



A licence to drive? Neurological illness, loss and disruption.

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Abstract:	<p>The sense of freedom and independence that being able to drive generates may be taken for granted by many until it is threatened by illness. Drawing on the 'mobility turn' in social sciences that emphasises the social and emotional significance of the car (Sheller and Urry 2006; 2000), this paper presents secondary analysis of narratives of driving and its significance across four neurological conditions (epilepsy, Parkinson's disease, transient ischaemic attack and motor neurone disease). Taking an interactionist approach we explore how the withdrawal of a driving licence can represent not just a practical and emotional loss of independence, but also loss of enjoyment; of a sense and feeling of 'normal' adulthood and social participation; and of an identity (in some cases gendered) of strength and power. Conversely the ability to keep driving can maintain an unbroken thread of narrative, for example enabling people with speech difficulties to feel and look normal behind the wheel. Moments of pleasure and normality illuminate the importance of examining the micro-strands of disruption illness can cause.</p>

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Abstract

The sense of freedom and independence that being able to drive generates may be taken for granted by many until it is threatened by illness. Drawing on the 'mobility turn' in social sciences that emphasises the social and emotional significance of the car (Sheller and Urry 2006; 2000), this paper presents secondary analysis of narratives of driving and its significance across four neurological conditions (epilepsy, Parkinson's disease, transient ischaemic attack and motor neurone disease). Taking an interactionist approach we explore how the withdrawal of a driving licence can represent not just a practical and emotional loss of independence, but also loss of enjoyment; of a sense and feeling of 'normal' adulthood and social participation; and of an identity (in some cases gendered) of strength and power. Conversely the ability to keep driving can maintain an unbroken thread of narrative, for example enabling people with speech difficulties to feel and look normal behind the wheel. Moments of pleasure and normality illuminate the importance of examining the micro-strands of disruption illness can cause.

Introduction

Mobility and movement are central to people's identities, their wellbeing and quality of life (Imrie 2000). The 'mobility turn' in sociology and more broadly the social sciences has grown in the last few decades and emphasises how movement through space is not only physical but social, cultural and emotional (Sheller and Urry 2006; Ziegler and Schwanen 2011). It suggests that mobility and movement are "at the center of constellations of power, the creation of identities and the microgeographies of everyday life" (Cresswell, 2011: 551). Within sociology, the mobility turn has impacted a number of concepts such as society, identity and culture, as well as having contemporary relevance in the context of a globalized and 'hyper-connected' world (Vannini, 2010). This turn draws on key ideas within sociology and geography – so that importantly, 'movement implies a sociological imagination for spatial matters and [conversely] a geographic sensitivity to understanding social and cultural processes of movement' (Vannini, 2010: 112).

This paper is located within this growing mobilities paradigm to explore the significance of driving in the daily lives of people who have neurological conditions. In the field of medical sociology, framing our research within this paradigm allows us to consider the socio-spatial importance of driving and the car in illness. Whilst much has been written about the biographical disruption illness can cause (Bury, 1982; Lawton, 2003), less focus has been

