

REVIEW

A systematic review on inequalities in accessing and using community-based social care in dementia

Clarissa Giebel,^{1,2}  Kerry Hanna,³  James Watson,¹  Thomas Faulkner,^{1,2,4}
Lena O'Connell,¹ Sandra Smith,² and Warren James Donnellan⁵

¹Department of Primary Care & Mental Health, University of Liverpool, Liverpool, UK

²NIHR Applied Research Collaboration North West Coast, Liverpool, UK

³School of Health Sciences, University of Liverpool, UK

⁴Mersey Care NHS Trust, UK

⁵Department of Psychology, University of Liverpool, Liverpool, UK

ABSTRACT

Objectives: To evaluate and synthesize the evidence base on barriers and facilitators to accessing and using community-based social care in dementia.

Design: Mixed-methods systematic review.

Setting: Community-based social care (such as day care, respite care, paid home care, and peer support groups).

Participants: People living with dementia and unpaid carers.

Measurements: Seven databases were searched in March 2022, including English and German evidence published from 2000 focusing on inequalities in community-based social care for dementia across the globe. Titles and abstracts were screened by two reviewers, with all full texts screened by two reviewers also. Study quality was assessed using QualSys.

Results: From 3,904 screened records, 39 papers were included. The majority of studies were qualitative, with 23 countries represented. Barriers and facilitators could be categorized into the following five categories/themes: situational, psychological, interpersonal, structural, and cultural. Barriers were notably more prominent than facilitators and were multifaceted, with many factors hindering or facilitating access to social care linked together.

Conclusions: People with dementia and carers experience significant barriers in accessing care in the community, and a varied approach on multiple levels is required to address systemic and individual-level barriers to enable more equitable access to care for all.

Key words: inequalities, social care, dementia

Introduction

Across the globe, the WHO estimates around 55 million people are currently living with dementia, the majority of which are residing in lower- and middle-income countries (ADI, 2022). This number is only rising, further exacerbating dementia as a global public health problem.

Correspondence should be addressed to: Clarissa Giebel, Department of Primary Care & Mental Health, University of Liverpool, Waterhouse Building Block A, Brownlow Street, Liverpool, UK. Email: Clarissa.Giebel@liverpool.ac.uk. Received 16 Dec 2022; revision requested 31 Jan 2023; revised version received 21 Mar 2023; accepted 06 Apr 2023. First published online 12 May 2023.

Social care and social support services such as paid home carers, respite care, day care centers, and peer support groups are all vital in enabling people with dementia and their carers to live well and to have some of the caring duties removed (i.e. Roes *et al.*, 2019; Samsi *et al.*, 2022). The value of social care and social support services for dementia has been highlighted starkly during the COVID-19 pandemic, when sudden service closures left people living with dementia (PLWD) and their carers bereft and experiencing poorer mental well-being (Giebel *et al.*, 2021a, 2021b). This lack of care and support has been corroborated in other research across the

globe (Rainero *et al.*, 2020; Rising *et al.*, 2022) and been synthesized in recent systematic reviews (i.e. Giebel *et al.*, 2022a, 2022b). Given different funding systems and care infrastructures across different countries, especially between lower- and middle-income countries and high-income countries, social care, and support services, may vary not only in their availability, but also in their formats, across different countries. Including a broad range of community-based services is thus important.

Barriers to accessing social care and support after a diagnosis were evident prior to the pandemic, but it appears they have been amplified since. There are a number of barriers for PLWD, and their carers, in accessing and utilizing the right care at the right time – including where they live (rural remote versus urban, the region within a country, as well as their postcode within a city), their ethnic, financial, and educational background, their health literacy, dementia subtype, living situation (alone or with a carer), and many others (Armstrong *et al.*, 2022; Stephan *et al.*, 2018; Watson *et al.*, 2021). People with dementia and their carers who are residing in more disadvantaged regions, for example, often have less choice, and awareness, of existing services, which is further amplified for people with rarer types of dementia, such as young-onset dementia. For those with rarer dementia subtypes, support groups which are mostly catering for older and Alzheimer's disease dementia attendees are not suitable due to age and symptomatology (Millenaar *et al.*, 2016). Similarly, people from minority ethnic backgrounds are often less likely to access external support and are instead mostly cared for by their family, despite external support offering some respite from caring (Nielsen *et al.*, 2021). While there is a growing body of literature on these individual barriers to accessing and using social care and support for dementia, these barriers and underpinning inequalities intersect and need to be considered jointly, not separately, in order to be addressed.

