

# Living With an Invisible Neurological Condition: An Interpretative Phenomenological Analysis Study

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# Abstract

Living with an invisible neurological condition can involve physical, cognitive and psychosocial challenges. The aim of this study was to explore the experience of living with an invisible neurological condition, particularly focusing on life within the context of the family. Four people were interviewed: a man and a woman with traumatic brain injury (TBI) and a man and a woman with prosopagnosia (face-blindness). The participants' ages ranged from 44 to 68 years, and all four were married with children whose ages ranged from preschool to adult. The interviews were transcribed verbatim and analysed using a blend of thematic analysis and Interpretative Phenomenological Analysis (IPA) methodology. Four major themes were developed: 1) Feeling different; 2) Learning to cope; 3) Loneliness; and 4) Moral failure. 1) The participants felt that their experiences were "bizarre", and they contrasted themselves with "normal" people and/or with their pre-injury selves. 2) The participants had learned and were learning strategies to cope with their condition including avoidance, acceptance of limitations, and active problem-solving. 3) The participants were lonely at times. They found social interaction difficult, but they wanted to be understood. 4) They felt that they did things that were somewhat shameful in order to live with their condition. They felt guilty when they were unable to meet their own and others' expectations, and believed that others judged them unfairly. This study extends the TBI literature by showing that there are similarities between the lived experiences of TBI and of another neurological condition. It enhances the literature regarding the lived experience of prosopagnosia, where little qualitative research has been done until recently. The findings demonstrate some of the psychosocial consequences of prosopagnosia and TBI. Health practitioners may benefit from having more awareness of these consequences in order to be better able to help people with these conditions to live well.

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# 1 Introduction

*“People don’t see it so they just assume and they think you’re nuts.”*

~Karl, a participant in this study, talking about his invisible brain injury.

It is easy to assume that because someone looks perfectly normal, they have no more struggles in their life than anyone else. But there are any number of hidden challenges which people face, and some of the most intriguing of these arise from neurological conditions. The body of knowledge pertaining to neurological conditions is growing rapidly (Levack, Kayes, & Fadyl, 2010) and it is important that as well as understanding the mechanics of these conditions, health practitioners also gain insight into the subjective experience of those who live with them. If they do not, they risk overlooking unmet needs among these populations, and perpetuating difficult situations which could be mitigated. The phenomenological approach offers tools for examining the experiences of a few people in depth in order to reveal what their lives are ‘really like’. At present, much of what is known about neurological conditions is taken from research performed in the highly contained, artificial and isolating environment of the laboratory. Daily life, on the other hand, is lived within a social context, and usually involves various family relationships. What impact does an invisible neurological condition have on family life?

Neurological conditions are disorders of the central and peripheral nervous systems and vary widely in aetiology and expression (World Health Organization, 2015). They can be congenital (Kennerknecht, Grueter, Welling, Wentzek, & Horst,

2006), perhaps associated with a broader developmental disorder (Riby, Doherty-Sneddon, & Bruce, 2008), or they can result from events during the prenatal, perinatal or early infancy periods (Yardley, McDermott, Pisarski, Duchaine, & Nakayama, 2008). They can be caused by traumatic brain events, either disease-associated such as tumours or strokes (Barton, 2008), or traumatic brain injury (TBI) (Skelton, Ross, Nerad, & Livingstone, 2006).

The effects of a neurological condition can be obvious to an observer, for example unusual gait or facial spasm (Stone, n.d.); or they can be 'invisible', for example fatigue, altered sensory perception or cognitive deficits (Chaudhuri & Behan, 2004; Du, Ciuffreda, & Kapoor, 2005; Schmahmann & Sherman, 1998). Invisible symptoms are relatively common but members of the general public may be unaware of this fact (Linden & Boylan, 2010). Fatigue is a common symptom of many neurological disorders, characterised by limited endurance of sustained mental and physical tasks and increased perceived effort (Chaudhuri & Behan, 2004). Perception of one or more senses may be diminished, as in the case of losing the sense of smell (Drummond, Douglas, & Olver, 2013), or heightened so that stimuli which would normally be moderate are experienced as uncomfortably intense (Du et al., 2005). A wide variety of cognitive deficits are associated with neurological conditions, including difficulties with concentration and memory (Schmahmann & Sherman, 1998), topographic orientation (Barton, 2011), and face recognition (Damasio, Tranel, & Damasio, 1990). I selected TBI and prosopagnosia as the disorders to focus on for this study because they are relatively common forms of acquired and congenital primary neurological conditions, respectively (Kennerknecht et al., 2006; Tagliaferri, Compagnone, Korsic, Servadei, & Kraus, 2006).

A search of online databases Web of Science™ Core Collection and Google Scholar for 'prosopagnosia' with additional search terms such as 'qualitative', 'phenomenology', and 'experience' returned very few qualitative studies of prosopagnosia. I review three such studies in section 1.1.7 below. I also searched directly for articles cited in quantitative and review studies of prosopagnosia, and found two first-hand narratives (including Zenonos, 2014). In contrast, a similar search for 'TBI' or 'brain injury' with 'qualitative' or 'experience' revealed an abundance of published qualitative research on TBI. This research includes studies of various elements in the timeline of the disorder, such as transition from hospital to home (Nalder, Fleming, Cornwell, Shields, & Foster, 2013), or returning to work or school (Hooson, Coetzer, Stew, & Moore, 2013; Plotts & Jantz, 2012); and studies specific to particular populations, including children with minor TBI (Sheehan et al., 2013), combat veterans with mild TBI (Daggett, Bakas, Buelow, Habermann, & Murray, 2013), and caregivers of family members with TBI (Nalder, Fleming, Cornwell, & Foster, 2012).

Living with a neurological condition may impose challenges beyond the physical or cognitive ones determined by the nature of the disorder. The family system may be affected, and the psychological health of the person with the condition may be at risk from anxiety and depression (Snell, Surgenor, Hay-Smith, & Siegert, 2009). Living with an invisible condition may pose additional challenges: from one's behaviours being misinterpreted, from failing to meet others' expectations, and from an internal sense of guilt at not 'feeling better' when nothing is obviously wrong (Levack et al., 2010; Yardley et al., 2008). For those with congenital neurological conditions, such as prosopagnosia, receiving a diagnosis of a condition which they have always had may or may not bring about a

change in self-identity, and it may in fact provide a sense of relief as it reduces their feeling of personal failure (Yardley et al., 2008). For people who have experienced a TBI, a key challenge highlighted in psychosocial research is that of coping with change and loss of a previously formed identity (Levack et al., 2010). In both cases, family relationships and routines of the person can be affected by their condition, and the person's experience of that condition can in turn be affected by their family context.

In the following two sections I provide an overview of prosopagnosia and TBI to set the scene for the qualitative analysis that follows. For each condition I outline their expression, aetiology, epidemiology, assessment, diagnosis, treatment interventions, and psychosocial impact, with a particular emphasis on previous qualitative studies. In the third section, I introduce the research questions.

## **1.1 Prosopagnosia**

Prosopagnosia ('face-blindness') is a neurological condition characterised by severe impairment in face recognition. It is observed both as a symptom of more widespread cognitive problems, as in Alzheimer's disease (Roudier et al., 1998) or autism (Riby et al., 2008), and as a syndrome in its own right (Barton, 2008). Broader conditions such as autism bring with them a plethora of other symptoms, which could mask the experiences specific to prosopagnosia and make phenomenological interpretation overly complex for a small qualitative study. Therefore, in the present study, I focused on the experience of prosopagnosia as a primary condition, not as a symptom of another disorder. In the following section I outline prosopagnosia and its impact in three sections. Firstly, I describe the subtypes of prosopagnosia in terms of expression (with or without perceptual

deficits) and of aetiology (caused by damage to the brain, whether by injury, surgery or other form of lesion; or congenital). Secondly, I summarise the developmental course of congenital prosopagnosia including epidemiology, assessment, diagnosis and interventions. Thirdly, I review the psychosocial impact of prosopagnosia and some of the reported associated mental health issues.

### **1.1.1 Expression of prosopagnosia**

In 1890, Lissauer (cited in Behrmann & Avidan, 2005) suggested that there are two distinct categories of prosopagnosia: associative and apperceptive. The associative subtype of prosopagnosia is observed when a patient is able to judge age, gaze, gender, expression and so on from images of faces but is not able to connect a face with an identity, implying that access to facial memories is the disrupted component of the facial recognition process. In the apperceptive subtype, judgment of these facial properties is impaired, suggesting that the cause of the deficit lies upstream in the facial encoding component of the process (Barton, 2008). Tranel and Denburg (2009) propose a third subtype: developmental prosopagnosia, as opposed to the two abovementioned subtypes which they define as being acquired through brain injury caused by trauma, infarctions or tumours.

### **1.1.2 Aetiology of prosopagnosia**

The aetiology of prosopagnosia can be broadly considered as either an acquired or a developmental condition. Acquired prosopagnosia is often seen with damage to the right medial occipitotemporal cortex, usually near the lingual and fusiform gyri, or to both inferior occipital and temporal visual association cortices (Barton, 2008; Tranel & Denburg, 2009). The first definition of prosopagnosia in

scientific literature was given in 1867 (Barton, 2008) as “an acquired impairment arising as a consequence of brain injury” (Yardley et al., 2008, p. 445). Transient prosopagnosia has also been reported following brain surgery (Mesad, Laff, & Devinsky, 2003; Otani et al., 2004).

Developmental prosopagnosia may be genetic. Kennerknecht et al. (2006) described a strong genetic component within people who had the condition, while Wilmer et al. (2010) found that 164 pairs of identical twins recruited from the general population in Australia showed more than twice the degree of correlation between their face recognition scores (.7) compared to 125 pairs of non-identical twins (.3). Research has begun into exactly which genes encode for face recognition (Brown et al., 2012). Prosopagnosia may also arise as a result of brain damage before birth or during early infancy, or from severely impaired vision during the period where the infant would normally be developing facial recognition pathways (Yardley et al., 2008). In practice, it may be impossible to tell whether childhood-onset prosopagnosia has a genetic component or not, if both family history and infancy events are consistent with its development, or if neither is.

### **1.1.3 Epidemiology of prosopagnosia**

Although acquired primary prosopagnosia is rare, it is common for people with acquired brain injury to have at least some difficulty with face recognition (Valentine, Powell, Davidoff, Letson, & Greenwood, 2006). Developmental prosopagnosia was originally considered very unusual but is now thought to occur in about 2-2.5% of the population (Duchaine, 2008; Kennerknecht et al., 2006; Kennerknecht, Ho, & Wong, 2008).

The condition often goes unrecognised because people with prosopagnosia may not be aware that their inability to recognise faces at a glance is unusual (Yardley et al., 2008). Therefore, the number of people with the condition is most likely considerably higher than the number diagnosed.

#### **1.1.4 Assessment and diagnosis of prosopagnosia**

Prosopagnosia is usually assessed with a series of face recognition tests and an interview or survey to rule out other possible causes of deficits, such as poor eyesight, autism, attention deficit disorders or social anxiety (Dalrymple, Corrow, Yonas, & Duchaine, 2012; Diaz, 2008; Yardley et al., 2008). Testing often includes such tools as the Cambridge Face Memory Test (Duchaine & Nakayama, 2006) and tests for recognition of famous faces or family (Grueter et al., 2007).

Prosopagnosia is commonly self-diagnosed, often after exposure to media on the subject<sup>1</sup>. The relief that is reported at the diagnosis of prosopagnosia may especially be the case for parents of children with developmental prosopagnosia, as the diagnosis makes sense of a puzzling range of symptoms which may have been causing problems for the family, such as ignoring family members or being overly comfortable with strangers (Dalrymple et al., 2012; Yardley et al., 2008). In a case described by Dalrymple et al. (2012), one child was tested for pervasive developmental disorder and Asperger's syndrome (now classed under autism spectrum disorders; American Psychiatric Association, 2013), but did not demonstrate the social and behavioural deficits required for this diagnosis.

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<sup>1</sup> For example, Oliver Sacks' book *The Man Who Mistook His Wife for a Hat* (1985), or the *60 Minutes* documentary on face blindness (Finkelstein, 2012).

*“Specialists were baffled for years, and it was only when her parents came across the term “face blindness” that they had the “Aha!” moment they had been waiting for”* (Dalrymple et al., 2012, p. 394).

### **1.1.5 Development of prosopagnosia**

The developmental course of early prosopagnosia is not well studied (Dalrymple et al., 2012). In general, face recognition difficulties will persist throughout childhood into adulthood and may be accompanied by other visual processing difficulties which may be discerned at a young age (Dalrymple et al., 2012) or may become apparent as task requirements change with age, such as landmark agnosia (the inability to recognise familiar places) (Barton, 2011).

### **1.1.6 Intervention in prosopagnosia**

Several attempts have been made to train people with prosopagnosia to recognize faces, both in childhood and adulthood (Dalrymple et al., 2012; DeGutis, Bentin, Robertson, & D'Esposito, 2007). Results have been mixed. In one reported intervention study, an 8-year-old child learned alternative methods for identifying familiar faces and at a 3-month follow-up maintained his improvements, although he was not able to generalize his new skills to faces which had not been part of the training set (Dalrymple et al., 2012). In another study, a 48-year-old woman received intensive training in face recognition tasks and improved her speed and accuracy on those tasks to the point where she matched performance by people without prosopagnosia; however, her improvements faded after a month, although retraining was quicker than initial training (DeGutis et al., 2007). This kind of training is time-consuming and repetitious (Dalrymple et al., 2012), and because of its limited generalisability it seems unlikely to provide much improvement to the

ongoing lived wellbeing of the person with the condition. Alternatively, cognitive behavioural therapy or training in social skills may allow individuals to find adaptive strategies (Yardley et al., 2008); while ecological interventions such as psychoeducation for relevant others, for example school staff (Diaz, 2008), can make life easier both for the individual and for their social community.<sup>2</sup> Additionally, people with prosopagnosia may develop their own compensatory social strategies, such as treating everybody with warmth, or conversing in generalities until the other person gives some verbal clue to their identity (Yardley et al., 2008).