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3 placed on the detailed components of this disruption, such as the loss of a driving licence or
4 the continued ability to drive. Khalili (2016) writes about the importance of understanding mi-
5 cro-moments of pleasure that offer an important (and potentially political) apparatus: alt-
6 hough Khalili (2016) is writing with a different context in mind – about the seaside in Beirut –
7 there are correlations with understanding the challenges and struggles of illness.
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11 In light of this, our paper pays particular attention to the (micro) practices, representations
12 and experiences of driving and how this impacts on people's sense of self, their sense of
13 normality and everyday social participation.
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16 What happens in the car and why has become increasingly important in exposing the com-
17 plex desires, affects, emotions and spatialities of drivers and passengers (Merriman 2009).
18 Laurier et al. (2008: 2) suggest, 'cars have, in short, become places we inhabit without nec-
19 essarily being places designed to be habitable'. Our journeys in cars involve diverse social
20 activities from eating breakfast, listening to music or news stories to everyday talk, argu-
21 ments, sharing lifts and conversations with family, friends and colleagues (Laurier et al.
22 2008). It is these micro-geographies and sociologies which illustrate the importance of the
23 car in our social and everyday lives. Thrift (2007) emphasises the emotional significance of
24 the car, with driving and 'passenger' as 'both profoundly embodied and sensuous experi-
25 ences' (pg.80). He goes on to suggest that people may experience cars as an extension of
26 their bodies with the boundary between human and technology increasingly blurred. Further,
27 Laurier et al. (2008) note that the car functions as a 'visibility device' whereby people are
28 recognisable and surveyable to those from the outside (pg.9). Judgments and social typolo-
29 gies are made about occupants of cars ('boy racer', 'Sunday driver').
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38 Much of this literature emphasizes the corporeal, sensorial and affective aspects of driving,
39 but often excludes a focus on illness and the significance of driving for people with health
40 conditions.
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43 More generally, there is a strong correlation between access to adequate mobility and ac-
44 cess to social capital (Farber and Páez 2009). Considerable literature cites the positive ef-
45 fects of car ownership and the economic benefits of increased mobility in terms of employ-
46 ment and returning to work (Ong, 1996; Cervero et al. 2002); the use of cars in urban policy
47 programmes to 'mobilise' poorer communities (see Fol et al. 2007) and the benefits on quali-
48 ty of life (Spinney et al. 2009). However, others have written about the ways in which forms
49 of transport (notably the car) can actually engender and reinforce social exclusions in con-
50 temporary society (see Cass et al. 2005). For Cass et al. (2005) inadequate mobility can re-
51 veal previous social exclusions. For example all forms of transport, particularly car owner-
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3 ship, require financial resources. Therefore the (in)ability to be mobile might reflect already
4 established patterns of inequality and power in communities.
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7 When ill-health threatens the ability to drive, the emotionally charged nature of giving up
8 driving and relinquishing autonomy (and becoming a passenger in someone else's car) can
9 be difficult (Betz et al. 2013). The loss of ability to drive may thus represent a specific com-
10 ponent of biographical disruption, one of many accumulating losses, both practical and emo-
11 tional. For Cass et al. (2005) inadequate mobility can also reveal previous social exclusions
12 (see also Farber and Páez 2009 for more on social participation and access).
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16 A substantial body of literature focusses on driving restrictions for older people at the onset
17 of illness. The importance of mobility in older people's general wellbeing and their quality of
18 life is well documented (Metz, 2000; Zeitler and Buys 2015) and research indicates that driv-
19 ing cessation is causally associated with higher levels of depression, morbidity and early
20 mortality, independent of other variables such as previous physical or mental ill health
21 (Ragland et al. 2005). Ragland et al. in this US based study, found both men and women
22 experienced depression after driving cessation, with higher levels in men. Siren and
23 Haustein (2015) compared older Danish drivers who gave up their driving licence and those
24 who were able to renew (see also Liddle et al. 2016 for the impact of driving cessation on
25 people with dementia). Whilst those who gave up their licence had poorer health at baseline,
26 they depended more heavily on others and eventually had worse overall outcomes for mobil-
27 ity needs especially for their leisure time.
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34 For older people who can no longer drive, trips to health services (doctors, clinics and hospi-
35 tals) are often most important, particularly for those living in rural areas (Ahern and Hine
36 2015). Evidence suggests that giving up driving in older age has a gendered dimension. For
37 example, as described earlier, Ragland et al. (2005) found depression levels were higher for
38 the men in their study; and female drivers were more likely than men to give up their driving
39 voluntarily and at a younger age and in better health (Hakamies-Blomqvist and Siren 2003;
40 Siren et al. 2004). While this literature provides an important focus on older people, it con-
41 centrates on health outcomes and ignores the affective dimensions of driving (or being
42 forced to give up).
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48 **Sociological research into driving and neurological conditions**

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50 There is little in-depth, qualitative social science research into the importance of driving for
51 the maintenance or loss of identity in illness. Driving is often mentioned in relation to a
52 broader qualitative analysis of particular medical conditions: for example, driving is men-
53 tioned as just one of several roles which had to be reassigned by couples living with Parkin-
54 son's disease alongside household maintenance and financial responsibility (Hodgson et al.
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2004). Car driving is thus acknowledged within a broader set of complex negotiations and adjustments.

Both in stroke and transient ischaemic attack, people engage in emotional labour to make sense of and attach meaning to their ability to drive when it is threatened (Patomella et al. 2009; Croot et al. 2014). Driving is experienced as a part of the individual's history and a way of maintaining everyday life and continuity, symbolising both freedom and opportunity. Being told that one cannot drive, even temporarily, has profound emotional and social as well as practical consequences and may result in advice given by physicians simply being ignored (Liddle et al 2009; Patomella 2014).

In stroke, driving cessation is usually sudden, unexpected and forced, resulting in a particularly sharp loss of sense of self, in contrast to other conditions where driving cessation may happen gradually over a period of time (Liddle et al. 2009). Health care professionals may need more support to help manage the issue of unlicensed driving, patients' strong emotional responses, and the transition to an 'immobile identity' (Liddle 2014).

