

'We're Not Doing It To Be Nasty': Caregivers' Ethical Dilemmas in Negotiating Driving Safety with Older Adults*

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Article

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Résumé

La présente recherche avait pour but d'examiner comment les aidants naturels gèrent et négocient la question de la sécurité de la conduite automobile avec leurs proches âgés lorsque ces derniers ne peuvent plus conduire en toute sécurité. Au total, 15 aidants de personnes âgées vivant à domicile ont participé à l'étude. Les participants prenaient soin de personnes souffrant de divers problèmes de santé compromettant considérablement la sécurité de la conduite, incluant la démence, la maladie de Parkinson, la schizophrénie, la dégénérescence maculaire et l'AVC. Une analyse thématique des témoignages a révélé les défis interpersonnels, sociaux et organisationnels complexes auxquels ces aidants ont fait face lorsque leurs proches ne reconnaissaient pas ou ne comprenaient pas la limitation de leurs facultés nécessaires à la conduite. L'analyse met en évidence le dilemme éthique au cœur de l'expérience des aidants. Elle fait ressortir l'importance de considérer l'enjeu et le blâme lors de l'élaboration de politiques et de pratiques respectueuses et efficaces.

Abstract

The purpose of this research was to investigate how informal caregivers of older adults cope with and negotiate driving safety when their loved one is no longer safe to drive. Fifteen informal caregivers of an older adult living at home took part in the present study. Participants cared for individuals with a range of health conditions that significantly impaired driving safety, including dementia, Parkinson's disease, macular degeneration, and stroke. A thematic analysis of participants' accounts identified the complex interpersonal, social, and organisational context they encountered when their loved one did not recognise or acknowledge limitations in their ability to drive. This analysis highlights the ethical dilemma at the heart of caregivers' experiences and identifies stake and blame as key considerations in the development of sensitive and effective policies and practices.

Introduction

The end of a driving career is recognised as a major life event akin to occupational retirement or bereavement (Byszewski, Molnar, & Aminzadeh, 2010; Sanford et al., 2018). Although the revocation of driving privileges can happen at any point in adulthood, research has focussed on driving cessation in later life as a function of health conditions that can accompany aging such as dementia, stroke, and Parkinson's disease (Turcotte, 2012; Yale, Hansotia, Knapp, & Ehrfurth, 2003). This literature reveals that driving cessation is often a markedly difficult process for drivers, their family members, and their health providers (Adler & Rottunda, 2006, 2011; Liang, Gustafsson, Liddle, & Fleming, 2015; Sanford et al., 2018). Moreover, driving cessation is associated with multiple adverse health outcomes for older adults including depression and social isolation (Chihuri et al., 2016; Gouliquer, Poulin, & Lesmana, 2015). Accordingly, decisions around driving cessation must be made judiciously.

Determining fitness to drive in these populations has proven to be a particularly difficult task. For instance, neither Alzheimer's nor Parkinson's disease has specific time frames or markers that clearly indicate when an individual is no longer safe to drive (Hebert, Martin-Cook, Svetlik, & Weiner, 2003; Turner, Liddle, & Pachana, 2017). Accordingly, the literature on driving cessation is dominated by efforts to develop and evaluate measures of driving ability (Bennett, Chekaluk, & Batchelor, 2016; Brown & Ott, 2004; Cameron et al., 2017; Haussmann, Buthut, & Donix, 2017; Piersma et al., 2018). Off-road tests, such as the Clinical Dementia Rating Scale or the Mini-Mental State Examination, have not been found to be sufficient measures of driving performance or risk level to determine when an individual is unsafe to drive (Bennett et al., 2016; Davis & Ohman, 2017). On-road tests are better predictors of collision risk than off-road tests; however, there is still no "gold standard" measure (Adler & Rottunda, 2017, p. 82).