### **1.1.7 Psychosocial impact of prosopagnosia**

Prosopagnosia can have both immediate and long-term psychosocial consequences. Immediate consequences may differ between children and adults. For example, children with prosopagnosia who are not able to distinguish between family members and strangers may, for example, allow themselves to be picked up from school by a strange adult (Dalrymple et al., 2012; Diaz, 2008), or they may be punished for failing to respond politely to known adults (Yardley et al., 2008). One twelve-year-old girl had her social opportunities limited by her parents after she was seen speaking with a strange man as if he were familiar (Dalrymple et al., 2014). Adults with prosopagnosia also may respond inappropriately to others, either with excessive familiarity or by ignoring someone well-known (Yardley et al., 2008); however, such social gaffes are more likely to lead to embarrassment and anxiety rather than physical danger or chastisement.

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<sup>2</sup> Technological solutions for people with prosopagnosia are currently being investigated (Xi, Xi, Prakash, Weidong, & Gnawali, 2013), and innovations like Google Glass™ may have significant impact in the future. However, these exciting developments are outside the scope of the present study as they did not enter the participants' lived experiences of prosopagnosia.

Both social anxiety and depression have been reported in people with prosopagnosia. Social anxiety disorder can seriously affect day-to-day functioning, as people fear and avoid potentially embarrassing social situations, and the disorder has been associated with poorer physical health when anxiety becomes somatised with symptoms such as palpitations and shortness of breath (Kroenke, Spitzer, Williams, Monahan, & Löwe, 2007; Simon, Gater, Kisely, & Piccinelli, 1996; Yardley et al., 2008). Depression can occur with social isolation and a sense of failure and guilt, especially if no clinical diagnosis of prosopagnosia has been made to offer an explanation for that failure (Yardley et al., 2008). For example, one young person with prosopagnosia suffered depression and suicidal ideation after feeling that he was continually failing to meet the social and behavioural requirements of high school (Diaz, 2008). Furthermore, people with prosopagnosia may find employment opportunities curtailed if they are unable to meet the demands of working directly with numerous other people, as in retail (Diaz, 2008). This is especially true for people with acquired prosopagnosia, who may have held such a job previously but have found their capacity changed following the prosopagnosia acquisition event (Riddoch, Johnston, Bracewell, Boutsen, & Humphreys, 2008). This concept of coping with capacity change will be covered in more detail in section 1.2.5 on TBI below.

Prosopagnosia can impact the family, but little is known about this from previous research. Much of the qualitative research available is in the form of case studies (for example Diaz, 2008) which focus on providing interventions for the individual, rather than an open-ended exploration of lived experience. Dalrymple et al.'s (2012) review of studies of developmental prosopagnosia includes a summary of existing case studies, but aims chiefly to extend understanding of

normal and abnormal face perception, and psychosocial effects are noted only briefly.

In repeated searches I have found only two qualitative studies of prosopagnosia. Most recently, Dalrymple et al. (2014) interviewed eight children (aged between 5 and 14 years, 3 of them girls) with developmental prosopagnosia and their parents. In order to establish a valid diagnosis of prosopagnosia, the research team had to develop a new set of tests for face perception and memory which were suitable for children (Croydon, Pimperton, Ewing, Duchaine, & Pellicano, 2014). The findings of this study were divided into three child themes and three parent themes: children were aware of their deficits, had coping strategies to manage them, and said their struggles were “not funny”; while their parents wished they knew what their children were experiencing, helped them to cope, and found it difficult that their children were struggling (Dalrymple et al., 2014, p.147). This study nicely draws out both individual and shared experiences from the participants, and integrates them into a coherent framework. Its purview is restricted to children, however.

The earlier, extensive study by Yardley et al. (2008) took a more wide-ranging approach. The second and third authors performed telephone interviews with 25 adults who scored below 44 out of 72 correct on the Cambridge Face Memory Test, asking a range of open-ended questions about living with developmental prosopagnosia. Their findings following thematic analysis covered a range of topics, organised into short-term and long-term psychosocial effects. This broad approach, however, meant that no topic was explored in great depth, including the person with prosopagnosia’s experience of family life (Yardley et al., 2008). The present qualitative study aimed to delve deeply into the lived

experience of family life from the perspective of a person with prosopagnosia or TBI.

## **1.2 Traumatic Brain Injury**

Traumatic brain injury (TBI) has been the subject of much qualitative and quantitative research in recent years. The guideline for best practice from the New Zealand government's no-fault injury insurance provider, the Accident Compensation Corporation (ACC), defines TBI as: "an acute brain injury resulting from mechanical energy to the head from external physical forces" which results in at least one of the following: "confusion or disorientation; loss of consciousness; post-traumatic amnesia; other neurological abnormalities" (New Zealand Guidelines Group, 2006, p. 22). Usually, and in the present study, the term 'person with TBI' is used to mean someone who is experiencing the consequences of having sustained such an injury, even if any acute markers of injury such as contusions or lacerations have resolved. In this section I will first briefly describe some commonly experienced symptoms of TBI. Secondly, I will outline epidemiology, assessment, diagnosis and treatment. Thirdly, I will explore psychosocial aspects of living with TBI, with particular reference to its impact on families.

### **1.2.1 Symptoms of traumatic brain injury**

A person sustaining a TBI may subsequently experience a wide variety of behavioural, functional, physiological and psychological problems. These problems are sometimes obvious to outside observers; sometimes they are not (Robertson, 2008). Obvious deficits may include: altered gait, blindness, paralysis,

or visible scarring. Less obvious deficits may include anxiety, fatigue, head and neck pain, irritability, low mood, and loss of concentration and memory (Snell & Surgenor, 2006). More rarely, there may be loss of sensory perception (e.g. olfaction: Drummond et al., 2013), loss of specific cognitive skills (e.g. face recognition or loss of spatial navigation skills: Barton, 2008; Skelton et al., 2006), and personality change (Conneeley, 2002). These deficits may be transient or they may be permanent (Lorenz, 2010).

### **1.2.2 Epidemiology of traumatic brain injury**

A recent New Zealand study found an incidence of 790 TBIs per 100 000 people per year, substantially higher than the rate in Europe (up to 453) or North America (up to 618) (Feigin et al., 2013). According to this population-based incidence study of the Waikato region and Hamilton city<sup>3</sup> carried out from 1 March 2010 to 28 February 2011, the incidence of TBI was higher among males than females, higher among Māori than other ethnic groups, and 95% of TBIs were classified as mild. The most common causes of TBI were falls (especially in the under 5- and over 65-year age categories), exposure to mechanical force, transport accidents, and assault (Feigin et al., 2013).

Prevalence of TBI is difficult to assess, because definitions of TBI differ, severity varies widely between patients, and the brain injury event often goes unreported (Frost, Farrer, Primosch, & Hedges, 2013). One meta-analysis of fifteen studies which reported on TBI prevalence in the general adult population in the USA, Canada, Australia and New Zealand suggested a figure of 12.1% of adults with

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<sup>3</sup> This region was selected because it was found to be demographically representative of New Zealand as a whole (Feigin et al., 2013).

a lifetime history of TBI, or 16.68% of men and 8.55% of women (Frost et al., 2013).

### **1.2.3 Assessment and diagnosis of traumatic brain injury**

Diagnosis of TBI usually follows assessment in a hospital emergency department or by a general practitioner, accounting for the patient's history and presentation with symptoms such as "confusion, disorientation, loss of consciousness, post-traumatic amnesia or other neurological abnormalities (such as focal neurological signs, seizures or intracranial lesions)" (Levack et al., 2010, p. 988; New Zealand Guidelines Group, 2006). The severity of the injury is usually classified according to the Glasgow Coma Scale, where the patient's response to stimuli is assessed against three standardised criteria: eye opening, verbal response and motor response (Gonzalez & Moore, 2012; Teasdale & Jennett, 1974). A higher score indicates a higher level of consciousness. The scores categories are defined as follows: a score between 3 (the lowest possible score) and 8 is classed as severe TBI; a score between 9 and 12 represents a moderate TBI; and a score of 13 or over represents a mild TBI (New Zealand Guidelines Group, 2006).

### **1.2.4 Treatment of traumatic brain injury**

Traumatic brain injury is a complex disorder with cognitive, sensory, physical and psychological sequelae which develop over varying timescales. Treatment of a TBI typically involves phases of acute injury management (often within a general hospital), rehabilitation (often in a specialist rehabilitation centre) and community reintegration (Snell et al., 2009). Rehabilitation approaches may include both restorative (seeking to help the patient restore lost function) and compensatory therapies (to help the patient adapt their behaviours to work

around deficits) and may incorporate drug regimens, physiotherapy, cognitive retraining, behavioural interventions and a variety of alternative treatments such as art or music therapy (National Institutes of Health, 1998). The support offered during the community reintegration phase may range from structured follow-up and community care, through provision of educational material, to no further formal input (Snell et al., 2009).

Patient-centred philosophies of rehabilitation which include subjective measures of wellness (such as feelings of enjoyment, or of achieving something worthwhile) (Levack, McPherson, & McNaughton, 2004) are beginning to have an impact on governmental guidelines for rehabilitation (for example New Zealand Guidelines Group, 2006). Additionally, as endorsed by Levack, Siegert, Dean, and McPherson (2009), treatment guidelines for TBI now consider the effect of the TBI on the patient's family as a whole (New Zealand Guidelines Group, 2006). This is especially vital in a New Zealand context, given the centrality of whānau in Māori culture (Levack et al., 2009).

### **1.2.5 Psychosocial impact of traumatic brain injury**

Qualitative studies with TBI participants reveal that feelings of having lost one's identity after brain injury are common, along with a disconnect from one's social world, and the need to rebuild one's identity in a way that includes both old and new characteristics. To provide a broad overview, Levack et al. (2010) performed a systematic metasynthesis of 23 qualitative studies of TBI participants' experience of rehabilitation and outcomes including research from New Zealand, Australia, the United Kingdom and North America. A metasynthesis is similar to thematic analysis of primary data, but the data analysed are prior research

findings. The full research articles were entered into computer software designed to manage qualitative data; the research team then categorised the reported findings, discussing emerging themes until the team reached consensus on a final structure for the synthesis of the data (Levack et al., 2010). The three common themes Levack et al. identified across participant experiences of TBI were: 1) disconnect with their pre-injury self, mind/body disconnect, and social disconnect, within an overwhelming sense of loss and suffering; 2) reconstruction of their self-identity, their place in the world and their personhood; and 3) the internal and external resources used to facilitate those reconstructions. These themes may seem to represent linear stages of progression but Levack et al. (2010) emphasised the iterative nature of TBI experience, such that some participants reported feeling strong emotions of “loss and personal suffering” (p. 990) many years after clinical symptoms had settled or disappeared. Loss of the pre-injury self was embodied in changes to personality, loss of memory, and a subjective “ineffable” sense of “just [feeling] different” (Levack et al., 2010, p. 994). Mind/body disconnect was experienced as a loss of control over a body that was slower, less agile or lacked stamina, or with a sense of unfamiliarity which did not necessarily diminish over time. Social disconnect was sometimes deliberately initiated by people with TBI as a coping strategy, and sometimes occurred when family members or friends of the person with TBI used avoidant strategies to cope with TBI-associated changes. When there was no outward sign of injury, onlookers sometimes mistook coordination and balance deficits for inebriation, and other subtle issues for mental illness, so some participants would avoid social contact out of a rational fear of negative reactions from others (Howes, Benton, & Edwards, 2005). Additionally, people with TBI sometimes lost jobs (and often thereby their contact

with workmates) or intimate relationships. These losses were accompanied by strong negative emotions including grief, loneliness, guilt, self-blame, vulnerability and powerlessness (Levack et al., 2010).

The effect of TBI in changing social relationships and the mixed feelings of people with TBI towards these changes are clearly illustrated in a study by Conneeley (2002). Eighteen patients with severe TBI and their “significant other” were interviewed individually at three points in time: on discharge from a neurological rehabilitation hospital, six months later and then another six months after that. Participants, both the persons with TBI and their significant others, felt that others saw the person with a TBI predominantly as a “head-injured patient”, rather than as a friend or colleague (Conneeley, 2002, p. 360). Some participant dyads felt that they deliberately chose a lifestyle with fewer social engagements as a way for the person with TBI to rest and recover, or because that is what they had always preferred. Others felt that changes in their social relationships were a natural part of life—for example, when social activities were restricted by having small children. Relationships within the family were often reported as having changed as a result of the injury, but not necessarily for the worse. Some participants felt that their relationships were improved because of each partner’s increased appreciation of the strengths of the other, or because the person with the TBI had more time at home to spend with family (Conneeley, 2002).

For a person with a TBI, reconstruction of his or her self-identity can involve both acceptance of the newly vulnerable or impaired body, and purposeful focusing on strengths (Lorenz, 2010). Reconstructing a place in the world requires support from friends, family and health professionals to find opportunities for rehabilitative activities and for reintegration into public situations, including work,

which may need to be adapted to suit the needs of the person with TBI (Levack et al., 2010). Family members may be seen as “an integral part of the ... rehabilitation process” (Levack et al., 2009, p. 195). Reconstruction of personhood can be described as spiritual “in the broad sense of finding meaning and purpose in life” and as such can be part of rehabilitative goal setting (Siegert, Ward, Levack, & McPherson, 2007, p. 1608). Some people continue to struggle to redefine themselves after TBI (Howes et al., 2005; Jones & Curtin, 2011a), while others find a positive angle. The participant-author in one autoethnographic study wrote:

*“My deficits remain; but I have learned to live relatively peaceful [sic] with them, integrating them into my being and managing to enjoy a life which is still rich and active. It is not my previous life. Most people live once; I have had the opportunity to live twice.”* (Lawson, Delamere, & Hutchinson, 2008, p. 249).

