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Shifting gears versus sudden stops: a qualitative study of consultations about driving in patients with cognitive impairment

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Title

Shifting gears versus sudden stops: a qualitative study of consultations about driving in patients with cognitive impairment

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Abstract

Objective

Primary care physicians (PCPs) report finding consultations on fitness to drive (FtD) in people with cognitive impairment difficult, and potentially damaging to the physician-patient relationship. We aimed to explore PCP and patient experiences to understand how the negative impacts associated with FtD consultations may be mitigated.

Methods

Individual qualitative interviews were conducted with PCPs and patients in the Republic of Ireland. We recruited a maximum variation sample of PCPs using criteria of length-of-time qualified, practice location and practice size. Patients with cognitive impairment were recruited via driving assessment services and participating general practices. Interviews were audio-recorded, transcribed, and analysed thematically by the multidisciplinary research team using an approach informed by the framework method.

Findings

The issue of FtD arose in consultations in two ways: introduced by PCPs to proactively prepare patients for future driving cessation, or by patients who urgently needed a medical report for an expiring driving license. The former strategy, implementable by PCPs who had strong relational continuity with their patients, helped prevent crisis consultations from arising. The latter scenario became acrimonious if cognition had not been openly discussed with patients previously and was now potentially impacting on their right to drive. Patients called for greater clarity and empathy for the threat of driving cessation from their PCPs.

Conclusion

PCPs used their longitudinal relationship with cognitively impaired patients to reduce the potential for conflict in consultations on FtD. These efforts could be augmented by explicit discussion of cognitive impairment at an earlier stage for all affected patients. Patients would benefit from greater input into planning driving cessation and acknowledgement from their PCPs of the impact this may have on their quality of life.

Strengths and limitations of this study

- This multi-perspective qualitative study examined the experiences of both healthcare professionals' and patients with cognitive impairment to understand both sides of sensitive consultations on medical fitness to drive in the setting of cognitive impairment.
- The transferability of our findings is enhanced by a maximum variation sample of primary care physicians in terms of different practice contexts (large versus small group practices, urban versus rural locations) and variable level of professional experience.
- The validity of interviews with primary care physicians was enhanced by using the technique of chart-stimulated recall.
- We found that engaging older patients with cognitive impairment in our research was challenging and countered this by expanding on approaches to recruitment.

Introduction

For older adults, driving cessation can limit access to family, friends, and services and is an independent risk factor for entry to a nursing home¹. Unsurprisingly, primary care physicians (PCPs) are often wary of consultations on medical fitness-to-drive (FtD) because of potential negative impacts on a patient's sense of autonomy, quality of life, and the doctor-patient relationship². This discomfort is amplified in patients where there is concern about cognition, as PCPs can also be reluctant to address the earlier stages of cognitive impairment with older patients due to fear of causing unnecessary anxiety, labelling and stigma³.

Cognitive impairment exists across a spectrum from mild cognitive impairment to mild, moderate and advanced dementia. Prevalence estimates for these conditions vary by study design and population examined but approximations for the prevalence of mild cognitive impairment in older adults are 6-20% and for dementia are 4-7%. While not all patients with mild cognitive impairment go to develop dementia, approximately 10% per year do progress with the majority of these people experiencing decline in driving abilities over time⁴. Cognitive decline is associated with crash risk across the cognitive spectrum⁵, but the point where an individual patient must consider driving cessation varies case by case². Severe dementia is a contraindication to driving and safe driving is generally unlikely in the presence of moderate dementia. Many patients with mild dementia and the majority with mild cognitive impairment may be deemed fit to continue driving but should be re-evaluated every six to twelve months or sooner if indicated². Problems arise given the shortcomings in the detection, diagnosis and disclosure of cognitive impairment: approximately 50% of older adults with dementia are either undiagnosed or unaware of the diagnosis⁶.

Qualitative research examining PCPs' perspectives on FtD consultations for patients with possible cognitive impairment demonstrates that their discomfort with these consultations transcends differences in regional policies on licensing and road-safety⁷. Findings include PCPs' view of themselves as reluctant regulators⁸, who "hate" that driving assessment has anything to do with their role^{9,10}, and frequent uncertainty about their legal and ethical obligations¹¹⁻¹⁶. Evaluations of patients' responses to the prospect of driving cessation in the context of cognitive impairment highlight a range of negative emotions such as anger, frustration, and sadness, the disruption to self-identity and fear of loss of independence^{17,18}. Up to one fifth of PCPs report a patient leaving their practice because of FtD consultations that have gone badly, highlighting just how distressing these consultations can be for patients¹⁶.

International strategies for managing the rising global prevalence of cognitive impairment and dementia prioritize management in the community and PCPs are assuming an ever increasing role in the on-going management of these conditions, including the assessment and re-assessment of medical FtD¹⁹. However, there has been little examination of the consultation strategies used by PCPs in an effort to lessen the emotional impact of FtD consultations for patients with cognitive impairment, nor have patients views on PCPs' consultation strategies been explored. In this study, we examine both sides of the FtD consultation- PCPs and patients with cognitive impairment - in order to understand how the negative aspects of these consultations may be mitigated. We were specifically interested in how, in the setting of cognitive impairment, FtD is introduced into consultations in primary care; what consultation strategies PCPs use; the influences on PCPs' approach; and aspects of the FtD consultation that could be improved from patients' and PCPs' perspectives.

Methods

A multi-perspective qualitative design was used. The setting was primary care in the Republic of Ireland.

PCP participants and interviews

Semi-structured qualitative interviews were conducted with PCPs between February and July 2017. Inclusion criteria were fully trained PCPs working in clinical practice. Participants were recruited via online PCP discussion groups and two regional professional development meetings. We sought a maximum variation sample of PCPs against the following criteria: length-of-time qualified (over/under ten years), practice location (rural/urban), and practice size (<3/≥3 full-time PCPs). Recruitment continued until the sample represented a satisfactory mix of these criteria and preliminary data analysis indicated that further interviews were unlikely to generate additional information power²⁰.

During interviews, the researcher (KML) drew on the technique of chart-stimulated recall²¹. This technique involves asking participants to choose patients from their caseload for whom consultations on FtD included concerns about cognition. We asked PCPs to choose at least two cases, ideally one where the FtD consultation went well and one where it did not go so well. During the interviews, PCPs were asked to provide a narrative account of the patient's FtD consultation and subsequent consultations, using the patient's medical chart as an aide memoire (see topic guide in appendix). This approach focused interviews on PCPs practice-based experience rather than rhetorical discussions of FtD, gave insight into the breadth of a PCPs experience of FtD consultations in cognitive impairment and facilitated exploration of both unsuccessful approaches as well approaches which could be usefully implemented by others. Interviews were conducted in the PCPs' practices, allowing them to refer to case notes to facilitate recall of the consultations. The acceptability, reliability, and validity of chart-stimulated recall for retrospectively assessing clinical practice has been demonstrated in previous studies²¹.

Patient PCP participants and interviews

Semi-structured qualitative interviews were conducted with patients between June and November 2017. Inclusion criteria were patients with cognitive impairment (mild cognitive impairment or mild dementia). We invited patients to participate using mail-outs to people who had attended driving assessment services after being referred to that service by their PCP due to concerns about cognitive impairment. As this initial recruitment strategy was unfortunately not very successful, we expanded recruitment by asking participating PCPs to invite patients with cognitive impairment directly. Once a potential participant expressed interest in the study, the qualitative interviewers (KML, CSh) ensured that the person had a full understanding of the process and confirmed their capacity to participate. One person was interested in participating but suffered from aphasia as a feature of her cognitive impairment (although she was still deemed fit to drive after assessment); in this case we offered the patient's family carer an opportunity to be interviewed instead.

We conducted interviews in the participant's home, the university or other location of their choice. A topic guide, which was written in collaboration with the Alzheimer's Society of Ireland was used in interviews (see appendix); in summary participants were asked to recount their experiences of, thoughts on and preferences for (or those of the person they care for) FtD consultations in primary care. Both interviewers (KML, CSh) had extensive experience in interviewing in sensitive situations in the fields of dementia and gerontology.

Data analysis

All interviews were audio-recorded, transcribed in full and de-identified. After the first five PCP interviews and all patient interviews, the interviewers (KML and CSh) presented reflexive accounts and field notes to two other team members (CS and CB), leading to iterative modification of topic guides. We used a framework approach to analysis²². Once data collection was complete, each transcript was thematically coded by at least two members of the multidisciplinary research team (KML-health service researcher, CS, TF, CB- all academic PCPs, LH-occupational therapist, CSh-social scientist) to familiarize ourselves with the data. We used this list of themes to create an inductive matrix for further analysis. The matrix placed emphasis on the PCPs' approach to FtD consultations and the events that ensued within those consultations. After indexing interview data into the matrix, further rounds of coding were conducted to develop, interpret and refine themes within the matrix. Divergent accounts were sought within the data. Transcripts were not provided to participants for feedback. NVivo software was used to support data analysis. All participants provided written informed consent. Research ethics approval was granted by the Clinical Research Ethics Committee of the Cork Teaching Hospitals.

Patient and Public Involvement

We developed the patient invitations, information letters, and expression of interest forms in collaboration with patient and public representatives from the Alzheimer's Society of Ireland (acknowledged below). Patient and public representatives also reviewed and rephrased the topic guide for interviews with patients with cognitive impairment. Patients with cognitive impairment were interviewed in this study as described above.

Findings

Eighteen people participated: twelve PCPs, five people with cognitive impairment and one carer. The characteristics of PCP participants are shown in Table 1. Amongst patient participants, three patients lived in rural locations and three had been assessed (by driving assessment services) as fit to drive despite their cognitive impairment. On average, PCP interviews lasted 20 minutes (range 10 to 43) and patient interviews lasted 29 minutes (range 8 to 120). The themes are presented narratively incorporating quotes from the data (shown in *italics*).

Table 1. Characteristics of participants

	Practice location	Practice size at time of interview (small group <3 full time PCPs/ larger group ≥3 full time PCPs)	Years qualified as PCP
PCP1	Urban	Larger group	Over ten years
PCP2	Urban	Small group	Less than ten years
PCP3	Rural	Small group	Less than ten years
PCP4	Rural	Large group	Over ten years
PCP5	Mixed	Large group	Less than ten years
PCP6	Rural	Larger group	Over ten years
PCP7	Rural	Larger group	Less than ten years
PCP8	Rural	Small group	Over ten years
PCP9	Urban	Large group	Over ten years
PCP10	Urban	Small group	Over ten years
PCP11	Urban	Small group	Less than ten years
PCP12	Urban	Small group	Less than ten years

Route to the consultation: Shifting gears versus sudden stops

The issue of FtD tended to arise in consultations in two ways. If cognitive impairment was acknowledged as a problem between the patient and their PCPs, PCPs tended to introduce the topic of FtD into routine consultations to proactively prepare patients for future changes in driving status. This measured approach included use of “*warning shots*” that changes may be required, revisiting the issue over multiple consultations, and signing medical reports for only one year at a time to alert the patient to the PCP’s concerns.

“Sometimes what I will do, I will give the person a heads up and say, “Ok, I am going to certify you for the next year but be aware of the fact that in a year’s time you may not be in a position to drive the car and you might need to think about getting someone else to do the driving for you.” PCP6

In contrast, in many cases the issue of driving arose abruptly because of a patient’s request for an urgent driving license medical report. (In Ireland, all drivers must submit a medical declaration with their driving license application, which comes up for renewal after defined intervals of one, three or ten years depending on the age of the patient and caveats attached to their previous license; generally, one’s PCP signs a medical report to accompany the medical declaration.) If pre-existing concerns about the patient’s cognition had either not been discussed openly with the patient or the specific issue of their driving had not been addressed with them previously, the FtD consultations could become contentious. Being confronted with the possibility of cognitive impairment and

1
2
3 potential restrictions on their driving in the one encounter led to patients becoming upset and
4 consultations becoming fraught. As PCPs had no forewarning for the patient's reason for attendance
5 and often had insufficient time to comprehensively review the patient's case during the ten minute
6 consultation, they either made rapid decisions on the patient's FtD or deferred decision-making,
7 meaning the patient would not be able to stay on the road until further evaluation was carried out.
8

9 *"I had not realized that she was driving until she asked me to sign the driving renewal form ...*
10 *I was actually quite shocked that she was driving because it was clear to me that she was*
11 *not...well anyway, I explained to her the reasons why I didn't think it was a good idea for her*
12 *to drive and she was quite upset over that"* PCP10
13

14 PCPs described patient responses as "furious" PCP5; "really unhappy" PCP9; "very upset" PCP12;
15 "angry" PCP3&4; "grumpy" PCP2; and "very cross" PCP1. The patient's response led to reactive
16 feelings of remorse or regret in PCPs. In some cases the physician-patient relationship was damaged
17 to the extent that patients switched practice.
18

19 Patients themselves appeared guarded in their descriptions of the emotional impact of FtD
20 consultations (with one clear divergent case), despite reassurance of the independence of the
21 research interviewer. However, during these interviews, the interviewers noted patients' non-verbal
22 signs of frustration and sadness.
23

24 *"Well, I was a bit upset I suppose...(pause)... my blood pressure increased. An anxiety I*
25 *suppose."* Patient 2
26

27 *"...you feel awful and it's really awkward and you've only 15 minutes. And then it is 'next!'*
28 *It's actually terribly difficult."* PCP5
29

