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# Dementia in rural settings: a scoping review exploring the personal experiences of people with dementia and their carers

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## Abstract

Rural areas tend to be inhabited by more older people and thus have a higher prevalence of dementia. Combined with lower population densities and more sparse geography, rural areas pose numerous barriers and costs relating to support and resource provision. This may leave people with dementia in rural places at a significant disadvantage, leading to a heavy reliance on informal support networks. The present study explores the personal experiences of people living with dementia and carers living in rural areas, seeking to discover both benefits and challenges, as well as recommendations within the literature for improving the lives of those affected by dementia in rural areas. A scoping review following the framework of Arksey and O'Malley identified 60 studies that describe or discuss the personal experience of dementia (either by the person with dementia or carer), in relation to living in rural or remote geographical areas. Four overarching themes were derived, namely the possible benefits of living in a rural community (supportive rural communities), sources of strength described by people affected by dementia in rural areas (managing and coping), detrimental aspects of living in a rural community (rural community challenges) and difficulties with dementia care services. Three further themes yielded recommendations for improving the experience of dementia in rural areas. This review highlights some potential opportunities related to living in rural areas for people living with dementia. These often come with parallel challenges, reflecting a delicate balance between being well-supported and being in crisis for those living in rural areas. Given the limited access to formal services, supporting people with dementia in rural areas requires input and innovation from the people, organisations and services local to those communities.

**Keywords:** dementia; rural; scoping review; lived experience; carer; care-giver

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## Introduction

Dementia is one of the greatest health challenges of our time and in 2012 the World Health Organization (WHO) and Alzheimer's Disease International (ADI) called on governments worldwide to make it a public health priority (WHO and ADI, 2012). People are living longer, and the risk of developing dementia increases with age (although this is not the only risk factor). There are currently around 50 million people living with dementia globally and this number is projected to increase to 132–135 million by 2050 (ADI, 2013; WHO, 2017), concomitantly with the ageing world population.

Worldwide, younger people tend to migrate to urban places, whereas older adults are more likely to live in rural areas (WHO, 2015) which in turn is associated with a higher prevalence of dementia (Russ *et al.*, 2012; Jia *et al.*, 2014; Weden *et al.*, 2018). Not only this, but the lower population density and the geography of rural areas pose additional barriers and costs relating to service and support provision, travel costs and time, and discrepancies in resource allocation (Szymczynska *et al.*, 2011; Palmer *et al.*, 2019). This may leave people with dementia in rural places at a significant disadvantage compared to their urban counterparts, leading to a heavy reliance on unpaid sources of support from family and friends. The international economic cost of dementia was estimated at US \$1.3 trillion in 2019, with on average 50 per cent of these costs being attributable to informal care-giving (WHO, 2021).

National dementia strategies put an emphasis on those facing inequalities in care, including those who live in rural and remote places. For example, in the United Kingdom (UK), the Dementia Action Plan for Wales (Welsh Government, 2018) acknowledges that living with dementia in rural and remote areas is a core area of consideration across the dementia care pathway, particularly as the environment/neighbourhood may support or exacerbate the experience of living with dementia. Internationally, the new dementia strategy for Canada recognises the challenges faced by people living in rural and remote locations as well as those providing services and support and the need for solutions and interventions to be specific to their unique needs (Public Health Agency of Canada, 2019).

The specific issues facing people affected by dementia in rural areas were examined by Innes *et al.* (2011), who reviewed international published scientific literature on dementia care and service provision in rural and remote settings in relation to informal/family care-giving. Twenty-six papers were included in their synthesis, with considerable variation in how rurality was defined, including standardised classifications, definitions developed by researchers, as well as general descriptions (e.g. 'rural'). The majority of the studies focused on the experience, use and barriers to formal service provision (15 papers), with limited attention given to the education and support needs of carers (six papers), and a 'remarkable lack of consideration' (Innes *et al.*, 2011: 44) given to personal, carer experiences (five papers). The review included studies reporting low service availability and inappropriate services in rural areas, as well as other factors affecting both formal and informal support, such as a lack of awareness of what is available, a lack of dementia awareness and education, geographical distance and transport issues, lack of privacy and stigma. There were some conflicting findings around obligation to care, with

care-giving being perceived as a family duty in some rural areas, whereas in another study rural carers felt less obliged than urban carers to provide care. Some perceived benefits of living in a rural area were also reported, such as support from extended family and the wider community, and personal relationships with health-care providers. The authors draw attention to the need for more research about the impact of rurality on care-giving and the needs of rural informal family carers and conclude:

Rural areas globally have aging populations that will require adaptable solutions to their local context. However, to date there is insufficient information available to develop rural dementia care services that support the person with dementia and their family carers. (Innes *et al.*, 2011: 45)

Ten years on, Bayly *et al.* (2020) published a review addressing the gap in the literature around education and support needs, putting a specific focus on service needs, accessibility and use in rural areas for both carers and people living with dementia. Evidence was sought from studies of people affected by dementia, service providers and interventions between 1997 and 2017, finding that most rural areas were not equipped to provide sufficient services to people affected by dementia.

The Alzheimer's Society indicates a notable absence of contemporary research and knowledge about the impact of dementia in rural Wales and that 'without better data it will be impossible to tackle' (Alzheimer's Society, 2016: 9), rendering policy solutions difficult to formulate. While service and education availability and needs are certainly an important factor to consider in their impact on people with dementia in rural areas, this may not paint the whole picture of the challenges and benefits of living in such areas. The present study pays attention to the limited evidence around the personal experiences of rural carers highlighted by Innes *et al.* (2011), but importantly extending to also incorporate the personal experiences and perceptions of people living with dementia themselves. A decade later, it is timely to discover to what extent this gap in the literature has been addressed, and how any new evidence may contribute to supporting people living with dementia in rural areas.

### **Aim of this review**

This paper explores the personal experiences of people affected by dementia in rural places. It will update the findings of informal family carers conducted by Innes *et al.* (2011) and identify further research that focuses on the personal experiences of the person living with dementia. Specifically, it will undertake a scoping review to map the research in this area systematically. The following research question was formulated:

- What is known from the literature about the personal experiences of people affected by dementia (carers and those living with the condition) who live in a rural area?

### **Methods**

#### **Study design**

A scoping review followed the framework of Arksey and O'Malley (2005), comprising five stages: identifying the study purpose; study identification; screening

process; data extraction; and collating, summarising and reporting results. The PRISMA-ScR checklist was followed to ensure clarity of reporting (Tricco *et al.*, 2018). The approach of a scoping review enables a broad range of literature to be captured, including all types of study design. As the purpose is to provide an overview of the research, sources of evidence are not critically appraised and their quality assessed as in a systematic review. However, the reviewers critically appraised the findings of the included papers to ensure the authors' interpretation represents the data presented. The team developed a protocol as a working document to guide the review process.

### **Study identification**

A comprehensive search of the literature was conducted from inception to 19 February 2019, updated 17 April 2020 and 14 July 2021. Databases searched were Applied Social Science Index and Abstracts (ASSIA), Cumulative Index to Nursing and Allied Health Literature (CINAHL PLUS), Proquest, PsycINFO, MEDLINE and the Cochrane Library. Searches of titles and abstracts were undertaken by JRR, using combinations of the following terms: (dement\* OR Alzheimer\* OR memory problem\*) AND (rural OR remote OR countryside).

### **Screening**

#### *Inclusion criteria*

Peer-reviewed journal articles of empirical research were included that describe or discuss the personal experience of dementia (either by the person with dementia or carer), in relation to living in rural or remote geographical areas. No *a priori* definitions were specified for 'rural' or 'remote' and the review sought studies where the authors clearly identified these aspects as the setting for their work, either by being explicit in their description that the research took part in a rural area or by providing an official definition of 'rural'. All types of study designs were considered except for previous literature reviews. 'Grey literature' was included if the report/article was publicly available (*e.g.* from a website) and presented primary research. The time-scale for inclusion of papers was: (a) literature on carers from 2010 (to update the findings of Innes *et al.*, 2011) and (b) no time restriction for literature on people living with dementia, to capture any work potentially not found in the systematic review by Innes *et al.* (2011).

