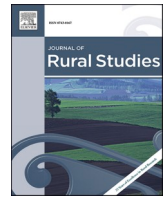


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For more information, please contact [wrapteam@worc.ac.uk](mailto:wrapteam@worc.ac.uk)



# Experiences of dementia in farming communities: A scoping review

Jennifer Rhiannon Roberts<sup>a,\*</sup>, Bethan Naunton Morgan<sup>a</sup>, Catrin Hedd Jones<sup>b</sup>, Gill Windle<sup>a</sup>

<sup>a</sup> DSDC Wales Research Centre, School of Health Sciences, Bangor University, Bangor, UK

<sup>b</sup> Association for Dementia Studies, School of Health and Wellbeing, University of Worcester, Worcester, UK

## ABSTRACT

Farming communities experience significant rates of dementia, however research exploring the support needs of this population is scarce. In response, this scoping review examined published literature on the experiences of dementia in farming communities. Five databases were searched for peer-reviewed articles and a general google search conducted for grey literature. Eighteen articles were included in the review. The majority ( $n = 12$ ) were grey literature including magazine and newspaper articles, demonstrating a large research gap in this area. Thematic analysis generated thirteen sub-themes that are presented within two overarching themes: 'challenges' and 'fostering resilience'. A stakeholder meeting was organised with representatives from eight organisations that support farmers in Wales, to discuss themes and gain additional insights. Findings indicate a unique set of challenges faced by farming communities in relation to dementia, that are in addition to those faced by people living rurally in general. Importantly, this review also highlights helpful advice around opportunities for fostering resilience in people living with dementia and their families in farming communities. The findings of this review could be used to guide the development of healthcare information and support tailored to the unique needs of farming populations.

## 1. Introduction

Like many professions, being a farmer is not just a job, it is an identity that can include a sense of self, purpose, and community (Conway et al., 2022; Kelly and Yarwood, 2018). Farmers feel a sense of belonging and emotional attachment to the land and to their farm (Holloway et al., 2021). Due to this emotional connection to the role, farmers often work beyond retirement age (Conway et al., 2022), and therefore the average age of farmers is high worldwide. For example, the average age of farmers is 57 years in Ireland (Central Statistics Office, 2020), 59 in Wales (Henley and Morris, 2019), 58.1 in the United States (United States Department of Agriculture, 2022), 56 in Canada (Dyck, 2024), and 60 in Africa (Food and Agriculture Organization, 2014).

There are more than 55 million people living with dementia globally (World Health Organization, 2021). However, dementia rates are disproportionately higher in farming communities compared to the general working population, with a 46 % increased chance for developing dementia in people working in farming (Arora et al., 2021). This may be driven by a combination of unique occupational, environmental, and social factors (Arora et al., 2021), including the higher-than-average age for farmers compared with other occupations (ONS, 2023). The physically and psychologically demanding nature of agricultural work often exposes farmers to risk factors that significantly increase the likelihood of developing dementia (Arora et al., 2021). For example, prolonged exposure to pesticides has been linked to an increased risk of

cognitive decline (Petit et al., 2023), while regular use of loud machinery can lead to hearing loss, a condition associated with dementia (Livingston et al., 2020). Moreover, factors such as stress, isolation and long work hours are related to a higher prevalence of depression in farmers compared to non-farmers (Onwuameze et al., 2013; Sanne et al., 2004), which is also associated with risk of developing dementia (Livingston et al., 2024).

These occupational hazards are intensified by geographic isolation, creating barriers to timely diagnosis and access to healthcare services (Innes et al., 2011; Roberts et al., 2023). The distance from specialised dementia care and support resources can delay early recognition and post diagnosis interventions (Roberts et al., 2024). A report by the Office of Health Economics has highlighted rurality as a health inequality for people living with dementia, demonstrated by longer waits to receive a diagnosis and higher rates of undiagnosed dementia than urban areas (Hodgson et al., 2024). This is further compounded by the stigma surrounding mental health in farming communities, where discussions about dementia may be discouraged, leading to underreporting of symptoms and a reluctance to seek help (Kelly and Yarwood, 2018). Lower levels of awareness about dementia in rural areas can also impact diagnosis rates or result in an overall lack of understanding about how to manage the condition effectively (Innes et al., 2011; Roberts et al., 2023).

The impact of dementia on families and carers is also profound. Due to the limited availability of professional care services, families in

\* Corresponding author. Dementia Services Development Centre (DSDC), Bangor University, Ardudwy Hall, Normal Site, Bangor, Gwynedd, LL57 2PZ, UK.  
E-mail address: [j.roberts@bangor.ac.uk](mailto:j.roberts@bangor.ac.uk) (J.R. Roberts).

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farming communities often shoulder the caregiving burden themselves (Chisholm and Bischooping, 2019; Kelly and Yarwood, 2018). The combination of financial strain, emotional toll, and disruption to farm operations can create a cycle of hardship that affects individual families, and the broader rural economy. Appropriate support services such as respite care, counselling, and carer support groups are often scarce, leaving families without the necessary resources to cope (Roberts et al., 2023).

Healthcare inequality between rural and urban areas results in residents within rural communities being frequently underserved in terms of specialised dementia care. This inequity in resource allocation and service provision in rural areas exacerbates the challenges faced by farmers and their families (Innes et al., 2011; Roberts et al., 2023, 2024). Current healthcare policies often overlook the specific needs of rural communities, failing to address the unique occupational risks, isolation, and support gaps (Innes et al., 2011; Arsenault-Lapierre et al., 2023). As a result, rural populations are left vulnerable to significant disparities in the quality of dementia care compared to their urban counterparts (Kelly and Yarwood, 2018).

