

# Independence, loss, and social identity: Perspectives on driving cessation and dementia

Dementia

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**Abstract**

The purpose of this study on driving cessation was to explore the process of coping, decision-making and adaptation through this major life transition. We sought to examine understandings of the emotional responses of drivers and ex-drivers with dementia from the perspective of health-care providers and family caregivers of persons with dementia. Interviews and focus groups were conducted with several key informant groups: healthcare providers who work with patients with dementia and their families ( $N = 10$ ), representatives from organizations that provide services and support for persons with dementia ( $N = 6$ ), and family caregivers of drivers and former drivers with dementia ( $N = 13$ ). Data analysis involved inductive analytic techniques to generate descriptive and analytic themes from the data. The main themes from the analysis involve the: (1) Loss of independence and disruption to identity connected to emotional responses to driving cessation; (2) Experience of driving cessation as one loss within a series of losses related to dementia; (3) Importance of addressing emotional and identity-related effects in supportive responses to driving cessation; and (4) Support for maintained and adapted roles as a strategy to provide meaning and purpose in the context of driving cessation. Driving cessation can represent a significant disruption to identity, and is closely linked to losses, such as independence, within people's broader experiences of grief and loss associated with dementia. The findings suggest the need for supportive responses that address unique emotion and identity-related aspects of driving cessation for people with dementia and their family caregivers.

**Keywords**

driving cessation, grief, identity, life transitions, qualitative research, role, social participation

**Introduction**

Driving cessation is widely considered to be a major life transition, comparable to occupational retirement or the loss of a loved one in older age, and can have a significant impact on the health and well-being of older drivers, including those with medical conditions that affect driving ability (Liddle, Turpin, Carlson, & McKenna, 2008; Vrkljan & Polgar, 2007). A growing body of research demonstrates the important link between driving cessation and adverse outcomes such as an increase in depressive symptoms, a decrease in social

engagement, and poorer general health (Chihuri et al., 2016). These outcomes indicate a need to consider the emotional and psychological consequences of driving cessation in support for older adults. Drivers and former drivers with dementia have been noted to have unique experiences of driving decision-making and cessation, compared to other older adults, with an increased dependency on family caregivers and declining insight due to cognitive impairment (Adler, 2010; Liddle et al., 2016). Furthermore, physicians and family members have identified emotional responses (e.g., anger or social withdrawal) of people with dementia as being a significant barrier to acceptance of recommendations to stop driving, due to declining abilities (Byszewski, Molnar, & Aminzadeh, 2010; Chacko, Wright, Worrall, Adamson, & Cheung, 2015).

Cessation from driving can have a profound impact on a person's sense of self. While driving is a form of transportation with the utilitarian function of enabling successful mobility and daily living (King et al., 2011), for many it is also intimately connected to social identity (King et al., 2011; Liddle et al., 2012, 2013, 2016; Rudman, Friedland, Chipman, & Sciortino, 2006). Driving enables older people, with and without cognitive impairment, to engage in key activities that are symbolic markers of social participation and belonging, and thus is closely linked to an individual's sense of control and independence, both of which are highly valued in 21st century Western countries (Jetten & Pachana, 2012; Musselwhite & Shergold, 2013).

In this context, driving fulfills different needs for older adults, including formal (e.g., shopping or medical appointments) and informal practical activities (e.g., socializing with friends), as well as affective (e.g., comfort and security) and aesthetic purposes (e.g., scenery from a drive in the countryside) (Horowitz, Boerner, & Reinhardt, 2002; King et al., 2011; Musselwhite & Haddad, 2010). While most of the literature on driving cessation emphasizes the importance of driving for access to essential and social services, the meaning of driving, beyond how it contributes to survival, is important and understudied in terms of its impact on well-being. As the authors of one study of older drivers and former drivers note about driving for leisure, "[Q]uality of life is enhanced by the very fact that the journey is not necessary. They often view quality of life as immersion in a world beyond everyday survival and completion of ordinary tasks to a higher level of quality" (Musselwhite & Haddad, 2010, p. 31).

Driving is frequently attached to life milestones, friendships, livelihood, social group belonging, participation in family life, sense of self-esteem, and understandings of normalcy in the context of illness and well-being (Liddle et al., 2012). For some, driving is intimately connected to the social roles that people embody over their lifetime, such as parent or caregiver, and is simultaneously linked to the capacity to contribute within roles and relationships, and to society more broadly (Horowitz et al., 2002). In this paper, we draw from recent work on social identity and identity change in the context of driving cessation (Jetten & Pachana, 2012; Pachana, Jetten, Gustafsson, & Liddle, 2016), which asserts that both personal and social identity are implicated in this important life transition. Those authors propose that driving cessation among older adults can be highly stressful due to its impact of losing a valued identity, its symbolic and concrete attachment to aging, and potential disruption of social networks. In this context, they argue that maintaining continuity in people's social life and continued group membership can have positive effects for the well-being of former drivers. We suggest that understanding of disruption to identity linked to driving cessation needs to account for unique factors marking the experiences of drivers with dementia.

