It's] easy to get irritable, too much activity, can't snuggle up and play, feel on guard due to the physical [chance of getting hit again]... Changed how we play.” Two participants whose role at work changed shared, “Demoted from supervisor to mechanic. Some relationships strained, personally hurtful, degrading, and humiliating,” and “They took away new position.” Related to familial responsibilities one participant shared, “I don't fill the same role I used to.”

Life management changes.

Participants reported making changes to their life management strategies after their ABI. Participants have had to make decisions about how to manage their energy budget, life balance, and priorities as well as make decisions about whether to experience the “cost” of participating in certain activities (see Table 18). While some participants articulated knowingly choosing to do

an activity that will lead to not feeling well, others seemed to be less aware of it as it happens and more after the fact.

Table 18

Examples of Life Management Changes in Reference to Specific Activities

Item	<i>n</i>	%	Examples
Energy budget, life balance, prioritizing	7	23.3	"Learning how to manage everything I have to do, and make sure I have enough (energy) for rest of day is hard."
Communicating with another person			"Depends on how day goes, energy budget, takes more energy to listen, do what I can to get by."
Recreation			"Cut down a lot, lights, busy, life balance a perpetual struggle (work, life, care)."
Spousal Relationship			"Feel like just getting by, all the energy I have goes to my children and work."
Cost of participating			"Put everything into work and self getting better. No time left for anything else. Don't have play room. I pay for it for a day or two if I try. Personal and social needs/wants/desires get put to the side."
Employment	5	16.7	"I can still overdo it and not feel well, spending too much time in the chaos of my employment, not realizing it has affected me until later, affect: hung over, whole body, light headed, not feeling well, dizziness, nausea."
Sporting events			"Loud, movement, lights, it costs me, I go less, but I enjoy it, want to do it, [I] have to think about cost."
Home maintenance			"If I decide to clean, it is not done to my satisfaction, mental and physical fallout lasts for days: headache, backache, frustration, fatigue."

Discussion

The purpose of this study was to describe participation in everyday activities and social roles and quality of life for people with ABI-related oculomotor impairments. This small sample of adults with primarily TBI/concussion/PCS was able to do most basic personal cares (basic ADL). However, many areas of participation were challenging, including recreational activities, education, work, home maintenance and community life to name the primary participation areas. Participants also experienced a significant level of visual symptoms and a lower quality of life.

Building on the Literature

Participants' self-reported visual symptoms (including light sensitivity, inability to do sustained reading, eye discomfort/strain, slower pace and losing place with reading, and motion sensitivity) are consistent with prior research (Goodrich et al., 2007; Greenwald et al., 2012; Kapoor & Ciuffreda, 2002). While there has been limited research on quality of life for those with oculomotor impairments, this study supports prior research in that there is likely a difference in quality of life between those with visual symptoms and those without (Lemke Cockerham, Glynn-Miller, & Cockerham, 2013; Heitger et al., 2009). Implications regarding quality of life are further explored later in this section.

Excluding personal care and nutrition, the participant's scores on the LIFE-H were below the normative scores of a group of elderly community living adults (Desrosiers, J. & Robichaud, 2009; education and employment were not included in normative scores). Given the low scores of the participants on education and employment, it is reasonable to assume that those scores would be below the expected age-matched normative scores as well. For the individual items, other than riding a bicycle, the top items considered very difficult, accomplished with assist/proxy, or not accomplished, are all activities that require a combination of skills and

activities (including computer use, communicating with a group of people, reading, and driving). Participants seemed to find the isolated tasks less difficult than putting them all together.

Prior literature has stated that people with oculomotor impairments after an ABI may have difficulty with reading, mobility (gait), ADLs (Greenwald et al., 2012; Rowe et al., 2009; Wolter & Preda, 2006), and work/vocations (Heitger et al., 2009; Thiagarajan, Ciuffreda & Ludlam, 2011). However, only the activity of reading has been more fully researched in terms of the prevalence and degree of challenges (Ciuffreda, Han, Kapoor, & Ficarra, 2006; Rowe et al., 2011; Thiagarajan et al., 2014). This study attempted to further identify challenges in everyday activities and social roles while expanding the understanding of the difficulties with participation for this population.

Complex Situation: Not Just Vision

The narrative responses to the LIFE-H follow-up questions, along with the responses to the questionnaires, reflected the complexity of the challenges experienced by people with ABI-related oculomotor impairments. Participation-related roles and activities place large demands on vision especially with certain high visually loaded tasks (e.g. reading, computer use, mobility [walking and driving], shopping, etc.) (Greenwald et al., 2012; Scheiman, 2011a) which may require those with oculomotor impairment to slow down to take more time to process and respond. However, it is not just the motor components of the visual system that appear to be affected. Participants experienced light sensitivity and ambient/focal issues (i.e. movement in the periphery) which have more to do with sensory input. Beyond the visual system, participants reported sensitivity to other senses including sound, smell, taste, and texture. Cognitive function and balance appear to be affected as well for those with ABI. While the visual system is integrally involved in cognition and balance, it is unclear how much it contributes to the

challenges experienced. There appears to be a combination of symptoms that this population experiences including environmental sensitivity, cognitive and communication difficulties, impaired balance, pain, fatigue, and difficult emotional responses. These challenges are consistent with the literature (Hellerstein & Scheiman, 2011; Killington et al., 2015; Suter et al., 2011). All these challenges together and in isolation interfere with participation in everyday activities and social roles. This may cause financial difficulties and loss of roles which leads to loss of quality of life and well-being which this sample demonstrated.

Challenges and Difficulties

The narrative responses to the follow-up questions provided insight into the experience of people with oculomotor impairments. Participation in some activities (e.g. reading, computer use, communicating in a group and driving) appears to increase symptoms. Certain environments (e.g. bright, loud, and busy) also appear to lead to symptoms. Personal difficulties also contributed to the challenges with participation in certain activities (e.g. holding a job, participating in educational activities, recreational activities, reading, and communicating with others). An interaction between the person, activity and environment occurs that limits the ability to participate in certain activities and thus participate in one's social roles.

It appears that participation may be enhanced by modifying and adapting the task, how the task is performed, and the setting of the task. Recognizing what is difficult, how that difficulty may affect an individual, and making informed decisions about how to engage in an activity is critical for this group's ability to participate in everyday tasks and social roles.