The importance of living as well as possible after a diagnosis of dementia has been highlighted in policies internationally (e.g., Government of Canada, 2019; Government of Netherlands, 2020; Welsh Government, 2018). Consequently, the key aims within national dementia strategies include raising awareness, reducing stigma, improving access to services and support, and improving quality of care (Chow et al., 2018). This indicates the need for support in the early stages of dementia, ensuring people have access to information on dementia and available support services regardless of where they might live, and that support is personalised and flexible to meet people's needs. Living well with dementia has been linked to the concept of resilience (Lamont et al., 2020). A new model of resilience specifically designed for and with people living with dementia suggests resilience encompasses the daily struggles of living with a dementia; people are not flourishing, thriving or 'bouncing back', but are managing and adapting under pressure and stress. This model suggests resilience may be achieved through the collective and collaborative role of psychological strengths, practical approaches to adapting to life with dementia, continuing with hobbies, interests and activities, strong relationships with family and friends, peer support and education, participating in community activities and support from healthcare professionals (Windle et al., 2023). Improving resilience has also emerged as a key priority of Health 2020, the European policy framework (WHO, 2013; 2017), indicating international recognition of the importance of using strengths-based approaches to support people and communities.

1.1. Aim of this review

Despite the growing research interest in improving support and reducing inequalities for people living with dementia in rural areas, evidence relating to the experiences of people living with dementia in farming communities is scarce. By better understanding their unique challenges and needs, more effective support strategies may be developed for this underserved population. In response, this review seeks to provide insights that will guide future research and better access to support. This scoping review aimed to answer the follow question:

What is known about the experiences of people affected by dementia in farming communities?

2. Methods

2.1. Study design

A scoping review methodology is useful when a subject area has not been extensively explored, enabling a broad range of literature to be captured, regardless of study design (Arksey and O'Malley, 2005). The present review follows Arksey and O'Malley's (2005) six step framework

for conducting scoping reviews. To ensure clarity of reporting, the PRISMA extension for scoping reviews checklist was followed (PRISMA-ScR, Tricco et al., 2018). The checklist contains 20 essential and 2 optional reporting items to include when completing a scoping review.

2.2. Identifying relevant studies

Literature searches were conducted from the 8<sup>th</sup> July 2024 to the 23<sup>rd</sup> July 2024. A University academic Librarian was involved in the development of the search terms and the selection of the databases (Table 1). Five databases were searched: ProQuest, CINAHL Plus with Full Text, PsycINFO, Web of Science, and MEDLINE. These databases were selected for their inclusion of social and health sciences literature. A Google search was also undertaken, to capture any grey literature around the subject, such as reports. Titles and abstracts were searched with no date restrictions.

2.3. Eligibility criteria

2.3.1. Inclusion criteria

Peer reviewed studies and grey literature, written in English (to avoid inaccurate online translations or change/loss of meaning from other languages), that discussed the experiences of people living in farming communities affected by dementia were selected. There were no date or study design restrictions. The population involved those with experiences of dementia from farming communities, including professionals, informal carers and people living with dementia.

For the purposes of this review, the farm refers to the physical land and buildings used for agricultural production, including fields, pastures, barns, storage facilities, but also including the farmhouse. Farming households are individuals or families who own, manage, or work on a farm as their primary residence and source of income. Finally, farming communities are groups of people living in rural areas who are directly or indirectly engaged in agricultural activities in a broader context to the farming household. This includes farmers, their families, agricultural workers, and others whose work and social lives are closely tied to farming.

2.3.2. Exclusion criteria

Articles were excluded if they did not discuss the experiences of people in farming communities affected by dementia, for example, if they were focused on farming and agricultural practices; disorders other than dementia; prevalence of dementia; animal studies; care farming

Table 1  
Databases and terms used in literature search.

Database	Search terms
ProQuest	Summary (smallhold* OR crofter* OR agriculture worker* OR agricultural worker* OR farm worker* OR farm*) AND summary (dementia OR Alzheimer* OR memory loss OR cognitive decline OR cognitive impairment OR cognitive function OR neuropsychological function)
CINAHL Plus with Full Text	AB (smallhold* OR crofter* OR agriculture worker* OR agricultural worker* OR farm worker* OR farm*) AND AB (dementia OR Alzheimer* OR memory loss OR cognitive decline OR cognitive impairment OR cognitive function OR neuropsychological function)
PsycINFO	Abstract: smallhold* OR Abstract: crofter* OR Abstract: agriculture worker* OR Abstract: agricultural worker* OR Abstract: farm worker* OR Abstract: farm* AND Abstract: dementia OR Abstract: Alzheimer* OR Abstract: memory loss OR Abstract: cognitive decline OR Abstract: cognitive impairment OR Abstract: cognitive function OR Abstract: neuropsychological function
Web of Science	farmers or agricultural or farm workers and dementia or alzheimer's or memory loss
MEDLINE	farmers or agricultural or farm workers AND dementia or alzheimer's or memory loss

(unless they included the experience of people from a farming background), and biological or drug studies.

## 2.4. Study selection

The search results were saved into the reference manager software Mendeley, and duplicates removed. Titles and abstracts were screened by BNM, followed by 173 full texts. A random 20 % (36 texts, 18 each) full texts were screened by JR and CHJ to ensure consistent application of the inclusion/exclusion criteria, with 97 % agreement. Any disagreements ( $n = 1$ ) were discussed until a consensus was reached.

## 2.5. Charting the data

A data extraction table was created based on guidelines from Arksey and O'Malley (2005) to include author(s), date, article type, and key findings relating to the research question. JRR and BNM separately extracted data from all articles, then compared extractions to confirm consistency. Following the data extraction performed by JRR and BNM, CHJ independently reviewed each article to verify accuracy and completeness.

## 2.6. Collating, summarising and reporting the results

A hybrid approach to qualitative analysis was used wherein data pertaining to the experiences of people living in farming communities affected by dementia was extracted and coded using NVivo and analysed following Braun and Clarke's (2019) reflexive approach. This involved generating candidate themes through an iterative process of detailed reading, inductive coding, and reviewing and refining codes and themes through ongoing discussions between BNM, JRR and CHJ. The resulting themes were then categorised as sub-themes into the overarching themes 'challenges' and 'fostering resilience' to illustrate the challenges faced by people in farming communities affected by dementia and/or advice on how to adapt and cope with these challenges and 'foster resilience'.