30 *"I was unable to sign his driving license application form on this occasion. And I never saw*
31 *him again....and that was 15 months ago."* PCP4
32
33
34

35 **Consultation strategies**

36 PCPs drew on a number of consultation and communication strategies when faced with this sensitive
37 topic. They used these approaches both when adopting the pro-active approach to introduce the
38 patient to the idea of driving cessation, and during the more acute consultations in an effort to
39 reduce potential damage to the doctor-patient relationship.
40

41 **Reflecting and echoing**

42 A common approach was to echo patients' perceptions of their own road safety, their self-imposed
43 restrictions, and their level of comfort and confidence while driving back at them. In this way, PCPs
44 appealed to patients' remaining insight in an approach akin to motivational interviewing.
45

46 *"we started talking about him driving and I asked "Do you still feel comfortable to drive?"*
47 *because - the word he used and I just echoed it was- sometimes he feels foggy."* PCP7
48
49

50 **Incorporating objective tests**

51 In an effort to prevent FtD decisions being viewed as "doctor's discretion"(PCP1), PCPs found it
52 useful to work through cognitive screening tools during consultations. Some PCPs purposively added
53 cognitive tests (such as the MiniCog, GPCOG and the MMSE) to their driving assessment proformas,
54 to both prompt themselves to assess cognition, and to "show" patients that cognitive assessment
55 was necessary.
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3 *"I added the Minicog to our template not so that people must use it but more to remind*
4 *them" PCP9*

6 **Blaming guidelines**

7 To protect the physician-patient relationship, many PCPs "blamed" the national driving guidelines in
8 consultations where they were deferring or denying patients' medical certification to drive.
9

10 *"you can sort of externalize things – you know it's not me – it's them. I am just acting along*
11 *these guidelines. It's not that I am saying you can't drive, it's the guidelines that say you*
12 *can't drive. So you are depersonalizing things to some degree and you can continue the*
13 *relationship with the patient ..erm...by blaming big brother!" PCP2*

14
15 While guidelines suggested different approaches for patients with mild cognitive impairment versus
16 dementia, in practice PCPs did not see such a clear distinction between these conditions. Despite
17 guidelines not always matching the reality of assessing FtD as PCPs experienced it, they were still
18 happy to have them as a "prop" to the consultation if they needed to.
19

20 *"If you're not happy with it, you are the one who actually has to defend yourself and sleep at*
21 *night so [...].you try and use those [guidelines] like a resource" PCP12*

23 **Shift responsibility to external assessors**

24 PCPs opted to refer patients for external driving assessment (e.g. independent mobility assessment
25 services, geriatricians, neurologists, old age psychiatrists) for three main reasons. Some PCPs used
26 these services as a means of protecting the physician-patient relationship while assessing or
27 convincing patients of the need for driving cessation. Others needed reassurance in cases which
28 were "borderline" (PCP4 & PCP9), due in part to the risk of litigation perceived by PCPs if patients
29 were subsequently involved in a road traffic accident. Lastly, many PCPs reported referring patients
30 because doing a satisfactory assessment "can be very hard in a 10 or 15 minute consultation" PCP11.
31 Access to these services was patchy, with most patients having to pay out of pocket which some
32 PCPs felt introduced an element of inequity into care.
33
34

35 *"Her license came up for renewal and she lives 4 miles out the country so it was going to be a*
36 *huge thing to say you can't. But I had sort of given her a few warning shots so when it came*
37 *up for renewal I said "Look, I can't really make this decision now on my own. So that is why I*
38 *referred her.""* PCP8

39 *"Am I really going to make a cut off to say someone can't drive anymore? (Sighs)...If I am*
40 *unsure then I would refer to the assessors. Do as I do...at least you are medico legally*
41 *covered."* PCP3

42
43
44 Patients were confused about the role of external assessment, with some interpreting it as a sign of
45 PCPs' uncertainty about how to proceed. Other patients reported a preference for on-road
46 assessment over being questioned about driving by their PCP.
47

48 *"Well the ideal way to test a person driving is to go out with them in the car – that must be*
49 *the greatest way there is rather than sitting there and asking me questions about driving*
50 *because at my age anyway, asking questions about driving is more for young people who are*
51 *more alert to all questions...used to exams and that."* Patient 2
52
53

54 **The value of continuity**

55 Patients reported mixed feelings about having their PCPs conduct FtD assessments, with some
56 asking why PCPs would be considered to know anything about a person's FtD and another
57
58
59

1
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3 recognising the potential of FtD assessment to interfere negatively with the physician-patient
4 relationship.

5
6 *"I can understand a difficulty with a doctor that is your own doctor asking questions like that*
7 *because the doctor could feel like...that he's causing a bit of a muddle between yourself and*
8 *himself which shouldn't happen at all. Doctor and patient need to get on and maybe it isn't*
9 *appropriate for a doctor to be doing that."* Patient 2

10
11 However, patients were consistent in their view that if medical assessment of FtD is to remain the
12 duty of PCPs, then it should be with their own PCP and not with a locum or an unfamiliar PCP. They
13 felt their own longstanding PCP would have a better "sense" of them and discuss FtD without
14 causing alarm.

15
16 *"The scenario would never have arisen if it was her own doctor. She is capable of driving, her*
17 *problem is her communication, and that doesn't affect her driving ability."* Carer 1 discussing
18 her aunt who was subsequently deemed fit to drive

19
20 Correspondingly, PCPs working in the one practice for many years felt that continuity of care helped
21 them to identify signs of cognitive impairment early and facilitated discussions with patients before
22 a crisis developed. This approach supported patient involvement in plans for driving cessation while
23 also allowing them to continue driving for as long as was safely possible.

24
25 *"It took about three consultations before we got around to it [discussing driving] head on"*
26 PCP1, working in the one practice for more than ten years.

27
28 *"Discussion re: driving seems ok at present but advised likely to need to stop soon."* PCP9
29 reading from her notes.

30
31 In contrast, recently qualified PCPs, new PCPs in a practice and locums were less likely to sign
32 patients off as fit to drive, tending instead to first discuss cases with colleagues or refer for external
33 assessments. PCPs reported the greatest difficulties when they were working as locums because
34 they encountered patients to whom they were essentially strangers without any warning of what
35 the consultation would be about. Having not anticipated any reluctance to sign the medical report,
36 patients could then understandably become aggravated in the consultation.

37
38 *"someone comes in and they present a form for driving with no warning, no preparation for*
39 *it, and often you have never met them before.... she nearly lunged at me when I said to her*
40 *that I don't know if I can sign it. She nearly jumped across the table and she said "How am I*
41 *supposed to do my shopping?"* PCP5

42 43 44 45 **The road ahead: what needs to change**

46 47 **Mapping the journey**

48 Patients wanted their PCPs to explain clearly why there were concerns about their driving and the
49 reasons behind the decisions they had made. Patients recognised that external driving assessment
50 was for the benefit of public road safety, but requested that they be told what to expect from the
51 assessment and what steps would follow. Patients also felt that the plan should move quickly so that
52 they would not be off the road for an unnecessarily long duration.

53
54
55 *"Well I would like them to sit down and explain things to people. To say your memory isn't*
56 *the best and it would be safer if you didn't drive. Researcher: Would that be better if he had*
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3 *just come out and said that? Patient: I think so...I said 'I have a 16 (new) car in my drive..'*
4 *and he said 'you will probably be back driving again'" Patient 5 who was found unfit to drive*
5 *in her driving assessment*

6
7 *"we were totally...we actually didn't know about it [driving assessment] before so it was*
8 *totally new, I didn't know of anyone who had it done before" Carer 1*
9

10 **Walk in the patients shoes**

11 Patients spoke of the huge emotional impact that driving cessation would have on their lives,
12 including constricted social opportunities, loneliness and increased dependence on family and
13 neighbours. Although it was evident that PCPs recognized this emotional impact, it appeared that
14 they had not acknowledged or helped patients deal with it sufficiently, and this added to the upset
15 that patients had experienced.
16

17 *"If I couldn't drive, well I'd feel loneliness actually, it is something I would feel. I am single you*
18 *know" Patient 2*
19

20 *"Patient: He said he just couldn't sign it, and that was it.*

21 *Interviewer: Were you satisfied with the information he gave you?*

22 *Patient: No certainly not...I was annoyed...[...]...I don't want to be dependent on my children*
23 *to go places, I was always able to get into my car and drive... now I have to get one of the*
24 *girls to drive me down, and that's not on." Patient 5*
25
26

27 **Increase two way traffic between PCPs and licensing system**

28 To ease the discomfort associated with the task of assessing medical fitness to drive, PCPs called for
29 better lines of communication from the national driving authority and resources to support longer,
30 more comprehensive assessment in their practices. For instance, recent changes had been
31 introduced to the medical report allowing for restricted driving for patients (licenses to drive short
32 distances, in local areas, during day light hours etc.) but participating PCPs reported they had not
33 received instruction on how they should make decisions on restricted driving, leaving them feeling
34 undermined in the consultation.
35

36 *"I suppose you have heard that the driving licence forms miraculously changed this week.*
37 *Nobody told us. The first we knew was when a patient came in clutching the form and we*
38 *were looking at it." PCP1*
39
40
41

42 **Discussion**

43
44 In this multi-perspective qualitative study, we found that where cognitive impairment has been
45 addressed openly in primary care, PCPs could use their relational continuity with the patient to
46 prevent or mitigate the emotional response of patients to the threat of driving cessation. Where
47 cognitive impairment is known, PCPs can revisit the issue of driving over multiple consultations, and
48 use nuanced communication strategies to maintain some sense of patient autonomy and engage
49 them in planning for driving cessation before a crisis develops. However, the abrupt introduction of
50 concern about cognition when patients present for medical driving reports is problematic. Being
51 confronted with unanticipated hesitations about FtD, while simultaneously learning of the possibility
52 of cognitive impairment, represents a double whammy for patients that understandably leads to
53 consultations becoming heated.
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Comparison with existing literature

Similar to others¹⁵, we found that patients themselves rarely raise the issue of driving in a proactive way, unless attending to get medical reports signed. In Canada, a campaign called “Not if but when” encourages PCPs to introduce the topic of driving early in the course of caring for an older adult with dementia²³. We would extend on this recommendation by suggesting that driving is also discussed in routine follow-up of patients with mild cognitive impairment.

Prior literature also highlights that patients and their carers want to actively share in FtD decisions¹⁸²⁴²⁵. Our study provides more insight into patients’ perceptions of and preferences for FtD consultations. Patients accept the need for driving assessment to determine their FtD, but want clear detail on what to expect from this assessment and what will follow. As with any loss, the threat of driving cessation may elicit a grief reaction, amplified by the potential changes in independence, status, and social interaction¹⁷. While PCPs are well placed to guide and offer compassionate support to patients through these adjustments²⁶, we found that their current efforts seem to fall short of patients’ expectations; patient participants requested more empathy and acknowledgement for the impact of driving cessation on their quality of life.

Strengths and Limitations

The transferability of our findings is enhanced by our sample of PCPs and patients which represents diverse professional characteristics and a range of perspectives. Credibility is supported by triangulation of PCP data with patient experiences and use of chart-stimulated recall in PCP interviews. Chart-stimulated recall focused conversations on PCPs’ practice-based experience of FtD consultations rather than rhetoric or views. We used peer-debriefing to bring reflexivity and sensitivity to data collection, while data analysis harnessed multidisciplinary involvement in every iteration.

Similar to other teams, we found that engaging older patients with cognitive impairment in our research was challenging²⁷. When we encountered low participation rates initially, we expanded our recruitment strategies. The level of patient engagement was still somewhat disappointing, but the diversity of patients who did participate enhanced the robustness of our findings, as did the recurrence of themes in the data.

Some patient participants appeared cautious about the detail they provided, despite reassurance of the independent nature of the research interviewer. That this occurred despite enrolling only patients who were deemed to have sufficient capacity, and utilisation of the professional skills of both interviewers indicates just how sensitive a topic FtD in cognitive impairment is.

Implications for practice, policy and future research

Across the spectrum of mild cognitive impairment to early dementia, many patients remain safe to drive²⁸. However, in light of the increasing prevalence of these conditions, our findings offer suggestions to support assessment of medical FtD for people with cognitive impairment in primary care. Firstly, due to the sensitive nature of FtD consultations, it is preferable that patients see their regular PCP for FtD assessments. We identified that this sensitive topic is not suitable for review by locum doctors, but requires the full strength of relational continuity that primary care has the potential to offer. This requires policy and procedures at practice level, and could be further encouraged by having a requirement on the medical report form to say how long the assessing physician has known the patient.

A second recommendation is that a discussion of driving should be introduced into routine consultations for all patients with cognitive impairment, even in the absence of apparent functional

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2
3 impairment. For patients with established dementia, FtD discussions should be incorporated into
4 routine post-diagnosis management along with discussion of other legal issues, will-making,
5 advanced care directives etc. By taking a proactive approach to driving, PCPs may avoid the distress
6 associated with an unanticipated yet imminent threat of driving cessation that was witnessed in
7 some cases in this study. Engendering a sense of agency, input and control over their own plans for
8 driving cessation may also help patient adjust better to these changes¹⁷. This approach requires that
9 PCPs engage in open communication, early disclosure, education and support for patients with
10 cognitive impairment and dementia, in line with the recommendations of several international
11 guidelines²⁹.