To date, there appears to have been no systematic review critically analyzing and synthesizing the literature on inequalities in access to and use of post-diagnostic community-based dementia social care. A recent systematic review has focused on inequalities in accessing health care for dementia based on routine and cohort data studies (Watson *et al.*, 2021), and one review specifically focused on one barrier – ethnicity, over a decade ago (Cooper *et al.*, 2010). Instead, some systematic reviews appear to focus on risk factors of dementia based on socioeconomic backgrounds (i.e. Bodryzlova *et al.*, 2022). In order to address inequalities in dementia care, we first need to have a coherent overview and critical understanding of those barriers and the evidence behind them, to then develop targeted solutions and generate facilitators to

enable access to dementia care in different countries and settings.

Therefore, the aim of this mixed-methods systematic review was to explore and synthesize the evidence base on the barriers and enablers faced by PLWD in accessing and using community-based social care services. This will provide clearer solutions to addressing the intersectionality of barriers to accessing care and enable policy recommendations which need to be tailored to individual countries.

Methods

The protocol of this mixed-method systematic review was prospectively registered on PROSPERO [ID: CRD42022306150].

Search strategy

JW performed searches of seven electronic databases in March 2022 (APA Psycinfo, CINAHL Plus, Medline, Web of Science, PubMed, Scopus, and Cochrane Library). Databases were searched for qualitative and quantitative studies published since 01/01/2000 using the following search term strategy:

(‘dementia’) AND (‘inequalit’ OR ‘inequit*’ OR ‘barrier*’) AND (‘social care’ OR ‘social support’ OR ‘day care’ OR ‘respite care’ OR ‘domiciliary care’ OR ‘home care’ OR ‘support’) NOT (‘pharmacolog*’ OR ‘medicat*’ OR ‘drug’)*

Results from literature searches were exported into Endnote, where duplicates were removed. Snowballing of references from electronic literature searches for additional papers were also performed to locate any further, pertinent papers.

Inclusion and exclusion criteria

This systematic review included both quantitative and qualitative studies published from 2000 until February 2022, in English or German. Studies were included if they reported on access and usage to community-based social care and social support services for PLWD and/or unpaid carers. Community-based social care and social support services included day care, respite care, paid home care, befriending services, peer support groups, social activities, and meal deliveries. Studies were excluded if they were not published in English or German, contained no peer-reviewed data (i.e. letter to the editor, commentary, editorial, and thesis); did not focus on people with dementia and/or carers; did not include evidence on inequalities in accessing and using social care; or focused on residential long-term care. This was based on what was indicated first in the title and abstract, and then in the full text, as also described under study selection. Where social care and support service data

were not referred to in the abstract, the paper was not advanced for full-text screening.

Study selection

Two researchers (WD, LO) assessed the title and abstracts of retrieved records against inclusion criteria and exclude papers that failed to meet inclusion criteria in Stage 1. The selected records were read in full in Stage 2 by two researchers (KH, WD), and papers that met the inclusion criteria were included in the final review. Any discrepancies at Stage 1 or 2 were resolved in discussion with a third researcher.

Data extraction

JW extracted data from the 39 papers included in this systematic review. All pertinent data were extracted by reading through each paper to identify the relevant information. JW generated a Microsoft Excel spreadsheet, with a column noting the following for each study: author, year of publication, study location (country(ies), geographic regions) study method (qualitative, quantitative or mixed-methods), design (semi-structured interviews, focus groups, surveys, etc.), the demographic or socioeconomic data, if any, collected of participants. Following the development of the themes in the findings section by KH and WD, fields for the types of barriers and facilitators studied in each paper, and a summary of the papers' findings were added to the spreadsheet.