Clinical Implications

This study attempted to describe participation and quality of life for people with oculomotor impairments after ABI and provide recommendations for occupational therapists and

other health care providers who encounter this population. Findings suggest that occupational therapists and other health care providers should assess whether clients with ABI are experiencing challenges related to visual impairments. When assessing everyday tasks and social roles, difficulty with the following areas should warrant a vision screen or referral to a vision specialist: recreation activities, education, work, home maintenance, volunteering, social groups, spiritual practice, driving, reading, computer use, and communicating in a group. Two possible assessments to use that would cover these areas include the Canadian Occupational Performance Measure (COPM, 2017) and the Rivermead Head Injury Follow Up Questionnaire (Crawford, Wenden, & Wade, 1996). When using these measures, clinicians are advised to ask specific questions about driving, reading, computer use and communicating in a group. Visual symptoms should also be assessed. While the ABI Vision Questionnaire is recommended, not all health care providers have the time to use it or may have other symptom questionnaires of their own. If so, visual impairments should be further evaluated if the client complains of light sensitivity, eye discomfort/pain with reading and near tasks, reading at a slower pace, losing one's place while reading, and/or being bothered by movement in the environment. If an occupational therapist encounters a client with ABI who has difficulties with these areas and the identified symptoms, a vision screen is warranted. For other health care providers, and occupational therapists who have identified potential visual impairments by a vision screen, a referral to a vision specialist should be made.

Study findings suggest that individuals with ABI typically have vision problems concurrent with cognition, balance, fatigue, and socioemotional difficulties which interact to restrict participation in social roles. Treatment should not only include remediation of vision, but also teaching of compensatory methods (fatigue management and modifications of activities

tasks) and exploring life management strategies (energy budget, prioritization), in addition to addressing balance, cognitive and psychological issues. A team of health care professionals are needed to address such a complex situation. Team members may include neurologist, physicians, optometrists, ophthalmologists, occupational therapists, physical therapists, and psychologists. Clients may be seen initially by any one of these health care professionals. Screens of all areas should be completed and referrals to the appropriate health care professionals should be made.

Limitations

This project had numerous limitations that limit the generalization of the outcomes. The sample was a small convenience sample from one organization in central Minnesota. Only participants who were seeing an occupational therapist were considered, and the identified visual difficulties were identified by occupational therapy screens, not always diagnosed by a vision specialist at the time of the interview. The participants had wide variability in age, time since precipitating event, and stage of recovery. Conversely, there were large majorities of female and white participants. The recommendations for clinical practice are most appropriate for ABI diagnoses of TBI/concussion/PCS as there were only a few participants with strokes and one tumor resection.

The responses to the questionnaires also had high variability in the scoring. Given the nature of the self-report questionnaires, the participants' perceptions of difficulties with participation and visual symptoms were subjective. In addition the participants' responses may have been influenced by the Hawthorne effect, knowledge that they were participating in a research study (Polit & Hungler, 1999).

Lastly, while some of the participation challenges and difficulties expressed by the participants were obviously vision related, not everything was. This sample of adults with ABI

experienced a complexity of challenges in their social participation and performance of everyday activities. Thus, the challenges may not be solely attributed to visual impairment, but vision may be considered a contributing factor.

Future Suggestions and Questions

This study described participation in everyday activities and social roles for adults with ABI-related oculomotor impairments. It was a foundational study to define the problem for this population. Further research is needed to more fully address the issues described. Suggested projects and questions to address may include:

- Examine the influences of confounding factors and comorbidities.
- Determine how health care professionals are assessing the impairments for this population. In particular how vision is assessed.
- Determine what the current standards of practice for referral and treatment are.
- What treatments are currently being used for oculomotor impairments (including remedial, compensatory, and life management strategy training)?
- What is the client experience of recovery and treatment for those with oculomotor impairments? What is most helpful?
- What is the relationship between oculomotor impairment and sensory sensitivities? What are the remedial treatment options for sensitivities?
- What is the balance between remediation and management of the symptoms? If patients complain of being overwhelmed and stressed, is it possible to remediate?

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Appendix A: Recruitment Materials

Appendix A.1: Screening Sheet for Therapists

Screening Sheet for Therapists: Vision Study (2016-2017)

- ☐ Documented ABI (e.g. stroke, traumatic brain injury, non-traumatic brain injury [e.g. tumor, tumor resection], concussion, post-concussion syndrome).
- ☐ Primary Diagnosis _____
- ☐ Identified oculomotor or binocular impairments by occupational therapy screen (circle):
- convergence insufficiency divergence insufficiency impaired pursuits
- impaired saccades double vision Other _____
- ☐ 18 years of age or older
- ☐ Corrected visual acuity of 20/70 or better
- ☐ Sufficient cognitive, language and hearing capability to participate in the consent process and assessments as indicated by a Functional Independence Measure (FIM) score of 5 or more for the comprehension, expression, memory and problem solving subtests.
- ☐ English speaking
- ☐ No visual field cut
- ☐ No evidence of hemi-inattention or spatial neglect, and
- ☐ No significant physical impairment that affects level of difficulty to perform basic activities of daily living or that physical assistance is required.
- ☐ Provided flyer

_____ (name of patient) qualifies for the vision study on participation and quality of life.

I am interested in possibly participating in this study. I give my permission for my therapist to pass on my name and phone number to the researcher to call me and tell me more about it.

Patient signature _____ Date: _____

Phone number to call: _____

Best day/time to call: _____

Therapist: _____ Date: _____

Site: _____

Appendix A.2: Functional Independence Measure Resource for Occupational Therapists

IRF-PAI Training Manual

Revised 01/16/02

COMPREHENSION: *Comprehension* includes understanding of either auditory or visual communication (e.g., writing, sign language, gestures). Evaluate and indicate the more usual mode of comprehension ("Auditory" or "Visual"). If both are used about equally, code "Both."

NO HELPER

- 7 Complete Independence—The patient understands *complex or abstract directions and conversation*, and understands either spoken or written language (not necessarily English).
- 6 Modified Independence—In most situations, the patient understands readily or with only mild difficulty *complex or abstract directions and conversation*. The patient does not require prompting, though (s)he may require a hearing or visual aid, other assistive device, or extra time to understand the information.

HELPER

- 5 Standby Prompting—The patient understands *directions and conversation about basic daily needs* more than 90% of the time. The patient requires prompting (slowed speech rate, use of repetition, stressing particular words or phrases, pauses, visual or gestural cues) less than 10% of the time.
- 4 Minimal Prompting—The patient understands *directions and conversation about basic daily needs* 75 to 90% of the time.
- 3 Moderate Prompting—The patient understands *directions and conversation about basic daily needs* 50 to 74% of the time.
- 2 Maximal Prompting—The patient understands *directions and conversation about basic daily needs* 25 to 49% of the time. Understands only *simple, commonly used spoken expressions* (e.g., *hello, how are you*) or gestures (e.g., waving good-bye, thank you). Requires prompting more than half the time.
- 1 Total Assistance—The patient understands *directions and conversation about basic daily needs* less than 25% of the time, or does not understand *simple, commonly used spoken expressions* (e.g., *hello, how are you*) or gestures (e.g., waving good-bye, thank you), or does not respond appropriately or consistently despite prompting.