## 2.7. Consultation exercise

A stakeholder engagement meeting was organised to discuss the findings from the scoping review with representatives ( $n = 9$ ) from eight key organisations that support farmers in Wales: Young Farmers Clubs (YFC), Farming Community Network (FCN), Mamwlad, Rural Health and Care Wales (RHCW), The DPJ Foundation, Royal Agricultural Benevolent Institution (RABI), National Farming Union Cymru (NFU Cymru), and Tir Dewi. For context, Wales is a largely rural country and 90 % of the total land area is used for farming (Devenish, 2022). Stakeholders included professionals who work with farmers across Wales and therefore had an overview of the challenges and support needs of farmers nationally ( $n = 7$ ), and others who work on regional projects supporting farmers and their families ( $n = 2$ ). Themes were presented by JRR during an online meeting in which attendees were asked whether the themes resonated and whether they had any further insights to add to the findings.

The themes were also presented at the Rural Health and Care Wales Conference 2024 and the Rural Dementia Action Research (RaDAR) summit in Saskatchewan 2024). Feedback was invited from the audience was invited as an additional exercise to gain alternative national and international perspectives and inputs.

## 3. Results

The literature searches provided 3452 results and 4 were identified from other sources via Google search. Initially 1560 duplicates were removed before the title and abstracts were screened which removed a further 1723 results. Articles removed at this stage included multiple news articles reporting on the findings from the study by Kelly and Yarwood (2018), unless the article included new/additional evidence. This resulted in 173 full texts being reviewed and a further 155 excluded, including those looking at prevalence/risk factors of dementia, other disorders (not dementia), not farming communities, farming/agricultural practices, and those not looking specifically at people's experiences. Fig. 1 visualises the process.

The searches identified 6 peer reviewed articles (Kelly and Yarwood, 2018; Eisenhauer et al., 2015; Chisholm and Bischooping, 2019; Herron and Rosenberg, 2017; Morgan et al., 2002; Greenlee, 2013). These consisted of an ethnographic study (Eisenhauer et al., 2015), an opinion piece (Greenlee, 2013), three case studies (Kelly and Yarwood, 2018; Herron and Rosenberg, 2017; Chisholm and Bischooping, 2019) and an exploratory qualitative study (Morgan et al., 2002).

Twelve of the articles (67 %) are grey literature that discussed the experiences of dementia in farming communities. These included 2 reports by farming unions (Evans and Farming Community Network, 2022; Farming Community Network, 2021), 5 newspaper articles (Case, 2016; Laird, 2009; Pilditch, 2018; Robins, 2006; The Newsroom, 2017), 4 magazine articles (Lammers-Helps, 2015; National Farming Union [NFU], 2024; Ryan, 2022; "Emma Harper praises", 2018), and a social media post (Froese, 2020). All grey literature was identified using the ProQuest database except the report by Evans and Farming Community Network (2022), which was identified via Google search.

Nine of the articles were from the UK (Case, 2016; Evans and Farming Community Network [FCN], 2022; Farming Community Network, 2021; Kelly and Yarwood, 2018; NFU, 2024; Pilditch, 2018; Robins, 2006; "Emma Harper praises", 2018; The Newsroom, 2017), 3 from the US (Eisenhauer et al., 2015; Greenlee, 2013; Ryan, 2022), 5 from Canada (Chisholm and Bischooping, 2019; Froese, 2020; Herron and Rosenberg, 2017; Lammers-Helps, 2015; Morgan et al., 2002), and 1 from New Zealand (Laird, 2009). Source dates ranged from 2002 to 2024. Supplementary material 1 provides a summary of the key findings from each article.

The perspectives of the following groups of people were included: people living with dementia (Herron and Rosenberg, 2017; Lammers-Helps, 2015), spousal carers (Morgan et al., 2002; Herron and Rosenberg, 2017; Kelly and Yarwood, 2018; Evans & FCN, 2022; FCN, 2021); adult child carers (Chisholm and Bischooping, 2019; Herron and Rosenberg, 2017; Kelly and Yarwood, 2018; NFU, 2024; Laird, 2009; Ryan, 2022; Pilditch, 2018; Froese, 2020; Case, 2016; Robins, 2006) grandchildren (NFU, 2024; Greenlee, 2013), other family members (Herron and Rosenberg, 2017; Morgan et al., 2002), community-dwelling rural older women from a farming community (Eisenhauer et al., 2015) and representatives from networks and organisations that support farming communities ("Emma Harper praises", 2018; The Newsroom, 2017).

In terms of the diagnosis of people living with dementia described, six articles do not provide a specific diagnosis beyond 'dementia' (Morgan et al., 2002; Kelly and Yarwood, 2018; Pilditch, 2018; Greenlee, 2013; Evans & FCN, 2022; FCN, 2021). Others discuss experiences related to Alzheimer's disease (Herron and Rosenberg, 2017; Laird, 2009; Ryan, 2022; Lammers-Helps, 2015; Froese, 2020; Case, 2016; Robins, 2006); dementia with Lewy bodies (Herron and Rosenberg, 2017); vascular dementia (NFU, 2024); and frontotemporal dementia (FTD) and posterior cortical atrophy (PCA) (Chisholm and Bischooping, 2019). Eisenhauer et al.'s (2015) study describes perceptions relating to cognitive decline.