#### *Exclusion criteria*

Articles were excluded at title/abstract screening if they were not published in English (English being the language available to the authors), non-human participants; molecular/cellular-focused research; not focused on carers or people living with dementia; drug trials; about any condition other than dementia (*e.g.* obesity, schizophrenia, epilepsy, depression); focused on professionals/paid carers/service providers (due to being focused on the lived experiences of people personally affected by dementia); the location is clearly not related to rural or remote places. At full-text reviewing, articles were excluded if they did not describe the first-hand experience of rural living/caring; if the data were the perceptions of service providers; intervention or service effectiveness studies; non-empirical research

(*e.g.* commentaries, editorials, book reviews or opinion pieces); dissertation studies if they were presented elsewhere within peer-reviewed journal articles.

### **Study selection**

Titles and abstracts were screened by JRR and a random sample of 10 per cent checked by AS. Full-text screening (N = 149) was carried out by JRR, AS and AG, with 80 per cent agreement regarding inclusion/exclusion. Discrepancies (20%) were discussed before making a final decision.

### **Data charting**

A data extraction document was developed by the lead author. This captured publication information (authors, year and country); study design (objectives, method and participants); descriptive information (*e.g.* definition of rural); key findings relating to living with dementia in a rural area; and lessons learned from their research as reported by authors of the included papers. This was first piloted where JRR and AS independently reviewed and extracted data for three studies. These were then compared and discussed, with a high degree of accuracy reported. Following agreement, papers were sorted alphabetically, divided equally between JRR and AS, and reviewed independently. Following the data extraction by JRR and AS, GW independently reviewed each individual study and the corresponding extraction to verify accuracy, completeness and to minimise potential for bias. The lead author also later revisited all papers for additional quality assurance. Minor amendments were recorded, and the table updated.

### **Collation, summarising and synthesis**

Thematic analysis of the extracted data was performed by JRR, guided by Braun and Clarke (2006). Data pertaining to the personal experience of living in a rural area by people living with dementia and/or carers were extracted. Initially, a deductive thematic analysis approach was undertaken using the preconceived overarching categories 'opportunities' and 'challenges' in relation to the research question, in order to identify aspects of rural living that may be beneficial and supportive and/or detrimental and unhelpful. Themes were then generated taking an inductive approach via an iterative process of reading, generating initial codes, re-reading, reviewing and refining (through discussions between JRR and GW). Reflecting the iterative process of the review, discussions within the review team suggested that there was an opportunity to identify some of the solutions and recommendations made by the authors of the included papers in relation to the challenges and opportunities identified. A further category, 'lessons learned', was used to identify suggestions within the included papers for future care provision. Further consideration of the analysis led to some of the themes initially considered under the 'opportunities' category to be represented by a more appropriate overarching theme 'coping and managing'. Similarly, 'lessons learned' are reframed under the overarching theme 'improving the experience of dementia in rural areas'. A narrative synthesis of the data is presented below.

## Results

Database searches yielded 4,286 records, reduced to 2,053 after removal of duplicates. From title and abstract screening, 149 studies were identified as being potentially relevant and were screened in full-text and an additional two peer-reviewed articles and three publicly available reports were also included. After full-text screening, 60 articles were included: 30 qualitative, 20 quantitative and ten mixed-methods studies. [Figure 1](#) visualises the process, including the reasons for exclusion.

Table S1 in the online supplementary material provides an overview of the study characteristics (including full reference citation, study objectives, methods, participants, definition of rural or remote, and findings relating to the research question regarding the personal experience of living with dementia in rural places). The highest number of studies was from Canada (N = 18), followed by the United States of America (USA; N = 13), Australia (N = 8), the UK (N = 8), Sweden (N = 2), Austria (N = 2), Uganda (N = 2), Germany (N = 2). and one study from

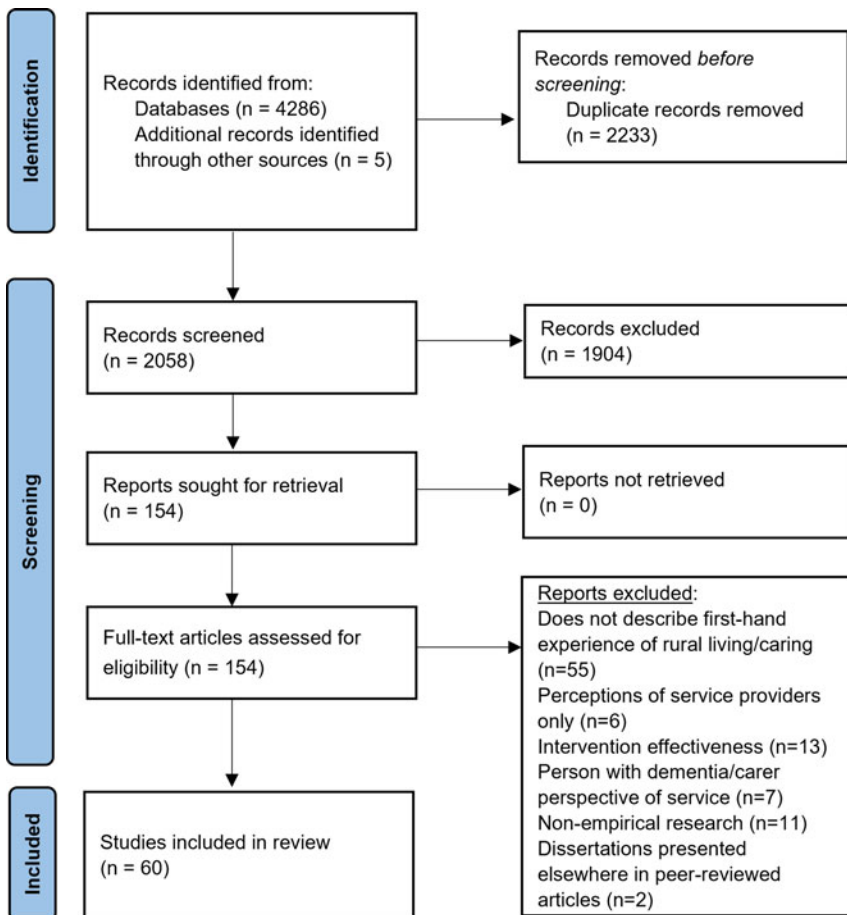


Figure 1. A PRISMA flow diagram of the exclusion process.

Mexico, China, Tanzania, Italy and Ireland. The majority of the studies were qualitative and cross-sectional. Study participants were primarily carers (N = 34; with nine of these also including interviews with service providers or community members) or both carers and people with dementia (N = 22), with some of these (N = 11) also including service providers. Data from service providers or community members were not extracted. Only four studies focused on the person living with dementia alone (Innes *et al.*, 2003; Wu *et al.*, 2018; Hicks *et al.*, 2021; Müller *et al.*, 2021).

There is a lack of cultural diversity both within and between studies. Ethnicity information was provided in 13 studies. Of these, nine were directly interested in the experiences of people with dementia/carers by race/ethnicity (Kaufman *et al.*, 2010; Sun *et al.*, 2010a, 2010b; Smith *et al.*, 2011; Saunders, 2013; Xie *et al.*, 2018; Cox *et al.*, 2019; Yahalom, 2019; Disbrow *et al.*, 2021). The remaining four disclosed that the samples included a high percentage (almost all) of Caucasian participants.

The majority of studies do not disclose the type of dementia diagnosed (N = 44). Alzheimer's disease was the most frequently reported diagnosis among study participants, with six papers explicitly focusing on experiences with diagnoses of Alzheimer's disease and in papers that reported multiple diagnoses (N = 10) Alzheimer's disease was consistently the most frequent (N = 9 papers). Other diagnoses included mild cognitive impairment (N = 6 papers), frontotemporal dementia (N = 4 papers), Lewy body dementia (N = 3 papers), vascular dementia (N = 4 papers), young onset (N = 1 paper), and frontotemporal dementia and primary progressive aphasia (N = 1 paper).

No detailed definition of rural was provided in over half of the studies (N = 31). For those that did define rural, definitions were made by distance from urban/population centres (N = 7), population density/populations of less than a defined number (N = 8), both distance from urban centre and population information (N = 5), rural-urban commuting area codes (N = 2), US Census Bureau definition (N = 2) and other definitions (N = 5; *see* Table S1 in the online supplementary material).