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Although health care providers such as family doctors hold professional responsibility for revoking driving privileges, because of the lack of reliable assessment tools they often rely on the reports of informal caregivers such as spouses or adult children (Adler, Rottunda, Rasmussen, & Kuskowski, 2000). Indeed, it is increasingly recognized that family members are the “key decision-makers in the final decision to stop driving” (Adler, 2010, p. 54). Despite their central role, there has been little research that focuses on caregivers’ experiences of managing driving safety. When caregivers are included in research, the purpose is often limited to assessing their ability to judge fitness to drive, with results suggesting that they are poor and unreliable informants (Adler et al., 2000; Gergerich, 2016; Hebert et al., 2003). In the current research, we examine caregivers’ accounts of managing their loved one’s driving safety, paying particular attention to the social and organisational context in which this process unfolds. In doing so, we hope to illuminate a more complex understanding of the challenges caregivers face in assessing and addressing driving safety.

In their scoping review of the literature, Liang, Gustafsson, Liddle, and Fleming (2015) reported that research investigating family members’ experiences with driving cessation only began in 2000 and has resulted in a small body of research. Within this literature, researchers have explored various facets of driving cessation including coping strategies (Jett, Tappen, & Rosselli, 2005), the process of stopping driving (Liddle et al., 2013), family dynamics (Liddle et al., 2015), and the role of emotion (Turner et al., 2017). Although this literature is instructive, its attention to caregivers’ experiences is limited in that it is almost exclusively made up of studies that “contain perspectives of family members alongside other stakeholders” such as retired drivers and health professionals (Liang et al., 2015, p. 2116). Moreover, in several studies, caregivers and drivers were interviewed together, significantly limiting how candid caregivers could be in their reports (Liddle et al., 2013, 2015; Turner et al., 2017).

In their review, Liang et al. (2015) identified only four articles on driving cessation that attended exclusively to the experiences of caregivers.¹ D’Ambrosio et al. (2009) investigated caregivers’ communication with loved ones with dementia about driving reduction or cessation. Consistent with other research, this study found that caregivers viewed themselves as “essential elements” in decision-making around driving (D’Ambrosio et al., 2009, p. 37). Despite their concerns, however, caregivers struggled to develop a plan for dealing with driving cessation. These findings are echoed in the research by Connell, Harmon, Janevic, and Kostyniuk (2012) who conducted a study with adult children. Participants were worried about their parents’ driving but tended to avoid planning for driving cessation. These studies suggest that despite their significant concerns, caregivers are not particularly effective in bringing about behaviour change.

Factors that might contribute to caregivers’ struggles to intervene were explored by Adler, Rottunda, Rasmussen, and Kuskowski (2000) and Hebert, Martin-Cook, Svetlik, and Weiner (2003). Adler et al. (2000) compared dependent caregivers (who did not drive and relied on care recipient for transportation) and independent caregivers. They found that dependent caregivers were significantly less likely than independent caregivers to believe that their loved one should stop driving and to actively encourage driving cessation. The authors suggested that personal investment in transportation interfered in dependent caregivers’ ability to judge driving performance. Ability to assess driving ability in relation to dementia was also explored by Hebert et al. (2003). They compared caregivers’ responses to fictitious scenarios about dangerous driving and their own experiences of their loved one’s dangerous driving. Although participants clearly identified that the

fictitious driver with dementia should stop or restrict his driving, they responded in equal measure that their loved one continued to drive despite comparable impairments.

These four studies reveal important schisms between caregivers’ concern and action, objective reasoning, and decision making. Explanations for these schisms are often posed in individual terms such as cognitive appraisals. For instance, Hebert et al. (2003) suggested that “caregivers may have difficulty objectively evaluating driving abilities of their loved one and/or comprehending risks of their continued driving” (p. 26). However, in order to more fully understand experiences of driving cessation, researchers have signalled the need to go beyond an individual level of analysis (e.g., thoughts and motivations) and to give greater consideration to the interpersonal, social, and organisational context in which driving cessation occurs (Rudman, Friedland, Chipman, & Sciortino, 2006, p. 72). Following this suggestion, the purpose of this research was to investigate how informal caregivers of older adults cope with and negotiate driving safety, paying close attention to the social and organisational context of their experiences.

Methods

As researchers, we adopt a critical realist epistemology, in which we acknowledge the reality of a material world, while maintaining an understanding that the world is necessarily mediated through discourse (Parker, 1992; Willig, 1999). Consistent with this perspective, we adopted a “contextualist” approach to thematic analysis (Braun & Clarke, 2006) in which we attended not only to the content of participants’ account but also to its construction and rhetorical effects. That is, in line with a critical realist epistemology, this approach to thematic analysis “works both to reflect reality and to unpick or unravel the surface of “reality” (Braun & Clarke, 2006, p. 81). In the sections that follow, we outline how we conducted this research, including descriptions of participant demographics and recruitment procedures, how we conducted interviews, and analysed the data.