The inter-dependence of family caregivers and persons with dementia is often greater than for older adults with other health conditions, and many caregivers shoulder considerable responsibility with respect to facilitating social networks and other important identity-related activities for their loved ones. Family caregivers are frequently reliant on healthcare providers for support around practical and emotional issues associated with driving cessation and dementia. This is especially the case as families seek to care for people with dementia for as long as possible in community, rather than institutional, settings with the support of healthcare providers (Elliott & Parker, 2012). Furthermore, family caregivers and healthcare providers are often implicated in negative emotional responses to recommendations to stop driving, due to their close relationship with the former driver and/or their role in delivering the directive. In this light, the effects of driving cessation are often shared between drivers/former drivers and these groups, particularly family caregivers.

The purpose of this paper is to explore the emotional experiences, viewpoints and needs identified by family caregivers and health and social service providers in relation to driving cessation and dementia in order to further understanding of this transition. While much of the literature on driving in older age recognizes the emotional effects of driving cessation, there is a lack of in-depth qualitative analyses that: provide rich description of *how* driving cessation is intimately connected with psychological and emotional experiences of loss and grief among persons with dementia, or explore strategies that families and others use to cope with negative emotional responses to driving cessation. Furthermore, the issue of loss of independence is commonly discussed in studies on driving cessation, but rarely is the relationship between independence and emotion analyzed in detail. Healthcare providers and family caregivers are well-positioned to provide insight into this topic due to their supportive roles, and can provide perspective on programs or services that address the needs of people with dementia that relate to driving cessation.

The study was designed to explore the perspectives of key informants on the strategies that first facilitate decision-making about driving for people with dementia, and then promote coping and adaptation following driving cessation. The paper explores the unique experiences and perspectives of respondents by analyzing the relationship between identity, independence and emotional responses in the context of broader loss associated with the progression of dementia.

## Methods

### *Study participants*

The study sample strategy was purposive (Patton, 1990); key informant participants were identified, and included, according to their potential to contribute to understanding about the challenges faced and strategies employed in making decisions about driving and coping after stopping driving for persons with dementia and their families. The sample included family caregivers ( $N = 13$ ) due to the knowledge that drivers with dementia are often dependent on spouses and adult children for the provision of support for social participation and other everyday activities (see Table 1 for further information about the sample). Healthcare providers ( $N = 10$ ) who are involved in discussions and decision-making about driving cessation with patients who have dementia were included because of their key role in communication and providing other supports to patients and family members. Representatives from other organizations ( $N = 6$ ) were also identified as key informants in order to add

**Table 1.** Caregiver participants.

Caregiver to current driver or former driver <sup>a</sup>	Number of participants	Mean age	Sex	Relationship to driver
Current driver	5	73.0 yrs	4 Female 1 Male	5 Spouses or ex-spouses
Former driver	8	66.9 yrs	8 Female	5 Spouses or ex-spouses 3 Adult daughters
Total	13	69.2 yrs	12 Female 1 Male	10 Spouses or ex-spouses 3 Adult daughters

<sup>a</sup>Three focus groups conducted in Waterloo, ON and Victoria, BC: Focus group 1 (*n* = 5) consisted of three caregivers of current drivers and two caregivers of former drivers; Focus group 2 (*n* = 3) consisted of two caregivers of former drivers and one caregiver of a current driver; Focus group 3 (*n* = 2) consisted of caregivers of one former driver and one current driver. Three interviews were conducted with three caregivers of former drivers.

perspectives on driving cessation, and strategies to maintain social participation and mobility, outside of clinical or health-related practice.

The healthcare provider participants included two Occupational therapists, three Registered nurses, two Family physicians, one Geriatrician, and two Social workers practicing in urban and rural regions in Ontario. Their practice types consisted of community-based programs, memory clinics, family health teams, hospital programs, and specialized geriatric programs. The organizational representative participants included two from advocacy organizations for older adults, two local alternative transportation providers, and two support and advocacy organizations for people living with dementia, and their caregivers. The ex-driver partners of caregivers (*N* = 8) had stopped driving within 1.5 and 6 years of the data collection, and had driven for a range of 33–62 years prior to cessation. Six ex-drivers had stopped due to concern from family members or healthcare providers, or both, and two had made the decision to stop on their own. Five of the caregiver participants had a family member with dementia who was still driving. All caregivers except for one adult daughter of an ex-driver were current drivers themselves.