12
13 The point where driving cessation is indicated for a patient with dementia represents an important
14 and emotional transition in their illness. Patient and caregiver accounts identify driving cessation as
15 one of a series of losses in dementia and represents a point of transition in the illness to increasing
16 dependence, reduced social participation and a negative view of one's self¹⁷. Empowering PCPs to
17 address patients' psychological and emotional responses of loss and grief will require advanced
18 communication skills, especially in the context of cognitive impairment where patient insight may be
19 impaired. However, existing educational resources in FtD have been criticized for lack of applicability
20 ^{9 11 30}. We suggest that future educational resources frame consultations where driving cessation
21 may be indicated as involving non-bereavement loss and draw on communication skills traditionally
22 associated with breaking bad news³¹. We also recommend that existing educational programmes on
23 the management of cognitive impairment highlight the benefit of addressing, diagnosing and
24 disclosing cognitive impairment early with patients, and empower PCPs to adopt a pro-active
25 approach that facilitates maintenance of a patient's autonomy for as long as is safely possible.

26 27 28 29 **Conclusion**

30
31 PCPs used their longitudinal relationship with cognitively impaired patients to reduce the potential
32 for conflict in consultations on FtD. These efforts could be augmented by explicit discussion of
33 cognitive impairment at an earlier stage for all patients affected by cognitive impairment from mild
34 cognitive impairment right through to dementia. Patients would benefit from greater input into
35 planning driving cessation and acknowledgement from their PCPs of the impact this may have on
36 their quality of life.

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47 48 49 **Declaration of conflicting interests**

50 The Authors declares that there is no conflict of interest.

51 52 **Author contributions**

53
54 CS, TF, CB and LH planned the original study, wrote the protocol, won funding and oversaw the
55 original study. CS, TF, CB, KM, CS and LH designed, planned and carried out analyses for this paper.

CS drafted this manuscript and revised it in response to critical revisions from all authors. CS and CB are the co-guarantors of the study. All authors read and approved the final manuscript.

Ethics approval

Research ethics approval was granted by the Clinical Research Ethics Committee, ECM 4 (aa) 06/09/2016.

Data sharing statement

Participants were not consented for sharing of interview data. However additional quotes to support the themes are available on request from cs926@medschl.cam.ac.uk.

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For peer review only

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*Topic guides for interviews***GP INTERVIEW TOPIC GUIDE****Introduction:**

Driving allows people independence, social engagement and interaction, and is a contributor to quality of life and well-being. However, discussions between GPs and patients on fitness to drive can be fraught, with up to a fifth of GPs reporting that patients have left their practice after the GP did not approve their driving license application. Difficulties discussing fitness to drive can be compounded by the presence of unacknowledged or undiagnosed mild cognitive impairment, which is the focus of this interview. We want to discuss your experience of speaking to patients with mild cognitive impairment (or their carers) about your fitness to drive, to see what works and what does not work well in practice.

Overview of interview:

- 20-30minutes long
- Record interview
- No patient identifying information will be published or shared.
- Ethics approval was granted. Obtain consent.
- Full confidentiality, data will be password protected in UCC only.

Questions	Prompt/probe
1. Can you describe your practice location and practice population in general terms please?	<ul style="list-style-type: none"> • Number of gps • Number of patients • Rural/ urban location • Level of deprivation • Available social supports • Available level of public transport
2. How frequently do you encounter consultations in the issue of fitness to drive?	
3. What provokes this discussion?	<ul style="list-style-type: none"> • Patient concern • Carer concern • GP concern • Letter from specialist • Others provocation?
4. Can you choose two patients with cognitive impairment from your caseload and tell me how consultations on fitness to drive went these patients? <ol style="list-style-type: none"> a. Refer to case notes b. Choose patient where it went well and not so well 	<ul style="list-style-type: none"> • Who brought it up? • How did you broach the issue? • What words used? • Re-visited multiple times? • Discussion with patient or carer or other family/friends.

Topic guides for interviews

5. Did you get the patient response that you wanted?	Why/ why not? Please explain/elaborate.
6. What actions followed the consultation?	Referral? Assessment? Repeat consultation?
7. Were you prepared for this?	What training have you had in this area? Is there any available? Is it needed?
8. Have you had consultations on fitness to drive in patients with mild cognitive impairment that have gone particularly well or badly?	Explain details of case. Refer to notes if helps.
9. In your opinion, what would have made this process easier for you?	Additional community resources/ other health care professionals/ knowledge resources.
10. What advice would you offer to GPs about they can best deal with this sensitive issue?	
Finish 11. Is there anything else you would like to elaborate on? Thank for your time today	

Topic guides for interviews

PATIENT INTERVIEW TOPIC GUIDE

Questions	Prompt/probe
1. Can you give your first name, age and tell me where you live please?	
2. We are interested in discussions about fitness to drive in people with mild cognitive impairment. Would you like to speak about your fitness to drive or the fitness to drive of the person you care for?	If relates to carer, who are they caring for, for how long, etc.
3. What would be important in an conversation about fitness to drive?	
4. What approaches would be challenging/unwelcome?	
5. When did the issue of fitness to drive first arise for you?	When was fitness to drive an issue (months or years ago), what brought this to attention, what provoked it?
6. How was it first discussed by your GP?	Brought up by patient, carer or GP?
7. Can you tell me how that conversation went?	Was it too theoretical or technical? Too long? Too short? Confusing? How did it make you feel?
8. Did you get the answers/ information you wanted?	Please explain/elaborate.
9. Was this conversation something you expected?	Why? Why not?
10. What actions followed the consultation/ discussion with the GP?	Referral? Assessment? Repeat consultation? Were you prepared for this?

Topic guides for interviews

11. In your opinion, what would have made this process easier for you or the person you care for?	
12. What advice would you offer to GPs about they can best deal with this sensitive issue?	
13. What went well from your perspective?	Involvement of GP/ other healthcare professionals/ family members...
14. How have things changed since then?	
Finish 15. Is there anything else you would like to tell me? Thank for your time today	

Manuscript: Shifting gears versus sudden stops: a qualitative study of consultations about driving in patients with cognitive impairment

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
<i>Personal Characteristics</i>		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	3-4
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	4
3. Occupation	What was their occupation at the time of the study?	4
4. Gender	Was the researcher male or female?	4
5. Experience and training	What experience or training did the researcher have?	4
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to study commencement?	4
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	4, 7
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	4, 11
Domain 2: study design		
<i>Theoretical framework</i>		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	4
<i>Participant selection</i>		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	3-4
11. Method of approach	How were participants approached? e.g.	3-4

	face-to-face, telephone, mail, email	
12. Sample size	How many participants were in the study?	5
13. Non-participation	How many people refused to participate or dropped out? Reasons?	4
<i>Setting</i>		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	4
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	4
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	5
<i>Data collection</i>		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	4, appendix
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	Not applicable
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	4
20. Field notes	Were field notes made during and/or after the inter view or focus group?	4
21. Duration	What was the duration of the inter views or focus group?	5
22. Data saturation	Was data saturation discussed?	3
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	4
Domain 3: analysis and findings		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data?	4
25. Description of the coding tree	Did authors provide a description of the coding tree?	4
26. Derivation of themes	Were themes identified in advance or derived from the data?	4
27. Software	What software, if applicable, was used to manage the data?	4
28. Participant checking	Did participants provide feedback on the findings?	4
<i>Reporting</i>		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	5-10
30. Data and findings consistent	Was there consistency between the data presented and the findings?	5-10
31. Clarity of major themes	Were major themes clearly presented in the findings?	5-10
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	5-10

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Shifting gears versus sudden stops: a qualitative study of consultations about driving in patients with cognitive impairment

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Manuscripts

Title

Shifting gears versus sudden stops: a qualitative study of consultations about driving in patients with cognitive impairment

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Abstract

Objective

General practitioners (GPs) report finding consultations on fitness to drive (FtD) in people with cognitive impairment difficult, and potentially damaging to the physician-patient relationship. We aimed to explore GP and patient experiences to understand how the negative impacts associated with FtD consultations may be mitigated.

Methods

Individual qualitative interviews were conducted with GPs and patients in the Republic of Ireland. We recruited a maximum variation sample of GPs using criteria of length-of-time qualified, practice location and practice size. Patients with cognitive impairment were recruited via driving assessment services and participating general practices. Interviews were audio-recorded, transcribed, and analysed thematically by the multidisciplinary research team using an approach informed by the framework method.

Findings

The issue of FtD arose in consultations in two ways: introduced by GPs to proactively prepare patients for future driving cessation, or by patients who urgently needed a medical report for an expiring driving license. The former strategy, implementable by GPs who had strong relational continuity with their patients, helped prevent crisis consultations from arising. The latter scenario became acrimonious if cognition had not been openly discussed with patients previously and was now potentially impacting on their right to drive. Patients called for greater clarity and empathy for the threat of driving cessation from their GPs.

Conclusion

GPs used their longitudinal relationship with cognitively impaired patients to reduce the potential for conflict in consultations on FtD. These efforts could be augmented by explicit discussion of cognitive impairment at an earlier stage for all affected patients. Patients would benefit from greater input into planning driving cessation and acknowledgement from their GPs of the impact this may have on their quality of life.

Strengths and limitations of this study

- This multi-perspective qualitative study examined the experiences of both healthcare professionals' and patients with cognitive impairment to understand both sides of sensitive consultations on medical fitness to drive in the setting of cognitive impairment.
- The transferability of our findings is enhanced by a maximum variation sample of General Practitioners (GPs) in terms of different practice contexts (large versus small group practices, urban versus rural locations) and variable level of professional experience.
- The validity of interviews with GPs was enhanced by using the technique of chart-stimulated recall.
- We found that engaging older patients with cognitive impairment in our research was challenging and countered this by expanding on approaches to recruitment.

Introduction

For older adults, driving cessation can limit access to family, friends, and services and is an independent risk factor for entry to a nursing home¹. General Practitioners (GPs) may be wary of consultations on medical fitness-to-drive (FtD) because of potential negative impacts on a patient's sense of autonomy, quality of life, and the doctor-patient relationship². This discomfort is amplified in patients where there is concern about cognition, as GPs can also be reluctant to address the earlier stages of cognitive impairment with older patients due to fear of causing unnecessary anxiety, labelling and stigma³.

Cognitive impairment exists across a spectrum from mild cognitive impairment to mild, moderate and advanced dementia. Prevalence estimates for these conditions vary by study design and population examined but approximations for the prevalence of mild cognitive impairment in older adults (aged over 50 years) are 6-20% and for dementia are 4-7%. While not all patients with mild cognitive impairment go on to develop dementia, approximately 10% per year do progress with the majority of these people experiencing decline in driving abilities over time^{2,4}. Cognitive decline is associated with crash risk across the cognitive spectrum⁵, but the point where an individual patient must consider driving cessation varies case by case². Severe dementia is a contraindication to driving and safe driving is generally unlikely in the presence of moderate dementia. Many patients with mild dementia and the majority with mild cognitive impairment may be deemed fit to continue driving but should be re-evaluated every six to twelve months or sooner if indicated². Problems may arise due to shortcomings in the detection, diagnosis and disclosure of cognitive impairment: approximately 50% of older adults with dementia are either undiagnosed or unaware of the diagnosis⁶.

GPs' obligations with respect to FtD assessment and reporting differ across jurisdictions. In Ireland, the UK, Australia and parts of Canada, health professionals have an obligation to give clear advice to drivers in cases where an illness or injury may compromise their FtD, but the responsibility for notifying the licensing authority normally falls to the driver^{7,8,9,10}. Where a healthcare professional believes that a driver is not compliant with advice to stop driving or notify authorities, the healthcare professional has a duty to notify the authorities in the interests of public safety. In some US states and many Canadian jurisdictions, physicians are required to report directly to state licensing departments on patients who have specific medical conditions, including dementia^{10,11}. Additionally, in Ireland where this study took place, driving licenses must be renewed after intervals of one, three or ten years depending on the age and health of the driver and must be accompanied by a medical report in the case of injury or illness that may affect FtD⁷. The medical report is generally signed by the patient's GP, and the requirement for this report is a trigger for many consultations on FtD in Irish general practice.

Qualitative research examining GPs' perspectives on FtD consultations for patients with possible cognitive impairment demonstrates that their discomfort with these consultations transcends differences in regional policies on licensing and road-safety¹². Findings include GPs' view of themselves as reluctant regulators¹³; who "hate" that driving assessment has anything to do with their role^{14,15}; and frequent uncertainty about their legal and ethical obligations¹⁶⁻²¹. Evaluations of patients' responses to the prospect of driving cessation in the context of cognitive impairment highlight a range of negative emotions such as anger, frustration, and sadness, the disruption to self-identity and fear of loss of independence^{22,23}. Up to one fifth of GPs report a patient leaving their

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3 practice because of FtD consultations that have gone badly, highlighting just how distressing these
4 consultations can be for patients ²¹.

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6 International strategies for managing the rising global prevalence of cognitive impairment and
7 dementia prioritize management in the community and GPs are assuming an ever increasing role in
8 the on-going management of these conditions, including the assessment and re-assessment of
9 medical FtD ²⁴. However, there has been little examination of the consultation strategies used by GPs
10 in an effort to lessen the emotional impact of FtD consultations for patients with cognitive
11 impairment, nor have patients views on GPs' consultation strategies been explored. In this study, we
12 examine both sides of the FtD consultation- GPs and patients with cognitive impairment - in order to
13 understand how the negative aspects of these consultations may be mitigated. We were specifically
14 interested in how, in the setting of cognitive impairment, FtD is introduced into consultations in
15 primary care; what consultation strategies GPs use; the influences on GPs' approach; and aspects of
16 the FtD consultation that could be improved from patients' and GPs' perspectives.