Do not use code "0" for Comprehension.

COMMENT: *Comprehension* of complex or abstract information includes (but is not limited to) understanding current events appearing in television programs or newspaper articles, or abstract information on subjects such as religion, humor, math, or finances used in daily living. *Comprehension of complex or abstract information* may also include understanding information given during a group conversation. Information about *basic daily needs* refers to conversation, directions, and questions or statements related to the patient's need for nutrition, fluids, elimination, hygiene or sleep (physiological needs).

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EXPRESSION: *Expression* includes clear vocal or nonvocal expression of language. This item includes either intelligible speech or clear expression of language using writing or a communication device. Evaluate and indicate the more usual mode of expression ("Vocal" or "Nonvocal"). If both are used about equally, code "Both".

NO HELPER

- 7 Complete Independence—The patient expresses *complex or abstract ideas* clearly and fluently (not necessarily in English).
- 6 Modified Independence—In most situations, the patient expresses *complex or abstract ideas* relatively clearly or with only mild difficulty. The patient does not need any prompting, but (s)he may require an augmentative communication device or system.

HELPER

- 5 Standby Prompting—The patient expresses *basic daily needs and ideas* more than 90% of the time. Requires prompting (e.g., frequent repetition) less than 10% of the time to be understood.
- 4 Minimal Prompting—The patient expresses *basic daily needs and ideas* 75 to 90% of the time.
- 3 Moderate Prompting—The patient expresses *basic daily needs and ideas* 50 to 74% of the time.
- 2 Maximal Prompting—The patient expresses *basic daily needs and ideas* 25 to 49% of the time. The patient uses only single words or gestures, and (s)he needs prompting more than half the time.
- 1 Total Assistance—The patient expresses *basic daily needs and ideas* less than 25% of the time, or does not express basic needs appropriately or consistently despite prompting.

Do not use code "0" for Expression.

COMMENT: Examples of *complex or abstract ideas* include (but are not limited to) discussing current events, religion, or relationships with others. Expression of *basic needs and ideas* refers to the patient's ability to communicate about necessary daily activities such as nutrition, fluids, elimination, hygiene, and sleep (physiological needs).

PROBLEM SOLVING: *Problem Solving* includes skills related to solving problems of daily living. This means making reasonable, safe, and timely decisions regarding financial, social, and personal affairs, as well as the initiation, sequencing, and self-correcting of tasks and activities to solve problems.

NO HELPER

- 7 Complete Independence—The patient consistently recognizes problems when present, makes appropriate decisions, initiates and carries out a sequence of steps to solve *complex problems* until the task is completed, and self-corrects if errors are made.
- 6 Modified Independence—In most situations, the patient recognizes a present problem, and with only mild difficulty makes appropriate decisions, initiates and carries out a sequence of steps to solve *complex problems*, or requires more than a reasonable time to make appropriate decisions or solve complex problems.

HELPER

- 5 Supervision—The patient requires supervision (e.g., cuing or coaxing) to solve less *routine problems* only under stressful or unfamiliar conditions, but no more than 10% of the time.
- 4 Minimal Direction—The patient solves *routine problems* 75 to 90% of the time.
- 3 Moderate Direction—The patient solves *routine problems* 50 to 74% of the time.
- 2 Maximal Direction—The patient solves *routine problems* 25 to 49% of the time. The patient needs direction more than half the time to initiate, plan, or complete simple daily activities, and may need restraint for safety.
- 1 Total Assistance—The patient solves *routine problems* less than 25% of the time. The patient needs direction nearly all the time, or does not effectively solve problems, and may require constant one-to-one direction to complete simple daily activities. The patient may need a restraint for safety.

Do not use code "0" for Problem Solving.

COMMENT: Examples of *complex problem-solving* includes activities such as managing a checking account, participating in discharge plans, self-administering medications, confronting interpersonal problems, and making employment decisions. *Routine problem-solving* includes successfully completing daily tasks or dealing with unplanned events or hazards that occur during daily activities. More specific examples of routine problems include asking for assistance appropriately during transfer, asking for a new milk carton if milk is sour or missing, unbuttoning a shirt before trying to put it on, and asking for utensils missing from a meal tray.

MEMORY: *Memory* includes skills related to recognizing and remembering while performing daily activities in an institutional or community setting. Memory in this context includes the ability to store and retrieve information, particularly verbal and visual. The functional evidence of memory includes recognizing people frequently encountered, remembering daily routines, and executing requests without being reminded. A deficit in memory impairs learning as well as performance of tasks.

NO HELPER

- 7 Complete Independence—The patient recognizes people frequently encountered, remembers daily routines, and executes requests of others without need for repetition.
- 6 Modified Independence—The patient appears to have only mild difficulty recognizing people frequently encountered, remembering daily routines, and responding to requests of others. The patient may use self-initiated or environmental cues, prompts, or aids.

HELPER

- 5 Supervision—The patient requires prompting (e.g., cuing, repetition, reminders) only under stressful or unfamiliar conditions, but no more than 10% of the time.
- 4 Minimal Prompting—The patient recognizes and remembers 75 to 90% of the time.
- 3 Moderate Prompting—The patient recognizes and remembers 50 to 74% of the time.
- 2 Maximal Prompting—The patient recognizes and remembers 25 to 49% of the time, and needs prompting more than half the time.
- 1 Total Assistance—The patient recognizes and remembers less than 25% of the time, or does not effectively recognize and remember.

Do not use code "0" for Memory.

Appendix A.3: Study Flyer

COURAGE KENNY RESEARCH CENTER

You are invited to participate in a research study



If you are willing to participate and you qualify:
 You will be invited to attend a one-time meeting that will last for one to two hours to complete three questionnaires.

Benefits of participating in the study:

- no direct medical benefits
- in appreciation of your time, you will receive a \$25 gift certificate.
- knowing that you have contributed to knowledge that will inform health care providers.

If you are interested or have questions, please contact:
 Sharon Gowdy Wagener, OTR/L
 612-863-6198
sharon.gowdywagener@allina.com

Participation and quality of life for people with oculomotor impairments after stroke or brain injury

After stroke or brain injury, some people may experience eye movement and vision problems including:

- eye strain
- blurriness
- headaches
- poor reading comprehension
- difficulty with depth perception, hand-eye coordination and movement.

