



UNIVERSITY of LIMERICK
OLLSCOIL LUIMNIGH

"Passenger my way around"

An exploratory study of the lived experiences of driving cessation consequent to acquired brain injury in an Irish population under the age of sixty years - perspectives of ex-drivers and their spouses.

Student number: 09000079

Research Supervisor: Sherrie Buckley

Submission date: April 10th 2012

Word count: 5,247 (including abstract of 200 words)

Module Leader: Dr. Judi Pettigrew

Module name: Occupational Therapy Project 4

Module code: OT6054

Table of contents

- **Acknowledgements.....p 3**
- **Abstract.....p 4**
- **Introduction.....p 4**
- **Literature review.....p 5**
- **Methodology.....p 6**
- **Results.....p 9**
- **Discussion.....p 13**
- **Conclusion.....p 17**
- **Reference list.....p 19**
- **Appendices.....p 22**

Acknowledgments

The author wishes to express sincere gratitude to all of the participants who gave so willingly of their time and shared their stories. Furthermore, thank you to Brí who acted as gatekeeper for the project, and in particular Dr. Paul Barrett. Finally, many thanks to Sherrie Buckley for the time, advice and interest she generously invested in the supervision of this research.

"Passenger my way around"

An exploratory study of the lived experiences of driving cessation consequent to acquired brain injury in an Irish population under the age of sixty years - perspectives of ex-drivers and their spouses.

Abstract

Driving is an enabler of occupation, facilitating us to independently access our communities and to engage in meaningful occupations outside of the home. Such occupations can have many functions including productivity, social participation, recreation and care of others. This exploratory study examines the narratives of people under the age of sixty who were obliged to relinquish their role as a driver as a result of an acquired brain injury, through exploring how it affects them and their family members.

Participants were recruited through Brí, an Irish organisation providing support, information and advocacy for people with brain injuries. Employing a phenomenological methodology, eight people were interviewed using semi-structured questions; five ex-drivers and three spouses. Four themes emerged: occupational identity; emotional effect; community mobility; and separating the driving from the brain injury.

This study examines the experiences of a population who were working pre-morbidly. The experiences of this demographic group within the population of acquired brain injury survivors have not yet been acknowledged in Irish literature, a gap which this research seeks to address. It is anticipated that this small scale study will help inform current practice by raising awareness among occupational therapists about the mobility needs of people following driving cessation.

Introduction

Driving facilitates access to the community and is strongly linked with independence and ability to participate in life roles (Shope 2003). According to the American Occupational Therapy Association (2008), driving is both an occupation enabler and a meaningful occupation in itself. Within an Irish context, this is an occupation which is strongly valued, and literature suggests that driving in Western culture is associated with wellbeing, mobility and autonomy (Burns 1999; O'Neill *et al* 2000; Lossius *et al* 2010). This research was motivated by the scarcity of occupational therapy literature in the context of driving cessation following a brain injury, particularly among a population under sixty.

The impact of driving cessation on the individual is not widely explored in published literature; available literature focuses mainly on older people, with the under sixty age group studied in epilepsy and dementia literature, but very little in ABI literature.

Arising from the review of the literature, this research seeks to answer the following questions: What are the experiences of people under the age of sixty who have experienced driving cessation consequent to acquired brain injury in Ireland, and what are the experiences of their families? This exploratory study endeavours to understand the meanings that people attribute to driving and how their occupation patterns are affected by having to relinquish this instrumental activity of daily living. It also seeks to determine if driving cessation alters how people access their communities and what, if any, compensatory strategies people employ. Finally, the intention is to ascertain the effect that driving cessation has on people's families, particularly spouses.

Literature review

Driving is an activity of daily living which holds significant value and meaning for people. The acquisition of a driving licence is perceived in Western culture as an important and exciting symbol of entry into adult life (Lundqvist 2001). The ability to drive promotes feelings of autonomy, independence and competence (Bonnell 1999; Liddle *et al* 2012). A phenomenological study by Vrkljan and Polgar (2007), indicated that driving is significant for people in terms of maintaining self-esteem, personal identity and one's perceived role within the family and society, confirming Eisenhandler's findings (1990). Driving is an enabler of social participation, and is immensely convenient (Persson 1993); being able to take off in the car at a moment's notice is undeniably liberating. Driving is regarded as both an occupation and an occupation enabler (Stav 2008) and given the relationship between occupation and health, it can be concluded that the ability to drive is conducive to wellbeing for many people.

In Ireland, there is no national database for recording acquired brain injuries (ABIs) but based on the information available, Headway (2011) estimate that up to 18,000 people experience an ABI annually. ABIs can result from a variety of causes including trauma to the head, cerebrovascular accident, haemorrhage, virus, encephalitis, tumours, hypoxia or substance misuse (Collins and Dean 2002). An ABI can impact on many different areas of a person's functioning, including memory, learning, attention and concentration, information processing speed, orientation, decision-making, organisation, planning and flexibility (Brí 2011; Giuffrida *et al* 2009). These functions are all involved in driving to a greater or lesser degree (Lundqvist 2001). Johansson and Tham (2006) found that following ABI, people strive for "normality" but often do not achieve success in returning to pre-morbid occupations. Quantitative research by Coetzer *et al* (2002) found that in a cohort of rural dwellers who were working pre-morbidly, just thirty percent (30%) returned to work after ABI.