20 21 **Methods**

22
23 A multi-perspective qualitative design was used. The setting was primary care in the Republic of
24 Ireland.

25 26 27 **GP participants and interviews**

28 Semi-structured qualitative interviews were conducted with GPs between February and July 2017.
29 Inclusion criteria were fully trained GPs working in clinical practice. Participants were recruited via
30 online GP discussion groups and two regional professional development meetings. We sought a
31 maximum variation sample of GPs against the following criteria: length-of-time qualified (over/under
32 ten years), practice location (rural/urban), and practice size (<3/≥3 full-time GPs). Recruitment
33 continued until the sample represented a satisfactory mix of these criteria and preliminary data
34 analysis indicated that further interviews were unlikely to generate additional information power ²⁵.

35
36 During interviews, the researcher (KML) drew on the technique of chart-stimulated recall ²⁶. This
37 technique was adapted for research from the field of medical education, and involves asking a
38 healthcare professional to describe their management of a case, and the reasoning behind the
39 clinical decisions they had made, using the patient's medical chart as an aide memoire to the
40 narrative. The acceptability, reliability, and validity of chart-stimulated recall for retrospectively
41 assessing clinical practice has been demonstrated in previous studies ²⁶. We asked participants to
42 choose patients from their caseload for whom recent consultations on FtD included concerns about
43 cognition and to refer to the notes they had made during the consultation when describing the index
44 consultation and subsequent consultations with that patient. We asked GPs to choose at least two
45 cases, ideally one where the FtD consultation went well and one where it did not go so well. This
46 approach focused interviews on GPs practice-based experience rather than rhetorical discussions of
47 FtD; gave insight into the breadth of a GPs experience of FtD consultations in cognitive impairment;
48 and facilitated exploration of both unsuccessful approaches as well approaches which could be
49 usefully implemented by others. Interviews were conducted in the GPs' practices to allow access to
50 case notes and facilitate recall of the consultations ²⁶.

51 52 53 54 55 56 57 **Patient participants and interviews**

58 Semi-structured qualitative interviews were conducted with patients between June and November
59 2017. Inclusion criteria were patients with cognitive impairment (mild cognitive impairment or mild
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3 dementia). We invited patients to participate using mail-outs to people who had attended driving
4 assessment services after being referred to that service by their GP due to concerns about cognitive
5 impairment. As this initial recruitment strategy was, unfortunately, not very successful, we expanded
6 recruitment by asking participating GPs to invite patients with cognitive impairment directly. Once a
7 potential participant expressed interest in the study, the qualitative interviewers (KML, CSh) ensured
8 that the person had a full understanding of the process and confirmed their capacity to participate.
9 One person was interested in participating but suffered from aphasia as a feature of her cognitive
10 impairment (although she was still deemed fit to drive after assessment); in this case we offered the
11 patient's family carer an opportunity to be interviewed instead. No personal identifying information
12 was collected on the patients discussed by GPs and there was no intentional overlap between the
13 patients discussed by GPs and the patient participants.
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17 We conducted interviews in the participant's home, the university, or other location of their choice.
18 A topic guide, which was written in collaboration with the Alzheimer's Society of Ireland, was used in
19 interviews (see Appendix 1): in summary participants were asked to recount their experiences of,
20 thoughts on and preferences for (or those of the person they care for) FtD consultations in primary
21 care. Both interviewers (KML (PhD), CSh (PhD)) had extensive experience in interviewing in sensitive
22 situations in the fields of dementia and gerontology. None of the participants were known to the
23 interviewers before the study commenced.
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27 Data analysis

28 All interviews were audio-recorded, transcribed in full and de-identified. After the first five GP
29 interviews and all patient interviews, the interviewers (KML and CSh) presented reflexive accounts
30 and field notes to two other team members (CS and CB), leading to iterative modification of topic
31 guides. We used a framework approach to analysis²⁷. Once data collection was complete, each
32 transcript was thematically coded by at least two members of the multidisciplinary research team
33 (KML-health service researcher, CS, TF, CB- all academic GPs, LH-occupational therapist, CSh-social
34 scientist) to familiarize ourselves with the data. We used this list of themes to create an inductive
35 matrix for further analysis. The matrix placed emphasis on the GPs' approach to FtD consultations
36 and the events that ensued within those consultations. After indexing interview data into the matrix,
37 further rounds of coding were conducted to develop, interpret and refine themes within the matrix.
38 Divergent accounts were sought within the data. Interviews with patients were analysed in a similar
39 way but using a different matrix. The results from both matrices were merged and interpreted
40 together in the final stage of the analysis.
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45 Transcripts were not provided to participants for feedback. NVivo software was used to support data
46 analysis. All participants provided written informed consent. Research ethics approval was granted
47 by the Clinical Research Ethics Committee of the Cork Teaching Hospitals (ECM 4 (aa) 06/09/16). The
48 study report was written in adherence with the consolidated criteria for reporting qualitative
49 research (COREQ) checklist (Appendix 2).
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53 Patient and Public Involvement

54 We developed the patient invitations, information letters, and expression of interest forms in
55 collaboration with patient and public representatives from the Alzheimer's Society of Ireland
56 (acknowledged below). Patient and public representatives also reviewed and rephrased the topic
57 guide for interviews with patients with cognitive impairment.
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Findings

Eighteen people participated: twelve GPs, five people with cognitive impairment and one carer. The characteristics of GP participants are shown in Table 1. Amongst patient participants, three patients lived in rural locations. One patient was awaiting review by driving assessment services, two had been deemed not fit to drive after assessment, and the others had been deemed fit to drive after assessment. On average, GP interviews lasted 20 minutes (range 10 to 43) and patient interviews lasted 29 minutes (range 8 to 120). The themes are presented narratively incorporating quotes from the data (shown in italics).

Table 1. Characteristics of participants

	Practice location	Practice size at time of interview (small group <3 full time GPs/ larger group ≥3 full time GPs)	Years qualified as GP
GP1	Urban	Large group	Over ten years
GP2	Urban	Small group	Less than ten years
GP3	Rural	Small group	Less than ten years
GP4	Rural	Large group	Over ten years
GP5	Mixed	Large group	Less than ten years
GP6	Rural	Large group	Over ten years
GP7	Rural	Large group	Less than ten years
GP8	Rural	Small group	Over ten years
GP9	Urban	Large group	Over ten years
GP10	Urban	Small group	Over ten years
GP11	Urban	Small group	Less than ten years
GP12	Urban	Small group	Less then ten years

Route to the consultation: Shifting gears versus sudden stops

The issue of FtD tended to arise in consultations in two ways. If cognitive impairment was acknowledged as a problem between the patient and their GPs, GPs reported introducing the topic of FtD into routine consultations to proactively prepare patients for future changes in driving status. This measured approach included use of “*warning shots*” that changes may be required, revisiting the issue over multiple consultations, and signing medical reports for only one year at a time to alert the patient to the GP’s concerns.

“Sometimes what I will do, I will give the person a heads up and say, “Ok, I am going to certify you for the next year but be aware of the fact that in a year’s time you may not be in a position to drive the car and you might need to think about getting someone else to do the driving for you.” GP6

In contrast, in many cases the issue of driving arose abruptly because of a patient’s request for an urgent driving license medical report. If pre-existing concerns about the patient’s cognition had either not been discussed openly with the patient or the specific issue of their driving had not been addressed with them previously, the FtD consultations could become contentious. Being confronted with the possibility of cognitive impairment and potential restrictions on their driving in the one encounter led to patients becoming upset and consultations becoming fraught. As GPs had no

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3 forewarning for the patient's reason for attendance and often had insufficient time to
4 comprehensively review the patient's case during the ten minute consultation, they reported either
5 making rapid decisions on the patient's FtD or deferred decision-making, meaning the patient would
6 not be able to stay on the road until further evaluation was carried out.
7

8
9 *"I had not realized that she was driving until she asked me to sign the driving renewal form ...
10 I was actually quite shocked that she was driving because it was clear to me that she was
11 not...well anyway, I explained to her the reasons why I didn't think it was a good idea for her
12 to drive and she was quite upset over that"* GP10
13

14 GPs described patient responses as "furious" GP5; "really unhappy" GP9; "very upset" GP12; "angry"
15 GP3&4; "grumpy" GP2; and "very cross" GP1. The patient's response led to reactive feelings of
16 remorse or regret in GPs. Three GPs (GP1, GP4, GP5) reported patients switching practice due to
17 damaged physician-patient relationship after fitness to drive consultations.
18

19 Patients themselves appeared guarded in their descriptions of the emotional impact of FtD
20 consultations (with one clear divergent case who was openly frustrated and annoyed), despite
21 reassurance of the independence of the research interviewer. However, during these interviews, the
22 interviewers noted patients' non-verbal signs of frustration and sadness.
23

24
25 *"Well, I was a bit upset I suppose...(pause).... my blood pressure increased. An anxiety I
26 suppose."* Patient 2
27

28 *"what am I going to do?.. (I'm) not getting anywhere.. (I'm) not accepting the report"* Patient
29 3
30

31 *"...you feel awful and it's really awkward and you've only 15 minutes. And then it is 'next!'
32 It's actually terribly difficult."* GP5
33

34 *"I was unable to sign his driving license application form on this occasion. And I never saw
35 him again....and that was 15 months ago."* GP4
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40 Consultation strategies

41 GPs reported drawing on a number of consultation and communication strategies when faced with
42 this sensitive topic. They used these approaches both when adopting the pro-active approach to
43 introduce the patient to the idea of driving cessation, and during the more acute consultations in an
44 effort to reduce potential damage to the doctor-patient relationship.
45
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47 Reflecting and echoing

48 A common approach reported by GPs was to echo patients' perceptions of their own road safety,
49 their self-imposed restrictions, and their level of comfort and confidence while driving back at them.
50 In this way, GPs appealed to patients' remaining insight in an approach akin to motivational
51 interviewing.
52
53

54 *"we started talking about him driving and I asked "Do you still feel comfortable to drive?"
55 because - the word he used and I just echoed it was- sometimes he feels foggy."* GP7
56
57

58 Incorporating objective tests

59 In an effort to prevent FtD decisions being viewed as "doctor's discretion" (GP1), GPs described using
60

cognitive screening tools during consultations. Some GPs purposively added cognitive tests (such as the MiniCog, GPCOG and the MMSE) to their driving assessment proformas, to both prompt themselves to assess cognition, and to “show” patients that cognitive assessment was necessary.

“I added the Minicog to our template not so that people must use it but more to remind them” GP9

Blaming guidelines

To protect the physician-patient relationship, many GPs “blamed” the national driving guidelines in consultations where they were deferring or denying patients’ medical certification to drive.

“you can sort of externalize things – you know it’s not me – it’s them. I am just acting along these guidelines. It’s not that I am saying you can’t drive, it’s the guidelines that say you can’t drive. So you are depersonalizing things to some degree and you can continue the relationship with the patient ..erm...by blaming big brother!” GP2

While guidelines suggested different approaches for patients with mild cognitive impairment versus dementia, in practice GPs did not see such a clear distinction between these conditions. Despite guidelines not always matching the reality of assessing FtD as GPs experienced it, they were still happy to have them as a “prop” to the consultation if they needed to.

“If you’re not happy with it, you are the one who actually has to defend yourself and sleep at night so [...] you try and use those [guidelines] like a resource” GP12

Shift responsibility to external assessors

GPs reported referring patients for external driving assessment (e.g. independent mobility assessment services, geriatricians, neurologists, old age psychiatrists) for three main reasons. Some GPs used these services as a means of protecting the physician-patient relationship while assessing or convincing patients of the need for driving cessation. Others needed reassurance in cases which were “borderline” (GP4 & GP9), due in part to the risk of litigation perceived by GPs if patients were subsequently involved in a road traffic accident. Lastly, many GPs reported referring patients because doing a satisfactory assessment “can be very hard in a 10 or 15 minute consultation” GP11. Access to these services was patchy, with most patients having to pay out of pocket which some GPs felt introduced an element of inequity into care.

“Her license came up for renewal and she lives 4 miles out the country so it was going to be a huge thing to say you can’t. But I had sort of given her a few warning shots so when it came up for renewal I said “Look, I can’t really make this decision now on my own. So that is why I referred her.”” GP8

“Am I really going to make a cut off to say someone can’t drive anymore? (Sighs)...If I am unsure then I would refer to the assessors. Do as I do...at least you are medico legally covered.” GP3

Patients were confused about the role of external assessment, with some interpreting it as a sign of GPs’ uncertainty about how to proceed. Other patients reported a preference for on-road assessment over being questioned about driving by their GP.