Moreover, for clinicians in primary care settings there are real difficulties in assessing driving capability. Often tasked with assessing older people's driving safety, there can be inadequate resources and gaps in the education of clinicians and patients around the issue of giving up driving (Betz et al. 2015: 14). Discussions about "when to hang up the keys" are often avoided or delayed due to the very difficult nature of such conversations. Thus, clinicians may only discuss driving competence when specific 'red flags' emerge (Betz et al. 2013). These difficulties are also echoed in the literature on driving cessation and dementia (Liddle et al. 2016).

For people with epilepsy, there is considerable debate regarding the evidence in relation to the potential for increased risk of car accidents as a result of temporary impairment during a seizure (Yang et al., 2010). Whilst countries vary in their approach, commonly there is a requirement for a person to have seizure-free intervals, for example in the UK this is one year (ibid). McEwan et al. (2004), focusing on the quality of life and psycho-social development of adolescents with epilepsy, found that there was some confusion about driving legislation (see also Prinjha et al. 2005).

Previous research on various medical conditions has focused on driving within a broader examination of everyday life. Thus, driving is acknowledged as one factor amongst many complex negotiations, adjustments and responses to illness. To date no qualitative study has explicitly examined the emotional significance of driving and loss of license for people with neurological conditions. In this paper we use an interactionist approach (Blumer 1986) to understand the meaning(s) that driving or car ownership has for people with neurological

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3 conditions who are at risk of, or have, lost their ability (or right) to drive. Here, we are inter-
4 ested in the ways in which people talked about their interactions with cars, how their cars
5 mediated their interactions with the wider social world, and how the act of driving had (signif-
6 icant) meaning for them. This study builds on previous qualitative work in the wider mobili-
7 ties literature.
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10 **The research design**

11 *Original research*

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13 The data on which this paper is based forms part of a national archive of narrative interviews
14 on health and illness held at the University of Oxford (Ziebland and Hunt 2014). The studies
15 are typically conducted with the overarching research question: 'What are the experiences
16 and information and support needs of people with a given health condition?' The interview
17 collections included in this secondary analysis were people's experiences of MND (Motor
18 Neurone Disease) (36 interviews conducted in 2008); epilepsy (41 interviews conducted in
19 2003); Parkinson's disease (40 interviews conducted in 2008); and TIA or minor stroke (37
20 interviews conducted in 2010). Each specific study involved in-depth interviews about
21 participants' experiences, including symptoms and diagnosis, physical, emotional and
22 psychological impacts of the condition, experiences of treatments, and effects on other
23 areas of life such as family, work and social life. After signing a consent form, participants
24 were encouraged to talk about their experiences in their own words for as long as they
25 wished, without prompting. They discussed many aspects of their personal experience in-
26 cluding their feelings about the diagnosis, telling family and friends, interactions with health
27 professionals, and living with the condition. After this narrative part of the interview, an inter-
28 view guide, informed by the medical and social science literature on the condition, was used
29 to explore other relevant issues that had not been discussed. The narrative approach (San-
30 delowski 2007, Mishler 1991) allowed an oral history of each person's experience to be col-
31 lected, allowing participants to highlight their own priorities, concerns and meanings. Addi-
32 tional questions prompted reflection on particular areas, including topics identified through
33 the literature review and communication with health professionals and an advisory panel.
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48 Each study was conducted by experienced qualitative social scientists, including three of the
49 authors, Locock and Kirkpatrick who are sociologists, and Prinjha, an anthropologist. Step-
50 ney has a background in social geography and was able to provide the analysis of spatiality
51 within the driving narratives while Ryan took part in the formulation of ideas for a secondary
52 analysis and iterative discussions about the ongoing analysis. The studies have approval
53 from Eastern MREC (03/5/016) and Berkshire Research Ethics Committee (09/H0505/66).
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3 Participants are invited to copyright their interviews to the University of Oxford for use in
4 secondary analysis, among other specific purposes. For each of these studies, purposive
5 maximum variation sampling was used (Coyne 1997) in which variation was sought both
6 across types of experience (such as time since diagnosis and degree of disease severi-
7 ty/progression) and demographic variables (such as gender, age, ethnicity, socio-economic
8 group, region). A range of recruitment avenues were used, including through GPs, specialist
9 nurses and hospital clinics; voluntary support groups; media advertising; word of mouth and
10 snowballing. Recruitment continued in each project until there were no new themes or varia-
11 tions in themes arising.
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17 Interviews typically lasted between one and two hours and were conducted in the person's
18 own home or elsewhere if they preferred, and video or audio-recorded dependent on the
19 participant's preference. All interviews were digitally recorded, transcribed verbatim and re-
20 turned to participants for checking, correction, and comment. The interview transcripts were
21 coded using NVivo software and analysed thematically, drawing on grounded theory tech-
22 niques of constant comparison and deviant case analysis (Glaser & Strauss 1967). For
23 each study, a second researcher acted as a 'buddy' providing an additional critical perspec-
24 tive by independently analysing coding reports and comparing and discussing (their) inter-
25 pretation with that of the original researcher. Summarised findings of the full thematic analy-
26 sis of each study are available online at healthtalk.org.
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32 *Secondary analysis*