We are trying to better understand how eye movement problems effect participation in everyday life, social roles and quality of life.

Appendix A.4: Follow Up Letter to Confirm Meeting with Participants



Date

Dear ,

Thank you for your interest in my research study and your willingness to meet with me.

We have setup the following time to meet to complete the consent form and the questionnaires:

Day/Date: _____ Time: _____

Location: _____

Address: _____

Please find enclosed a copy of the consent form that we will review and sign at our meeting before starting the questionnaires.

If you have any questions or need to cancel please call me at: 612-863-6198

I am looking forward to meeting with you!

Sincerely,

Sharon Gowdy Wagener

enclosures

Appendix B: IRB Materials

Appendix B.1: Allina Health IRB Approval Letter



Allina Health
Human Research Protection Program
Institutional Review Board

P.O. Box 43 Mail Route 10105
Minneapolis, MN 55440-0043
Tel: 612-262-4920
Fax: 612-262-4953
www.allinahealth.org

NOTICE OF APPROVAL
ALLINA HEALTH FWA NUMBER 00002425

DATE: June 30, 2016

TO: Mary Vining Radomski, PhD
FROM: Allina Health IRB 1

PROJECT TITLE: Participation and Quality of Life for Persons with Oculomotor Impairments
after Acquired Brain Injury

REFERENCE #: 914239-1

SUBMISSION TYPE: New Project

SUBMISSION DATE: June 27, 2016

ACTION: APPROVED

APPROVAL DATE: June 28, 2016

EXPIRATION DATE: June 27, 2017

REVIEW TYPE: Expedited Review

REVIEW CATEGORY: Expedited review category # 5 and 7

Thank you for your submission of New Project materials for this project.

The following items were included in this submission:

- Advertisement - Vision Study Flyer (UPDATED: 06/21/2016)
- Allina Health - Application Part 1 - Allina Health - Application Part 1 (UPDATED: 06/23/2016)
- Application Form - Application 2 - Expedited (UPDATED: 06/23/2016)
- Consent Form - Consent Form (UPDATED: 06/23/2016)
- Data Collection - Demographic Data Collection Sheet (UPDATED: 06/7/2016)
- HIPAA Consent/Authorization - HIPAA Authorization Form (UPDATED: 06/23/2016)
- Letter - MOA (UPDATED: 06/8/2016)
- Other - Screening Supplement Communication and Cognition (UPDATED: 06/21/2016)
- Other - Phone Script (UPDATED: 06/9/2016)
- Other - Screening Sheet (UPDATED: 06/7/2016)

- Protocol - Protocol (UPDATED: 06/23/2016)
- Questionnaire/Survey - LIFE-H Follow up questions (UPDATED: 06/9/2016)
- Questionnaire/Survey - PROMIS Global Health Scale (UPDATED: 06/7/2016)
- Questionnaire/Survey - Assessment of Life Habits (UPDATED: 06/7/2016)
- Questionnaire/Survey - ABI Vision Questionnaire (UPDATED: 06/7/2016)

The Allina Health Institutional Review Board (IRB) for the protection of human subjects has reviewed and APPROVED the protocol referenced above. This approval is based on appropriate risk/benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

Please remember that informed consent is a process beginning with a description of the project and verification of participant understanding followed by a signed consent form. Informed consent must continue throughout the project via a dialogue between the researcher and research participant. Federal regulations require that each participant receives a copy of the consent document. Unless the IRB has approved an alternative process (such as oral consent), please use a copy of the consent form with the IRB approval stamp when you are obtaining signatures of consent. A copy of the IRB-approved consent form, bearing the Institutional Review Board [IRB] approval stamp, is available to you in the "Reviews" section of IRBNet.

Proposed changes to the research must be submitted to the IRB for review and approval prior to implementation, unless such a change is necessary to avoid immediate harm to subjects (45 CFR 46 and 21 CFR 50, 56). This requirement includes, but is not limited to, changes in any of the following: consent form(s), enrollment goal, principal investigator, research team, advertisements, study procedures, the investigator's brochure, or the study protocol.

All Unanticipated Problems Involving Risks to Subjects or Others (UPIRTSOs), Unanticipated Adverse Device Effects (UADEs), Suspensions or Terminations of the research, Deviations from the approved research plan, potential Non-Compliance, and Complaints must be reported to the IRB in accordance with Allina HRPP/IRB policies. If this study includes ongoing oversight by a Data Safety Monitoring Board (DSMB) or other such committee, reports generated by the DSMB or oversight committee must be submitted to the IRB.

Continuing review materials must be received at least six (6) weeks before the expiration date of June 27, 2017 to ensure adequate time for review. If the project has been completed prior to its expiration date, please submit a Final Report to close your project.

Please note that all research records must be retained for a minimum of three (3) years after the completion of the project or longer if required by regulation, grant terms, or contract.

If you have any questions, please contact Allina Health Institutional Review Board (IRB) Office at (612) 262-4920 or irb@allina.com. Please include your project title and IRBNet ID# in all correspondence.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within Allina Health IRB 1's records.

Appendix B.2: Allina Health IRB Approval Letter of Amendment



Allina Health
Human Research Protection Program
Institutional Review Board

P.O. Box 43 Mail Route 10105
Minneapolis, MN 55440-0043
Tel: 612-262-4920
Fax: 612-262-4953
www.allinahealth.org

NOTICE OF APPROVAL
ALLINA HEALTH FWA NUMBER 00002425

DATE: July 25, 2016

TO: Mary Vining Radomski, PhD
FROM: Allina Health IRB 1

PROJECT TITLE: Participation and Quality of Life for Persons with Oculomotor Impairments
after Acquired Brain Injury

REFERENCE #: 914239-2

SUBMISSION TYPE: Amendment/Modification

SUBMISSION DATE: July 18, 2016

ACTION: APPROVED

APPROVAL DATE: July 25, 2016

EXPIRATION DATE: June 27, 2017

REVIEW TYPE: Expedited Review

Thank you for your submission of Amendment/Modification materials for this project.

The following items were included in this submission:

- Allina Health - Application Part 1 - Allina Health - Application Part 1 (UPDATED: 07/14/2016)
- Amendment/Modification - Modification Request Form (UPDATED: 07/14/2016)
- Letter - Participant Letter to Confirm Appointment (UPDATED: 07/14/2016)

The Allina Health Institutional Review Board (IRB) for the protection of human subjects has reviewed and APPROVED the protocol referenced above. This approval is based on appropriate risk/benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

Proposed changes to the research must be submitted to the IRB for review and approval prior to implementation, unless such a change is necessary to avoid immediate harm to subjects (45 CFR 46 and 21 CFR 50, 56). This requirement includes, but is not limited to, changes in any of the following: consent form(s), enrollment goal, principal investigator, research team, advertisements, study procedures, the investigator's brochure, or the study protocol.