Quality assessment

Study quality was assessed using the QualSyst (Kmet *et al.*, 2004). The QualSyst tool encompasses checklists to assess the quality of quantitative and qualitative research methodologies. For qualitative studies there are ten criteria to assess quality, for quantitative studies there are fourteen criteria. There are potential scores between zero and two in response to any of the included criteria. A maximum score of two is given if the paper met the criteria completely, one for meeting the criteria partially and zero if the study failed to meet the criteria. There are some criteria in both qualitative and quantitative quality assessment checklists which may not be applicable, and so "N/A" can be stated, reducing the potential overall score, as the study may not include methods which are related to the specific criteria within the checklist. Papers were assessed using the QualSyst method by JW and TM independently, with any discrepancies between ratings were discussed jointly. Quality ratings did not influence study selection, but were used in guiding the discussion of findings and drawing conclusions. A score of 80% or above indicates a strong study, 70–80% indicates good, 50–69% indicates adequate, and below 50% indicates a poor-quality study.

Data synthesis

KH and WD discussed the findings of the 39 research papers included in this review, with the generated themes finalized in discussion with the wider research group (CG, JW, and SS). This involved narratively synthesizing the data extracted as specified above, focusing on different key barriers and facilitators identified while reading through the included studies. As this is a mixed-methods systematic review, we synthesized findings from both quantitative and qualitative studies. By including both quantitative and qualitative research, we interpreted findings complementarily, by synthesizing quantitative and qualitative evidence first separately, and then jointly. This enabled understanding whether either type of methodology confirmed findings from the other research methodology.

Results

Overview of included studies

There were 39 research studies included in this systematic review (see Table 1). The PRISMA Flowchart (Figure 1) depicts the inclusion process. All papers included findings related to barriers for PLWD and/or their carers in accessing or using community-based social care services and four contained findings related to enablers to social care access or use. It was not always possible to identify whether the PLWD, their carer or the dyad was accessing the dementia services reported in the included studies. If clearly stated in the study, the intended recipient of the care has been included in the results. However, the authors concur that services can benefit both groups directly and indirectly, and so have not otherwise attempted to interpret the intended service user within the findings of this review if unstated.

Thirty-five (89.7%) papers used qualitative methods, primarily employing semi-structured interviews and/or focus groups. Another three papers employed quantitative methods and one used a mixed-methods design. The three quantitative studies used different methods of analyses. These included pooled prevalence ratios for investigating equity of access to services across multiple countries (Albanese *et al.*, 2011), a cross-sectional survey using logistic regression to explore barriers to service access (Kyriopoulos *et al.*, 2014), and latent growth curve modeling using longitudinal data on unmet need, including the impact of various socioeconomic factors (Read *et al.*, 2021). Giebel *et al.* (2021) employed mixed-methods, with 103 carers of PLWD from either England or the Netherlands responding to a questionnaire, generating data on

Table 1. Descriptive summary of methods and setting of the research papers included in systematic review

AUTHOR (YEAR)	COUNTRY	SAMPLE SIZE	DEMOGRAPHIC / SOCIOECONOMIC DATA COLLECTED	QUALITATIVE / QUANTITATIVE	METHODS	BARRIERS	ENABLERS
Albanese <i>et al.</i> (2011)	China, India, Mexico, Peru, Dominican Republic, Puerto Rico, Venezuela and Nigeria	17,944	Age; Gender; Education, Marital Status, Dependents, mobility, health conditions Inequity: Assets, health insurance Ethnicity	Quantitative	Survey / Interviews	Situational	–
Armstrong <i>et al.</i> (2022)	United Kingdom	15	Ethnicity	Qualitative	Semi-structured interviews	Psychological Interpersonal Structural Cultural	–
Baghirathan <i>et al.</i> (2020)	Bristol, UK	92	Ethnicity	Qualitative	Grounded Theory Analysis Interviews Focus Groups Semi-structured interviews	Theory Psychological Structural	Structural
Bruce and Paterson (2000)	Australia	24	–	Qualitative	Focus groups Semi-structured interviews	Structural	–
Casado <i>et al.</i> (2015)	USA	23	Ethnicity	Qualitative	Focus groups	Psychological Cultural	–
Cascioli <i>et al.</i> (2008)	South Wales	45	–	Qualitative	Interviews	Psychological	–
Clarke and Bailey (2016)	North East England	75	Non-urban locations	Qualitative	Diaries and interviews	Psychological Structural	–
Contreras, Mioshi and Kishita (2022)	United Kingdom	12	Age; Gender; Relationship type; Education Level; Work status at time of diagnosis	Qualitative	Semi-structured interviews	Psychological Interpersonal	Interpersonal
Cotton <i>et al.</i> (2021)	Midwest, USA	10	Socioeconomic status	Qualitative	Semi-structured interviews	Situational Structural	–
Czapka and Sagbakken (2020)	Norway	8	Socioeconomic status, immigration status	Qualitative	Semi-structured interviews	Psychological Structural Cultural	–
Ferguson-Coleman <i>et al.</i> (2020)	Northern Ireland	3	–	Qualitative	Content analysis	Structural	–
Richardson <i>et al.</i> (2019)	Los Angeles, USA	15	Ethnicity; Cultural differences	Qualitative	Ethnocultural Semi-structured interviews Modified thematic analysis	Psychological Cultural	–