Figure 2 visualises the themes derived from the analysis. Two themes reflected possible benefits of living in a rural community: 'the person living with dementia continuing to contribute', reflecting the opportunities for ongoing activity; and 'support from the wider community', reflecting the potential cohesion within a rural community. 'Coping and managing' includes sources of strength described by people affected by dementia in rural areas, including 'support from family and friends', 'signs of resilience', 'strength through religion' and 'the internet'. Detrimental aspects of living in a rural community included 'the risk of isolation', 'the impact of stigma', 'carer distress', 'the financial impact' and challenges with 'the physical environment'. A further overarching theme, 'difficulties with dementia care services', included five sub-themes: 'diagnosis difficulties', 'complex care systems', 'lack of provision affecting continuity of care', 'transport and travelling' and 'language and cultural sensitivity'. Three themes reflected improving the experience of dementia in rural areas: 'involving people affected dementia', 'provision of services that are fully person-centred' and 'improving education and awareness for professionals and public'.

Table 1 summarises the findings of the analysis according to the themes (and sub-themes), noting which studies provide evidence in support of each theme.

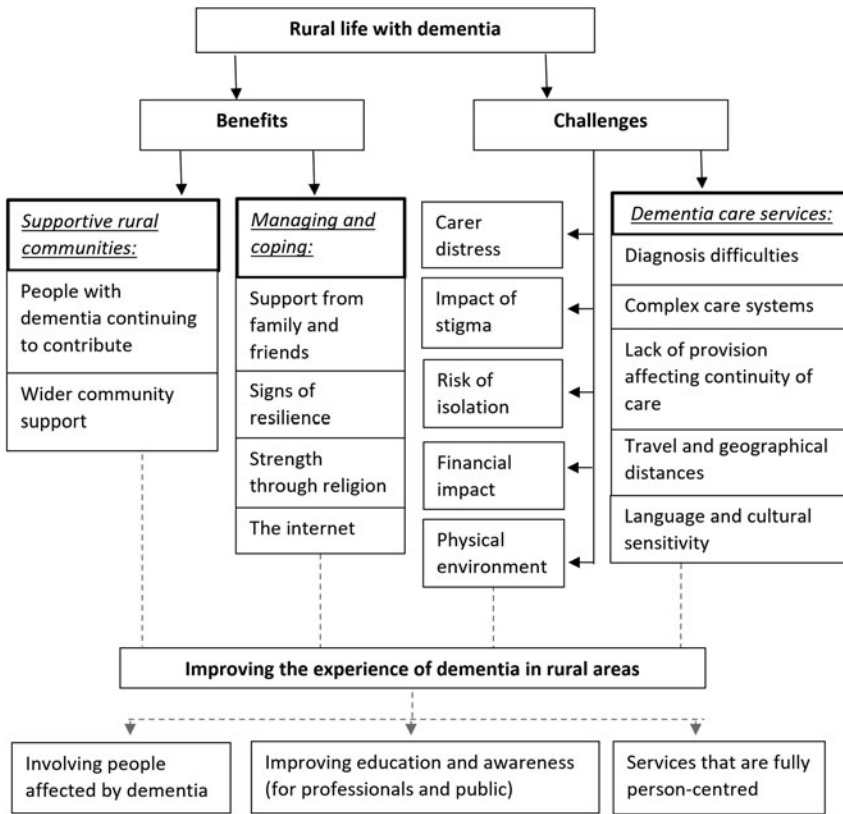


Figure 2. A visual representation of findings.

### **Rural communities as beneficial and supportive**

#### *Continuing to contribute*

Thirteen studies reflected the theme 'continuing to contribute' (see Table 1). Continuing with normal activities, keeping busy or being useful is important for people with dementia in rural places. In the earlier stages of dementia, people still have goals that they want to achieve and wish to contribute to their communities by participating in activities, including being productive and working. People with dementia wish to be included, to be enabled to do what they can and do what they enjoy.

#### *Support from the wider community*

Familiarity and being known in a community is described as supportive, with people looking out for the person with dementia and offering either practical or emotional support if needed (Innes *et al.*, 2003; Clarke and Bailey, 2016; von Kutzleben *et al.*, 2016; Wiersma and Denton, 2016; Herron and Rosenberg, 2017). This is at least up to the point where symptoms progress to a stage where they become perceived as 'anti-social' (e.g. hallucinations, abusive behaviours, wandering, incontinence; Forbes *et al.*, 2011) or 'publicly confronting' (Orpin *et al.*, 2014).



**Table 1.** Themes and sub-themes derived from the thematic analysis

Themes and sub-themes	Studies
Rural communities as beneficial and supportive:	
People with dementia continuing to contribute:	
Continuing with normal activities, keeping busy or being useful is important for people with dementia	Innes <i>et al.</i> (2003); Forbes <i>et al.</i> (2011, 2018); Herron <i>et al.</i> (2016); Wiersma and Denton (2016); Alzheimer's Society (2017); Herron and Rosenberg (2017); Kelly and Yarwood (2018); Chisholm and Bischofing (2019); Cox <i>et al.</i> (2019); Gibson <i>et al.</i> (2019); Nankinga <i>et al.</i> (2020); Müller <i>et al.</i> (2021)
Support from wider community:	
Being known in a community is supportive, with people looking out for the person with dementia and offering practical or emotional support if needed	Innes <i>et al.</i> (2003); Clarke and Bailey (2016); von Kutzleben <i>et al.</i> (2016); Wiersma and Denton (2016); Herron and Rosenberg (2017)
A sense of safety for the person with dementia and carer through being known, increased community awareness and less stigma	Gilmour (2004); Burgener <i>et al.</i> (2015); Di Gregorio <i>et al.</i> (2015); Clarke and Bailey (2016); Wiersma and Denton (2016); Hicks <i>et al.</i> (2021)
Communities supportive until behaviours of people with dementia perceived as 'anti-social' or 'publicly confronting'	Forbes <i>et al.</i> (2011); Orpin <i>et al.</i> (2014)
Appreciation of support groups or memory cafes, when available and accessible, providing the opportunity to share experiences with others who understand	Innes <i>et al.</i> (2014); Herron and Rosenberg (2017, 2019); Forbes <i>et al.</i> (2018); Gibson <i>et al.</i> (2019); Saunders and Groh (2020); Hicks <i>et al.</i> (2021)
Managing and coping:	
Support from family and friends:	
One of the key approaches to coping and resources of successful care-giving	Vellone <i>et al.</i> (2012); Ehrlich <i>et al.</i> (2015); Branger <i>et al.</i> (2016a); Gibson <i>et al.</i> (2019); Saunders and Groh (2020)
Rural carers found it easier to get help from family and friends, and a stronger sense of 'togetherness' than urban carers	Ehrlich <i>et al.</i> (2015, 2017)
Societal roles in certain cultures expecting family to care for people with dementia	Smith <i>et al.</i> (2011); Dotchin <i>et al.</i> (2014); Cox <i>et al.</i> (2019); Yahalom (2019); Nankinga <i>et al.</i> (2020)

(Continued)

**Table 1.** (Continued.)

Themes and sub-themes	Studies
High levels of support, satisfaction with support and openness within families	Kaufman <i>et al.</i> (2010); Forbes <i>et al.</i> (2012, 2013); Orpin <i>et al.</i> (2014); von Kutzleben <i>et al.</i> (2016)
People with dementia appreciate and prefer support provided by family	Innes <i>et al.</i> (2003); Alzheimer's Society (2017); Nankinga <i>et al.</i> (2020)
Signs of resilience:	
Satisfaction, emotional closeness, family bonding from care-giving, linked to quality of life	Vellone <i>et al.</i> (2012); Ehrlich <i>et al.</i> (2015, 2017); Krutter <i>et al.</i> (2020)
Carer life satisfaction related to social support	Kaufman <i>et al.</i> (2010)
Better carer mental health irrespective of the symptoms of the person with dementia in rural areas	Alhasan <i>et al.</i> (2021)
Strength through religion:	
Religiosity: a key coping mechanism, linked to lower carer burden	Sun <i>et al.</i> (2010a, 2010b); Branger <i>et al.</i> (2016a); Gibson <i>et al.</i> (2019); Saunders and Groh (2020)
The internet:	
The internet as an important source of information and support	Forbes <i>et al.</i> (2012, 2018); Xie <i>et al.</i> (2018); Gibson <i>et al.</i> (2019); Saunders and Groh (2020)
Rural community challenges:	
Carer distress:	
Carers committed to supporting the person with dementia to remain at home, often despite high physical and emotional costs	Alzheimer's Australia (2007); Forbes <i>et al.</i> (2011, 2018); Ehrlich <i>et al.</i> (2015); Wertz <i>et al.</i> (2015); Herron and Rosenberg (2017, 2019); Kelly and Yarwood (2018); Ainamani <i>et al.</i> (2020); Saunders and Groh (2020); Walsh <i>et al.</i> (2021)
No rural-urban differences on burden, distress, grief, worry, loneliness	O'Connell <i>et al.</i> (2013); Branger <i>et al.</i> (2016b); Ehrlich <i>et al.</i> (2017)
Carer burden related to unmet service needs	Li <i>et al.</i> (2012)
Lack of informal support increases likelihood of carer burden, dissatisfaction and family conflict	Sun <i>et al.</i> (2010a); Krutter <i>et al.</i> (2020)
Behavioural and psychological symptoms of dementia related to carer burden	Heggie <i>et al.</i> (2012); Ervin <i>et al.</i> (2015); Stewart <i>et al.</i> (2016); Yang <i>et al.</i> (2019)

