Vision-Related Quality of Life in Patients with Pituitary Tumours

Questionnaire Development

Project Report 2015

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INTRODUCTION

Difficulty with vision is the most common complaint of individuals with tumours in the pituitary region of the brain. These tumours often encroach on integral components of the visual pathway, and can cause a variety of vision-related symptoms through compression of the optic nerves and chiasm. Deficits from this phenomenon can include decreased visual acuity, diminished colour perception, visual field defects, and optic disc atrophy, among other sequelae.[1,2] Consequently, it is important to monitor visual function and assess vision-related quality of life in this patient population.

Presently, a combination of qualitative and quantitative methods are used to detect and monitor the effects of pituitary lesions on vision.[3] These include charts for visual acuity, tests of colour perception, visual field perimetry, fundoscopy of the optic disc, ocular coherence tomography, and the measurement of intraocular pressure. The current standard of care for visual function testing involves ophthalmologic methods that require expensive, specialized equipment and highly trained personnel to operate. Importantly, domains such as functionality in activities of daily living, mental health, ongoing role difficulties, and impact of vision on social interactions are not assessed by visual function tests, resulting in a need for qualitative and subjective tools of measurement that can assess the impact of visual changes on the illness experience of patients with pituitary tumours.

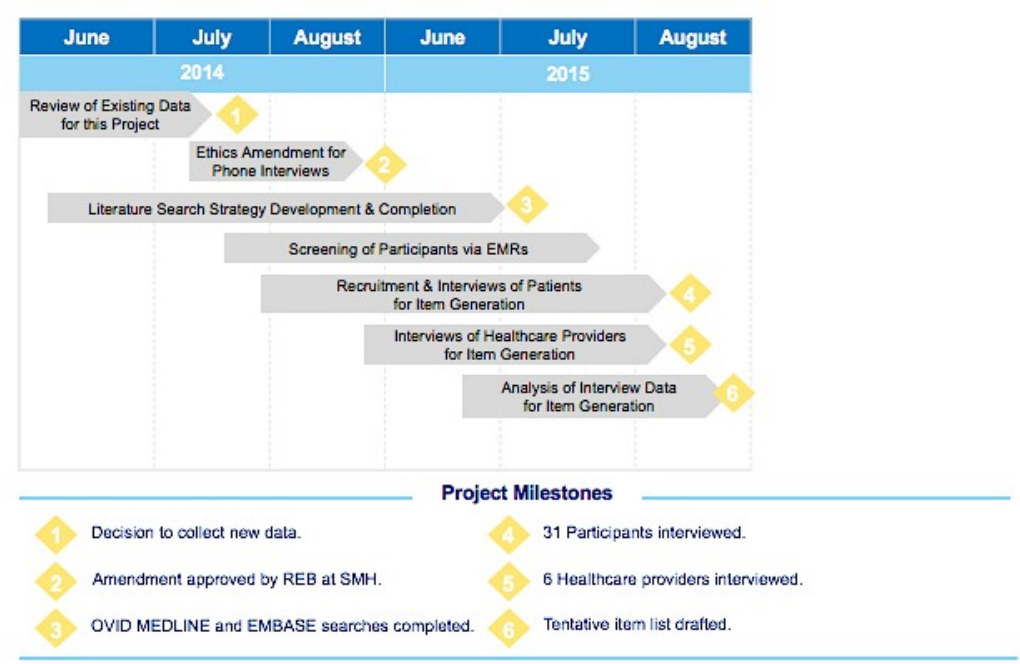
At this time, no vision-related quality-of-life (VR-QOL) metrics have been designed specifically for use in patients with tumours on or around the pituitary gland. For this reason, it is our hypothesis that current VR-QOL measures do not adequately investigate the unique issues that are faced by this patient population.

OBJECTIVES

The goal of this project is to develop a simple self-report questionnaire and assess its ability to reliably and accurately measure the effect of pituitary tumors on vision and vision-related quality-of-life, enhance clinical decision-making, and gauge patient responses to treatment over time.

METHODS & RESULTS

FIGURE 1: TIMELINE OF PROJECT MILESTONES ACHIEVED FROM JUNE 2014 – AUGUST 2015.



ITEM GENERATION

The item-generation phase of this study aimed to establish a comprehensive list of factors that contribute to VR-QOL in pituitary tumour patients. In order to do this, semi-structured interviews were carried out with pituitary tumour patients, along with open-ended interviews with healthcare providers who work closely with this patient population. In addition, a thorough literature search of VR-QOL in pituitary tumour patients was completed using multiple research databases (OVID MEDLINE, PSYCHINFO, EMBASE, CINAHL).

RECRUITMENT & SAMPLE DATA

Pre- and post-operative participants were recruited for the item-generation phase of this project from July to August of 2014 and from June to August of 2015. Patient lists from the Neurosurgery, Pituitary, and Neuro-Ophthalmology Clinics were screened for inclusion/exclusion criteria using electronic medical records at St. Michael's Hospital, in addition to recommendations by the Primary Investigator (Dr. Michael D. Cusimano), who was actively involved in the identification of suitable candidates

The study inclusion criteria are as follows:
1. Age 18+
2. Individuals with tumours on or around the pituitary gland
3. Physicians and nurses providing care to patients with tumours on or around the pituitary gland

The exclusion criteria are:
1. Inability to communicate in English

Eligible participants were then introduced to the Research Student by a member of the patient's circle of care in the clinic. After having an opportunity to review and ask questions about the research objectives and protocol, all patients interested in participating provided informed consent.