Table 1. Continued

AUTHOR (YEAR)	COUNTRY	DEMOGRAPHIC / SOCIOECONOMIC DATA COLLECTED	QUALITATIVE / QUANTITATIVE	METHODS	BARRIERS	ENABLERS
Gibson <i>et al.</i> (2015)	North East England	39	Qualitative	Semi-structured interviews	Psychological Structural	–
Giebel <i>et al.</i> (2021)	England, Netherlands	103; 13	Mixed-methods	Questionnaires Interviews	Psychological Structural	–
Giebel <i>et al.</i> (3)	North West England	15	Qualitative	Semi-structured interviews	Psychological Structural	Structural
Herat-Gunaratne <i>et al.</i> (2020)	UK	10	Qualitative	Semi-structured interviews	Psychological Structural Cultural	–
Hindley <i>et al.</i> (2017)	Tanzania	56	Qualitative	Semi-structured interviews	Psychological Interpersonal Cultural	–
Holm and Ziguras (2003)	Australia	10	Qualitative	Semi-structured interviews	Situational	–
Judkins and Roberto (2001)	USA	2	Qualitative	Observations Interviews (case studies)	Psychological Interpersonal	–
Jutla (2015)	UK	12	Qualitative	Narrative interviews	Situational Cultural	–
Ketchum <i>et al.</i> (2022)	USA, Germany	18	Qualitative	Semi-structured interviews	Psychological Structural Cultural	–
Kyriopoulos <i>et al.</i> (2014)	Greece	394	Quantitative	Cross-sectional study	Situational Structural	–
Leong, <i>et al.</i> (2001)	Australia	94; 10	Qualitative	Survey Interviews	Psychological Structural	–
Marsack-Topolewski and Brady (2020)	USA	6	Qualitative	Semi-structured interviews	Structural	–
Macleod <i>et al.</i> (2017)	Australia	24	Qualitative	Semi-structured interviews	Psychological Structural	Psychological Interpersonal Structural
McHugh <i>et al.</i> (2012)	Ireland	8	Qualitative	Semi-structured interviews	Structural	–
Nielsen <i>et al.</i> (2021)	Denmark	21; 6	Qualitative	Semi-structured interviews; Focus Groups	Psychological Structural Cultural	–
Nyman <i>et al.</i> (2017)	UK	21; 5	Qualitative	Joint interviews; individual inter-views	Psychological Structural	–

Table 1. Continued

AUTHOR (YEAR)	COUNTRY	DEMOGRAPHIC / SOCIOECONOMIC DATA COLLECTED	QUALITATIVE / QUANTITATIVE	METHODS	ENABLERS
Phillipson and Jones (2012)	Australia	Age; Gender; Language; Country of origin	Qualitative	Semi-structured interviews; Focus Groups	Situational Psychological
Read <i>et al.</i> (2021)	England	Age; Sex; Occupation; Home ownership; Wealth; Qualification	Quantitative	Latent growth curve models	Situational
Robinson <i>et al.</i> (2012)	Australia	Age; Gender	Qualitative	Semi-structured interviews	Psychological Structural
Ryan (2021)	Ireland	Gender; Urban-Rural class	Qualitative	Semi-structured interviews	Psychological Interpersonal
Stephan <i>et al.</i> (2018)	Germany, Ireland, Italy, Netherlands, Norway, Portugal, Sweden, UK	Age; Gender; Living situation	Qualitative	Focus Groups	Psychological
Sun <i>et al.</i> (2014)	USA	Gender; Ethnicity; Profession; Country of origin	Qualitative	Focus Groups	Psychological Interpersonal Cultural
Tetley (2013)	UK	Age; Gender	Qualitative	Participatory observations Interviews	Psychological Structural
Vickrey <i>et al.</i> (2007)	USA	Age; Gender; Ethnicity; Education; Employment	Qualitative	Focus Groups	Psychological Structural Cultural
Winslow (2003)	USA	Gender, Ethnicity	Qualitative	Semi-structured interviews	Situational Psychological
Yiu <i>et al.</i> (2020)	Hong Kong	Age; Gender; Education; Living situation	Qualitative	Semi-structured interviews	Cultural
Zhan (2004)	USA	Age; Gender; Marital Status; Education; Birthplace; Language; Living situation	Qualitative	Semi-structured interviews	Psychological Interpersonal