Multiple recruitment strategies were employed to enroll participants in the study. Study participants were recruited at three separate cities across Canada (Toronto and Waterloo, Ontario, and Victoria, British Columbia) using various methods. Healthcare providers and organizational representatives were recruited directly through email addresses on public websites of community health organizations and practices that serve older adults and people with dementia. The purposive sample was augmented by a snowball recruitment strategy where researchers requested that healthcare providers and organizational representatives identify others who might be appropriate for inclusion in the study. Snowball sampling is an appropriate way to enhance purposive sampling to identify and recruit research participants when there is an initial small group that is known and accessible to the researchers who are familiar with others who share the characteristics that make them eligible for inclusion in the study (Morgan, 2008). Caregiver participants were recruited through various sources including community day programs for older adults and advertisements in relevant community organizational newsletters and listservs (see Table 2 for details on recruitment). The sampling strategy did not involve screening or confirming a diagnosis of dementia for inclusion purposes, instead we were concerned with whether participants self-identified as caregivers of current- and ex-drivers with dementia.

**Table 2.** Recruitment information.

Sample sub-group	Study site(s) or location	Recruitment strategies
Healthcare providers & Organization representatives	Across Ontario	Purposive, snowball Recruited via: email through publically available websites (dementia-related services and programs, community health practices, and other health services) listing healthcare providers working in the field and organizations that provide services, programs and advocacy for older adults and older adults with dementia; established networks of research team members.
Caregivers	Toronto, Ontario Waterloo, Ontario Victoria, British Columbia	Purposive Recruited via: advertisements in local newsletters of university alumni groups and Alzheimer society chapters; flyers at various community sites that provide services to older adults including community health centers, hospitals, and social day programs for older adults; advertisement through a university-based educational research program on dementia.

### *Data collection*

The research was reviewed and approved by Ethics Review Boards at all three of the data collection sites, and informed consent was obtained from individuals prior to their participation in the study. Data was collected from early November 2015 to late April 2016. The interviews and focus groups employed open-ended questions representing areas of inquiry that were initially developed through a review of the literature. The semi-structured format enabled tailoring to the participant's expertise and experience, through detailed follow-up about specific responses. As data collection progressed, the interview guides were revised and adapted to account for emerging findings. Thus, while the broad areas of inquiry were pre-determined to some extent by the parameters of existing literature and thus deductive in nature, the subsequent analytic approach was inductive. We conducted in-depth interviews with all of the healthcare provider and organizational representative participants. Three focus groups were completed with 10 caregiver participants, as well as three interviews with caregiver participants who were unable to attend the focus groups. Thirteen of the interviews were conducted by phone, six were in-person, and all of the focus groups were conducted in person.

### *Data analysis*

Focus groups and interviews were recorded, transcribed verbatim and entered into NVivo™ 9. Data were coded using a coding matrix that was subject to ongoing development. Standard thematic analysis techniques were used, which involved an inductive analytic approach that developed descriptive and analytic themes directly from the data (Denzin & Lincoln, 1998; Patton, 1990; Sandelowski, 2000). Researchers moved iteratively between data collection and analysis in order to develop the analytic focus over time. At least two

researchers (SS, SH and SL) coded each of the transcripts and the coding matrix was subject to ongoing refinement as researchers became more immersed in the data. In instances where there was conflict in coding between researchers, consensus was reached through discussion and deliberation. Data were initially coded by close readings and the assignment of labels to describe and summarize phenomenon found in the text. Broader descriptive codes were developed based on the initial coding and data segments were then assigned a descriptive code as a basis for category formation. Thus, codes were systematically applied, but also derived directly from the data. Through this inductive, iterative process, categories with related content were examined for interrelationships, and then synthesized and refined to develop conceptual analytic themes. This paper presents a focused, detailed thematic analysis (Braun & Clarke, 2006) of the role of emotion in responses to driving cessation, and how this challenge interconnects with understandings of identity.

Emerging themes were discussed regularly in meetings with the research team, which includes a range of expertise on driving cessation and dementia, to corroborate, expand upon or modify the evolving interpretation of findings. Standard practices for ensuring rigor in qualitative research were used, such as prolonged engagement with the data and the development of an audit trail that included interview guides, audio recordings, transcript quality checking, field notes and analysis memos, and other data analysis products (Lincoln & Guba, 1985). Quotes from the data are included below to illustrate the analytic themes.