### **1.3 Summary of the Reviewed Literature**

Prosopagnosia and TBI are relatively common examples of congenital and acquired neurological conditions, respectively, and they have well-described symptoms, which make them ideal candidates as conditions for study. There are some similarities between them, and some obvious differences. Both are invisible to an observer, and both have sequelae which affect social behaviour and relationships. Themes of social isolation were seen in the literature surrounding both conditions (Levack et al., 2010; Yardley et al., 2008) and in both I found mention of coping strategies. For both conditions, these strategies include working to improve the participant’s skills and finding ways to work around permanent deficits.

The key difference between the two conditions is the nature of the condition's onset. Much of the qualitative literature on TBI deals with managing the change from pre-injury to post-injury self, whereas this is not seen in congenital or developmental prosopagnosia. The diagnosis of prosopagnosia (whether formal or informal) of this lifelong condition may have a significant psychological impact, but this is not well known or described. This introduces a second contrast between the literature on TBI and prosopagnosia: the amount of qualitative research available. What is available regarding prosopagnosia largely deals with public contexts (i.e. school and employment). The lived experience of prosopagnosia within the context of family life has not yet been covered in any depth. By contrast, there is a wealth of qualitative research of varying methodologies into TBI, but again I found little which covered the experience of family life from the perspective of a person with TBI.

## **1.4 Research Questions**

The aim of the present qualitative study was to explore in depth the experience of living with an invisible neurological condition such as prosopagnosia or TBI, particularly in the context of family life. This aim may be framed by the following four questions: 1) How does having an invisible neurological condition affect the day-to-day functioning of this person in the world? 2) How has this person experienced the effect of their invisible neurological condition on their family life, in terms of their interactions with their partner and children? 3) How are these experiences affected by the aetiology of the condition – be it congenital (prosopagnosia) or acquired (TBI)? And finally, 4) are there gender-based

differences in the way family life is experienced between men and women with an invisible neurological condition?

## 2 Methodology and Methods

### 2.1 Methodology: Interpretative Phenomenological Analysis

Interpretative phenomenological analysis (IPA) was selected as the methodology for the present study because it is well-suited to answering research questions about lived experiences. I approached my research with no hypotheses, but I was interested in the participants' experiences of their condition and the meanings they attached to those experiences. My research questions about the effect of condition aetiology and participant gender on experience (section 1.4 above) were exploratory questions, not hypotheses of difference. Two key elements of IPA which made it the ideal methodology for this study are flexibility and the "double hermeneutic" (Smith, 2004, p. 40). Smith and Osborn (2008) stated that: "research questions in IPA are usually framed broadly and openly. There is no attempt to test a predetermined hypothesis of the researcher; rather, the aim is to explore, flexibly and in detail, an area of concern" (p. 55). The term 'double hermeneutic' means that participants engage in making sense of their experiences, and then the researcher engages in making sense of the participants' sense-making (Smith, 2004).

In the following sections, I firstly locate IPA in the spectrum of qualitative methodologies, and secondly I describe its core practices of 1) interpreting experience and 2) reflexivity. The remainder of the chapter will describe the study methods.

### **2.1.1 IPA among qualitative methodologies**

IPA is a qualitative methodology that involves examining the details of individual participants' experiences, usually as recounted in semi-structured interviews, and relating those details to overarching themes drawn from interviews with a series of participants (Smith, 2004). IPA studies have similarities with grounded theory studies, where the aim is to develop theories to explain social processes (Starks & Brown Trinidad, 2007), and also with narrative psychology research or discourse analysis, which tend to focus on a single participant's story (Murray, 2008).

In grounded theory methodology, researchers begin to construct theories early on, and the theories under construction shape the data collection process (Charmaz, 1990). Data collection continues until theoretical saturation is reached and no new constructs are being formed. This can lead to sample sizes of up to 60 people (Starks & Brown Trinidad, 2007), or repeated interviews and "a stack of transcripts and field notes" (Charmaz, 2008, p. 81). By contrast, IPA researchers make no attempt to uncover all possible expressions of a theme, but instead explore the embodied perceptions of a small, carefully selected group of participants in order to illuminate a common experience (Starks & Brown Trinidad, 2007). Nor does IPA seek to develop theories; rather, published theories provide a potential framework for making sense of experience. This theoretical framing is one of the final stages of IPA research, once themes have been extracted from interview transcripts and one or more themes are recognised as supporting an existing theory (Smith, Flowers, & Larkin, 2009).

Discourse analysis, narrative research, and other similar forms of qualitative methodology focus primarily on the words participants use. The philosophical

underpinning of these methodologies is that participants' knowledge is constructed by the words they and others use, and therefore the exact form of words that participants use is minutely examined (Starks & Brown Trinidad, 2007). This is particularly striking in conversation analysis, where the very length of pauses is recorded (Drew, 2008). By contrast, phenomenological philosophy holds that there is such a thing as a 'real' experience, which becomes a 'phenomenon' when we reflect upon that experience and interpret it (Smith et al., 2009); therefore, in IPA the focus is less on the words and more on the meaning of the experience under examination.

### **2.1.2 Interpreting experience**

The term 'phenomenology' comes from the philosophies of Edmund Husserl, Martin Heidegger and George Herbert Mead, in which IPA has its roots (Hale, Treharne, & Kitas, 2007). These philosophers focused on the way people perceive their lives in the world and make sense of their experiences. According to phenomenologists, a meaningful experience contains many components and thus has many levels available for interpretation, termed a "hierarchy of experience" (Smith et al., 2009, p. 2). Smith et al. (2009) gave a hypothetical example of a formerly enthusiastic swimmer returning to a public beach to swim for the first time since major surgery. At its most basic, this person can describe their experience in terms of sensory input: "becoming aware of the pebbles or the heat of the sun" (Smith et al., 2009, p. 2). At a higher level of interpretation, significant events will often be accompanied by emotion, in this case joyful anticipation mingled with concern about unsightly scars or whether one is still able to swim, which form another component of the experience. A third level of interpretation

would describe its “larger significance in the person’s life”: its connection to important past events, thus being a marker of recovery or of “return of a lost self” (Smith et al., 2009, p. 2). Finally, these themes would be placed within a theoretical framework of illness experience and recovery, which involves interpretation by the researcher. The role of the researcher in making sense of the participants’ personal experiences is central and is made explicit through reflexive practice (Finlay, 2002).

### **2.1.3 Reflexivity**

In IPA, it is acknowledged that all researchers have their own lived experience, understandings and background, which they cannot help but bring to their research; phenomenologists question the very notion of objectivity (Finlay, 2002). It is critical that the researcher is aware of her<sup>4</sup> own biases and preconceptions, otherwise she could be guilty of shaping her interview questions, analyses, or even participant selection to address her own theories rather than hearing what participants have to say (Hale, Treharne, & Kitas, 2008). Therefore, at every step of the process, the researcher must make herself known to readers in order that her role may be taken into account (Finlay, 2002).

In undertaking the present study, as I planned the interviews I bore in mind that because I am Pākehā<sup>5</sup> and a Christian, I come from a cultural and religious background that values independence and the ability to work, as well as heterosexual marriage and the nuclear family. Therefore I expected that participants would want to return to work, and would want to maintain marital

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<sup>4</sup> I have given the hypothetical researcher the feminine pronoun throughout, since I am talking about research I have done, and I am a woman.

<sup>5</sup> This is my preferred term for my ethnicity, being a New Zealand citizen of mostly European descent.

relationships. Additionally, having spent two years with an invisible but mildly debilitating neurological condition, I expected the study participants to have experienced similar fatigue and isolation, and to have relied similarly on family support.

Having recognised these expectations in myself, I put together a schedule of open-ended interview questions, which were discussed with my supervisors. I have had training in reflective listening and communication skills for an extracurricular voluntary position, and I endeavoured to approach each interview with open-minded curiosity, listening to participants carefully and respectfully. Additionally, as is common in qualitative research (Guba, 1981), after performing my analysis I discussed the individual case summary and combined themes with each participant, to ensure firstly that our conversation had been captured accurately, and secondly that the themes I identified made sense to them (Hale et al., 2008). This process is analogous to internal validity checking in a quantitative study in that it provides a means to guard against bias or selective attention on the part of the researcher.

## **2.2 Procedure**

### **2.2.1 Ethics**

I obtained ethics approval from the University of Otago Human Ethics Committee (see Appendix 6.1). This required attention to the ethical principles of: 1) informed consent; 2) cultural sensitivity; 3) protection from harm; and 4) confidentiality. These principles were addressed by the following processes: 1) Before arranging interview sessions, I provided each participant with separate

information and consent forms, ensuring that they were aware of the purpose and procedure of the study and that they had the right to withdraw at any time. 2) I consulted with local iwi (Ngāi Tahu) via the University of Otago's formal consultation process (Appendices 6.2 and 6.3), and recorded each participant's ethnic identity as they preferred. 3) I ensured that each participant was encouraged to have a support person present during the interview if they so desired, and I took to each interview a sheet with options for further support (Appendix 6.4) in case the participant seemed distressed (Hale et al., 2008). This list was generated in consultation with Cathy Matthews, the liaison person for the local branch of the Brain Injury Society. 4) All names and identifying details of participants or their family members were removed from transcripts, and necessary contact details and other information were kept in password protected computer files or physically under lock and key. Contact details were separated from other details and the links preserved using participant codes. In the write-up, all names and identifying details were removed or changed. Sometimes in qualitative research a participant wishes to have their real name published (Tilley & Woodthorpe, 2011). Because this study focused on effects on the family, however, more people than the individual participant had the potential to be affected by publication of the research, and it would not be feasible to gain consent from all involved. Therefore, participants' anonymity was mandatory.

### **2.2.2 Participants**

The participants were purposively selected members of the general public who were currently experiencing effects of a specific neurological condition. To be included, participants had to have either 1) a self-reported history of traumatic

brain injury with problems which had persisted for at least twelve months following injury and which they were still experiencing, or 2) a self-reported diagnosis matching congenital (lifelong) prosopagnosia. It is typical in phenomenological studies of this type to select a homogeneous sample in order to explore shared themes of experience. One focus of the study was family life, and for the purpose of this study family was defined as having a partner and children. Accordingly to be included participants had to have a current partner and children. Because the other focus of the study was the effect of having an invisible condition, people who had visible physical impairments following a brain injury were excluded. Finally, people with other severe or terminal health conditions, or with broader conditions whose symptoms could be similar to those under study (autism spectrum disorder, for example) were not invited to participate.

Selection methods varied among participants. Information on the study was sent to a number of relevant groups, selected from a comprehensive website listing disability support services, after phone and email contact requesting that they display a recruitment poster where potential participants or caregivers would see it (see Appendix 6.5). This strategy generated a response from only one person, who did not meet inclusion criteria. At a “Brain Day” expo run by the Neurological Society in 2013, I had visited the booths staffed by various groups and informed them of my proposed research. I maintained contact with the liaison person of the local Brain Injury Society after that, and when I informed her that I was ready to start finding participants, she spoke to two people who met the inclusion criteria and gained permission to give their contact details to me. I telephoned both of them and subsequently emailed the study information. The local newspaper printed an article about the prosopagnosia angle of the study (see Appendix 6.6)

and called for recruits; eleven people responded, of whom two were selected. My final participant group comprised one man and one woman with TBI and one man and one woman with prosopagnosia (see Table 1).

**Table 1: Participants at Time of First Interview**

<b>Pseudonym (Gender)</b>	<b>Ethnicity</b>	<b>Age (years since diagnosis)</b>	<b>Condition</b>	<b>Occupation (before injury)</b>
Charlotte (F)	NZ European / Pākehā	44 (14)	TBI	Homemaker (manager)
Huia (F)	NZ European / Pākehā	51 (2)	Prosopagnosia	Teacher
Karl (M)	NZ European / Pākehā	47 (4)	TBI	Homemaker (forester)
Murray (M)	NZ European / Pākehā	68 (2)	Prosopagnosia	Farmer

### **2.2.3 Data Collection**

I created a list of interview questions and prompts and discussed them with my supervisors. I aimed to make the questions as open-ended as possible, in order to minimise the impact of my own expectations (Hale et al., 2008). The interview schedule (Appendix 6.7) was designed to follow a natural flow of conversation, starting with fact-based questions (for example, “Tell me about when you had your injury”) and moving towards those with a more intimate bent (for example, “What effect do you think it has, the fact that people can’t see anything ‘wrong’ with you?”), in order to allow time for trust and rapport to be built between myself and the participant.

An information sheet (Appendix 6.8) was emailed to potential participants. Once the research team was satisfied that a participant met inclusion criteria, the

consent form (Appendix 6.9), demographic questionnaire (Appendix 6.10) and interview questions were emailed to him or her. The interview questions were sent in advance so that participants would have the opportunity to reflect before the interview, and perhaps be able to provide more insight than if they were facing the questions 'on the spot'. This was in accordance with research on working with people with communication difficulties (Paterson & Scott-Findlay, 2002). I gave each person the option of being interviewed at their own home or at the University, or by Skype<sup>6</sup> if they lived out of the local area. I interviewed two local participants in their homes and one at her workplace and I arranged a Skype interview with the fourth participant who lived more than 100 kilometres away.