Studies which addressed driving cessation provide a valuable insight. A mixed method study of fifty six elderly ex-drivers by Persson(1993) found that a fundamental consequence of driving cessation is the significant reduction in one's independence. This sentiment was echoed by Taylor and Tripodes'(2001), who found that people who were deemed unsafe to drive reported feelings of dependency on family members for accessing social and recreational activities. Paradoxically, they also found that driving cessation of the only driver in households can cause significant transportation difficulties for family members with regard to accessing the community. In research focusing on experiences of spouses(Wall and Chard 2010), participants reported feelings of social isolation as a result of the driving cessation of a partner. In a recent qualitative study, Liddle *et al*(2012) found that driving cessation caused considerable disruption to family members with regards to participation in meaningful occupations. A multitude of consequences for the ex-driver were reported in a qualitative study by Bonnel(1999); participants reported that driving cessation resulted in decreased opportunities for socialising and visiting family, increased incidence of boredom and loneliness leading to feelings of social isolation and decreased access to medical and religious services. The disablement of spontaneity was highlighted as a frustrating barrier to engagement in meaningful occupations.

Much of the published research to date focuses on driving cessation with an elderly population(Persson 1993; Liddle *et al* 2008) or persons with dementia(Kapust and Weintraub 1992; Wall and Chard 2010) and although studies have been published exploring driving cessation due to ABI,(Lister 1999; Whitehead *et al* 2006), these too document the experiences of older drivers. A single article examining people under sixty years of age's experiences of driving cessation was identified(Liddle *et al* 2012). Considering that 75% of all ABIs are likely to occur between the ages of 15-24 years(BRÍ 2011), it is timely to explore the implications that this has for drivers under sixty and their families in Ireland.

Methodology

A qualitative methodology was chosen, as it is considered inductive and there is no set hypothesis or expected result; rather, themes emerge from the data gathered and a hypothesis is then formed, making for a completely open result, guided by the experiences recounted(Morse and Field 1998). As this is a study which explores in depth the lived experiences of people in relation to a particular event, a phenomenological approach was deemed most appropriate. Van Manen(1990) indicates the utilisation of phenomenology for the purpose of describing, analysing and making sense of human behaviour from the participant's point of view.

Eight participants in total(five ex-drivers and three spouses) were recruited through Brí; an independent charity which provides support for people who have experienced ABI and for their

families. Brí was contacted and the study aims and proposed design explained. Following discussion, Brí agreed to facilitate this project by acting as gatekeeper. Participants were chosen by Brí via purposive sampling. The researcher contacted potential participants and provided an information sheet (Appendix A) and consent form (Appendix B) to those who expressed interest. Criteria for participation are set out in Table 2. The final number of participants was eight (see Table 1).

Table 1. Basic demographic information

Pseudonym	Participation basis	Time since driving cessation
Brendan	Ex-driver	Less than 10 years
Darragh	Spouse	N/A
Deirdre	Ex-driver	More than 10 years
Eve	Ex-driver	Less than 10 years
Joan	Spouse	N/A
Kathleen	Spouse	N/A
Pat	Ex-driver	Less than 10 years
Rory	Ex-driver	More than 10 years

Consent was obtained from each participant. Ex-drivers had the option of participating in one or two semi-structured interviews, as per their preferences; if they wished to involve their family it was two interviews, if not it was one. The ex-driver had the option of participating in the research without the input of their family. However, family could not participate in the research independently of the ex-driver. Two participants engaged in one individual interview each, and three couples each participated in one joint interview and one individual interview per spouse. All participants were given the option of withdrawal from the study at any time.

Table 2. Selection, exclusion and withdrawal criteria

<p>Selection criteria</p>	<ul style="list-style-type: none"> • Persons aged eighteen to fifty nine(18-59) who experienced driving cessation as a result of an ABI.(This age bracket was chosen as there is very little published research exploring the experiences of driving cessation among a population under sixty years of age) • Partners who the ex-driver agrees can be interviewed • Persons who are fluent in the English language • Persons without a significant communication impairment • Persons without a significant cognitive impairment
<p>Exclusion criteria</p>	<ul style="list-style-type: none"> • Persons outside of the specified age bracket • Partners who the ex-driver does not wish to be interviewed • Persons who are not fluent in the English language • Persons with a significant cognitive impairment, which would considerably restrict the expression of their views • Persons with a significant cognitive impairment which may compromise their understanding of their participation in the research
<p>Withdrawal criteria</p>	<ul style="list-style-type: none"> • Participants who indicated at any time that they did not wish to continue

First the researcher conducted a face-to-face joint interview between the ex-driver and their spouse. A single prompt was initially utilised, adapted from Wall and Chard(2010);"I want you to think back to the time when you realised that you could no longer drive. Please can you describe the experience?" It was hoped that this probe would open up a discussion between the participants. It is recognised that people who have experienced an ABI often find abstract thinking difficult(Golisz 2009);therefore the researcher used cues when necessary. At the end of the session a mutually convenient time to conduct the second interview was arranged where applicable.

Before second interviews commenced, recordings were examined to identify emerging themes from the narratives.Interview schedules were compiled,ensuring that interviews stayed person centred(Appendix C and D).These were individual to each participant, guided by what arose in the first interview, and included some pre-set prompts, adapted from Lister(1999).According to Bryman(2008),the use of previously piloted questions increases reliability and validity of one's

research. Second interviews were conducted either face-to-face or by telephone. After all interviews were completed, recordings were transcribed by the principal researcher. Subsequent to transcription, member checking was facilitated either face-to-face or by post depending on each participant's wishes.