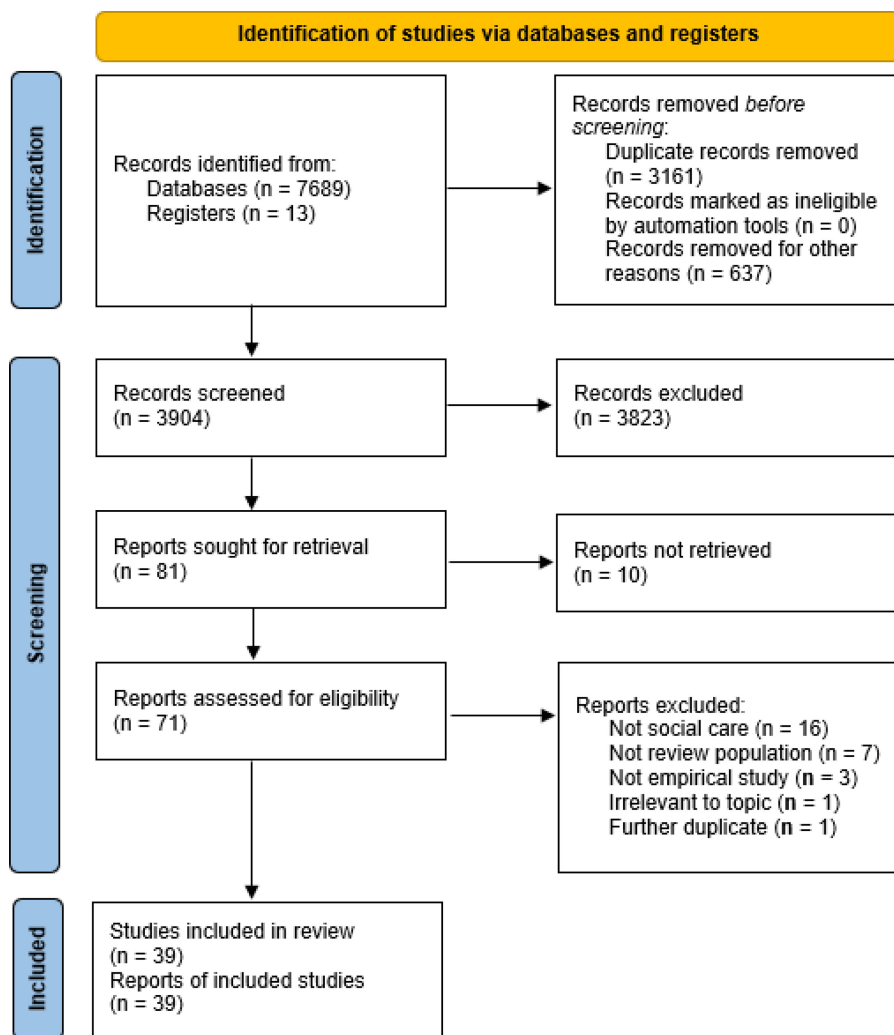


Figure 1. PRISMA flowchart of papers included based on inclusion/exclusion criteria.

participant characteristics and access and use of social support services. A subset of the questionnaire respondents was recruited for semi-structured interviews, to understand their lived experiences and views of potential barriers to accessing and using post-diagnostic dementia care.