“Well the ideal way to test a person driving is to go out with them in the car – that must be the greatest way there is rather than sitting there and asking me questions about driving

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3 *because at my age anyway, asking questions about driving is more for young people who are*
4 *more alert to all questions...used to exams and that.” Patient 2*
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9 **The value of continuity**

10 Patients reported mixed feelings about having their GPs conduct FtD assessments, with some asking
11 why GPs would be considered to know anything about a person’s FtD and another recognising the
12 potential of FtD assessment to interfere negatively with the physician-patient relationship.
13

14 *“Well the doctor, what would the doctor know about your driving?” Patient 4*

15
16 *“I can understand a difficulty with a doctor that is your own doctor asking questions like that*
17 *because the doctor could feel like...that he’s causing a bit of a muddle between yourself and*
18 *himself which shouldn’t happen at all. Doctor and patient need to get on and maybe it isn’t*
19 *appropriate for a doctor to be doing that.” Patient 2*
20
21

22 However, patients were consistent in their view that if medical assessment of FtD is to remain the
23 duty of GPs, then it should be with their own GP and not with a locum or an unfamiliar GP. They felt
24 their own longstanding GP would have a better “sense” of them and discuss FtD without causing
25 alarm.
26

27 *“The scenario would never have arisen if it was her own doctor. She is capable of driving, her*
28 *problem is her communication, and that doesn’t affect her driving ability.” Carer 1 discussing*
29 *her aunt who was subsequently deemed fit to drive*
30

31 Correspondingly, GPs working in the one practice for many years felt that continuity of care helped
32 them to identify signs of cognitive impairment early and facilitated discussions with patients before
33 a crisis developed. This approach supported patient involvement in plans for driving cessation while
34 also allowing them to continue driving for as long as was safely possible.
35
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37 *“It took about three consultations before we got around to it [discussing driving] head on”*
38 *GP1, working in the one practice for more than ten years.*

39
40 *“Discussion re: driving seems ok at present but advised likely to need to stop soon.” GP9*
41 *reading from her notes.*
42

43 In contrast, recently qualified GPs, new GPs in a practice and locums were less likely to sign patients
44 off as fit to drive, tending instead to first discuss cases with colleagues or refer for external
45 assessments. GPs reported the greatest difficulties when they were working as locums because they
46 encountered patients to whom they were essentially strangers without any warning of what the
47 consultation would be about. Having not anticipated any reluctance to sign the medical report,
48 patients could then understandably become aggravated in the consultation.
49
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51 *“someone comes in and they present a form for driving with no warning, no preparation for*
52 *it, and often you have never met them before.... she nearly lunged at me when I said to her*
53 *that I don’t know if I can sign it. She nearly jumped across the table and she said “How am I*
54 *supposed to do my shopping?” GP5*
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The road ahead: what needs to change

Mapping the journey

Patients wanted their GPs to explain clearly why there were concerns about their driving and the reasons behind the decisions they had made. Patients recognised that external driving assessment was for the benefit of public road safety, but requested that they be told what to expect from the assessment and what steps would follow. Patients also felt that the plan should move quickly so that they would not be off the road for an unnecessarily long duration.

“Well I would like them to sit down and explain things to people. To say your memory isn’t the best and it would be safer if you didn’t drive. Researcher: Would that be better if he had just come out and said that? Patient: I think so...I said ‘ I have a 16 (new) car in my drive..’ and he said ‘you will probably be back driving again’” Patient 5 who was found unfit to drive in her driving assessment

“we were totally...we actually didn’t know about it [driving assessment] before so it was totally new, I didn’t know of anyone who had it done before” Carer 1

Walk in the patient’s shoes

Patients spoke of the huge emotional impact that driving cessation would have on their lives, including constricted social opportunities, loneliness and increased dependence on family and neighbours. Although it was evident that GPs recognized this emotional impact, it appeared that they had not acknowledged or helped patients deal with it sufficiently, and this added to the upset that patients had experienced.

“If I couldn’t drive, well I’d feel loneliness actually, it is something I would feel. I am single you know” Patient 2

“Patient: He said he just couldn’t sign it, and that was it.

Interviewer: Were you satisfied with the information he gave you?

Patient: No certainly not...I was annoyed...[...]...I don’t want to be dependent on my children to go places, I was always able to get into my car and drive... now I have to get one of the girls to drive me down, and that’s not on.” Patient 5

Increase two way traffic between GPs and licensing system

To ease the discomfort associated with the task of assessing medical fitness to drive, GPs called for better lines of communication from the national driving authority and resources to support longer, more comprehensive assessment in their practices. For instance, recent changes had been introduced to the medical report allowing for restricted driving for patients (licenses to drive short distances, in local areas, during day light hours etc.) but participating GPs reported they had not received instruction on how they should make decisions on restricted driving, leaving them feeling undermined in the consultation.

“ I suppose you have heard that the driving licence forms miraculously changed this week. Nobody told us. The first we knew was when a patient came in clutching the form and we were looking at it.” GP1

Discussion

In this multi-perspective qualitative study, we found that where cognitive impairment has already been discussed openly with a patient in primary care, GPs can use relational continuity to prevent or mitigate patients' emotional response to the threat of driving cessation. Where cognitive impairment is known, GPs can revisit the issue of driving over multiple consultations, and use nuanced communication strategies to maintain some sense of patient autonomy and engage them in planning for driving cessation before a crisis develops. However, the abrupt introduction of concern about cognition when patients present for medical driving reports is problematic. Being confronted with unanticipated hesitations about FtD, while simultaneously learning of the possibility of cognitive impairment, represents a double whammy for patients that understandably leads to consultations becoming heated.

Comparison with existing literature

Similar to others²⁰, we found that patients themselves rarely raise the issue of driving in a proactive way, unless attending to get medical reports signed. In Canada, a campaign called "Not if but when" encourages GPs to introduce the topic of driving early in the course of caring for an older adult with dementia²⁸. We would extend on this recommendation by suggesting that driving is also discussed in routine follow-up of patients with mild cognitive impairment.

Prior studies of older adults' communication preferences for driving cessation, although they were not focused specifically on cognitive impairment, have similarly identified that communication should occur over a period of time rather than suddenly as well as the importance of maintaining older adults' agency in the decision to stop driving.^{23 29-32} Betz et al have suggested that the latter could be achieved via advance driving directives^{29 30}.

Patients with cognitive impairment can react to recommendations to stop driving with shock, anger, and denial³³. Our study builds on others to show how this emotional turmoil may be mitigated not only by addressing driving early but by addressing it separately from the disclosure of diagnosis of cognitive impairment³⁴. Following this, patients in this study accepted the need for driving assessment to determine their FtD, but wanted clear information on what to expect from driving assessment and what will follow.

As with any loss, driving cessation may elicit a grief reaction, amplified by the potential changes in independence, status, and social interaction^{22 33}. While GPs are well placed to guide and offer compassionate support to patients through these adjustments³⁵, we found that their current efforts seem to fall short of patients' expectations; patient participants requested more empathy and acknowledgement for the impact of driving cessation on their quality of life.

Strengths and Limitations

The transferability of our findings is enhanced by our sample of GPs and patients which represents diverse professional characteristics and a range of perspectives. Credibility is supported by triangulation of GP data with patient experiences and use of chart-stimulated recall in GP interviews. Chart-stimulated recall focused conversations on GPs' practice-based experience of FtD consultations rather than rhetoric or views. However, actual observation or recording of consultations may have added further depth and veracity to the data. We used peer-debriefing to bring reflexivity and sensitivity to data collection, while data analysis harnessed multidisciplinary involvement in every iteration.

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3 Similar to other teams, we found that engaging older patients with cognitive impairment in our
4 research was challenging³⁶. When we encountered low participation rates initially, we expanded our
5 recruitment strategies. The level of patient engagement was still somewhat disappointing, but the
6 diversity of patients who did participate enhanced the robustness of our findings, as did the
7 recurrence of themes in the data.
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10 Some patient participants appeared cautious about the detail they provided, despite reassurance of
11 the independent nature of the research interviewer. That this occurred despite enrolling only
12 patients with sufficient capacity to consent to participate in the study, and utilisation of the
13 professional skills of both interviewers indicates just how sensitive a topic FtD in cognitive
14 impairment is.
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17 **Implications for practice, policy and future research**

18 Across the spectrum of mild cognitive impairment to early dementia, many patients remain safe to
19 drive³⁷. However, in light of the increasing prevalence of these conditions, our findings offer
20 suggestions to support assessment of medical FtD for people with cognitive impairment in primary
21 care. Firstly, due to the sensitive nature of FtD consultations, it is preferable that patients see their
22 regular GP for FtD assessments. We identified that this sensitive topic is not suitable for review by
23 locum doctors,- it requires the full strength of relational continuity that primary care has the
24 potential to offer. This requires policy and procedures at practice level, and could be further
25 encouraged by having a requirement on the medical report form to say how long the assessing
26 physician has known the patient.
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32 A second recommendation is that a discussion of driving should be introduced into routine
33 consultations for all patients with cognitive impairment, even in the absence of apparent functional
34 impairment. For patients with established dementia, FtD discussions should be incorporated into
35 routine post-diagnosis management along with discussion of other legal issues such as will-making,
36 and advanced care directives³⁰. By taking a proactive approach to driving, healthcare professionals
37 may avoid the distress associated with an unanticipated yet imminent threat of driving cessation.
38 Engendering a sense of agency, input and control over their own plans for driving cessation may also
39 help patients adjust better to these changes²². This approach requires that GPs engage in open
40 communication, early disclosure, education and support for patients with cognitive impairment and
41 dementia, in line with the recommendations of several international guidelines³⁸. Further,
42 promotion of early and open conversation about FtD by the lay media, patient advocacy groups and
43 healthcare professionals may prompt better discussions about driving between patients and their
44 physicians^{13 28}.
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49 The point where driving cessation is indicated for a patient with dementia represents an important
50 and emotional transition in their illness. Patient and caregiver accounts identify driving cessation as
51 one of a series of losses in dementia and represents a point of transition in the illness to increasing
52 dependence, reduced social participation and a negative view of one's self²². Empowering GPs to
53 address patients' psychological and emotional responses of loss and grief will require advanced
54 communication skills, especially in the context of cognitive impairment where patient insight may be
55 impaired. However, existing educational resources in FtD have been criticized for lack of applicability
56 ^{14 16 39}. We suggest that future educational resources frame consultations where driving cessation
57 may be indicated as involving non-bereavement loss and draw on communication skills traditionally
58 associated with breaking bad news^{40 33}. We also recommend that existing educational programmes
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3 on the management of cognitive impairment highlight the benefit of addressing, diagnosing and
4 disclosing cognitive impairment early with patients, and empower GPs to adopt a pro-active
5 approach that facilitates maintenance of a patient's autonomy for as long as is safely possible.
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7 Where uncertainty about a patient's fitness to drive exists, or additional evidence is needed to
8 convince a patient that they are no longer fit to drive, assessment by third parties such as
9 occupational therapists or specialist physicians can be helpful. However, in Ireland and elsewhere ²¹
10 ⁴¹, many patients face geographical and/or financial barriers to accessing such services. Providing
11 universal access to assessment services would better support GPs in making decisions on FtD and
12 communicating these decisions to patients.
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14

15 16 **Conclusion**

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18 GPs used their longitudinal relationship with cognitively impaired patients to reduce the potential
19 for conflict in consultations on FtD. These efforts could be augmented by explicit discussion of
20 cognitive impairment at an earlier stage for all patients affected by cognitive impairment from mild
21 cognitive impairment right through to dementia. Patients would benefit from greater input into
22 planning driving cessation and acknowledgement from their GPs of the impact this may have on
23 their quality of life.
24
25

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35
36

37 38 **Declaration of conflicting interests**

39 The Authors declares that there is no conflict of interest.
40

41 42 **Author contributions**

43 CS, TF, CB and LH planned the original study, wrote the protocol, won funding and oversaw the
44 original study. CS, TF, CB, KM, CS and LH designed, planned and carried out analyses for this paper.
45 CS drafted this manuscript and revised it in response to critical revisions from all authors. CS and CB
46 are the co-guarantors of the study. All authors read and approved the final manuscript.
47

48 49 **Ethics approval**

50 Research ethics approval was granted by the Clinical Research Ethics Committee, ECM 4 (aa)
51 06/09/2016.
52

53 54 **Data sharing statement**

55 Participants were not consented for sharing of interview data. However additional quotes to support
56 the themes are available on request from cs926@medschl.cam.ac.uk.
57

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*Topic guides for interviews***GP INTERVIEW TOPIC GUIDE****Introduction:**

Driving allows people independence, social engagement and interaction, and is a contributor to quality of life and well-being. However, discussions between GPs and patients on fitness to drive can be fraught, with up to a fifth of GPs reporting that patients have left their practice after the GP did not approve their driving license application. Difficulties discussing fitness to drive can be compounded by the presence of unacknowledged or undiagnosed mild cognitive impairment, which is the focus of this interview. We want to discuss your experience of speaking to patients with mild cognitive impairment (or their carers) about fitness to drive, to see what works and what does not work well in practice.

Overview of interview:

- 20-30minutes long
- Record interview
- No patient identifying information will be published or shared.
- Ethics approval was granted. Obtain consent.
- Full confidentiality, data will be password protected in UCC only.

Questions	Prompt/probe
1. Can you describe your practice location and practice population in general terms please?	<ul style="list-style-type: none"> • Number of gps • Number of patients • Rural/ urban location • Level of deprivation • Available social supports • Available level of public transport
2. How frequently do you encounter consultations in the issue of fitness to drive?	
3. What provokes this discussion?	<ul style="list-style-type: none"> • Patient concern • Carer concern • GP concern • Letter from specialist • Others provocation?
4. Can you choose two patients with cognitive impairment from your caseload and tell me how consultations on fitness to drive went these patients? <ol style="list-style-type: none"> a. Refer to case notes b. Choose patient where it went well and not so well 	<ul style="list-style-type: none"> • Who brought it up? • How did you broach the issue? • What words used? • Re-visited multiple times? • Discussion with patient or carer or other family/friends.