All Unanticipated Problems Involving Risks to Subjects or Others (UPIRTSOs), Unanticipated Adverse Device Effects (UADEs), Suspensions or Terminations of the research, Deviations from the approved

research plan, potential Non-Compliance, and Complaints must be reported to the IRB in accordance with Allina HRPP/IRB policies. If this study includes ongoing oversight by a Data Safety Monitoring Board (DSMB) or other such committee, reports generated by the DSMB or oversight committee must be submitted to the IRB.

Continuing review materials must be received at least six (6) weeks before the expiration date of June 27, 2017 to ensure adequate time for review. If the project has been completed prior to its expiration date, please submit a Final Report to close your project.

Please note that all research records must be retained for a minimum of three (3) years after the completion of the project or longer if required by regulation, grant terms, or contract.

If you have any questions, please contact Allina Health Institutional Review Board (IRB) Office at (612) 262-4920 or irb@allina.com. Please include your project title and IRBNet ID# in all correspondence.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within Allina Health IRB 1's records.

Appendix B.3: St. Catherine University IRB Approval Letter

*St. Catherine University IRB**Approval Notification*

To: Sharon Wagener
From: John Schmitt
Subject: Protocol #696
Date: 08/15/2016

As the IRB Coordinator, with the support of the IRB Chair John Schmitt, I have approved the delegation of IRB responsibility for the protocol titled:

Participation and Quality of Life for Persons with Oculomotor Impairments after Acquired Brain Injury

If you have any questions, feel free to contact me.

John Schmitt,
IRB Coordinator
jsschmitt@stkate.edu

Appendix B.4: Letter of Institutional Support



Date: 11/11/15

To whom it may concern:

This is a letter of support for Sharon Gowdy Wagener's doctoral research project that she would be working on over the course of the next year as a student at St. Catherine University, St. Paul, MN. The project, *Participation and Quality of Life with Oculomotor Impairments after Acquired Brain Injury*, will use a cross-sectional descriptive study design.

The Courage Kenny Research Center will provide Sharon access to the following over the duration of this project:

- Desk top computer with access to Allina Health's secure network, office supplies, and locked cabinet space for storage of hard copies of participant information.
- Mentoring from various research center staff for:
 - Defining and writing the protocol
 - Development of grant application (if applicable)
 - Development and submission of Allina Health IRB application
 - Access to potential study participants through the system wide outpatient clinics
 - Data management
 - Statistical analysis
- Space to do interviews/assessments at the clinics must be negotiated with the clinicians/clinics at the respective sites.

As a research scientist and an experienced reviewer of research proposals, I believe this research project is important, feasible, and consistent with Courage Kenny Rehabilitation Institutes goal to maximize the quality of life and health of the people that we serve. I am hopeful that this proposal will be a success.

Please do not hesitate to contact me with additional questions.

Sincerely,

A handwritten signature in black ink that reads "Nilanjana Banerji". The signature is written in a cursive, flowing style.

Nilanjana Banerji, MS, PhD

Director Clinical Research

Courage Kenny Rehabilitation Institute • Allina Health

John Nasseff Neuroscience Institute • Allina Health

Phone: 612-863-3042 • Pager: 612-654-4856 • Fax: 612-863-3305 • Nilanjana.Banerji@allina.com

Research Bridgeline: 612-863-3452

Mail Route 13418 • 800 E. 28th Street • Minneapolis, MN 55407

Appendix B.5: Mentor Contract

St. Catherine University
Occupational Therapy Doctorate
Mentor Contract

Date September 27, 2016Name of Student Sharon E Gowdy
WagenerName of Mentor Mary Vining RadomskiMentor's Place of Employment Courage Kenny Research Center

I Mary Vining Radomski (mentor) agree to work with and support Sharon Gowdy Wagener (student) for her doctoral project. This entails meeting with the student regularly throughout the time of the project implementation and write up to discuss progress and provide direction. I will collaborate with the student to provide assistance and support for overall project management, logistics, and reporting. The final findings and recommendations will be shared with me (and others if appropriate) by the student. My qualifications are experience as a PI for two federally-funded studies and in either conducting or providing mentorship for over 10 studies funded by either CKF or ANW Foundation.

I do not see a conflict of interest with my involvement in this project.

Sharon and I will meet on a semi-regular basis (at least once every 2 weeks initiated by Sharon) to discuss progress and problem solve any difficulties.

It is my understanding that mentors will be given a copy of the student's final project, SCU library privileges during the time of mentorship, and 12 contact hours for their work.

Mary Radomski
Signature of mentor

9-27-16
Date

Sharon E Gowdy Wagener
Signature of student

9-27-16
Date

Appendix C: Data Collection Form and Questionnaires

Appendix C.1: Demographic Data Collection Sheet

Demographic Data Collection Sheet

Date:

	Date	Responses (includes calculated time since onset and starting OT)
Identification #		
ABI diagnosis		
Onset date/Time since onset		
Visual diagnosis (es)		
Date of first OT/Time since OT started		
Number of OT visits		
Age		
Sex		
Race		
Marital status		
Employment status		
Occupation/Job description		
Living alone/with		
Living Situation (own home/rent)		
Number of children (dependents)		

Appendix C.2: ABI Vision Questionnaire

ABI (Acquired Brain Injury) Vision Questionnaire

Participant ID _____

Date _____

Instructions: We would like to better understand how and if your vision is affecting you in your everyday life. Read each question and respond based on your typical experience with a check or an "X". Feel free to add notes.

	Never	Not too Often	Some times	Fairly Often	Always
1. Do your eyes feel tired when reading or doing close work?					
2. Do your eyes feel uncomfortable when reading or doing close work?					
3. Do you have headaches when reading or doing close work?					
4. Do you feel sleepy when reading or doing close work?					
5. Do you lose concentration when reading or doing close work?					
6. Do you have trouble remembering what you have read?					
7. Do you have double vision when reading or doing close work?					
8. Do you see the words move, jump, swim or appear to float on the page when reading or doing close work?					
9. Do you feel like you read slowly?					
10. Do your eyes ever hurt when reading or doing close work?					

