

Not If, But when: A Communication-Based Intervention for Driving Cessation

Paige Moorhouse^{1,2*} and Laura Hamilton¹

¹Geriatric Medicine Research Unit, Capital District Health Authority & Dalhousie University, Halifax, NS, Canada

²Division of Geriatric Medicine, Capital District Health Authority & Dalhousie University, Halifax, NS, Canada

Abstract

Background: Within 5 years of diagnosis, approximately 50% of those with dementia will be involved in a motor vehicle collision (MVC). Caregivers play a major role in the driving cessation process however, there is often a delay between the recognition of driving deficits and the initiation of the driving cessation process.

Methods: Quantitative before and after study of a knowledge translation strategy that included a public service announcement (PSA) and website.

Results: Approximately half of follow-up respondents viewed the PSA and 32% were aware of the www.notifbutwhen.ca website. Caregiver self-report of taking steps to promote driving cessation did not change between baseline and follow-up, however, at follow-up there was a trend towards rural caregivers being more likely to have concerns about driving ($x^2=3.2$, $P=0.08$) and to have spoken with a doctor about their concerns ($x^2=2.8$, $P=0.09$).

Conclusion: There is a persistent knowledge need on the part of caregivers for more information and dialogue with health care providers regarding the dangers of driving and dementia.

Keywords: Dementia; Driving; Public awareness; Driving cessation; Knowledge translation

Introduction

Alzheimer's disease (AD), the most common form of dementia (approximately 64% of all cases [1-5]), is a progressive neurodegenerative disease which leads to behavioural changes and functional impairment; including changes in driving ability [6-8]. Approximately 25 to 30% of individuals with AD continue to drive after diagnosis [2,9-11]. Due to population aging, the number of older drivers with dementia is expected to triple in the next 25 years, so that by 2030, one in every 25 drivers over the age of 65 will have dementia [12]. Due to impaired attention and judgement [13,14], co-ordination [15] and reaction time [16], mild to moderate AD is associated with a risk of motor vehicle crash (MVC) up to eight times that of non-demented older adults. MVCs in all older adults (including those with dementia) are associated with significantly increased risk of injury and death, not only to the driver, but also passengers and third parties [17,18].

Driving cessation may result in cognitive decline, depression, isolation, and caregiver burden [19-21]. Therefore, a delicate balance must be sought between enabling drivers who are medically fit to continue driving, while ensuring that cessation occurs before the safety of the driver, passengers, or third parties is compromised.

Strategies for influencing cessation can be divided into imposed strategies, in which direct actions (e.g., license revocation) are taken to prevent driving, or involved strategies, in which the driver is actively involved in the decision making process [22]. Involved strategies are widely preferred over imposed strategies by caregivers, health professionals, and older drivers with dementia [22,23]. Furthermore, imposed strategies have not been associated with consistent reductions in MVC fatalities [22,24,25].

Driving cessation is often unplanned and the decision making process that informs driving cessation is not well- understood [26]. However, several key determinants have been studied. Primary determinants for the driver include risk perception and knowledge. Individuals with AD rarely stop driving voluntarily [4]. Even healthy older adults may perceive themselves to be above average drivers for their age, regardless of current driving test performance or history

of MVCs [20,21,27,28]. As dementia progresses, early loss of insight and declining complex reasoning skills may augment the distortion of risk perception [29] and impede self-imposed driving cessation [30]. Knowledge of alternative means of transportation also appears to be a determinant of openness to driving cessation in dementia [23,31].

Caregivers and other family members play a major role in the cessation process [2,3], however, there is often a high-risk delay between their recognition of driving deficits and their initiation of the cessation process [4,22]. The significant lag may be due to a lack of knowledge about dementia and its impact on driving, and fear over increased burden of care [32]. Caregivers may respond to changes in driving ability by acting as a "willing co-pilot" a strategy that has not been associated with reduction in MVC risk.

