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Loss and transitions following a dementia diagnosis: A qualitative exploration

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Submitted in partial fulfilment of the requirements for the degree of

Doctorate in Clinical Psychology

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July 2026

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Acknowledgements

Firstly, I would like to thank the participants who took the time to share their experiences. I am grateful for your willingness to speak so openly and honestly. I hope this work has represented your voices with care and contributes, in some small way, to improving understanding and support for people living with dementia.

I would like to express my deepest gratitude to my academic supervisors, Dr Alex Fradera and Dr Lynda Russell. Thank you for your patience, compassion, and belief in me throughout this journey. Your knowledge, guidance, and insight have strengthened this thesis and helped me grow in confidence as a researcher. During the times I felt overwhelmed and doubted whether I could reach the finish line, your reassurance and confidence in me helped me to keep going. I am especially grateful to Lynda for making time for our writing sessions over the past few months. Those sessions gave me the structure and accountability I needed as I balanced completing this thesis with starting a new role, and they made more of a difference than you probably realise. I will always be grateful for the time, generosity, and expertise you both invested in this thesis.

A special thank you to my field supervisor, Dr Eleni Morfiri. It has been a privilege to work alongside you during my specialist placement while completing this thesis. Thank you for your kindness, wisdom, and thoughtful insights, which have enriched both this thesis and my clinical development.

I am also very grateful to Dr Katja Weides for her valuable advice and steady encouragement throughout this project. I would like to thank Paul Cannon for his expertise and guidance, which greatly supported the development of this systematic review.

I would like to thank Dr Stephanie Crawford and Dr John Hickey for your compassion, understanding, and flexibility in supporting me to complete this thesis alongside starting my new role. I would also like to thank everyone within the Older People Psychology Service for your ongoing support.

To the friends I met both before and during this journey, thank you for the friendships that have brought laughter, perspective and connection when I needed them most.

To my mum and sister, thank you for always believing in me. Your love, encouragement, and constant support have meant more than you will ever know.

To my partner, Calum, thank you for being beside me through every stage of this journey. Thank you for your patience, love, and constant support, especially during the moments when this thesis felt all-consuming. You celebrated every achievement, carried me through the difficult days, and always reminded me to keep things in perspective. I feel incredibly grateful for the life we are building together. And finally, to my cats Sprinkles and Buttons, for the welcome distractions, the company during long writing days, and the daily reminders to step away from my laptop every now and then.

Chapter 1

The emotional and psychosocial experiences of driving cessation following a diagnosis of dementia: A qualitative systematic review

Prepared in accordance with the author requirements for:

Dementia

(Author Guidelines)

Abstract

Background: Ceasing to drive following a dementia diagnosis can bring changes that extend beyond the practical loss of driving. People with dementia may experience changes to their independence, identity, and everyday life, with emotional and psychosocial consequences. Although research has explored the impact of driving cessation, less is known about how people with dementia experience this transition.

Method: A systematic search of Embase, CINAHL, MEDLINE, PsycINFO and Web of Science identified qualitative studies examining driving cessation following a dementia diagnosis. Study quality was appraised using the Critical Appraisal Skills Programme (CASP) checklist, and data were analysed using thematic synthesis.

Findings: Nine studies were included in the synthesis. Two analytical themes were developed. *Losing the Licence, Losing the Self* captured how driving cessation represented more than the loss of a driving licence, reflecting valued roles that driving represented and marking the beginning of an ongoing process of loss that reshaped everyday life. *Living Beyond Driving Cessation* reflected how participants adjusted to these losses through understanding changes in their driving ability, remaining involved in decisions about stopping driving, and gradually adapting to life without driving.

Conclusions: This review suggests that driving cessation should be recognised as more than the practical loss of driving. It represents a significant life transition for people with dementia. Adjustment was shaped by personal, interpersonal, and wider systemic influences, highlighting the importance of psychologically informed, person-centred support that acknowledges both the emotional and practical consequences of relinquishing driving.

Keywords: Dementia; driving cessation; emotional wellbeing; psychosocial impact; thematic synthesis

Introduction

Ceasing to drive following a diagnosis of dementia can involve emotional and psychosocial losses that extend beyond the practical loss of driving. For older people more broadly, driving can support independence, valued roles and social participation and access to meaningful everyday activities (Qin et al., 2020; Savoie et al., 2024). As dementia progresses, changes in memory, attention, visuospatial abilities, and executive functioning may affect the complex skills required for safe driving, meaning that many people will eventually cease driving (Ott & Daiello, 2010). Consequently, driving cessation may represent one of the earliest and most tangible changes associated with dementia, requiring adjustment not only to the practical loss of driving but also to broader changes in everyday life. Driving cessation decisions are clinically complex, requiring consideration of autonomy, psychological wellbeing, risk, family concerns, and public safety. Understanding these experiences is therefore essential for informing clinical decision-making during this transition.

Despite discussions about driving cessation often focusing on fitness to drive, qualitative research suggests that the experience extends beyond these practical concerns. People with dementia describe loss, changes to identity, reduced independence, altered relationships, and uncertainty about the future, suggesting that driving cessation may represent a significant life transition rather than simply the end of driving (Liddle et al., 2024). Developing a clearer understanding of these experiences is therefore important for informing psychologically informed, person-centred support. These experiences may also influence engagement with clinical recommendations, collaborative discussions around driving decisions, and the therapeutic relationships through which these discussions occur.

Driving cessation and transport in later life

Driving cessation is also recognised as an important transition in later life more broadly. For older people, access to transport can support independence, social participation, access to healthcare and engagement in valued activities. Research has consistently

linked driving cessation with changes in social participation, including reduced engagement in leisure activities, volunteering and community involvement (Qin et al., 2020). The availability of alternative transport appears particularly important in shaping these experiences, with limited transport options associated with greater restrictions on mobility and social participation. This is reflected within the World Health Organization's age-friendly communities framework, which identifies transportation as a key environmental factor supporting older people to remain connected and participate in community life (World Health Organization, 2007). More recent research similarly highlights the importance of accessible and affordable transport in supporting mobility and social participation following driving cessation (Rosenbaum et al., 2024). These findings suggest that the consequences of driving cessation are shaped not only by the loss of driving itself, but also by the wider environments and resources available to support continued mobility.

Existing research on the experiences of driving cessation in dementia

The majority of research on driving cessation in dementia has traditionally focused on driving assessment and fitness to drive determination, alongside decisions around driving retirement (Bennett et al., 2016; Hird et al., 2016). This emphasis reflects understandable concerns regarding road safety, legal responsibilities, and risk management (Andrew et al., 2015). As the evidence base has developed, attention has shifted towards understanding the lived experience of driving cessation, with qualitative research beginning to explore how people with dementia and those around them experience this process (Sanford et al., 2020).

The first qualitative evidence syntheses relevant to people with dementia highlighted driving cessation as a transition that is shaped by relational and social contexts. Sanford et al. (2020) synthesised the experiences of people with dementia, family members, and healthcare professionals, highlighting the emotional complexity of driving cessation alongside the interpersonal and social factors that shape this transition. Whilst this review provided valuable insight into driving cessation across different perspectives, the accounts of people with dementia were considered alongside those of family members

and professionals. As a result, it was difficult to develop an in-depth understanding of first-person experiences. Subsequent reviews have focused on different stages of driving cessation or specific dementia populations, highlight similar relational themes. Holden and Pusey (2021) examined experiences following driving cessation, identifying the importance of family support, alternative transport, and interventions that may facilitate adjustment. Similarly, Scott et al., (2023) explored the experiences of people with younger-onset dementia, highlighting the influence of age, employment, and changing family roles on driving cessation. Taken together, these reviews suggest that driving cessation is rarely experienced in isolation, with family relationships and wider social circumstance shaping how the transition is understood and managed. Whilst these reviews provide valuable insight into aspects of the driving cessation experience, their findings may not transfer to the wider dementia population, and uncertainty therefore remains regarding how people with dementia experience driving cessation more broadly.

Conceptual and theoretical models of driving cessation

Several conceptual frameworks help explain why driving cessation may be experienced as a significant life transition following a diagnosis of dementia.

Transition Theory (Schlossberg, 2011) provides a framework for understanding driving cessation as a significant life transition. This theory proposes that adaptation is influenced by an individual's circumstances, available support, and coping strategies. This may be relevant in dementia, where the transition from driver to non-driver often involves adjusting to changing abilities, altered roles, and increased dependence on others. Applying this framework, Bertrand et al. (2021) conceptualised driving cessation as an ongoing process of adaptation, with adjustment supported by social support and alternative ways of maintaining participation in everyday life.

Whilst Transition Theory helps explain driving cessation as a significant life transition, it provides less insight into why this transition may be experienced as such a profound personal loss. Continuity Theory (Atchley, 1989) provides a further useful framework for understanding why driving cessation may be experienced as psychologically significant.

The theory proposes that individuals attempt to maintain continuity in their identity and patterns of living as they age or adapt to illness. Within dementia, driving may help maintain this continuity by supporting independence, social participation, and engagement in valued activities. Consequently, losing the ability to drive may challenge an individual's sense of self and disrupt previously established ways of maintaining autonomy (Menne et al., 2002)

Whilst Continuity Theory helps explain why driving cessation may threaten identity and autonomy, it does not explain why individuals respond to this transition in different ways. The Transactional Model of Stress and Coping (Folkman, 1984) suggests emotional responses are influenced by how individuals interpret a stressful event and the resources available to manage it. Within dementia, this framework may help explain why people experience driving cessation differently, with perceived control and coping strategies potentially influencing how this transition is understood and experienced (Marigold et al., 2025).

Whilst these frameworks offer complementary perspectives, they have rarely been examined through the first-person accounts of people with dementia. Consequently, it remains unclear how closely these theoretical perspectives reflect the emotional and psychosocial experiences associated with this transition. Exploring these experiences may therefore help to refine theoretical understanding, whilst informing more psychologically meaningful post-diagnostic support.

Review rationale

Despite growing recognition of driving cessation as an emotional and psychosocial transition, comparatively little is known about how it is experienced following a dementia diagnosis. This limits evidence available to support clinical conversations, adjustment, and person-centred care. The present review addresses this gap by synthesising qualitative evidence examining the emotional and psychosocial experiences of driving cessation following a diagnosis of dementia. Understanding these experiences may help clinicians support adjustment, facilitate collaborative discussions around driving

decisions, and strengthen therapeutic relationships. The synthesis centres the perspectives of people with dementia while drawing on the accounts of family members and healthcare professionals where these enhance understanding of those experiences. By providing an analytical synthesis of how driving cessation is experienced and what shapes adjustment, the review aims to strengthen person-centred post-diagnostic support, inform psychologically informed clinical practice, and identify priorities for future qualitative research.

Aim

The primary aim of this review was to synthesise qualitative evidence examining the emotional and psychosocial experiences of driving cessation among people with dementia. The review centred the perspectives of people with dementia while drawing on the accounts of family members and healthcare professionals where these enriched understanding of those experiences.

Review Question

What is the emotional and psychosocial impact of driving cessation following a diagnosis of dementia?

Methods

Registration

This qualitative systematic review was prospectively registered with the International Prospective Register of Systematic Reviews (PROSPERO) on 27 October 2025 (Registration No. CRD420251171254). The registration was updated on 10 July 2026 to reflect amendments made during the review process. The review was reported in

accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 statement (Page et al., 2021). The completed PRISMA checklist (Appendix 1.1) is provided to enhance the transparency and rigour of the review.

Search Strategy

The search strategy was developed using the SPIDER framework (Sample, Phenomenon of Interest, Design, Evaluation, Research) (Cooke et al., 2012), which was selected because it was specifically developed for qualitative research and has been shown to improve the identification of studies exploring lived experience compared with frameworks designed for quantitative research. The SPIDER framework was applied as follows:

> **Sample (S):** People with dementia. Studies including family members, caregivers and healthcare professionals were also eligible where their perspectives contributed to understanding the experiences of people with dementia.
>
> **Phenomenon of Interest (PI):** The emotional and psychosocial experience of driving cessation for people with dementia.
>
> **Design (D):** Qualitative study designs (e.g. interpretative phenomenological analysis, thematic analysis, grounded theory and qualitative descriptive studies) using methods such as interviews or focus groups. Mixed-methods studies were also eligible where qualitative findings could be clearly identified and extracted.
>
> **Evaluation (E):** How driving cessation is experienced and understood by people with dementia.
>
> **Research Type (R):** Qualitative and mixed-methods research.

Search terms were developed around the two key concepts of dementia and driving cessation. Initial scoping searches were undertaken to identify relevant terminology, and the final strategy was refined in consultation with a specialist university librarian. Electronic searches were conducted across five databases: Embase, CINAHL, MEDLINE,

PsycINFO and Web of Science. Searches were limited to English-language publications available up to 5 March 2026.

Search strategies were adapted for each database using controlled vocabulary (e.g., MeSH and Emtree terms) alongside free-text keywords where appropriate. Synonymous terms within each concept were combined using the Boolean operator OR, and the two concepts were combined using AND. Truncation (*) and adjacency operators were used to maximise retrieval of relevant studies. The complete search strategy is presented in Appendix 1.2.

The principal search concepts were:

1. Dementia: Dementia, Alzheimer Disease, Vascular Dementia, Dementia with Lewy Bodies and Frontotemporal Dementia.
2. Driving cessation: Automobile Driving, Driver License, Traffic Accident, together with free-text terms relating to driving ability, competence, safety, continuation and cessation.
3. Combined search: 1 AND 2.

To maximise the identification of relevant studies, supplementary search methods were undertaken. Google Scholar was searched to identify additional potentially relevant peer-reviewed publications. Backward citation searching (screening reference lists) and forward citation searching (identifying studies citing included papers) were conducted for all included studies and relevant systematic reviews. Search results were exported to Rayyan (Ouzzani et al., 2016) for reference management and screening.

Inclusion / Exclusion Criteria

The eligibility criteria are listed below.

Table 1. Systematic Review Inclusions and Exclusion Criteria

Criterion	Inclusion	Exclusion

Participants	People with dementia, family members, caregivers and healthcare professionals.	Studies that did not contribute to understanding the experiences of driving cessation for people with dementia.
Phenomenon of Interest	Driving cessation following a diagnosis of dementia.	Studies focusing solely on driving assessment, fitness to drive or road safety without exploring experiences of driving cessation.
Methodology	Qualitative and mixed-methods studies with extractable qualitative findings.	Quantitative studies without qualitative findings
Publication Type	Peer-reviewed journal articles, theses and grey literature.	Book chapters, editorials, commentaries, conference abstracts and poster presentations without sufficient qualitative data.
Language	English-language publications	

Data Extraction

A data extraction tool was developed specifically for this review (Appendix 1.3). The primary author extracted study characteristics, participant characteristics, study aims, methodology, data collection methods and analytical approach. Data extraction also included participant quotations (first-order constructs) and authors' interpretations (second-order constructs), which informed the development of the analytical themes. Consistent with the review aim, data relating to people with dementia were prioritised. Where studies included carers or healthcare professionals, data were extracted where they contributed to understanding the emotional and psychosocial experiences of driving cessation for people with dementia.