Participants

The analysis we present here is derived from a larger study exploring the experiences of informal caregivers of older adults aging in place in Atlantic Canada (Lafrance, Gouliquer, & Poulin, 2018). Participants included in the present analysis were 15 individuals who identified driving safety as a concern they faced as caregivers. Participants cared for individuals with a variety of health conditions, including dementia, Parkinson’s disease, schizophrenia, stroke, heart condition, and macular degeneration.

All participants were caregivers at the time of the interview, or in the recent past. They cared for spouses, parents, or in-laws. They ranged in age from 41 to 78. Thirteen were women and two were men. Seven of the participants were living in rural regions and eight were living in urban centres. One participant had completed high school, four had college degrees, five had attended or graduated from university, and five had graduate degrees. Participants’ income ranged from \$5,000 to over \$150,000 CAD. All participants included in the present study were interviewed in English (the larger study also includes interviews in French, but we conducted those interviews after completing the present analysis).

Data Collection

Following approval from our institutional Research Ethics Board (REB #2016-17), we recruited participants by inviting them to take

part in a study on the experiences of caregivers of older adults aging in place. These invitations were distributed through flyers, community newsletters, and a Facebook post. We asked potential participants to contact the first author, at which time they were fully informed about the nature of the study. We also sent informed consent letters to potential participants by mail or email to allow them time to consider this information. At the time of the interview, the interviewer and participant met in a quiet space of the participant's choice, such as their home, the first author's office on campus, or an interview room in a public library. The interviewer gave each participant \$20.00 at the beginning of the interview as a token of appreciation.

The first author conducted the interviews, which were semi-structured, and lasted between one and three hours. The topics explored in the interviews included participants' everyday experiences of providing care, their responsibilities, the challenges they faced, and what helped in providing care. The interviewer encouraged participants to orient to issues that were important to them. The interviewer recorded the interviews, and trained research assistants transcribed them verbatim. We replaced participants' names with pseudonyms which we used to ensure anonymity.

In consultation with the entire team, the first two authors analysed the transcripts using thematic analysis as described by Braun and Clarke (2006, 2013). In our early analysis, we identified the key theme of "driving safety" as a central concern for many participants. In this article, we present our analysis of this theme. In developing this analysis, we first coded all instances in which participants talked about driving. We read the data in this code multiple times as we worked collaboratively to identify patterns of consistency and variability across the accounts. Through this process, we developed separate files for each theme that we identified, and these included all relevant text across the interviews. Again, we read and reread the data files as we clarified themes within and across the data. In this way, the analysis involved a detailed examination of participants' talk of their experiences of managing driving safety, including what helped and hindered this process.

Analysis

Participants described layers of challenges in managing driving safety. First, they encountered the challenge of gauging risk in which it was often unclear if the older adult they cared for was fit to drive. Several participants indicated that the clarity came only after serious incidents, such as a car accident. A second and overlapping challenge was that attempts to intervene were often met with significant anger on the part of drivers and other family members, threatening these important relationships. These accounts of resistance signalled not only a rejection of the negative assessment of fitness to drive, but also the suggestion that there was a "problem" to begin with (such as the onset of dementia). In the analysis, we highlight the challenges participants faced as an ethical dilemma. On the one hand, removing the licence threatened to cause significant distress to their loved one and caused strife in the family. On the other hand, failing to intervene risked the safety of their loved one, themselves (frequently passengers), and the public. In the final section of the analysis, we explore participants' (sometimes failed) efforts to work with doctors and government officials to protect the safety of drivers and the public. We conclude with an exploration of stake and blame as key considerations in the development of sensitive and effective policies and practices.