Topic guides for interviews

5. Did you get the patient response that you wanted?	Why/ why not? Please explain/elaborate.
6. What actions followed the consultation?	Referral? Assessment? Repeat consultation?
7. Were you prepared for this?	What training have you had in this area? Is there any available? Is it needed?
8. Have you had consultations on fitness to drive in patients with mild cognitive impairment that have gone particularly well or badly?	Explain details of case. Refer to notes if helps.
9. In your opinion, what would have made this process easier for you?	Additional community resources/ other health care professionals/ knowledge resources.
10. What advice would you offer to GPs about they can best deal with this sensitive issue?	
Finish 11. Is there anything else you would like to elaborate on? Thank for your time today	

*Topic guides for interviews***PATIENT INTERVIEW TOPIC GUIDE**

Questions	Prompt/probe
1. Can you give your first name, age and tell me where you live please?	
2. We are interested in discussions about fitness to drive in people with mild cognitive impairment. Would you like to speak about your fitness to drive or the fitness to drive of the person you care for?	If relates to carer, who are they caring for, for how long, etc.
3. What would be important in a conversation about fitness to drive?	
4. What approaches would be challenging/unwelcome?	
5. When did the issue of fitness to drive first arise for you?	When was fitness to drive an issue (months or years ago), what brought this to attention, what provoked it?
6. How was it first discussed by your GP?	Brought up by patient, carer or GP?
7. Can you tell me how that conversation went?	Was it too theoretical or technical? Too long? Too short? Confusing? How did it make you feel?
8. Did you get the answers/ information you wanted?	Please explain/elaborate.
9. Was this conversation something you expected?	Why? Why not?
10. What actions followed the consultation/discussion with the GP?	Referral? Assessment? Repeat consultation? Were you prepared for this?

Topic guides for interviews

11. In your opinion, what would have made this process easier for you or the person you care for?	
12. What advice would you offer to GPs about they can best deal with this sensitive issue?	
13. What went well from your perspective?	Involvement of GP/ other healthcare professionals/ family members...
14. How have things changed since then?	
Finish 15. Is there anything else you would like to tell me? Thank for your time today	

Manuscript: Shifting gears versus sudden stops: a qualitative study of consultations about driving in patients with cognitive impairment

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
<i>Personal Characteristics</i>		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	6-7
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	7
3. Occupation	What was their occupation at the time of the study?	7
4. Gender	Was the researcher male or female?	1
5. Experience and training	What experience or training did the researcher have?	7
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to study commencement?	6, 7
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	6, 7
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	6, 7
Domain 2: study design		
<i>Theoretical framework</i>		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	7
<i>Participant selection</i>		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	6, 7
11. Method of approach	How were participants approached? e.g.	6, 7

	face-to-face, telephone, mail, email	
12. Sample size	How many participants were in the study?	9
13. Non-participation	How many people refused to participate or dropped out? Reasons?	6
<i>Setting</i>		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	6, 7
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	6, 7
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	9
<i>Data collection</i>		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	6, 7. Appendix 1
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	Not applicable
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	7
20. Field notes	Were field notes made during and/or after the inter view or focus group?	7
21. Duration	What was the duration of the inter views or focus group?	9
22. Data saturation	Was data saturation discussed?	6
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	7
Domain 3: analysis and findings		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data?	7
25. Description of the coding tree	Did authors provide a description of the coding tree?	7
26. Derivation of themes	Were themes identified in advance or derived from the data?	7
27. Software	What software, if applicable, was used to manage the data?	7
28. Participant checking	Did participants provide feedback on the findings?	7
<i>Reporting</i>		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	9-13
30. Data and findings consistent	Was there consistency between the data presented and the findings?	9-13
31. Clarity of major themes	Were major themes clearly presented in the findings?	9-13
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	9-13

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Shifting gears versus sudden stops: a qualitative study of consultations about driving in patients with cognitive impairment

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Manuscripts

Title

Shifting gears versus sudden stops: a qualitative study of consultations about driving in patients with cognitive impairment

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Abstract

Objective

General practitioners (GPs) report finding consultations on fitness to drive (FtD) in people with cognitive impairment difficult, and potentially damaging to the physician-patient relationship. We aimed to explore GP and patient experiences to understand how the negative impacts associated with FtD consultations may be mitigated.

Methods

Individual qualitative interviews were conducted with GPs (n=12) and patients/carers (n=6) in the Republic of Ireland. We recruited a maximum variation sample of GPs using criteria of length-of-time qualified, practice location and practice size. Patients with cognitive impairment were recruited via driving assessment services and participating general practices. Interviews were audio-recorded, transcribed, and analysed thematically by the multidisciplinary research team using an approach informed by the framework method.

Results

The issue of FtD arose in consultations in two ways: introduced by GPs to proactively prepare patients for future driving cessation, or by patients who urgently needed a medical report for an expiring driving license. The former strategy, implementable by GPs who had strong relational continuity with their patients, helped prevent crisis consultations from arising. The latter scenario became acrimonious if cognition had not been openly discussed with patients previously and was now potentially impacting on their right to drive. Patients called for greater clarity and empathy for the threat of driving cessation from their GPs.

Conclusion

GPs used their longitudinal relationship with cognitively impaired patients to reduce the potential for conflict in consultations on FtD. These efforts could be augmented by explicit discussion of cognitive impairment at an earlier stage for all affected patients. Patients would benefit from greater input into planning driving cessation and acknowledgement from their GPs of the impact this may have on their quality of life.

Strengths and limitations of this study

- This multi-perspective qualitative study examined the experiences of both healthcare professionals' and patients with cognitive impairment to understand both sides of sensitive consultations on medical fitness to drive in the setting of cognitive impairment.
- The transferability of our findings is enhanced by a maximum variation sample of General Practitioners (GPs) in terms of different practice contexts (large versus small group practices, urban versus rural locations) and variable level of professional experience.
- The validity of interviews with GPs was enhanced by using the technique of chart-stimulated recall.
- We found that engaging older patients with cognitive impairment in our research was challenging and countered this by expanding on approaches to recruitment.

Introduction

For older adults, driving cessation can limit access to family, friends, and services and is an independent risk factor for entry to a nursing home¹. General Practitioners (GPs) may be wary of consultations on medical fitness-to-drive (FtD) because of potential negative impacts on a patient's sense of autonomy, quality of life, and the doctor-patient relationship². This discomfort is amplified in patients where there is concern about cognition, as GPs can also be reluctant to address the earlier stages of cognitive impairment with older patients due to fear of causing unnecessary anxiety, labelling and stigma³.

Cognitive impairment exists across a spectrum from mild cognitive impairment to mild, moderate and advanced dementia. Prevalence estimates for these conditions vary by study design and population examined but approximations for the prevalence of mild cognitive impairment in older adults (aged over 50 years) are 6-20% and for dementia are 4-7%. While not all patients with mild cognitive impairment go on to develop dementia, approximately 10% per year do progress with the majority of these people experiencing decline in driving abilities over time^{2,4}. Cognitive decline is associated with crash risk across the cognitive spectrum⁵, but the point where an individual patient must consider driving cessation varies case by case². Severe dementia is a contraindication to driving and safe driving is generally unlikely in the presence of moderate dementia. Many patients with mild dementia and the majority with mild cognitive impairment may be deemed fit to continue driving but should be re-evaluated every six to twelve months or sooner if indicated². Problems may arise due to shortcomings in the detection, diagnosis and disclosure of cognitive impairment: approximately 50% of older adults with dementia are either undiagnosed or unaware of the diagnosis⁶.

GPs' obligations with respect to FtD assessment and reporting differ across jurisdictions. In Ireland, the UK, Australia and parts of Canada, health professionals have an obligation to give clear advice to drivers in cases where an illness or injury may compromise their FtD, but the responsibility for notifying the licensing authority normally falls to the driver^{7,8,9,10}. Where a healthcare professional believes that a driver is not compliant with advice to stop driving or notify authorities, the healthcare professional has a duty to notify the authorities in the interests of public safety. In some US states and many Canadian jurisdictions, physicians are required to report directly to state licensing departments on patients who have specific medical conditions, including dementia^{10,11}. Additionally, in Ireland where this study took place, driving licenses must be renewed after intervals of one, three or ten years depending on the age and health of the driver and must be accompanied by a medical report in the case of injury or illness that may affect FtD⁷. The medical report is generally signed by the patient's GP, and the requirement for this report is a trigger for many consultations on FtD in Irish general practice.

Qualitative research examining GPs' perspectives on FtD consultations for patients with possible cognitive impairment demonstrates that their discomfort with these consultations transcends differences in regional policies on licensing and road-safety¹². Findings include GPs' view of themselves as reluctant regulators¹³; who "hate" that driving assessment has anything to do with their role^{14,15}; and frequent uncertainty about their legal and ethical obligations¹⁶⁻²¹. Evaluations of patients' responses to the prospect of driving cessation in the context of cognitive impairment highlight a range of negative emotions such as anger, frustration, and sadness, the disruption to self-identity and fear of loss of independence^{22,23}. Up to one fifth of GPs report a patient leaving their

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3 practice because of FtD consultations that have gone badly, highlighting just how distressing these
4 consultations can be for patients ²¹.
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6 International strategies for managing the rising global prevalence of cognitive impairment and
7 dementia prioritize management in the community and GPs are assuming an ever increasing role in
8 the on-going management of these conditions, including the assessment and re-assessment of
9 medical FtD ²⁴. However, there has been little examination of the consultation strategies used by GPs
10 in an effort to lessen the emotional impact of FtD consultations for patients with cognitive
11 impairment, nor have patients views on GPs' consultation strategies been explored. In this study, we
12 examine both sides of the FtD consultation- GPs and patients with cognitive impairment - in order to
13 understand how the negative aspects of these consultations may be mitigated. We were specifically
14 interested in how, in the setting of cognitive impairment, FtD is introduced into consultations in
15 primary care; what consultation strategies GPs use; the influences on GPs' approach; and aspects of
16 the FtD consultation that could be improved from patients' and GPs' perspectives.
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21 **Methods**

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23 A multi-perspective qualitative design was used. The setting was primary care in the Republic of
24 Ireland.
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26 **GP participants and interviews**

27 Semi-structured qualitative interviews were conducted with GPs between February and July 2017.
28 Inclusion criteria were fully trained GPs working in clinical practice. Participants were recruited via
29 online GP discussion groups and two regional professional development meetings. We sought a
30 maximum variation sample of GPs against the following criteria: length-of-time qualified (over/under
31 ten years), practice location (rural/urban), and practice size (<3/≥3 full-time GPs). Recruitment
32 continued until the sample represented a satisfactory mix of these criteria and preliminary data
33 analysis indicated that further interviews were unlikely to generate additional information power ²⁵.
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36 During interviews, the researcher (KML) drew on the technique of chart-stimulated recall ²⁶. This
37 technique was adapted for research from the field of medical education, and involves asking a
38 healthcare professional to describe their management of a case, and the reasoning behind the
39 clinical decisions they had made, using the patient's medical chart as an aide memoire to the
40 narrative. The acceptability, reliability, and validity of chart-stimulated recall for retrospectively
41 assessing clinical practice has been demonstrated in previous studies ²⁶. We asked participants to
42 choose patients from their caseload for whom recent consultations on FtD included concerns about
43 cognition and to refer to the notes they had made during the consultation when describing the index
44 consultation and subsequent consultations with that patient. We asked GPs to choose at least two
45 cases, ideally one where the FtD consultation went well and one where it did not go so well. This
46 approach focused interviews on GPs practice-based experience rather than rhetorical discussions of
47 FtD; gave insight into the breadth of a GPs experience of FtD consultations in cognitive impairment;
48 and facilitated exploration of both unsuccessful approaches as well approaches which could be
49 usefully implemented by others. Interviews were conducted in the GPs' practices to allow access to
50 case notes and facilitate recall of the consultations ²⁶.
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57 **Patient participants and interviews**

58 Semi-structured qualitative interviews were conducted with patients between June and November
59 2017. Inclusion criteria were patients with cognitive impairment (mild cognitive impairment or mild
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3 dementia). We invited patients to participate using mail-outs to people who had attended driving
4 assessment services after being referred to that service by their GP due to concerns about cognitive
5 impairment. As this initial recruitment strategy was, unfortunately, not very successful, we expanded
6 recruitment by asking participating GPs to invite patients with cognitive impairment directly. Once a
7 potential participant expressed interest in the study, the qualitative interviewers (KML, CSh) ensured
8 that the person had a full understanding of the process and confirmed their capacity to participate.
9 One person was interested in participating but suffered from aphasia as a feature of her cognitive
10 impairment (although she was still deemed fit to drive after assessment); in this case we offered the
11 patient's family carer an opportunity to be interviewed instead. No personal identifying information
12 was collected on the patients discussed by GPs and there was no intentional overlap between the
13 patients discussed by GPs and the patient participants.
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17 We conducted interviews in the participant's home, the university, or other location of their choice.
18 A topic guide, which was written in collaboration with the Alzheimer's Society of Ireland, was used in
19 interviews (see Appendix 1): in summary participants were asked to recount their experiences of,
20 thoughts on and preferences for (or those of the person they care for) FtD consultations in primary
21 care. Both interviewers (KML (PhD), CSh (PhD)) had extensive experience in interviewing in sensitive
22 situations in the fields of dementia and gerontology. None of the participants were known to the
23 interviewers before the study commenced.
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27 **Data analysis**