Quality Appraisal

The Critical Appraisal Skills Programme (CASP) qualitative checklist (2024) was used to appraise the methodological quality of the included studies. This tool was selected

because it is widely used in the appraisal of qualitative research (Majid & Vanstone, 2018) and health-related qualitative evidence syntheses (Long et al., 2020). The CASP checklist comprises ten questions designed to evaluate the methodological quality and rigour of qualitative studies, with strengths in assessing the transparency of reporting across key stages of the research process. A copy of the CASP checklist is provided in Appendix 1.4.

The CASP does not provide a standardised scoring system, which may introduce subjectivity in interpreting and comparing study quality (Long et al., 2020). Therefore, this current review utilised the same scoring system adopted by Holden and Pusey (2021) in their integrative review. A 'Yes' response to eight or more questions made a 'good' quality rating and a score of 'Yes' to six or seven questions was described as 'adequate. A score of less than six was labelled as 'poor'.

The primary author appraised all nine included studies. To enhance reliability, seven out of the nine studies (77%) were independently assessed by the second reviewer. Minor discrepancies were identified in three of the seven independently appraised studies (43%), relating to research, recruitment strategy and consideration of ethics. These differences were discussed until consensus was reached.

Thematic Synthesis

A thematic synthesis approach, as outlined by Thomas and Harden (2008), was selected because of its systematic approach to synthesising qualitative evidence and generating analytical themes across studies. This approach involves three stages: line-by-line coding, the development of descriptive themes, and the generation of analytical themes. Although the synthesis primarily centred the perspectives of people with dementia, data from carers and healthcare professionals were integrated where they enhanced understanding of the emotional and psychosocial experiences of driving cessation for people with dementia. This approach reflected the limited qualitative evidence available from people with dementia, while ensuring that the synthesis remained focused on the review question.

In the first stage, all text labelled as Results or Findings within the included studies was coded line by line. Every sentence had at least one code applied. Codes were generated inductively and organised into descriptive themes that remained closely aligned with the original meanings, ensuring a robust understanding of the data. Throughout this process, codes were continually compared within and across studies, with new codes developed where necessary to ensure that all relevant data were captured within the developing thematic framework.

These descriptive themes were subsequently grouped and organised into a table to facilitate the translation of concepts across studies. As each study was reviewed, existing codes and themes were continually refined to ensure that concepts from each study were represented within the developing synthesis.

In the final stage, analytical themes were developed through the application of the primary author's interpretative lens, moving beyond the original findings of the included studies to generate new interpretative constructs, explanations and hypotheses. This process enabled the synthesis to address the review question by developing analytical themes that provided a richer understanding of the emotional and psychosocial experiences of driving cessation following a diagnosis of dementia.

No studies were excluded based on methodological quality. However, CASP ratings were considered during the synthesis, with higher-quality studies analysed first to inform the development of the analytical themes.

Theoretical Position and Reflexivity

The primary author is a female Trainee Clinical Psychologist based in Scotland, with both clinical and personal experiences relevant to the review topic. Clinically, this includes experience of working with people with dementia and discussing driving cessation as part of pre-diagnostic neuropsychological assessments. Personally, the author has experience of supporting a family member following a diagnosis of dementia. These experiences informed the interpretative lens through which the data were analysed, when interpreting accounts of identity, loss and adjustment following driving cessation.

The review was conducted from an interpretivist perspective, which recognises that knowledge is co-constructed through the interaction between the researcher and the data and seeks to understand the subjective meanings individuals attribute to their experiences (Creswell & Poth, 2016). Reflexivity was maintained throughout the review, during thematic synthesis, through ongoing consideration of how the author's assumptions, experiences and developing understanding of grief and loss following a diagnosis of dementia may have shaped analytical decisions. Attention was paid to ensuring that concepts developed inductively from the included studies rather than being influenced by findings from the author's concurrent qualitative research.

To enhance the transparency and trustworthiness of the analysis, reflexive notes (Appendix 1.5) were maintained throughout the review and discussed regularly with both field and research supervisors during supervision. Throughout the synthesis, the author remained mindful of ensuring that the analytical themes remained centred on the experiences of people with dementia while recognising the contextual insights offered by family members and healthcare professionals.

Results

Review Process

Search results were exported into Rayyan, yielding a total of 4,362 articles. A total of 1,614 duplicate records were removed prior to screening. Deduplication was initially performed using Rayyan's automated function and subsequently verified by the primary reviewer to ensure accuracy.

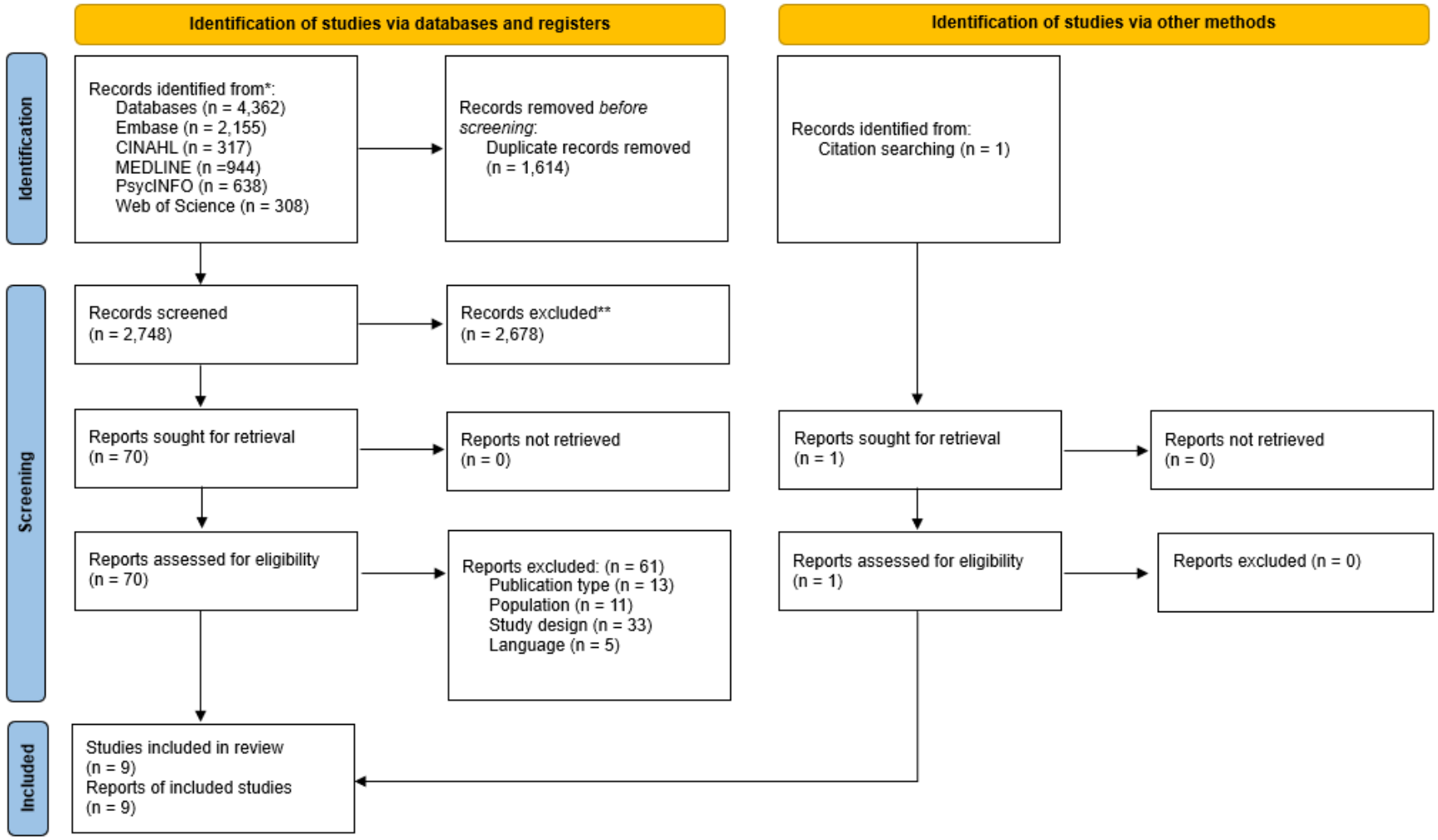
The first phase of the review process involved screening the titles and abstracts of the remaining 2,748 articles in accordance with the predefined inclusion and exclusion criteria. Articles that clearly did not meet the criteria (unrelated population, focus, outcomes, language, publication type, or methodology) were excluded at this stage. To enhance the reliability of the screening process, a random sample of 10% of articles (275/2,748) was independently screened by a second reviewer (BH, Trainee Clinical

Psychologist). Minor discrepancies related to studies where the relevance of the qualitative findings could not be determined from the abstract alone. These studies were discussed until consensus was reached, resulting in 100% agreement.

Following this, 70 articles were identified for full text review. These articles were reviewed in full, with attention to the methods and results sections. Where driving cessation formed part of a broader study, full texts were examined in detail to determine whether the findings were relevant to the review question. To further enhance the reliability of the review process, a random sample of 10% of full-text articles (7/70) was independently screened by the second reviewer. Inter-rater agreement at the full-text stage was 100%, with no discrepancies identified. Nine studies met the inclusion criteria following full-text screening.

An additional search of Google Scholar identified one further study that met the inclusion criteria. Forward and backward citation searching of the included studies and relevant systematic reviews did not identify any additional eligible studies. In total, nine studies were included in the review. The results of the study selection process are presented in the PRISMA flow diagram (Figure 1).

Figure 1. PRISMA Study Identification and Screening Process



Study and Participant Characteristics

The review included nine qualitative studies published between 2010 and 2023. Six studies, all of which included people with dementia, informed the primary thematic synthesis. Three additional qualitative studies that did not include people with dementia directly were retained to provide contextual insight. Although these studies did not contribute to the primary thematic synthesis, they met the review's eligibility criteria, addressed the research question, and offered relevant perspectives that supported the interpretation and development of the analytical themes. A summary of study characteristics is presented in Table 2. Four studies were conducted in Australia, two in Canada, two in the United States, and one in New Zealand.

Across the nine studies, there were 261 participants, including 69 people with dementia (26%), 76 family carers (29%), and 116 healthcare professionals or community organisation staff (44%). Sample sizes ranged from 14 to 65 participants. Participant ages ranged from 50 to 91 years, reflecting the predominantly older adult population affected by dementia, although one study focused specifically on people with young-onset dementia. While this review centred the experiences of people with dementia, the relatively small number of 69 first-person participants (26%), highlights the limited qualitative evidence available from this population.

Semi-structured interviews were the most common method of data collection, although focus groups and longitudinal interviews were also used. Analytical approaches included thematic analysis, interpretive description, phenomenology, grounded theory-informed analysis, and qualitative descriptive methods.

Table 2. Summary of Study Characteristics

Study No	Authors (Year and Country)	Participant Characteristics	Aim/ Phenomenon of Interest	Stage of Driving	Data Collection, Design and Analysis	Key Emotional and Psychosocial Findings/ Interpretations	Study Role
S1	Adler (2010) USA	Total = 65 PwD = 20 Carers = 45 (20 spouses of current drivers; 25 spouses of former drivers) Professionals = 0 Gender = PwD: 75% male; carers: predominantly female Age = PwD mean 70 years Ethnicity = Predominantly Caucasian	Explore attitudes, motives and actions relating to driving cessation. Explore how driving decisions are made by drivers with dementia and their spouses	Mixed	Focus groups Qualitative exploratory Inductive thematic analysis	Identity and independence Insight into driving ability Planning for driving cessation/ Adjustment Family and professional involvement Diagnostic uncertainty	Primary thematic synthesis
S2	Byszewski et al. (2010) Canada	Total = 30 PwD = 15 Carers = 15 Professionals = 0	Explore patient and caregiver experiences of disclosure of unfitness to drive	Transition	Interviews, follow-up interviews and caregiver focus groups	Identity and independence Emotional distress	Primary thematic synthesis

		Gender = 53% female (PwD) Age = Mean 81 years Ethnicity = Not reported	following a dementia diagnosis. Examine emotional reactions to recommendations for driving cessation. Develop recommendations to inform clinical practice		Qualitative descriptive exploratory Inductive thematic analysis	Acceptance as a gradual process Family involvement Professional communication	
S3	Chacko et al. (2015) New Zealand	Total = 14 (7 PwD-supporter pairs) PwD = 7 Carers = 7 Professionals = 0 Gender = 3 male; 4 female (PwD) Age = Mean 78 years (range 69-90) Ethnicity = Not reported	Explore the psychosocial impact of driving cessation for PwD and their supporters. Examine adjustment during the first six months following driving cessation. Identify emotional and practical consequences for PwD and supporters.	Post	Longitudinal semi-structured interviews (1 month and 6 months) Qualitative study informed by grounded theory Open coding and thematic analysis	Independence Loss of autonomy Emotional adjustment following driving cessation Family burden and relationship changes Professional communication and legitimacy of decisions	Primary thematic synthesis

S4*	Liddle et al. (2016) Australia	Total = 32 PwD = 5 retired drivers with dementia Carers = 12 family caregivers Professionals = 15 health professionals Gender = PwD: 80% male; carers: 75% female; professionals: 60% female Age = PwD median 73 years (range 67-75) Ethnicity = Not reported	Explore how families experience and manage driving cessation following dementia. Examine family dynamics and factors influencing collaboration and conflict. Identify family support needs to inform tailored clinical interventions.	Mixed	Semi-structured interviews Descriptive phenomenology Thematic analysis	Identity and independence Loss of autonomy and changing family roles Insight and awareness influencing adjustment Emotional distress Family collaboration and conflict during driving cessation	Primary thematic synthesis
S5	Nixon (2011) Australia	Total = 22 PwD = 6 Carers = 7 Professionals = 9 (GPs, medical specialist, ACAT staff, occupational therapist, case	Explore the experiences of PwD, families and key decision-makers during driving retirement in rural New South Wales.	Post	Semi-structured interviews and medical record review (case series) Qualitative descriptive case study	Identity and independence Emotional distress and grief following driving cessation	Primary thematic synthesis

		manager, RTA representative) Gender = PwD: 3 male, 3 female Age = 74-91 years (PwD) Ethnicity = Not reported	Identify practical, emotional and informational support needs before, during and after driving cessation. Inform improvements in planning and service provision for driving retirement.		Thematic analysis	Loss of autonomy and reduced social participation Family relationships and changing roles Stigma and social exclusion Planning for driving cessation/ Adjustment	
S6	Scott et al. (2023) Australia	Total = 18 PwD = 10 people with YOD Carers = 8 family caregivers Professionals = 0 Gender = PwD: 50% female; carers: 75% female Age = PwD mean 62 years (range 50-74); carers mean	Explore the lived experiences of driving change and driving cessation among people with YOD. Identify the emotional, practical and psychosocial needs associated with driving cessation. Inform interventions that support	Mixed	Semi-structured interviews Descriptive phenomenology Inductive and deductive thematic analysis	Identity and independence Grief and loss Loss of autonomy and reduced social participation Family relationships and changing roles Emotional adjustment and maintaining agency	Primary thematic synthesis