## Results

### *Driving cessation: Independence, loss, and identity*

As has been well documented in the literature on driving cessation, participants described a strong link between driving and independence, where driving represented the freedom to “go anywhere” for their care partners. Many caregiver participants described the loss of autonomy for their family member as a considerable effect of driving cessation:

“I don’t know how you can soften that blow, because with the loss of driving, there’s a degree of loss of independence. A great deal of independence . . . So that isn’t a decision [to stop driving] that he made. It was made for him” (CP1; Spouse of ex-driver)

The loss of driving privileges, along with greater dependency on others, was also described as resulting in negative emotional responses, such as anger, frustration and sadness:

“Well, in my mom’s case, like I said, it was like losing a spouse. It was really traumatic. And in her situation, because she’d never used public transportation before and because of the vascular dementia, she literally did not go anywhere. So that meant she couldn’t get her own groceries, she couldn’t do her own banking. Literally had to rely on someone else . . . And she will openly still say that losing the use of the vehicle was losing her independence. And, because of her pride, she would never even ask a neighbour . . . you know for a ride or anything like that; just so proud. And literally she would just sit in her house and go nowhere. So, it was devastating. Devastating.” (CP12; Adult daughter of ex-driver)

“So, my dad isn’t driving anymore, because of his Alzheimer’s. He was clearly able to articulate what it meant to him . . . [It] was his loss of freedom and independence. So, he also says he feels



helpless ... He just had a very angry reaction. And, I think also a reaction that he thought it wasn't fair." (CP7; Adult daughter of ex-driver)

These quotes demonstrate feelings of helplessness and loss of ability to participate independently in activities, such as grocery shopping, following driving cessation.

Several healthcare provider and organizational representative participants made an explicit link between independence, identity and loss, suggesting that these emotional responses stem from grief over loss of a core aspect of the former driver's identity:

"And it's a huge loss in the matters of their identity and independence, autonomy. It's very much tapped into their feeling of, you know, incapacity, inefficacy, or incompetence." (Occupational Therapist)

"I never cease to be amazed at how strong the emotions are around this topic. It cuts to the core of what, is, actually, the identity of a lot of people." (Representative from organization that provides services and advocacy for people with dementia, families and caregivers)

Importantly, not all respondents noted this negative emotional response to loss of driving privileges, and several participants described relatively unemotional responses by their family members or patients:

"But, we're fortunate that he's ... a very calm person. He's got a good sense of humour and he ... doesn't get upset ... So, some of the stories that I've heard from friends whose parents are older. You know, the anger issues ... we don't deal with anything like that." (CP2; Adult daughter of ex-driver)

"I would say, often people deal with it a lot better than I would ... I think, because a lot of folks with dementia, (a) have memory loss, then (b) have a lot of apathy. Sometimes that's very protective in this type of situation, and they're kind of like, 'Okay.' You know, and they actually deal with it a lot better than the family expected them to." (Physician)

As the adult daughter of a former driver describes in the above quote, her father was relatively untroubled about his loss of license. While she explained this in terms of individual personality traits (as did other participants), she also described an impressive network of family members (four adult children and several grandchildren) that supported his continued participation in valued social activities. This familial support network, in combination with outside social service organizations, allowed him to continue to live alone and engage in regular activities with relative independence, including church services, social programs and weekly visits to the horse racetracks. Healthcare providers described responses by patients or clients as mixed, and as one physician pointed out in the above quote, the symptoms of the illness can be protective against the negative emotional responses of drivers to cessation directives.

### *Dementia and the "series of losses": Driving cessation as a marker of decline*

While the above section on independence, loss, and identity might also reasonably relate to general experiences of driving cessation, there was a distinction in participants' accounts



that framed driving loss as a marker of decline within the general experience of dementia. Emotional disturbances due to the often-abrupt loss of license coupled with an already stressful dementia diagnosis were described as particularly traumatic for some people. Caregiver participants frequently placed the emotional effects of driving loss within broader experiences of dementia:

“[M]y biggest struggle is keeping her positive, and out of this, sort of, depressed state. Because she clearly knows that there is some cognitive decline, with her memory loss and things like that. Which is very upsetting for her. And not being able to function. And she’s living a lot in the past, in, ‘well, I used to be able to do this.’ She had a very vibrant, active lifestyle. So she’s also lamenting the loss of that.” (CP12; Adult daughter of ex-driver)

In this quote, the daughter of an ex-driver situates her mother’s struggle with losing her license in the context of many other losses attributed to her experience of dementia, providing the examples of declining memory and function, and loss of a previously “vibrant” way of life. The revocation of driving privileges was described as one of a series of losses within a broader decline associated with the illness:

“[I]t’s very difficult to assess whether the changes [in daily activities] come from solely that one facet of losing his independence or to his general cognitive decline. And there’s certainly been a cognitive decline. My husband was a very pragmatic, independent, ‘do it yourself’ person, active, you know. All those things have changed. And I can’t say it’s just because of the driving. That just adds to it ... but you have to look at the bigger picture.” (CP1; Spouse of ex-driver)

“It’s like a double, a quadruple—whatever number you want to put on it—whammy. In addition to having to deal with this illness, they’re suddenly confronted with their license being taken away. And the lack of independence and autonomy, and all the frustration and anger that goes along with that ... [it’s] very difficult.” (Social Worker)