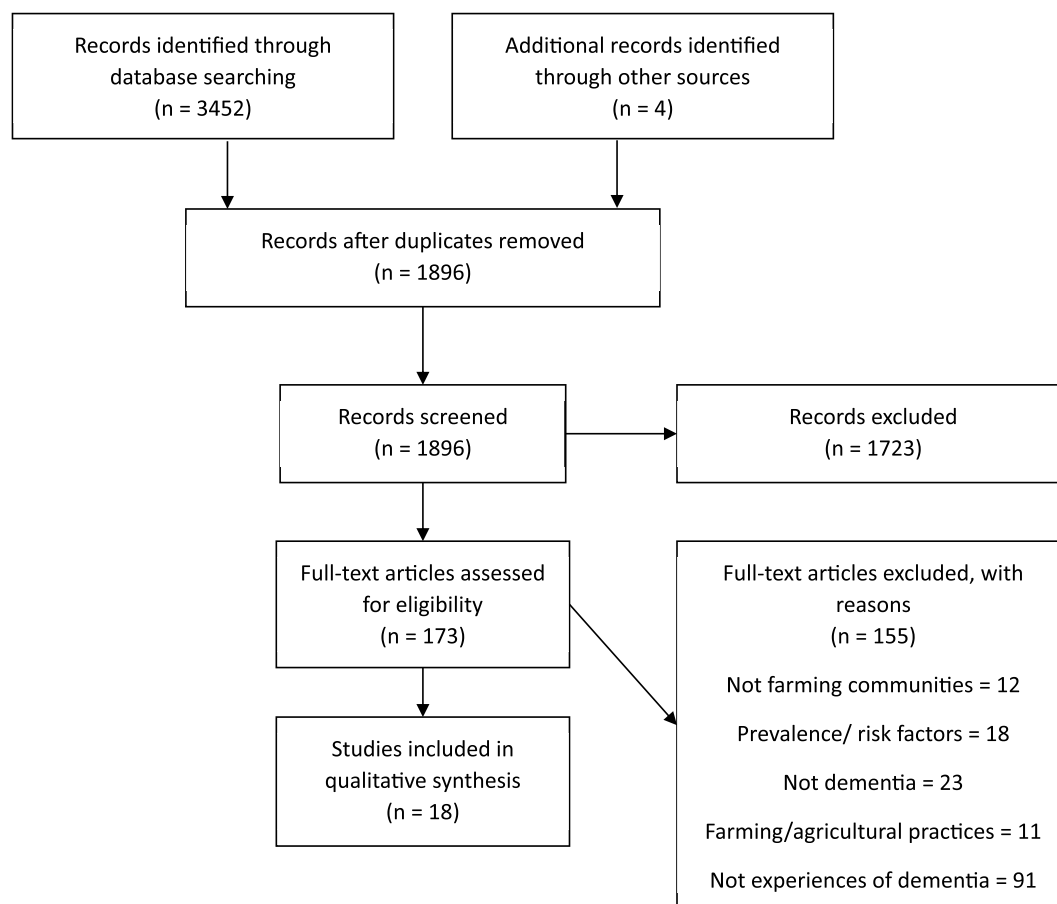


Fig. 1. A PRISMA flow diagram of the exclusion process.

### 3.1. Themes

Themes were divided into the challenges faced by farming families in relation to dementia and ways to foster resilience. Fig. 2 represents the themes generated from the analysis. Representatives from community organisations agreed with the themes presented in the stakeholder engagement activities. Additional analytical insights were raised by stakeholders, and these are described within the themes presented below.

#### 3.1.1. Challenges

**3.1.1.1. Denial, fear, and stigma.** Barriers relating to denial and reluctance to seek help were due to: being frightened (Evans and Farming Community Network, 2022; Kelly and Yarwood, 2018), a fear of being taken away and put in a home or of losing the farm (The Newsroom, 2017), and fear of judgement by others (Eisenhauer et al., 2015; Herron and Rosenberg, 2017). Herron and Rosenberg (2017) describe a person who “did not want her neighbours and other community members thinking she was ‘nuts’, so she said she was depressed” (pp. 84), which demonstrates the prevailing stigma surrounding dementia. This stigma

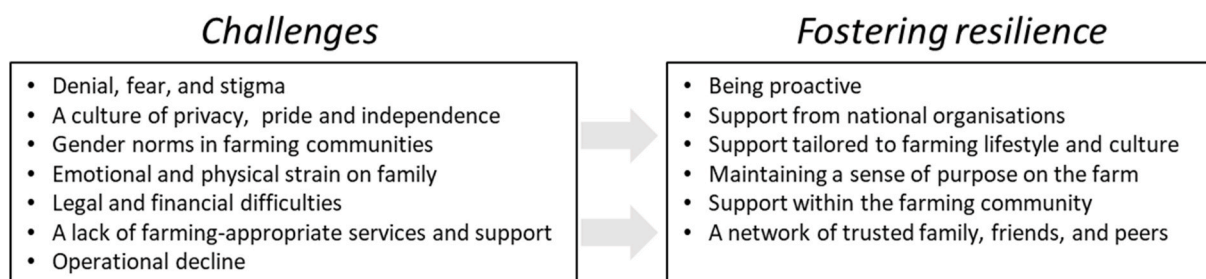


Fig. 2. Overview of themes relating to the challenges and ways to foster resilience in farming communities affected by dementia.



can result in people living with dementia experiencing negative reactions within the farming community, where they can be avoided (Eisenhauer et al., 2015) or ignored by others (Chisholm and Bischooping, 2019; Herron and Rosenberg, 2017). Chisholm and Bischooping (2019) describe a tight-knit community where most people know each another, meaning that “deliberate non-interactions are acutely visible” (pp. 1451) in the community marketplace.

**3.1.1.2. A culture of privacy, pride, and independence.** A culture of privacy, pride, and independence can exist within farming communities, which impacts openness to support (Chisholm and Bischooping, 2019; Herron and Rosenberg, 2017; Kelly and Yarwood, 2018; The Newsroom, 2017; NFU, 2024). Symptoms may be ignored if there is nobody else available to take on a person’s responsibilities on the farm (Eisenhauer et al., 2015) and because “farmers are known for putting their work and responsibilities first” (The Newsroom, 2017, pp. 2). The farm is often prioritised above all else, including health (Eisenhauer et al., 2015; Kelly and Yarwood, 2018). It can also lead to a delay in accessing formal services resulting in delayed diagnoses and a lack of appropriate care for people with dementia (Herron and Rosenberg, 2017; Kelly and Yarwood, 2018; Evans & FCN, 2022; NFU, 2024; Eisenhauer et al., 2015). Further, it can lead to social isolation (Herron and Rosenberg, 2017; Kelly and Yarwood, 2018; Lammers-Helps, 2015). As a participant in Herron and Rosenberg (2017) explained “Support groups are not a normal rural solution, when you’re raised on the opposite side of the snowstorm to everybody else you learn how to fix it yourself” (pp. 85). The ‘norm’ of not seeking support can result in a lack of planning to adapt to life with dementia. This could also lead to farming families reaching crisis which not only impacts the members psychologically, but also can have financial implications as the farm also represents a livelihood and home.