		64 years (range 45-85) Ethnicity = Not reported	adjustment to driving loss for people with YOD and their families				
S7	Sanford et al. (2019) Canada	Total = 29 PwD = 0 Carers = 13 family caregivers Professionals = 16 (10 healthcare professionals; 6 community organisation representatives)	Explore coping, decision-making and adaptation during driving cessation in dementia. Examine caregiver and professional understandings of the emotional responses of PwD.	Mixed	Semi-structured interviews and focus groups Qualitative exploratory study Inductive thematic analysis	Identity and independence Grief and loss Loss of autonomy Family relationships and changing roles Maintaining meaningful roles and purpose Professional communication and emotional support needs	Supporting study

S8	Stasiulis et al. (2020) Canada	Total = 15 PwD = 0 Carers = 0 Professionals = 15 Alzheimer Society staff	Explore Alzheimer Society staff perspectives on the challenges of driving cessation for PwD and family carers. Identify barriers and facilitators to implementing a dementia driving cessation toolkit.	Mixed	In-depth semi-structured interviews Qualitative descriptive study Interpretive thematic analysis	Emotional distress Grief and loss Loss of autonomy and social participation Professional and system support Family relationships and dynamics Planning for driving cessation/ Adjustment	Supporting study
S9	Scott et al. (2020) Australia	Total = 29 PwD = 0 Carers = 0 Professionals = 29 GPs Gender = 48% female Age = Mean 49 years Ethnicity = Not reported	Explore GPs' experiences of managing driving cessation in PwD. Identify facilitators, barriers and strategies used during driving cessation discussions.	Mixed	Focus groups Interpretive description Thematic analysis	Grief and anger Loss of trust and dignity Insight into driving ability Loss of autonomy Professional and system support	Supporting study

						Family relationships and dynamics	

Key:
Studies with * = Contain the same pool of participants
PwD = People with dementia, YOD = Young onset dementia, GPs = General practitioner

Quality Appraisal

Overall, the methodological quality of the included studies was judged to be moderate to good. Most studies demonstrated clear research aims and employed qualitative methodologies and research designs that were appropriate to exploring the experiences of driving cessation following a diagnosis of dementia. No studies were excluded based on quality, consistent with recommendations for qualitative evidence synthesis (Thomas & Harden, 2008). However, greater interpretative weight was given to studies judged to be of higher methodological quality during the development of analytical themes, while findings from lower quality studies were used primarily to support or contextualise emerging interpretations.

Ethical considerations were addressed in most studies, with several reporting ethical approval and consent procedures (Scott et al., 2020; Theresa L. Scott et al., 2023). However, when assessed against CASP criteria, reporting was often limited. In several studies, ethical procedures were described but not clearly explained. Although ethical procedures were described, several studies provided insufficient detail regarding how consent was obtained, capacity was assessed, or participant distress was managed (Byszewski et al., 2010; Nixon, 2011). Consequently, 'Can't tell' ratings were applied in these areas.

Reflexivity was the weakest reported aspect of methodological quality, with most studies providing little or no consideration of the researchers' role or influence on the research process (Adler, 2010; Stasiulis et al., 2020). Although some studies acknowledged researcher involvement, these reflections were typically brief, while others did not address reflexivity despite clear researcher engagement (Liddle et al., 2016; Sanford et al., 2019).This limited the transparency with which readers could evaluate how researchers' assumptions and perspectives may have shaped the findings.

Data collection methods were generally appropriate and most commonly involved semi-structured interviews. However, reporting of recruitment and sampling strategies was often limited. Although analytical approaches were broadly appropriate, several studies provided insufficient detail regarding their analytic procedures, including coding

processes, theme development, and how the adequacy of the data was judged. Consequently, it was sometimes difficult to fully evaluate the rigour of the analytical process.

Findings were clearly presented and supported by participant quotes, providing valuable insight into the experiences of driving cessation. CASP ratings were applied conservatively and based on what was reported rather than assumed. As a result, the higher number of 'Can't tell' ratings are likely to reflect limitations in reporting rather than weakness in study quality (Chacko et al., 2015). An overview of the quality appraisal is presented in Table 3 below.

Table 3. Critical Appraisal Skills Programme Checklist Results

Study #	Authors	Clear statement of aims?	Appropriate qualitative methodology?	Appropriate research design?	Recruitment strategy?	Data collected to address research	Positionality addressed?	Ethical issues?	Rigorous data analysis?	Clear statement of findings?	Valuable research?
S1	Adler (2010)*	✓	✓	✓	?	✓	x	?	?	✓	✓
S2	Byszewski et al. (2010)	✓	✓	?	?	✓	x	?	?	✓	✓
S3	Chacko et al. (2015)*	✓	✓	✓	✓	?	x	x	?	?	✓
S4	Liddle et al. (2016)*	✓	✓	✓	✓	✓	x	✓	✓	✓	✓
S5	Nixon (2011) *	✓	✓	✓	✓	✓	?	?	?	✓	✓
S6	Scott et al., (2023)*	✓	✓	✓	✓	?	?	✓	✓	✓	✓
S7	Sanford et al. (2019)	✓	✓	?	✓	✓	✓	✓	?	✓	✓

S8	Stasiulis et al. (2020)*	✓	✓	✓	✓	✓	x	✓	?	✓	✓
S9	Scott et al. (2020)*	✓	✓	✓	✓	?	✓	✓	?	✓	✓

Key: * indicates CASP checked by second reviewer
Yes = ✓ No = x Can't tell = ?
(Good = 'Yes' to >8. Adequate = 'Yes' to 6-7. Poor = 'Yes' to <6)

Thematic Synthesis

Thematic synthesis of the included studies generated two analytical themes, each comprising three subthemes. These themes represent shared patterns across the included studies while remaining grounded in the individual accounts and interpretations presented within the primary research. The analytical themes and subthemes are presented in Table 4.

Table 4. Themes and sub-themes identified by Thematic Synthesis

Analytical Theme	**Subthemes**
1. Losing the Licence, Losing the Self	1.1 Identity and Independence
	1.2 Acute Emotional Distress
	1.3 A Shrinking World
2. Living Beyond Driving Cessation	2.1 Awareness of Changes in Driving Ability
	2.2 Negotiating Autonomy during Driving Cessation
	2.3 Acceptance as an Ongoing Process.

Theme 1: Losing the Licence, Losing the Self

Across the included studies, driving embodied independence, autonomy, competence and valued social roles, making its relinquishment a significant emotional and psychosocial transition. Participants described the loss of driving as disrupting their sense of identity, provoking emotional distress, and as a progressive narrowing of everyday life.

Three subthemes were identified: (1) *Identity and Independence*; (2) *Acute Emotional Distress*; and (3) *A Shrinking World*.

1.1: Identity and Independence

Across five of the studies, driving was consistently described as a symbol of independence, autonomy, competence and valued social roles, becoming closely linked with participants' sense of identity (Adler, 2010; Byszewski et al., 2010; Liddle et al., 2016; Nixon, 2011; Scott et al., 2023). Rather than being viewed solely as a means of mobility, driving represented who participants were as capable, independent and socially engaged individuals.

Participants frequently described driving as providing freedom, choice and autonomy. Scott et al. (2023) characterised driving cessation as the transition from the valued identity of *"driver"* to *"non-driver"*, reflecting the symbolic significance participants attached to driving. As one participant explained:

> *"I miss the freedom to do what I want, when I want."* (Scott et al., 2023, p. 3)

This account illustrates that participants valued driving not simply for the act of driving itself, but for what it represented. Across the included studies, driving symbolised personal competence and the ability to fulfil valued social and familial roles, reinforcing participants' identities as capable and autonomous individuals (Adler, 2010; Byszewski et al., 2010; Liddle et al., 2016; Nixon, 2011).

Taken together, these findings suggest that driving functioned as a symbolic expression of identity, making it an important component of how they understood themselves.

1.2: Acute Emotional Distress

Across five of the studies, driving cessation was consistently experienced as a profoundly distressing event. Participants described sadness, anger, frustration, grief and despair following the loss of their licence or the decision to stop driving (Adler, 2010; Byszewski et al., 2010; Nixon, 2011; Scott et al., 2023; Stasiulis et al., 2020). Researchers similarly observed participants becoming visibly tearful, withdrawn and distressed when discussing driving cessation (Byszewski et al., 2010), suggesting that stopping driving evoked an immediate and powerful emotional response.

Participants frequently relied on vivid embodied metaphors to communicate the intensity of this distress, suggesting that ordinary emotional language was insufficient to capture their experience. As one participant reflected:

> *"I really feel like I've been castrated, if I was a man. It's like cutting my legs off*." (Byszewski et al., 2010, p. 158)

Comparable emotions and descriptions emerged across the included studies. A participant in Nixon (2011) described losing the ability to drive as feeling "*like my arm had been cut off"* (p. 4), while Scott et al. (2023) adopted the phrase *"it's like you get your legs cut off"* (p. 5) as the title of their study. These quotes highlight that participants repeatedly drew on images of bodily injury to communicate the intensity of their emotional reactions. The recurrence of these metaphors across studies suggests that participants found the emotional impact of driving cessation difficult to express through ordinary language.

The emotional impact of driving cessation was also recognised by family members and healthcare professionals, who described witnessing intense distress following licence withdrawal. One clinician recalled informing an older woman that reporting her licence *"was like we had killed her child"* (Stasiulis et al., 2020, p. 1267), illustrating that this distress was evident not only in participants' own accounts but also to those supporting them through the process.

1.3: A Shrinking World

Across the included studies, participants described a progressive narrowing of everyday life following driving cessation. As dependence on others increased, opportunities to participate in valued activities, maintain social relationships and sustain established routines became increasingly restricted (Byszewski et al., 2010; Chacko et al., 2015; Liddle et al., 2016; Nixon, 2011; Scott et al., 2023). Rather than describing a single moment of loss, participants portrayed an ongoing reduction of their everyday worlds as the practical consequences of no longer driving unfolded over time. One participant captured this gradual change by explaining:

> "I wait, wait, wait… if somebody can take me… if they can't, well, you don't go." (Scott et al., 2023, p. 4)

This account illustrates how everyday activities became increasingly dependent on the availability of others. Rather than deciding when and where to travel, participants described waiting for opportunities to arise, reducing spontaneity and limiting control over their daily lives.

Across the included studies, increasing reliance on family members and friends for transport affected participants' ability to socialise, volunteer, attend appointments and remain involved in their communities. Participants described disrupted routines and fewer opportunities to maintain valued activities, while those living in rural areas experienced additional restrictions because of limited transport alternatives (Nixon, 2011). These findings suggest that the consequences of driving cessation were shaped not only by the loss of driving itself but also by the wider social and environmental contexts in which participants lived.

Taken together, these findings suggest that driving cessation progressively reshaped participants' everyday lives through the gradual accumulation of practical and social restrictions. As dependence on others increased, participants described their worlds becoming smaller, with diminishing opportunities for spontaneity, participation and social connectedness.

Theme 2: Living Beyond Driving Cessation

This theme explores how people with dementia negotiated the transition from driver to non-driver and gradually learned to live with its consequences. Participants' experiences were shaped by their awareness of changing driving ability, the extent to which they remained involved in decisions about driving cessation, and their ongoing efforts to reconstruct everyday life following the loss of driving. Rather than representing a linear process, these experiences illustrate how awareness, autonomy and acceptance interacted to influence how participants understood, responded to and accommodated driving cessation. Together, the findings suggest that living beyond driving involved not simply accepting the loss of driving, but actively rebuilding everyday life through adaptation, supportive relationships and continued engagement in meaningful activities.

Three subthemes were identified: (1) *Awareness of Changes in Driving Ability*; (2) *Negotiating Autonomy during Driving Cessation*; and (3) *Acceptance as an Ongoing* Process.

2.1 Awareness of Changes in Driving Ability

Across four studies, participants demonstrated varying levels of awareness of changes in their driving ability, which shaped how they understood and responded to driving cessation (Adler, 2010; Byszewski et al., 2010; Liddle et al., 2016; Scott et al., 2023). While some participants recognised changes in their confidence, concentration or driving performance, others questioned the need to stop driving or disagreed with concerns raised by family members and healthcare professionals. These differences in awareness influenced how participants interpreted discussions about driving cessation and the extent to which they perceived it as necessary.

Participants who recognised changes in their driving ability often described becoming increasingly aware of their limitations and the potential risks associated with continuing to drive. Some reflected on feeling less confident, avoiding unfamiliar routes or more challenging driving situations, and acknowledging that driving had become more demanding. One participant reflected:

> *"I knew I was Alzheimer-ish… stopping was dead simple"* (Liddle et al., 2016, p. 116)

This illustrates how awareness of cognitive decline could facilitate recognition that driving cessation had become necessary. Across the studies, this awareness was frequently associated with greater acceptance that driving cessation might eventually be required (Adler, 2010; Byszewski et al., 2010; Liddle et al., 2016).

In contrast, other participants expressed little awareness of any decline or questioned decisions to restrict or stop their driving. One participant questioned the decision to stop driving, stating:

> *"There's nothing in that report that says I'm going to be a bad driver"* (Byszewski et al., 2010, p. 158).

Family members and healthcare professionals similarly described situations in which participants perceived themselves to be safe drivers despite evidence of declining cognitive abilities or concerns raised by others (Byszewski et al., 2010; Liddle et al., 2016; Scott et al., 2023). Rather than reflecting deliberate resistance, these differences often appeared to arise from reduced insight due to the cognitive changes associated with dementia, highlighting the complexity of assessing driving ability within the context of a progressive condition.

Taken together, these findings suggest that variations in insight, influenced by the cognitive changes associated with dementia, shaped how participants understood and responded to driving cessation. For those with reduced awareness of declining ability, recommendations to stop driving could conflict with their own perception of themselves as capable drivers, contributing to frustration, confusion and distress.

2.2 Negotiating Autonomy during Driving Cessation

Across the included studies, participants' experiences of driving cessation were shaped not only by the decision to stop driving, but by the extent to which they remained involved in the decision-making process (Adler, 2010; Liddle et al., 2016; Nixon, 2011; Scott et al., 2023). Although many recognised that they might eventually need to stop driving,

maintaining a sense of autonomy over when and how this occurred was an important aspect of preserving personal control within the context of a progressive condition.