Impact of stigma:	
People with dementia refrain from sharing their diagnosis or reluctant to seek help, due to the stigma associated with it and fears of people in the rural community talking about them	Forbes <i>et al.</i> (2012, 2013, 2018); Saunders (2013); Wiersma and Denton (2016); Herron and Rosenberg (2017); Bauer <i>et al.</i> (2019); Cox <i>et al.</i> (2019)
Feeling excluded and hurt, losing friends, people visiting less	Innes <i>et al.</i> (2003); Alzheimer's Australia (2007); Forbes <i>et al.</i> (2011); Vellone <i>et al.</i> (2012); Clarke and Bailey (2016); Alzheimer's Society (2017); Chisholm and Bischofing (2019); Hicks <i>et al.</i> (2021)
Risk of isolation:	
Some rural carers report more feelings of abandonment, limited support and isolation from family members, particularly if they do not live nearby	Alzheimer Australia (2007); Ehrlich <i>et al.</i> (2015); Herron and Rosenberg (2019); Saunders and Groh (2020)
Lack of transport can affect social isolation for people with dementia	Alzheimer's Society (2017)
Financial impact:	
High cost and financial burden of living in a rural area	Smith <i>et al.</i> (2011); Saunders (2013); Ehrlich <i>et al.</i> (2015); Gibson <i>et al.</i> (2019); Ainamani <i>et al.</i> (2020); Saunders and Groh (2020)
More financial difficulty in some populations (African Americans and Hispanics compared to white Americans)	Kaufman <i>et al.</i> (2010); Xie <i>et al.</i> (2018)
People with dementia in deprived areas have a decreased ability to live well	Wu <i>et al.</i> (2018)
The physical environment:	
The rural environment can become dangerous as symptoms progress	Forbes <i>et al.</i> (2011); Kelly and Yarwood (2018); Hicks <i>et al.</i> (2021)
Difficulties with dementia care services:	
Diagnosis difficulties	
Difficulties obtaining a diagnosis, limited access to specialists in rural areas, and diagnosis depending on the skills and knowledge of primary care providers/GPs	Saunders (2013); Dal Bello-Haas <i>et al.</i> (2014); Morgan <i>et al.</i> (2014); Orpin <i>et al.</i> (2014); Di Gregorio <i>et al.</i> (2015); Stewart <i>et al.</i> (2016); Prorok <i>et al.</i> (2017); Bauer <i>et al.</i> (2019)
GPs accessible and supportive, but information and support post-diagnosis not tailored for rural areas	Innes <i>et al.</i> (2014); Alzheimer's Society (2017)

(Continued)

**Table 1.** (Continued.)

Themes and sub-themes	Studies
Feelings of relief from dyads or carers upon obtaining the diagnosis	Morgan <i>et al.</i> (2014); Mattos <i>et al.</i> (2018)
Complex care systems:	
People finding it difficult to navigate the system to receive appropriate care	Saunders (2013); Ervin and Reid (2015); Prorok <i>et al.</i> (2017); Kelly and Yarwood (2018); Herron and Rosenberg (2019)
People struggling to cope and unaware of available support	Alzheimer's Australia (2007); Smith <i>et al.</i> (2011); Di Gregorio <i>et al.</i> (2015)
Underutilisation of services related to behavioural and psychological symptoms of people with dementia	Ervin and Reid (2015); Krutter <i>et al.</i> (2022)
Lack of provision affecting continuity of care:	
A lack of resources restricts the quality and quantity of community-based services	Forbes <i>et al.</i> (2011, 2012); Dal Bello-Haas <i>et al.</i> (2014); Di Gregorio <i>et al.</i> (2015); Herron <i>et al.</i> (2016); Herron and Rosenberg (2017, 2019); Gibson <i>et al.</i> (2019); Saunders and Groh (2020); Walsh <i>et al.</i> (2021)
Unmet needs related to increased carer burden, and decreased quality of life	Alzheimer's Australia (2007); Li <i>et al.</i> (2012); Vellone <i>et al.</i> (2012)
Travel and geographical distances:	
People with dementia having to travel to urban centres or significant distances to access appropriate services, support groups and formal care	Alzheimer's Australia (2007); Saunders (2013); Innes <i>et al.</i> (2014); Di Gregorio <i>et al.</i> (2015); Herron <i>et al.</i> (2016); Mattos <i>et al.</i> (2018); Gibson <i>et al.</i> (2019); Hicks <i>et al.</i> (2021)
Home care staff travelling long distances resulting in shortened and fewer visits	Forbes <i>et al.</i> (2012); Herron and Rosenberg (2019)
High cost of fuel and lack of public transport affects access to services	Smith <i>et al.</i> (2011)
Language and cultural sensitivity:	
Culture or traditions in rural places should be taken into account	Sun <i>et al.</i> (2010b); Smith <i>et al.</i> (2011); Vellone <i>et al.</i> (2012); Forbes <i>et al.</i> (2013); Saunders (2013); Dotchin <i>et al.</i> (2014); Alzheimer's Society (2017); Xie <i>et al.</i> (2018); Chisholm and Bischooping (2019); Cox <i>et al.</i> (2019); Yahalom (2019); Disbrow <i>et al.</i> (2021)

Improving the experience of dementia in rural areas:	
Involving people affected by dementia:	
Preserving a sense of normality by continuing with long-term friendships and activities is important for people with dementia and carers; also opportunities to connect with peers	Innes <i>et al.</i> (2003); Forbes <i>et al.</i> (2011, 2018); Gibson <i>et al.</i> (2019)
People with dementia should be enabled to do the things they enjoy	Herron <i>et al.</i> (2016); Alzheimer's Society (2017)
People with dementia in rural places should be actively involved in decisions that affect their lives, including service development and improvement	Innes <i>et al.</i> (2003); Forbes <i>et al.</i> (2011, 2012, 2013); Morgan <i>et al.</i> (2014); Herron <i>et al.</i> (2016); Krutter <i>et al.</i> (2020)
Services that are fully person-centred:	
Appropriate services should be based on the opinions, wishes and plans of the people that they are for, and should enhance their existing resources	Innes <i>et al.</i> (2003); Forbes <i>et al.</i> (2011, 2012); Ehrlich <i>et al.</i> (2015, 2017); Clarke and Bailey (2016); Gibson <i>et al.</i> (2019); Hicks <i>et al.</i> (2021)
Policy should address the unique rural needs, ensuring informal support does not replace formal services	Forbes <i>et al.</i> (2011); Dal Bello-Haas <i>et al.</i> (2014); Wiersma and Denton (2016)
To meet the needs of people with dementia, services should work to reduce carer burden in rural places	Heggie <i>et al.</i> (2012); Li <i>et al.</i> (2012); Werntz <i>et al.</i> (2015); Ainamani <i>et al.</i> (2020)
Improving education and awareness (for professionals and public):	
Rural GPs should be trained to detect, diagnose and support people with dementia	Forbes <i>et al.</i> (2012); Saunders (2013); Morgan <i>et al.</i> (2014); Alzheimer's Society (2017)
Education should be available to people with dementia to help prepare	Di Gregorio <i>et al.</i> (2015)
Education, training and courses should be available to carers, to help them prepare, and to enhance their skills in providing the best care possible	Alzheimer's Australia (2007); Saunders (2013); Innes <i>et al.</i> (2014); Werntz <i>et al.</i> (2015); Alzheimer's Society (2017); Bauer <i>et al.</i> (2019); Cox <i>et al.</i> (2019); Gibson <i>et al.</i> (2019); Krutter <i>et al.</i> (2020); Bardach <i>et al.</i> (2021)
Dementia support groups and educative sessions about dementia should be promoted to increase awareness and acceptance, and reduce stigma in rural places	Forbes <i>et al.</i> (2013, 2018); Morgan <i>et al.</i> (2014); Di Gregorio <i>et al.</i> (2015); Herron and Rosenberg (2017); Bauer <i>et al.</i> (2019)

(Continued)

Table 1. (Continued.)