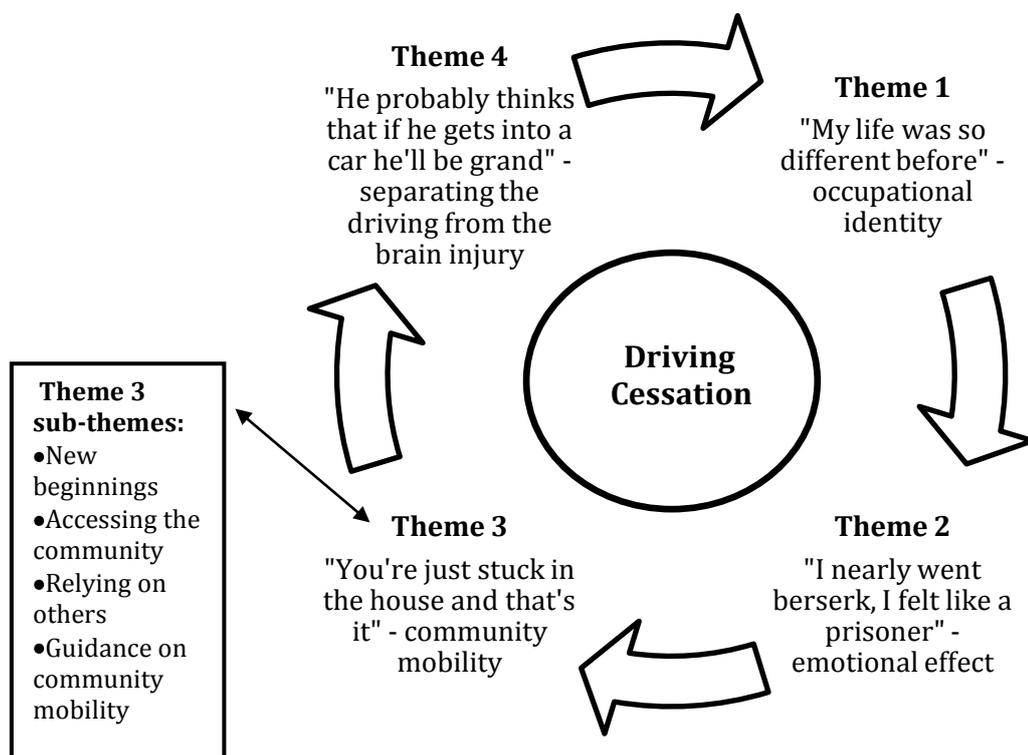
Ethical considerations

Ethical approval was granted by the Ethics Committee of the Faculty of Education and Health Sciences at the University of Limerick (approval number CTREC11-63). Potentially identifying information was changed and pseudonyms assigned to participants. Cleaned transcripts were stored on a password protected computer. While all reasonable measures have been taken to protect confidentiality, due to the small nature of the participating community absolute anonymity cannot be guaranteed. Demographic information provided is minimal for this reason.

Results

This section presents the overall findings from thematic analysis of the interviews. Four themes emerged from the data analysis: Occupational identity; emotional effect; community mobility; and separating driving from the brain injury. Pertinent themes are explored further in the discussion.

Figure 1. Diagrammatic representation of themes and subthemes



Theme 1:

"My life was so different before"-occupational identity

Work cessation was a common concern amongst participants, touching four out of five of ex-drivers. Eve illustrates the impact this restriction has: *"to get working I need to drive...its very hard if you've spent your entire life working to suddenly not have a job, not have prospects"*. She explains the implications of this role loss: *"...I've always worked and even the social aspect of working.....I like the challenge of it.....I've always loved working so I miss that very much"*. Furthermore, both individuals and spouses describe the negative repercussions that driving cessation has on their activities of daily living. Outings such as *"going to weddings.....or sports...."* were affected for Pat. Brendan explained how his weekly routine now differs, *"I was working 5 or 6 days a week....I'd always like to go for a pint on Friday night"*. Kathleen described how she *"was going back to school again and all that and I'd to give it all up.....your life is not your own anymore"*. Unsurprisingly, participants felt that this altered sense of personal identity predominantly impacted negatively upon their psychological wellbeing, which is further explored in Theme Two.

Theme 2:

"I nearly went berserk, I felt like a prisoner"-emotional effect

The majority of participants identified strong feelings of frustration and reduced autonomy; *"a neighbour of mine brings me you know, down the town....that's very frustrating.....to say that I couldn't do that on my own"*-Pat. These feelings were echoed by spouses, having restrictions imposed on their own activities and schedules resulting from being the primary driver. Darragh found the reduced leisure time challenging and loss of spontaneity at odds with his nature *"it's tiring and it's stressful....you know, it's not resentment or anything but you just.....you just feel pressure"*. All spouses pinpointed increased time spent on the road as being responsible for reducing their own opportunities for engagement in meaningful occupation; *"I was more like a taxi driver than anything else"*-Kathleen.

Conversely, one participant reported that driving cessation does not majorly impact on his way of life or sense of independence: *"I suppose it's a bit....restrictive in the wider sense.....I can't say it's really sort of bugging me hugely"*-Rory.

A common analogy was that of incarceration, used by both spouses and individuals to illustrate the situation of those who experienced driving cessation. Darragh, describing his wife's situation, remarks *"It's really, for want of a better word.....a form of imprisonment"*. This predicament posed

significant logistical difficulties for most individuals, with compensatory strategies identified in Theme Three.

Theme 3

"You're just stuck in the house and that's it"-community mobility

New beginnings

Interestingly, in all participating families, another member had either learned to drive or was in the process of it in the period since driving cessation. Kathleen was required to learn to drive and described how time consuming it was: "*I was taking driving lessons for two years*". That being said she was visibly proud of this accomplishment.

Relying on others

Family provided the primary means of transport, although this had drawbacks. Eve highlights a less obvious impact of her driving cessation while describing her relationship with her daughters "*...little days out that I would often have with the girls, we don't really do that now.....so it's not the same relationship, mother and daughter...*". Darragh, referring to bringing his wife to her mother's house, explains the inconvenience resulting from her dependence on him "*sometimes I would stay but I thought maybe it would be good for her to talk to her Mum so again, a two way trip*". Others were less inconvenienced by this dependence, particularly Rory: "*....I'm happy enough leaving the driving to others.....you know, passengering my way around*".