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34 Three of the original researchers are co-authors on this paper (MND, epilepsy and TIA) and
35 had detailed knowledge of the data, participants and interview context. Although driving was
36 not the main focus of these studies, the narrative interviews invited participants to talk about
37 many of the things that mattered to them, including driving which was spontaneously men-
38 tioned in the majority of interviews often without prompting. For example, in the case of the
39 epilepsy interviews, it was sometimes discussed in relation to using public transport and not
40 being allowed to drive.
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45 Blumer (1969) advocates meticulous inspection in the analysis of data; inspection that is
46 "flexible, imaginative, creative and free to take new directions". This paper emerged out of a
47 shared recognition of the importance of driving to participants in the four projects by all three
48 of the original researchers. This recognition was discussed in a workshop setting and over a
49 few months, as the analysis was developed (Ziebland & McPherson 2006). Following an in-
50 teractionist approach, we viewed the data from different angles, and raised questions, draw-
51 ing on different approaches and concepts. We have drawn on Blumer's articulation of sym-
52 bolic interactionism (rather than a phenomenological approach) because we were interested
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3 in the ways in which people reported (through their narratives) the interactions they had with
4 their cars and how their cars mediated their interactions with their wider social world – and in
5 this way, the meanings that arose from those interactions.
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8 We re-analysed existing coding reports relating to driving where they existed, or recoded
9 transcripts specifically for driving where no existing coding report was available. Drawing on
10 data across the four conditions offered a far richer data set for the purpose of secondary
11 analysis, with potential to strengthen the nuance of the analysis and enabling more robust
12 findings (Ridge et al. 2015). We were able to compare similarities and differences between
13 conditions, and discuss and agree interpretation of the data.
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17 Our secondary analysis falls within Heaton's (2004) categories of amplified and supplemen-
18 tary analysis. Supplementary analysis involves a more in-depth focus on an emergent as-
19 pect of the data which was not addressed (or partially addressed) in the primary studies,
20 whilst amplified analysis involves examining common or divergent themes across existing
21 data sets. During this process key words were noted, and groupings relating to themes and
22 ideas, and a list of possible factors that affected responses was developed. In the following
23 section we present four themes/threads from the narratives: *Driving, emotions and embodi-*
24 *ment; Feelings of normality; Policing and Gendered identities.*
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32 Findings

33 *Driving, emotions and embodiment*

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36 Some participants expressed strong feelings and emotions about their car, or driving. Anita
37 and William (TIA) described how driving provided them with a sense of pleasure and com-
38 fort.
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41 *Driving I must say is – some people drive to get there and some people drive as a re-*
42 *laxation, and I think [um] my husband was, “it’s a nuisance but I will get you there”,*
43 *and mine is I enjoy it. (Anita, TIA)*
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46 *I’m very happy in a car. You know, other things like walking, I get fed up with walking*
47 *for a long way but [um] I wouldn’t mind driving from here to, to the South Coast, you*
48 *know, as long as I had a break in the middle somewhere [...] Yes, I feel at home in a*
49 *car. (William, TIA)*
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53 Driving could be seen both as a physical means to get around, but also as an emotional in-
54 vestment. Both Mark (MND) and Paul (MND) had previously been employed in the motor
55 industry and talked about their love of cars and driving.
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3 *It's a passion. Driving isn't A to B [...], it never has been for me.* (Mark, MND)

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5 For some, the car itself represented a space in which a sense of ease and familiarity could
6 be felt, echoing the sense of comfort and feeling 'at home' that William (TIA) described.
7
8 Frank had Parkinson's disease, and had volunteered to undergo a test to assess his driving
9 abilities, which had been questioned. Although his movement and mobility were impaired,
10 he felt that once he was settled in the car, his driving capability came naturally.
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13 *Getting in and out of the car is the problem. But actually when you're behind the*
14 *controls, it's straightforward, second nature.* (Frank, PD)
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18 Similarly, Sara who also has Parkinson's, referred to struggles with movement and mobility
19 that generally slowed her down physically, but for a short while, driving could provide some
20 'relief' from the feelings of difference and separation from other people through being able to
21 move, overtake and demonstrate her character by being 'mega aggressive'.
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24 *I don't walk very well, I drive an exceptionally flash car, a soft top with a very power-*
25 *ful engine, a little baby. So when I get in that car I'm not on my feet anymore. I can*
26 *move like the rest of you. I can overtake you, I can cut you up, I can be mega-*
27 *aggressive, because that's how I move best in this life. And it's a sheer relief, in the*
28 *car, and just feel you can go like the rest of the world.* (Sara, PD)
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32 For Sara, being in the car itself helps to replicate some of the feelings of embodied power
33 and strength that she has lost. These temporary moments of pleasure, defiance and tri-
34 umph represented temporary moments of enjoyment that could provide some relief from the
35 difficulties of having Parkinson's.
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41 **Feelings of normality**