“Because you want them to be aware early on that, at some point down the road, unfortunately, we know with dementia, you get to that point where ... you can’t take care of yourself. When you do get to that point, you’re probably going to have to go and reside in some form of a long-term-care facility. That way, when the issue comes up further down the road, again, it’s, ‘you know how we had the discussion about how things, tend to decline?’ And the same with driving ... driving is just one piece of the whole dementia piece, right? Because there’s so many things that we have to be mindful of and keep an eye on while we’re dealing with our clients with dementia.” (Registered Nurse)

Reduced social participation due to driving cessation was explained as part of a broader loss in independence and activity experienced as a result of the dementia progression, and participants pointed out that emotional responses need to be understood in relation to the anticipated loss around the impending trajectory of the disease. In fact, many caregivers described their partner’s feelings of despair that their “life was or would be over” once they were no longer able to drive, and in this way, loss of license was symbolic of a broader deterioration:

“I just dread the thought of what [my husband] would be like ... if he loses his license. Because to him, it’s that unfortunately, the number one question that everyone asks him, ‘you still

driving? Oh, then you're doing fine.' That's what the general public says to him ... And he knows himself that if he loses his license, then he is really declining." (CP3; Spouse of current driver)

"But we can anticipate a need to help people deal with the anger, the rage, and the grief that is underlying that ... And that the anger is about, 'here's another thing that is going wrong, in this trajectory downhill' ... I mean, there are always going to be exceptions ... But, I think if we can help families to see this as, typically, a tremendous loss in a series of losses." (Representative from organization that provides services and advocacy for people with dementia, families and caregivers)

In the context of these losses, driving cessation was described as an important transition within family experiences of dementia, along with projected changes, such as increased support with activities of daily living, a reduction of social roles and responsibilities, and the eventual move into a long-term care home.

### *The importance of recognizing and supporting the emotional dimensions of driving cessation*

Participants emphasized the importance of acknowledging the potential grief associated with the driving cessation process, and recognized that emotional and identity-related factors are frequently overlooked in supportive responses:

"We focus so much ... on thinking of alternatives. Learning about, you know, what public transportation is available ... That doesn't get, at all, at the underlying issues. You talk to people about that they're, like, 'yeah, yeah, whatever. But that's not like getting in my car and going whenever I feel like it, wherever I want.' And it isn't, no matter how you slice it. Because driving, usually, is not just about getting from point A to point B, right? We need to tune into the meaning of driving for people. And how are we going to deal with that loss?" (Representative from organization that provides services and advocacy for people with dementia, families and caregivers)

"And maybe that's another way you could fit in, providing that support ... If there were a number, say four or five people who are in a group and they had just lost their license, then, 'how do we go on from here? What do we do? How do we view ourselves? Does that mean we're diminished?' I think that would be helpful ... I think if [my husband] had been able to talk to a group, he could've expressed his own personal frustrations." (CP1; Spouse of ex-driver)

Participants conveyed the idea that supportive programs need to recognize the broader meaning and impact of driving beyond its effect on practical elements of everyday life related to mobility and community access, and in doing so address issues such as diminished sense of self associated with the loss of license. Many caregivers urged that support programs be designed to explicitly address the issues of trauma and loss for those who are undergoing driving transitions:

"Like I said to you, it was ... I liken the trauma of losing her vehicle; the use of her vehicle, was as traumatic as losing my dad. It was like losing a spouse. And so, just like you have grief

counselling for losing a spouse, you should have grief counselling for transitioning to non-driving.” (CP12; Adult daughter of ex-driver)

“Whatever you do for grief or bereavement. My mom said my dad was absolutely ballistic over there at [the retirement home] when he actually found out [that he was having his license revoked] ... I think, if he would have been able to go somewhere understanding ... But for different people it would be different things. Because his reaction was rage and anger. So how do other people react to grief? They maybe isolate themselves or squirrel away?” (CP7; Adult daughter of ex-driver)

Healthcare provider participants and organizational representatives also identified their role in the provision of emotional support, and several providers stated that their teams had limited access to resources that might facilitate coping with these effects:

“We have a lot of people who are very, very angry about their driver’s license being taken away. To the point where they don’t want to return to the clinic to see the physician who’s pulled their license. I think we can always do a better job at providing that emotional support. I’m not sure that we do it consistently.” (Social Worker)

“There’s not a lot of counselling or therapy sessions ... available for people with dementia when they have their license taken away. There’s no services like that ... the individual with dementia in the early or middle stages, still can understand what’s going on, but can’t do certain tasks and they just can’t remember certain things. But they still have an awareness and no one to share their concerns with ... So who comes in with that one-on-one counsellor? It’s not our norm that families would bring in a counsellor for somebody with dementia. It’s not a norm, it should be, but it’s not.” (Representative from organization that provides services and advocacy for people with dementia, families and caregivers)

The need to address the emotional effects of driving cessation through supportive programs that focus on individual experiences of loss and grief was a central theme that emerged from our analysis.