Is There a Problem? Gauging Risk

Participants typically talked about a long process in which there was an accumulation of events and, in particular, driving events, which over time signalled that there was "something wrong". For instance, Margaret described slowly coming to the realization that her father-in-law was becoming disoriented. She said:

Quite often he would call me and say, "I'm looking at a hotel that says this, how do I get home from here?". And you know, the first thing I thought, "Oh he's joking!" Second or third time it happened I thought, "Hmmm, he's not joking anymore." So that's when I started to push the family to say, "No he can't [drive]." (Margaret)

Margaret then went on to describe how her brothers- and sisters-in-law rejected her concerns and her father-in-law continued to drive until he drove into a building. Similarly, Julie described that her father was involved in several driving incidents before the family intervened:

I noticed that, you know, Dad's not getting around as well as he should and one day ... [I got a call from his dentist's office who reported that when] he was leaving the parking lot of the dental office he backed into a car. Didn't notice. Pulled out and ran into another car. Didn't notice. Put the car in reverse and drove off! So two vehicles were damaged! So *then* it became a full-time thing; now what do we do? (Julie)

Julie's account continues with a description of how her father did not recognise a stop sign near his house. She then recounted being at a family event in which her father parked in front of her. She described what happened when they left the party:

When we came out, I said, "Now *Dad* I have to back out. I want you to be very, very careful and wait till I'm out of the driveway before you put your car in reverse." Well he came so close to hitting me [...] The next thing you know the back end of my father's car is coming towards me standing there and I had to jump in the ditch. He didn't even realise I was standing there so that's when I called, uh, a family meeting and I said to my brothers, "I have to ... we have to take get Dad's licence gone!" (Julie)

Viewed from the perspective of the assessment literature, these instances might be considered further evidence that caregivers are poor judges of fitness to drive – that they simply misjudge driving competence and fail to intervene appropriately. However, a deeper examination of caregivers' accounts reveals a complex interpersonal and organisational context that was extremely challenging to navigate. Notably, participants talked at length about the anger and resistance incited in the driver and other family members who rejected their conclusion that they should no longer drive. Before outlining this theme in the data, however, it is worth mentioning that not all participants described such challenges. In the next section, we outline these exceptions.

Exceptions: Voluntarily Hanging Up the Keys

In some instances, drivers had insight into their physical and/or cognitive changes and volunteered to stop driving on their own. For instance, Kathy recounted how her mother's sudden loss of vision signalled the abrupt end of her driving career:

She was at a friend's place visiting and started to drive home and suddenly she couldn't see. She had macular degeneration, but she didn't know it and it was at just at that moment that it really, it just sort of clicked and [she] barely got home by the grace of God and never drove again because she was terrified. (Kathy)

Similarly, Susan stated that her husband accepted his diagnosis of Alzheimer's disease and recognised his inability to drive. She recounted, "He drove once, came home thank goodness, and just

said, 'I can't do it anymore.' He got lost. He didn't know where he was going. So, he just hung his keys up." For Susan and Kathy, the voluntary cessation of driving meant that they did not face the challenging process described by other participants. In contrast, most participants described that their efforts to intervene were met with anger, resistance, and family conflict.

"He Was So Mad!" Interventions Inciting Conflict

When drivers refused to stop driving, caregivers intervened by (a) asking the doctor to revoke the licence (Diane, David, Susan, Margaret, Marilyn, Carolyn, Janet), (b) contacting the Motor Vehicle Branch (Julie), (c) removing the vehicle (Judith, Angela, Carolyn), or (d) disabling it (Janet). Predictably, these efforts were often met with intense negative reactions. For example, following a stroke, Susan's mother had her licence revoked by her doctor. Susan emphasised her mother's angry reaction by repeating, "She was so mad ... she was so mad." Similarly, after Marilyn initiated the removal of her father's licence, she said, "My father was so upset with me. He was angry with me, he kept saying, 'When I get better I'm gonna get my licence'". In her interview, Judith talked at length about how angry her husband was when his licence was revoked after the progression of Alzheimer's disease. She said, "It was devastating – to this *day* he will talk [...] about losing his licence and how that wasn't fair [...]; it was *absolutely* catastrophic."