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43 The importance of 'normality' became a clear focus for participants when threatened with
44 losing a license or regaining it again after a period of driving cessation. There were remark-
45 able similarities between participant accounts. Many spoke about their desire for 'normality'
46 and indicated that driving gave them that feeling of being normal.
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50 *Once I was allowed to drive again, you know, I felt then, yes, I'm back to normal.*
51 (Alan, TIA).
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55 *I feel totally normal behind the wheel. I don't have to speak, [um] and it's the one sit-*
56 *uation where – certainly at the moment – I totally feel normal.* (Hugh, MND)
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3 Being able to drive helped some people to forget or 'erase' the fact of having a condition for
4 a short time. Lisa, who was diagnosed with a rare inherited form of MND 8 years before she
5 was interviewed, had weakness in her arms and legs as well as speech difficulties and, like
6 Frank (PD) (above), difficulties with walking:
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9 *I often joke to my friends that, "People must freak when they see me pull up, and you*
10 *get the scooter out of the boot and I hobble out of the car [laughs], and they must*
11 *think, "Jesus, is she allowed on the road?". But when I'm behind the wheel of my car,*
12 *I'm the same as anybody else. Sudden, suddenly I've got nothing wrong with me.*
13 *Nobody can tell. It's only when I get, park and get out or walk. (Lisa, MND)*
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17 Just as Sara (PD) refers to her "relief" that driving allows her to be temporarily part of a fast-
18 er paced world once again, the ability to drive and the ownership of a car for Lisa enables
19 her to regain a healthy identity, for a time. Hugh (MND) expressed similar feelings when driv-
20 ing, as although his speech had been affected by MND, his physical mobility was still rela-
21 tively unaffected. As driving required no speaking he was able for a short while to regain a
22 sense of normality.
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26 The onset of epileptic seizures had a number of negative consequences for Linda's life. She
27 describes how, after being seizure free for four years, suddenly having a seizure on holiday
28 represented a move away from her normal life, and from her sense of who she was; "*my*
29 *world fell apart again. That was the end of the driving" [...] it really started to damage my ca-*
30 *reer and also my self-confidence".*
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34 Similarly Caroline (EP) indicated how not being able to drive meant '*putting her life on hold*':
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37 *I'm just waiting for my licence to come back. [...] that will open so many doors for me.*
38 *I mean my career had to be put on hold, you know in the building industry because I*
39 *couldn't jump in a car and go and visit customers and clients and things. So that to*
40 *me is going to be the biggest change in my life, being able to drive'. (Caroline, EP)*
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44 Not being allowed to drive was also often described in terms of the loss of the normal inde-
45 pendence and freedom that most people enjoy. Commonly people referred to some of the
46 practical consequences, such as having to rely on others for lifts, difficulties attending hospi-
47 tal appointments, the extra time that using public transport involved, being unable to visit
48 family and friends or do shopping without help.
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52 *It restricts your independence to be able, to not be able to go out in the car. Yeah, it*
53 *does. It does. [...] it's becoming dependent on other people again. [...] I mean, I'm*
54 *going out tonight. My friend's got to pick me up and bring me home again because*
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3 *my husband won't be here. He'll be at work. So, you know, it's, I hate being de-*
4 *pendant on other people. (Lynette, TIA)*
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7 **Policing**