### *Strategies to counter reduced independence and negative emotional effects: Meaningful roles and support for social activities and engagement*

An important strategy used by caregivers was the cultivation of meaningful roles or activities to create a sense of self-worth and control, purpose and well-being in both drivers and former drivers with dementia. The goal of these activities was to prevent or mitigate some of the negative emotional effects of driving cessation. Others pointed to the importance of preserving a sense of dignity in light of the considerable social stigma faced by persons with dementia. As patients and caregivers anticipate the decline associated with the disease, preservation of roles and dignity was considered to be important for the well-being of drivers and ex-drivers:

“[W]ith Alzheimer’s ... or really for many people, we all need purpose, right? And so, that’s why the [Alzheimer’s research group], really, is now working on the [local project on creating dementia-friendly communities]. Which, we’re still in the planning stage ... that is something

that [my husband] likes, too, because he's involved and ... Because he really likes to be the up-front guy, you know." (CP3; Spouse of current driver)

"When [my husband] went to the day program, he wasn't *going* to the day program, he was 'volunteering' there, right? And he told everybody he had a job. So, that's how we presented it ... So, he was the volunteer there and we'd read the program and this was the activity and we would go and ... he was a teacher, so we have lots of resources, that he would bring ... And so, I think it's the purpose thing ... you've got to try and keep their dignity." (CP5; Spouse of ex-driver)

Caregivers provided specific examples of the ways that they encourage continued engagement for their partners, including contribution to dementia-specific community programming or initiatives, or involvement in household activities, such as financial planning. They described these roles as encouraging a sense of responsibility and self-worth, while not comparing what they do now with what they used to be able to do:

"Well, today, as a matter of fact, when I pick him up we're going to go to the bank because ... property taxes are due ... and then he'll pay the bill. I will be there, but he will do it. So, in a way, it's allowing him to be cognizant of financial things that are happening ... So, he's not doing what he did before; he's not able to. But, I want him to be responsible for something ... It gives him an idea that there are positive things he can do ... So encouraging him to do things that make him feel worthwhile. And not comparing them to what he used to do." (CP1; Spouse of ex-driver)

Like caregiver participants, healthcare provider and organizational representative participants also identified the importance of engagement in meaningful activity in order to counter the negative consequences of driving cessation. Specifically, the issue of reciprocity was introduced as a way of maintaining a sense of meaning and self-worth:

"I try to help them think of ways that would give great satisfaction, like, 'Would you be able to have [friends] over for lunch?' 'Oh, they'd never want to come to my place.' And I would say, 'Well, how lovely that could be. You could just phone for Chinese food or something.' ... And that's worked several times, because ... the reciprocity allows them to feel worthwhile while still accepting the fact that they are asking this friend to drive them ... I think if we work with the self-worth of every person ... is there a way that we can still keep a very well-meaning life together for this person, even if they don't drive?" (Registered Nurse)

"I just remember a friend of mine got his grandmother's car after [she stopped driving], and she was happy that he had it. And she would count on him to come and, you know, do groceries. 'You can have my car, but, you know, can you help me, to take me to this place once a week,' like a family agreement that works in the benefit of the individual who's giving up so much." (Representative from advocacy organization for older adults)

These illustrations emphasize the importance of reframing previous ideas about social roles within valued relationships in order to promote a sense of self-worth in individuals with dementia. While some participants described their efforts to support loved ones to maintain roles and activities that they had developed over their lives, others acknowledged that these

practices had changed since the progression of dementia. Participants described new roles that their loved ones had acquired since their dementia diagnosis and loss of driving, such as the gradual acceptance of the role as passenger, in place of driver:

“Really he still drives. And, he was horrible at the beginning. He would tell me what to do. He’d get so upset ... And, he didn’t want to sit in the passenger seat ... And, we had some fights [Chuckles] when we started ... and even today he’ll tell me, ‘Oh, watch this. Do that. Go here. Stop here.’ But, it’s the only time he really perks up is when he sits in the car ... Because he’s interested in it ... I have trouble getting him to do menial things he’s not interested in, basically. But, you sit him in that car, boy ...” (CP13; Spouse of ex-driver)

It was evident that promoting meaningful engagement required substantial effort and commitment on the part of the caregivers:

“Well, it will change for me too [when my husband stops driving]. Because I know that already, I need to spend more time with him. I’m so used to going places on my own and having my own social world. And he was always just content at home. He still is to a large extent. But, I know that, for his own development and what he needs for stimulation, is more socializing. And, you know, so we’ll have friends over and that’s really good for him. But, I have a list ... Stuff I’d write up of activities and all that and we can walk to a lot of it ... It’s all typed on a schedule of everything that we could do in a day that’s of any interest to him at all.” (CP3; Spouse of current driver)