**3.1.1.3. Gender norms in farming communities.** People continue with traditional duties on the farm or inside the farmhouse for as long as possible. These involve ‘alpha male’ narratives, in which the male runs the farm and the outdoor farm work (Chisholm and Bischooping, 2019; Evans & FCN, 2022; FCN, 2021). Related to these traditional values, barriers to accessing support includes the farmers themselves, with male partners being known to refuse support (Herron and Rosenberg, 2017; Morgan et al., 2002; Kelly and Yarwood, 2018). For women, a rural identity as a “good woman” (Eisenhauer et al., 2015) was reported, and the roles relating to maintaining the household (Chisholm and Bischooping, 2019; Eisenhauer et al., 2015; Evans & FCN, 2022; Herron and Rosenberg, 2017; Greenlee, 2013). After a diagnosis of dementia, women still provide support to their families and to the running of the household (Herron and Rosenberg, 2017). Dementia can impact the identity of farmers, who have a deep connection to their land and see their work as integral to their self-concept (Chisholm and Bischooping, 2019; Froese, 2020; Kelly and Yarwood, 2018; Ryan, 2022). Kelly and Yarwood (2018) elaborate that as the dementia progresses, traditional gender roles can change, with farmers having to relinquish responsibilities relating to running their farming business.

**3.1.1.4. Emotional and physical strain on the family.** Farming families affected by dementia experience emotional and physical strain. Family members often need to take on two new roles – the role of caring and the farm-based responsibilities that had previously belonged to the person living with dementia (Evans & FCN, 2022; FCN, 2021; Kelly and Yarwood, 2018; NFU, 2024). The consequences of this are serious, as described in NFU (2024), “Dad left his job and ploughed the vast majority of his life savings into settling bills and getting the accounts back into the black while simultaneously his mental health seeped into the red” (pp. 3).

Adult children experience challenges relating to juggling work and/or family life with responsibilities related to caring for the family farm.

Adult children with young families can find a combination of farm work, caring for a parent living with dementia, raising one’s own family and off-farm employment overwhelming (Morgan et al., 2002; Robins, 2006; NFU, 2024). Further, some find themselves inheriting a farm to run, while living and working elsewhere (Ryan, 2022). Grandchildren also provide support, highlighting the presence of young carers in farming communities as described in NFU (2024, p.3): “With her dementia progressing and dad now singlehandedly running both the admin and practical side of the farm, I would take a dinner up to her after school and spend as much time with her as I could”.

**3.1.1.5. Legal and financial difficulties.** Care costs can threaten the financial stability of the farm (Robins, 2006; NFU, 2024; Laird, 2009; Evans & FCN, 2022). Sometimes, the farm must be sold, or parts of it, to pay for care (Laird, 2009; NFU, 2024). The stakeholder engagement activity highlighted an additional issue around benefits and entitlements. It was suggested that when farmers are still working, they often do not realise that they are eligible to claim certain benefits, and most would never pick up the phone to ask. Additional complexities were reported regarding the benefit system and how is not appropriate for farmers. For example, universal credit (a UK-based social security payment to help with living costs) requires monthly income to be declared which is not suitable with seasonal fluctuations in productivity and cashflow.

Legal troubles relating to dementia are commonplace (Case, 2016; Froese, 2020; Kelly and Yarwood, 2018; NFU, 2024; Pilditch, 2018). Dementia complicates succession planning and difficulties often arise, particularly when no plans are in place, such as up-to-date wills or lasting power of attorney (Froese, 2020; Kelly and Yarwood, 2018; NFU, 2024). This is relatively common, as Froese (2020) remarks: “It saddens me every time I survey my audiences and find that 25 percent of them don’t even have a will. Some have wills but no power of attorney” (pp. 2). Disputes over farm ownership and inheritance are common, leading to legal battles within families (Pilditch, 2018; Case, 2016; Froese, 2020).

**3.1.1.6. A lack of farming-appropriate services and support.** Local services can be lacking in farming communities (Eisenhauer et al., 2015; Froese, 2020; Laird, 2009; Lammers-Helps, 2015; NFU, 2024). Difficulties related to transport and geographical distances (Eisenhauer et al., 2015; Morgan et al., 2002), lack of specialists (Lammers-Helps, 2015) lack of respite care (Laird, 2009), and lack of access to social workers (NFU, 2024) are reported. Froese (2020) adds that due to rurality and distance from formal support, farming families affected by dementia may need to “create your own team of friends to help you navigate the losses ahead” (pp. 3).

A lack of specialised farming support and information is a barrier to accessing appropriate care and support (Evans & FCN, 2022; FCN, 2021; NFU, 2024; Eisenhauer et al., 2015; Kelly and Yarwood, 2018). Services, information, and advice are perceived to be ‘urban-centric’ and not suitable for supporting farmers and the farming lifestyle and identity (Kelly and Yarwood, 2018; Eisenhauer et al., 2015; Evans & FCN, 2022). The NFU (2024) suggests that “The lack of dementia awareness, information and resources within agriculture is definitely something that need to be rectified” (pp. 4).

**3.1.1.7. Operational decline.** Dementia can result in an operational decline on the farm (Evans & FCN, 2022; FCN, 2021; Froese, 2020; Kelly and Yarwood, 2018; NFU, 2024). Administrative tasks and paperwork can become difficult (Kelly and Yarwood, 2018; NFU, 2024), as can taking care of animals (Kelly and Yarwood, 2018). Given the constant maintenance work required to farm, older buildings, sheds, fences, and gates can fall into disrepair (Evans & FCN, 2022; FCN, 2021). Furthermore, dementia affects the ability to perform farm tasks safely and efficiently, posing an increased risk of accidents or injury (Chisholm and

Bischoping, 2019; Eisenhauer et al., 2015; Lammers-Helps, 2015; Kelly and Yarwood, 2018). The stakeholder engagement meeting added that physical challenges can extend to the farmhouse, as they are generally older buildings with steep staircases and poor insulation and heating.