For some participants, choosing when to stop driving represented an opportunity to retain autonomy despite increasing losses in other areas of life. As one participant explained:

> *"If I become unable to [drive safely] I will have the sense to stop."* (Adler, 2010, p. 52)

This account illustrates participants' desire to remain active participants in decisions about their own driving. Across the included studies, being able to exercise judgement about their changing abilities appeared to support a greater sense of ownership over the transition from driver to non-driver.

In contrast, participants who experienced driving cessation as externally imposed more frequently described frustration, resistance and a loss of control. One participant reflected:

> *"They didn't face me and say 'Well your time is up and you should be giving up driving now'. No one faced me and said let's go and have a driving test."* (Nixon, 2011, p. 20)

Rather than objecting solely to the outcome, this account suggests that participants experienced distress when they felt excluded from decisions about their own driving. Another participant described becoming *"more aggressive, more argumentative… my whole life had been kerbed… I was like a cornered rat"* (Nixon, 2011, p. 19), illustrating how the loss of autonomy could intensify the emotional impact of driving cessation. Family members similarly described becoming the focus of participants' anger when they were perceived to have contributed to driving cessation (Liddle et al., 2016).

2.3 Acceptance as an Ongoing Process

Across the included studies, acceptance of driving cessation was rarely described as a single event or final outcome. Instead, participants portrayed it as an ongoing process of

reconstructing everyday life while accommodating the emotional and practical consequences of no longer driving (Adler, 2010; Chacko et al., 2015; Liddle et al., 2016; Scott et al., 2023). Rather than signifying the resolution of loss, acceptance was expressed through adapting routines, accepting support from others, and finding new ways to remain engaged in meaningful activities.

For some participants, acceptance began with recognising that driving cessation had become necessary despite the sadness associated with relinquishing driving. As one participant reflected:

> "You have to accept it because there's nothing you can do about it." (Scott et al., 2023, p.5)

Rather than conveying resignation alone, this account reflects an active process of adjusting expectations and accommodating a reality that could not be changed. Participants who had chosen to stop driving themselves often described greater peace with their decision, although many continued to miss the independence and freedom that driving had represented (Chacko et al., 2015; Liddle et al., 2016).

Acceptance was also evident in the ways participants gradually reconstructed everyday life following driving cessation. Across the included studies, participants described adapting established routines, planning journeys differently, relying on family members and friends for transport, and identifying alternative ways to remain involved in valued activities (Chacko et al., 2015; Liddle et al., 2016; T. L. Scott et al., 2023). Although accepting support from others often represented a significant adjustment, these practical adaptations enabled many participants to preserve social connections and maintain participation in aspects of everyday life that remained meaningful to them.

Discussion

This review synthesised qualitative evidence examining the lived experiences of driving cessation among people with dementia. Two analytical themes were identified; *Losing the Licence, Losing the Self* and *Living Beyond Driving Cessation* which illustrate both the

emotional and psychosocial impact of relinquishing driving and the processes through which people with dementia adjusted to this transition.

Integration with Existing Literature

Across the synthesis, driving represented far more than a means of transport. It symbolised identity, independence, competence and valued social roles, making its relinquishment a significant disruption to participants' sense of self. This helps explain why participants experienced driving cessation not only as acute emotional distress but also as an ongoing narrowing of their everyday world.

The finding that driving cessation was associated with a progressive narrowing of everyday life is consistent with broader research among older people. Qin et al. (2020) found that driving cessation was associated with reduced social participation, while Liddle et al. (2024) identified loss, grief and difficulties adjusting following cessation. These findings suggest that the experiences identified in the present review reflect wider challenges associated with stopping driving in later life.

However, the present synthesis provides further insight into how these experiences may be understood in the context of dementia. Participants described not only restrictions to mobility and social participation, but also disruption to identity, autonomy and valued roles. This is consistent with previous dementia-specific research, which has highlighted the emotional significance of driving cessation and the importance of family relationships, alternative transport and support during adjustment (Holden & Pusey, 2021; Sanford et al., 2020). The findings therefore suggest that driving cessation may occur alongside changes in cognitive abilities, increasing dependence and adjustment to a new diagnosis. Driving cessation may consequently represent one component of a wider period of transition and loss following diagnosis.

This interpretation also aligns closely with Continuity Theory (Atchley, 1989), which proposes that individuals seek to maintain continuity in identity and established ways of living. The findings suggest that driving supported this continuity by enabling participants

to maintain competence and valued social roles. Relinquishing driving therefore disrupted not only everyday activities, but also an important way in which participants maintained a sense of self. This helps explain why driving cessation was experienced as a loss of identity and not simply as a practical change in how people travelled.

These findings both reinforce and develop previous understandings of adjustment following driving cessation. Holden and Pusey (2021) emphasised the importance of family support, alternative transport and interventions that facilitate adjustment after driving cessation, while Sanford et al. (2020) highlighted the influence of interpersonal relationships throughout the cessation process. The present synthesis extends these findings by demonstrating that adjustment is not simply the outcome of receiving support, but an ongoing process shaped by awareness of changing abilities, opportunities to retain autonomy, and the practical reconstruction of everyday life. This is consistent with Schlossberg's Transition Theory (2011), which conceptualises adjustment as a dynamic process influenced by individual circumstances, coping resources and available support. This also resonates with the Transactional Model of Stress and Coping (Folkman, 1984), whereby participants' experiences were influenced by how they interpreted driving cessation, the extent to which they perceived control over the process, and the resources available to support adjustment.

The importance of alternative transport is particularly relevant to understanding the finding of a "shrinking world". The World Health Organization identifies accessible and affordable transport as an important component of age-friendly communities, supporting older people to remain involved in their communities (World Health Organization, 2007). Rosenbaum et al. (2024) similarly highlighted the importance of transport and neighbourhood environments in supporting mobility and social participation following driving cessation. This wider literature helps to explain participants' experiences of relying on others and losing opportunities for social participation when alternative transport was unavailable. The findings therefore suggest that adjustment is shaped not only by individual coping, but also by the transport opportunities available within the wider community.

Taken together, these findings suggest that supporting adjustment involves more than helping people stop driving safely. It also involves supporting opportunities to remain

involved in decisions about driving and to continue participating in meaningful aspects of everyday life.

Clinical and Policy Implications

This review suggests that conversations about driving cessation should extend beyond assessments of driving safety to acknowledge its wider psychological consequences. Services should therefore ensure that conversations about driving cessation continue beyond decisions about fitness to drive, creating opportunities to acknowledge its emotional impact over time. Increased awareness of the emotional significance of driving cessation across dementia services may help staff provide more empathic communication, emotional support, collaborative problem-solving, and support for family members to better understand the impact of driving cessation on their loved one. Given the prominence of identity-related losses within participants' accounts, Clinical Psychologists may be particularly well placed to support people living with dementia to make sense of these losses. Formulation-led approaches, including values-based approaches where appropriate, may help people with dementia maintain continuity with valued aspects of their lives whilst adapting to the loss of driving.

This review suggests that adjustment to driving cessation is best understood as an ongoing process rather than a discrete event. Participants described ongoing changes to everyday life, increasing reliance on others, and reduced opportunities to participate in their communities long after driving had ceased. Support should therefore extend beyond licence surrender, recognising that many of its consequences emerge gradually. Within Older People's Mental Health Services, clinicians should routinely explore what driving means to people with dementia, how stopping driving has affected everyday life and relationships, and what support may help maintain valued activities and social participation.

This review also highlights the importance of involving people with dementia in decisions about driving wherever possible. Remaining involved in decisions about driving appeared to support adjustment by helping people maintain a sense of autonomy. Participants who

remained involved described greater acceptance of driving cessation, whereas externally imposed decisions were more often associated with frustration and distress. Clinicians should therefore involve people with dementia in discussions about driving as early as possible and revisit these conversations as circumstances change. Clinical Psychologists may also support multidisciplinary teams through consultation and formulation, helping staff explore the emotional meaning of driving cessation alongside practical discussions about safety and licence withdrawal. Collaborative working with Occupational Therapists and wider community services may further support planning around alternative transport and continued engagement in valued activities.

Strengths and Limitations

This review focused on the emotional and psychosocial impact of driving cessation, whereas previous reviews have looked at driving cessation in dementia more broadly. The accounts of people with dementia were centred, with family and professional accounts used to add context. By bringing together findings across studies, the review gives a fuller picture of the emotional and psychosocial experiences of driving cessation than individual studies alone. The review was strengthened through transparent quality appraisal using the CASP checklist. A systematic analytical process, regular supervision, and an audit trail supported consideration of alternative interpretations throughout the synthesis and enhanced the credibility of the findings.

However, several limitations should be acknowledged. The quality and richness of the included studies varied, with some providing detailed participant quotations and clear analytical interpretations, whilst others offered more limited analytic depth. This variation appeared to reflect differences in reporting rather than the conceptual importance of individual findings.

Most participants were White and recruited through memory clinics or specialist dementia services. This limits understanding of the experiences of people from more diverse cultural and socioeconomic backgrounds, or those with limited access to post-diagnostic support. Demographic characteristics were also reported inconsistently,

restricting exploration of how ethnicity, socioeconomic status, and other intersecting identities may shape experiences of driving cessation. In addition, few studies employed longitudinal designs, limiting understanding of how experiences change over time.

As with all qualitative evidence syntheses, the review is shaped by interpretative decisions. Regular supervision, a reflective diary, and an audit trail supported reflexivity throughout the analytical process. Conducting an Interpretative Phenomenological Analysis alongside this review may also have increased sensitivity to themes of loss, identity, and adjustment. However, similar findings were identified across studies conducted in different countries and healthcare settings, suggesting that these experiences were not unique to individual studies.

Future Research Directions

Although adjustment was experienced as evolving over time, most studies captured it at a single time point. Longitudinal qualitative research could examine how adaptation develops as dementia develops and identify factors that support or hinder adjustment. This may also help clarify how the experience of driving cessation interacts with other transitions associated with dementia over time, including changes in independence, relationships and participation.

Although this review synthesised first-person accounts, people with dementia represented only 26% of participants, with many studies relying primarily on caregiver perspectives. Research should prioritise the voices of people with dementia to understand the losses and adaptations associated with no longer driving, so evidence better reflects their priorities and lived experiences.

Finally, future research should examine experiences of driving cessation across more diverse populations and contexts. The included studies were conducted exclusively in Australia, North America, and New Zealand, and no qualitative studies were identified from the UK, wider Europe or low to medium income countries. Research should explore how the experience of driving cessation differs within UK settings, where factors such as living in rural areas, access to alternative transport, health and social care systems may

shape adaptation. This would help establish how transferable the current evidence base is to UK settings and other underrepresented contexts.

Conclusion

This review demonstrates that driving cessation following a diagnosis of dementia represents far more than the practical loss of driving. It is a psychologically significant life transition, with adjustment shaped by changes to identity, autonomy, and participation in everyday life. By centring the voices of people with dementia, this review suggests that it is not driving cessation alone that determines how people adjust, but how they are supported to navigate its wider emotional and psychosocial consequences. Recognising this may help ensure that post-diagnostic care extends beyond driving safety to provide psychologically informed, person-centred support.

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Chapter 2

Making sense of grief and loss following a dementia diagnosis: An Interpretative Phenomenological Analysis

Prepared in accordance with the author requirements for:

Dementia

(Author Guidelines)

Plain Language Summary

Title: Making sense of grief and loss following a dementia diagnosis: An Interpretative Phenomenological Analysis

Background: Receiving a diagnosis of dementia can bring many changes to a person's life. Alongside changes in memory and thinking, people may experience losses relating to their independence, valued roles, identity, and hopes for the future. These experiences may lead to feelings of grief. However, most research on grief in dementia has focused on family members and carers rather than people with dementia themselves. As a result, little is known about how people with dementia experience and make sense of grief and loss following a dementia diagnosis.

Aims: This study aimed to understand how people with dementia experience and make sense of grief and loss following a dementia diagnosis. It also explored whether these experiences were recognised and understood by others.

Research Questions:

This study explored:

1. How people with dementia experience grief and loss following a dementia diagnosis?
2. Whether people with dementia feel these experiences are recognised and understood by others?
3. What support or strategies do people find helpful when experiencing grief and loss?

Methods: Seven people who had received a diagnosis of dementia within the previous year took part in interviews. All participants were receiving support from an Older People's Community Mental Health Team (OPCMHT) within NHS Scotland.

Participants were asked about their experiences of dementia, grief, loss, and support. The interviews were analysed using a qualitative research method called Interpretative Phenomenological Analysis (IPA), which focuses on understanding how people make sense of their personal experiences.

Main Findings: The study found that participants experienced many losses that extended beyond memory difficulties. People described noticing changes in themselves and grieving the loss of valued roles, independence, and aspects of their identity. Many also spoke about feelings of injustice, uncertainty, and fear about the future.

Participants described how these experiences of grief were often not recognised or understood by others. Some felt that people avoided talking about the emotional impact of dementia, while others felt their experiences were dismissed or overlooked. As a result, grief often remained unspoken. Many participants also described keeping these feelings to themselves, avoiding conversations about their distress or feeling unable to fully express what they were experiencing. This contributed to significant emotional pain and feelings of hopelessness. For some participants, these experiences were also associated with thoughts about suicide.

Conclusions: The findings suggest that grief may be a central yet often unrecognised part of living with dementia following diagnosis. While practical advice and support remain important, people may also benefit from opportunities to talk about loss, grief, and the emotional impact of dementia. Creating space for these conversations may help people feel understood, validated, and better supported as they adjust to changes in their lives.

Abstract

Receiving a diagnosis of dementia is associated with ongoing losses affecting identity, independence, valued roles, and future expectations. Despite this, little is known about how people with dementia themselves experience grief and loss following a dementia diagnosis. This study explored how people with dementia experience and make sense of grief and loss following diagnosis.

A qualitative design using Interpretative Phenomenological Analysis (IPA) was utilised. Seven older adults diagnosed with dementia within the previous year were recruited through Older People's Community Mental Health Teams (OPCMHTs) within NHS Scotland. Semi-structured interviews were conducted in participants' homes and analysed using IPA.

Two Group Experiential Themes were developed. (1) *"I'm not who I was": Living with ongoing loss* captured participants' awareness of changes in themselves and the losses associated with identity, independence, valued roles, and anticipated future decline. (2) "*Let's not make a thing of it": Silencing and unspoken grief* reflected how emotional responses to these losses were often unrecognised or minimised by others and, at times, by participants themselves. This contributed to experiences of disenfranchised and self-disenfranchised grief, including processes of silencing and self-silencing, which were associated with significant emotional distress and, for some participants, thoughts of suicide.