FIGURE 2: TOTAL RECRUITMENT NUMBERS FOR ITEM-GENERATION FROM JULY 2014 - AUGUST 2015.

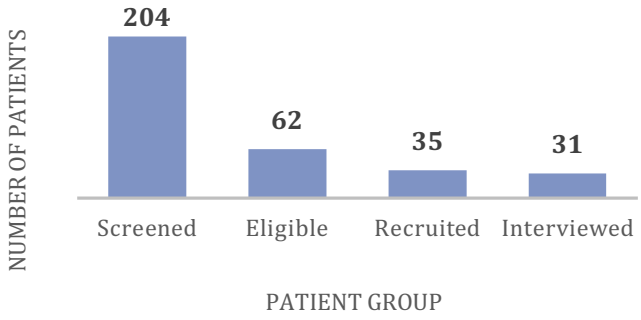
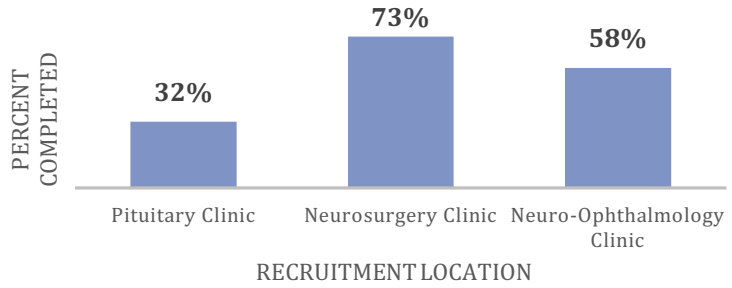


Figure 2 outlines the number of patients involved in stages of Item-Generation for this project. Of the 35 participants recruited, 31 completed the semi-structured interview, while 5 were lost to follow up due to scheduling difficulties and/or lack of response to communication efforts. All 5 of the participants lost to follow-up had opted to have phone-interviews due to time constraints that limited their ability to remain at the clinic in-person after their medical appointments. Of the interviews that were completed, 24 were carried out in-person in the clinics, while 7 were conducted by phone. These numbers demonstrate that it is optimal to conduct interviews in-person at the time of recruitment, and that a greater degree of attrition occurs when interviews are delayed to a later date. A further breakdown of recruitment numbers per site is shown in Table 1.

TABLE 1: RECRUITMENT NUMBERS PER SITE FOR ITEM-GENERATION FROM JULY 2014 – AUGUST 2015.

Recruitment Site	# Screened	# Eligible	# Recruited	# Interviewed
Neurosurgery Clinic	100	11	9	8
Neuro-Ophthalmology Clinic	67	26	17	15
Pituitary Clinic	37	25	9	8

FIGURE 3: PERCENTAGE OF ELIGIBLE PARTICIPANTS THAT COMPLETED THE SEMI-STRUCTURED INTERVIEW BY RECRUITMENT SITE.



As shown in Figure 3, there was a difference in the percentage of eligible participants that completed the semi-structured interview per recruitment site. This is noteworthy because many patients with pituitary tumours attend all three of these clinics on a regular basis, and it is often by chance that individuals are recruited from one clinic as opposed to another on any given day.

What this trend suggests is that the environment in certain clinics is more conducive to recruitment and testing compared to others. For example, the monthly Pituitary Clinics have very high numbers of eligible participants (since almost all patients attending these clinics have pituitary tumours and meet study inclusion criteria). However, because appointments are scheduled back-to-back, opportunities to recruit are often missed because participants generally prefer to be interviewed in-person after their appointments, and semi-structured interviews take a fair amount of time to complete. Additionally, because multiple research studies are being carried out with this population at St. Michael's Hospital, patients are approached by numerous research personnel and are sometimes reluctant to participate in more than one project. This is partly why there is a large difference between the number of patients eligible (62) and the number recruited (35), as reported in Figure 2.

Conversely, the Neurosurgery and Neuro-Ophthalmology Clinics tend to have a variety of different patients scheduled throughout the day including individuals with skull-base tumours, traumatic brain injuries, hydrocephalus, aneurysms, or neurological disorders such as multiple sclerosis. Consequently, the appointments times of patients with pituitary tumours are spread out, allowing for interview completion without loss of recruitment opportunities. In addition, Neurosurgery Clinics occur once per week, and Neuro-Ophthalmology Clinics run 3-4 days per week allowing for more frequent recruitment, despite a decreased number of eligible patients per clinic compared to the Pituitary Clinic.

It is also imperative to note that not all eligible patients (based on study inclusion criteria) experienced visual symptoms as a result of their tumour. Consequently, patients without past or present visual dysfunction generally declined to participate in VR-QOL research, also contributing to the lower number of recruited patients.

Given the relatively small number of patients involved in the Item-Generation phase, sample characteristics can have a large influence the external validity of data collected through semi-structured interviews. While a comprehensive literature search can help to decrease sampling bias, it is important to be aware of demographic characteristics of the patient population interviewed.

FIGURE 4: AGE AND NUMBER OF YEARS OF EDUCATION OF PARTICIPANTS WHO COMPLETED THE SEMI-STRUCTURED INTERVIEW.