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9 As we have seen, driving can help people retain some level of autonomy, and may represent
10 a means to resist, defy, or adapt to the new reality of having a neurological condition. Often
11 participants described how the loss or retention of their driving licence removed their sense
12 of autonomy, as it was generally instigated, 'policed' or monitored by others, which left them
13 feeling a sense of discomfort at being watched or observed.
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17 Sara (PD) described how oppressive this felt to her, and the impact of that on her sense of
18 self while Duncan (TIA) indicated that even if he had wanted to drive again, his wife would
19 have prevented it.
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22 *It's difficult to pin it down. It's, it's something about my desire to just be normal and*
23 *to vanish and just get on, but it's also something in their eyes. It's it's as a sort of*
24 *turning off in their eyes, where they expect less of me than anybody else. [4 secs]*
25 *And that's, kills a bit of me. (Sara, PD)*
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29 *[My wife] would have either of hidden or thrown the keys [...] so I wouldn't be able to*
30 *drive anyway [...] [my wife] was quite capable of [um] you know, policing that".*
31 *(Duncan, TIA)*
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34 Sandra (EP) had saved money for driving lessons but was stopped from going ahead with
35 driving by both her GP and mother:
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38 *Oh I wanted to drive. I so much wanted to learn to drive and of course I just thought*
39 *well I'll save the money to take the lessons and I'll be able to do it. So I in fact had*
40 *three driving lessons and I'd paid for it myself and my mum was very, very worried*
41 *about this, but she wouldn't say it to me. So what she did was she went to see my*
42 *GP[...] What they did between them was that mum came home and she said "Oh*
43 *Sandra I've made an appointment for you to go and see your GP because he thinks*
44 *that you need, he needs to look at your medication again." [...] So ignorant to it all I*
45 *went to see him and he sat down and he spoke with me.....So I stopped taking the*
46 *lessons.*
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53 **Gendered identities**

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3 The *experience* of driving was sometimes expressed in gendered terms. Some participants
4 actively conformed to expected gendered notions (most notably on masculinity and cars)
5 whilst others actively challenged traditional expectations.
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8 Paul's (MND) previous job, which he described more as a "*hobby*" demonstrating "*very ex-*
9 "*ensive motor cars to people*" was central to his masculine identity where the "*high pow-*
10 "*ered*" cars he was "*running around in*" were "*boys' toys*". Having worked in the motor indus-
11 try, driving represented much more to him than independence. After a driving assessment,
12 Paul was "*terrified*" at the prospect of losing his licence.
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17 *I mean, my driving was everything to me [...] it was my manly, macho image was*
18 *about driving, you know. You drove, nobody drove me. I drove. And I really wanted to*
19 *keep driving.* (Paul, MND)
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22 Paul was allowed to continue driving and had his car modified with a left-handed accelerator
23 pedal with an automatic transmission. But his narrative illustrates how the restraints on his
24 physical mobility were of lesser importance to him than the disruption to his masculine identi-
25 ty as a strong and capable man. Being able to continue driving allowed him to retain a feel-
26 ing of masculinity, control and autonomy.
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30 A few female participants like Sara (PD) similarly expressed attachment to their cars. Sara
31 actively challenged traditional gendered conceptions of cars and driving as inherently mas-
32 culine, taking pride in her "*exceptionally flash*" car with a "*soft top*" and a "*very powerful en-*
33 "*gine*", with an emphasis on a driving style and skills. Similarly, Elisabet conveys the centrali-
34 ty of her skills and ability to her identity:
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38 *We have a veteran car which is not automatic and I'm the only person who can, can*
39 *manage to gear down so my skills are needed".* (Elisabet, PD)
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42 Both Helen (EP) and Sheila (EP) positioned themselves as 'non-drivers' and within a chang-
43 ing social (and gendered) context, comparing the past with the present.
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46 *Now not being able to drive has worried I am sure a lot of people because also it's a*
47 *lot more well known that women drive and so on. Having not driven I don't miss it.*
48 (Sheila, EP)
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52 *The only thing is I can't do is drive and I've never wanted to drive. But I must say*
53 *over the last few years I'd like to drive, so that bugs me a little bit, a lot more women*
54 *drive now, they didn't years ago so that didn't matter to me.* (Helen, EP)
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3 For some participants, traditional roles of men driving and women as passengers were chal-
4 lenged by the onset of illness when roles reversed.
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6 Frances, who cared for her husband with Parkinson's, had taken over "*most of the driving*"
7 now that her husband's reactions were getting slower, and although Kevin (PD) still drove
8 regularly, he was "*quite happy*" to be a passenger in the car when his wife drove. Nigel (PD)
9 explicitly described gendered roles with his partner, with the exception of driving, which he
10 continued to 'retain' as his domain.
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14 *My partner works full time, we just basically decided to swap roles, I do, I do the*
15 *housework now. I do all the ironing [...] but I drive. (Nigel, PD)*
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18 On the other hand, Jane (MND) had always done the driving in the past, equating it with
19 household chores such as shopping and running the household, which are often associated
20 as more traditionally female roles. But since the onset of her illness, her husband had had to
21 take over.
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24 *He's, he's very willing, but it's been an awful [um] job for him in many ways. Be-*
25 *cause I always have run the household and done all the shopping and all the clean-*
26 *ing. And [um] I was the one who did most of the driving of the car [um] within towns*
27 *and things. So really to have me stop doing all those things put a big load on to him*
28 *really. (Jane, MND)*
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32 Lisa (MND) was still driving, but had changed from a manual to an automatic car. Whilst she
33 herself took pleasure in still being able to drive, switching to an automatic car was viewed as
34 not 'real driving' by her son.
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37 *My son doesn't like it, he doesn't think it's proper driving. But I think that's a man thing.*
38 *They need a gear stick don't they?' (Lisa, MND)*
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42 **Discussion:**