These findings suggest that grief may be a central yet often unrecognised aspect of the post-diagnostic experience of dementia. Participants described losses relating to their sense of self and future, yet opportunities to recognise and express these experiences appeared limited. Post-diagnostic support should therefore provide space for people with dementia to discuss and make sense of grief and loss alongside practical support and future planning. This may help to address the self-silencing and emotional distress described by participants and support psychological adjustment following diagnosis.

Keywords: Dementia, Grief, Disenfranchised Grief, Loss, Interpretative Phenomenological Analysis

Introduction

Receiving a diagnosis of dementia can involve experiences of grief and loss as people become aware of changes to their memory, thinking, abilities, and future. Whilst dementia is often understood in terms of cognitive decline, people with dementia may also experience losses relating to their identity, independence, valued roles, and sense of who they are (Yuile, 2019). Within the early stages of dementia, many people retain awareness of these changes (Wheeldon, 2020), meaning that losses may be experienced not only as practical difficulties but also as emotionally significant changes that require ongoing adjustment.

Experiences of grief and loss have also been described in people living with other life changing health conditions. In cancer, for example, grief has been described as a response involving anticipated losses, existential concerns, and changes to identity, and may be under-recognised in patients themselves (Mattson et al., 2025). Anticipatory grief has also been described in people with advanced cancer, in response to losses that have already happened, are happening now, and are still to come (Zhang et al., 2023). Changes to identity and experiences of loss have also been described in people living with neurological conditions, including Parkinson's disease (Nehra et al., 2023) and, in later life, cerebral palsy (Dark et al., 2016). Whilst these conditions differ from dementia, this suggests that grief may be a wider response to life changing illness, and one that may be closely linked to adjustment and identity. In dementia, however, the progressive nature of the condition and changes to memory and thinking may make it harder for people to make sense of these losses and to talk about them.

Despite dementia affecting approximately one million people in the United Kingdom (Alzheimer's Society, 2025), the first-hand experience of grief following a dementia diagnosis remains under-researched (Waddington et al., 2024). In particular, little is known about how people with dementia experience and make sense of grief and loss themselves, or whether these experiences are recognised and understood by others. When grief is not acknowledged or validated, it may become disenfranchised, making it more difficult to express and process (Doka, 2010). Developing a clearer understanding of these experiences is therefore important for informing post-diagnostic support that

enables people with dementia to recognise, express, and make sense of grief and loss following diagnosis.

Existing research on grief and loss in dementia

Caregivers' experience of grief and loss

The majority of research on grief and loss in dementia has predominantly focused on the perspective of caregivers, particularly in relation to anticipatory or pre-death grief. A qualitative synthesis by Large and Slinger (2015) identified themes including changes within relationships, emotional strain, coping efforts, and the evolving nature of caregiving over time. Similarly, Chan et al. (2013) described caregiver grief as a response to cumulative losses, characterised by uncertainty and emotions such as anger, frustration and guilt. While this body of work provides valuable insight into the experience of grief in dementia, it primarily reflects the perspectives of those supporting the person with dementia rather than those living with the condition themselves. As a result, current understandings of grief in dementia are largely constructed indirectly rather than from a first-person perspective.

People living with dementia: experiences of grief and loss

Research exploring grief and loss from the perspective of people with dementia remains limited. Where people with dementia have been included, their accounts have often been analysed alongside those of caregivers and professionals. For example, Waddington et al. (2024) included people with dementia and without within their synthesis of 19 studies, making it difficult to isolate and examine first-person experiences of grief.

Where studies have focused exclusively on people with dementia, this has often been within specific and less common subtypes, such as primary progressive aphasia (Lo et al., 2022; Waddington et al., 2025). Whilst these studies offer important insights into the experiences of grief and loss, their findings may not transfer to the wider dementia

population. Consequently, uncertainty remains regarding how people living with more common forms of dementia experience and make sense of grief and loss following diagnosis.

Limitations of existing research

People living with dementia excluded from research

The limited understanding of grief and loss in dementia reflects, in part, the underrepresentation of people with dementia in research. Participation has often been limited by concerns regarding cognitive impairment, communication difficulties and ethical challenges surrounding informed consent (Taylor et al., 2012), alongside practical barriers such as cultural and financial considerations (Goodman et al., 2011). As a result, research has often prioritised more accessible perspectives, particularly those of caregivers. However, evidence suggests that meaningful participation is both feasible and valuable when appropriate methods are used (McKeown et al., 2010).

Grief and loss as a secondary focus

In addition, grief and loss have rarely been examined as a primary focus within studies involving people with dementia. Instead, grief is often discussed indirectly within broader research exploring adjustment, identity or role change (Waddington et al., 2024). Whilst these studies provide valuable insight into the wider experience of living with dementia, they can obscure the specific nature and significance of grief. As a result, grief is often conceptualised as one aspect of adjustment, rather than as a potentially ongoing and meaningful response the losses associated with dementia. This limits the understanding of how grief is experienced, how it changes over time and the extent to which it may influence emotional wellbeing following diagnosis.

Context of dementia care and support

The limited understanding of grief and loss within the research literature is reflected within dementia care and support services. In Scotland, people diagnosed with dementia are entitled to at least one year of post-diagnostic support (Alzheimer Scotland; Scottish Government, 2024). Although this represents an important development in dementia care, support has often focused on providing information, practical advice, and future planning, with less emphasis on recognising and responding to experiences of grief and loss.

Opportunities to acknowledge grief may extend beyond formal post-diagnostic support. Emotional responses to dementia can emerge during assessment, at the point of diagnosis, throughout follow-up care within Older People's Community Mental Health Teams, and during transitions to residential care. Given the progressive nature of dementia, experiences of loss may continue to evolve over time and require ongoing recognition. Although services can provide opportunities for people with dementia to reflect on and adjust to these changes (Milne, 2010), grief remains relatively under-addressed within mental health services (Rupp et al., 2024). Consequently, there appears to be a disconnect between the emotional impact of dementia and the focus of current care pathways, meaning that experiences of grief and loss may remain insufficiently recognised and addressed across the course of dementia care.

Rationale for the present study

Taken together, the literature highlights important gaps in our understanding of how people with dementia experience grief and loss. Despite growing recognition of the emotional impact of dementia, relatively little is known about how people with dementia make sense of these losses from a first-person perspective. Furthermore, limited attention has been given to how experiences of grief are recognised, expressed, or understood following diagnosis. Developing a richer understanding of these experiences may help to inform more psychologically meaningful approaches to dementia care and

support, particularly by creating greater opportunities to recognise, discuss, and respond to grief and loss following diagnosis and throughout the course of dementia.

Research aims and questions

The aim of this study was to explore whether people with dementia experience grief and loss in relation to receiving a diagnosis of dementia and how they make sense of these experiences.

The study addresses the following questions:

1. How do people with dementia experience grief and loss related to their diagnosis?
2. How do people with dementia experience their grief as acknowledged or understood by others?
3. What support or strategies do people find helpful when experiencing grief and loss?

Methods

Ethical considerations

This study was reviewed by the North of Scotland Research Ethics Committee (2), which granted a favourable opinion on the 23rd of July 2025 (Ref: 25/NS/0075, see Appendix 2.2). NHS Scotland Research and Innovation granted approval on the 28th of July 2025 (Ref: UGN25NE269, see Appendix 2.3). Approval was also obtained from the Lead Consultant Clinical Psychologist for the Older People's Psychology Service (OPPS), in line with local governance requirements.

Design

A qualitative design was adopted to explore how people with dementia experience and make sense of grief and loss following a recent diagnosis. Interpretative Phenomenological Analysis (IPA) was selected due to its focus on lived experience and meaning making, particularly in situations shaped by uncertainty and change (Smith et al., 2022). IPA is grounded in phenomenology, hermeneutics and idiography making this approach well suited to explore how people with dementia interpret and make sense of grief and loss.

Recruitment

Recruitment took place through the Older People's Community Mental Health Teams (OPCMHT's) within NHS Scotland. Study information which included eligibility criteria and an outline of what participation involved was shared via email with clinicians, who identified potential participants from their case load.

Clinicians acted as the initial point of contact, introducing the study and providing information sheets. Potential participants who wished to hear more gave verbal consent for their contact details to be passed to the primary investigator (PI).

The PI then contacted potential participants by telephone to confirm initial consent, explain the right to withdraw and discussed any adaptations required to support their engagement (e.g. interview length, breaks, preferred setting). This call also provided an opportunity to answer questions and establish familiarity prior to the interview.

Once the target sample size had been reached, recruitment closed and clinicians were informed. Please see Appendices 2.4 to 2.7 for participant facing documentation.

Table 1. Inclusion and Exclusion Criteria

Inclusion	**Exclusion**
Aged 65+ and diagnosed with dementia	Secondary dementia diagnosis

Open to NHS Scotland OPCMHT's	Severe cognitive impairment
Diagnosis of dementia received within the past year	Lacking capacity and under the Adults with Incapacity (Scotland) Act 2000
In the early stages of dementia	

Participant Characteristics

Seven older adults took part in the study, all of whom had received a formal diagnosis of dementia within the past year and were open to OPCMHT's within NHS Scotland. Participants were aged between 67 and 83 years and all identified as white British. All participants were married and lived with their spouse who provided day-to-day support.

Dementia diagnoses included Alzheimer's Disease (n = 3), Lewy Body Dementia (n = 1), Mixed Alzheimer's/ Vascular Dementia (n = 1), Unspecified Dementia (n = 1) and Vascular Dementia (n = 1), with all participants in the early stages of their condition.

Most participants had engaged with a Post-Diagnostic Support (PDS) worker. Full details of participant characteristics can be seen within Table 2.

Table 2. Participant Characteristics

Participant Number	Pseudonym	Gender	Age	Dementia Type
1	Ann	Female	76	Alzheimer's Disease
2	Bruce	Male	76	Unspecified Dementia
3	Charles	Male	68	Lewy Body Dementia

4	Diana	Female	78	Alzheimer's Disease
5	Edward	Male	83	Mixed Alzheimer's/ Vascular Dementia
6	Frances	Female	78	Vascular Dementia
7	Gerrard	Male	67	Alzheimer's Disease

Sample Size

In line with IPA guidance, the study aimed to recruit between four and eight participants (Smith et al., 2022). A purposive sampling approach was used to identify potential participants that would be able to provide rich and meaningful accounts (Gray et al., 2023). The decision on when to stop recruitment was guided by information power, whereby sample size is determined by the depth and relevance of the data (Malterud et al., 2016). This approach is consistent with previous IPA studies in dementia research (Larsson et al., 2019).

Data Collection

A semi-structured interview was developed to allow participants to reflect on experiences of grief and loss that were meaningful to them (Larkin et al., 2006). The interview schedule was informed by existing literature on dementia and discussion with Field and Research supervisors. To ensure that the questions were accessible, the PI consulted with experts by experience via Alzheimer Scotland and their feedback was incorporated. Please see Appendix 2.8 for the Interview Schedule.

Interviews were conducted in participants' homes, which reflected their preference for a familiar and comfortable environment, reducing practical barriers to engagement for this often-excluded population (Taylor et al., 2012). Before beginning the interview,

participants were reminded of their right to withdraw and given time to ask questions. Written consent was gathered to conduct the interviews and audio-record via Dictaphone.

Recordings were stored securely on an NHS Scotland drive and then deleted once the PI had transcribed the interviews verbatim. All transcripts were pseudonymised, with participants assigned pseudonyms and all identifiable information (e.g. all names, locations, services) removed prior to analysis. Transcripts were shared only with the Field and Research supervisors.

Following the interviews, participants received a debrief document and information on local support services, along with guidance on how to contact their OPCMHT should they require further support.

Analysis and Reflexivity

Interviews were analysed using IPA (Smith et al., 2022), informed by phenomenological, hermeneutic and idiographic principles. A hermeneutic stance acknowledged the PI's interpretative role in understanding how participants made sense of their emotions and experiences (the double hermeneutic), whilst an idiographic focus helped the PI remain closely grounded in each participant's account before exploring patterns across cases.

Each transcript was read several times, including at least one reading alongside the audio recording, which supported familiarity with participants' experiences. Exploratory notes were developed for each participant and included descriptive, linguistic and conceptual comments. These notes helped the PI to attend to how participants expressed and understood their experiences.

Personal Experiential Themes (PETs) were developed for each case before being examined across participants to identify patterns of convergence and divergence, resulting in the development of Group Experiential Themes (GETs).

The PI's positioning and potential influences on the research process were considered through the development of a positionality and reflexivity statement (Appendix 2.9).

Reflexive notes were maintained throughout data collection and analysis to support ongoing awareness of the PI's role in interpretation, document early impressions, thoughts and questions, and facilitate critical reflection within research supervision (see Appendix 2.10 for an example diary excerpt).

In addition, to enhance methodological rigour, two transcripts were independently reviewed by the PI's Field and Research Supervisors. These discussions promoted transparency throughout the analytic process and provided opportunities to consider alternative interpretations. See Appendix 2.11 for the Detailed Analysis Plan and Appendices 2.12 to 2.13 for examples of the IPA analytic process. In addition, adherence to COREQ also ensured reflexivity, rigour and high-quality reporting (Appendix 2.1)

Results

Using idiographic analysis, two Group Experiential Themes (GETs) were developed. These themes reflect shared patterns of meaning across participants, while remaining grounded in individual accounts. Each GET comprises three subthemes that capture distinct aspects of participants' experience of grief and loss following a dementia diagnosis. The Group Experiential Themes and subthemes are presented in Table 3. Both GETs were represented across the majority of participant accounts (Appendix 2.14), although there was variation in how individual subthemes were experienced and expressed.

Table 3. Group Experiential Themes and Subthemes

Group Experiential Theme (GET) (Number of participants that contributed to GET)	**Subthemes** (Number of participants that contributed to subtheme)
1. "*I'm not who I was*": Living with ongoing loss (7)	1.1 "*I know I'm not myself*": Painful awareness of change (7)

	1.2 "*The cognitive aspects… it doesn't inhibit me"*: Loss beyond memory (5)
	1.3 "*Why me?*": Injustice, uncertainty and fear of the future (5)
2. "*Let's not make a thing of it*": Silencing and unspoken grief (7)	2.1 "*Do you realise what I've got?*": Grief not recognised (7)
	2.2 "*Don't make a thing of it*": Silencing and self-silencing (6)
	2.3 "*I keep thinking that and I don't know why*": Distress and suicidality (5)

1. "*I'm not who I was*": Living with ongoing loss

All participants described experiences of loss following a diagnosis of dementia. Rather than occurring at a single point in time, these losses were experienced as ongoing and repeatedly throughout everyday life. Participants described becoming aware of changes in who they were, the impact of dementia on aspects of life beyond memory, and the emotional consequences of living with an uncertain future.

Three subthemes were identified within this Group Experiential Theme: (1) "*I know I'm not myself*": Painful awareness of change; (2) "*The cognitive aspects… it doesn't inhibit me"*: Loss beyond memory; and (3) "*Why me?*": Injustice, uncertainty and fear of the future.