Accessing the community

Experiences with public transport were mixed. Rory describes his village as being well served and public transport meeting his needs "*I can just wander down to the bridge and hop on a bus to get into town*". In most situations however, the data suggests that people don't have viable alternatives. "*.... 'twas the worst thing in the world to me, 'cause I knew well I couldn't get around if I couldn't drive*" -Deirdre.

It arose that even if public transport exists in an area, it's not necessarily suitable for this population due to cognition difficulties. Similarly, walking is not an option: "*If I go out, I'll either forget where I'm going or forget my way back....there really are no alternatives...*" -Eve. This family is now considering moving house into the town, such is the impact that driving cessation has on family life. Eve regretfully admits "*it is largely because I'm not driving*". This finding highlights the less obvious barriers to community mobility.

Guidance on community mobility

A common experience was that driving and community mobility was not addressed with participants after their ABI, leaving them uncertain as to their situation. Rory voluntarily relinquished his licence, having decided that he probably should not be driving following his ABI *"I just thought....it was the thing to do, to you know....send my driving license in; nobody asked me to"*. Eve acknowledges that her ability to drive is now altered, but is frustrated at the lack of information available *"there's nothing that I'm aware of in place to say that there's a certain period where you shouldn't drive....I don't know if there is a test available, I don't know of anyone who does know, I asked lots of people and no-one seems to have an answer"*. Despite being treated in one of Ireland's larger hospitals, Eve reports that at no stage did any healthcare professional address driving.

Theme 4

"He probably thinks that if he gets into a car he'll be grand"-Separating the driving from the brain injury

Joan articulated a pertinent issue: the complexity of trying to separate the driving from the ABI itself, a common thread running through the various narratives. *"I know they're linked and I know that driving....does stop him from getting anywhere, but because of his brain injury he can't go anywhere anyway"*.

Eve also alluded to the complex overlap between the driving and ABI and how difficult it can be to see which is at the root of the issue. She admits that the ABI poses additional problems that affect community mobility *"because of memory and concentration problems I can't just be dropped in town to wander around"*.

The findings of this study expose some interesting revelations. Occupational identity, the emotional effect of driving cessation, community mobility and separating the driving from the brain injury have all emerged as key themes. The narratives of the ex-drivers and spouses provide an insight into the significance that driving carries, and the impact of driving cessation on their everyday occupations. These results are particularly interesting given the age group of participants.

Discussion

Having presented the key findings of the data, the next section will focus on the implications of the results, both for the ABI population and occupational therapy research and practice. Several significant issues were identified during analysis of themes. Overall, findings confirm the importance of driving as an enabler of occupation, and the difficulty of adapting to driving cessation.

Identity

Participants spoke about personal identity and how, for them, the ability to drive is intrinsically linked with sense of self. This was identified both in terms of how they now view themselves, and the chosen occupations by which people previously defined themselves. Many of these meaningful occupations are now inaccessible as a consequence of driving cessation. This experience also applies to spouses, who found that increased time spent driving meant less time for other occupations. One spouse was returning to education at the time, which she had to forsake as a result of the extra driving, adding that she felt more like a taxi driver than anything else. The concept of identity being influenced by participation in occupation was exemplified in Vrkljan and Polgar's research (2007), where it was illustrated that disruption to occupation patterns can have negative effects on one's identity. It is suggested that maintaining a sense of self is closely linked with the ability to engage in meaningful occupations (ibid). Decreased opportunities for participation can lead to reduced quality of life and occupational alienation, which has been defined by Townsend and Wilcock (2004) as dearth of meaning or purpose in everyday occupations. This concept was poignantly illustrated in some comments made by participants, where people spoke about feeling useless and sitting around the house trying to fill time.

Related to identity, role loss and role reversal were also suggested. Although not the primary driver in every instance, each of the ex-drivers drove on a regular basis pre-morbidly: four out of five daily for work. The driving cessation had far reaching consequences; each of these ex-drivers had to relinquish working outside the home, a loss which was felt regardless of how long ago the event occurred. This is a significant role loss, one discussed extensively in the literature (Eisenhandler 1990; Shope 2003; Liddle *et al* 2012). Benefits of working outside the home are identified by Jahoda (1981) as imposing time structure on the day, encouraging activity, allowing individuals increased status, and social contact with peers. The same study concluded that loss of time structure has the greatest effect on psychological wellbeing of people who cease working, a consequence which has been indicated here.

This study highlighted for participating families that since the time of driving cessation another member had learned to drive or was in the process of doing so. It was found that the likelihood is that the reduced number of drivers in the household accelerated this process. This feature was not found to

be reported in any published research, however while it is worth noting, due to the small sample size it is not generalisable. This new finding merits further research to ascertain its validity.

Driving or ABI?

Participants highlighted how driving cessation altered their routines and how sometimes it is difficult to untangle the intertwined issues of ABI and driving cessation in relation to community mobility. This finding matches results described by Liddle *et al*(2012), where it is acknowledged that driving cessation following ABI has additional challenges. In collecting narratives for this exploratory study, the researcher heard how one spouse had not fully considered the issue of driving, seeing it as secondary to other problems her husband experienced. She explained that it's not as simple as hopping into the car and going somewhere, because due to her husband's memory and visual impairments he cannot be on his own in unfamiliar environments. This participant felt that if driving was the sole issue, this could be overcome by hiring a driver if necessary; she didn't consider the driving cessation to be the main problem for her husband, given his other difficulties. Conversely, he described driving cessation as a big deal and added that the resulting loss of his independence was devastating for him, having a significant effect on his self identity. This led to a pivotal reflection for the researcher- is this a lack of insight on the man's part, a well documented consequence of ABI?(Lucas and Fleming 2005). If the occupational therapist is practicing in a truly client centred manner, focusing on the subjective experience of the individual, then if the client regards something as a huge problem for them, it is a huge problem for them regardless of insight.