“Well, like I said, he realized himself [that he had to stop driving] ... So when he announced it at [social program for people with Dementia], I didn’t even know he was going to say it. He said, ‘I have an announcement to make, I have decided that I can no longer drive.’ I just about fell off the chair. Because I wasn’t ready for him to stop [Laughter] because I knew I was going to be tied down then.” (CP5; Spouse of ex-driver)

Caregiver participants described the great lengths that they go to in order to maintain social roles for their care partners, often in the context of a progressive decline in health due to the dementia, or competing caregiving roles due to their responsibilities to others. Healthcare providers also acknowledged that effective responses to emotional losses associated with dementia and driving should be social and emphasize cessation as a shared experience or norm to facilitate acceptance:

“You know, if it were to become a cultural norm. In terms of, we all will lose our license [at some point]. Then when people get together in a support group and they can talk about, ‘Oh, well, this is a pain in the derriere. My doctor came in and just said today I can’t drive’ ... to have other buddies that have been through that process and know that, you know, life goes on.” (Occupational Therapist)

## **Discussion**

The transition to non-driving for older adults is often fraught with difficulties linked to an array of complex social factors. The effect of greater dependence on others for

transportation and social support following driving cessation has been well documented in terms of its potential to negatively impact quality of life (Byszewski et al., 2010; Liddle et al., 2012, 2013; Rudman et al., 2006; Vrkljan & Polgar, 2007). At the same time, loss of driving privileges, and subsequent independence, can represent symbolic losses that extend beyond the practical aspects of everyday survival (Andrew, Traynor, & Iverson, 2015). For those with dementia, the amplification of grief due to dual loss associated with driving cessation and worsening dementia has also been acknowledged (Byszewski et al., 2010; Liddle et al., 2013). The more intangible effects of driving cessation, such as those that explore the implications for identity, sense of self, and potential loss of roles that have developed over a lifespan (e.g., occupational or caregiver) (Liddle et al., 2012; Windsor, Anstey, Butterworth, Luszcz, & Andrews, 2007), are relatively underexplored in research to-date.

The present study contributes to an emerging, yet understudied, area of dementia experiences that focuses on the symbolic aspects of driving, linking driving cessation to changed self-concept and sense of social belonging (Jetten & Pachana, 2012; Pachana et al., 2016). This paper provides a rich description of family caregiver, and other key informants', perspectives on the relationship between emotional response and social identity for older adults with dementia who are experiencing driving cessation. Consistent with prior research, participants described experiences of grief and anger. When the transition to non-driving is disruptive to identity, it can be accompanied by seemingly extreme emotional responses that families and healthcare providers are frequently unequipped to deal with. These emotional responses are intimately tied to loss of independence, changed roles, activities and relationships, and associated declines in feelings of self-worth and competence (Pachana et al., 2016; Rudman et al., 2006). Pachana et al.'s (2016) exploratory survey of older adults without dementia who had stopped driving or were intending to stop driving revealed that "driving cessation is an important identity change marker" and that people tended to view themselves as *older* following driving cessation (p. 8).

Accounts of driving cessation located loss of license as one aspect within the broader experience of dementia-related losses, representing a potential advancement to a more severe stage of dementia. In light of these findings, driving cessation should be conceptualized as one of several important transitions experienced by persons following a dementia diagnosis. The symbolic connection between the perception of an impending decline and loss of license as described by caregivers, healthcare providers and organizational representatives in this study suggests that support for driving cessation be provided within a broader approach that addresses other experiences, such as loss of independence, memory or social roles. This is particularly the case since most people with dementia and their families can expect to face other major life changes (e.g., to assisted living arrangements) within a shorter time-frame than other older adult groups.

Making sense of dementia-related loss is a complex process, and maintaining social roles, and navigating changing relationships and roles can be useful adaptive coping strategies (Robinson, Clare, & Evans, 2005). Caregiver participants in our study described their efforts to maintain purpose and meaning for their care partners through cultivating roles within the community, promoting continued engagement in household activities (e.g., financial planning, albeit under supervision), and adapting to new driving-related roles as a non-driver (e.g., active passenger). As well, the support of new ways of contributing within social relationships (e.g., providing meals for friends) was framed by some in terms of promoting reciprocity in order to contribute to feelings of self-worth. At the same time, healthcare and organizational participants suggested that supports to address the identity-related aspects of



driving (e.g., counseling, or integration of emotional and identity-related dimensions in healthcare provider responses to driving cessation) are often lacking in dementia care. Our analysis indicates that efforts to address these needs may also account for other dementia-related losses for some individuals.