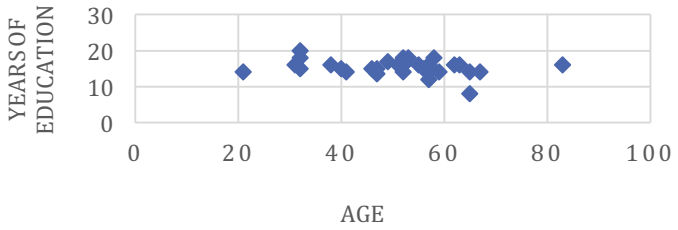


Figure 4 shows the distribution of participants based on age and years of education. The average age of participants that completed semi-structured interviews was 51, with a standard deviation of 12.75 (range: 21-83). The average number of years of education of participants was 15, with a standard deviation of 2.11 (range: 8-20). It is important to note that as a group, our sample of was highly educated, and 71% of participants were employed at the time of their interview.

FIGURE 5: ETHNICITIES OF PARTICIPANTS THAT COMPLETED SEMI-STRUCTURED INTERVIEWS.

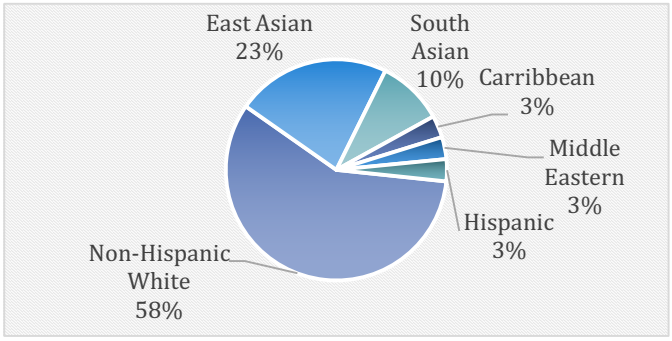


FIGURE 6: PERCENTAGE DISTRIBUTION OF PARTICPANTS IN REGIONS OF ONTARIO BASED ON CONTACT INFORMATION AREA CODES.

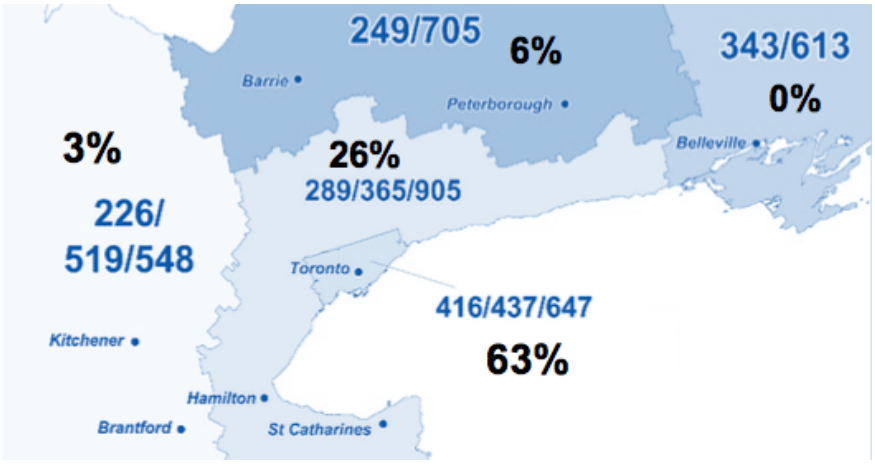


Image modified from: http://www.cnac.ca/area_code_maps/southern_ontario_area_code_map_lowres.pn

LITERATURE SEARCH

A search strategy was developed with the assistance of David Lightfoot, Information Specialist at the Health Sciences Library at St. Michael's Hospital. Thus far, literature searches have been completed using OVID MEDLINE and EMBASE, and are in progress for PSYCHINFO and CINAHL. The search of OVID MEDLINE yielded 90 articles related to visual symptoms of pituitary tumours and VR-QOL in this population, while the search of EMBASE yielded 459 articles. These results have been screened for relevance, and applicable articles are currently being reviewed for content that should be included in the item list.

INTERVIEW DATA

During the semi-structured interviews, patients were asked a series of 28 questions about their symptoms, diagnosis, surgery (if post-operative), other treatments, recovery, and overall experiences surrounding care. Specific questions were asked about the impact of the pituitary tumour on physical and mental health, as well as functionality in activities of daily living. Patients were also questioned about any challenges they faced in receiving health care, financial burdens due to vision-related care, and the emotional and social consequences of visual dysfunction.

On analysis of interview content, several key themes emerged. With regards to visual symptoms, 42% of patients reported increased photosensitivity to certain intensities of light. Most commonly, this phenomenon was experienced outdoors but in some cases also occurred indoors when patients were near televisions, cell phones, or computer screens, or in environments under fluorescent lighting. Some individuals felt that light sensitivity impaired their ability to work indoors in an office, go shopping at the mall, or engage in outdoor activities.

Another symptom that 23% of patients in our sample experienced was diplopia (double vision). The majority of patients who had diplopia felt that this was by far the most challenging visual symptom to cope with. In several of the cases, diplopia was also the symptom that alerted patients of an urgent health problem, and prompted them to seek medical attention leading to their diagnosis. In addition, 3% of patients experienced diplopia after treatment (surgery or radiation), with two patients reporting that the diplopia was the first symptom of tumour recurrence. At the time of the interview, most patients had stopped having double vision, however, the one patient who had constant diplopia appeared to be quite distraught during her interview, and a handful of other pre-operative patients reported that they were currently experiencing it sporadically in their daily life. The consequences of diplopia on functionality were huge, and often compromised patient independence by making it very difficult for individuals to drive, work, and read. One patient described his experience with diplopia as follows:

> *"After the surgery I had some pretty severe [double vision]. I mean so bad that they couldn't even put prisms in my glasses to correct it, it was just… terrible. One eye essentially looked almost up at 30 degrees and the other eye looked straight forward. They were trying to correct it with prisms and they couldn't, so they said "you're just going to have to live with it" and I said "ok…" but what I did was set targets up on the windows in the backyard of the house and I worked on focusing and putting the two images together. I just worked, and worked, and worked, and worked. And nothing happened for about 6 months. Absolutely nothing and then one day I was working and… the images came together! In a matter of about 20 seconds, the right eye just rotated down, and rotated down, and rotated down until the two images were in focus, and I had stereoscopic vision for the first time in 6 months. It was a very emotional kind of situation." – Participant 033*

Of the interviewed participants, 16% experienced colour vision abnormalities. While these changes were not felt to be as functionally damaging as other visual symptoms, one patient recounted her experience with colour vision prior to being diagnosed:

> *"One [thing] that I noticed was that just looking at the [eye] chart isn't good enough because… my distance vision was deteriorating slowly, but what was deteriorating even more was that I couldn't focus close up … and also the brightness. In hindsight I should've looked at colour charts and brightness to gauge. Because what really alerted me was that every week I go to church and every week I noticed it was getting dimmer… Something about brightness and colour. Even in my right eye at the very end… I didn't have 20/20 anymore but I could still read [the eye chart] to a certain level, and that didn't deteriorate very much. It was just the brightness and colour that were going. My reds weren't as red… you know?... I kept saying my eyes are getting dimmer and I can't see colours but I couldn't quantify that." – Participant 017*

When asked about visual field defects, 31% of participants stated that they had deficits in this area at some point in time. The degree of visual field loss varied greatly, and consequently appeared to have an equally variable impact on quality-of-life for each patient. Several patients stated that the field loss affected their reading and driving abilities, and that they eventually stopped driving out of safety concerns. A number of patients noted an improvement in their visual fields post-operatively, but many had residual loss after treatment. One patient described the effect of visual field loss on his healthcare experience:

> *"I remember very well that [in] 2004, I went through all the [visual] testing, I passed all of them and I was almost at the door and I returned back to the chair and said "look something is really not… I cannot express it but something is wrong." Well, she hesitantly gave me … a requisition for a visual field test. And from that visual field test the guy, straight from looking through the chart said "you have a pituitary adenoma." He showed me the textbook example, actually the chart, and it was almost like a match. So I never went back to that ophthalmologist because I did everything possible. I understand it's very hard to catch the symptoms because I have a peripheral vision deficiency… [But] that's basically how. I begged the visual field test and that's how that was discovered. And I would say as advice, if someone says he has these symptoms… [And] he cannot explain them, you take that seriously. Don't underestimate in your practice later because I couldn't tell specifically what's the problem, I was expecting the expert to tell me back, but the expert cannot tell me if I cannot quantify it. Compared to visual acuity which is easy to detect, this is hard to detect." – Participant 027*

In addition, a large number of patients reported decreased visual acuity with near and distance vision, but many were unsure if this was related to aging rather than the pituitary tumour. Other, less common symptoms that patients reported included painful eyes (6%), watering of eyes (10%), complete or near-complete vision loss (10%), decreased night vision (23%), halos around lights (13%), altered depth perception (14%), blurry vision (13%) and ptosis (3%). Of these, complete vision loss, blurry vision, and ptosis appeared to be the most functionally impairing.

The influence of vision-related symptoms on mental health was explored in great detail, and many of the patients reported a specific fear of becoming blind due to their tumour. As well, 66% of participants stated that knowledge of the tumour in general had caused them to feel an overwhelming degree of stress and anxiety. When asked, "in what way has your diagnosis affected or influenced your general health?" one participant responded:

> *"Hugely, psychologically. It was a huge impact. The stress was unbelievable. Overall I would say that is a huge area of zero care… There are glossy pamphlets but nothing to really to actually help. Going through what I've gone through, that's my number one suggestion. Incorporate psychology into multidisciplinary teams for sure. I did have to ask… It wasn't brought forward… There was a buddy system, so eventually I did get a buddy who had gone through it and I could call them on my own. But they're not a professional… Who knows what their backgrounds are? I was a little leery of that. They're not trained and you're at the mercy of someone else's schedule." – Participant 016*

A number of participants also reported that they were dealing with additional non-visual, tumour-related symptoms, particularly those with functional tumours that were secreting hormones. A patient with double vision and Cushing's Disease, when asked, "what kinds of challenges do you face with regards to your general health on a day-to-day basis?" replied:

> *"Yes, it does stop me from doing daily tasks… I don't exercise as much as I'd like to. I don't have the strength to do these things. My garden work, I can't do, what I do normally, I can't go jogging because my spine hurts. I'm starting to drive again now but driving is a real challenge because I have to turn my head around [very] far to see. Anything related to driving, grocery shopping, doctor's appointments in the city, that kind of stuff. I can't work right now. So therefore you deal… Eventually it becomes very frustrating and very depressing because you have to… learn to do different things from what you were doing before. So it's a big change. And your interests and your drive... That goes together with depression I suppose. It's hard to stay positive and cheerful." - Participant 025*

Furthermore, some patients also had long-standing medical conditions that were entirely separate from the effects of the tumour. In discussing barriers to care, a few individuals spoke about the importance of the doctor-patient relationship, and one participant described the effect of having her symptoms validated by her healthcare provider:

> *"Once I saw [Neurosurgeon's] team they right away said, you know, "jeez this is so classic," and they understood that I was losing my sight, its not something that … that is a figment of my imagination. For some reason the other doctors I've seen kept thinking it was a figment of my imagination or at least I felt that way! That's how they were treating me… Only when I saw the ophthalmologist … and when she saw me and got the diagnosis from the radiologist, and referred me to [Neurosurgeon], I finally felt I was being heard and that an action was taken. So I was very happy with the responsiveness." – Participant 017*

Ultimately, the semi-structured interviews provided a great deal of insight regarding factors that influence the quality-of-life of pituitary tumour patients. In addition to these interviews, 5 healthcare providers that work closely with pituitary tumour patients were asked about their perspective on enhancing quality-of-life in this population. The group of healthcare providers at St. Michael's Hospital included two neurosurgeons: Dr. Antonio Di Ieva, and Dr. Michael Meier, endocrinologist Dr. Jeanette Goguen, nurse practitioner Martine Andrews, and case manager Linda Lo.

One of the key themes that emerged from the healthcare provider interviews was the role of visual assessment in determining the need for, and urgency of surgery. Patients that are losing their vision become top priority, because conservation of vision is one of the essential outcomes of care.

One of the team members has also noticed that there is an "effect of hospitalization," in that patients tend to become more aware of their visual deficits while in hospital.

Another important topic was ensuring that patients are aware that they are looked after by a team, and that specific issues will be managed by different team members. Making sure that patients know who to call when they have problems, and following up with individuals post-operatively are key factors that can improve the care of pituitary tumour patients. Occupational therapists are also members of the team who can teach patients to cope with their vision loss and maintain as much independence as possible. Furthermore, in a team-based approach, all staff members are made aware of patients' visual impairments so that they may accommodate, and assist these individuals with tasks such as ambulation, since these patients are at increased risk of falls and injuries in hospital. Other small but important measures are also put in place to improve patient care, such as having staff members call out to patients and introduce themselves when entering the room, or explaining to patients where trays and other items are located in the room, and verifying that patients are able to access these items.

With regards to other important areas in vision-related quality of life, driving was identified as an important factor by health care providers because it correlated with patients' perceived independence and freedom. Another important tumour-related factor that can be quite important to mental health is the effect of the tumour and/or surgery on the appearance and self image of patients, an area that has not been widely assessed in quality-of-life questionnaires.

ITEM LIST

Based on the content analysis of the interviews and the literature search findings, the following item list has been generated for the item reduction phase of the project. This list will be sent to 30 patients, who will rank the questions based on perceived importance and relevance to vision-related quality-of-life.

Please rate each question from 1 to 5, based on how important you feel the question is for understanding the vision-related quality of life of patients with pituitary tumours.

(1 = Not Important) 1 2 3 4 5 (5 = Very Important)

Demographic Information:

1 2 3 4 5 Age: ____
1 2 3 4 5 Sex: ____
1 2 3 4 5 Occupation: _____

Please select all that apply:

1 2 3 4 5 *Are you currently…?*

- ☐ Employed
- ☐ Unemployed
- ☐ Unable to work due to health
- ☐ Retired
- ☐ Student or homemaker

1 2 3 4 5 *What is your total household income?*

- ☐ Less than $10,000
- ☐ $10,000 to $39,999
- ☐ $40,000 to $69,999
- ☐ $100,000 to $149,999
- ☐ $150,000 or more
- ☐ I prefer not to answer

1 2 3 4 5 *Please specify your race/ethnicity…*

☐ Indigenous or First Nations
☐ Asian
☐ Black or African Canadian
☐ Non-Hispanic White
☐ Hispanic, Latino or Spanish origin

1 2 3 4 5 *Do you currently have…?*

☐ Health coverage through OHIP or another provincial health care plan
☐ Supplementary Health Insurance through an employer
☐ No medical coverage or insurance

1 2 3 4 5 *Have you received any of the following for your tumour?*

☐ Surgery
☐ Radiation therapy
☐ Medical therapy (e.g. cabergoline, bromocriptine or octreotide)

1 2 3 4 5 Was your diagnosis incidental (i.e. not due to any tumour-related symptoms)?

1 2 3 4 5 Was your diagnosis a result of visual symptoms?

Visual Symptoms:

Light sensitivity:

1 2 3 4 5 How often do you experience sensitivity to sunlight outdoors?

1 2 3 4 5 How often does your sun sensitivity prevent you from going out during the day?

1 2 3 4 5 How often is your sun sensitivity resolved by wearing sunglasses?

1 2 3 4 5 How often do you experience sensitivity to light when you are indoors?

1 2 3 4 5 How much difficulty do you have performing tasks in natural lighting?

1 2 3 4 5 How much difficulty do you have performing tasks in fluorescent lighting?

1 2 3 4 5 How often do you experience sensitivity to light from computer screens, televisions or cellular phones?

1 2 3 4 5 How much difficulty do you have working on a computer screen due to light sensitivity?

1 2 3 4 5 How long have you had light sensitivity for?

Double vision:

1 2 3 4 5 How often do you experience double vision?

1 2 3 4 5 How much difficulty do you have performing daily tasks due to your double vision?

1 2 3 4 5 How much difficulty do you have reading because of your double vision?

1 2 3 4 5 How much difficulty do you have working on a computer because of your

double vision?

1 2 3 4 5 How often do you feel frustrated because of your double vision?

Colour vision:

1 2 3 4 5 How often do you notice changes in your colour vision?