### 3.1.2. Fostering resilience

Alongside the challenges faced by farming communities in relation to dementia, a number of themes were identified relating to taking positive or helpful action and fostering resilience.

**3.1.2.1. Being proactive.** Planning ahead for any eventuality is vital, to effectively support both families and businesses. Wills, business plans and Lasting Power of Attorney should be made and kept up to date (Froese, 2020; The Newsroom, 2017; NFU, 2024). As Froese (2020) elaborates: "My intent in writing this piece is to alert farm families to wipe out all procrastination of getting your wills, financial plans, business plan, and vision for the farm in place while you have good brain power of all the farm team" (pp. 2).

Several articles described being proactive in response to a diagnosis of dementia (Evans & FCN, 2022; Froese, 2020; Lammers-Helps, 2015; NFU, 2024). Suggestions included asking for support pre-diagnosis, writing a checklist, keeping a log or a diary (Evans & FCN, 2022), and getting educated to help cope with the changes (Evans & FCN, 2022; NFU, 2024; Lammers-Helps, 2015). In terms of education, some carers recommended books as useful sources and suggested that online resources were not suitable for all (Evans & FCN, 2022; NFU, 2024). This was echoed in the stakeholder meeting.

Educating others was also recommended. In some instances, people living with dementia take steps to educate other people to attempt to minimise gossip and to increase understanding and sensitivity toward the person living with dementia (Herron and Rosenberg, 2017). Lammers-Helps (2015) also highlights the importance of informing others on how they may support the person with dementia and their carer.

**3.1.2.2. Support from national organisations.** National organisations are available to offer support in some countries, and making contact to discover how they may be able to help is important (Lammers-Helps, 2015; Evans & FCN, 2022; Kelly and Yarwood, 2018). Froese (2020) and Lammers-Helps (2015) suggest contacting charities that support people living with dementia for education and support around coping strategies. However, national organisations that support farmers may be in a good position to offer support and advice relating to the challenges specific to farming families (Evans & FCN, 2022; FCN, 2021; Kelly and Yarwood, 2018; The Newsroom, 2017; NFU, 2024). National organisations can provide anonymity which may help people to seek support while avoiding stigma (Kelly and Yarwood, 2018). The stakeholder engagement activity suggested that services and organisations that offer support, "have to go to them rather than expect them to come to us" and that continuity is needed to build trust and relationships.

**3.1.2.3. Support tailored to farming lifestyle and culture.** People living in farming communities have a very strong attachment to the land and the identity of a farmer is intricately linked to the neighbourhood, the farm, and their sense of self (Chisholm and Bischoping, 2019; Froese, 2020; Greenlee, 2013; Herron and Rosenberg, 2017; Kelly and Yarwood, 2018; Ryan, 2022). This attachment can be used to tailor support and make it more person-centred. Using the farmhouse as a location to provide services has been noted as useful particularly in the early stages of dementia as a private, convenient, and familiar place for people living with dementia (Evans & FCN, 2022). As Kelly and Yarwood (2018, p.101) explain: "There were cases in which the private space of the farmhouse could be employed to encourage farmers and their families to use medical or welfare support."

The language in which support is provided was viewed as important during the stakeholder engagement activities but not mentioned in the

literature. This could be due to the articles describing the experiences of people in predominantly monolingual communities; however, because none of the articles comment on language, we cannot be certain. Using a person's first language when discussing sensitive topics such as dementia is important for comprehension and also for developing a trusting relationship which will make someone more likely to reach out for support in the future as their needs change. A high percentage of farmers in Wales are first language Welsh speakers, therefore conducting assessments in English can be challenging if a person is more fluent in Welsh. Further, stakeholders and rural conference attendees noted how it can be harder for services to build relationships and trust if people are not comfortable speaking in their second language. One Welsh speaker described this during the consultation phase: "Speaking English is like wearing court shoes, but speaking Welsh is like wearing my slippers, it's more comfortable".

The value of including people living with dementia and supporting them to be "active partners" in decisions about their own care was also reported (Kelly and Yarwood, 2018). Lammers-Helps (2015) elaborates that it is particularly important for families to include the person living with dementia in decisions about their own care because "it's dehumanizing to exclude them" (pp. 2). Ensuring that support services align with the cultural and linguistic needs of farming communities not only enhances accessibility but also fosters trust, improving engagement with services and well-being outcomes for people living with dementia.

**3.1.2.4. Maintaining a sense of purpose on the farm.** Occupation and feelings of usefulness are vital for people affected by dementia and in farming communities this is part of the farmer identity. Chisholm and Bischoping (2019) describe this connection: "He is this land" (pp. 1448). Maintaining involvement in farm activities helps preserve identity and feelings of usefulness (Chisholm and Bischoping, 2019; Evans & FCN, 2022; Herron and Rosenberg, 2017; Kelly and Yarwood, 2018; Lammers-Helps, 2015). Herron and Rosenberg (2017) further highlight the need to recognise the contributions people with dementia can make. However, safety was raised as an important consideration: "While continuing to work on the farm can help those afflicted with cognitive problems to feel useful and valued, families need to be aware of the person's limitations." Lammers-Helps (2015, pp. 2).

**3.1.2.5. Support within the farming community.** In contrast with themes relating to privacy, pride, and independence, farming communities foster resilience through tailored support and strong caregiving cultures, and local networks like the Farming Community Network (FCN) provide practical and emotional assistance (Evans & FCN, 2022). Herron and Rosenberg (2017) emphasise the value of community networks in reducing isolation and encouraging participation, and they argue "More attention needs to be paid to what people with dementia can offer their communities" (pp. 86). One example in the literature included a retired Farmers Group that enabled individuals to pass on their knowledge and advice to younger farmers ("Emma Harper praises", 2018). Farming communities are also known for their strong commitment to mutual aid, as Ryan (2022) articulates: "Farmers will drop anything to help a neighbour" (pp. 1). Similarly, The Newsroom (2017) notes, "Our farming communities look after their elderly residents within the farming family probably more than any other sector" (pp. 1).