On arrival at a participant's home or workplace (or at the start of the Skype interview), I confirmed that he or she had read the information and consent forms, and gained signed consent. Following the usual cultural practice, I was offered a hot drink by the three participants I interviewed in person. I felt that accepting hospitality could help reduce any implicit power imbalance between researcher and participant, and therefore I agreed to a 'cuppa'. In the case of the Skype interview, I verbally mentioned this common practice in order to set a comfortable atmosphere: "Normally at this stage of the interview, you know, I'd come in and have a cup of tea and meet your cat and things like that [laugh]." Each participant then completed the demographic questionnaire if they had not done so already, and was interviewed using the semi-structured interview format which they had received. In the case of the Skype interview, the participant had jotted notes on the interview schedule I had sent and sent it back to me, which indicated that perhaps my purpose in sending the questions was unclear. In this case I explained that we

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<sup>6</sup> Freely downloadable and widely used video-conferencing software.

would go more fully into the answers and expand on what I had been given. Interviews ranged between 31 and 46 minutes in length and were recorded using a digital audio recorder. In the case of the Skype interview, I placed the digital audio recorder on the laptop computer I was using for the interview so that it could clearly record the sound from the laptop's speakers. One participant chose to have his wife present during the interview, and she contributed as well, although I maintained my focus of questioning on the participant himself. I took to each interview the sheet with options for further support (Appendix 6.4), as detailed in the section on ethics above, in case the participant seemed distressed by the conversation; however, it was not required by anyone. A few days after each interview, the participants were mailed a thank-you card and a \$20 voucher (funded by the University of Otago Psychology Department) to reimburse them for any expenses incurred. I transcribed the interviews fully, including hesitations and underlining words that the participant had emphasised. Each transcript was reviewed by the whole research team and checked for accuracy by a fellow postgraduate student in the Health Psychology laboratory.

I arranged a second interview with each participant approximately one year later, in which I checked with them their individual case summary (Appendices 6.11.1-4) and a summary of the overarching themes I had developed. This second interview was not recorded and transcribed, but field notes were taken and the participants' input taken into account in the final writing up of the findings.

#### **2.2.4 Analysis**

To analyse the data, I blended Smith et al.'s (2009) guidance on IPA with some of the processes described by Braun and Clarke (2006). I read the

transcripts repeatedly, firstly copying them into a spreadsheet programme and noting any recurring themes within each individual's interview. For example, Charlotte used the words "achiever", "successful" and "pushed myself" in her answer to my first question, which called attention to her predominant narrative of determination and hard work leading to success. Having repeated this process for each of the four transcripts, I printed out a clean copy of each and went over them, systematically coding them line by line. I then searched the highlighted and annotated transcripts for commonalities. I began charting common themes as they emerged, organising them to ensure they flowed together well and did not overlap excessively. Throughout this phase I continually returned to the data to ensure that the themes truly reflected the participants' experiences. During this process I had regular meetings with my two supervisors and discussed the emerging content of themes. Finally I refined the names of the themes and selected key quotes to illustrate each. The final flow and content of each theme was refined as I wrote the Findings section.

## 3 Findings

Four overarching themes were formulated from the four participants' narratives. These themes encapsulate separate but interconnected aspects of living with an invisible neurological condition. The themes were: 1) Feeling different; 2) Learning to cope; 3) Loneliness; and 4) Moral failure. All four of these themes were experienced by each participant in their own unique way. The first theme, 'Feeling different', expresses how the participants felt that they were not "normal" and contrasted themselves with others around them. Feeling that they struggled with tasks and situations that others managed easily led to the participants feeling stressed. The second theme, 'Learning to cope', describes how they had all learned and were still learning various ways to manage their condition. The third theme, 'Loneliness', shows that the participants all felt socially isolated at times, but had mixed feelings towards this isolation. The fourth theme, 'Moral failure', expresses how the participants all felt at times that they were failing morally and not doing things they ought to be doing. In this section I will expand on each of these four themes in order.

### 3.1 Feeling Different

This theme is divided into four subthemes. 3.1.1) Being unusual: the participants felt they were not "normal". 3.1.2) Comparing selves to others: the participants contrasted themselves with other people, in that they needed help with ordinary tasks. 3.1.3) Contrast with pre-diagnosis self: the participants with TBI contrasted themselves with their pre-injury self, while those with

prosopagnosia believed that their minds worked in abnormal ways, since they had found out about their condition. 3.1.4) Stress of being different: all four participants spoke of feeling stressed by the extra demands of living with their condition.

### **3.1.1 Being unusual**

The participants all expressed a sense of being unusual, and of having “strange” or “bizarre” experiences. They described their experiences to me with a tone that suggested that they expected me to be surprised. Murray had the “feeling that people may look at you strangely”. Huia described her inability to remember meeting her son’s friends as “a bit weird, bit disconcerting.” Karl recalled hallucinating “silver raindrops” and trying to touch them to see if they were real or not, an episode which he said was “bizarre.” Charlotte used the same word regarding her communication difficulties: “I say the most stupid bizarre things!” These experiences highlighted to the participants that they were different from others.

### **3.1.2 Comparing selves to others**

The participants contrasted themselves to other people or to what they considered normal. They felt that they were unable to do things that other people could, and that they needed more help with things than others did. Karl attempted to return to work not long after his accident but found he was unable to manage “a normal day’s work, I can’t go [...] even an eight hour distance”: in this phrase, the word “even” expresses his belief that eight hours is a normal and reasonable length of time to be able to work. Huia felt different from the other teachers at her workplace who could learn the names of the children in their classes in “maybe a

couple of weeks,” while she was still unable to do so by the middle of the year. Both Charlotte and Murray needed their spouses to help them: Charlotte said “often you have to be parented by your husband to be a parent;” Murray left it up to his wife to take their children places, and relied on her to give him clues as to who people were in social conversations.

### **3.1.3 Contrast with pre-diagnosis self**

As well as comparing themselves to others, the participants with TBI contrasted themselves to how they had been before their accidents. They spoke about how things had changed since their accidents: Charlotte used to be a very social person but the TBI made conversation exhausting, for example, while Karl talked about how he was now unable to do much of the “bloke stuff” he used to enjoy as hobbies. They considered these things that they used to do “normal”, and therefore the life they lived now was not normal, as Karl put it: “I just want life to get back to normal.”

Those with prosopagnosia also felt different, in that the way their minds worked was not “normal”, or as Huia put it, they believed that their brain was “not quite wired up” properly. This belief stemmed from the time when they learned about prosopagnosia as a condition. Murray described the moment he realised he could have a neurological condition as being when “it suddenly registered the impact or that it was not normal, perhaps. Or that it wasn’t that I was just not good with faces.” Discovering prosopagnosia and diagnosing themselves with it was a positive experience for both. Huia said that finding out that “it might not be me personally” was a relief, while Murray said that “realising that you have got some

difference makes it easier". Nonetheless, living with this unusual condition added stress to their lives.

### **3.1.4 Stress of being different**

All the participants talked about the stress of living with their condition, as it made life more difficult than they felt it ought to be. Three of them described feeling frustrated, even angry. Murray and Huia found it stressful having to deal with large numbers of people at once in work environments, particularly when they needed to know others' names. Huia provided an illustration:

*"Staff meetings. Every so often we take a turn at [...] chairing the meeting so people put up their hands and I can't call their names ... yeah, so it causes quite a lot of stress."*

Karl found that the financial stress of being out of work compounded with the stress arising from his condition, where he needed "peace and quiet" to deal with fatigue but was surrounded by a family of small children, and that "there [was] no respite." Because her accident was fourteen years ago at the time of the interview, Charlotte had had longer than the others to learn to manage the stress of her condition, but still found tasks like supermarket shopping stressful:

*"You're so determined about what you want and you're trying to find it and you get so frustrated when they change the damn packaging and things 'cause you can't damn well find it!"*

At our follow-up interview, Charlotte emphasised that because she had had more than ten years to learn to live with her TBI, she no longer felt the stress and frustration so strongly. She believed she had learned to cope. The other participants were still in the process of learning.

## 3.2 Learning to Cope

All the participants spoke of the ways that they had learned to manage their condition. They had developed strategies over time as they learned from experience what was helpful in various situations. Three different methods of coping were described by the participants, and these constitute the three subthemes of this section: 3.2.1) Avoidance, 3.2.2) Accepting limitations, and 3.2.3) Using active strategies.

### 3.2.1 Avoidance

Two different forms of avoidance were illustrated within the participants' narratives: 1) cognitive or emotional avoidance, for example Karl trying to think about other things when feeling "depressed"; and 2) behavioural avoidance, like the participants with prosopagnosia avoiding tasks which required face recognition. Karl underlined his reliance on cognitive avoidance at our second discussion by essentially repeating what he had said in the first interview:

*"That's the best I've come up with so far, just try and slap myself out of the thinking process and try something different. And just jump [...] from one railway line to a different railway line."*

Karl had also learned to switch tasks as a means of promoting cognitive avoidance, to stop unwanted rumination: "I know now to try and do something else, to get away from that thinking process." Charlotte said she learned what was important and put the things that were not important "somewhere else," demonstrating behavioural avoidance. Similarly, Murray and Huia, with face-blindness, avoided tasks which would require unaided facial recognition. Huia described her feelings about being asked to do tasks which were beyond her:

*"I used to put that sort of job off, and I'd be trying to think of what I was going to do about it and getting worried about it, but now I just go, 'oh, I'll get one of the kids to do it. Great.'"*

This demonstrates that Huia found behavioural avoidance was originally attended with feelings of anxiety, but became a more positive form of coping as she began to accept her limitations.

### **3.2.2 Accepting limitations**

The participants to some degree had come to accept the limitations that their condition imposed on them: they were not entirely in control of their lives, but forces outside of them were at work. Because they could not change their condition, they had to accept its reality and instead adapt their roles and expectations. The participants spoke of their condition as an outside agent which imposed restrictions on them, as Murray said: "It restricts the directions you go or what you take on." Charlotte personified her TBI: "It's the head injury that pulls us down a huge amount." Karl spoke with deep emotion about being compelled to give up a job which had reinforced his strongly masculine identity: "Is this where I've been...?" His sentence trailed off at this point but his implication was of having been left in a bleak situation by an external force.

Natural forces were seen as also having positive effects, as three participants expressed the feeling that things would improve without their input. Karl said he was "slowly getting better." Charlotte said her tolerance for sensory stimulation had improved since the early years of living with TBI, and she was able to function better after her children were old enough not to keep her awake at night. Huia discovered to her surprise that when she had called the roll in her class a few days

before our interview, she was looking at the right person when she called a name more often than she expected (although her recognition ability was still not approaching that of other teachers). Huia interpreted this experience as showing that perhaps “relaxing” about her deficits had helped her “make more connections”, and that there were “levels” of person-recognition which were not impaired by her condition. She was cautiously optimistic that she would continue to improve.

Three of the participants had changed their roles, and all of them had changed their expectations. Before her accident Charlotte was a successful businesswoman, but now she was “not allowed” to work, as she explained:

*“[I] get paid every three months from ACC<sup>7</sup> and as part of that [...] you do a whole set of sort of neurological tests or whatever, and they say to me “you can’t work again because your injury is so severe”.”*

Karl was no longer able to work in forestry, but had become the primary caregiver for his children, while his wife took on the ‘breadwinner’ role. Huia was a waitress early in her career, but found that her inability to recognise regular patrons made the job impossible to sustain. By contrast, Murray had been farming “all [his] life,” which he had resented when he was younger, but had come to accept: “I’m perhaps in more the right place than I would have thought once.”<sup>8</sup>

The three participants who had had (or known about) their condition for less than five years were beginning to accept their limitations, as Charlotte had over

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<sup>7</sup> Accident Compensation Corporation, New Zealand’s state-owned no-fault accident insurance provider.

<sup>8</sup> Interestingly, at the time of our second interview, Murray had decided to move off the farm and into town. This made me reflect on the comment I had written in his case summary (see Appendix 6.9.4) about him being like “an espaliered tree,” a metaphor he had initially rejected (he told me at our second interview) but had gradually come to accept as correct. I wondered whether my interpretation of his narrative had influenced his decision to leave the farm. I was somewhat unnerved when I thought that I might have had considerable power in a relative stranger’s life.

the 14 years since her accident. Huia was “starting to understand that [having trouble with some everyday tasks is] okay” and felt “a bit more in control” once she knew about prosopagnosia as a condition. When I asked how she dealt with the stress she sometimes experienced, she replied, “Ah... joke about it,” which indicated that she was comfortable enough about her condition to make light of it. Murray talked about his deficits as “things that you work around or you live with,” and, similarly, said that now that he knew about prosopagnosia he didn’t “feel quite as bad about it.” Karl recognised that some of the issues he faced were “all part of this silly thing,” and was able to joke a little, but he was still struggling to come to terms with his condition. As he laughingly said,

*“I wanna get out working. It’s easier to go to work than be a bloody parent at home! Oh my goodness! Lord, if this is a test, oh I’ve flunked! [...] No, men need to be at work, women wish<sup>9</sup> to be at work.”*

One of the most striking features of Karl’s narrative was that he blamed outside forces for many of the problems he faced:

*“These things just destroy your hope.”*

*“ACC got rid of us [...] and then stopped us from getting any help.”*

*“They’ve just squashed us.”*

*“No-one will employ me.”*

I compared Karl’s interpretations of his experiences with Charlotte’s and found conspicuous differences:

*“They say to me ‘you can’t work again because your injury is so severe’ [...] and besides you know you can’t work.”<sup>9</sup>*

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<sup>9</sup> Underlined words denote the participant’s spoken emphasis, as described in Section 2.2.3 Method: Data Collection.