Physician advice is a frequently cited determinant of driving cessation [2]. However, primary care physicians (PCPs) often lack confidence in assessing driving fitness in older adults [33,34] and in those with dementia [35,36]. Performance-based measures are recommended for individual skill assessment [37-39] however there are currently no validated in-office tests for predicting fitness to drive in dementia [40]. Physicians have reported their reluctance to address the issue of driving safety, sometimes avoiding the issue in an attempt to protect the physician-patient relationship [35,36]. Physicians require further training and education on the assessment of driving safety, collaboration with other health professionals who may contribute to assessment of driving safety (e.g., occupational therapists), strategies

***Corresponding author:** Paige Moorhouse, Division of Geriatric Medicine, Dalhousie University, 1421-5955 Veterans' Memorial Lane, Halifax, NS, B3H 2E1 Canada, Tel: (902) 473-4995; Fax: (902) 473-1308; E-mail: paige.moorhouse@cdha.nshealth.ca

Received January 04, 2015; Accepted May 27, 2015; Published May 29, 2015

Citation: Moorhouse P, Hamilton L (2015) Not If, But when: A Communication-Based Intervention for Driving Cessation. J Gerontol Geriatr Res 4: 215. doi:10.4172/2167-7182.1000215

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for achieving cessation, resources for families and patients, and local reporting requirements and procedures [35,36,38].

Previous work by our group examined PCP self-reported barriers to assessing fitness to drive in individuals with dementia, and resulted in the creation of practical resources for all health care professionals and caregivers [35,36]. An evidence-based public awareness campaign promoting driving cessation was designed with caregivers as the target audience. In this study, we aimed to evaluate the effectiveness of this public service awareness (PSA) campaign at increasing caregiver participation in the driving cessation process.

Methods

Phase one

Examination of the determinants of driving cessation

Stakeholder consultation: Three consultation sessions were held with local stakeholders including Regional Police, the Provincial Alzheimer Society, primary care physicians, occupational therapists from the local Driving Assessment program, and representatives from the Medical Fitness Department of the provincial Registry of Motor Vehicles. The purpose of these sessions was to encourage stakeholder involvement in the campaign and to gain insight from professionals who are affected by driving and dementia. Stakeholders were presented with the proposed intervention and asked to provide feedback and insight on the campaign, as well as current stakeholder perceived challenges barriers to driving cessation in dementia. Information gathered during these sessions led to a project examining physician assessments of fitness to drive for individuals with dementia [35,36].

Focus groups: Three focus group sessions were conducted with individuals with mild to moderate AD who had been told by a physician that they were, or would soon be, medically unfit to drive, and their carers/family members. Individuals from both rural (n=5) and urban (n=10) communities were in attendance. At each session, participants were asked to discuss their general attitudes towards driving with dementia, reactions to learning that they were, or would soon be, medically unfit to drive, the perceived risks of driving with dementia, and barriers to driving cessation. Information gathered during the focus group sessions was not subject to formal qualitative analysis but was used to shape the content and style of the PSA campaign.

Baseline surveys: Anonymous surveys were collected at five primary and tertiary care sites in urban and rural settings across the province of Nova Scotia in order to assess baseline attitudes and behaviours of people caring for individuals with dementia who were driving or had recently stopped. Survey questions asked about caregivers' concerns about driving and which actions they, or a health care provider, had taken to facilitate cessation.

Phase two

Creation and dissemination of a driving and dementia PSA campaign

Online resource: Through the support of the Canadian Dementia Knowledge Translation Network, a custom-developed online resource (www.notifbutwhen.ca) was designed to educate and guide health care providers and caregivers through the driving cessation process. A study evaluating the impact of the website on physician attitudes and behaviours showed that the release of the website was associated with fewer physician reports of avoidance of driving discussions with

dementia patients [36]. The caregiver portal of the site presents relevant information about dementia and driving, provides summaries and links to provincial resources and encourages caregivers to actively facilitate the cessation process by initiating discussions about driving safety with a health care providers, and by utilizing the knowledge and support of local experts (e.g., Alzheimer Society of Nova Scotia, and occupational therapists were applicable) when struggling with this complex process.

Print materials: A partnership with the Alzheimer Society of Nova Scotia (ASNS) was cultivated and all campaign materials included the message that the website and toll-free ASNS Information Line could be accessed for more information and support when health care providers or caregivers have concerns about driving. Materials included: bumper stickers, advertisements on local transit, information cards for physicians to provide to patients and families, and plain-language information sheets for family members and care providers.