1 2 3 4 5 How often do you notice a difference between colour vision between your two eyes?

1 2 3 4 5 How often do you notice decreased brightness of your colour vision?

1 2 3 4 5 How would you describe your colour vision over the past month?

1 2 3 4 5 How often do you notice that different colours are blending together?

1 2 3 4 5 Do you have a pre-existing colour blindness or colour vision deficiency (i.e. red-green colour blindness)?

Vision Loss:

1 2 3 4 5 How often do you notice vision loss?

1 2 3 4 5 How much difficulty do you have completing tasks because of your vision loss?

1 2 3 4 5 How would you describe your vision loss over the past month?

1 2 3 4 5 How much difficulty do you have driving because of your vision?

1 2 3 4 5 How often are things around you hidden from your sight?

1 2 3 4 5 How much difficulty do you have reading because of your vision loss?

1 2 3 4 5 Do you need to move the newspaper or book around in order to read it?

Pain in or around eyes:

1 2 3 4 5 How often do you feel pain in or around your eyes?

1 2 3 4 5 How much difficulty do you have falling asleep, or staying asleep because of pain in or around your eyes?

1 2 3 4 5 How much difficulty do you have completing tasks because of pain in or around your eyes?

Watering of eyes:

1 2 3 4 5 How often do you experience watering of your eyes?

1 2 3 4 5 How often does the eye watering bother you?

1 2 3 4 5 Is the watering associated with pain, irritation or redness of your eyes?

Distortion of vision?

1 2 3 4 5 How often do you experience distortion of your vision?

1 2 3 4 5 How much difficulty do you have performing tasks due to the distortion of your vision?

1 2 3 4 5 How often does distortion of vision bother you?

Sudden or worsening loss of vision:

1 2 3 4 5 *Please check all that apply:*

- ☐ I have had sudden loss of vision in one eye
- ☐ I have had sudden loss of vision in both eyes
- ☐ I have had progressive loss of vision in one eye
- ☐ I have had progressive loss of vision in both eyes

Near and Distance Vision:

1 2 3 4 5 How much difficulty do you have seeing close up?

1 2 3 4 5 How much difficulty do you have reading books or the newspaper because of your near vision?

1 2 3 4 5 How would you describe your near vision over the past month?

1 2 3 4 5 How much difficulty do you have seeing far away?

1 2 3 4 5 How much difficulty do you have reading signs far away due to your vision?

1 2 3 4 5 How would you describe your distance vision over the past month?

1 2 3 4 5 *Check all that may apply:*

- ☐ I feel my near vision has changed because of the tumor
- ☐ I feel my near vision has changed due to aging
- ☐ I feel my near vision has changed due to another cause
- ☐ I feel my distance vision has changed because of the tumour
- ☐ I feel my distance vision has changed because of aging
- ☐ I feel my distance vision has changed due to another cause

Decreased night/low-light vision?

1 2 3 4 5 How would you describe your low-light vision over the past month?

1 2 3 4 5 How much difficulty do you have performing tasks at night due to decreased night vision?

1 2 3 4 5 How much difficulty do you have driving at night due to decreased night vision?

1 2 3 4 5 How much difficulty do you have seeing signs on the road when driving at night?

1 2 3 4 5 How much difficulty do you have driving in poor weather due to decreased low-light vision?

1 2 3 4 5 Check all that apply:

- ☐ I feel nervous driving at night because of my vision
- ☐ I have stopped driving at night because of my vision

Halos around lights/glare:

1 2 3 4 5 How often do you see halos around light sources at night?

1 2 3 4 5 How often do you experience light sensitivity at night?

1 2 3 4 5 How much difficulty do you have driving due to halos at night?

1 2 3 4 5 How much difficulty do you have using computers or cellular phones due to halos at night?

1 2 3 4 5 How much difficulty do you have completing tasks during the day due to glare from sunlight?

Depth perception?

1 2 3 4 5 How much difficulty do you have figuring out where objects are in the space in front of you?

1 2 3 4 5 How much difficulty do you have reaching out to grab an object due to your vision? (i.e. a doorknob)

1 2 3 4 5 How much difficulty do you have with tasks that require hand-eye coordination? (i.e. playing tennis)

1 2 3 4 5 How much difficulty do you have parking a car due to altered depth perception?

Sensation around eyes?

1 2 3 4 5 How often do you feel numbness or tingling in or around your eye?

1 2 3 4 5 How often do you feel numbness or tingling around your cheeks?

Blurry vision:

1 2 3 4 5 How often do you experience blurry vision?

1 2 3 4 5 How much difficulty do you have completing tasks because of blurry vision?

1 2 3 4 5 How often do you experience blurry vision after physical activity?

1 2 3 4 5 How often do you experience blurry vision after reading small print?

Drooping Eye-Lid:

1 2 3 4 5 How often do you feel your eyelid is drooping?

1 2 3 4 5 How much difficulty do you have performing tasks because of a drooping eyelid?

1 2 3 4 5 How much are you bothered by a drooping eyelid?

Other:

1 2 3 4 5 How often do you see a bright light when you close your eyes in a dark room?

1 2 3 4 5 How often do you feel one or both of your eyes are bulging forward?

1 2 3 4 5 How often do you feel one or both of your eyes are protruding or bulging more than usual?

General:

1 2 3 4 5 How often do you have difficulty characterizing what is wrong with your vision?

Mental Health/Emotional Impact:

1 2 3 4 5 How often do you worry about your vision?