Themes and sub-themes	Studies
Promotion of support groups and educative sessions in rural places by using online or video technology	Alzheimer's Australia (2007); Saunders (2013); Xie <i>et al.</i> (2018); Bauer <i>et al.</i> (2019); Gibson <i>et al.</i> (2019); Saunders and Groh (2020); Bardach <i>et al.</i> (2021)
Promotion of support and educative sessions in rural places by other means (social workers, media campaigns, Dementia-friendly Communities)	Li <i>et al.</i> (2012); Vellone <i>et al.</i> (2012); Alzheimer's Society (2017)
Educate service staff about dementia, carer burden, locally available resources and elder abuse	Forbes <i>et al.</i> (2011); Smith <i>et al.</i> (2011); Innes <i>et al.</i> (2014); Ervin and Reid (2015)
Involve, educate and train church leaders about dementia	Sun <i>et al.</i> (2010b); Nankinga <i>et al.</i> (2020)
Make use of resources in rural communities (e.g. halls) to provide support and activities	Saunders (2013); Alzheimer's Society (2017)

Note: GP: general practitioner.

Knowing everyone within a community can lead to a sense of safety for the person with dementia and their carer (Gilmour, 2004; Clarke and Bailey, 2016; Hicks *et al.*, 2021), even to the extent of communities having informal systems of monitoring people with dementia (Wiersma and Denton, 2016). A study in Canada discovered although understanding of dementia as a condition was minimal within rural communities, there was an increased awareness when a member of the community was struggling with their cognition (Di Gregorio *et al.*, 2015). Caring for people with dementia was a community responsibility, providing them with support that enabled them to remain at home for as long as possible. This type of community awareness is given as an explanation by Burgener *et al.* (2015) for people with dementia living in rural settings being less susceptible to the effects of perceived stigma than those in urban places.

Appreciation of support groups or memory cafes is described in some studies, when they were available and accessible (Innes *et al.*, 2014; Herron and Rosenberg, 2017, 2019; Forbes *et al.*, 2018; Gibson *et al.*, 2019; Saunders and Groh, 2020; Hicks *et al.*, 2021), providing the opportunity to share experiences with others who understand their situation (Forbes *et al.*, 2018; Herron and Rosenberg, 2019; Saunders and Groh, 2020).

## **Managing and coping**

### *Support from family and friends*

Eighteen studies describe the importance of support from family and friends (see Table 1). Family and friends are a key resource for rural care-giving and coping (Vellone *et al.*, 2012; Ehrlich *et al.*, 2015; Branger *et al.*, 2016a; Gibson *et al.*, 2019; Saunders and Groh, 2020) and rural carers found it easier to get help from family and friends than urban carers (Ehrlich *et al.*, 2015).

More recent work aimed to better understand approaches to care-giving, comparing rural and urban settings (Ehrlich *et al.*, 2017). They again found family and friends to be important, irrespective of the geographical setting. However, carers from rural areas were more accepting of care-giving challenges, attempting to maintain a sense of normality, whereas in urban areas care-giving was viewed more as an obligation. Rural carers talked about themselves being part of a family or couple, with a stronger sense of 'togetherness'.

Dotchin *et al.* (2014) reported lower carer burden scores in the rural Hai district of Tanzania in carers of people with dementia as compared to Parkinson's disease, suggesting this may be due to dementia being considered a normal part of ageing in Hai and societal roles expecting younger family members to care for older people. Similarly, some Aboriginal families feel responsibility to care for people with dementia, and to maintain connections to culture (Smith *et al.*, 2011; Cox *et al.*, 2019), and Nankinga *et al.* (2020) reports families consistently stepping in to care for people with dementia in south-western Uganda. This is consistent with findings reported in Innes *et al.* (2011) where care-giving was seen as a family duty in Japan, highlighting the impact of cultural values and societal roles on uptake of both informal and formal dementia care.

People with dementia in rural areas appreciate the support provided by family (Innes *et al.*, 2003; Alzheimer's Society, 2017; Nankinga *et al.*, 2020). It allows

them to maintain a social life, keep up meaningful activities and, in some instances, to remain at home (Innes *et al.*, 2003; Nankinga *et al.*, 2020). In Wales, people with dementia were more positive about their care and support when provided by a family or friend support network as opposed to formal sources of support, and some carers noted they were comfortable providing personal care (Alzheimer's Society, 2017).

### *Signs of resilience*

Some carers are fortunate to experience positive aspects of care-giving. A recent study found better mental health in rural as opposed to urban carers, irrespective of the symptoms of the person with dementia (Alhasan *et al.*, 2021). This is supported in part by Ehrlich *et al.* (2015) who found carers to be highly satisfied with caring for a relative with dementia, despite the major limitations of care-giving on their daily lives, although this was true in both urban and rural areas. Other studies report relationships between life satisfaction and quality of life (Vellone *et al.*, 2012) and social support (Kaufman *et al.*, 2010) by rural carers.

Although many aspects of carer burden are expressed by family carers, they also describe rewarding aspects such as emotional closeness (Ehrlich *et al.*, 2017), strong family cohesion, the opportunity to give something good back to the person with dementia, noticing expressions of gratitude from them, knowing that care at home is what the person would prefer, and the acquisition of new knowledge and skills to better cope with the situation (Krutter *et al.*, 2020).

### *Strength through religion*

Religion is a frequently used coping mechanism for rural carers (Sun *et al.*, 2010a, 2010b; Branger *et al.*, 2016a; Gibson *et al.*, 2019; Saunders and Groh, 2020). Supporting findings from Innes *et al.* (2011), religiosity has been associated with lower carer burden in African American than white rural carers (Sun *et al.*, 2010b). The authors suggest that religious involvement provides spiritual and social benefits to carers, being particularly important in rural locations where access to formal services is scarce.

### *The internet*

The internet has been reported as an important source of information and support to people affected by dementia in rural areas, particularly in more recent years (Forbes *et al.*, 2012, 2018; Xie *et al.*, 2018; Gibson *et al.*, 2019; Saunders and Groh, 2020). For example, online resources such as websites and social media platforms were used by rural widows for information and support, both during care-giving years and thereafter (Saunders and Groh, 2020). However, this is not always the case, with one study finding that no rural carers had used the internet for support, for reasons such as lack of computer use, access or awareness of available online resources (Disbrow *et al.*, 2021).

## **Rural community challenges**

### *Carer distress*

It is well recognised that many carers are committed to supporting the person with dementia to remain at home for as long as possible, despite high physical and



emotional costs to themselves, which is echoed in 11 studies in this review (see Table 1). Walsh *et al.* (2021) found lower community care costs and lower rates of admission to long-term care in rural as opposed to urban areas, but this was attributed to families providing high levels of care with little support from the government. Carer burden has been linked to unmet needs from formal services (Li *et al.*, 2012) as well as to a lack of informal support (Sun *et al.*, 2010a; Krutter *et al.*, 2020) in rural areas. However, explorations of rural–urban differences found no effect of rurality on burden, distress, worry, frustration and loneliness (O’Connell *et al.*, 2013; Branger *et al.*, 2016b; Ehrlich *et al.*, 2017). O’Connell *et al.* (2013) suggest the lack of rural–urban difference may be linked to rural carers depending more on informal support to substitute for the services that are lacking in rural areas.

The behavioural and psychological symptoms of a person with dementia were found to be related to carer burden (Heggie *et al.*, 2012; Ervin *et al.*, 2015; Stewart *et al.*, 2016; Yang *et al.*, 2019). Again, these findings corroborate those from people in urban places, but the difference being that those in rural areas may have limited formal support from services to address such issues (Heggie *et al.*, 2012), and/or that they may be reluctant to utilise services due to the effects of stigma in rural areas (Krutter *et al.*, 2022).

### *Impact of stigma*

In contrast to the benefits of support from the wider community, being known within a community also leads to issues relating to stigma. People with dementia can refrain from sharing their diagnosis with others, or be reluctant to seek help, due to the stigma associated with it and fears of gossip (Forbes *et al.*, 2012, 2013, 2018; Saunders, 2013; Wiersma and Denton, 2016; Herron and Rosenberg, 2017; Bauer *et al.*, 2019; Cox *et al.*, 2019).