Other family members were also described as actively resisting intervention attempts. In particular, it was common for siblings who were less involved in their parents' care than participants to dismiss the need to intervene. For instance, Julie (whose father ran into two cars at the dentist's office – described above) stated that her brothers thought that having his licence revoked "was just a horrible thing to do". Similarly, Margaret was the only one to speak up about her father-in-law's dangerous driving and appealed to her husband to talk with his siblings. She said, "It was difficult in that my husband *agreed* with me but he's the second youngest of six and wasn't really prepared to go against his older siblings because they [said], you know, 'Of course he can still drive!'" Marilyn also reported challenges with her brother after she initiated the removal of their father's driver's licence. She stated, "My brother blames me. My brother says to me, 'You were the one who took Daddy's licence away from him'".

The Meaning of Losing a Driver's Licence

Importantly, these accounts of resistance marked not only a rejection of the conclusion that the loved one should not drive, but a rejection of the conclusion that "there was a problem" to begin with. Thus, acknowledging impairments in driving was often part and parcel of acknowledging the development of illnesses or conditions, most notably dementia. For instance, Angela reported that after a diagnosis of Alzheimer's disease and the revocation of her licence, her mother resisted both by stating, "They may say I have this [Alzheimer's], but I can still drive". In a similar way, David vividly described his wife's anger and rejection at the suggestion of Alzheimer's:

[She] was extremely angry about the notion that she might have Alzheimer's. Really angry and she didn't want to hear that word and she didn't want anybody talking about it. And so really, she put on a pretty good front with her doctor [...] who was pretty much misled into thinking she was pretty much okay. (David)

Later in his account, David described how his wife pointed to her ability to drive as an indication that she did *not* have

Alzheimer's – that she was "fine". He lamented how difficult it was to manage her driving safety on his own, given her anger and denial:

Well, this is the only disease I'm aware of where, the person who has the disease, doesn't want to know about the disease [...] so it's really left to the caregiver to carry that whole load, that for most diseases, is shared with the patient. That's a really big deal. She [claimed she] was fine, as recently as two years ago, yeah, [...] she] would say "Well, I'm walking, I'm writing, I'm driving – I'm, you know, I'm still driving aren't I, David?" You know, "I'm fine." (David)

The intense emotional reaction of drivers and family members highlighted the significance of what it means to have, and more importantly, to *lose* driving privileges. Being able to drive was described as a measure of fitness and competence. After all, getting one's driver's licence is a marker of adulthood and independence (Adler & Rottunda, 2006; Hebert et al., 2003; Sanford et al., 2018). In previous research with older drivers, driving was found to be "an indicator of independence and well-being and stopping driving as an indicator of dependence and decline" (Rudman et al., 2006, p. 68). Thus, continuing to drive despite family and physician concern can, in some cases, be understood as an act of resistance against an unwanted, and for some, a terrifying diagnosis.

Consistent with past research (Liddle et al., 2015; Sanford et al., 2018), the revocation of the licence was also depicted as a monumental and even tragic event in loved ones' lives. For instance, in reflecting on all the losses her father endured over the past several years, Diane said, "The guy lost his wife, lost his home, *then* his licence, then we took his licence away." In equating the loss of his licence with that of his wife and home, Diane's account highlights the magnitude of this loss. The significance of losing one's driver's licence was echoed by Carolyn. She poignantly stated that the day her father lost his licence after his stroke was the "hardest day of [his] life."

Between a Rock and a Hard Place: Intervening as an Ethical Dilemma

Given the significant consequences of removing the driver's licence, participants often described being hesitant to intervene until convinced that their loved one was no longer safe to drive. This often meant that the issue culminated into a crisis, such as an accident. Participants' accounts of reluctance to intervene until the danger was palpable mirrors findings from research with older drivers that found that most "do not plan for the cessation of driving", and that, indeed, many "explained that only an accident or near-accident would lead ... them to cease driving" (Rudman et al., 2006, p. 74). In our interviews with caregivers, the enormity of the challenge they faced became most visible in their accounts of how they finally took action. Here, participants repeatedly highlighted the risks of *both* intervening and failing to intervene. Accordingly, their situation came into view as an acute ethical dilemma. On the one hand, removing the licence threatened to cause significant distress to their loved one and strife in the family. On the other hand, failing to intervene risked the safety of their loved one, themselves (frequently passengers), and the public. The following quotations illustrate the ethical bind caregivers faced when they intervened regarding their loved one's driving:

The two brothers thought that was just a horrible thing to do and I felt so guilty! But I thought he's either going to kill himself or he's going to kill a child or some innocent person. (Julie)

She was so mad ... she was so mad. And she never knew I was the one that instigated it [the removal of the licence ...]. I mean I would be just as responsible if she had an accident as her! More so than her. (Susan)

As he worsened, I said to the doctor, “We need to take his licence away from him. I’m afraid he can’t drive. Daddy would never forgive himself if he hurt somebody else and I would never forgive *myself* if something happened to him.” But ... my brother blames me. (Marilyn)

In these accounts, participants defended their actions by repeatedly invoking the risk of potentially fatal accidents. In positioning their decisions to intervene in this way, participants defended their actions as reasonable, just, and indeed, as obligatory. As Betty said, “there was just too much at stake”. At the same time, these very same efforts made them the targets of blame and anger, thereby threatening the caregiver’s relationship with the driver, and by extension, their care and health. Therefore, these accounts highlight the complex interpersonal context in which caregivers must make decisions about managing their loved one’s driving safety. Decisions to intervene are revealed as not simply the result of an assessment of driving ability (e.g., passing or failing a test), but as the product of a complex consideration of important relationships, others’ evaluations (e.g., drivers, family members), and the risks and consequences of action (anger and resistance) and inaction (accident risk).

Managing Stake and Deflecting Blame: What Helped or Hindered

In the final section of the analysis, we explore the key piece that participants described as helping or hindering this navigational process – namely, managing stake and deflecting blame. When drivers did not understand or acknowledge their limitations, the revocation of their licence was perceived as an injustice and an action that warranted blame and elicited anger. Most often, participants appealed to their doctors to revoke their loved one’s licence and doing so helped them to deflect blame and preserve these important familial relationships. For instance, although Julie reported her father directly to the Motor Vehicle Branch, she was happy when her doctor invited her to blame him instead:

I told his doctor that I had done that and he said, “Good because I was about to send them a letter anyway.” And he said, “If your father has any problems with this you can blame it on me.” And I said, “Okay!” (Julie)

However, several participants described working with doctors who refused to intervene. As a consequence, these caregivers were left “holding the blame”, which fundamentally threatened their relationship with their loved one and, in turn, their ability to offer essential support. For instance, Carolyn indicated that two doctors involved in her father’s care did not know that they were able to revoke driving privileges. David lamented, “We had to initiate the driver’s licence removal, [but] it should have been the doctor.” He explained that doctors are sometimes “afraid to because they are pilloried for doing it” and worried about “how many people are driving on the highway who shouldn’t because their doctors don’t want to create a hassle.”

Professionals’ evasion of responsibility and blame for revoking the driver’s licence proved to be a central challenge in Diane’s role as a caregiver. She described at length how, despite the fact that her father failed multiple driving tests, his doctor refused to revoke his licence or discuss the issue further. She explained:

Some of the challenges [were] dealing with the doctors. Since then the doctor that we had...um...has...left the profession of gerontology and gone to a GP practice because she had too many lawsuits against her. She wouldn’t take my father’s licence away when I asked. Like he was driving on the left-hand side of [the highway] instead of the right [...] So it was time...Anyways she didn’t want to take his licence away! So I basically just said to her, “If you don’t, if something – if he kills somebody, I’m suing you and if my father gets killed, I’m suing you. Just a heads up!” So, I had to go to

our family doctor. He wrote a letter to take it away. She wrote a letter not to take it away. So, the province got ahold of me. They said, “What’s going on, we got two doctors that – ” and I say, “I want it taken away.” And she says, “Well, okay that’s not a problem.” But she says, “We’re going to be putting on your father’s file you are the one who wants it taken away.” And I go, “He lives with me – like, give me a break!” And she says, “Nope that’s how it works!” And I’m going, “That’s not fair!” I said, “I’m trying to save lives here and you guys are just putting sticks in the spokes here!” (Diane)

Here, Diane recounted working through layers of red tape in her effort to protect her father and the public. The geriatrician refused to take the blame for revoking the licence, and then later, so did the government. Consequently, on top of all her work as a caregiver, she had to negotiate a system that obstructed her efforts to ensure her father’s safety and that of the public. Exasperated, she said, “fighting with the government, like, do I really have to do this?” In reflecting on their struggles, both Diane and David suggested the need for caregivers’ voices to be better heard:

People should listen to the family. We know them best ‘cause he [doctor] only saw her maybe two hours a year [...] So that’s one of the things that I’m sure all the families go through. You know, we’re not doing it to be nasty! (Diane)

This was a real system failure with dementia. [...] It seems as though there is no protocol that, as soon as there is a suspicion of dementia, then, what should kick in is not only a meeting with the patient but then a separate meeting with the patient’s family because in the early stages denial is a big factor. (David)

Several participants indicated that whatever system was developed, it ought to take into account preserving caregivers’ relationships with their loved ones. Currently, as Diane stated, intervening threatens to position caregivers as “nasty” and fundamentally disrupt their ability to provide care that enables their loved ones to live in the community.

Discussion

Several articles have explored the “ethical dilemma” faced by doctors assessing driving fitness among older patients – “finding the balance between public safety and the safety, freedom, and independence of the patient” (Adler & Rottunda, 2017, p. 77; Mazer et al., 2016). It appears well-acknowledged in this literature that, “[w]hen the physician’s role of caring for patients collides with the duty of societal protection, a dramatic and controversial dynamic occurs that often strains the doctor–patient relationship” (Rapoport et al., 2007). The present research extends this perspective by also situating caregivers at the intersection of this difficult dilemma, but without the professional resources available to health care providers (e.g., professional codes of ethics and laws, detailed analyses of ethical decision-making). It reveals the complex social and organisational negotiation required of caregivers in gauging driving fitness while balancing threats to the well-being of their loved one, their relationships, and the public.

To date, research in the area has emphasised an individualistic approach wherein informal caregivers are regarded as individual and autonomous agents called upon to make objective decisions around driving safety. In these terms, caregivers often fail and are readily framed as poor informants. Of course, caregivers can be wrong in their assessments of fitness to drive, influenced by factors such as ageism or ulterior motives. However, in taking a broader socio-political lens on the issue, this analysis exposes the complex context in which caregivers attempt to assess and manage driving safety. In this frame, informal caregivers are revealed as contending

with not only the matter of gauging driving safety, but also with the competing evaluations of long-trusted loved ones (drivers and family members), as well as the risks and consequences of action (anger and resistance) and inaction (accident risk). Accordingly, this research points to the need for reforms to policy and practice in order to better support older adults and their allies.

Recommendations for Policy and Practice

When individuals do not volunteer to stop driving when they are no longer safe to do so, then revoking the licence is seen as an injustice, for which someone is to be blamed. Unfortunately, that blame most often falls to care recipients' two most important allies: caregivers and doctors (Rudman et al., 2006). This arrangement fundamentally threatens these essential relationships, in turn risking the care and health of the care recipient (Adler & Rotunda, 2017). As a result, both caregivers and doctors have been found to be reluctant to intervene (D'Ambrosio et al., 2009; Nichols & Martindale-Adams, 2006). Knowing that allies struggle to report unsafe driving and yet continuing to rely on them to do so amounts to collectively burying our heads in the sand. A greater understanding of the systemic challenges that allies face requires systemic yet caring solutions, and importantly, ones that address the central issues of stake and blame.

A number of editorials in Canadian medical journals situate driving with dementia as a public health concern that requires a public health response (MacDonald & Hébert, 2010; Rapoport et al., 2007). As the authors made clear, "the point is not to get seniors – who are, for the most part, our safest drivers – off the roads" (MacDonald & Hébert, 2010, p. 645). However, with an aging population, it is imperative to address driving safety in relation to diagnoses such as dementia. To address this challenge, Rapoport et al. (2007) suggested the need to establish a national agency that assesses fitness to drive with on-road testing measures, which are superior to in-office tests. They liken this to referrals to Children's Aid, where doctors or the public can (anonymously) refer to the agency if there is a reasonable suspicion of safety risk. Not only would this result in more accurate assessments of fitness to drive because of on-road assessment, but the "blame" would lie outside of the support network, thereby helping to preserve key relationships (Rudman et al., 2006). Instead of adopting ageist or punitive approaches, such an agency could be developed and marketed in ways that support safe driving across the lifespan. Skill training and maintenance could be encouraged throughout driving years, rather than merely at the time of licensing. Drivers' education workshops could become routine and incentivised with lower insurance rates. Importantly, these suggestions align with older drivers' preferences for policy reform around driving safety across the lifespan (Rudman et al., 2006).