As has been reported in other studies (Betz, Jones, Petroff, & Schwartz, 2013; Betz, Scott, Jones, & DiGuseppi, 2016; Liddle et al., 2008), there was some indication that those drivers and former drivers who responded more positively to driving cessation either had greater control over their decision to stop driving, or had been able to maintain, with minimal disruption, the social and daily activities from which they derived meaning and value (Jetten & Pachana, 2012). This supports individualized approaches to the emotional needs of people with dementia, and accounts for various factors, such as the person's readiness to stop driving, level of involvement in the decision to stop driving, family dynamics (e.g., degree of conflict in relationships), levels of support for mobility needs or degree of insight and acceptance (Liddle et al., 2016). Within these approaches, the support of caregivers who work hard to help maintain purpose and meaning for their care partners is also of major importance.

The search for effective strategies that facilitate acceptance of driving cessation for people with dementia is ongoing (Andrew et al., 2015). Recent research explores the provision of person-centered support for drivers with dementia through interventions such as decision-making support and mobility counselling (Carr & O'Neill, 2015; Carr & Ott, 2010). One example includes the Dementia and Driving Decision Aid, a tool that includes content on planning for alternative modes of transport in order to maintain social and other activities (Carmody, Traynor, Iverson, & Andrew, 2017). Interventions that support drivers and caregivers during cessation should be comprehensive, and integrate concerns about emotional and mental health with those that address social identity and belonging. Conversations about alternatives to driving, such as those that occur through mobility counselling, should also occur as early as possible (Carr & O'Neill, 2015).

There are several policy-related implications that stem from these findings. These include: investment in social and therapeutic programs and approaches that address emotion and identity-oriented experiences of driving cessation, as well as attention to barriers that impede access to these; investment in age-friendly environments including alternative transportation (public and private) infrastructure to support continued engagement; and initiatives to change norms and perceptions of dementia that contribute to stigmatized identities associated with diminished competence and worth. The meanings attached to driving also draw from broader social values about dependence and autonomy, aging and decline, and flexibility and convenience (King et al., 2011; Liddle et al., 2012). Importantly, these values are reflected in the degree of investment into alternatives to driving, and healthy, accessible environments in the context of aging and the increasing prevalence of dementia.

This paper reports on findings from a qualitative exploratory study that examined the subjective perspectives and experiences of key informants on strategies that facilitate driving cessation for persons with dementia and informal caregivers. Our findings reveal the profound effect of losses of autonomy associated with dementia as conveyed through the perspectives and experiences of family caregivers, and further demonstrate that such losses are shared between the person with dementia and their spouse and family members (Robinson et al., 2005). This paper marks a beginning into the investigation of emotional and identity-related dimensions of driving cessation from the perspective of healthcare



providers and family caregivers of persons with dementia. At the same time, future research should focus on increasing inclusion of drivers and former drivers living with dementia in order to expand understanding of this topic. This approach might examine how identity-related losses are shared or diverge through the inclusion of dyads of patients with dementia and their caregiver. Caregivers and healthcare provider participants felt strongly that transitions to non-driving had strong emotional consequences and represented both symbolic and real losses that deeply impacted the driver/ex-driver's sense of identity. Future research might also seek to examine the implications of this conviction for caregivers' understanding of their own emotional and identity-related experiences through the driving cessation transition with their loved one.

The caregivers included in this study represent a relatively homogenous sample in terms of characteristics such as sex (92% female caregiver) and geographical location (all urban and semi-urban). The relationship between driving and identity is likely to vary according to different urban, rural, and suburban settings. Research on rural drivers have examined the link between identity and independence to explain why older drivers disregard recommendations to stop driving (Johnson, 2002). While this study was conducted in Canada, and in areas where many people are highly dependent on private vehicle use for transportation, residents in other countries or regions may experience driving cessation differently. For example, people who experience cessation of driving in major metropolitan areas, such as New York or Paris, which are designed around public transit systems rather than private vehicle use, would presumably experience less disruption than the participants in this study. This observation also supports increased investment into physical infrastructure and environments to align the transportation needs of older adults with available resources, and maintain social belonging (Carr & O'Neill, 2015).

Further investigation into the ways that driving and driving cessation is related to identity and meaning may shed light on variations linked to social characteristics, such as gender differences in driving behaviors and emotional response to driving cessation (Morgan, Winter, Classen, McCarthy, & Awadzi, 2009), and the way that these characteristics intersect with environmental features such as rurality or disparities in available transportation alternatives. Finally, our findings also illustrate that loss of driving privileges associated with dementia are not always negatively experienced in emotional and other terms, as some drivers express indifference or even relief following the decision to stop driving (Byszewski et al., 2010). Further research that attends to the symbolic dimensions of driving would enhance understandings of the complexity in variations in responses to driving cessation by including greater diversity in sample characteristics and accounting for these differences within analytic approaches.

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