*“You’ve had to work things out for yourself.”*

*“You have to gradually do a certain amount and then do it, and then see how you’re feeling at the end of the day. Okay, that means I can do that again. You gotta try it out and you gotta try and push yourself a little bit more each time to see, all other things being equal, can I do that amount? And then how do I feel?”*

From these quotes, it is evident that Charlotte largely felt in control of her life, while Karl did not. This contrast led me to consider the role of attributions and perceived self-efficacy in the way people with neurological conditions cope with difficulties, which will be covered in more detail in the Discussion (section 4.2.2 below). Karl’s inability to return to his former identity was a serious challenge to him; however, he was able to try some different approaches to manage his symptoms actively.

### **3.2.3 Using active strategies**

Three different types of active strategies were described by the participants. They experimented with different aids to help them manage everyday tasks, sought help from other people, and learned preventive strategies to forestall negative experiences. One important preventive strategy all four participants used was hiding their condition from others in order to avoid judgment or discrimination.

**Using aids.** The participants had experimented with different techniques and had found aids which helped them. Murray and Charlotte found computers useful in different ways: Murray had worked for some time in a reception job and the appointments screen on the computer “usually gave me a pretty strong

indication who would walk in the door;" Charlotte used the computer in her kitchen to read my information sheet aloud to her while she made me a cup of tea when I arrived for our interview, and explained that she often used it this way. Karl found that he was able to manage swimming if he used a snorkel to prevent the vertigo caused by repeatedly turning his head to breathe. Huia created file cards full of details on her students to help her remember personal details so she could demonstrate to them and their parents at parent-teacher interviews that she knew and cared about them.

**Seeking help.** The participants asked others for help, both within and outside of the family. Huia and Murray both asked their spouses to tell them who people were, and Huia's husband helped her follow movie plots. Karl approached several agencies, but he did not receive all the help he asked for: "I need help, you can't get that help." Charlotte, in contrast, received government-funded home assistance. She used this assistance in combination with her self-developed strategies of resting during the day and writing everything down "so you're not worried about things when you go to bed": she would write down tasks for the "girls" (her home helpers) so they would do things the way she wanted them to.

**Using preventive strategies.** Charlotte resting during the day is an example of a preventive strategy, which the participants had all developed in various forms. Preventive strategies differ from avoidance in that the participants were not using them to avoid situations as they arose, but taking steps beforehand to ensure they did not have to deal with worse situations later. Both Charlotte and Karl found they were not as badly affected by the fatigue consequent on their TBI if they rested during the day, and Charlotte found that she slept better at night if she made sure to exercise during the day. Both Murray and Huia were "very careful about

using people's names," and Huia said she would "call them 'Miss' or 'sweetie', or, 'would you mind doing so-and-so?' without directly saying who it is." This compensatory strategy prevented the embarrassment of potentially calling someone well-known by the wrong name.

All four participants had hidden their condition at times and used secrecy as a means of coping, seeking to avert discrimination from others. Charlotte liked that if she did not tell people about her condition, she was "just like everyone else." Karl told "porkies"<sup>10</sup> when he was asked if he was fit to return to work, to avoid the "humiliation" of having to tell people he was struggling with poor concentration and vertigo. Huia found that when she did tell one class about her condition, they took advantage of it with "a bit of game-playing, you know, fourteen-year-old girls, bit of game-playing," which for some time afterward sapped her confidence in sharing her needs with others. This illustrates the dilemma the participants faced: they did not want to stand out as different, but they faced challenges that others did not face and did not understand. This could be lonely.

### **3.3 Loneliness**

Loneliness was a fact of life for the participants. Three subthemes within the theme of loneliness were formulated from the participants' narratives, as outlined in the following sections. 3.3.1) Ambivalence: the participants were ambivalent about their social isolation: they felt lonely, but the two with prosopagnosia believed they had introverted personalities and were comfortable being alone, while the two with TBI welcomed solitude as providing relief from the demands of interacting with others. 3.3.2) Difficulty with social interaction: all the

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<sup>10</sup> That is, lies. From cockney rhyming slang: pork pies = lies (Wilkes & Krebs, 1991).

participants found social interaction challenging. 3.3.3) Wanting to be understood: the participants wanted others to understand their condition. They felt misunderstood, even by those closest to them.

### **3.3.1 Ambivalence**

The participants spoke matter-of-factly about having limited social activity. Both Karl and Charlotte said they had no real social life, while Murray said, “I don’t network.” Huia said she had “some good strong friends and people who I know, but yeah, [prosopagnosia] does get in the way of those relationships.” The two participants with prosopagnosia wondered if their failure to make connections with people was partly because of their personality. Huia remarked that she was an “introvert [...] in many respects”, while Murray called himself a “loner.” The two with TBI sometimes felt that they wanted to be alone because of fatigue or the demands of interacting with others. Karl stated this strongly: “I wanna be alone! I just want peace and quiet! I don't want the nagging.” Charlotte told a series of stories which illustrated her experience of “crappy” social interactions which she preferred to avoid, and agreed with my summary:

*Interviewer: “Do you feel like, perhaps, you feel the need to be a bit choosy because of your energy levels, and just chatting is really exhausting?”*

*Charlotte: “Yup, yup, absolutely. [...] What you’re saying is exactly right.”*

### **3.3.2 Difficulty with social interaction**

The condition itself made social interaction difficult. For the participants with TBI, this was because of sensory and concentration issues or miscommunication. Hypersensitivity to sound was a barrier to enjoying social events. Karl explained:

*“in the last two years I think we went out twice. [...] Any loud music, and it just drives me insane, just wanna go up and punch the bloody drummers and things.”*

Similarly, Charlotte likened hearing loud noises to being kicked in the head.

Halfway through our interview, she told me: “this interview, simple questions but it’s absolutely exhausting and it’ll probably wipe up the rest of my day.” Both Charlotte and Karl several times asked me to repeat questions (“what was the question again, sorry?”) and lost their train of thought. Karl said there were times when he had miscommunicated with someone and was “unaware that I’m actually upsetting them.”

For the participants with prosopagnosia, the fact that they could not remember people meant they could not easily build relationships. As Murray said: “I might know a lot of people if I could remember them!” Prosopagnosia made it hard to hold conversations as the participants were worried about making mistakes, and this worry persisted even though they had learned strategies to reduce the risk of embarrassment, as outlined in section 3.2.3 above. Murray laughed as he explained that he was wary about using people’s names during conversation because he might “have the wrong person.” Huia found it frustrating that because she could not easily “get to know my students on a personal level,” she could not build the kind of warm relationships she wanted, and added: “that’s a bit of sadness really.” Huia and Murray also both mentioned that they often fail to make eye contact with people, which Huia suggested might contribute to her inadequacy at building relationships, while Murray mused on the connection between eye contact and social relationships with prosopagnosia:

*“Maybe you don’t take enough notice of faces because they don’t mean much to us! I suspect I don’t look people in the face—no, doesn’t register—and that’s probably ‘cause I’m not getting a lot of feedback. [...] That might be one of the reasons [unclear]<sup>11</sup> I haven’t really looked that closely at the face but they’re all, tend to be the same.”*

### **3.3.3 Wanting to be understood**

The participants wanted to be understood, and to allow others to be open with them as well. Huia and Charlotte spoke about telling others about their difficulties. Huia said that although she didn’t want to burden her students with her problems, she wanted a “bit of understanding – it’s a bit of a two-way street.” In a similar vein, Charlotte said that when she “exposed a bit” about herself, that allowed others to share their experiences of TBI with her, and that was “actually really good.”

The participants felt that other people didn’t understand their condition, even those closest to them. Karl and Murray both described how their wives were unaware of the extent of their difficulties (though Murray’s wife understood more after watching a television documentary about face-blindness). Karl poignantly expressed the desperate feeling of loneliness caused by this lack of understanding:

*“when I’m bedridden, I’m just so exhausted, [...] and then I get [high pitched angry voice] “Get outta bed, you’re just being lazy!” It’s just like, I can’t function.<sup>12</sup> But that, no-one sees it. No-one sees it.”*

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<sup>11</sup> Murray’s interview was carried out via Skype and occasionally the sound quality was poor.

<sup>12</sup> Underlined words denote the participant’s spoken emphasis.

This quote demonstrates how the theme of loneliness is strongly connected with the following theme of moral failure: others often seemed to assume that the participants were lazy or rude because they didn't understand their impairments.

### 3.4 Moral Failure

The theme of Moral Failure is divided into three subthemes. 3.4.1) Doing 'wrong' things: the participants sometimes did things which they felt were 'wrong' in order to manage their condition. 3.4.2) Guilt at deficiencies: the participants felt guilty because of their deficiencies in social situations. 3.4.3) Feeling judged: they believed that other people made moral judgments about their failures, and this belief contributed to the participants' social anxiety and isolation. Charlotte's experience at an ANZAC Day parade encapsulates this theme neatly:

*"I remember going to a ANZAC Day [dawn service], and I had to sit down! And I had to sit down amongst all these older people, and I could feel them all just like, "what is this woman doing sitting where we are?" And you know, I had to sit down. And I get quite panicky, it's like I'd have to. [...] And yeah, I could just feel them "why is this woman sitting with us, she looks okay!" And I just thought they just have no idea at all."<sup>13</sup>*

#### 3.4.1 Doing 'wrong' things

The participants sometimes did things which were arguably 'wrong' in order to live with their condition. Karl told "porkies" to his employers about his health in order to give himself a chance to test his limits at work, as well as to save himself the humiliation of saying he was unable to perform. Huia used what she described

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<sup>13</sup> Underlined words denote the participant's spoken emphasis.

as “sneaky” means of recognising people, such as memorising their clothes and hairstyles, when she could not manage the ‘proper’ means of remembering faces; she also “overcompensated” by being friendly to everyone in order to avoid being seen as rude. Charlotte “upset” her children by removing their toys from the living areas of the home in order to maintain the tidy and peaceful environment she found necessary to manage her sensory hypersensitivity.

### **3.4.2 Guilt at deficiencies**

The participants felt that they were not able to do things that they should be able to do, or that they did things that they should not do. Nobody criticised Charlotte for sitting down at the ANZAC Day dawn service, but she felt defensive and “panicky” when her need to manage her TBI conflicted with socially acceptable behaviour. Karl described saying things he regretted and berating himself later. Murray said that he made “some horrible faux pas!” and that sometimes after talking to someone suddenly he would “click” he should have known them. Huia was embarrassed and concerned when she was unable to remember whether she had met her son’s girlfriends before. Even though the participants knew that they were not to blame for these things, they still experienced a sense of moral failure, a feeling that they were at fault. As Huia put it: “there’s still that sorta guilty feeling about, oh, [...] ‘if I was really interested in them, you know, if I really cared’ ...”

### **3.4.3 Feeling judged**

The participants believed that other people thought that these things they did (or did not do) were because they were lazy or crazy or rude or aloof. Charlotte spoke with some chagrin of being called “exclusive” because she was quite selective with her social interactions. Murray thought that others found him

“aloof” or “remote.” Huia articulated the trial of living with prosopagnosia in a sentence: “We have such a connection with identity that people think you’re being really rude if you don’t know their name, you don’t care about them.” Karl succinctly summed up the problem of the invisible nature of mild-moderate TBI: “People don't see it so they just assume and they think you're nuts.”

## 4 Discussion

In this study, I sought answers to four research questions: 1) How does having an invisible neurological condition affect the day-to-day functioning of this person in the world? 2) How has this person experienced the effect of their invisible neurological condition on their family life, in terms of their interactions with their partner and children? 3) How are these experiences affected by the aetiology of the condition – be it congenital (prosopagnosia) or acquired (TBI)? And finally, 4) are there gender-based differences in the way family life is experienced between men and women with an invisible neurological condition? Because I used an inductive research process—which is to say I followed where my participants led—I was not seeking definitive answers to all four of these questions. Instead, my aim was to gain insight into the day-to-day functioning of a person with an invisible neurological condition, and I did see some possible patterns of experience which were shaped by the aetiology of the condition; however, the participants did not distinguish family life from other contexts when talking about their experiences, and I did not find any themes which appeared unique to one gender or the other.

In this section I first summarise my findings; secondly, I describe how these findings connect with existing literature and theories; thirdly, I discuss the strengths and limitations of the present study; and finally I propose directions for future research.

## **4.1 Summary of Findings**

Because of their TBI or prosopagnosia, the participants felt different from others around them. They felt that their experiences were bizarre, and they contrasted themselves with 'normal' people. Those with TBI compared themselves with how they had been before their injury, while those with prosopagnosia felt that their brains were faulty. All four participants felt stressed by the demands of being different. The participants had learned, and were learning, ways to cope with their condition. They avoided upsetting thoughts and difficult tasks, they accepted that they had limitations, and they had learned active strategies to compensate for their deficits. These active strategies included using aids, asking others for help, and doing what they could to prevent issues from arising. One key preventive strategy that they all used was to hide their condition from others. The participants were lonely at times. They were ambivalent about social isolation, as they found social interaction difficult, but they wanted to be understood. They felt that they did things that were arguably wrong in order to live with their condition. They felt guilty when they were unable to meet their own and others' expectations, and believed that others judged them unfairly.

## **4.2 Relation to Existing Literature**

### **4.2.1 Feeling different**

My finding that my participants felt different from others around them is consistent with the literature on both prosopagnosia and TBI discussed in the Introduction (sections 1.1.1.7 and 1.1.2.5 above). Yardley et al. (2008) carried out semi-structured telephone interviews with 25 people with developmental

prosopagnosia (18 women, age range 26 to 74 years), asking questions about how prosopagnosia affected their life, how they believed others saw them, and how they coped with negative experiences and emotions that arose from their condition. One participant is reported as saying “I didn’t talk to anyone about it ’cause I thought everybody else had this and they were managing and it was like I wasn’t managing to do what everybody else was doing” (Yardley et al., 2008, p. 448). This is similar to Murray, in the present study, who for many years assumed that he “was just not good with faces” and did not realise “that it was not normal” (see Findings section 3.1.3). Diaz (2008) presented a case study of a thirteen-year-old boy and his mother with congenital prosopagnosia, detailing the development of a programme to help the boy function better at school. He gained a reputation for being “weird” (Diaz, 2008, p.287), which seems likely to have been reported by the child himself (as no interviews with his peers are mentioned) indicating that he felt himself to be weird. He was also quoted as saying that he liked “being his own person, not a copy of another kid” (Diaz, 2008, p.288), which showed that he was able to accept his uniqueness as positive. In the present study, Huia said that she was “starting to understand that that’s okay,” being different and having difficulty with things that others found easy (Findings section 3.2.2).