28 All interviews were audio-recorded, transcribed in full and de-identified. After the first five GP
29 interviews and all patient interviews, the interviewers (KML and CSh) presented reflexive accounts
30 and field notes to two other team members (CS and CB), leading to iterative modification of topic
31 guides. We used a framework approach to analysis²⁷. Once data collection was complete, each
32 transcript was thematically coded by at least two members of the multidisciplinary research team
33 (KML-health service researcher, CS, TF, CB- all academic GPs, LH-occupational therapist, CSh-social
34 scientist) to familiarize ourselves with the data. We used this list of themes to create an inductive
35 matrix for further analysis. The matrix placed emphasis on the GPs' approach to FtD consultations
36 and the events that ensued within those consultations. After indexing interview data into the matrix,
37 further rounds of coding were conducted to develop, interpret and refine themes within the matrix.
38 Divergent accounts were sought within the data. Interviews with patients were analysed in a similar
39 way but using a different matrix. The results from both matrices were merged and interpreted
40 together in the final stage of the analysis.
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45 Transcripts were not provided to participants for feedback. NVivo software was used to support data
46 analysis. All participants provided written informed consent. Research ethics approval was granted
47 by the Clinical Research Ethics Committee of the Cork Teaching Hospitals (ECM 4 (aa) 06/09/16). The
48 study report was written in adherence with the consolidated criteria for reporting qualitative
49 research (COREQ) checklist (Appendix 2).
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53 **Patient and Public Involvement**

54 We developed the patient invitations, information letters, and expression of interest forms in
55 collaboration with patient and public representatives from the Alzheimer's Society of Ireland
56 (acknowledged below). Patient and public representatives also reviewed and rephrased the topic
57 guide for interviews with patients with cognitive impairment.
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Findings

Eighteen people participated: twelve GPs, five people with cognitive impairment and one carer. The characteristics of GP participants are shown in Table 1. Amongst patient participants, three patients lived in rural locations. One patient was awaiting review by driving assessment services, two had been deemed not fit to drive after assessment, and the others had been deemed fit to drive after assessment. On average, GP interviews lasted 20 minutes (range 10 to 43) and patient interviews lasted 29 minutes (range 8 to 120). The themes are presented narratively incorporating quotes from the data (shown in italics).

Table 1. Characteristics of participants

	Practice location	Practice size at time of interview (small group <3 full time GPs/ larger group ≥3 full time GPs)	Years qualified as GP
GP1	Urban	Large group	Over ten years
GP2	Urban	Small group	Less than ten years
GP3	Rural	Small group	Less than ten years
GP4	Rural	Large group	Over ten years
GP5	Mixed	Large group	Less than ten years
GP6	Rural	Large group	Over ten years
GP7	Rural	Large group	Less than ten years
GP8	Rural	Small group	Over ten years
GP9	Urban	Large group	Over ten years
GP10	Urban	Small group	Over ten years
GP11	Urban	Small group	Less than ten years
GP12	Urban	Small group	Less than ten years

Route to the consultation: Shifting gears versus sudden stops

The issue of FtD tended to arise in consultations in two ways. If cognitive impairment was acknowledged as a problem between the patient and their GPs, GPs reported introducing the topic of FtD into routine consultations to proactively prepare patients for future changes in driving status. This measured approach included use of “*warning shots*” that changes may be required, revisiting the issue over multiple consultations, and signing medical reports for only one year at a time to alert the patient to the GP’s concerns.

“Sometimes what I will do, I will give the person a heads up and say, “Ok, I am going to certify you for the next year but be aware of the fact that in a year’s time you may not be in a position to drive the car and you might need to think about getting someone else to do the driving for you.” GP6

In contrast, in many cases the issue of driving arose abruptly because of a patient’s request for an urgent driving license medical report. If pre-existing concerns about the patient’s cognition had either not been discussed openly with the patient or the specific issue of their driving had not been addressed with them previously, the FtD consultations could become contentious. Being confronted with the possibility of cognitive impairment and potential restrictions on their driving in the one encounter led to patients becoming upset and consultations becoming fraught. As GPs had no

forewarning for the patient's reason for attendance and often had insufficient time to comprehensively review the patient's case during the ten minute consultation, they reported either making rapid decisions on the patient's FtD or deferred decision-making, meaning the patient would not be able to stay on the road until further evaluation was carried out.

"I had not realized that she was driving until she asked me to sign the driving renewal form ... I was actually quite shocked that she was driving because it was clear to me that she was not...well anyway, I explained to her the reasons why I didn't think it was a good idea for her to drive and she was quite upset over that" GP10

GPs described patient responses as "furious" GP5; "really unhappy" GP9; "very upset" GP12; "angry" GP3&4; "grumpy" GP2; and "very cross" GP1. The patient's response led to reactive feelings of remorse or regret in GPs. Three GPs (GP1, GP4, GP5) reported patients switching practice due to damaged physician-patient relationship after fitness to drive consultations.

Patients themselves appeared guarded in their descriptions of the emotional impact of FtD consultations (with one clear divergent case who was openly frustrated and annoyed), despite reassurance of the independence of the research interviewer. However, during these interviews, the interviewers noted patients' non-verbal signs of frustration and sadness.

"Well, I was a bit upset I suppose...(pause).... my blood pressure increased. An anxiety I suppose." Patient 2

"what am I going to do?.. (I'm) not getting anywhere.. (I'm) not accepting the report" Patient 3

"...you feel awful and it's really awkward and you've only 15 minutes. And then it is 'next!' It's actually terribly difficult." GP5

"I was unable to sign his driving license application form on this occasion. And I never saw him again....and that was 15 months ago." GP4

Consultation strategies

GPs reported drawing on a number of consultation and communication strategies when faced with this sensitive topic. They used these approaches both when adopting the pro-active approach to introduce the patient to the idea of driving cessation, and during the more acute consultations in an effort to reduce potential damage to the doctor-patient relationship.

Reflecting and echoing

A common approach reported by GPs was to echo patients' perceptions of their own road safety, their self-imposed restrictions, and their level of comfort and confidence while driving back at them. In this way, GPs appealed to patients' remaining insight in an approach akin to motivational interviewing.

"we started talking about him driving and I asked "Do you still feel comfortable to drive?" because - the word he used and I just echoed it was- sometimes he feels foggy." GP7

Incorporating objective tests

In an effort to prevent FtD decisions being viewed as "doctor's discretion" (GP1), GPs described using

cognitive screening tools during consultations. Some GPs purposively added cognitive tests (such as the MiniCog, GPCOG and the MMSE) to their driving assessment proformas, to both prompt themselves to assess cognition, and to “show” patients that cognitive assessment was necessary.

“I added the Minicog to our template not so that people must use it but more to remind them” GP9

Blaming guidelines

To protect the physician-patient relationship, many GPs “blamed” the national driving guidelines in consultations where they were deferring or denying patients’ medical certification to drive.

“you can sort of externalize things – you know it’s not me – it’s them. I am just acting along these guidelines. It’s not that I am saying you can’t drive, it’s the guidelines that say you can’t drive. So you are depersonalizing things to some degree and you can continue the relationship with the patient ..erm...by blaming big brother!” GP2

While guidelines suggested different approaches for patients with mild cognitive impairment versus dementia, in practice GPs did not see such a clear distinction between these conditions. Despite guidelines not always matching the reality of assessing FtD as GPs experienced it, they were still happy to have them as a “prop” to the consultation if they needed to.

“If you’re not happy with it, you are the one who actually has to defend yourself and sleep at night so [...] you try and use those [guidelines] like a resource” GP12

Shift responsibility to external assessors

GPs reported referring patients for external driving assessment (e.g. independent mobility assessment services, geriatricians, neurologists, old age psychiatrists) for three main reasons. Some GPs used these services as a means of protecting the physician-patient relationship while assessing or convincing patients of the need for driving cessation. Others needed reassurance in cases which were “borderline” (GP4 & GP9), due in part to the risk of litigation perceived by GPs if patients were subsequently involved in a road traffic accident. Lastly, many GPs reported referring patients because doing a satisfactory assessment “can be very hard in a 10 or 15 minute consultation” GP11. Access to these services was patchy, with most patients having to pay out of pocket which some GPs felt introduced an element of inequity into care.

“Her license came up for renewal and she lives 4 miles out the country so it was going to be a huge thing to say you can’t. But I had sort of given her a few warning shots so when it came up for renewal I said “Look, I can’t really make this decision now on my own. So that is why I referred her.”” GP8

“Am I really going to make a cut off to say someone can’t drive anymore? (Sighs)...If I am unsure then I would refer to the assessors. Do as I do...at least you are medico legally covered.” GP3

Patients were confused about the role of external assessment, with some interpreting it as a sign of GPs’ uncertainty about how to proceed. Other patients reported a preference for on-road assessment over being questioned about driving by their GP.

“Well the ideal way to test a person driving is to go out with them in the car – that must be the greatest way there is rather than sitting there and asking me questions about driving

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3 *because at my age anyway, asking questions about driving is more for young people who are*
4 *more alert to all questions...used to exams and that.” Patient 2*
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9 **The value of continuity**

10 Patients reported mixed feelings about having their GPs conduct FtD assessments, with some asking
11 why GPs would be considered to know anything about a person’s FtD and another recognising the
12 potential of FtD assessment to interfere negatively with the physician-patient relationship.
13

14 *“Well the doctor, what would the doctor know about your driving?” Patient 4*

15
16 *“I can understand a difficulty with a doctor that is your own doctor asking questions like that*
17 *because the doctor could feel like...that he’s causing a bit of a muddle between yourself and*
18 *himself which shouldn’t happen at all. Doctor and patient need to get on and maybe it isn’t*
19 *appropriate for a doctor to be doing that.” Patient 2*
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22 However, patients were consistent in their view that if medical assessment of FtD is to remain the
23 duty of GPs, then it should be with their own GP and not with a locum or an unfamiliar GP. They felt
24 their own longstanding GP would have a better “sense” of them and discuss FtD without causing
25 alarm.
26

27 *“The scenario would never have arisen if it was her own doctor. She is capable of driving, her*
28 *problem is her communication, and that doesn’t affect her driving ability.” Carer 1 discussing*
29 *her aunt who was subsequently deemed fit to drive*
30

31 Correspondingly, GPs working in the one practice for many years felt that continuity of care helped
32 them to identify signs of cognitive impairment early and facilitated discussions with patients before
33 a crisis developed. This approach supported patient involvement in plans for driving cessation while
34 also allowing them to continue driving for as long as was safely possible.
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36

37 *“It took about three consultations before we got around to it [discussing driving] head on”*
38 *GP1, working in the one practice for more than ten years.*

39
40 *“Discussion re: driving seems ok at present but advised likely to need to stop soon.” GP9*
41 *reading from her notes.*
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43 In contrast, recently qualified GPs, new GPs in a practice and locums were less likely to sign patients
44 off as fit to drive, tending instead to first discuss cases with colleagues or refer for external
45 assessments. GPs reported the greatest difficulties when they were working as locums because they
46 encountered patients to whom they were essentially strangers without any warning of what the
47 consultation would be about. Having not anticipated any reluctance to sign the medical report,
48 patients could then understandably become aggravated in the consultation.
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51 *“someone comes in and they present a form for driving with no warning, no preparation for*
52 *it, and often you have never met them before.... she nearly lunged at me when I said to her*
53 *that I don’t know if I can sign it. She nearly jumped across the table and she said “How am I*
54 *supposed to do my shopping?” GP5*
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The road ahead: what needs to change

Mapping the journey

Patients wanted their GPs to explain clearly why there were concerns about their driving and the reasons behind the decisions they had made. Patients recognised that external driving assessment was for the benefit of public road safety, but requested that they be told what to expect from the assessment and what steps would follow. Patients also felt that the plan should move quickly so that they would not be off the road for an unnecessarily long duration.

“Well I would like them to sit down and explain things to people. To say your memory isn’t the best and it would be safer if you didn’t drive. Researcher: Would that be better if he had just come out and said that? Patient: I think so...I said ‘ I have a 16 (new) car in my drive..’ and he said ‘you will probably be back driving again’” Patient 5 who was found unfit to drive in her driving assessment

“we were totally...we actually didn’t know about it [driving assessment] before so it was totally new, I didn’t know of anyone who had it done before” Carer 1

Walk in the patient’s shoes

Patients spoke of the huge emotional impact that driving cessation would have on their lives, including constricted social opportunities, loneliness and increased dependence on family and neighbours. Although it was evident that GPs recognized this emotional impact, it appeared that they had not acknowledged or helped patients deal with it sufficiently, and this added to the upset that patients had experienced.

“If I couldn’t drive, well I’d feel loneliness actually, it is something I would feel. I am single you know” Patient 2

“Patient: He said he just couldn’t sign it, and that was it.

Interviewer: Were you satisfied with the information he gave you?

Patient: No certainly not...I was annoyed...[...]...I don’t want to be dependent on my children to go places, I was always able to get into my car and drive... now I have to get one of the girls to drive me down, and that’s not on.” Patient 5

Increase two way traffic between GPs and licensing system

To ease the discomfort associated with the task of assessing medical fitness to drive, GPs called for better lines of communication from the national driving authority and resources to support longer, more comprehensive assessment in their practices. For instance, recent changes had been introduced to the medical report allowing for restricted driving for patients (licenses to drive short distances, in local areas, during day light hours etc.) but participating GPs reported they had not received instruction on how they should make decisions on restricted driving, leaving them feeling undermined in the consultation.