Community mobility

One could easily assume that ex-drivers could use public transport as a compensatory measure, but this carries a host of difficulties, including poor availability of public transport in rural Ireland. The Central Statistics Office(2009) estimate that more than half of people living in rural Ireland experience difficulty in accessing public transport. Participants described how cognitive issues and sensory disturbances make the prospect of travelling by public transport a stressful, difficult experience, correlating with the findings of Mukherjee *et al*(2006). These difficulties include short-term memory problems, reduced attention and concentration, hypersensitivity to noise, visual impairments and poor thermoregulation. Added to this for many people is physical disability from ABI; the inaccessibility of much public transport in Ireland is recognised as a significant barrier to social participation for people with reduced mobility(Citizens Information Board 2009). A valid point was raised by one participant; given the difficulties sometimes encountered trying to learn new things following an ABI(Giuffrida *et al* 2009), if a person was not pre-morbidly accustomed to taking public transport, this unfamiliar experience could prove virtually impossible. All in all, public transport was deemed a satisfactory

alternative method of accessing the community by just one participant. This finding corresponds with Stav(2008) who concluded that using public transport carries considerable challenges for older persons. In Ireland currently, Dublin Bus employs travel assistants to aid anybody who wants to use the bus independently but according to the Citizen's Information Board(2008) these are the only organisation in Ireland known to offer this service. More recent information was not available. Stav(2008) notes that there is limited evidence to support the use of these initiatives.

Different perspectives

While four out of five participants narrated experiences congruent with current literature(Liddle *et al* 2012), one person offered an alternative perspective. In contrast to other participants, this individual felt that driving cessation had minimal impact on his occupational performance. Interestingly, this participant's driving cessation occurred at a time when he was embarking on a lifestyle change. He subsequently moved to a village well served by public transport, and built up a network of friends who drive him around. Although this was not explored, one may hypothesise that this individual had his driving cessation in mind when choosing a neighbourhood, so as to ensure access to his community in the absence of being able to drive.

Need for information

Contrary to this participant's experience, all other ex-drivers recalled feeling frustration at the realisation that they could no longer drive. Furthermore, lack of information about ABIs and driving was identified as being a substantial source of anxiety and uncertainty. Driving is an area in which occupational therapists have a strong role as distinct from other healthcare professionals. According to Liddle *et al*(2012), occupational therapists are in an ideal position to address community mobility and fitness to drive with clients because of their expertise in, and holistic focus on, life roles and quality of life. Participants reported that following ABI, driving was never addressed with them, and they were unsure whose role this should be. In one case a participant repeatedly tried to get information about how to go about getting assessed for fitness to drive, yet invariably encountered obscurity. This finding echoes sentiments expressed in Scannell and Buckley's research(2011) whereby young adults with epilepsy reported frustration at lack of information and mixed messages from healthcare professionals. Although both of these studies are Irish, parallel frustrations have been encountered in an Australian context, as Liddle *et al*(2008) discovered; the authors hypothesise that this may be due to health professionals regarding driving as lower priority than other rehabilitation needs. Unsurprisingly, an occupational therapist led driving cessation support group reported by Gustafsson *et al*(2011) was found to positively impact on ex-drivers perceptions of driving cessation. No such intervention has been identified in an Irish context, however this may be partially due to

ambiguity regarding fitness to drive. In Ireland to date, no legislation regarding the procedures required on the assessment of fitness to drive or guidelines on the role of occupational therapists in the process exists (Road Safety Authority 2010). Nevertheless, with the establishment of an Office for Traffic Medicine and having an occupational therapist in its working group (Royal College of Physicians of Ireland 2012), hopefully change is afoot.

Contribution to current knowledge

This small scale research project adds to the knowledge base in several ways. Primarily, just one other study has been found (Liddle *et al* 2012) which explores the experiences of a population under sixty, who were all working at the time of ABI. At the time this research was undertaken, there was no published research on this specific population. In an Irish context this exploratory study is unique. "Passenger my way around" is also distinctive in that it examines the perspectives of the ex-driver and their spouses, both together and separately. It complements literature currently available and highlights the domain of community mobility as an area which needs further consideration by a number of parties. Additionally these findings support existing literature in emphasising the unsystematic manner in which driving is addressed in Ireland.

Implications for occupational therapy

Despite being an exploratory study, this research reveals essential messages for the profession of occupational therapy. Publication of this research will raise awareness about the importance of driving as an occupation and as an occupation enabler. Occupational science has informed us about the relationship between meaningful occupation and wellbeing and now it is our responsibility to weave this philosophy into our clinical interactions. Driving cessation and fitness to drive are topics which need to be addressed in policy, but unless occupational therapists from diverse clinical areas become involved in the discourse, this issue will continue to go unaddressed for many clients. Community mobility is a key area in which occupational therapists have a strong advocacy role, yet too often this is neglected, or at best, assumed that the issue solely affects our clients. When examining the multifaceted contexts of our clients and their families, it is rarely just one person affected by driving cessation and it is our duty, as occupational therapists, to understand clients and their families in the context of their everyday roles and routines.

Limitations

Several limitations emerged from this small scale study. Although Dickerson (2006) asserts that the number of participants is considered less important than the richness of the data and the quality of analysis in qualitative research, the relatively small sample size may mean that the findings are not

generalisable to the wider Irish population. Purposive sampling is recognised as a desirable method in exploratory studies (Adler and Clark 2011); however it may add unintentional bias.