43 In line with the literature on the 'mobility turn' in social sciences, our secondary analysis of
44 datasets across four neurological conditions demonstrates how driving and being in a car
45 represents much more than physically accessing places or moving from A-to-B. We have
46 explored how an emotional sense of enjoyment and pleasure is generated by driving for
47 many people with neurological conditions. Following Laurier (2008), Thrift (2007) and others,
48 we find the meanings people ascribe to driving to be an embodied and emotional experi-
49 ence. In this way, we suggest that cars and driving can be very important for people's identi-
50 ties, providing positive reinforcement of who they are and how they feel about themselves.
51 Following Khalili (2016) we suggest that participants described temporary moments of en-
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3 joyment, defiance and pleasure which offer an important apparatus against a backdrop of
4 difficulty and challenge. For those participants who had difficulties with speech and walking,
5 their cars and driving sometimes provided a great source of enjoyment. Pleasurable driving
6 may therefore not simply be an act of consumerism but instead represent an important
7 recognition of ordinary life in difficult times. As Khaili (2016) argues, if these moments of
8 pleasure are at all political, they are so because they are harder to sustain in the face of ad-
9 versity.

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14 Moreover, the car as a space represents somewhere where people can feel a sense of
15 “normality” away from their illness or diagnosis, and indeed protected from the assessment
16 of others. This was often the case when people had obvious physical impairments such as
17 problems with speech or walking. The wish to “vanish”, “erase” and blend into normal life (as
18 explained by Sara, PD) was strongly evident in such narratives.

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22 Our analysis reveals the complexity of driving and car ownership and the different meanings
23 people ascribed to both the car as a thing, the car as a space and the practice of driving.
24 The narratives showed that there was sometimes a blurred distinction between the car as a
25 space (as object/possession, as location, as extension of the body, as symbol) and driving
26 as an act in itself as well as a means to an end. For Paul, his car was modified to better ‘fit’
27 his changing embodiment (his right leg “not working”). The car or the act of driving do not, in
28 and of themselves, have meaning; it is the meaning people ascribe which, in turn, is gener-
29 ated or interpreted through interaction with others and the car itself (Blumer 1986). Some
30 participants discussed driving in relation to others, domestic order and organisation while
31 others engage with driving emotionally but again drawing on an interactional arena (being
32 alongside other drivers and appearing to be normal, i.e., the same as them). The functions
33 of the car and the action of driving were multivariate: to get from A-B, exhilaration, normali-
34 sation, refuge, release and relaxation. A deeper understanding of these meanings will allow
35 health and social care professionals to better understand the implications of being able to
36 drive, or not being able to drive, for patients with neurological conditions.

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45 As earlier research has shown, limited mobility can reveal previous social exclusions and
46 established patterns of inequality and power in communities (Cass et al. 2005). Social ex-
47 clusion may be further entrenched and compounded by those diagnosed with ill health (Car-
48 lisle et al. 2005). However, our data reveals that being “behind the wheel” could provide, for
49 some, a ‘normalising’ or ‘erasing’ effect helping people to feel “the same as anybody else”.
50 The transient nature of this might not reveal (or fundamentally challenge) wider social exclu-
51 sions. Nevertheless, the importance of these micro temporary mobilities should be recog-
52 nised, as for some participants it signified a time when they felt an “equal” to others (Paul,
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3 MND). We suggest that the car not only provides a refuge and a safe space for those with
4 neurological conditions, but a powerful physical and emotional space in which to regain a
5 sense of autonomy and identity. Momentary recognitions of everyday ordinary life gained
6 through driving are important attempts to reclaim 'normality' during illness. As Khalili (2016)
7 points out, these momentary recognitions of ordinary life may be an attempt to regain con-
8 viviality and pleasure amidst the struggles and challenges of illness.
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12 Our interview narratives reveal a number of interesting dualisms – between private/public,
13 solitary/social, liberation/oppression: the car can provide on the one hand a private 'refuge'
14 or space for people to 'erase' their neurological conditions temporarily in a very public arena.
15 Conversely participant's driving abilities, health and vulnerabilities are publicly assessed or
16 policed by others. As Laurier et al. (2008) note, the car can be a 'visibility device', thus ren-
17 dering the car a potential site of oppression. Further, driving can be a solitary endeavour but
18 typically involves interacting socially with other drivers. At the same time it may be viewed
19 as, and utilised as, an antisocial activity and a way to express emotions (Sara, PD talked
20 about driving aggressively and cutting others up).
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27 We found that driving was sometimes expressed in gendered terms. For some male partici-
28 pants this was conveyed through conversations about their abilities, skills, strength and
29 power which fitted hegemonic cultural conceptions of masculinity. At the same time, several
30 female participants challenged these traditional notions. There were moments of enjoyment
31 with taking on (or challenging) particular roles. At the same time, there were clear negotia-
32 tions and adaptations to this, with couples "swapping roles" and sharing driving or relinquish-
33 ing their 'original' roles, sometimes reluctantly.
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38 *Limitations*