11. Do your eyes ever feel sore when reading or doing close work?					
12. Do you feel a "pulling" feeling around your eyes when reading or doing close work?					
13. Do you notice the words blurring or coming in and out of focus when reading or doing close work?					
14. Do you lose your place while reading or doing close work?					
15. Do you have to reread the same line of words when reading?					
16. Do you have blurred vision at a far distance?					
17. Do you have a loss of peripheral vision?					
18. Do you feel dizziness?					
19. Do you have sensitivity to light?					
20. Do you cover or close one eye to see well?					
21. Are you unable to sustain reading or close work for adequate periods?					
22. Are you bothered by movement in the surrounding environment?					
23. Do you notice postural shifts when standing or walking?					

Appendix C.3: PROMIS Global Health Scale

PROMIS v.1.0/1.1 - Global

Global Health Scale

Please respond to each item by marking one box per row.

		Excellent	Very good	Good	Fair	Poor						
Global01	In general, would you say your health is:	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1						
Global02	In general, would you say your quality of life is:.....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1						
Global03	In general, how would you rate your physical health?	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1						
Global04	In general, how would you rate your mental health, including your mood and your ability to think?	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1						
Global05	In general, how would you rate your satisfaction with your social activities and relationships?	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1						
Global09	In general, please rate how well you carry out your usual social activities and roles. (This includes activities at home, at work and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.).....	<input type="checkbox"/> 5	<input type="checkbox"/> 4	<input type="checkbox"/> 3	<input type="checkbox"/> 2	<input type="checkbox"/> 1						
Global06	To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?	Completely <input type="checkbox"/> 5	Mostly <input type="checkbox"/> 4	Moderately <input type="checkbox"/> 3	A little <input type="checkbox"/> 2	Not at all <input type="checkbox"/> 1						
In the past 7 days...												
Global10	How often have you been bothered by emotional problems such as feeling anxious, depressed or irritable?	Never <input type="checkbox"/> 1	Rarely <input type="checkbox"/> 2	Sometimes <input type="checkbox"/> 3	Often <input type="checkbox"/> 4	Always <input type="checkbox"/> 5						
Global08	How would you rate your fatigue on average?	None <input type="checkbox"/> 1	Mild <input type="checkbox"/> 2	Moderate <input type="checkbox"/> 3	Severe <input type="checkbox"/> 4	Very severe <input type="checkbox"/> 5						
Global07	How would you rate your pain on average?.....	<input type="checkbox"/> 0 No pain	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10 Worst imaginable pain

Appendix C.4: Assessment of Life Habits (LIFE-H 3.1)

Assessment of Life Habits

(LIFE-H 3.1)

General Short Form Information Record Form

1 Name _____

2 Date of birth DD / MM / YYYY _____

3 Gender ☐ Female ☐ Male

4 Date of evaluation DD / MM / YYYY _____

5 How the questionnaire was completed
☐ Self-administered
☐ Interview

6 The respondent is
☐ The person
☐ A significant other
☐ A professional (name and discipline) _____

7 The level of satisfaction is that of
☐ The person
☐ The significant other
☐ The professional

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INDCP
 525, boul. Wilfrid-Hamel Est, local A-08
 Quebec (Quebec) Canada G1M 2S8
 Email: ripph@irdpq.qc.ca

Identification of the Person

1 Name

2 Date of birth DD MM YYYY
/ /

3 Gender ☐ Female ☐ Male

4 Date of evaluation DD MM YYYY
/ /

5 How the questionnaire was completed

- ☐ Self-administered
☐ Interview

6 The respondent is

- ☐ The person
☐ A significant other
☐ A professional (name and discipline)

7 The level of satisfaction is that of

- ☐ The person
☐ The significant other
☐ The professional

Questionnaire

**Answer the following two questions.
(Check the appropriate boxes.)**

- 1** For each of the following life habits, indicate
A. How the person generally accomplishes it,
and
B. The type of assistance required to
accomplish it.
- 2** For each of the following life habits, indicate
the level of satisfaction with the way it is
accomplished.

Note: Keep in mind that answers should reflect the person's
usual way of carrying out life habits.

	Question 1					Question 2				
	A Level of Accomplishment (Check only 1)					B Type of Assistance (Check 1 or more, as required)				
	No difficulty	With difficulty	Accomplished by a proxy	Not accomplished	Not applicable	No assistance	Assistive device	Adaptation	Human assistance	Level of Satisfaction (Check only 1)
Nutrition										
Selecting appropriate food for your meals, according to your taste and particular needs (quantity, type of food)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	1.1 <input type="checkbox"/>
Preparing your meals (including using electric kitchen appliances)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	1.2 <input type="checkbox"/>
Eating meals (including the use of dishes, utensils and standard table manners)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	1.3.1 <input type="checkbox"/>
Eating in restaurants (table service and fast-food)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	1.3.2 <input type="checkbox"/>
Fitness										
Getting in and out of bed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	2.1 <input type="checkbox"/>
Sleep (comfort, duration, continuity, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	2.2 <input type="checkbox"/>
Participating in physical activities to maintain or improve your physical fitness or health (walking, individual or group exercise)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	2.3 <input type="checkbox"/>
Participating in relaxation, unwinding, or mental focus activities to ensure your psychological or mental well-being (yoga, meditation, personal growth, chess, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	2.4 <input type="checkbox"/>
Personal Care										
Attending to your personal hygiene (washing yourself, doing your hair, taking a bath or shower, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	3.1 <input type="checkbox"/>
Using the bathroom and toilet in your home (and other devices for elimination)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	3.2.1 <input type="checkbox"/>
Using a bathroom and toilet other than those in your home (and other devices for elimination)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	3.2.2 <input type="checkbox"/>

**Answer the following two questions.
(Check the appropriate boxes.)**

1 For each of the following life habits, indicate
A. How the person generally accomplishes it,
and
B. The type of assistance required to
accomplish it.

2 For each of the following life habits, indicate
the level of satisfaction with the way it is
accomplished.

Note: Keep in mind that answers should reflect the person's
usual way of carrying out life habits.