Recommendations

This research endeavours to emphasise the relevance of occupational therapy with regards to the domain of driving and community mobility. The findings of this study strongly suggest that the role of the occupational therapist needs to be delineated and its contribution highlighted to individuals who may be encountering driving cessation. In this way, appropriate pathways can be implemented for care delivery along with referral systems from our multi-disciplinary colleagues. The role of occupational therapists in primary care and their potential involvement in community mobility should be considered, as should new findings. Occupational therapists need to ensure that they have an awareness surrounding policy, legislation and transport options in Ireland. It is hoped that these findings will encourage further research into this under-researched area as several directions for future research have been highlighted.

Conclusion

Community mobility is an essential aspect of human participation, enabling engagement in meaningful occupations outside of the home (Stav 2008). The work of Vrijkkan and Polgar (2007) shows that as individuals navigate life's path they engage in a variety of occupations, including driving, that are meaningful and/or necessary for continued health, wellbeing and quality of life. Driving is seen in Western cultures as being representative of independence and autonomy (Bonnell 1999) and is both an occupation and an enabler of occupation (Stav 2008). Literature informs us that driving cessation can have a negative impact on quality of life, self-esteem, perceived self-efficacy and ability to fulfil meaningful roles (Liddle *et al* 2008; Eisenhandler 1990). Furthermore, evidence suggests that ABIs can bring immense challenges (Johansson and Tham 2006); according to Brí (2011), cognition, visual perception, physical function and personality can all be affected.

This exploratory study used a phenomenological method of inquiry to gather narratives of persons under the age of sixty years who live with driving cessation consequent to ABIs. In order to achieve a rounded perspective, ex-drivers and their families were invited to participate. Eight people contributed through semi-structured interviews; five ex-drivers and three spouses.

This research has indicated that for adults under sixty, driving cessation has significant consequences. Four themes were identified: "My life was so different before"-occupational identity; "I nearly went berserk, I felt like a prisoner"-emotional effect; "You're just stuck in the house and that's it"-community mobility; and "He probably thinks that if he gets into a car he'll be grand"-separating the driving from the brain injury. Subthemes emerged from one theme. Results suggest that driving

cessation impacts on one's sense of independence, self-efficacy, identity, participation in meaningful activities, fulfilment of occupational roles, and ability to access the community. Similarly, this transition was shown to have a considerable effect on the roles and routines of family members, in particular spouses. For the ex-drivers, this is compounded by the presence of feelings of imprisonment, frustration, helplessness and boredom that accompany sudden driving cessation. For spouses, an increased burden of driving, reduced spontaneity and frustration at their partner's situation adds to the difficulty of everyday life.

Overall, findings correlated with the sparse literature body. Identity was found to be fundamentally altered by driving cessation, attributable to the barriers encountered to performing formerly valued roles and occupations. This negative effect was experienced by ex-drivers and spouses alike. Another finding of significance was the difficulty of attempting to separate the driving from the ABI. This dimension illustrates the complexity of human nature and merits further consideration- while both strands of participant drew attention to this, limited evidence was found in the literature. An element which the author found surprising was the radically different perspective of one participant who didn't experience driving cessation as a negative life transition. This encourages one to reflect on the different meanings that we, as occupational beings, attribute to various roles. Finally, the provision of information, and initiation of dialogue around community mobility by healthcare professionals was shown to be unsatisfactory within this sample, a finding confirmed by Liddle *et al*(2012).

This research adds to the literature bodies surrounding driving cessation, ABIs and occupational identity respectively. Additionally it highlights the scope of occupational therapy's role in community mobility and provides important recommendations. Hopefully through dissemination of this research at occupational therapy conferences and brain injury conferences further interest in this type of research will be stimulated, giving greater opportunity for people affected to have their voices heard and to have barriers to participation acknowledged and hopefully reduced in time.

It is anticipated that future publication of this research will benefit the wider community of ABI survivors and their families, by indirectly influencing policy formation and service planning in Ireland.

Reference list

- Adler, E. S., & Clark, R. (2011) *An Invitation to Social Research: How it's Done*. Belmont, CA, Wadsworth
- American Occupational Therapy Association. (2008) 'Occupational therapy practice framework: Domain and process', *American Journal of Occupational Therapy*, 62, 625-683.
- Bonnel, W. B. (1999) 'Giving up the car: Older women's losses and experiences', *Journal of Psychosocial Nursing*, 37(5), 10-15.
- Burns, P. C. (1999) "Navigation and the mobility of older drivers", *Journal of Gerontology: Social Sciences*, 54, 49-55.
- Brí (2011) *Information Sheet - Facts about Acquired Brain Injury* [Online], (Brí), Available from:<http://www.briireland.ie/bri/Files/Information%20sheet%20brain%20injury%20facts.pdf> [accessed 10 April 2011].
- Bryman, A. (2008) *Social Research Methods*, 3rd ed., Oxford: Oxford University Press.
- Central Statistics Office (2009) 'Survey on Income and Living Conditions (Housing Module) 2007' (online), available: <http://www.cso.ie/releasespublications/documents/silc/2007/silchousing2007.pdf> (accessed 09 Jan 2012).
- Citizens Information Board (2008) '*Factsheet 6: Transport and travel for people with disabilities*' (online), available:
http://www.citizensinformationboard.ie/publications/providers/factsheets/publications_disability_factsheet6.html (accessed 12 Feb 2012).
- Citizens Information Board (2009) '*Getting There: Transport and Access to Social Services*', (online), available http://www.citizensinformationboard.ie/downloads/Getting_There_Report_2010.pdf (accessed 18 March 2012).
- Coetzer, B. R., Hayes, N. M., Du Toit, P.L. (2002) 'Long-term employment outcomes in a rural area following traumatic brain injury', *Australian Journal of Rural Health*, 10 (4), 229-232.
- Collins, C. and Dean, J. (2002) 'Acquired brain injury' in Turner, A., Foster, M. and Johnson, S. E., eds., *Occupational therapy and physical dysfunction: Principles, skills and practice*, Philadelphia: Churchill Livingstone Elsevier.
- Dickerson, A. E. (2006) Securing Samples for Effective Research Across Research Designs, in Kielhofner, G., *Research in Occupational Therapy: Methods of Inquiry for Enhancing Practice*, United States of America: F.A. Davis Company, 515-529.
- Eisenhandler, S. A. (1990) 'The asphalt identikit: Old age and the driver's license', *The International Journal of Aging and Human Development*, 30(1), 1-14.
- Giuffrida, C. G., Demery, J. A., Reyes, L. R., Lebowitz, B. K., Hanlon, R. E. (2009) 'Functional skill learning in men with traumatic brain injury', *American Journal of Occupational Therapy* 63, 398-407.