**3.1.2.6. A network of trusted family, friends, and peers.** A trusted circle of family and friends is critical for farming families living with dementia, providing both emotional and practical support. Such networks often include family members, neighbours, and close community connections. Eisenhauer et al. (2015) emphasise this reliance of how "Older women were quite adept at using their trusted, 'insider' network of family and neighbours for health resources" (pp. 138). Similarly, the Farming Community Network (2021) highlight the breadth of this support: "Family, neighbours - and even some most unlikely friends - also helped"

(pp. 4). [Lammers-Helps \(2015\)](#) further notes the importance of trusted relationships in adapting to changing roles within farming families, particularly during transitions in caregiving responsibilities.

Relatedly, [Evans and FCN \(2022\)](#) emphasise the value of peer-led support: "Find locals who have experienced this in their family. They will be your best help, and become immediate friends" (pp. 12). Local initiatives, such as the Retired Farmers Group, create opportunities for peer support and mutual aid. "[Emma Harper praises](#)" (2018) highlights its impact: "We have a right good blether and discuss different things about farming and other things" (pp. 2). Such networks reduce isolation and provide practical guidance tailored to the unique challenges of farming.

#### 4. Discussion

This study examined the challenges faced by farming communities relating to dementia and explored strategies to foster resilience. This is important because if policy and practice changes are to be made to improve support within farming communities affected by dementia, greater understanding is required of rural contexts and their residents with lived experience. The findings reveal a combination of factors that influence access to dementia care and support in farming contexts. Addressing these challenges requires targeted interventions and a commitment to tailoring support to the unique strengths, assets, and needs of farming populations.

##### 4.1. Addressing barriers to accessing support

Barriers to dementia support can be closely linked to the culture of farming. A strong sense of privacy, pride, and self-reliance often delays help-seeking behaviour ([Chisholm and Bischooping, 2019](#); [Herron and Rosenberg, 2017](#); [Kelly and Yarwood, 2018](#); [The Newsroom, 2017](#); [NFU, 2024](#)). Fear and stigma surrounding dementia further exacerbate this issue, with individuals reluctant to access support due to concerns about judgement or the potential loss of autonomy ([Evans & FCN, 2022](#); [Herron and Rosenberg, 2017](#)), demonstrating the need to raise awareness and understanding about dementia and reduce stigma through targeted outreach. These findings primarily come from articles reporting the experiences of male farmers tending to the land and business and women in 'household' roles, representing traditional gender roles. Women in primary farming roles are underrepresented in research ([Wheeler and Nye, 2025](#)), and thus future research may wish to explore what can be learned from women in these positions and their readiness to seek support.

The findings relating to farming culture align with previous research on mental health and loneliness in farming communities, which has identified challenges linked to farming identities and culture ([Wheeler et al., 2023](#)). Studies on farming populations frequently highlight the impacts of isolation, stigma, and cultural pride on help-seeking behaviours, as well as the importance of community networks in supporting people in farming communities ([Wheeler et al., 2022](#)). These overlaps suggest that interventions addressing mental health and loneliness in farming communities may provide valuable insights for providing dementia support. In particular, the shared emphasis on strong social connections and tailored support underscores the need for approaches that integrate mental health and dementia strategies for people affected by dementia in farming communities.

The importance of considering language preferences was not well-represented in the literature identified in the scoping review but was raised during stakeholder engagement and conference presentation feedback. The wider literature around language preferences in health-care support this argument, revealing barriers to support and effective communication when language needs are not met ([Spencer, Cooledge & Hoare, 2025](#)). Specifically for people living with dementia evidence suggests this can lead to negative care experiences ([Giebel et al., 2024](#)) and be detrimental to wellbeing ([Martin, Woods & Williams, 2019](#)). In

Wales (UK), where this review and stakeholder engagement were undertaken, 43 % of farmers are Welsh speaking ([Welsh Government, 2019](#)), which further demonstrates the need for ensuring culturally and linguistically appropriate communication strategies in approaching support for farming families.

The wider literature around dementia in rural areas describes a lack of appropriate services resulting in an increased reliance on informal networks (e.g. [Roberts et al., 2023](#); [Bayly et al., 2020](#)). The findings from the present review support these findings but suggest an added level of complexity: Farming households are often intergenerational ([Morrison-Rees et al., 2023](#)), and adult children and grandchildren can be required to manage their own responsibilities with caregiving and maintaining the farm ([Morgan et al., 2002](#); [Robins, 2006](#); [NFU, 2024](#); [Ryan, 2022](#)). This indicates that farming families may be experiencing additional strain compared to those living in rural areas in general, relating to running a farm as both a business and family home. The intergenerational nature of farming households demonstrates a need for considering support for carers across the life course. Young members of the family may not identify themselves as carers and may be unsupported ([Masterson-Algar et al., 2023](#)). Consequently, the evidence presented here suggests that taking a whole family approach to care and support may be beneficial ([Kokorelias et al., 2019](#); [Braithwaite Stuart, Jones & Windle, 2022](#)), ensuring communication with all generations to avoid missing younger carers in farming families who may be taking on new roles both from a care perspective, but also relating to running the farm.

Many farming families live in a precarious financial situation, with low profits and subsidies providing a significant proportion of their income (e.g., [Devenish, 2022](#)). Dementia also poses a risk of significant and unique financial and legal problems for farming families, where the family home, business and associated assets are deeply intertwined. This is particularly the case if no advanced planning is in place. For example, some families are forced to sell land or assets to pay for care ([NFU, 2024](#)), and others may face legal and financial conflict relating to outdated wills or lack of power of attorney ([Froese, 2020](#); [Kelly and Yarwood, 2018](#); [NFU, 2024](#)). Planning ahead is critical, as emphasised by [Froese \(2020\)](#): "wipe out all procrastination of getting your wills, financial plans, business plan, and vision for the farm in place while you have good brain power of all the farm team" (pp. 2).