	Question 1					Question 2				
	A Level of Accomplishment (Check only 1)		B Type of Assistance (Check 1 or more, as required)			Level of Satisfaction (Check only 1)				
	No difficulty	With difficulty	Accomplished by a proxy	Not accomplished	Not applicable	No assistance	Assistive device	Adaptation	Human assistance	
	Very dissatisfied	Dissatisfied	More or less satisfied	Satisfied	Very satisfied					
Dressing and undressing the upper half of your body (clothing, accessories, including the choice of clothes)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	3.3.1 <input type="checkbox"/>
Dressing and undressing the lower half of your body (clothing, accessories, including the choice of clothes)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	3.3.2 <input type="checkbox"/>
Putting on, removing, and maintaining your assistive devices (orthotics, prosthetics, contact lenses, glasses, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	3.3.3 <input type="checkbox"/>
Taking care of your health (first aid, medication, following treatment instructions, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	3.4.1 <input type="checkbox"/>
Using services provided by a medical clinic, hospital or rehabilitation center.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	3.4.2 <input type="checkbox"/>
Communication										
Communicating with another person at home or in the community (expressing needs, holding a conversation, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	4.1.1 <input type="checkbox"/>
Communicating with a group of people at home or in the community (expressing needs, holding a conversation, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	4.1.2 <input type="checkbox"/>
Written communication (writing a letter, message, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	4.2.1 <input type="checkbox"/>
Reading and understanding written information (newspapers, books, letters, signs, etc.) Note: If you use glasses to read, check Assistive devices	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	4.2.2 <input type="checkbox"/>
Using a phone at home or at work	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	4.3.1 <input type="checkbox"/>
Using a public or cell phone	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	4.3.2 <input type="checkbox"/>
Using a computer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	4.3.3 <input type="checkbox"/>
Using a radio, television or sound system	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	4.3.4 <input type="checkbox"/>
Housing										
Choosing a home that suits your needs (house, apartment, group home)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	5.1 <input type="checkbox"/>

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(Check the appropriate boxes.)**

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the level of satisfaction with the way it is
accomplished.

Note: Keep in mind that answers should reflect the person's
usual way of carrying out life habits.

	Question 1										Question 2			
	A Level of Accomplishment (Check only 1)					B Type of Assistance (Check 1 or more, as required)					Level of Satisfaction (Check only 1)			
	No difficulty	With difficulty	Accomplished by a proxy	Not accomplished	Not applicable	No assistance	Assistive device	Adaptation	Human assistance	Very dissatisfied	Dissatisfied	More or less satisfied	Satisfied	Very satisfied
Maintaining your home (cleaning, laundry, minor repairs, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	5.2.1 <input type="checkbox"/>
Maintaining the grounds of your home (lawn, garden, snow removal, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	5.2.2 <input type="checkbox"/>
Doing major household tasks (spring cleaning, painting, major repairs, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	5.2.3 <input type="checkbox"/>
Entering and exiting your home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	5.3.1 <input type="checkbox"/>
Moving around within your home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	5.3.2 <input type="checkbox"/>
Using the furniture and home-furnishing equipment in your home (desk, thermostat, radiator system, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	5.3.3 <input type="checkbox"/>
Moving around outside your home (yard, grounds, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	5.3.4 <input type="checkbox"/>
Mobility														
Getting around on streets or sidewalks (including crossing streets)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	6.1.1 <input type="checkbox"/>
Getting around on slippery or uneven surfaces (snow, ice, grass, gravel, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	6.1.2 <input type="checkbox"/>
Driving a vehicle	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	6.2.1 <input type="checkbox"/>
Riding a bicycle (for transportation, recreation, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	6.2.2 <input type="checkbox"/>
Being a passenger in a vehicle (car, bus, taxi, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	6.2.3 <input type="checkbox"/>
Note: Adapted transport is an adaptation .														
Responsibilities														
Recognizing the value of money and correctly using the different denominations of paper and coin money	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	7.1.1 <input type="checkbox"/>
Using bank cards and automatic teller machines (ATMs)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	7.1.2 <input type="checkbox"/>
Making purchases (choosing merchandise, mode of payment, purchases by telephone, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	7.1.3 <input type="checkbox"/>
Planning your budget and meeting your financial obligations (spending, saving, paying bills, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	7.1.4 <input type="checkbox"/>

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usual way of carrying out life habits.

	Question 1					Question 2										
	A Level of Accomplishment (Check only 1)					B Type of Assistance (Check 1 or more, as required)							Level of Satisfaction (Check only 1)			
	No difficulty	With difficulty	Accomplished by a proxy	Not accomplished	Not applicable	No assistance	Assistive device	Adaptation	Human assistance	Very dissatisfied	Dissatisfied	More or less satisfied	Satisfied	Very satisfied		
Assuming your responsibilities towards others and society (respecting the rights and property of others, voting, obeying laws and by-laws, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	7.2	<input type="checkbox"/>
Assuming your personal or familial responsibilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	7.3.1	<input type="checkbox"/>
Ensuring the education of your children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	7.3.2	<input type="checkbox"/>
Taking care of your children (health, feeding, clothing, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	7.3.3	<input type="checkbox"/>
Interpersonal Relationships																
Maintaining a close relationship with your partner	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	8.1	<input type="checkbox"/>
Maintaining close relationships with your children	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	8.2.1	<input type="checkbox"/>
Maintaining close relationships with your parents	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	8.2.2	<input type="checkbox"/>
Maintaining close relationships with other members of your family (brothers, sisters, uncles, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	8.2.3	<input type="checkbox"/>
Maintaining friendships	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	8.2.4	<input type="checkbox"/>
Maintaining social relationships with those around you (neighbors, co-workers, fellow students, in leisure activities, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	8.2.5	<input type="checkbox"/>
Having a sexual relationship (healthy, appropriate, safe sex)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	8.3	<input type="checkbox"/>
Community Life																
Getting to public buildings in your community (governmental, financial, judicial, postal, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	9.1	<input type="checkbox"/>
Entering and getting around in public buildings in your community (governmental, financial, judicial, postal, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	9.1.2	<input type="checkbox"/>
Using the public services in your community (governmental, financial, judicial, postal, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	9.1.3	<input type="checkbox"/>
Getting to commercial establishments in your community (supermarket, shopping mall, convenience store, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	9.1.4	<input type="checkbox"/>