Stigmatisation after disclosure of the diagnosis can lead to feelings of estrangement and hurt (Vellone *et al.*, 2012; Clarke and Bailey, 2016; Chisholm and Bischooping, 2019; Hicks *et al.*, 2021), as people visit less often than before (Innes *et al.*, 2003; Alzheimer’s Australia, 2007; Alzheimer’s Society, 2017), particularly as symptoms progress (Forbes *et al.*, 2011).

### *Risk of isolation*

Although most descriptions of family support have been positive, some have been less so. Ehrlich *et al.* (2015) discovered that although rural carers found it easier than urban-living carers to get help from family and friends, the rural carers experienced more feelings of abandonment from family. Similarly, other carers have reported limited tangible support from friends and family (Saunders and Groh, 2020), particularly if they live apart (Alzheimer Australia, 2007; Herron and Rosenberg, 2019).

### *Financial impact*

Rural carers disclosed financial burden (Saunders, 2013; Gibson *et al.*, 2019; Ainamani *et al.*, 2020), which can affect the health of people with dementia and carers (Smith *et al.*, 2011). Two studies found rural carers reported higher financial difficulties than those living in an urban area (Ehrlich *et al.*, 2015; Saunders and Groh, 2020). Others reported financial differences by race (Kaufman *et al.*, 2010;

Xie *et al.*, 2018) and by a decreased ability to live well in deprived areas (Wu *et al.*, 2018).

### *The physical environment*

While the rural environment can offer people with dementia comfort, it can become dangerous as the disease progresses as people with dementia can face challenges navigating the rural landscape (Forbes *et al.*, 2011; Hicks *et al.*, 2021). Furthermore, within farming communities it can become difficult to keep people with dementia safe, with worries about accidents involving machinery and animals being an issue (Kelly and Yarwood, 2018).

### *Difficulties with dementia care services*

Many studies (N = 35) discussed issues relating to dementia care services, with most highlighting inconsistency in provision and variability in perceived usefulness. Five sub-themes were identified (diagnosis difficulties; complex care systems; lack of provision affecting continuity of care; travel and geographical distances; language and cultural sensitivity).

#### *Diagnosis difficulties*

Eight studies reported difficulties in obtaining a diagnosis, describing limited access to specialists in rural areas and diagnosis depending on the skills and knowledge of primary care providers/general practitioners (GPs) (*see Table 1*). In the UK, carers from rural Scotland (Innes *et al.*, 2014) reported satisfaction with the support from GPs and community mental health teams, with GPs reported to go ‘the extra mile’, whereas in Wales, rural GPs were often accessible, but people were often reluctant to visit the GP because they believed there to be no appropriate support or information available to their needs (Alzheimer’s Society, 2017). Prorok *et al.* (2017) described people in rural areas (in contrast to urban) expressing more favourable comments with regards to their primary care providers and obtaining a diagnosis, although people with dementia often had to prompt them for a diagnosis and referrals. Two studies report feelings of relief from dyads or carers upon obtaining the diagnosis (Morgan *et al.*, 2014; Mattos *et al.*, 2018).

#### *Complex care systems*

Although people affected by dementia from rural and urban areas share many challenges, there is evidence for additional challenges in accessing and utilising services in rural areas. From a farming perspective, Kelly and Yarwood (2018) described barriers to engaging with agencies, with families affected by dementia feeling that services were ‘urban centric’ and did not fit with the farming lifestyle. Furthermore, Prorok *et al.* (2017) describe challenges with home care and long-term care that were reported more by people with dementia in rural (in comparison to urban) areas, particularly the difficulties navigating the system to obtain home care and/or long-term care as well as their dissatisfaction with aspects of this care. A similar narrative is presented elsewhere (Saunders, 2013; Herron and Rosenberg, 2019). Moreover, people have reported difficulties accessing services due to lack of awareness of what is available to them (Alzheimer’s Australia,

2007; Smith *et al.*, 2011; Di Gregorio *et al.*, 2015) and fewer than half of carers in the study by Ervin and Reid (2015) utilised services that were available to them, suggested to be due to problems with referral mechanisms. However, these findings are not always the case, with a recent study in Austria finding high levels of awareness and utilisation of home care services in a rural area, as compared to a more urban area, and greater utilisation to be driven primarily by older age of carers, and female gender of the person with dementia (Krutter *et al.*, 2022). The authors discovered a decrease in service utilisation in connection with higher levels of disruptive behaviour of people with dementia, similar to other findings describing underutilisation of services by care-givers of people with dementia with behavioural and psychological symptoms (Ervin and Reid, 2015), suggested to be partly a consequence of the stigma associated with dementia in rural areas.

#### *Lack of provision affecting continuity of care*

A lack of resources restricts the quality and quantity of community-based services and support (Forbes *et al.*, 2011, 2012; Di Gregorio *et al.*, 2015; Herron *et al.*, 2016; Herron and Rosenberg, 2017, 2019; Gibson *et al.*, 2019; Walsh *et al.*, 2021) and a recent study by Saunders and Groh (2020) revealed that formal carer support was noticeably more limited in rural as compared to urban areas. Concordantly, informal carers express a need for more and better services in rural and remote places (Dal Bello-Haas *et al.*, 2014). Despite wishes for people with dementia to remain at home, there is often not enough support for them to do so without adversely affecting the health of the carer. Unmet service needs have been linked to carer burden (Li *et al.*, 2012), lower carer quality of life (Vellone *et al.*, 2012) and stress/burnout (Alzheimer's Australia, 2007). Carers in rural Wales felt taken for granted and used as a 'free service' and felt service provision was not forthcoming due to their commitment (Alzheimer's Society, 2017).

#### *Travel and geographical distances*

People with dementia often must travel to urban centres or significant distances to access appropriate services, support groups and formal care (Saunders, 2013; Innes *et al.*, 2014; Di Gregorio *et al.*, 2015; Herron *et al.*, 2016; Mattos *et al.*, 2018; Gibson *et al.*, 2019), leading to reliance on carers to provide transport (Bauer *et al.*, 2019; Hicks *et al.*, 2021). This is consistent with the findings from Innes *et al.* (2011) and is likely to be one of the reasons for which rural families use fewer services than urban families.

The impact of the distance travelled by formal services between clients include late and shortened home care visits (Herron and Rosenberg, 2019) and infrequent visits (Forbes *et al.*, 2012), leading to negative consequences for people with dementia. Likewise, long distances from services and support contributes to isolation of people with dementia (Alzheimer's Australia, 2007; Saunders, 2013). Where long-term care beds are not available locally, family and friends of people with dementia who are relocated for care face travelling great distances to visit (Di Gregorio *et al.*, 2015).

#### *Language and cultural sensitivity*

Twelve studies described the importance of considering culture or traditions in rural places (Sun *et al.*, 2010b; Smith *et al.*, 2011; Vellone *et al.*, 2012; Forbes *et al.*, 2013; Saunders, 2013; Dotchin *et al.*, 2014; Alzheimer's Society, 2017; Xie

*et al.*, 2018; Chisholm and Bischooping, 2019; Cox *et al.*, 2019; Yahalom, 2019; Disbrow *et al.*, 2021). For instance, there is evidence to suggest that some indigenous cultures view dementia as a normal part of ageing (Smith *et al.*, 2011; Cox *et al.*, 2019; Yahalom, 2019). Yahalom (2019) describes indigenous Zapotec carers who normalised the forgetfulness of people with dementia, maintaining Alzheimer's disease as a modern condition associated with stresses of non-traditional ways of living. Aboriginal carers can feel obliged to provide care to maintain connections to family, community and culture (Smith *et al.*, 2011; Cox *et al.*, 2019), and children were expected to care for their elders in Hai, Tanzania (Dotchin *et al.*, 2014). In rural Wales, some people affected by dementia noted the lack of Welsh-speaking staff and information in Welsh as a barrier to accessing dementia-specific support and information (Alzheimer's Society, 2017).