##### 4.2. Fostering resilience in farming communities

This study has key theoretical implications for dementia care in farming communities. The findings align with the resilience model of [Windle et al. \(2023\)](#), which stresses that resilience is not only about individual strength but also about the role of strong social networks and community support in helping individuals cope with challenges. Themes presented by [Windle et al. \(2023\)](#) that overlap with our findings include focusing on what one can do, maintaining pre-diagnosis activity as long as possible, adapting to changing abilities, having a sense of purpose, continuing with hobbies and interests, educating oneself and others, openness about the diagnosis, support from family, friends and peers, support from the community and from professional support services. Internationally, policies are increasingly promoting use of strengths-based approaches to supporting people requiring care or support ([Department of Health and Social Care, 2016](#); [Welsh Government, 2014](#); [Government of Canada, 2019](#); [Government of the Netherlands, 2020](#)) highlighting the value of working with people to identify their strengths and assets and tailor support accordingly. However, despite there being some evidence directly from people living with dementia in this review ([Herron and Rosenberg, 2017](#); [Lammers-Helps, 2015](#)), much of the evidence around fostering resilience in people living with dementia was by proxy, indicating a critical gap in understanding their perspectives within farming contexts. Furthermore, there was little mention of individuals affected by rare dementias. Therefore, further research exploring the experiences of more people



living with different types of dementia in farming communities is suggested to gain a better understanding of their needs.

Fostering resilience in farming communities requires nurturing strong community networks. Given that farming communities have a tradition of mutual support (Ryan, 2022; The Newsroom, 2017), the support offered from a trusted local presence within those communities such as agricultural agencies may be most readily accepted. Farming-appropriate peer support networks like the Retired Farmers Group (“Emma Harper praises”, 2018) and organisations such as those engaged in the stakeholder engagement meeting play a critical role in reducing isolation and providing practical assistance. It is essential that community support fits with the farming lifestyle and that those providing support understand the unique challenges faced. As Roberts et al. (2023) suggest “supporting people with dementia in rural areas requires input and innovation from the people, organisations and services local to those communities” (pp. 23). In farming communities affected by dementia, this means that resilience can be increased by leveraging community resources, peer support networks, and trusted local agencies.

Appropriate education and resources about dementia within agriculture that will equip farming communities with the information they need and encourage advanced planning and early help-seeking behaviour is required (Herron and Rosenberg, 2017; Evans & FCN, 2022; NFU, 2024). Some people may be unaware of the practical steps that can be taken to reduce the impact of dementia on the person, their family, and their farm. Evans and FCN (2022) highlighted that books and written information can be particularly useful. Members in the stakeholder engagement meeting discussed that many may be unlikely to make a phone call to ask for information or support. Furthermore, both stakeholder engagement and the review noted a reluctance to access information online. This suggests that written information that feels relevant with guidance around how and why to act upon it may be welcomed. The findings of this review could be used to guide the development of healthcare information tailored to the unique needs of farming populations. To ensure that any intervention or resource produced is suitable, we emphasise the importance of co-designing together with those they seek to serve, as well as representatives from organisations that support them.

Farmers’ deep connection to their land can be used to support resilience through maintaining a sense of purpose on the farm (Chisholm and Bischooping, 2019; Evans & FCN, 2022; Herron and Rosenberg, 2017; Kelly and Yarwood, 2018; Lammers-Helps, 2015), and thus supporting people to remain involved safely is key. However, as dementia progresses, their identity and ability to manage farm work is impacted (Chisholm and Bischooping, 2019; Froese, 2020). Roles may change, and new more formalised support may be required. Many farming families find care services to be urban-centric and unsuitable for their needs (Kelly and Yarwood, 2018). Research into the benefits of farming for people with care needs has grown in recent years and is known as care farming, social farming, connective farming, or green care farming (Jarábková et al., 2022). Care farming may offer a more person-centred alternative by integrating care with familiar farming environment, enabling individuals with dementia to remain connected to their identity and surroundings. This setting can be particularly beneficial for individuals who are accustomed to the routines and sensory experiences of farm life. The outdoor environment and opportunities for physical activity offer additional benefits, such as improving mood, reducing anxiety, and supporting overall well-being (Evans & FCN, 2022; Lammers-Helps, 2015). For those who may struggle to adapt to conventional care settings, care farming provides a tailored, supportive alternative that aligns with their values and lifestyle. Research around care farms was excluded from the present review, as we were interested in the experiences of people with a farming background. None of the articles describing care farms were focussed on the experiences of residents from farming backgrounds, therefore the impact of care farms on farmers living with dementia may be an avenue for further exploration.

## 5. Conclusions

Addressing dementia in farming communities requires comprehensive and targeted interventions. Tailored outreach and education efforts are crucial to raise awareness about dementia symptoms in farming communities (Herron and Rosenberg, 2017). Policymakers must consider the challenges faced by farming communities affected by dementia, that are additional to those faced by people living with dementia rurally in general. Support systems should be equipped to meet the unique set of needs of farming populations.

## CRedit authorship contribution statement

**Jennifer Rhiannon Roberts:** Writing – review & editing, Writing – original draft, Visualization, Supervision, Project administration, Methodology, Investigation, Formal analysis, Conceptualization. **Bethan Naunton Morgan:** Writing – review & editing, Writing – original draft, Project administration, Methodology, Investigation, Formal analysis. **Catrin Hedd Jones:** Writing – review & editing, Methodology, Formal analysis, Conceptualization. **Gill Windle:** Writing – review & editing, Funding acquisition.

## Ethical standards

The stakeholder engagement aspect of the study received a favourable opinion from the Bangor University Medical and Health Sciences Academic Ethics Committee (2024-0470).

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## Declaration of competing interest

None declared.

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.jrurstud.2025.103710>.

## Data availability

Data will be made available on request

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