People with TBI are also reported as feeling different from those around them. Conneeley (2002) interviewed eighteen patients with TBI, their significant other (a parent or spouse) and members of the patient’s rehabilitation team at three times during the year following their injury. They found that people with TBI may end up occupying the position of “stranger” in their social groups because they have had experiences that others in the group do not share.

Past research suggests that for people with TBI, the most salient experience of being different is in the change from a former self. The participants with TBI in the present study, as well as having “bizarre” episodes of miscommunication or hallucination, contrasted their present selves with their past. This “changed sense of personal identity” (Levack et al., 2010, p. 990) is a key finding in Levack et al.’s (2010) metasynthesis of 23 studies investigating the lived experience of TBI acquired during adulthood, and highlights one of the ways in which aetiology affects the experience of living with an invisible neurological condition. The participants with developmental prosopagnosia did not have the same sense of changed identity. When I asked how things had changed since learning about prosopagnosia, both Murray and Huia said that they themselves hadn’t changed, though they felt a little better about their difficulties.

#### **4.2.2 Attributions, stress and coping**

The stress experienced by people with a chronic condition, like the participants in the present study, can be categorised as arising from a chronic persistent event (Lazarus, 1984). Small hassles which were part of the participants’ everyday life, such as supermarket shopping, chairing meetings, dealing with tradesmen, and getting children to ballet class with all their gear, were appraised as a potential source of fatigue, failure or embarrassment and thus were stressful. Participants in the current study had a variety of ways of dealing with this stress. The themes I developed inductively from their narratives map fairly well onto three styles of coping outlined by Richards and Folkman (2000): emotion-focused coping is similar to my subtheme of avoidance (Findings section 3.2.1), problem-focused coping is similar to my subtheme of using active strategies

(Findings section 3.2.3), and meaning-based coping is similar to my subtheme of accepting limitations (Findings section 3.2.2). My participants used these styles of coping in their own individual ways and to varying degrees. This was one of the few areas where gender did appear to have some effect: both women talked about being organised, while both men seemed to prefer avoidant strategies.

In general, avoidant coping styles are associated with more problems than active coping methods when used long term (Taylor & Stanton, 2007). However, a recent study of 93 patients with acquired brain injury found that the use of problem-focused coping styles correlated with better outcomes in terms of self-reported quality of life for patients with higher executive function but poorer outcomes for patients who had more trouble with executive functioning (Gregorio et al., 2015). This would suggest that recommending problem-focused coping styles is not necessarily appropriate in all cases, and perhaps learned helplessness may in some cases be real helplessness due to difficulties with functioning. In such situations it may be most adaptive for people to change their paradigm of what constitutes a good quality of life.

This change in paradigm is termed “response shift” by Richards and Folkman (2000). According to their terminology, meaning-based coping comes into use when a person is unable to find a favourable resolution to a stressful situation by using problem- or emotion-focused coping, and response shift is the change from one interpretation of the meaning of an experience or event to a new interpretation. Results drawn from a longitudinal study of 145 gay men who were primary caregivers of partners with terminal AIDS revealed that those men who were able to reinterpret their situations to find positive meaning experienced sometimes surprisingly high levels of wellbeing during an extremely distressing

time (Folkman, Chesney, & Christopher-Richards, 1994, as cited by Richards & Folkman, 2000). Although the experience of living with a chronic neurological condition is very different from caring for a dying partner, it has some similarities in that the source of stress is chronic and unremitting (Lazarus, 1984).

Charlotte exhibited meaning-based coping when she described herself as being lucky to still be here, given that she had been in two car crashes, ten years apart, and in both cases her fellow passenger had been killed. I was amazed to hear that someone who had been through such trauma and experienced such damage could consider herself lucky. Charlotte was so grateful to be alive that she had begun attending church in order to express her gratitude to God. Her response is similar to that of some of the participants in Howes et al. (2005) study of women following TBI who made changes to their lives and came to “live for the moment [and] appreciate things more” (Howes et al., 2005, p. 136).

The striking contrast between Karl’s and Charlotte’s locus of control (Findings section 3.2.2) highlighted the important role of attributions in coping with a TBI. Hunt, Turner, Polatajko, Bottari, and Dawson (2013) reviewed literature dealing with attribution, executive function and self-regulation in adults with brain injury and clarified the connection between these three constructs. Being able to attribute events appropriately to internal or external factors has considerable influence on how someone plans and evaluates their self-regulatory behaviour. If they make incorrect attributions in either direction (thinking they have either more or less control over a situation than they actually do), they may experience repeated failures, with concomitant reduced self-efficacy and feelings of helplessness and emotional distress (Hunt et al., 2013). This could lead to a reduced quality of life and poorer outcomes. Moore and Stambrook (1995)

conceptualised the relationships between self-efficacy beliefs, coping patterns and quality of life outcomes following TBI. Their hypothesis, that the “after-effects of TBI may create a real life ‘learned helplessness’ with consequent deficits in coping and altered locus of control beliefs” (Moore & Stambrook, 1995, p. 109), is supported by recent studies by Brands, Koehler, Stapert, Wade, and van Heugten (2014) and Gregorio, Gould, Spitz, van Heugten, and Ponsford (2014) among others. In a study of 136 individuals with TBI assessed after discharge from rehabilitation and again after one year, those with higher perceived self-efficacy used more task-oriented coping and less emotion-oriented coping, while more emotion-oriented coping was used by patients with higher levels of emotional distress and worse executive function (Brands et al., 2014). Karl and Charlotte respectively seem to exemplify people with low and high perceived self-efficacy, perhaps arising from their respective external and internal attribution styles. Karl generally used emotion-focused coping, using tasks to distract him from “the stupidity of hopelessness”, while Charlotte focused on learning efficient methods to achieve all she wanted to without overtaxing her physical stamina or cognitive capacity. It is interesting to note that Karl and Charlotte had had very different experiences of government agency support from ACC, for while Charlotte received funded home help, Karl found himself with complex unresolved circumstances very similar to those described by Howes et al. (2005) as leading to feelings of persecution, helplessness and significant loss of self-esteem.

Murray and Huia demonstrated a response shift when they learned that their life-long struggle with remembering people was the result of a neurological condition. They changed their attribution of their failures from internal (thinking perhaps they were stupid or not trying hard enough) to external (believing there

was something in their brain that was “not quite wired up”), and found relief from the weight of guilt and frustration.

### **4.2.3 Stigma, judgment and guilt**

Stigma has been conceptualised as being composed of five interrelated components: labelling human differences; linking persons to negative stereotypes; separating ‘us’ from ‘them’; discrimination against the labelled person, leading to unequal outcomes; and finally, all these processes taking place within a context of social, economic and political power which makes such labelling, stereotyping, separation and discrimination possible (Link & Phelan, 2001). Negative stereotypes exist regarding people with TBI: they are expected by some to be more aggressive, dependent and unhappy than average, and to have some visible sign of their disability (Linden & Boylan, 2010). People treat them differently after they disclose their condition (Conneeley, 2002; Morris et al., 2005; Olney & Kim, 2001). Karl concealed his reason for not returning to work after his injury because he did not want his workmates to know he was struggling with vertigo and fatigue. He felt that revealing weakness in his forestry work context would have been humiliating for him. Fear of appearing weak is also seen in Yardley et al.’s (2008) study, where a participant said:

*“I wasn't managing to do what everybody else was doing so I was a bit weak, and so I didn't want to let anybody know how weak I was”* (Yardley et al., 2008, p. 448).

Negative stereotypes are also associated with mental deficiency, and people with developmental prosopagnosia may fear being stigmatised in this way if they reveal their condition (Yardley et al., 2008). The discomfort that can accompany

self-revelation was seen in Huia's narrative when she told the story of her class taking advantage of her face-blindness with a "bit of game-playing," and how this sapped her confidence to share her condition with others.

However, failing to reveal their condition can lead to people with neurological conditions having their behaviour misinterpreted as evidence of mental illness (another highly stigmatised condition), drunkenness, stupidity or laziness (Howes et al., 2005; Yardley et al., 2008). Psychotherapist Monica Zenonos wrote in an article based on her own experience of being face-blind,

*"Coming out as face-blind is similar to other coming out processes: embedded in shame, internalised oppression and insecurities about whether people will accept you or even believe that such a thing as face-blindness exists"*

(Zenonos, 2014, p. 22).

People who choose whether or not to disclose a new identity walk a precarious line between exposing themselves to discrimination or rejection if they do come out, and maintaining a false front, with all the attendant negative consequences to health and wellbeing, if they do not (Flowers & Buston, 2001). Charlotte said she felt lucky that she looked "just like everyone else." However she also said that sometimes it was "nice to be able to [...] pull something out of your pocket and that saves you a wee bit." Telling people she had a brain injury saved her from social judgment, because she had a socially acceptable reason for socially unacceptable behaviour.

### **4.3 Strengths and Limitations**

In this study I gained an in-depth understanding of the experiences of four people with self-reported invisible neurological conditions at a single point in time,

which is an appropriate sample size for a phenomenological study. All four participants were middle-aged and of European descent; experiences would likely be different for other demographics. I did not undertake any screening to support my participants' self-reported diagnoses. If this had been a larger scale or quantitative study, these details (for example Glasgow Coma scores or Cambridge Face Recognition Test results) would have been required. However, for a small-scale study focusing on lived experience, I decided that formal diagnoses were not as important as the participants' own beliefs about their condition, as these beliefs would have more impact on their daily lives than test scores. In the end, the recruitment process took longer and was more difficult than I anticipated, and adding an extra screening process could have extended the participant search beyond what was practicable.

I widened the pool of available participants by using Skype as an interview medium. I was able to recruit a participant (Murray) who lived more than 100 kilometres away and interview him in his home without having to expend the resources required to travel there. Skype interviews have the limitation that both interviewer and participant must have the appropriate software and an adequate internet connection, and in my experience there are inevitably minor difficulties initiating the connection. Additionally, as footnoted in Findings section 3.3.3, the sound quality was poorer than my face-to-face interviews and the image froze occasionally, which meant that more words were inaudible than in the other transcripts. Nevertheless I was still able to capture sufficient data to analyse so that Murray's narrative was in no way diminished in comparison to the other participants'.

My findings were given validation by presenting all four participants with their own individual case summary (Appendices 6.9.1-6.9.4 below) and a summary of the full findings at a second meeting with each participant, where all four enthusiastically endorsed my themes. The findings are not intended to be representative of all people with similar conditions, and my findings are therefore not able to be generalised. Nor am I able to make any predictions about the development of any of my themes over time, because this study comprised only one single in-depth interview. However, my findings do offer some insights into the variety and similarity of experiences that exist in people with TBI and prosopagnosia. Furthermore, because the sample was very small, I was able to become intimately acquainted with my data and allow the voices of my four participants to be clearly heard.

## **4.4 Future Research**

Invisible neurological conditions have not often been grouped together in the literature, and I believe it could be valuable to do so. Studies encompassing a wider range of invisible conditions could help to conceptualise the complex relationships between stigma, secrecy and self-revelation in contexts other than sexuality and mental health. Studies examining further aspects of each of the conditions in the present study would also enrich the literature. There is a great deal of scope for future research into the psychosocial aspects of prosopagnosia. Longitudinal qualitative studies would be able to chart changes over time both of the developmental condition itself and of coping strategies and provide more options for health professionals to help patients live well with their condition. A wealth of research into psychosocial aspects of TBI has been published, as

mentioned in the Introduction, but it would be valuable to look specifically at the effect of TBI on family dynamics from the point of view of the person with TBI.

The present study did not reveal very much about family experiences with prosopagnosia or with TBI despite that being a central aim. A study design involving a series of dyadic interviews amongst a family (as employed in the study of a family dealing with Alzheimer's disease by Perry and Olshansky, 1996), or a focus group-type study could potentially have teased out more of the shared experiences of the group, and informed the construction of more targeted individual interview schedules with different members of the family: parents, children, partners, and siblings. This could build up a very rich portrait of the shared family experience of the condition in question. I saw an element of this in my interview with one participant whose wife was present, as their shared conversation allowed for each to prompt and modify the other's recollections. Furthermore, a qualitative study exploring the experiences of multiple family members across generations with congenital prosopagnosia (as seen in Diaz, 2008) could be fascinating, to explore the roles of family culture, expectations and coping strategies.

It would also be interesting to consider more carefully the differences in experience between acquired and developmental prosopagnosia. Perhaps in the acquired condition, elements of identity change would be seen as they are in participants with adult-acquired TBI. Gender may have an effect on strategies and coping in both prosopagnosia and in other invisible neurological conditions. I did see an aspect of this (mentioned in section 4.2.2 above) where both women talked about being organised, while both men seemed to prefer avoidant strategies for dealing with stress. Studies on the effect of TBI specific to men and to women have

been published (for example Howes et al., 2005; Jones & Curtin, 2011b). A larger study including other invisible neurological conditions would be able to elucidate more of these differences.

## **4.5 Conclusion**

This study extends the TBI literature by showing that there are similarities between the lived experiences of TBI and of another neurological condition. It enhances the literature regarding the lived experience of prosopagnosia, where little qualitative research has been done until recently. The findings demonstrate some of the psychosocial consequences of prosopagnosia and TBI. Health practitioners may benefit from having more awareness of these consequences in order to be better able to help people with these conditions to live well.