1 2 3 4 5 How often do you worry about losing your vision?

1 2 3 4 5 Are you afraid that you will lose your sight?

1 2 3 4 5 Do you worry about what will happen to you if you lose your vision?

1 2 3 4 5 How often do you worry that your vision changes are permanent?

1 2 3 4 5 How often do you feel frustrated because of your vision?

1 2 3 4 5 How often do you feel tired because of your vision?

1 2 3 4 5 Do you worry that your vision will become worse with age?

1 2 3 4 5 How often do you feel sadness and anxiety because of your tumour?

1 2 3 4 5 How often do you feel anger or frustration because of your tumour?

1 2 3 4 5 How often do you worry about your future because of your tumour?

1 2 3 4 5 Do you feel hopeful about the future?

1 2 3 4 5 How often do you feel frustrated about your driving abilities due to your vision?

1 2 3 4 5 How often do you feel something is wrong with your vision?

1 2 3 4 5 How often do you worry about your appearance because of your tumour?

1 2 3 4 5 How often do you worry about your appearance because of treatment for your tumour?

1 2 3 4 5 How often do you feel embarrassed or self conscious about your behavior because of visual impairment?

Barriers to care:

1 2 3 4 5 How often do you have difficulty receiving care for your visual symptoms?

1 2 3 4 5 How often do you have difficulty receiving care for your tumour?

1 2 3 4 5 How often do you have financial barriers to receiving care for your visual symptoms?

1 2 3 4 5 How often do you your finances prevent you from receiving care for your tumour?

1 2 3 4 5 How often does your relationship with your doctor affect your quality of care?

1 2 3 4 5 How often does your geographical location limit your access to health care?

1 2 3 4 5 How supported do you feel by your healthcare team with regards to your vision?

1 2 3 4 5 How supported do you feel by your healthcare team with regards to your general health?

General health:

1 2 3 4 5 How often is your general health affected your visual symptoms?

1 2 3 4 5 How often is your general health affected by your tumour?

1 2 3 4 5 How often is your general health affected by medical conditions other than your tumour?

Activities of Daily Living/Vision-Related Functional Impairment:

1 2 3 4 5 How often does your vision affect your ability to dress, eat, go to the washroom, brush your teeth, dress, or shower?

1 2 3 4 5 To what degree does your vision impair your ability to dress, eat, go to the washroom, brush your teeth, dress, or shower?

1 2 3 4 5 How often does your visual symptoms affect your ability to manage your finances?

1 2 3 4 5 How often do your visual symptoms affect your ability to drive?

1 2 3 4 5 How often does your vision affect your ability to take public transportation?

1 2 3 4 5 How often does your vision affect your ability to manage your medications?

1 2 3 4 5 How often does your vision affect your ability to do your job or daily tasks?

Support Network:

1 2 3 4 5 How strong is your support network?

1 2 3 4 5 How much support do you receive from others?

1 2 3 4 5 Do you ever worry that you rely too much on others?

DISCUSSION

WHAT DO WE KNOW NOW THAT WE DIDN'T BEFORE?

Through the data collected from semi-structured interviews, we have gained a great deal of insight into the world of pituitary tumour patients. We have learned more about the wide range of symptoms patients experience leading up to their diagnosis and the struggles that individuals face in receiving care. For some patients, having their visual symptoms validated and taken seriously is a major factor in vision-related quality of life. Several patients advocated for themselves, in order to have various investigations done for their symptoms. One patient even felt the need to drive to the United States to pay and have a CT scan done. These

observations suggest that there may be a need to educate healthcare providers in greater details on the symptoms of pituitary tumours, and ways to recognize the subtle visual changes that can occur.

We also learned that there are not nearly enough mental health initiatives out there to support patients with pituitary tumours. Amongst our group of patients, there were individuals with functioning tumours that were secreting prolactin, growth hormone, and cortisol, in addition to causing visual problems. These patients had the greatest needs for psychological support due to the complex and pervasive syndromes that occur from hormone excess. Nearly every patient that was interviewed acknowledged some form of psychological distress throughout the process of diagnosis and treatment due to their visual problems. For this reason, it is critical to develop strong mental health resources that are widely accessible to this patient population.

As we continue on with this project, and collect data from a larger patient sample, we will undoubtedly learn more about gaps in the healthcare system, and ways to maximize the quality of life in patients with pituitary tumours and visual dysfunction.

WHAT ARE THE NEXT STEPS FOR THIS PROJECT?

The next steps for this project are the completion of the Item Reduction and Questionnaire Refinement phases of the study. The Item Reduction phase is currently underway, and is projected to take 1-2 months to complete. The Questionnaire Refinement phase of the study will take an additional 1-2 months following Item Reduction. We would like to respectfully request an extension of this project to February 28, 2016 to complete the remaining phases of the study.

ITEM REDUCTION & QUESTIONNAIRE DESIGN

During the Item Reduction phase of the study, 30 participants will be asked to take part in an online review process in which they will rank items from the list based on perceived importance and relevance to their VR-QOL. For each issue, patients will rate importance on a scale from 1 (not important) to 5 (extremely important). An impact score will then be assigned to each item, as described by Cusimano and Kan[4]. The impact scores will be used to determine the top 30 issues important to patients, and the broad list will be narrowed down to include the most relevant factors from the perspectives of both patients and physicians. Responses will be used to reduce and refine the question set into a final questionnaire. Participants will be asked for their email addresses so that they can be sent a URL link for FluidSurveys to participate in the refinement and validation phase of the questionnaire development.