PSA video: Given the early loss of insight in AD, caregivers were selected as target audience for the PSA. The video was designed using the tenets of the Health Belief Model [26] and theories of persuasive communication including Optimistic Bias [27], Inoculation Theory [28] and the Boomerang Effect [29]. The video content and style was informed by Phase One focus group discussions and portrayed a female caregiver "co-piloting" for her partner with dementia. The couple experience a number of "near miss" scenarios demonstrating the range of risks of driving and dementia. The voice over introduces the audience to idea that driving cessation is an inevitable part of dementia progression ("It's not if, but when") and encourages concerned caregivers to contact the ASNS Information Line, or to visit www.notifbutwhen.ca for more information and support (video YouTube link <https://youtu.be/J0d3tjif> [9-8]). The video was pilot tested with focus groups consisting of caregivers, individuals with dementia, and local stakeholders. Participant feedback was gathered to ensure the audience could identify and understand the message, were not offended by the message, and could relate to the content. Modifications to the PSA were completed based on feedback.

Dissemination: The campaign was initiated in June of 2010. The PSA video aired during the summer (June 9- July 4) and fall (October 25- December 5) across the province of Nova Scotia, with a higher saturation of air time in regions with larger populations of adults in our target age range (> 35). The video was also made available online (<https://www.youtube.com/watch?v=J0d3tjif> [9-8] and www.notifbutwhen.ca). Within the largest city in the province (Halifax), PSA print advertisements ran on transit busses between September and December of 2010. Additional dissemination strategies included: presentation of the information available on the website at professional and community meetings, and distribution of print materials to primary care physicians and caregivers. The ASNS assisted the campaign by providing materials to clients, featuring the campaign at provincial conferences, and collaborating with the PI to train their Information Line volunteers on the materials available on the website.

Phase three

Anonymous post-campaign surveys were collected at 4 sites across Nova Scotia from June 2011 until September 2012. Only surveys from caregivers of individuals with dementia who were currently driving, or had stopped since the initiation of the campaign (June 2010) were included in the follow-up analysis. Survey questions included all items from the Phase One survey, and a question regarding caregiver awareness of the campaign.

Ethics: The Institutional Research Ethics Boards for the Capital District Health Authority in Halifax, Nova Scotia approved the study protocol. Informed consent was obtained from focus group participants. Individuals completing anonymous surveys reviewed a cover letter describing the research and consent was implied based on whether the respondent decided to complete and submit the survey.

Analysis: Feedback from stakeholder consultations was informally collected by the authors (PM, LH) and a short-answer feedback forms completed by attendees. Focus groups were audio-recorded, and transcribed verbatim. Survey response data was examined using descriptive statistics and multivariable linear and logistic regression controlling for sex, urban/rural community of practice, and years of practice. A cut off value of $p < 0.05$ was used. Descriptive statistics were calculated using unpaired t-tests for continuous variables and the Chi squared test for dichotomous variables. Multivariable logistic regression controlling for age, sex and urban/rural address was used to evaluate.

Results

Focus groups

Fifteen individuals participated in the initial focus groups exploring the determinants of driving cessation from the perspectives of persons with dementia (n=6) and their female caregivers (n=9). While focus group data was not formally analysed using qualitative methodologies, caregiver perspectives were used to design the “near miss” and “worst fear” scenarios portrayed in the PSA video.

“He was fixated on the driving itself and not on what was going on around on the street he didn’t seem to notice people in his peripheral vision, he wasn’t checking his side views, he back views he wasn’t factoring in a person suddenly walking out in front of him even if they had the right of way it was just heart stopping really” (Wife of Patient F)

When asked about the risks of driving with dementia, caregivers described their fears that third parties would be injured. One caregiver articulated her specific fear about a child being the victim of an accident. “One of my biggest fears is that if he had an accident it’s actually hitting a pedestrian. His reaction time had slowed and I thought it only takes a split second for a child to and so many kids cross the street today and they don’t look” (Wife of Patient A)

Surveys

A total of 263 baseline and 312 follow-up surveys were returned. Fifty nine baseline surveys were excluded from analysis due to lack of diagnosis of dementia (n=12) and not living in Nova Scotia (n=47). More than half of the post-intervention surveys (n=161) were excluded from analysis due to the individual having stopped driving before commencement of the PSA campaign (n=27), a lack of diagnosis of dementia (n=95), or not living in Nova Scotia (n=39). Baseline (n=204) and post-intervention (n=151) survey data results were included in final analysis and indicate that the demographic descriptors (gender, urban/rural and age distribution) of respondents did not vary between baseline and follow-up surveys (Table 1).