### **Improving the experience of dementia in rural areas**

#### *Involving people affected by dementia*

Maintaining a social life and social inclusion emerged as important themes, both for people living with dementia and their carers. Preserving a sense of normality by continuing with long-term friendships and activities is important for the person with dementia and their carer (Innes *et al.*, 2003; Forbes *et al.*, 2011, 2018) and enabling them to do the things they enjoy (Herron *et al.*, 2016; Alzheimer's Society, 2017). Connecting people affected by dementia via peer-to-peer opportunities may reduce social isolation and provide opportunities for additional informal support (Gibson *et al.*, 2019). It is also recommended that people living with dementia in rural places are actively involved in decisions that affect their lives, including service development and improvement (Innes *et al.*, 2003; Forbes *et al.*, 2011, 2012, 2013; Morgan *et al.*, 2014; Herron *et al.*, 2016; Krutter *et al.*, 2020).

#### *Services that are fully 'person-centred'*

Akin to Innes *et al.* (2011), the most frequent recommendation found in the present review was the need for providing tailored, appropriate services, considering the individual needs of rural people. Appropriate services should be based on the opinions, wishes and plans of the people that they are for (Innes *et al.*, 2003; Forbes *et al.*, 2011, 2012; Ehrlich *et al.*, 2015, 2017; Clarke and Bailey, 2016; Gibson *et al.*, 2019; Hicks *et al.*, 2021). Policy recommendations also emphasise addressing the unique needs of people affected by dementia in rural areas, ensuring informal support does not replace formal services (Forbes *et al.*, 2011; Dal Bello-Haas *et al.*, 2014; Wiersma and Denton, 2016).

Suggestions include supporting families to provide meaningful care-giving and maintaining a normal life (Ehrlich *et al.*, 2015, 2017), enhancing existing resources available to carers and families (Gibson *et al.*, 2019), supporting people to remain connected and included in society (Clarke and Bailey, 2016) and training care staff to participate in meaningful activities with people in their homes (Forbes *et al.*, 2011). Li *et al.* (2012) suggest that to meet the needs of people with dementia in rural places, it is important to address the psychological and social needs of the carer, particularly to reduce levels of carer burden. Concordantly, others also

recommend that services should work to support carers to reduce levels of burden (Heggie *et al.*, 2012; Wertz *et al.*, 2015; Ainamani *et al.*, 2020).

### *Improving education and awareness for professionals and the public*

Due to the lack of specialists in rural areas there are proposals for education, awareness raising and training for service staff, and ensuring rural GPs are trained to diagnose and support people with dementia sufficiently (Forbes *et al.*, 2012; Saunders, 2013; Morgan *et al.*, 2014; Alzheimer's Society, 2017). Furthermore, educating people with a recent diagnosis of dementia about the services and supports that are available to them will assist them to make their own decisions about their future (Di Gregorio *et al.*, 2015). Carers have also recommended that education, training and courses be made available to them, to help them prepare and to enhance their skills in providing the best care possible (Alzheimer's Australia, 2007; Saunders, 2013; Innes *et al.*, 2014; Alzheimer's Society, 2017; Bauer *et al.*, 2019; Gibson *et al.*, 2019), and researchers have made similar recommendations for supporting carers (Wertz *et al.*, 2015; Cox *et al.*, 2019; Krutter *et al.*, 2020). A recent study of carers of people with dementia in rural Kentucky revealed gaps in information needs identified during a question-and-answer session, including risk factors, behaviour management, diagnosis and medication (Bardach *et al.*, 2021).

Promotion of dementia support groups and educative sessions for the public about dementia are needed to increase awareness and acceptance (Morgan *et al.*, 2014; Di Gregorio *et al.*, 2015; Forbes *et al.*, 2018) and thus reduce stigma and gossip (Forbes *et al.*, 2013; Herron and Rosenberg, 2017; Bauer *et al.*, 2019) in rural communities. Several studies suggest promoting such groups/sessions using online or video technology (Alzheimer's Australia, 2007; Saunders, 2013; Xie *et al.*, 2018; Bauer *et al.*, 2019; Gibson *et al.*, 2019; Saunders and Groh, 2020; Bardach *et al.*, 2021), as well as by other means (Li *et al.*, 2012; Vellone *et al.*, 2012; Alzheimer's Society, 2017).

Capitalising on the impact and influence of other existing rural community assets is also encouraged in various ways, such as educating rural service staff further (Forbes *et al.*, 2011; Smith *et al.*, 2011; Innes *et al.*, 2014; Ervin and Reid, 2015), involving church leaders (Sun *et al.*, 2010b; Nankinga *et al.*, 2020) and making use of physical resources available in rural communities (e.g. village halls) (Saunders, 2013; Alzheimer's Society, 2017).

## **Discussion**

To our knowledge this is the first scoping review focusing on the first-hand experiences of both people with dementia and their informal carers living in rural places. It updates a previous systematic review exploring dementia care and service provision in rural and remote settings in relation to informal/family care-giving (Innes *et al.*, 2011), presenting evidence from 60 new studies, and demonstrating the acceleration in interest in the subject area within the last decade. It adds a wealth of new evidence to the initial findings of Innes *et al.* (2011) and adds important new insights by putting a focus on the opportunities as well as the challenges experienced by both carers and people living with dementia. This is important, because if policy and practice changes are to be made to improve the experience and

support of people in rural areas, we must first understand how the people themselves experience life with dementia within such places.

Some of the findings around dementia care services, such as a lack of provision, lack of awareness of what is available and transport challenges, support findings presented in the reviews of Innes *et al.* (2011) and Bayly *et al.* (2020). There is still a dire need for formal care service improvement in rural areas. Despite national dementia strategies stressing the importance of funding dementia support services, including those who live in rural areas (e.g. Welsh Government, 2018), austerity has led to significant reductions in service provision (Thomson *et al.*, 2015), with challenges being exacerbated in rural areas. The cost of dementia care is high, with evidence suggesting a higher financial burden associated with living rurally (Kaufman *et al.*, 2010; Smith *et al.*, 2011; Saunders, 2013; Ehrlich *et al.*, 2015; Xie *et al.*, 2018; Gibson *et al.*, 2019). Families are often left to either provide care informally, or to pay for formal care, often having to relocate the person with dementia to long-term care in urban areas, due to lack of provision in rural areas (e.g. Di Gregorio *et al.*, 2015). A recent review found that relocation often has detrimental effects on the person with dementia, with the most positive care outcomes relating to involving people with dementia in decisions about their care and maintaining a sense of normality where possible (Ryman *et al.*, 2019), supporting findings from the present review that people with dementia should be involved in decisions that affect their lives (Innes *et al.*, 2003; Forbes *et al.*, 2011, 2012, 2013; Herron *et al.*, 2016) and preserving a sense of normality through continuing with long-term friendships and activities (Innes *et al.*, 2003; Forbes *et al.*, 2011, 2018; Ehrlich *et al.*, 2017).

An important challenge highlighted by this review that may be greater in rural areas (as opposed to urban areas) relates to the experience of getting a diagnosis of dementia. Difficulties obtaining a diagnosis due to a lack of specialised dementia services often leads to dependence on the skills and knowledge of local GPs for making and delivering the diagnosis (Saunders, 2013; Morgan *et al.*, 2014; Orpin *et al.*, 2014; Di Gregorio *et al.*, 2015; Bauer *et al.*, 2019). This is a potential area for solutions/interventions to upskill existing rural community formal resources, eliciting calls to improve training and education for rural GP practices around diagnosis and post-diagnosis support for people with dementia within their communities (e.g. Saunders, 2013; Morgan *et al.*, 2014). Having confidence in support provided by GPs may alleviate some of the psychological burdens of living with the diagnosis, for both people with dementia and carers.

It is important to acknowledge that a number of the difficulties faced by people affected by dementia in rural areas are applicable to people with dementia more broadly and not to rural life alone, such as reliance on informal support, carer distress, loss of friends and the negative experiences associated with stigma. However, rurality may exacerbate these difficulties due to limited access to services and the close-knit nature of many communities whereby individuals with dementia may be alienated due to a lack of awareness and education.

While much research on rural dementia focuses on negative experiences, inequalities and deficits, this review highlights some potential opportunities related to living in rural areas for people living with dementia. These often come with parallel challenges within the literature, essentially reflecting a delicate balance between being well-supported and being in crisis for those living in rural areas. For example,

family and friends are a key resource for successful care-giving in rural communities, likely attributable to lack of service availability in rural areas leading to dependency on other sources of support (Ehrlich *et al.*, 2015). Additionally, rural carers have expressed a desire for training and education to equip them with the skills to best support people with dementia (Alzheimer's Australia, 2007; Saunders, 2013; Innes *et al.*, 2014; Alzheimer's Society, 2017; Bauer *et al.*, 2019; Gibson *et al.*, 2019). However, an opposing narrative was found whereby there was a risk of isolation if family lived away or stopped visiting (Alzheimer Australia, 2007; Ehrlich *et al.*, 2015; Herron and Rosenberg, 2019).