1.1 "*I know I'm not myself*": Painful awareness of change

Participants experienced becoming aware that they were no longer the person they had previously been.

Participants experienced these changes as a loss of their previous self, rather than simply a change in ability. Ann described this directly:

> "*I have changed for sure. I'm not myself. I used to be a happy person, talk to people… I know I'm not myself."* (Ann)

This suggests that participants experienced change as affecting who they were, rather than simply what they could do. She later added, "*I want to be like the way I was*", and Frances similarly stated, "*I'd rather be back the way I was than just now*". Across these accounts, participants described a longing to return to a previous version of themselves. Holding their former self in mind appeared to make the difference between past and present difficult to accept. This suggests that participants remained psychologically connected to who they had previously been, meaning that awareness of change was experienced as the loss of a valued and familiar sense of self.

These experiences of change appeared to remain emotionally present and sustained. Ann's repeated use of "*I'm not myself*" suggests that this was not a single reflection, but something she continued to return to. Gerrard's account of things being "*different now*" reflects a similar awareness of identity disruption.

Participants differed in how they spoke about change, with some expressing visible distress and others adopting a more pragmatic stance.

> *"The fact that, that's your working career over and your driving career over. So, it's really just going to damage limitation." (Charles)*

Charles described his situation as "*damage limitation*", reflecting a more contained and pragmatic stance towards change. In contrast, Bruce stated *"I just wish I was the way I was, but it's not going to happen".* The certainty within "*it's not going to happen"* appears significant, suggesting an awareness that the losses he described could not be reversed. Both accounts reflected an acknowledgement that something important and valued had already been lost. This suggests that participants were not only becoming aware of change but also attempting to find ways of living alongside it in different ways.

Taken together, these accounts suggest that dementia had disrupted participants' sense of identity in an ongoing way. Changes associated with dementia were experienced not only as functional losses, but as disruptions to a previously familiar sense of self. The experience of loss therefore appeared rooted not simply in what had changed, but in participants' continued longing for who they had once been.

1.2 "*The cognitive aspects… it doesn't inhibit me*": Loss beyond memory

Alongside this painful awareness of change, participants described losses that extended far beyond memory difficulties. Loss of confidence, competence, valued roles and independence often became visible in ordinary moments, highlighting what had changed following diagnosis.

Participants described becoming aware of loss through activities that had previously felt familiar and effortless. Frances described standing in her kitchen and asking, "*How can I not do this?… I don't know where to start*" when trying to cook. This suggests that loss was encountered in situations that had once been routine. Similarly, Bruce stated:

> "*When I get my bass guitar and I say to myself, I'm not getting this am I, I can't get to it, that really does me in.*" (Bruce)

Across these accounts, the difficulty was not only in completing tasks, but in encountering unexpected difficulties within activities that had previously been familiar. These reminders of change seemingly confronted participants with losses that were difficult to ignore.

Participants also described how these changes affected their experiences within social situations. Diana described feeling like "*the odd one out*" when she could no longer divide a restaurant bill. This highlights how changes in ability could alter participants' sense of belonging, leaving them feeling different from those around them.

Participants experienced changes in their roles within the family and home, which were repeatedly encountered in everyday life.

> *"It was a big loss to me. The independence and just the actual enjoyment of driving" (Charles)*

The phrase "*big loss*" appears significant, suggesting that driving represented more than a practical activity and was closely connected to a sense of independence. Diana described having been "*the hub of the house*", indicating that her role had been central within the family. This suggests that losses became visible through shifts in participation, contribution and everyday responsibilities.

Some participants also described attempts to maintain a sense of continuity despite these changes.

> *"The cognitive aspects of the disease doesn't, at the moment, it doesn't inhibit me." (Charles)*

Across accounts, participants appeared to search for evidence that valued abilities and aspects of themselves were still present. Gerrard described that information was "*in there*", suggesting that abilities remained accessible in some form, even when they were more difficult to reach.

Taken together, these accounts suggest that loss was often encountered through ordinary moments, where changes to ability, participation, and valued roles became repeated reminders of what had changed. Rather than being experienced solely as cognitive difficulties, these losses carried broader implications for participants' everyday, social, and family lives.

1.3 "*Why me?*": Injustice, uncertainty and fear of the future

As participants described these multiple losses, they also spoke about trying to make sense of a diagnosis that felt unjust. Alongside noticing what had already changed, participants were aware that dementia was progressive, meaning that loss was experienced not only in the present but also in relation to what the future would bring.

Participants experienced questioning why this had happened to them, often describing the diagnosis as unfair and difficult to understand. Ann repeatedly asked;

> "*Why have I got it… Why did it come to me… What have I done… Have I done something wrong to get this*". (Ann)

The repeated questioning highlights how participants were not only seeking explanations for dementia but attempting to understand what the diagnosis meant within the context of their lives. Across accounts, these questions appeared to remain unresolved, leaving participants without a coherent explanation for why dementia had become a part of their lives. Edward similarly described:

"There is a certain touch of why me? I mean outside of dementia, I've had cancer and other health conditions on and off. And on top of all of that I get dementia. It seems unfair. They're not sharing it out. So, a sense of why me." (Edward)

Diana also reflected this mismatch:

"Angry, because I actually thought that because I did quite well, I had quite a good life with a pacemaker to start with... and I carried on doing everything I could." (Diana)

Rather than describing dementia as unfair, Diana appeared to question why the diagnosis had occurred despite her efforts to manage previous health difficulties and continue living her life. This suggests that dementia challenged assumptions about fairness, effort and how life was expected to unfold.

Participants also described fear and uncertainty about the future, where dementia was understood as involving continued decline. Diana stated, "*nothing's going forward, it's all going back"*. This suggests an experience of reversal, where the future was understood in terms of loss. Charles described dementia as a "*progressive condition*", suggesting an awareness that further change was expected. This suggests that participants were living with a future already shaped by anticipated decline, where losses appeared psychologically present long before they had occurred.

"I've only got a few years left... Where is the cure? There's nothing, absolutely nothing." (Edward)

The absence of a cure appeared to leave participants confronting anticipated losses that felt increasingly unavoidable. Rather than uncertainty alone, participants described a sense of inevitability about the progression of dementia and its consequences.

For some participants, this fear extended to concerns about identity itself. Gerrard described his worst fear as waking up and thinking:

"The worst thing I can think of is... there was no sense of reality, and the time being, if I woke up one morning and I thought, Who am I? Who's that in the mirror?" (Gerrard)

This reflects a fear that extends beyond functional decline and towards the possibility of no longer recognising oneself. Rather than fearing the loss of a particular ability, Gerrard appeared to fear losing the continuity of self that allowed him to know who he was.

Taken together, these accounts suggest that dementia was experienced as both a present and future loss. Participants appeared to carry both present and anticipated losses simultaneously, grieving not only for aspects of life that had already changed, but for futures, identities and possibilities that felt increasingly uncertain.

2. "Let's not make a thing of it": Silencing and unspoken grief

As described in the previous theme, participants experienced dementia as involving ongoing and meaningful losses. Participants described a context in which the emotional impact of these losses was often minimised, left unspoken, or managed indirectly.

These accounts suggest that participants were often left carrying emotional experiences without clear opportunities to share, validate or make sense of them.

Three subthemes were identified within this Group Experiential Theme: (1) "*Do you realise what I've got?*": Grief not recognised; (2) "*Don't make a thing of it*": Silencing and self-silencing; and (3) "*I keep thinking that and I don't know why":* Distress and suicidality

2.1 "*Do you realise what I've got?*": Grief not recognised

Participants described that the emotional impact of dementia was not always recognised by others. While practical changes were sometimes acknowledged, the grief associated with these losses was often less visible and less understood.

Participants described feeling that their experiences were not believed or understood by those closest to them.

> *"Do you realise what I've got. I've told him that before, do you realise what I've got. That hurts me the most, having to tell my husband do you realise what I've got."* (Ann)

The repeated question appears significant. Rather than a sense of shared understanding, Ann described repeatedly needing to explain her dementia diagnosis to her husband. This suggests that participants could experience a lack of recognition within their closest relationships. The phrase "*that hurts me the most*" highlights that the emotional impact of dementia was not located solely within the diagnosis itself, but in feeling that its significance was not fully understood by those closest to them.

Participants also described becoming aware of subtle changes in how others interacted with them following diagnosis.

> "*Well, it's just the fact that people are aware that you've got a progressive condition, so it's, I think there's a little resistance in conversation*" (Charles)

The phrase "*a little resistance in conversation*" appears important. Rather than describing overt rejection or dismissal, Charles identifies a subtle shift in everyday interactions. This suggests that participants may be aware of changes in how others engaged with them following diagnosis, even when these changes are not openly acknowledged.

In some cases, responses from others appeared to maintain normality, but also limited acknowledgement of change. Bruce described that his friends "*let you have it the way it used to be*". Whilst maintaining normality may have been intended as supportive, it could also leave little room for participants to talk about experiences of loss. This suggests that support and recognition did not always coexist.

Participants also described a broader lack of recognition of emotional experience within wider contexts such as services. Edward stated when discussing post-diagnostic support information:

> "*Most of the stuff, it concentrates on the carer and not the person being cared for, but there's some good material in there, I've read them all.*" (Edward)

This suggests that attention was often directed towards practical or caregiver needs rather than the emotional experiences of the person living with dementia.

Taken together, these accounts suggest that participants' grief was not always recognised or responded to by others. This suggests that the emotional impact of

dementia could remain hidden even when participants were surrounded by people involved in their care and support.

2.2 "*Don't make a thing of it*": Silencing and self-silencing

Alongside a lack of recognition from others, participants also described actively minimising, deflecting, or containing emotional experience themselves. Distress appeared difficult to stay with, and participants often moved away from emotional material as it emerged.

Participants described managing distress by maintaining familiar roles and routines within relationships. Diana described containing her emotions when her son visited:

> "*So, when he comes in, I don't always cry. I can't always talk. I don't sit about, so the first thing I do is get a cup of tea on for them.*" (Diana)

Rather than remaining with her distress, Diana moves towards caring for others. The act of making tea appears to do more than provide hospitality, allowing her to continue occupying a familiar role whilst directing attention away from her own emotional experience. Continuing to care for others appeared to provide a way of preserving a valued sense of self, whilst creating distance from emotions that felt difficult to express directly.

Participants also described limiting how much emotional experience could be spoken about.

> *"I don't want to moan. I don't want to moan… I don't want to keep going on about it." (Gerrard)*

The repetition appears significant. Rather than simply expressing a view, the phrase seems to function as a boundary around further discussion. Across accounts, participants often approached emotional material before moving away from it, suggesting an awareness that certain experiences were difficult or uncomfortable, and that these participants were actively regulating how much of their distress could be shared with others.

For some participants, this process appeared within the interview itself.

> *"Don't make that too strong… you know what I mean… don't make it sound worse than it is." (Edward)*

This statement appears to soften or edit what had already been disclosed. Emotional experiences appeared carefully moderated, even within an interview that explicitly invited participants to talk about them.

Whilst participants described a shared tendency to contain emotional experiences, there were differences in how this was expressed. Male participants more often used humour, minimisation, or moved quickly away from emotional content, whereas female participants appeared more openly distressed and more able to remain with the emotional impact of their experiences. This suggests that self-silencing did not occur in the same way across participants but reflected different ways of managing distress and maintaining emotional control.

Taken together, these accounts suggest that participants were not only living with unrecognised grief but were also managing it in ways that limited how far it could be spoken about or explored. Rather than remaining solely an interpersonal process, the lack of recognition described in the previous subtheme appeared to become internalised, shaping how participants related to their own emotional experiences. This suggests that grief became difficult not only for others to acknowledge, but at times for participants themselves to openly express or engage with, contributing to a process of self-disenfranchised grief and a sense of suffering in silence.

2.3 "*I keep thinking that and I don't know why":* Distress and suicidality

Building on this, some participants described significant distress that was difficult to express openly. This included thoughts of escape or ending their life, which were not always described immediately and often emerged gradually over the course of the interview.

Participants described thoughts of escape or death in response to ongoing loss and distress.

> "*I'd be as well as just going out and getting knocked down by a car… I keep thinking that and I don't know why*". (Ann)

This suggests that these thoughts were intrusive and difficult to understand. Rather than describing a clear intention to die, Ann appeared troubled by the presence of the thoughts themselves. Considered alongside participants' descriptions of change and loss, these thoughts may reflect the emotional impact of living with aspects of the self that no longer felt familiar. Rather than representing a wish to die, they may point towards distress associated with ongoing experiences of loss.

Participants also described these thoughts as connected to how they understood their situation over time. Diana reflected, "*I think I would've done something years ago*", suggesting a longer-standing sense of distress. This suggests that thoughts of death were not always experienced as isolated reactions to diagnosis, but to participants' understanding of their lives and circumstances.

> "*I'm not going to say that, you're a lady. No, I keep saying the difference is 22 or 82. I'm sure if I was 22, I think it would be a real shock. I wouldn't be surprised if people who are young commit suicide for something like that. I mean, it's practically ending their whole life.*" (Edward)

Although Edward was speaking about younger people, the quote appears significant in how he understood the impact of dementia. The diagnosis is described as "*practically ending*" a life, suggesting that dementia was experienced as threatening. This highlights how distress could emerge from what dementia was understood to mean for the life still ahead.

These experiences were often not immediately visible and could remain hidden beneath more contained presentations. Bruce began to disclose similar thoughts before moving away from the topic:

> "*Eh, well… dementia that got to me and I was really, really fed up with it you know, and felt like taking… [laughs], eh but now, eh, I know I've got dementia, right, but it's not, I'm not letting it get to me so bad, you know.*" (Bruce)

The unfinished statement appears important. Bruce begins to potentially disclose thoughts of suicide before interrupting himself and laughing, creating distance from what had just been introduced. Rather than remaining with the emotional significance of the disclosure, he quickly shifts towards describing how he was no longer letting dementia affect him "so bad". This suggests that significant distress could remain difficult to express directly, even when participants began to acknowledge it.

Similarly, Gerrard initially described things as manageable before later voicing, "*if it gets to a stage… I'd rather just take a pill*", indicating that he would rather end his life if his condition worsened. Across accounts, distress often emerged gradually rather than being disclosed immediately. This suggests that the absence of visible distress did not necessarily indicate its absence from participants' emotional lives. Distress seemed to arise not only from current difficulties but from anticipation of losses that were expected but had not yet occurred.

Taken together, these accounts suggest that distress was closely connected to experiences of ongoing loss, anticipated decline, and uncertainty about the future. Where grief and loss remained largely unspoken, participants could be left carrying experiences of despair that, at times, extended to thoughts of suicide. Rather than reflecting a single cause, these thoughts appeared to emerge within a broader context of identity disruption, anticipated losses and emotional experiences that were difficult to express, understand, or share with others.