QUESTIONNAIRE REFINEMENT & VALIDATION

The Questionnaire Validation phase of the study will involve recruiting 30 participants. These participants will be asked to complete a final internet-based version of the questionnaire through FluidSurveys, which will aid in the identification of recurring visual themes, and generate data that will be used assess the validity of the questionnaire itself. The questionnaire will be tested for concurrent validity (correlations with other existing scales like the VFQ-25, the pituitary QOL scale and the SF-36), extreme groups validity (comparing scores on our questionnaire in groups who are definitely known to differ markedly in objective visual tests like Humphrey Visual fields, papillary responses, color vision, tumor size, degree of optic chiasm compression and visual acuity), a factor analysis procedure, and reliability (test-retest reliability given the same questionnaire administered 4 weeks apart). Participants will also be asked to self-report social and demographic factors such as employment status, education levels, sex, first-language, neighbourhood factors and cultural background to determine if these factors play any role in the issues identified as important and in responses from the refined questionnaire. Patients will be informed that their medical record and diagnostic imaging (MRI) will be available for review as a part of the study as well.

WHAT ARE THE NEXT STEPS FOR THIS AREA OF RESEARCH?

The field of neuro-ophthalmology is widely expanding as new technologies are being developed, existing techniques are refined, and new applications are found. At St. Michael's Hospital, there are currently a number of ongoing studies related to the diagnostic value of saccadic eye-movements in tumour patients, skull-base tumours and ocular coherence tomography pre- and post-operatively, and website development for the education of patients with pituitary tumours, among other projects. Labs around the world are currently searching for ways to restore permanent vision-loss in patients, and initiatives are being developed to improve mental health in this patient population. It is our hope that vision-related quality-of-life will become a topic that is well understood by physicians in the future, and that healthcare providers will find better ways to quantify the physical and psychological components of visual dysfunction and use this information to improve patient-centered clinical decision-making.

PERSONAL IMPACT OF THIS AWARD

I am immensely grateful to have received this student research award from the Brain Tumour Foundation of Canada and Nexen Energy ULC in memory of Joan Horte and David Herbert. Over the past two years, this award has given me the opportunity to work closely with some of the most resilient and inspiring patients that I have ever met. I have immersed myself, with each interview, in the world of patients with brain tumours and have come to understand the challenging physical and psychological journey that individuals go through from diagnosis to recovery. I have had a chance to interview research participants at all stages along this continuum, and have had the privilege of being granted permission by pituitary tumour patients to observe their surgeries as a medical student in the operating room.

During this time, I have frequently found myself admiring the exceptional courage and perseverance that patients demonstrate on a daily basis, and have strengthened my resolve to improve the lives of individuals with brain tumours, as a medical student, and as a future physician. I have yet to decide on the particular field of medicine I would like to pursue, but have strong interests in neurosurgery and neurology, and have consequently requested clinical rotations in both of these areas this upcoming year. Notably, in January 2016, I will be completing a rotation in pediatric neurosurgery at the Children's Hospital of Western Ontario.

I am honoured that the Brain Tumour Foundation of Canada believed in my project and invested in making it a reality. I am also determined to complete the remainder of this project over the next few months, and ultimately produce questionnaire that can make a positive difference in patient care.

The generous gift of this award from Nexen Energy ULC has significantly lightened the burden of my annual tuition, and has brought me closer to fulfilling my dream of becoming a physician and giving back to the community. I hope to continue to honour the memory of Joan Horte and David Herbert through my work on this project, and in all my future endeavours in brain tumour research.

ACKNOWLEDGEMENTS

I would like to acknowledge members of the staff at St. Michael's Hospital for their unyielding support in all stages of this project. I would especially like to thank the Principal Investigator of this study, Dr. Michael D. Cusimano for taking me on as a research student for the past 3 years, guiding me through each phase of this fascinating project, and for always mentoring me in the fields of medicine and surgery.

I would also like to thank the Co-Investigator of this project, Dr. Irene Vanek, whose support and direction made an incredible difference this year with regards to recruitment and data collection. Her relentless efforts

to educate me in the field of neuro-ophthalmology have made me appreciate the vast importance of improving vision in tumour patients.

Finally, I would like to thank the Injury Prevention Research Coordinator, Stanley Zhang for his continued support, and acknowledge all of the healthcare providers at St. Michael's Hospital who took the time to speak with me about their unique perspectives on how to improve the care of patients with pituitary tumours: Dr. Antonio Di Ieva, Dr. Michael Meier, Dr. Jeannette Goguen, Linda Lo, and Martine Andrews.

REFERENCES

1. Newman, S.A. Opthalmologic Evaluation and Management. in *Sellar and Parasellar Tumours: Diagnosis, Treatments, and Outcomes* (eds. Laws, E.R., Jr. & Sheehan, J.) 80-138 (Thieme New York, 2012).

2. Barzaghi, L.R.*, et al.* Prognostic factors of visual field improvement after trans-sphenoidal approach for pituitary macroadenomas: review of the literature and analysis by quantitative method. *Neurosurgical review* **35**, 369-378; discussion 378-369 (2012).

3. Hoyt, W.F. Correlative functional anatomy of the optic chiasm. *Clin Neurosurg* **17**, 189-208 (1970).

4. Kan, P. & Cusimano, M. Validation of a quality-of-life questionnaire for patients with pituitary adenoma. The Canadian journal of neurological sciences. Le journal canadien des sciences neurologiques 33, 80-85 (2006).