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40 Secondary analysis may be criticised on several grounds. Firstly, the original researcher
41 may have brought insights to the interpretation which are not available to the secondary ana-
42 lyst; secondly, using narratives collected for a different purpose may mean that the new topic
43 of investigation is not explored in sufficient depth; and thirdly, the material may be out of
44 date (Ziebland and Hunt 2014). In our case, original researchers from three of the four inter-
45 view collections (MND, epilepsy and TIA) are co-authors on this paper, and were able to call
46 on their in-depth familiarity with the participants and the data. The researcher responsible for
47 the Parkinson's data collection has retired. However, all four studies were conducted by the
48 same research group, using consistent methods.
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3 Driving was not a central focus of any of the studies, the main purpose of which was to ex-
4 amine people's overall experience of neurological conditions. However, the narrative inter-
5 viewing style allowed people to talk about driving in depth and this occurred often without
6 prompting, demonstrating the importance of driving in people's lives. The fact that driving
7 emerged spontaneously as such a strong and common theme in people's narratives despite
8 not being a primary focus is in itself significant; it is mentioned in numerous interviews. In
9 MND and Parkinson's, where driving was planned as a prompt from the outset, it also
10 emerged unprompted in different parts of the interview. In TIA and epilepsy it became ap-
11 parent from early interviews that driving was a key concern, and became a prompt for later
12 interviews if not already raised spontaneously. In several cases in TIA and MND, people had
13 first noticed their symptoms while driving, so this was an issue right from the start of the in-
14 terview as people told their story.

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22 There are some differences between the conditions (for example people with epilepsy may
23 never have been allowed to drive; people with MND and Parkinson's may never drive again;
24 while not being allowed to drive after a TIA may be a temporary disruption). However, the
25 inclusion of four datasets with many common experiences and concerns across the condi-
26 tions lends weight to the findings; this size of sample is rarely possible in primary qualitative
27 research.

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32 The secondary analysis uses 154 narrative interviews collected over a seven-year period
33 from 2003 to 2010. The concern around 'out of date' data is not relevant here. For the most
34 part we do not believe that the importance of driving has changed significantly within that
35 period or since. One possible exception is with regard to gender and age. Since the mid-
36 1990s there has been a trend to a decline in car use among young adults, especially among
37 young men, but an increase in car use among women. This is found in the number of both
38 driving licences held and miles driven (Le Vine and Jones 2012). Despite the trends, at the
39 time of this report men still drove twice as much as women, but it is likely that over time the-
40 se differences will become less salient. This in turn has implications for the extent to which
41 both men and women will experience the inability to drive as a biographical disruption – or
42 not. As far as age is concerned, Green et al's (2017) study of young adults' attitudes to driv-
43 ing suggests little interest in cars as a status symbol or even in driving as the most favoured
44 form of mobility. They find that for young people, 'cars were simply mundane tools in a local
45 mobility network' which included other forms of transport such as buses and cycling, and
46 that it was 'a question of calculation (rather than desire) whether learning to drive was a pri-
47 ority or not' (pg 11). The sample for the study was drawn from geographical areas selected
48 to include a range by rurality, transport infrastructure, and area deprivation.

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4 Finally, although purposive maximum variation sampling was used for each study, some
5 perspectives may be under-represented in our findings, particularly those of people from mi-
6 nority ethnic backgrounds.
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10 In conclusion, we argue that driving provides vital micro-strands of pleasure and normality to
11 those with neurological health conditions. The withdrawal of a driving licence can represent
12 not just a practical and emotional loss of independence, but also loss of enjoyment; of a
13 sense and feeling of 'normal' adulthood and social participation; and of an identity (in some
14 cases gendered) of strength and power. Our analysis demonstrates the significance of driv-
15 ing for one's identity which is summarised and neatly captured by Paul, "my driving was eve-
16 rything to me".
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