- Golisz, K. (2009) *Occupational Therapy Practice Guidelines for Adults with Traumatic Brain Injury*, Bethesda, MD: AOTA Press.
- Gustaffson, L. A., Liddle, J. M., Lua, S., Hoyle, M. F., Pachana, N. A., Mithchell, G. K., McKenna, K. T. (2011) 'Participant feedback and satisfaction with the UQDRIVE groups for driving cessation'. *Canadian Journal of Occupational Therapy*, 78 (2), 110-117.
- Headway (2011) 'Brain Injury - The Basics', available: <http://www.headway.ie/information/> [accessed 28 Feb 2012].
- Jahoda, M. (1981) 'Work, employment, and unemployment: Values, theories, and approaches in social research', *American Psychologist*, 36(2), 184-191.
- Johansson, U. and Tham, K. (2006) 'The meaning of work after acquired brain injury', *American Journal of Occupational Therapy*, 60(1), 60-69.
- Kapust, L. R. and Weintraub, S. (1992) 'To drive or not to drive: Preliminary results from road testing of patients with dementia', *Journal of Geriatric Psychiatry and Neurology*, 5, 210-216.
- Liddle, J., Turpin, M., Carlson, G. and McKenna, K. (2008) 'The needs and experiences related to driving cessation for older people', *British Journal of Occupational Therapy*, 71(9), 379-388.
- Liddle, J., Fleming, J., McKenna, K., Turpin, M., Whitelaw, P. and Allen, S. (2012) 'Adjustment to loss of the driving role following traumatic brain injury, a qualitative exploration with key stakeholders', *Australian Occupational Therapy Journal*, 59, pp. 79–88. Available from: doi: 10.1111/j.1440-1630.2011.00978.x, [Accessed 02 April 2012]
- Lister, R. (1999) 'Loss of ability to drive following a stroke: The early experiences of three elderly people on discharge from hospital', *British Journal of Occupational Therapy*, 62(11), 514-520.
- Lossius, R., Kinge, K. O. and Nakken, K. O. (2010) 'Epilepsy and driving: considerations on how eligibility should be decided', *Acta Neurology Scandinavia*, 122(190), 67-71.
- Lucas, S. E. and M. Fleming, J. (2005) 'Interventions for improving self-awareness following acquired brain injury', *Australian Occupational Therapy Journal*, 52, pp. 160–170, Available from: doi: 10.1111/j.1440-1630.2005.00485.x [Accessed 05 April 2012].
- Lundqvist, A. (2001) *Cognitive functions in drivers with brain injury: Anticipation and Adaptation*, unpublished thesis The Swedish Institute for Disability Research.
- Morse, J. M. and Field, P. A. (1998) *Nursing Research: The Application of Qualitative Approaches*, Cheltenham: Stanley Thornes.
- Mukherjee D, Heller W, Alper J. (2001) 'Social and institutional factors in adjustment to traumatic brain injury', *Rehabilitation Psychology* [Online], 46(1), Available from: PsycARTICLES, Ipswich, MA, [Accessed 24th March 2012].
- O'Neill, D., Bruce, I., Kirby, M. and Lawlor, B. (2000) 'Older drivers, driving practices and health issues', *Clinical Gerontologist*, 22, 47-54.

- Persson, D. (1993) 'The elderly driver: Deciding when to stop', *The Gerontologist*, 33(1), 88-91.
- Road Safety Authority (2010) '*Medical Aspects of Driver Licensing*' available <http://www.rsa.ie/Documents/Licensed%20Drivers/Medical%20Aspects%20of%20Driver%20Licensing.pdf> (accessed 04 April 2012)
- Royal College of Physicians of Ireland (2012) '*National Programme Office for Traffic Medicine*', available <http://www.rcpi.ie/Collegestructure/Pages/TrafficMedicineHomePage.aspx> (accessed 04 April 2012).
- Scannell, B. and Buckley, S. (2011) *When driving takes a back seat to epilepsy: The meaning of driving for young adults with epilepsy*, unpublished thesis (M.Sc.), University of Limerick
- Shope, J. T. (2003) 'What does giving up driving mean to older drivers, and why is it so difficult?', *Generations*, 27(2), 57-59.
- Stav, W. B. (2008) 'Occupational therapy and older drivers: research, education, and practice', *Gerontology & Geriatrics education*, 29 (4), 336-350.
- Taylor, B. D. and Tripodes, S. (2001) 'The effects of driving cessation on the elderly with dementia and their caregivers', *Accident Analysis and Prevention*, 33, 519-528.
- Townsend, E., & Wilcock, A. (2004). Occupational justice and client-centred practice: A dialogue-in-progress. *Canadian Journal of Occupational Therapy*, 71, 75-87
- Van Manen, M. (1990) *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy*, Ontario: State University of New York Press.
- Vrkljan, B. H. and Polgar, J. M. (2007) 'Linking occupational participation and occupational identity: An exploratory study of the transition from driving to driving cessation in older adulthood', *Journal of Occupational Science*, 14(1), 30-39.
- Wall, O. and Chard, G. (2010) 'It's complicated to get someone off the road-spouses' experiences of driving cessation', *The Irish Journal of Occupational Therapy*, 38(1), 14-20.
- Whitehead, B. J., Howie, L. and Lovell, R. K. (2006) 'Older people's experience of driver licence cancellation: A phenomenological study', *Australian Occupational Therapy Journal*, 53(3), 173-180.