Approximately one half of all respondents (55% at baseline and 46% at follow-up) were aware that the person they cared for had been told by a health care provider to stop driving (Table 1). Of the 70 individuals who respondents indicated had been instructed to stop driving in the post-intervention group, 20% (n=15) continued to drive.

The majority of caregiver respondents (75% at baseline and 80%

Demographics	Baseline (n, %)	Follow-up (n, %)	p
sex (female)	129, 63.2	110, 72.8	ns
age			
<30	1, 0.5	1, 0.7	ns
31-50	33, 16.2	28, 18.5	ns
51-70	102, 50	68, 45	ns
71+	62, 30.4	54, 35.8	ns
urban	108, 52.9	78, 51.7	ns
aware of cessation recommendation	112 (54.9)	70 (46.4)	ns
Aware of PSA		80 (53)	

Table 1: Survey demographics.

Characteristic	Baseline (n,%) (n = 204)	Follow-up (n, %) (n=151)	p
worried about driving ability	152 (74.5)	121 (80.1)	ns
sex (female)	101 (62.7)	96 (75)	ns
urban	91 (56.5)	66 (51.6)	ns
cessation recommended	112 (54.9)	70 (46.4)	ns
individual still driving		52 (40.6)	ns
action taken to prevent driving	161 (78.9)	128 (84.8)	ns
shared concerns with the driver	144 (70.6)	113 (74.8)	ns
shared concerns with a physician	119 (58.3)	99 (65.6)	ns
refused to be a passenger	25 (15.5)	19 (14.8)	ns
contacted registry of motor vehicles	21 (13)	15 (11.7)	ns
sold a vehicle	21 (13)	14 (10.9)	ns
hid car keys	44 (27.3)	29 (22.7)	ns
other	65 (40.4)	35 (27.3)	ns

Table 2: Subgroup analysis of caregivers with worries about driving ability.

at follow-up) were worried about the person with dementia driving, and had voiced their concerns to the driver (Table 2). Of caregivers who were worried about driving behaviour, most (71% at baseline and 76% at follow-up) shared their concerns with a physician and/or took specific actions to facilitate driving cessation such as hiding the keys or refusing to be a passenger (73% at baseline and 69% at follow-up). When given the opportunity to list other strategies used to deter the patient from driving, some caregivers assumed driving responsibilities (n=10 at baseline and n=17 at follow-up). Less common strategies included disabling the car (n=2 at baseline and n=5 at follow-up), and requesting a driving assessment (n=6 at baseline and n=4 at follow-up). Few caregivers contacted a local authority (e.g., police, or provincial registry of motor vehicles) or insurance company.

No significant differences in behaviour between urban/rural caregivers or male/female caregivers were found. However, at baseline, rural caregivers were more likely to have taken action to promote driving cessation ($\chi^2=4.2$, $P=0.04$), and at follow-up urban caregivers were more likely to have shared their driving concerns with the individual with dementia ($\chi^2=4.4$, $p=0.03$)

Following the dissemination of the campaign, 53% of respondents reported having seen the PSA and 32% reporting being aware of the www.notifbutwhen.ca website. Self-report on the part of respondents about having discussions about driving cessation, refusal to act as a co-pilot or other steps to promote driving cessation did not show significant change between baseline and follow-up. No significant behaviour differences between urban/rural caregivers or male/ female

caregivers were identified between baseline and follow-up. However, at follow-up there was a trend towards rural caregivers being more likely to have concerns about driving ($\chi^2=3.2$, $p=0.08$) and to have spoken with a doctor about their concerns ($\chi^2=2.8$, $p=0.09$).