Charlotte, Huia, Karl and Murray each live with a condition which makes their lives more challenging as they deal with the daily routines of work, social life and family. They feel different from the people around them. They sometimes feel lonely and misunderstood, sometimes stressed and sometimes guilty, but they are coming to terms with their limitations and learning effective strategies to manage them. They are interesting people, and becoming connected with their lives has enriched my own.

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## 6.1 Appendix 1: Ethics Committee Approval



14/020

Academic Services  
Manager, Academic Committees, Mr Gary Witte

29 January 2014

Dr G Treharne  
Department of Psychology  
Division of Sciences  
Union Place East/Leith Walk

Dear Dr Treharne,

I am again writing to you concerning your proposal entitled "**A Qualitative Study of Living with an Invisible Neurological Condition, with Particular Reference to the Effects on the Family**", Ethics Committee reference number 14/020.

Thank you for your response of 28 January 2014, and for providing your revised Information Sheet and Consent Form. The Committee notes that you will now first offer participants an interview at home, with the option of being interviewed at the University as an alternative. Thank you for ensuring that the students will let their supervisors know where and when home interviews are occurring, and will make contact following the interviews to confirm all is well.

On the basis of this response, I am pleased to confirm that the proposal now has full ethical approval to proceed.

Approval is for up to three years from the date of this letter. If this project has not been completed within three years from the date of this letter, re-approval must be requested. If the nature, consent, location, procedures or personnel of your approved application change, please advise me in writing.

Yours sincerely,

A handwritten signature in cursive script that reads 'Gary Witte'.

Mr Gary Witte  
**Manager, Academic Committees**  
Tel: 479 8256  
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c.c. Professor D K Bilkey Head Department of Psychology

## 6.2 Appendix 2: Māori Consultation Submission



### A Qualitative Study Of Living With An Invisible Neurological Condition

#### Principal Investigator 1

**Name:** Dr Gareth Treharne  
**Department:** Department of Psychology  
**Campus:** DUNEDIN  
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#### Principal Investigator 2

**Name:** Mrs Anna Barham  
**Department:** Department of Psychology  
**Campus:** DUNEDIN  
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#### Principal Investigator 3

**Name:** Dr Deborah Snell  
 University of Otago Christchurch -  
**Department:** Orthopaedic Surgery and  
 Musculoskeletal Medicine  
**Campus:** UOC  
**Email:** debbie.snell@otago.ac.nz      **Telephone:** Not Supplied

#### Is this Otago District Health Board research?

No

#### Does this research involve human participants?

Yes

#### Description in lay terms of the proposed research

Living with an invisible neurological condition, whether acquired through injury or a lifelong condition such as prosopagnosia ("face blindness"), can have a considerable impact on the person. This study will seek to understand the experiences of a small number of people with such neurological conditions and the effects on family life. Participants will be asked to describe their experiences during interviews. These descriptions will be sorted into themes that are common across the participants.

#### Description in lay terms of the potential outcomes of the area of research

This research will hopefully lead to a better understanding of the lived experience of certain neurological conditions. The findings of this project may suggest new avenues for research into supporting people with neurological conditions.

#### Potential areas that are of interest to or of concern for Māori

Some participants may identify as Māori. All participants will be asked to record their ethnicity on the standard census question, including a space for Māori individuals to note their iwi and hapu.

**Collaborations in this area of research**

Brain Injury Association.

**Potential funding bodies****Location**

Department of Psychology, Dunedin

**Other relevant information****Relevance Score**

Medium - Maori

**Reference**

5654\_17144

## 6.3 Appendix 3: Māori Consultation Approval

### NGĀI TAHU RESEARCH CONSULTATION COMMITTEE TE KOMITI RAKAHAU KI KĀI TAHU

Tuesday, 21 January 2014.

Dr Gareth Treharne,  
Department of Psychology,  
DUNEDIN.

Tēnā koe Dr Gareth Treharne,

#### A Qualitative Study Of Living With An Invisible Neurological Condition

The Ngāi Tahu Research Consultation Committee (The Committee) met on Tuesday, 21 January 2014 to discuss your research proposition.

By way of introduction, this response from The Committee is provided as part of the Memorandum of Understanding between Te Rūnanga o Ngāi Tahu and the University. In the statement of principles of the memorandum it states "Ngāi Tahu acknowledges that the consultation process outline in this policy provides no power of veto by Ngāi Tahu to research undertaken at the University of Otago". As such, this response is not "approval" or "mandate" for the research, rather it is a mandated response from a Ngāi Tahu appointed committee. This process is part of a number of requirements for researchers to undertake and does not cover other issues relating to ethics, including methodology they are separate requirements with other committees, for example the Human Ethics Committee, etc.

Within the context of the Policy for Research Consultation with Māori, the Committee base consultation on that defined by Justice McGechan:

*"Consultation does not mean negotiation or agreement. It means: setting out a proposal not fully decided upon; adequately informing a party about relevant information upon which the proposal is based; listening to what the others have to say with an open mind (in that there is room to be persuaded against the proposal); undertaking that task in a genuine and not cosmetic manner. Reaching a decision that may or may not alter the original proposal."*

The Committee considers the research to be of importance to Māori health.

The Committee notes and commends that ethnicity data is to be collected using the questions on self-identified ethnicity and descent contained in the latest census.

The Committee suggests dissemination of the research findings to Māori health organisations regarding this study.

We wish you every success in your research and The Committee also requests a copy of the research findings.

This letter of suggestion, recommendation and advice is current for an 18 month period from Tuesday, 21 January 2014 to 10 July 2015.

The recommendations and suggestions above are provided on your proposal submitted through the consultation website process. These recommendations and suggestions do not

The Ngāi Tahu Research Consultation Committee has membership from:

*Te Rūnanga o Ōtākou Incorporated  
Kāi Huirapa Rūnaka ki Puketeraki  
Te Rūnanga o Moeraki*

## 6.4 Appendix 4: Support Information Sheet

TBI

### For Further Help

If our interview has raised serious issues for you and you think you would like to speak to a counsellor, the best thing to do is to contact your case worker or your GP (family doctor). They will be able to arrange suitable support for you, through Work and Income NZ if necessary.

Free confidential telephone counselling is available through  
Lifeline New Zealand  
0800 543 354  
[www.lifeline.co.nz](http://www.lifeline.co.nz)

If you would like more information about your condition, or would like to get in touch with other people who have similar conditions (a support group, for example), you could contact:

Otago Brain Injury Association.  
PO Box 5222  
Dunedin  
Phone (03) 471 6156  
Fax (03) 471 6174  
[liaison.dunedin@brain-injury.org.nz](mailto:liaison.dunedin@brain-injury.org.nz)

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Prosopagnosia

### For Further Help

If our interview has raised serious issues for you and you think you would like to speak to a counsellor, the best thing to do is to contact your GP (family doctor). They will be able to arrange suitable support for you, through Work and Income NZ if necessary.

Free confidential telephone counselling is available through  
Lifeline New Zealand  
0800 543 354  
[www.lifeline.co.nz](http://www.lifeline.co.nz)

If you are on Facebook, there is a Prosopagnosia support page (an open group) at <https://www.facebook.com/groups/11808741970/>



## 6.6 Appendix 6: Otago Daily Times Recruitment

### Article **Otago Daily Times**

Published on *Otago Daily Times Online News* (<http://www.odt.co.nz>)

#### Seeking face blind subjects

By *Shawn McAvinue*  
Created 11/04/14

ShareThis

If bells of recognition fail to ring when you see what should be a familiar face, a Dunedin student wants to study you.

University of Otago psychology department master's degree student Anna Barham, of Dunedin, is seeking people with face blindness for her research.

People with face blindness failed to instantly recognise someone they knew.

Mrs Barham said the cognitive disorder ranged in severity.

A Dunedin teacher with the condition recognised her family but failed to recognise her students if they changed their hairstyle or glasses.

Another person with the condition failed to recognise their child when collecting them after school.

The most severe cases included failing to recognise themselves in a photograph and failing to recognise a person's age, gender, race or facial expressions when looking at them.

"They can't tell if someone is frowning or smiling."

She wanted to interview people with the condition and a partner and children to better understand the "impacts" of the condition on family life.

People with the condition could become "socially isolated" and withdrawn by the fear of being incorrectly labelled a "rude snob".

Others coped by being friendly to everyone they passed to ensure nobody was offended.

She was hopeful people with the condition would come forward for her research.

"About 2% to 2.5% of people in the world have this from birth but a lot of people don't realise they have it."

- [shawn.mcavinue@odt.co.nz](mailto:shawn.mcavinue@odt.co.nz) <sup>[2]</sup>

#### **Face time**

University of Otago psychology department student Anna Barham would like to interview anyone older than 18 years old who either:

- Has always found it very difficult to recognise people from their faces.
- Had a head injury at least a year ago and is still experiencing difficulties which are not obvious to a casual observer.
- Because the study is about the effects of having a neurological condition on the family, you must have children and a current partner to participate.
- If you are interested, email [anna.barham@postgrad.otago.ac.nz](mailto:anna.barham@postgrad.otago.ac.nz)



<sup>[1]</sup> University of Otago Psychology Department student Anna Barham is seeking people with the cognitive disorder face blindness to research for her master's study. Photo by Gerard O'Brien.

University of Otago Dunedin

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Source URL (retrieved on 07/08/2015 - 21:38): <http://www.odt.co.nz/campus/university-otago/298528/seeking-face-blind-subjects>

#### Links:

[1]

[http://www.odt.co.nz/files/story/2014/04/university\\_of\\_otago\\_psychology\\_department\\_student\\_\\_534687f1d2.JPG](http://www.odt.co.nz/files/story/2014/04/university_of_otago_psychology_department_student__534687f1d2.JPG)

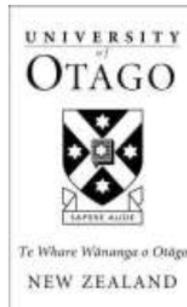
[2] <mailto:shawn.mcavinue@odt.co.nz>

## 6.7 Appendix 7: Interview Questions

Questions	Prompts
Tell me a bit about yourself.	What kind of person are you? What is important to you? What do you enjoy?
Tell me about when you had your injury. OR How did you come to realise you had prosopagnosia? When?	
How did [the above] make you feel?	At the time? Now? Have things changed? Tell me about that emotional 'journey'.
What effects do you think your condition has had on your family?	Spouse/partner? Children? Have they had to do things differently? Have they talked to you about their experience? What sort of things did they say?
What kind of effect has having [your condition] had on your work?  On your social life?	[TBI] Do you feel it has been affected? How?  [Prosopagnosia] Do you feel you do things differently from other people? How?
What effect do you think it has, the fact that people can't see anything 'wrong' with you? What effect does it have on your own feelings about your condition? About yourself?	
Thinking about having [your condition], do you expect things to change in the future? Why / why not? How?	Are you doing things to make changes? What? Are there events coming up which you expect to make a difference?

## 6.8 Appendix 8: Information Sheet

Reference Number 14/020  
28 January 2014



### LIVING WITH AN INVISIBLE NEUROLOGICAL CONDITION

#### INFORMATION SHEET FOR PARTICIPANTS

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to participate. If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

#### Aim

Your participation would provide valuable input in exploring personal experiences of living with an invisible neurological condition, and especially its effect on family life. This project is being undertaken by Anna Barham as part of the requirements for a Masters' Degree in Science.

#### Participants

- If you are interested in participating, please contact researcher Anna Barham to arrange a time to meet.
  - Phone: (03) 471 6942 or 027 475 3069 (text messages are fine)
  - Email: [anna.barham@postgrad.otago.ac.nz](mailto:anna.barham@postgrad.otago.ac.nz)
- We are seeking four participants over the age of 18 years old who either:
  - Had a head injury at least twelve months ago and are still experiencing difficulties which are not obvious to a casual observer,  
OR
  - Have always found it very difficult to recognise people from their faces (congenital prosopagnosia or 'face-blindness').
- Because this study is about the effects of having a neurological condition on the family, you must have children and a current partner to participate. You must also be comfortable communicating in English.
- A \$20 grocery voucher or petrol voucher will be offered to reimburse you for any expenses associated with participating.

### **What will you be asked to do?**

- If you agree to take part in this project, we will make a time for you to meet with the researcher either in your own home or at the University of Otago to discuss your experience of living with a neurological condition using a semi-structured interview format. The interview may take up to 2 hours but you are welcome to request the interview be ended sooner. You are also welcome to have a support person present to sit in on the interview.
- This project involves an open-questioning technique. The general line of questioning includes your personal experience of living with a neurological condition in relation to the onset, diagnosis or discovery of the condition, psychosocial factors, emotions, coping mechanisms, employment, family roles, and the impact on your partner and children. The list of questions will be sent to you before you come for the interview.
- The interview will be much like a natural conversation and the precise nature of all questions that will be asked has not been determined in advance. The University of Otago Human Ethics Committee is aware of the general areas to be explored in the interview, but the Committee has not been able to review the precise wording of all questions to be used. In the event that the line of questioning develops in such a way that you feel hesitant or uncomfortable you are reminded of your right to decline to answer any particular question(s) and also that you may withdraw from the project at any stage without any disadvantage to yourself of any kind.
- If you are uncomfortable with having the interview in your home and are also unable to come to the University for the interview, we are happy to arrange an alternative venue if possible.
- If you experience any emotional difficulties when talking about your experience, the researcher will make every possible effort to make you feel at ease and will offer you details of additional sources of support after the interview.

Please be aware that you may decide not to take part in the project without any disadvantage to yourself of any kind. You are free to withdraw from the project at any time.