Appendices

Appendix A - Participant Information Sheet

Appendix B - Consent form

Appendix C - Sample of interview prompt for ex-driver

Appendix D - Sample of interview prompts for spouse

Appendix A



UNIVERSITY of LIMERICK
OLLSCOIL LUIMNIGH

Information Sheet

Introduction

You are being invited to take part in research investigating the impact of driving cessation for people who have experienced an acquired brain injury, and their families.

In our everyday life, driving enables individuals to participate in meaningful occupations and to be active members in their communities.

Occupational Therapy research focuses on the activities that people find meaningful to them in order to inform therapists and enable them to facilitate client's participation in everyday life.

The focus of this study is on your experience of your own driving cessation or that of a family member and the meaning of this event for your daily functioning, whether it was yourself or a family member who stopped driving.

Procedures

- This research will involve you participating in two tape recorded interviews of approximately 45-60 minutes each.
- The first interview will be done jointly with a member(s) of your family, whereby I will ask you both about your memory of the time when the change occurred
- The second interview you will do on your own, another day, and you will be asked questions about the meaning of driving in your life, the impact of driving cessation on your daily routine and the supports available to you in overcoming driving cessation.
- I will also carry out an individual interview with the same member(s) of your family, who will be asked to tell me about the impact that the driving cessation had on their daily routine.
- A typed summary of your interview will be sent to you two weeks following the interview for you to check. If you wish you can telephone or send written feedback on this summary.

Confidentiality

All of the information you provide will be kept confidential at all times. Your name or identifying information about you will not be disclosed at any time during this research and will not be reported in any publications arising from the research.

Voluntary Participation

Taking part in this study is completely voluntary and you are completely entitled to refuse to participate

If you wish to participate please write your name and telephone on the attached expression of interest form and post it in the attached envelope

Further Information

If you require further information please contact me

Aideen Gavin
Student, MSc Occupational Therapy, University of Limerick
09000079@studentmail.ul.ie

Tel: 061 233628

If you have any concerns about this study and wish to contact someone independent, you may contact

The Chairman of the University of Limerick
Research Ethics Committee
C/ O Vice President Academic and Registrar's Office
University of Limerick
TEL: 061 202022

Appendix B



UNIVERSITY of LIMERICK
OLLSCOIL LUIMNIGH

Consent form

I _____ know that I am being invited to participate voluntarily in a research study about how stopping driving affects my life and my families lives.

I have read and understand the Information Sheet

I have been informed by the researcher, Aideen Gavin that

- I do not have to join the study and I am free to refuse to participate
- If I agree to take part I can stop at any time if I want to
- My participation and answers will be kept private at all times. I will not be identified nor will any identifiable information about me be reported in any publication arising from this research

I UNDERSTAND THAT BY SIGNING THIS FORM, I AM AGREEING TO TAKE PART IN THE STUDY DESCRIBED ABOVE

I have received two copies of this form, one for me to keep and one to return to the researcher, Aideen Gavin, MSc Occupational Therapy Student, University of Limerick (TEL 061 233628)

Signature of Participant Date

Signature of Researcher Date

I give permission for my family to take part in this interview

I do not give permission for my family to take part in this interview

Appendix C

Sample of interview prompts for ex-driver:

- In our last conversation you mentioned several aspects of your life that have been changed as a result of not being able to drive, and I'm just going to ask you to tell me a little bit more about a few of those things.....so the first one was work.....can you elaborate a bit more on how not being able to drive has impacted on this?
- And how does not being able to work affect you?
- What came across quite strongly in your first interview as well was the sense of social isolation that you're kind of experiencing as a result of not being able to drive.....can you tell me a bit more about that?
- You mentioned as well that your independence has been compromised.....can you tell me a bit more about that?
- You mentioned that you used to drive to the gym and to socialise.....how, if at all do you access these activities now?
- You talked about getting the train occasionally...is this the only public transport that you would use?
- Do you think that the loss of your freedom to drive has affected the way that you feel about yourself?
- Aside from the functional aspect of driving, like getting from A to B, do you actually miss driving in and itself as an activity?

Appendix D

Sample of interview prompts for spouse:

- Just to start, during our last conversation you said that as (ex-driver) has a few difficulties, for (ex-driver) it's different not being able to drive from somebody who is in the full of their health. Can you elaborate a bit on that?
- You also mentioned that you become responsible for more of the family driving as a result of (ex-driver) not being able to drive.....
- And tasks which you once shared, for example shopping or doing other jobs outside the home, do they all fall to you now?
- Do you find that difficult, having to be responsible for everything outside the home?
- Both yourself and (ex-driver) mentioned that (ex-driver)'s independence has been affected by not being able to drive, can you explain this a bit to me in your own words?
- Has (ex-driver)'s non-driving, in your opinion, had an impact on anyone else besides yourself and (ex-driver)?
- Would there have been anyone else, extended family that (ex-driver) would have visited or who would have been reliant on (ex-driver) for transport?
- Have any hobbies or activities of your own suffered as a result of (ex-driver) not driving?
- Have there been times that (ex-driver) not driving has affected your work, like having to bring (ex-driver) to appointments and that?