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	Question 1						Question 2							
	A Level of Accomplishment (Check only 1)			B Type of Assistance (Check 1 or more, as required)			Level of Satisfaction (Check only 1)							
	No difficulty	With difficulty	Accomplished by a proxy	Not accomplished	Not applicable	No assistance	Assistive device	Adaptation	Human assistance	Very dissatisfied	Dissatisfied	More or less satisfied	Satisfied	Very satisfied
Entering and moving around in commercial establishments in your community (supermarket, shopping mall, convenience store, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	9.1.5 <input type="checkbox"/>
Using your neighborhood businesses (supermarkets, shopping malls, dry cleaners, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	9.1.6 <input type="checkbox"/>
Participating in social or community groups (social clubs, charity or religious groups, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	9.2.1 <input type="checkbox"/>
Participating in spiritual or religious practices	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	9.2.2 <input type="checkbox"/>
Education														
Participating in educational activities or vocational training at the high school level (courses, homework, extracurricular activities, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	10.1 <input type="checkbox"/>
Undertaking vocational training (trade school, university, community college)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	10.2 <input type="checkbox"/>
Employment														
Choosing a career or profession	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	11.1 <input type="checkbox"/>
Seeking employment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	11.2 <input type="checkbox"/>
Holding a paid job	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	11.3.1 <input type="checkbox"/>
Note: If you are not currently working but you would like to work, check the Not accomplished box														
Taking part in unpaid activities (volunteering)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	11.3.2 <input type="checkbox"/>
Getting to your principal place of occupation (work, school, volunteer center, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	11.4.1 <input type="checkbox"/>
Entering and moving around in your principal place of occupation (work, school, volunteer center, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	11.4.2 <input type="checkbox"/>
Using the services at your principal place of occupation (work, school), including cafeteria, personnel/student services, etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	11.4.3 <input type="checkbox"/>
Carrying out family or home-making tasks as your main occupation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	11.4.4 <input type="checkbox"/>

**Answer the following two questions.
(Check the appropriate boxes.)**

1 For each of the following life habits, indicate
A. How the person generally accomplishes it,
and
B. The type of assistance required to
accomplish it.

2 For each of the following life habits, indicate
the level of satisfaction with the way it is
accomplished.

Note: Keep in mind that answers should reflect the person's
usual way of carrying out life habits.

	Question 1					Question 2								
	A Level of Accomplishment (Check only 1)		B Type of Assistance (Check 1 or more, as required)			Level of Satisfaction (Check only 1)								
	No difficulty	With difficulty	Accomplished by a proxy	Not accomplished	Not applicable	No assistance	Assistive device	Adaptation	Human assistance	Very dissatisfied	Dissatisfied	More or less satisfied	Satisfied	Very satisfied
Recreation														
Participating in sporting or recreational activities (walking, sports, games, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Participating in artistic, cultural or craft activities (music, dance, woodworking, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Going to sporting events (hockey, baseball, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Going to artistic or cultural events (concerts, movies, theater, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Participating in tourist activities (traveling, visiting natural or historic sites, camping, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Taking part in outdoor activities (hiking, camping, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Using your neighborhood recreational services (library, municipal recreation center, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Comments

Use the following lines for general comments or remarks related specifically to one or more of the categories in terms of

- a) The level of accomplishment
- b) The type of assistance required
- c) The level of satisfaction

or for general comments pertaining to any other aspect of this questionnaire.

SPECIMEN

Life Habits Accomplishment Scale		
Score	Difficulty Level	Assistance Type
9	No difficulty	No assistance
8	No difficulty	Assistive device (or adaptation)
7	With difficulty	No assistance
6	With difficulty	Assistive device (or adaptation)
5	No difficulty	Human assistance
4	No difficulty	Assistive device (or adaptation) and human assistance
3	With difficulty	Human assistance
2	With difficulty	Assistive device (or adaptation) and human assistance
1	Accomplished by a proxy	
0	Not accomplished	
N/A	Not applicable	

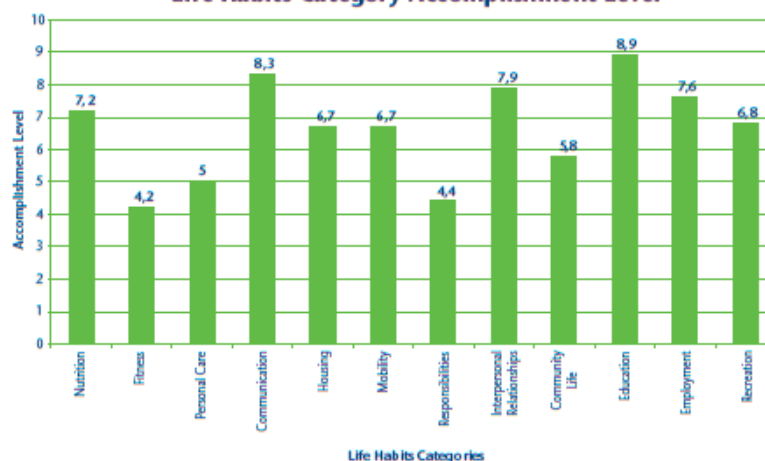
Formula: Calculation of the Accomplishment Level (Weighted Score)

$$(\sum \text{Scores} \times 10) \div (\text{Number of Applicable Life Habits} \times 9)$$

Example: Calculation of the Accomplishment Level
 (LIFE-H General Short Form 3.1)

Score Calculation			Example		
Categories	Number of Applicable Life Habits	Score (range)	Number of Applicable Life Habits	Raw Score	Weighted Score (0-10)
Nutrition	4	0-36	4	26	7,2
Fitness	4	0-36	4	15	4,2
Personal Care	8	0-72	8	36	5
Communication	8	0-72	8	60	8,3
Housing	8	0-72	8	48	6,7
Mobility	5	0-45	4	24	6,7
Responsibilities	8	0-72	7	28	4,4
Interpersonal Relationships	7	0-63	7	50	7,9
Community Life	8	0-72	8	42	5,8
Education	2	0-18	2	16	8,9
Employment	8	0-72	8	55	7,6
Recreation	7	0-63	7	43	6,8
Total	77	0-693	75	443	6,6/10

Life Habits Category Accomplishment Level



Appendix C.5: Assessment of Life Habits (LIFE-H) Follow-up Questions

For those selecting “with difficulty” under Level of Accomplishment: Participants will be asked to rate:

- A little difficult
- Really difficult

Follow up questions after completing full assessments:

- For broad activity areas that are moderately or very difficult:
 - Tell me what specific leisure activities/physical activities/tasks of work are hard?

Tell me what makes this activity hard? How is it hard?

Appendix D: Demographics of Participants

	<i>n</i>	%
Marital Status		
Single	6	20.0
Married	17	56.7
Partnered	4	13.3
Divorced	3	10.0
Living Arrangements		
Alone	3	10.0
With Spouse/SO	10	33.3
Spouse with Children	12	40.0
With Family/Shared	5	16.7
Education Level		
High School	2	6.7
Technical/Vocational Training	5	16.7
Some college	7	23.3
Bachelor	3	10.0
Post Graduate	13	43.3
Employment areas		
Education	7	23.3
Health care	6	20.0
Technical	4	13.3
Financial	3	10.0
Commercial	2	6.7
Homemaker	1	3.3
Legal	1	3.3
Other ^a	4	13.3

Note. ^aIncludes waitress, program coordinator, UPS driver and activist resource specialist.