### **Your data**

- Interviews will be recorded on digital audio. All audio files and the transcripts will be safely managed and are confidential material available only to the researcher, a professional, confidential transcriber and the research supervisors.
- The data collected will be securely stored in such a way that only those mentioned below will be able to gain access to it. Data obtained as a result of the research will be kept for at least 10 years in secure storage. Any personal information held on the participants such as contact details and audio recordings may be destroyed at the completion of the research even though the data derived from the research will, in most cases, be kept for much longer or possibly indefinitely.

- The results of the project may be published and will be available in the University of Otago Library (Dunedin, New Zealand) but every attempt will be made to preserve your anonymity. Any details which could identify either yourself or anyone you talk about will be removed or changed before publication.
- You will have an opportunity to view a summary of your interview and the themes that come from it before the research is completed. You will also be invited to a public presentation of the completed study.

**Any questions?**

If you have any questions about our project, either now or in the future, please feel free to contact either:-

Anna Barham, researcher  
Department of Psychology  
(03) 471 6942 or 027 475 3069  
anna.barham@postgrad.otago.ac.nz

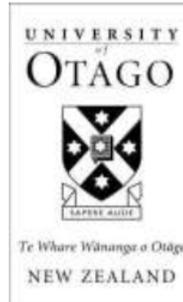
and/or

Dr Gareth Treharne, supervisor  
Department of Psychology  
(03) 479 7630  
gtreharne@psy.otago.ac.nz

This study has been approved by the University of Otago Human Ethics Committee. If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (phone 03 479 8256 or email gary.witte@otago.ac.nz). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

## 6.9 Appendix 9: Consent Form

Reference Number 14/020  
28 January 2014



### LIVING WITH AN INVISIBLE NEUROLOGICAL CONDITION

#### CONSENT FORM FOR PARTICIPANTS

I have read the Information Sheet concerning this project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

I know that:

1. My participation in the project is entirely voluntary;
2. I am free to withdraw from the project at any time without any disadvantage;
3. Personal identifying information including audio recordings and contact details will be destroyed at the conclusion of the project but any raw data on which the results of the project depend will be retained in secure storage for at least ten years;
4. This project involves an open-questioning technique. The general line of questioning includes my personal experience of living with a neurological condition in relation to the onset, diagnosis or discovery of the condition, psychosocial factors, emotions, coping mechanisms, employment, family roles, and the impact on my partner and children. The precise nature of the questions which will be asked has not been determined in advance, but will depend on the way in which the interview develops and in the event that the line of questioning develops in such a way that I feel hesitant or uncomfortable I may decline to answer any particular question(s) and/or may withdraw from the project without any disadvantage of any kind;
5. A \$20 grocery voucher or petrol voucher will be offered to me to reimburse any expenses associated with participating;
6. The results of the project may be published and will be available in the University of Otago Library (Dunedin, New Zealand) but every attempt will be made to preserve my anonymity. Any details which could identify either myself or anyone I talk about will be removed or changed before publication.

I agree to take part in this project.

.....  
(Signature of participant)

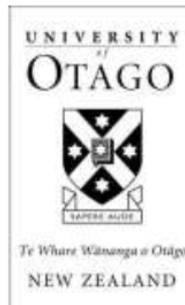
.....  
(Date)

.....  
(Printed Name)

This study has been approved by the University of Otago Human Ethics Committee. If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (phone 03 479 8256 or email [gary.witte@otago.ac.nz](mailto:gary.witte@otago.ac.nz)). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

## 6.10 Appendix 10: Demographic Questionnaire

Study ID.....  
Reference Number 14/020  
28 January 2014



### LIVING WITH AN INVISIBLE NEUROLOGICAL CONDITION

#### DEMOGRAPHIC INFORMATION OF PARTICIPANTS

Thank you for choosing to participate in this project. Please take a moment to complete this form. Your demographic details will only be used to describe the group characteristics of participants in reports about the study and will not be linked to your name. If there is any question that you would prefer not to answer, you can skip it and leave the space blank. This form will be stored in a locked cupboard. Any electronic records based on this form will be stored in password-protected files.

Please bring the questionnaire along to your interview.

If found, please return to:

Anna Barham (027 475 3069)

Department of Psychology

University of Otago

PO Box 56, Dunedin 9054

This study has been approved by the University of Otago Human Ethics Committee. If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (phone 03 479 8256). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

**Who do you live with?** (Please tick all boxes that apply to you)

- .... Spouse or partner
- .... Children (please list their ages) .....
- .... Others (please state who e.g., parents, sister) .....

**How would you describe your gender identity?** (Please tick one box)

- .... Female
- .... Male
- .... Other identity (please give any details you would like to share)  
.....

**How would you describe yourself?** (Please tick one box)

- .... Asexual
- .... Bisexual
- .... Gay or lesbian or takatāpui
- .... Straight (heterosexual)
- .... Other (please give any details you would like to share) .....

**How would you describe your origins?** (Please tick all boxes that apply to you)

- .... New Zealand European / Pākehā
- .... New Zealand Māori
- .... Cook Islands Māori
- .... Niuean
- .... Samoan
- .... Tongan
- .... Other European (please give details) .....
- .... Chinese
- .... Indian
- .... Other specific origin or origins (please give details) .....

**Which qualifications do you hold?** (Please tick all boxes that apply to you)

- .... I have no formal qualifications
- .... Vocational or trade qualification (please give details) .....
- .... NCEA Level 1 or 2 (or equivalent, e.g. School Certificate, GCSEs)
- .... NCEA Level 3 (or equivalent, e.g. Bursary, High School Diploma, A-levels)
- .... Bachelor's degree
- .... Postgraduate degree or diploma
- .... Other (please give details) .....

**What is your current job status?** (Please tick all boxes that apply to you)

- .... Employed full-time
- .... Employed part-time
- .... Homemaker
- .... Retired
- .... Student
- .... Unable to work due to illness
- .... Unemployed

## **6.11 Appendix 11: Case Summaries**

### **6.11.1 Charlotte**

Charlotte (not her real name) is a 44-year-old woman who sustained a traumatic brain injury in a car crash fourteen years ago. The accident which caused her injury is the second major car crash she has experienced, the first being in the late 1980s. In both cases, her boyfriend at the time was also in the car and was killed. She is now married and has two children at primary school, while she is a full-time homemaker. She describes herself before the injury as a “very high achiever” in every area of her life and says that she hasn’t changed, although the head injury “pulls [the family] down a huge amount.”

Charlotte finds fatigue the biggest problem she has to contend with. Tasks which require extended periods of concentration are now very difficult. She also suffers from hyperacute hearing and vision: she finds loud sounds literally painful, and described wearing her sunglasses to the supermarket to reduce the visual stimulation. In order to combat fatigue while still ensuring good quality sleep at night, she finds she has to rest in the afternoons and maintain daily exercise. She has a small social circle, because she finds social interaction tiring and does not enjoy expending precious energy on small talk.

In terms of the effect of her brain injury on her family, Charlotte said her husband “hates it. With a passion. He’s a major high achiever and my head injury rules the house.” In the interests of keeping her home clean and tidy, Charlotte has removed many of the children’s toys from the living area and describes this as “unfortunately” making the children “suffer a little bit”.

Charlotte has learned strategies to deal with her condition. She is tactical about what tasks she gives her home helpers to allow her to spend time with her children as well as by herself. She has come to accept gradual, small improvements in her fitness and ability to perform tasks. She is glad that her condition is not visible, as it allows her to keep it private if she wishes. She has been pleasantly surprised at how many people have some experience of head injury within their circles of acquaintance, and she is cheered by hearing that many people do similarly “dilly” things without having a brain injury to blame it on.

Charlotte expressed her feeling of being lucky several times. She shared with great emotion that she is very thankful to be alive, and she has returned to some of the Christian practices which were part of her upbringing, in order to express her gratitude to God.

Charlotte’s narrative contains a strong theme of being determined and working hard to achieve success. Before the accident Charlotte attained success in academic, sporting and career fields: “I was a very very high achiever [...] and I just worked incredibly hard at everything I did.” Now she has turned her determination to bear on dealing successfully with her injury: “Post injury I haven’t changed, and I guess I’ve been very lucky that a lot of the skills I learnt pre injury I have pushed myself and maintained, or gone when I’ve developed other things.”

Her experiences illustrate one facet of adapting to limitations, in that she has been able to maintain her sense of identity as a high achiever while learning to accommodate changes in her physical and cognitive capacities.

### **6.11.2 Huia**

Huia (not her real name) is a 51-year-old woman who came to believe that she has face-blindness after reading about the condition on the internet some years ago. She is married and has one adult child. Huia works in a high school, which she says “is a really important part of my identity.” Environmental issues are also important to her and she helps take care of a nearby conservation area.

Huia has reflected on the relationship between her condition and her core values of caring and valuing others’ identities. She finds it hard that although she makes a great effort to learn the names of the students in her classes and to note down and remember things that are important to them, her efforts are undermined by her condition when she cannot put a name to a face. It makes her sad that she is not able to build the close relationships she would like to have. She feels that others think she has not bothered and does not care, when this is the very opposite of the truth: “I try and be very organised [...] I make the extra effort to compensate in other areas”.

She also finds that her inability to put a name to most of her students has an impact on the power that she needs to have as an authority figure. For example, having to ask other students nearby for an offender’s name made it difficult to impose discipline in the playground at lunchtime.

Learning about face-blindness was a relief for Huia, as it explained some of the difficulties she faces. She initially thought that her problem was with her memory, and that if she just worked harder she would be able to succeed. She now feels less “stupid”, more “in control of it,” and is able to make allowances for herself: for example, asking students to take the roll or to name the people in photographs for the school magazine. However, when she tried telling one of her

classes about her condition, she found that they took advantage of her and misbehaved, which she said “sapped my confidence of being able to deal with it.”

Huia described how her immediate family are not greatly affected by her condition, although they do find it annoying when she does not remember, for example, her son’s girlfriend or friends who have stayed over at their house. She finds her inability to remember such important figures in her son’s life “a bit weird, bit disconcerting.” Her husband is accustomed to explaining television shows and movies to her. However, as Huia explained: “I see it more tied with the work that I do, with a few different hats on, than so much with family stuff.”

Huia’s narrative contained a strong theme of connecting to people: how important this is for us as human beings, and how difficult it is when it is disrupted by face-blindness. Even close friends find it hard to understand the struggles caused by living with that condition. Speaking of her students, she says: “You don’t wanna burden them with stuff, but you want a bit of understanding. It’s a bit of a two-way street.”

### **6.11.3 Karl**

Karl (not his real name) is a 47-year-old man who sustained a traumatic brain injury four years ago while working as a forester. Before the accident he used to enjoy many different outdoor activities like hunting, fishing and diving – “just bloke stuff” – and was a soldier for a time. Karl is married and lives with his wife and three children, one a teenager and two under six. He has been unable to return to forestry or full-time work following his accident, so has reluctantly become the primary caregiver and homemaker for the family while his wife works.

Karl described how he is still in the process of working out how to live with his condition. He struggles with fatigue, vertigo and an inability to tolerate noise. He sometimes miscommunicates with people and loses his train of thought in conversation. He describes feeling like “someone that’s drunk [...] at every moment of the day,” and while some days and moments are better than others, the feeling never really leaves him. He has found some strategies which help but is still unsure of his capabilities and limitations. He feels that the help he needs is denied him.

Karl’s treatment by ACC and other organisations contributed significantly to the stress he experienced after the accident. His marriage has been strained since his TBI. He feels that his wife does not really understand what he is going through, and that he is unable to live up to her expectations. He finds it hard to tolerate the noise and demands of his energetic family, although this is improving. The financial pressure and worry which arise from his being unable to return to work contribute to his stress. Because his injury is invisible, Karl says that no-one sees his struggles, and he feels very alone.

Karl's narrative contains the theme of dealing with challenges to a masculine identity. Before his accident, Karl saw himself as a man who very much fit the "bloke" mould. Now, both his ability to be a 'good provider' and to enjoy masculine hobbies have been disrupted, and furthermore his desire to fight the system which contributed to this disruption has been discouraged by his wife and friends. The sense of impotence in the face of injustice is hard for him to bear.

#### **6.11.4 Murray**

Murray (not his real name) is a 68-year-old man who came to believe that he has prosopagnosia after watching a television show on the subject in March 2012. He is married and has two adult sons. Murray and his twin brother grew up on a farm, and he has been a farmer all his life. He describes himself as a “somewhat solo person or loner.” His brother tended to take the lead in social situations from a young age. Murray is not certain whether they are identical or not, nor whether his twin shares his condition. Murray believes that his father also had difficulty recognising faces, as he now remembers him saying of regularly visiting stock-truck drivers: “oh they all know me, I don’t know them.”

In terms of the impact of his prosopagnosia on his family, Murray felt that he left anything involving social interaction to his wife. She used to get frustrated with him but now that she understands the condition better she gives him “clues” to subtly tell him who people are. For Murray, the fact of being an apparently identical twin is very salient. When he sees people on the street who seem to recognise him, he doesn’t know whether it is actually him that they know, and therefore he should recognise them, or if they know his brother and are strangers to him. Therefore, when we talk about family impact, Murray is more inclined to think of the impact of his family situation on his condition, rather than the reverse.

Murray has several other mild conditions – he is colour-blind and suspects that he has some degree of ADHD – which he is inclined to link with his prosopagnosia. He wonders about the relationship between his prosopagnosia and his tendency to solitude and the fact that he doesn’t look at people’s faces much.

Murray’s narrative contains the theme of constructing a coherent identity which makes sense of his background, his prosopagnosia and his other various

issues. He has adopted the self-definition of being a loner which matches his deficits but not necessarily his desired life. It seems to me that he feels that he has adapted to life with his condition(s), but rather in the manner of an espaliered tree, forced into a certain shape to suit others.