“ I suppose you have heard that the driving licence forms miraculously changed this week. Nobody told us. The first we knew was when a patient came in clutching the form and we were looking at it.” GP1

Discussion

In this multi-perspective qualitative study, we found that where cognitive impairment has already been discussed openly with a patient in primary care, GPs can use relational continuity to prevent or mitigate patients' emotional response to the threat of driving cessation. Where cognitive impairment is known, GPs can revisit the issue of driving over multiple consultations, and use nuanced communication strategies to maintain some sense of patient autonomy and engage them in planning for driving cessation before a crisis develops. However, the abrupt introduction of concern about cognition when patients present for medical driving reports is problematic. Being confronted with unanticipated hesitations about FtD, while simultaneously learning of the possibility of cognitive impairment, represents a double whammy for patients that understandably leads to consultations becoming heated.

Comparison with existing literature

Similar to others²⁰, we found that patients themselves rarely raise the issue of driving in a proactive way, unless attending to get medical reports signed. In Canada, a campaign called "Not if but when" encourages GPs to introduce the topic of driving early in the course of caring for an older adult with dementia²⁸. We would extend on this recommendation by suggesting that driving is also discussed in routine follow-up of patients with mild cognitive impairment.

Prior studies of older adults' communication preferences for driving cessation, although they were not focused specifically on cognitive impairment, have similarly identified that communication should occur over a period of time rather than suddenly as well as the importance of maintaining older adults' agency in the decision to stop driving.^{23 29-32} Betz et al have suggested that the latter could be achieved via advance driving directives^{29 30}.

Patients with cognitive impairment can react to recommendations to stop driving with shock, anger, and denial³³. Our study builds on others to show how this emotional turmoil may be mitigated not only by addressing driving early but by addressing it separately from the disclosure of diagnosis of cognitive impairment³⁴. Following this, patients in this study accepted the need for driving assessment to determine their FtD, but wanted clear information on what to expect from driving assessment and what will follow.

As with any loss, driving cessation may elicit a grief reaction, amplified by the potential changes in independence, status, and social interaction^{22 33}. While GPs are well placed to guide and offer compassionate support to patients through these adjustments³⁵, we found that their current efforts seem to fall short of patients' expectations; patient participants requested more empathy and acknowledgement for the impact of driving cessation on their quality of life.

Strengths and Limitations

The transferability of our findings is enhanced by our sample of GPs and patients which represents diverse professional characteristics and a range of perspectives. However, each of these perspectives represents only one of the multiple truths that can exist for these consultations. Direct observation or recording of consultations would have generated a different perspective and may have added further insights into the conduct and content of these challenging doctor-patient interactions. The credibility of our findings is supported by triangulation of GP data with patient experiences and use of chart-stimulated recall in GP interviews. Chart-stimulated recall focused conversations on GPs' practice-based experience of FtD consultations rather than rhetoric or views.

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3 We used peer-debriefing to bring reflexivity and sensitivity to data collection, while data analysis
4 harnessed multidisciplinary involvement in every iteration.
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6 Similar to other teams, we found that engaging older patients with cognitive impairment in our
7 research was challenging³⁶. When we encountered low participation rates initially, we expanded our
8 recruitment strategies. The level of patient engagement was still somewhat disappointing, but the
9 diversity of patients who did participate enhanced the robustness of our findings, as did the
10 recurrence of themes in the data.
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13 Some patient participants appeared cautious about the detail they provided, despite reassurance of
14 the independent nature of the research interviewer. That this occurred despite enrolling only
15 patients with sufficient capacity to consent to participate in the study, and utilisation of the
16 professional skills of both interviewers indicates just how sensitive a topic FtD in cognitive
17 impairment is.
18

19 20 **Implications for practice, policy and future research**

21 Across the spectrum of mild cognitive impairment to early dementia, many patients remain safe to
22 drive³⁷. However, in light of the increasing prevalence of these conditions, our findings offer
23 suggestions to support assessment of medical FtD for people with cognitive impairment in primary
24 care. Firstly, due to the sensitive nature of FtD consultations, it is preferable that patients see their
25 regular GP for FtD assessments. We identified that this sensitive topic is not suitable for review by
26 locum doctors, - it requires the full strength of relational continuity that primary care has the
27 potential to offer. This requires policy and procedures at practice level, and could be further
28 encouraged by having a requirement on the medical report form to say how long the assessing
29 physician has known the patient.
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35 A second recommendation is that a discussion of driving should be introduced into routine
36 consultations for all patients with cognitive impairment, even in the absence of apparent functional
37 impairment. For patients with established dementia, FtD discussions should be incorporated into
38 routine post-diagnosis management along with discussion of other legal issues such as will-making,
39 and advanced care directives³⁰. By taking a proactive approach to driving, healthcare professionals
40 may avoid the distress associated with an unanticipated yet imminent threat of driving cessation.
41 Engendering a sense of agency, input and control over their own plans for driving cessation may also
42 help patients adjust better to these changes²². This approach requires that GPs engage in open
43 communication, early disclosure, education and support for patients with cognitive impairment and
44 dementia, in line with the recommendations of several international guidelines³⁸. Further,
45 promotion of early and open conversation about FtD by the lay media, patient advocacy groups and
46 healthcare professionals may prompt better discussions about driving between patients and their
47 physicians^{13 28}.
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51 The point where driving cessation is indicated for a patient with dementia represents an important
52 and emotional transition in their illness. Patient and caregiver accounts identify driving cessation as
53 one of a series of losses in dementia and represents a point of transition in the illness to increasing
54 dependence, reduced social participation and a negative view of one's self²². Empowering GPs to
55 address patients' psychological and emotional responses of loss and grief will require advanced
56 communication skills, especially in the context of cognitive impairment where patient insight may be
57 impaired. However, existing educational resources in FtD have been criticized for lack of applicability
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60 ^{14 16 39}. We suggest that future educational resources frame consultations where driving cessation

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3 may be indicated as involving non-bereavement loss and draw on communication skills traditionally
4 associated with breaking bad news^{40 33}. We also recommend that existing educational programmes
5 on the management of cognitive impairment highlight the benefit of addressing, diagnosing and
6 disclosing cognitive impairment early with patients, and empower GPs to adopt a pro-active
7 approach that facilitates maintenance of a patient's autonomy for as long as is safely possible.
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10 Where uncertainty about a patient's fitness to drive exists, or additional evidence is needed to
11 convince a patient that they are no longer fit to drive, assessment by third parties such as
12 occupational therapists or specialist physicians can be helpful. However, in Ireland and elsewhere²¹
13⁴¹, many patients face geographical and/or financial barriers to accessing such services. Providing
14 universal access to assessment services would better support GPs in making decisions on FtD and
15 communicating these decisions to patients.
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18 Conclusion

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21 GPs used their longitudinal relationship with cognitively impaired patients to reduce the potential
22 for conflict in consultations on FtD. These efforts could be augmented by explicit discussion of
23 cognitive impairment at an earlier stage for all patients affected by cognitive impairment from mild
24 cognitive impairment right through to dementia. Patients would benefit from greater input into
25 planning driving cessation and acknowledgement from their GPs of the impact this may have on
26 their quality of life.
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36
37

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39 The Authors declares that there is no conflict of interest.
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41

42 Author contributions

43 CS, TF, CB and LH planned the original study, wrote the protocol, won funding and oversaw the
44 original study. CS, TF, CB, KM, CSh and LH designed, planned and carried out analyses for this paper.
45 CS drafted this manuscript and revised it in response to critical revisions from all authors. CS and CB
46 are the co-guarantors of the study. All authors read and approved the final manuscript.
47
48
49

50 Ethics approval

51 Research ethics approval was granted by the Clinical Research Ethics Committee, ECM 4 (aa)
52 06/09/2016.
53
54

55 Data sharing statement

56 Participants were not consented for sharing of interview data. However additional quotes to support
57 the themes are available on request from cs926@medschl.cam.ac.uk.
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*Topic guides for interviews***GP INTERVIEW TOPIC GUIDE****Introduction:**

Driving allows people independence, social engagement and interaction, and is a contributor to quality of life and well-being. However, discussions between GPs and patients on fitness to drive can be fraught, with up to a fifth of GPs reporting that patients have left their practice after the GP did not approve their driving license application. Difficulties discussing fitness to drive can be compounded by the presence of unacknowledged or undiagnosed mild cognitive impairment, which is the focus of this interview. We want to discuss your experience of speaking to patients with mild cognitive impairment (or their carers) about fitness to drive, to see what works and what does not work well in practice.

Overview of interview:

- 20-30minutes long
- Record interview
- No patient identifying information will be published or shared.
- Ethics approval was granted. Obtain consent.
- Full confidentiality, data will be password protected in UCC only.

Questions	Prompt/probe
1. Can you describe your practice location and practice population in general terms please?	<ul style="list-style-type: none"> • Number of gps • Number of patients • Rural/ urban location • Level of deprivation • Available social supports • Available level of public transport
2. How frequently do you encounter consultations in the issue of fitness to drive?	
3. What provokes this discussion?	<ul style="list-style-type: none"> • Patient concern • Carer concern • GP concern • Letter from specialist • Others provocation?
4. Can you choose two patients with cognitive impairment from your caseload and tell me how consultations on fitness to drive went these patients? <ol style="list-style-type: none"> a. Refer to case notes b. Choose patient where it went well and not so well 	<ul style="list-style-type: none"> • Who brought it up? • How did you broach the issue? • What words used? • Re-visited multiple times? • Discussion with patient or carer or other family/friends.

Topic guides for interviews

5. Did you get the patient response that you wanted?	Why/ why not? Please explain/elaborate.
6. What actions followed the consultation?	Referral? Assessment? Repeat consultation?
7. Were you prepared for this?	What training have you had in this area? Is there any available? Is it needed?
8. Have you had consultations on fitness to drive in patients with mild cognitive impairment that have gone particularly well or badly?	Explain details of case. Refer to notes if helps.
9. In your opinion, what would have made this process easier for you?	Additional community resources/ other health care professionals/ knowledge resources.
10. What advice would you offer to GPs about they can best deal with this sensitive issue?	
Finish 11. Is there anything else you would like to elaborate on? Thank for your time today	

*Topic guides for interviews***PATIENT INTERVIEW TOPIC GUIDE**

Questions	Prompt/probe
1. Can you give your first name, age and tell me where you live please?	
2. We are interested in discussions about fitness to drive in people with mild cognitive impairment. Would you like to speak about your fitness to drive or the fitness to drive of the person you care for?	If relates to carer, who are they caring for, for how long, etc.
3. What would be important in a conversation about fitness to drive?	
4. What approaches would be challenging/unwelcome?	
5. When did the issue of fitness to drive first arise for you?	When was fitness to drive an issue (months or years ago), what brought this to attention, what provoked it?
6. How was it first discussed by your GP?	Brought up by patient, carer or GP?
7. Can you tell me how that conversation went?	Was it too theoretical or technical? Too long? Too short? Confusing? How did it make you feel?
8. Did you get the answers/ information you wanted?	Please explain/elaborate.
9. Was this conversation something you expected?	Why? Why not?
10. What actions followed the consultation/ discussion with the GP?	Referral? Assessment? Repeat consultation? Were you prepared for this?

Topic guides for interviews

11. In your opinion, what would have made this process easier for you or the person you care for?	
12. What advice would you offer to GPs about they can best deal with this sensitive issue?	
13. What went well from your perspective?	Involvement of GP/ other healthcare professionals/ family members...
14. How have things changed since then?	
Finish 15. Is there anything else you would like to tell me? Thank for your time today	

Manuscript: Shifting gears versus sudden stops: a qualitative study of consultations about driving in patients with cognitive impairment

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reflexivity		
<i>Personal Characteristics</i>		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	6-7
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	7
3. Occupation	What was their occupation at the time of the study?	7
4. Gender	Was the researcher male or female?	1
5. Experience and training	What experience or training did the researcher have?	7
<i>Relationship with participants</i>		
6. Relationship established	Was a relationship established prior to study commencement?	6, 7
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	6, 7
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	6, 7
Domain 2: study design		
<i>Theoretical framework</i>		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	7
<i>Participant selection</i>		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	6, 7
11. Method of approach	How were participants approached? e.g.	6, 7

	face-to-face, telephone, mail, email	
12. Sample size	How many participants were in the study?	9
13. Non-participation	How many people refused to participate or dropped out? Reasons?	6
<i>Setting</i>		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	6, 7
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	6, 7
16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	9
<i>Data collection</i>		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	6, 7. Appendix 1
18. Repeat interviews	Were repeat interviews carried out? If yes, how many?	Not applicable
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	7
20. Field notes	Were field notes made during and/or after the inter view or focus group?	7
21. Duration	What was the duration of the inter views or focus group?	9
22. Data saturation	Was data saturation discussed?	6
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	7
Domain 3: analysis and findings		
<i>Data analysis</i>		
24. Number of data coders	How many data coders coded the data?	7
25. Description of the coding tree	Did authors provide a description of the coding tree?	7
26. Derivation of themes	Were themes identified in advance or derived from the data?	7
27. Software	What software, if applicable, was used to manage the data?	7
28. Participant checking	Did participants provide feedback on the findings?	7
<i>Reporting</i>		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	9-13
30. Data and findings consistent	Was there consistency between the data presented and the findings?	9-13
31. Clarity of major themes	Were major themes clearly presented in the findings?	9-13
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	9-13