Further, public awareness campaigns could encourage self-regulation and proactive discussions about driving interruption or retirement. For instance, such campaigns could directly address the eventual need to stop driving among those with progressive diseases like Alzheimer's or Parkinson's by encouraging families to have these difficult discussions early in the process. Campaigns could also reinforce the benefits of compensatory strategies such as limiting driving to familiar areas, low traffic times, and daylight hours – strategies that would also benefit new drivers. In bringing these issues to light, such efforts would raise public awareness, help families broach difficult conversations, and ultimately, support safe driving across the lifespan.

A consideration of driving safety also opens up broader needs in terms of ensuring that those who can no longer drive are not

isolated (Gouliquer et al., 2015; MacDonald & Hébert, 2010; Sinha et al., 2016). Most Canadians live in neighbourhoods that were designed for individual drivers (Turcotte, 2012). Therefore, attention to urban planning, and innovating transportation programs, are essential to ensure that those who are no longer able to drive can continue to be active in their community (Gouliquer et al., 2015; MacDonald & Hébert, 2010; Sinha et al., 2016).

Direction for Future Research

Although there is value in attending to the combined accounts of drivers, caregivers, and health professionals (e.g., Jett et al., 2005; Liddle et al., 2013, 2015), this methodological approach tends to flatten and erase contradictions and tensions across stakeholders' perspectives. In the current research, attending exclusively to the accounts of informal caregivers exposed important conflicts among caregivers, doctors, and family members, thereby revealing the central challenge around "taking the blame". To our knowledge, this is the first study that identified conflicts in the family, particularly between siblings, as a barrier to caregivers' intervention around driving safety. Importantly, these accounts helped to clarify that resistance of driving interventions by both drivers and family members was at times also a rejection of the suggestion that there was "a problem" (e.g., dementia) to begin with.

In exploring the accounts of caregivers of individuals with a range of diagnoses, this analysis also highlights the key role of insight. Analytic themes developed not around diagnoses or impairments, but the degree to which drivers understood and acknowledged their driving limitations. Lack of awareness ("anosognosia") is associated with a range of neurological conditions including traumatic brain injury, dementia, and stroke (Chen et al., 2020). However, recent research suggests that overestimating driving performance is common even among adults without cognitive impairment (Chen et al., 2020). Thus, the findings of this research highlight the importance of accurate self-awareness and self-monitoring in education and support campaigns around driving safety across the lifespan.

A limitation of this research is its sole focus on the accounts of caregivers who identified driving safety as a concern and took actions to address it. In future research, those who do not discuss this as a challenge, despite licence revocation, could be interviewed to better understand if or how they orient to the ethical dilemma. Further, regarding caregivers as not merely poor judges of driving fitness but as individuals caught in the crossroads of a complex interpersonal, professional, and organisational issue might be useful in facilitating therapeutic conversations between health care providers and caregivers. Directly acknowledging this challenge might help to bring clarity and understanding to a "shared" vision of public responsibility, while still supporting caregivers and health care providers. Thus, the clinical utility of addressing the ethical dilemma in therapeutic conversations and public awareness campaigns could also be examined. Finally, future research could explore family dynamics as a key role in driving cessation, by interviewing various members of family and support networks.

Conclusion

In the health care system, as in the driving cessation literature, the accounts of informal caregivers of older adults can be muted or left unheard. In contrast, the findings of this study highlight their important role in informing policy and practice around driving

safety. Notably, attending to the accounts of informal caregivers brings to the fore the complex interpersonal and organisational negotiation they encounter when their loved one does not recognise or acknowledge limitations in their ability to drive. This analysis highlights the ethical dilemma at the heart of caregivers' experiences and identifies "blame" as a key consideration in the development of sensitive and effective policies and practices.

Note

1 Liang and colleagues subsequently studied driving disruption among caregivers of individuals with traumatic brain injury. However, since this research involved (often temporary) disruption rather than cessation, these are not reviewed here.

Declaration of interest. None

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