Discussion

This study aimed to explore how people with dementia experience and make sense of grief and loss following a dementia diagnosis. Two Group Experiential Themes (GETs) were developed, offering an in-depth understanding of how participants understood, responded to, and lived with these experiences.

Participants described grief as extending beyond the point of diagnosis and becoming intertwined with the everyday experience of living with dementia. Everyday activities, changing roles, and awareness of future decline repeatedly confronted participants with

what had been lost, meaning that grief was continually reactivated through ordinary daily experiences. Rather than remaining constant, grief appeared to resurface when participants became aware of changes in their abilities or threats to valued aspects of their identity. These findings are consistent with previous qualitative research showing that dementia diagnosis can disrupt identity, independence and continuity of self while introducing uncertainty about the future (Nimmons et al., 2023; Read et al., 2017). Similar experiences of loss and disruption to identity have also been described in people living with other life changing illnesses, including cancer (Aoun et al., 2016), Parkinson's disease (Nehra et al., 2023) and cerebral palsy (Dark et al., 2016). This suggests that some of what participants described may not be specific to dementia, and may not reflect grief alone. However, the current findings extend this literature by suggesting that grief was not simply sustained over time but was repeatedly reawakened through participants' ongoing awareness of change. Rather than representing a single process of adjustment following diagnosis, grief appeared to fluctuate, resurfacing as new losses emerged or previously valued aspects of their sense of self became increasingly threatened.

These ongoing experiences of loss also shaped how participants understood themselves. Accounts of feeling "not myself" and longing to be "the way I was" reflected attempts to reconcile an established sense of identity with the changes brought about by dementia. Meaning Making Theory (Neimeyer, 2001) proposes that following loss, individuals attempt to reconstruct a sense of self and understanding of their world. These findings support this theory by illustrating participants' efforts to integrate dementia into their understanding of themselves. However, they also suggest that meaning making may be particularly challenging in progressive conditions such as dementia, where the losses requiring integration continue to evolve (Menne, et al., 2002). Rather than gradually reconstructing meaning following a single significant event, participants appeared to repeatedly revisit and renegotiate their understanding of themselves as new losses emerged. Consequently, participants' understanding of themselves remained open to continual revision, as each new loss challenged previously established interpretations of who they were and what the diagnosis meant for their lives. Similar efforts to make sense of a threatening diagnosis have been described in people with cancer (Nilsen et al.,

2021), suggesting that questions such as "why me?" may be part of a wider attempt to understand what the diagnosis means.

Participants' accounts also suggested that grief remained difficult to resolve because they were responding not only to losses that had already occurred but also to anticipated losses that had yet to happen. This pattern is consistent with Boss's (2007) concept of ambiguous loss, which describes experiences of loss that lack clear resolution or closure. The theory helps explain why participants' grief remained emotionally present and why losses appeared difficult to fully integrate into their lives (Boss, 2016). However, the present findings also suggest that ambiguity itself was continually recreated as participants encountered new losses and became increasingly aware of future decline. Rather than reflecting a single unresolved loss, participants described living with an evolving experience of loss in which each new change reshaped both what had been lost and what was still feared to come. Fears about the future and thoughts of suicide may also reflect hopelessness, low mood or anxiety, and low mood and anxiety are common in people with dementia (Leung et al., 2021). It is difficult to separate grief from these processes, and it is likely that they overlap.

Despite these ongoing challenges, participants also described actively working to preserve continuity within their lives by maintaining valued roles, routines, relationships and retained abilities. These accounts suggest that participants were not solely preoccupied with loss but were simultaneously attempting to sustain a valued sense of self despite progressive change. This pattern aligns with Stroebe and Schut's (2010) Dual Process Model, which conceptualises grief as an oscillation between loss-oriented and restoration-oriented coping. Although the model provides a useful framework for understanding how participants moved between confronting losses and preserving normality, it was originally developed to explain bereavement following death. The present findings suggest that, in the context of dementia, restoration is not a gradual movement away from grief but an ongoing effort that exists alongside continuing experiences of loss. Rather than progressing towards resolution, participants appeared to move repeatedly between confronting what had changed and investing in aspects of life that continued to provide identity, purpose and connection. These findings are similar to research on adjustment in early dementia, where people have been described as

moving between loss and adaptation (Stockwell-Smith et al., 2019). This suggests that grief may occur alongside adjustment and coping, rather than replacing them, meaning that each may influence the other.

Participants described grief as frequently remaining unrecognised, both within their relationships with others and, at times, in how they related to their own emotional experiences. These findings suggest that recognition played an important role in shaping how participants understood and expressed their grief. Doka's (2010) concept of disenfranchised grief provides a useful framework for understanding these experiences, highlighting how grief may become difficult to express when it is not socially recognised or validated. This may help explain why participants often struggled to openly communicate emotional experiences and why grief frequently remained hidden within their accounts. However, the current findings suggest that participants' accounts may reflect a process of both social and self-disenfranchisement. Participants described not only experiences of external invalidation, but also increasingly regulating, containing, and silencing their own grief. This may indicate that the ways in which others responded to participants' grief shaped not only whether it was openly expressed, but also whether it came to be recognised and acknowledged by participants themselves (Cesur-Soysal & Arı, 2024). This extends Doka's conceptualisation by suggesting that disenfranchisement may operate not only within interpersonal relationships but also within individuals' own meaning-making. Consequently, grief may become increasingly difficult to recognise, validate, and express, leaving participants with fewer opportunities to make sense of their experiences or share them with others. Whilst disenfranchised grief offers a useful way of understanding this silencing, it may also reflect stigma about dementia (Brigiano et al., 2025), not wanting to be a burden, or a wish to cope privately, which may in part relate to participants' age. Disenfranchised grief may therefore be one of several processes shaping what participants felt able to share.

Clinical Implications

This study highlights the importance of recognising grief as a meaningful aspect of the post-diagnostic experience of dementia. Although participants described relatively few

specific sources of support, their accounts suggest that opportunities to have grief recognised, understood, and openly discussed may facilitate adjustment following a dementia diagnosis. Participants described ongoing losses relating to identity, independence, valued roles, and anticipated future decline, yet these experiences were not always acknowledged or explored within relationships or services. Distress was often minimised, left unspoken, or expressed indirectly. Services should therefore ensure that post-diagnostic support provides opportunities for grief and loss to be recognised, discussed, and revisited over time, rather than focusing solely on the practical consequences of dementia. Given the prominence of identity-related losses within participants' accounts, Clinical Psychologists may be particularly well placed to support people with dementia to make sense of changes to their sense of self. Formulation-led, narrative, and meaning-making approaches may help individuals maintain continuity with valued aspects of identity whilst adapting to ongoing change. Given that grief appeared to sit alongside other processes, such as identity change, adjustment and, for some, low mood or anxiety, it may not be helpful to treat grief as a separate difficulty. Instead, support may need to be guided by a formulation of how these processes fit together for each person and how they influence one another.

The findings also highlight the importance of attending directly to psychological distress and suicide risk following diagnosis. Participants described experiences of despair and, at times, thoughts of death or suicide in response to ongoing loss and anticipated decline. These experiences were not always immediately visible and often emerged gradually throughout interviews. This is particularly important given evidence that the period following a dementia diagnosis may be associated with an increased risk of suicide (Medeisyte et al., 2025). Clinicians should therefore routinely explore emotional wellbeing, hopelessness, and thoughts of death as part of post-diagnostic care, in line with Scotland's suicide prevention strategy (Scottish Government, 2022). Clinical Psychologists are well placed to support this through formulation-led approaches, direct intervention, and consultation that enhances staff confidence in recognising and responding to distress.

The findings further highlight the importance of adopting a relational and systemic approach. Participants described how the responses of partners, family members,

friends, and services influenced not only whether grief was expressed, but also whether it came to be recognised and understood by participants themselves. To create environments in which grief can be more openly acknowledged and shared, services should consider involving family members in conversations about grief and adjustment, alongside providing psychoeducation about the emotional as well as cognitive consequences of dementia. This could include explaining that grief, adjustment and low mood are common responses that can occur together, which may make them easier for people to talk about, particularly where stigma makes this difficult (Brigiano et al., 2025). More broadly, increasing public understanding of dementia as a condition associated with meaningful losses and psychological adjustment may help reduce the likelihood that grief remains hidden or unsupported. Similar implications may extend beyond dementia care, particularly in contexts where significant losses are not readily recognised as grief, such as early pregnancy loss (Lang et al., 2011).

Strengths and Limitations

This study offers a novel contribution by providing the first UK-based Interpretative Phenomenological Analysis of how people living with common forms of dementia experience and make sense of grief and loss following diagnosis. IPA enabled an in-depth exploration of participants' meaning making, allowing the analysis to move beyond surface level accounts to capture the complexity of how grief was experienced within everyday life and relationships. This is important as it highlights the need for clinicians to adopt a more interpretative and relational approach to assessment and post-diagnostic support.

The inclusion of people with dementia enhanced inclusivity, relevance and ecological validity, while challenging assumptions about the accessibility of this population within research (Goodman et al., 2011; Taylor et al., 2012). Regular supervision and collaborative analysis of two participant transcripts with field and research supervisors, alongside maintaining an audit trail and reflective diary, enhanced transparency and analytic rigour by supporting the consideration of alternative interpretations of themes and making analytic decisions explicit.

However, several limitations should be acknowledged. The study included only participants with capacity to consent, excluding those with more advanced dementia. This limits insight into how experiences of grief and loss may be understood and expressed at later stages of dementia.

Participants were recruited through Older People's Community Mental Health Teams and were actively engaged with services at the time of recruitment. The study may therefore not capture the experiences of individuals who have disengaged from services, declined support, or experienced barriers to accessing post-diagnostic care.

Finally, the sample was highly homogenous in terms of demographics, which did not represent the diversity in ethnic, cultural and socio-economic backgrounds within the Scottish population. This may limit the extent to which the findings reflect the diversity of people accessing mental health services for dementia and may further exclude already underrepresented populations.

Future Research

Future research should continue to build on the limited evidence exploring grief and loss in the context of dementia. Whilst the present findings suggest that grief is an ongoing process shaped by current and anticipated losses, little is known about how these experiences develop over time. Longitudinal research may therefore provide valuable insight into how grief, adjustment, identity, and emotional wellbeing evolve across the course of dementia.

Further research is required to refine conceptual and theoretical understandings of grief in dementia. Whilst existing frameworks, including ambiguous loss, disenfranchised grief, meaning-making theory, and the Dual Process Model, offer useful insights, the current findings suggest that experiences of grief may involve a complex interplay of identity disruption, anticipated decline, and processes of silencing and self-silencing. Future research should therefore explore whether existing models adequately capture these experiences or whether dementia-specific conceptualisations of grief are required.

Finally, future research should examine how grief is recognised and responded to within dementia services. The present findings suggest that grief often remained unspoken, minimised, or difficult to express, raising questions about how clinicians understand and respond to these experiences in practice (Rupp et al., 2024). Research exploring clinicians' perspectives may help identify barriers to recognising grief and inform training, service development, and intervention design. Future studies should also evaluate approaches that support people with dementia to discuss and make sense of grief and loss within post-diagnostic care.

Conclusion

This study provides an in-depth exploration of how people with dementia experience and make sense of grief within the first year following diagnosis. The findings suggest that grief is a central and ongoing aspect of the post-diagnostic journey, shaped by changes in identity, independence, and anticipated future decline. Rather than being confined to the point of diagnosis, grief was experienced as something repeatedly encountered through participants' everyday experiences of ongoing loss.

Importantly, grief was not always explicitly recognised or expressed. Instead, it was shaped within interpersonal contexts and influenced by how others responded, as well as by how participants related to their own experiences. At times, grief appeared to be minimised, silenced, or unacknowledged. This suggests that grief in dementia may be both socially and self-disenfranchised, limiting opportunities for it to be acknowledged and processed.

These findings extend existing literature by conceptualising grief in dementia as ongoing, relational, and often unspoken, rather than as a response to discrete losses. Clinically, this highlights the importance of recognising forms of grief that may not be directly expressed and of creating psychologically safe spaces where these experiences can be explored. Supporting people to engage with these experiences may help them to make sense of ongoing changes and adapt to shifts in identity over time, contributing to more psychologically informed and person-centred approaches to dementia care. More

broadly, this study highlights the importance of recognising grief as a meaningful psychological response to dementia, rather than an experience that remains hidden, overlooked, or secondary to cognitive decline.

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Appendices

Appendix 1.1: PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	p12
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	p13
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	p17
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	p17
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	p20
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	p19
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	p19, 92
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	p20
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	p21
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	p20
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	p20
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	p21
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	n/a
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	p20

Section and Topic	Item #	Checklist item	Location where item is reported
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	n/a
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	p22, 27, 35
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	p20
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	n/a
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	n/a
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	p21
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	n/a
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	p22
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	p22
Study characteristics	17	Cite each included study and present its characteristics.	p27
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	p37
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	n/a
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	p37
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	n/a
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	n/a
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	n/a
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	n/a
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	n/a
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	p43

Section and Topic	Item #	Checklist item	Location where item is reported
	23b	Discuss any limitations of the evidence included in the review.	p46
	23c	Discuss any limitations of the review processes used.	p46
	23d	Discuss implications of the results for practice, policy, and future research.	p45, 47
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	p18
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	p18
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	n/a
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	n/a
Competing interests	26	Declare any competing interests of review authors.	n/a
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	n/a

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71. This work is licensed under CC BY 4.0. To view a copy of this license, visit https://creativecommons.org/licenses/by/4.0/

Appendix 1.2: Search Terms and Search History (Conducted 4th March 2026)

Systematic Review Search Strategy 4th March 2026

Systematic Review Title: The emotional and psychosocial experiences of driving cessation following a diagnosis of dementia: A qualitative systematic review

PROSPERO link - https://www.crd.york.ac.uk/PROSPERO/view/CRD420251171254.

The databases I will search are:

- *OVID MEDLINE*
- OVID Embase
- OVID PsycInfo
- *EBSCOhost CINAHL - Cumulative Index to Nursing and Allied Health Literature*
- *Web of Science*

Web of Science Core Collection and hand searches of reference lists from relevant papers.

Subject headings:

- Dementia
- Driving (cessation)

The following will also apply:

- Google Scholar will be searched
- Reference list of included papers

Full search strategy is as follows:

Database	**Search Strategy**
Source: MEDLINE(R) ALL <1946 to March 4, 2026> Interface: OVID Search date: 04/03/2026	1 exp Dementia/ 2 Alzheimer Disease/ 3 Dementia, Vascular/ 4 Dementia with Lewy Bodies/ 5 Frontotemporal Dementia/ 6 (dement* or Alzheimer* or "vascular dementia" or "lewy* bod*" or "frontotemporal dementia"). ti, ab, kw.