Furthermore, living in a close-knit rural community, often for many years, appears to elicit a unique asset for people affected by dementia. For example, the wider community has been shown to step up and provide additional support and religious involvement can also be a key area of rural support. Moreover, the opportunity for people with dementia to continue to contribute was also a key theme, as was the recommendation to involve people with dementia. However, there were also findings related to stigma in which people would gossip in rural communities, leading to social withdrawal and reluctance to seek help (Forbes *et al.*, 2012, 2013, 2018; Saunders, 2013; Wiersma and Denton, 2016; Herron and Rosenberg, 2017). Moreover, community support can be present until the presentation of 'anti-social' symptoms related to dementia (Forbes *et al.*, 2011; Orpin *et al.*, 2014). Accordingly, there may be more of a reluctance to utilise services as behavioural symptoms of dementia increase, assumed to be due to stigma also (Ervin and Reid, 2015; Krutter *et al.*, 2022). These findings appear to suggest that given the correct 'ingredients' there can be benefits to living in a rural community, however, it is not guaranteed that families and the wider communities and environment will support people with dementia in rural places. Those who are neither supported informally by family or community, nor formally due to lack of service provision, are in grave danger of being left to fend for themselves.

While it is well-known that there is an inequity of access to formal services in rural areas, opportunities identified through this research relate to the potential for engaging and involving existing community members and resources. National and international policies promote the establishment of dementia-friendly communities to ensure people are socially included in their community and the WHO (2017) has called for global action to develop dementia-friendly initiatives. According to Li *et al.* (2021), well-connected communities for people with dementia include connections with family, friends and neighbours through belonging, responsibilities and identification within groups; attachment to places in the community; and actively seeking to live independently and uphold community connections. This supports themes identified in the present study and strengthens the argument for policies to highlight dementia-friendly community initiatives in rural areas as a priority area, which have as yet received limited attention (Shannon *et al.*, 2019; Gan *et al.*, 2022). A key area for consideration is the potential of bolstering the skills, knowledge and awareness, of public and professionals living and working in rural areas, as well as capitalising on other assets within the rural environment that are considered supportive by community members (*e.g.* village halls, churches): supporting people with dementia in rural areas requires input and innovation from the people, organisations and services local to those communities.

### Strengths and limitations

In relation to the methods of this study, a strength of the scoping review methodology is that it enables a broad overview of the literature to be captured, rather than evaluating the quality of existing literature (Levac *et al.*, 2010). A further strength is that this method allowed inclusion of grey literature, gaining wider insight into the experiences of people affected by dementia in rural areas from numerous important reports. To enhance trustworthiness, a comprehensive search strategy was used across multiple databases with no date restrictions, and study identification and selection was subject to a double review process.

The results of this review presented a number of gaps in this area of research. First, the majority of research originates from Western countries. Very few studies present findings from developing countries ( $N = 3$ ). This is an important area for consideration given the differing status of health care, finances and societal traditions that can exist in developing countries. However, as the searches were performed in English and sought studies presented in English, we acknowledge that some evidence from developing countries could have been missed. Moreover, a lack of cultural diversity is observed within the samples, with only 13 studies sharing ethnicity information (four of which merely stated that their samples consisted of a high percentage (almost all) Caucasian participants). Future research must put effort into gaining knowledge from more diverse backgrounds.

In addition, only studies that examined the lived experiences of people with dementia and carers were considered. Exploration of the effectiveness of technology and online interventions may further our understanding of what is available to rural-dwelling people to assist with life with dementia. Given the surge in interest in this type of intervention research over the past decade, we chose not to include intervention studies in the present review, as it is something that would benefit from being explored separately. The importance of this has increased since the COVID-19 pandemic has encouraged and required people to access more online resources and support.

Innes *et al.* (2011) highlighted variability in how authors defined rurality in their studies, which was confirmed in the present review. For instance, many Canadian studies define rurality by distance from an urban centre (*e.g.* O'Connell *et al.*, 2013; Di Gregorio *et al.*, 2015) or as 'all territory outside of an urban centre' (*e.g.* Forbes *et al.*, 2012; Wiersma and Denton, 2016). Internationally, there are definitions of rurality by population density, with variation in descriptions ranging between 0.1 (Saskatchewan, Canada; Dal Bello-Haas *et al.*, 2014) to 13.1 persons per square kilometre (Sweden; Ehrlich *et al.*, 2017). Some provide the population figures of regions studied, with 'rural' ranging from less than 3,000 (Scotland; Wu *et al.*, 2018) to less than 10,000 people (*e.g.* Wales; Alzheimer's Society, 2017), and others have simply used a general description. This lack of a universal definition of rurality in both research and policy makes comparison across studies and countries very difficult. Within Canada alone, this difficulty has been highlighted on numerous occasions (*e.g.* Ministerial Advisory Council on Rural Health, 2002; 8; DesMeules *et al.*, 2006: 7). What is evident is that what constitutes 'rural' differs



both between and within countries and it follows that there is likely to be associated variance in the experiences of inhabitants across degrees of rurality. While it seems unlikely that international consensus will be reached in defining rurality, a challenge for future research would be to conduct a case study exploring the experience of dementia across multiple rural areas, building up a detailed 'rural profile' of each location prior to conducting interviews. This may allow comparison on a continuum of rurality, with remoteness being at the more extreme end.

### **Implications for research**

The majority of studies presented in this review do not disclose the type of dementia diagnosed to participants and, of those reported, most appear to report the more common types of dementia. The few studies that include a small number of people with rarer forms of dementia as participants, in addition to other subtypes (Morgan *et al.*, 2014; Stewart *et al.*, 2016; Wu *et al.*, 2018), do not differentiate between people with different forms of dementia in their analyses. As mentioned above, there may be differences in experiences according to the symptoms displayed, therefore an important avenue for future investigation would be to explore the experiences of people living with rarer forms of dementia in rural areas.

There appears to be a gap in the research literature regarding exploring the experiences of people with dementia alone (*i.e.* without simultaneously studying carers, or other individuals), with four studies doing so in the present review (Innes *et al.*, 2003; Wu *et al.*, 2018; Hicks *et al.*, 2021; Müller *et al.*, 2021). Moreover, despite there being a total of 19 studies that included the voice of people with dementia by means of qualitative interviews (people with dementia alone,  $N = 2$ ; people with dementia and carers/others,  $N = 17$ ), only four of these explicitly claimed to have undertaken individual interviews with people with dementia (Innes *et al.*, 2003; Gilmour, 2004; Herron and Rosenberg, 2017; Hicks *et al.*, 2021). Others undertook focus groups, joint interviews, or the methods do not clarify whether or not people with dementia were interviewed alone (in studies that also included other participants). In most of these cases, it is difficult to estimate the amount of input provided by the people with dementia themselves. While it can be beneficial to include others in the interview process, there is also acknowledgement that proxy accounts or the presence of others may influence the narrative that is presented from the perspective of people with dementia (Oldfield, 2021). For example, Murphy *et al.* (2015: 801) found that many studies combined data from people with dementia and carers, often resulting in a reduced focus on the person with dementia. Inclusion and recruitment of more people with dementia may require finding creative ways to make the research design 'fit' for participants, employing flexible and adaptive strategies that are tailored to both person and location, such as, for example, building relationships prior to data collection and adapting methods to fit around participant capacity, preferences and routines (Webb *et al.*, 2020). Future research, policy and practice efforts should consider ensuring the perspective of people with dementia is clearly sought and presented wherever possible, for dementia-friendliness of a community is more likely to be achieved if the voices of those living with a diagnosis are at the forefront of consultations and decisions affecting their lives.

## Conclusion

This scoping review identified articles that describe or discuss the personal experience of dementia, either by the person with dementia or carer, in relation to living in rural or remote geographical areas. Challenges of rural living included difficulties with dementia care services and detrimental aspects of living in a rural community. Conversely, opportunities identified through this research relate to the potential for engaging and involving existing community members and resources in improving the experiences of people affected by dementia. Input and innovation from the people, organisations and services local to rural communities provide scope for improving the lives of people affected by dementia in those areas.

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