Discussion

The issue of driving and dementia continues to be a common and contentious issue encountered by individuals with dementia, their caregivers, and health care providers. Our findings are consistent with other reports indicating that dementia caregivers are likely to recognize and worry about changes in driving ability [8]. While the majority of caregivers admitted to having concerns about driving safety, (Table 1) few had discussed their concerns with a health care provider. This may explain why only half of caregivers were aware that driving cessation had been recommended for the individual with dementia. Nova Scotian physicians have reported that they routinely address the issues of driving safety, however physicians at all levels of experience admit to finding these discussions uncomfortable, and admit to sometimes avoiding them [35,36]. While non-physician care providers (e.g. occupational therapists) may assist with the routine assessment of driving ability in dementia, this service is not widely available in Nova Scotia. Caregivers may therefore need to be pro-active in initiating discussions about driving, especially in situations where the physician may have reservations about approaching this emotionally-charged topic.

Previous studies have found physician advice to be a pertinent factor in driving cessation [2]. Unfortunately, 20% of individuals reported ignoring physician recommendations for driving cessation. This result highlights the important role caregivers and other family members play in the cessation process to heed and re-enforce medical recommendations, and also highlights the need for accessible alternatives means of transportation [2,3]. Dialogue and agreement between the physician and the caregiver is essential in ensuring cessation occurs.

Many survey respondents had previously discussed their concerns with the driver and/or a physician, and were more likely to have such conversations than to take direct actions to impose cessation. When imposed strategies were used, they were commonly non-confrontational (i.e., hiding the keys). This passive strategy may be in response to the lack of acceptance of change in driving ability and the negative response commonly associated with having one's driving privileges limited or removed.

Only a small proportion of caregivers reported refusing to be a "co-pilot". This trend is worrisome given the tendency for female caregivers to facilitate continued driving in dementia by acting as a co-pilot [22]. The PSA video specifically targeted this behaviour by portraying a female co-pilot. Further efforts are required to increase awareness about the ineffectiveness (and danger) of co-piloting as a strategy to mitigate risk in driving and dementia. Additionally, few caregivers reported contacting provincial regulatory bodies. This result is not surprising given the limited impact imposed strategies such as license revocations appear to have on the decision to stop driving for persona with dementia [2,3].

While before and after data collection failed to indicate significant change in caregiver behaviour in relation to driving and dementia through a PSA campaign, there are several limitations to the results. First, we expect a bias in self-selected participants. Loss of driving privileges is known to be a sensitive issue for patients and caregivers,

and is a common barrier to dementia screening [41]. Therefore, we anticipate that those caregivers who voluntarily completed the survey in a geriatric/memory clinic setting would be more open to accepting the impact of dementia on driving ability, were currently concerned about driving, or had previous positive experiences with the driving cessation process. Therefore, our results potentially represent an over-estimation of the proportion of caregivers with worries about driving safety, and the proportion who act to facilitate driving cessation. Second, many surveys had to be excluded from final analysis due to not meeting criteria for inclusion (i.e. driving cessation prior to commencement of the PSA campaign). Third, several sites had low survey response numbers, and there were significant delays and gaps in the PSA video airing due to complications with video production. As a result, data collection periods had to be extended. The follow-up data collection period, for example, spans more than 12 months so that the PSA had been only available online for up to 19 months at the time surveys were completed. Collection of completion dates on the baseline and follow-up surveys may have enabled us to better understand trends in awareness of the PSA related to air time. Future projects would also include funding for consultation with an advertising firm to determine how best to reach and gather data from our target audience. For example, we did not accurately estimate the saturation of PSA television air time that would reasonably be required to effect change in awareness or behaviour, and consequently did not budget sufficient funding for PSA air time.

Our results demonstrate a persistent knowledge need on the part of caregivers for more information and dialogue with health care providers regarding the dangers of driving and dementia. Beyond the valuable information gathered about the pervasiveness of the issue of driving and dementia, the project resulted in a PSA that can be used in the future, as well as a web resource that continues to be used by, caregivers and primary care providers.

Acknowledgements

This project was funded by the Canadian Dementia Knowledge Translation Network and the Nova Scotia Health Research Foundation (PSO 2008-4666). The authors would like to recognize the following individuals who assisted with data collection: the nurses at the Geriatric Medicine Clinic; Dr. Mary Gorman, Dr. Ian MacKay, Gayle Ogilvie and the Nova Scotia Alzheimer's Association.

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