Retrieved records: 944	7 or/ 1-6 8 Automobile Driving/ 9 Driver License/ 10 Accidents, Traffic/ 11 (driv* adj3 (assess* or abil* or competen* or perform* or safety or continu* or cessation)). ti, ab, kw. 12 (motor adj2 vehicle*). ti, ab, kw. 13 (car or automobile*). ti, ab, kw. 14 or/ 8-13 15 7 and 14 16 limit 15 to English language
Source: Embase <1996 to 2026 Week 09> Interface: OVID Search date: 04/03/2026 Retrieved records: 2,155	1 exp dementia/ 2 exp Alzheimer disease/ 3 exp vascular dementia 4 exp dementia with lewy bodies/ 5 exp frontotemporal dementia/ 6 (dement* or alzheimer* or “vascular dementia” or “lewy* bod*” or “frontotemporal dementia”). ti, ab, kw. 7 or/1-6 8 exp automobile driving/ 9 exp driver license/ 10 exp traffic accident/ 11 (driv* adj3 (assess* or abil* or competen* or perform* or safety or continu* or cessation)). ti, ab, kw. 12 (motor adj2 vehicle*). ti, ab, kw. 13 (car or automobile*). ti, ab, kw. 14 or/ 8-13 15 7 and 14 16 limit 15 to English language 17 limit 15 to humans

Source: APA PsycINFO <1806 to February 2026 Week 3> Interface: OVID Search date: 04/03/2026 Retrieved records: 638	S1 DE "Dementia" OR DE "Alzheimer's Disease" OR DE "Vascular Dementia" OR DE "Lewy Body Dementia" OR DE "Frontotemporal Dementia" OR TI(dement* OR alzheimer* OR "vascular dementia" OR "lewy* bod*" OR "frontotemporal dementia") OR AB(dement* OR alzheimer* OR "vascular dementia" OR "lewy* bod*" OR "frontotemporal dementia") S2 TI(driv* N3 (assess* OR abil* OR competen* OR perform* OR safety OR continu* OR cessation OR decision*) OR car OR automobile* OR "motor vehicle*") OR AB(driv* N3 (assess* OR abil* OR competen* OR perform* OR safety OR continu* OR cessation OR decision*) OR car OR automobile* OR "motor vehicle*") OR DE (Driving OR Automobiles OR Traffic)
Source: CINAHL Interface: EBSCOhost Search date: 04/03/2026 Retrieved records: 317	S1 MH "Dementia" OR MH "Alzheimer's Disease" OR MH "Vascular Dementia" OR MH "Lewy Body Dementia" OR MH "Frontotemporal Dementia" OR TI(dement* OR alzheimer* OR "vascular dementia" OR "lewy* bod*" OR "frontotemporal dementia") OR AB(dement* OR alzheimer* OR "vascular dementia" OR "lewy* bod*" OR "frontotemporal dementia") S2 TI(driv* N3 (assess* OR abil* OR competen* OR perform* OR safety OR continu* OR cessation OR decision*) OR car OR automobile* OR "motor vehicle*")

	OR AB(driv* N3 (assess* OR abil* OR competen* OR perform* OR safety OR continu* OR cessation OR decision*) OR car OR automobile* OR “motor vehicle*”) OR SU(driving OR automobiles OR traffic) Limiters - English Language
Source: Web of Science Interface: ProQuest Search date: 04/03/2026 Retrieved records: 308	S1 TI (dement* OR Alzheimer* OR “vascular dementia” OR “lewy* bod*” OR “frontotemporal dementia”) S2 AB (dement* OR Alzheimer* OR “vascular dementia” OR “lewy* bod*” OR “frontotemporal dementia”) S3 SU (dementia OR Alzheimer*) S4 OR S2 OR S3 S5 TI (driv* NEAR/3 (assess* OR abil* OR competen* OR perform* OR safety OR continu* OR cessation OR decision*) OR car OR automobile* OR “motor vehicle*”) S6 AB (driv* NEAR/3 (assess* OR abil* OR competen* OR perform* OR safety OR continu* OR cessation OR decision*) OR car OR automobile* OR “motor vehicle*”) S7 SU (driving OR automobiles OR traffic) S8 S5 OR S6 OR S7 S9 S4 AND S8 S10 Limit S9 to English Language

Appendix 1.3: Data Extraction Template

Data Extraction Template

General Information
Authors:
Year:
Article Title:
Journal:
Country of Origin:
Source of funding:

Participant Characteristics
Participant group: People with dementia / caregivers / professionals
Dementia type:
Age:
Ethnicity:
Number of participants:

Study Characteristics
Aims/objectives of the study:
Study design:
Data collection:
Qualitative Analysis:

Findings
Clearly identify which participant group contributed to each theme/subtheme:
Number of themes:
Number of subthemes:
Theme 1:
Quotes:
Theme 2:
Quotes:
Theme 3:
Quotes

Study Conclusions:
Conclusions of the study:
Limitations of the study as described by author:
Limitations identified by Trainee:
Quality Assessment: CASP rating

Appendix 1.4: CASP Checklist

Available for download at: CASP Critical Appraisal Skills Programme Checklist for Qualitative Research

Appendix 1.5: Extract of SR reflexive journal entry

During the Screening Process

When I completed the initial screening process, I remember feeling concerned by how few studies appeared to directly address my research question. Given the breadth of the literature on dementia and driving, I had expected to find more first-hand accounts from people with dementia. Instead, I found myself questioning whether I had missed relevant studies or whether my search strategy had been too narrow.

Rather than relying on my own judgement, I discussed these concerns in supervision and arranged to revisit my search strategy with the specialist librarian. We reviewed the search terms together, and I repeated the searches across all databases to reassure myself that I had not overlooked any relevant qualitative studies. Although this did not identify additional eligible papers, it gave me much greater confidence in the rigour of the review.

As I continued screening, I realised the limited number of first-person accounts reflected the evidence base rather than my search strategy. I had noticed a similar pattern during my MRP, where the voices of people with dementia were also relatively underrepresented. Seeing this again made me reflect on how often dementia research relies on the perspectives of others, despite increasing recognition of the importance of lived experience.

This reinforced my decision to prioritise first-person accounts throughout the review whilst recognising that family and professional perspectives could still provide important contextual information. It also reminded me that systematic reviews are not only about identifying evidence but also about recognising whose voices are, and are not, represented within it.

During the Thematic Analysis

As I began coding the included studies, I became aware of how different this felt from analysing my own interview data using IPA. During my MRP, I had conducted the interviews myself and found it easier to hold each participant and their story in mind throughout the analysis. In contrast, I was working with research that I had not conducted myself. Rather than becoming familiar with a small number of participants over time, I needed to move between participants' quotations, the authors' interpretations, and my own developing understanding across multiple studies. At first, this felt like quite a different and uncertain way of working.

I spoke about this in research supervision, where I reflected on my uncertainty about how best to approach the synthesis. Talking this through helped me recognise that thematic synthesis required a different way of engaging with qualitative data rather than trying to apply IPA to published studies. As my confidence developed, I became more comfortable moving between individual studies whilst considering how findings converged and diverged across the evidence base.

Throughout the synthesis, I found myself returning to participants' quotations wherever possible. Having recognised during screening how few studies prioritised the voices of people with dementia, I became increasingly conscious of ensuring that their accounts remained central to my analysis. This experience reminded me of the importance of continually returning to participants' own words to ensure that my developing interpretations remained grounded in their lived experiences whilst drawing together findings across studies.

Appendix 1.6: Thematic Analysis Coding Excerpt - Study No. 4

The table below illustrates how the analysis progressed from the generation of initial codes (drawn from all nine included studies), through the development of descriptive themes, and ultimately toward the analytic themes. The descriptive themes were not intended to map neatly onto the analytic themes; instead, they served as an intermediate step that helped build familiarity with the data. Working at this level supported clearer interpretation and made it possible to develop the final analytic themes.

Quote (participant or author interpretations)	Initial Code	Descriptive Theme	Analytical Theme	Notes
It meant transport, it meant independence, but it was also something about the activity itself that was so important to him… It was his manly activity. (Diana, FM)	independence and identity	Driving as part of identity	Losing the Driver, Losing the Self (Identity and Independence)	Driving much more than transport Part of identity
She turned a lot of her anger on to me, that I had taken the car away and she wouldn't speak to me for months. (Tanya, caregiver)	Anger after stopping driving	Emotional impact of licence loss	Losing the Driver, Losing the Self (Acute Emotional Distress)	Emotional distress Impact on close relationships
You sort of think 'Oh, I wouldn't mind seeing that,' then you realize you can't. (Molly, FM)	Unable to do things independently	Changes to everyday life	Losing the Driver, Losing the Self (A Shrinking World)	Reduced opportunities for day to day life

Oh everybody does it… everybody does that. (Rob, RD, after driving on wrong side of road)	Limited awareness of driving difficulties	Different levels of awareness	Living Beyond Driving Cessation (Awareness of Changes in Driving Ability)	Awareness of driving difficulties
Well you can if you want to or not. That's your decision.' And I said, 'Well okay. Why wait?' (Olive, RD)	Choosing when to stop driving	Remaining involved in decisions	Living Beyond Driving Cessation (Negotiating Autonomy during Driving Cessation)	Importance of being involved in discussions about when to stop driving
He just announced that he felt he should stop. (Dulcie, FM, describing Michael)	Deciding to stop driving	Remaining involved in decisions	Living Beyond Driving Cessation (Negotiating Autonomy during Driving Cessation)	Helped maintain a sense of choice and control.
If people have time to prepare… they're more likely to accept it. (Occupational therapist)	Time to prepare for stopping driving	Acceptance developing over time	Living Beyond Driving Cessation (Acceptance as an Ongoing Process)	Acceptance developed gradually over time

Appendix 1.7: Theme frequency table

Theme	Identity, Loss and Grief			Living Beyond Driving Cessation		
	Identity and Independence	Acute Emotional Distress	A Shrinking World	Awareness of Changes Driving Ability	Negotiating Autonomy during Driving Cessation	Acceptance as an Ongoing Process
Study						
S1 Adler (2010)	Y	Y		Y	Y	Y
S2 Byszewski et al. (2010)	Y	Y	Y	Y		Y
S3 Chacko et al. (2010)	Y	Y	Y			Y
S4 Liddle et al. (2016)	Y	Y	Y	Y	Y	Y
S5 Nixon (2011)	Y	Y	Y		Y	
S6 Scott et al., (2023)	Y	Y	Y	Y	Y	Y
S7 Sanford et al. (2019)	Y	Y			Y	
S8 Stasiulis et al. (2020)		Y			Y	Y
S9 Scott et al. (2020)		Y		Y	Y	

Appendix 2.1: COREQ Checklist

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 32item checklist for interviews and focus groups. International Journal for Quality in Health Care. 2007. Volume 19, Number 6: pp. 349 – 357

Topic	**Item No.**	**Guide Questions/Description**	**Reported on Page No.**
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/ facilitator	1	Which author/s conducted the interview or focus group?	65
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	115
Occupation	3	What was their occupation at the time of the study?	115
Gender	4	Was the researcher male or female?	115
Experience and training	5	What experience or training did the researcher have?	115
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	115
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	115
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	115
Domain 2: Study design			
Theoretical framework			
Methodologica l orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	62
Participant selection			

Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	62
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	62
Sample size	12	How many participants were in the study?	63
Non-participation	13	How many people refused to participate or dropped out? Reasons?	n/a
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	65
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	65
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	63
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	65
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	65
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	65
Field notes	20	Were field notes made during and/or after the interview or focus group?	65
Duration	21	What was the duration of the inter views or focus group?	65
Data saturation	22	Was data saturation discussed?	n/a
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	n/a
Domain 3: analysis and findings			
Data analysis			

Number of data coders	24	How many data coders coded the data?	117
Description of the coding tree	25	Did authors provide a description of the coding tree?	n/a
Derivation of themes	26	Were themes identified in advance or derived from the data?	118, 119, 120
Software	27	What software, if applicable, was used to manage the data?	n/a
Participant checking	28	Did participants provide feedback on the findings?	n/a
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	68, 117
Data and findings consistent	30	Was there consistency between the data presented and the findings?	118, 119, 120
Clarity of major themes	31	Were major themes clearly presented in the findings?	67
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	67

Appendix 2.2: Ethical Approval Letter

Ethical Approval removed due to confidentiality issues.

Appendix 2.3: NHS Scotland Board Approval Letter

NHS Scotland Board Approval Letter removed due to confidentiality issues.

Appendix 2.4: Participant Information Sheet

Available for download: https://osf.io/g7c48

Appendix 2.5: Participant Consent Form

Available for download: https://osf.io/g7c48

Appendix 2.6: Participant Debrief Sheet

Available for download: https://osf.io/g7c48

Appendix 2.7: Participant Debrief Support Information

Available for download: https://osf.io/g7c48

Appendix 2.8: Semi-structured Interview Schedule

Available for download: https://osf.io/g7c48

Appendix 2.9 Reflexivity Statement

Available for download: https://osf.io/g7c48

Appendix 2.10: Reflective Diary Example

Available for download: https://osf.io/g7c48

Appendix 2.11: Detailed Analysis Plan

Available for download: https://osf.io/g7c48

Appendix 2.12: Example of Exploratory Noting

Available for download: https://osf.io/g7c48

Appendix 2.13: Examples of Personal Experiential Themes (PETs)

Available for download: https://osf.io/g7c48

Appendix 2.14: Group Experiential Themes (GETs)

GETs	Ann	Bruce	Charles	Diana	Edward	Frances	Gerrard
***"I'm not who I was":* Living with ongoing loss**							
"*I know I'm not myself*": Painful awareness of change	Yes	Yes	Yes	Yes	Yes	Yes	Yes
"*The cognitive aspects… it doesn't inhibit me"*: Loss beyond memory		Yes	Yes	Yes		Yes	Yes
"*Why me?*": Injustice, uncertainty and fear of the future	Yes		Yes	Yes	Yes		Yes
"*Let's not make a thing of it*": Silencing and unspoken grief							
"*Do you realise what I've got?*": Grief not recognised	Yes	Yes	Yes	Yes	Yes	Yes	Yes
"*Don't make a thing of it*": Silencing and self-silencing	Yes	Yes	Yes	Yes	Yes		Yes
"*I keep thinking that and I don't know why*": Distress and suicidality	Yes	Yes		Yes	Yes		Yes

Yes indicates whether this GET was present in each participants PETs.

Yes indicates illustrative quotes used in the write-up of the results section.

Appendix 2.15: Final Approved MRP Proposal

Final Approved MRP Proposal removed due to confidentiality issues.

Appendix 2.16: Data Availability Statement

The data from this study is not available for sharing due to strict ethical and confidentiality considerations. It contains sensitive, personal information related to participants experiences of grief and loss in relation to their diagnosis of dementia, and participants did not consent to its disclosure beyond the research team. For any queries about the data, please contact the corresponding author.