Of the 39 studies, four were conducted in more than one country, including Albanese *et al.* (2011), Giebel *et al.* (2021), Ketchum *et al.* (2022), and Stephan *et al.* (2018). A total of 23 countries were represented within these studies, with seven countries included in more than one study: UK (14), USA (10), Australia (6), the Netherlands (3), Ireland (3), Germany (2), and Norway (2).

An iterative process resulted in authors generating five themes under which the nature of barriers and / or enablers to social care access fell, including (1) situational (aspects of the PLWD/carers' life or living situation); (2) psychological (cognitive or emotional aspects); (3) interpersonal (family/friend

networks and communication with services); (4) structural (characteristics of the services themselves); and (5) cultural (aspects of a given culture, religion, norms), with studies often encompassing findings in relation to more than one of the five social care access themes (Table 2), as discussed below.

Quality ratings

Although initial scores differed minutely for 33 papers, discussions resulted in subsequent agreements for individual criteria and the overall scores for all 39 research papers (Table 3, Appendix I).

Eight studies were deemed adequate, with the remainder either good-quality (12) or strong (19). None of the studies were deemed to be of poor quality. The strength of the research included therefore can be the basis for a strong synthesis of the existing literature in relation to the aims of this systematic review.

Table 2. Summary of findings from papers included, in relation to barriers and/or facilitators to social care access and use

AUTHOR (YEAR)	BARRIERS	ENABLERS	BARRIER FINDINGS	ENABLER FINDINGS
Albanese <i>et al.</i> (2011)	Situational	–	Number of physical impairments (pooled prevalence ratio 1.37, 95% CI 1.26-1.49) and ICD-10 depressive episode (pooled PR 1.21, 95% CI 1.07-1.38) were associated with service use, but dementia was inversely associated (pooled PR 0.93, 95% CI 0.90-0.97). Other correlates were female sex, higher education, more household assets, receiving a pension, and health insurance. Standardisation for age, sex, physical impairments, depression, and dementia did not explain variation in service use.	–
Armstrong <i>et al.</i> (2022)	Psychological Interpersonal Structural Cultural	–	At the organizational level, there was some evidence of a perceived lack of person-centered and culturally sensitive care from healthcare professionals, as well as concerns around care homes as places of safety. At the neighborhood community level, participants discussed both a distrust as well as a strengthening of relationships and, at the individual level, factors such as knowledge of services, identity, and faith influenced their experience of the pandemic.	–
Baghirathan <i>et al.</i> (2020)	Psychological	Structural	Fear of ‘diminishment’ was present across all communities: participants both needed and wanted support, but they were reluctant to accept this if it came at the cost of being diminished as a person.	To resolve fear of diminishment, informants turned to BAME-led VCSOs, which provided ongoing support and advocated on behalf of their members.
Bruce and Paterson (2000)	Structural	–	Problems with health care agencies were reported by a majority of the carers to be contributors to their distress. General practitioners were perceived to have referred dementia sufferers late for community care, despite the carer having experienced difficulties for a considerable time period. Carers also complained that too little information was provided about the diagnosis of dementia, how to deal with problem behaviors and how to access support services before and after the assessment procedure.	–

Table 2. Continued

AUTHOR (YEAR)	BARRIERS	ENABLERS	BARRIER FINDINGS	ENABLER FINDINGS
Casado <i>et al.</i> (2015)	Psychological Cultural	–	We conducted four focus groups with 23 family caregivers of older Korean Americans with dementia symptoms and identified eight themes. Relevant themes include: (c) doing it by themselves; (e) limited knowledge and misconceptions; (g) undiagnosed dementia and misunderstandings about medical care; and (h) barriers to use of services and need for culturally responsive services.	–
Cascioli <i>et al.</i> (2008)	Psychological	–	On the whole, the carers were satisfied with the services provided, although their use of these services was not extensive. Carers requested more information regarding available services, suggesting that perceived lack of information could be a barrier.	–
Clarke and Bailey (2016)	Psychological Structural	–	Key themes identified included: Others Knowing and Responding; Socially Withdrawing and Feeling Excluded; Sustaining and Changing Activities; Belonging and Estrangement from Place; Engaging Services and Supports.	–
Contreras <i>et al.</i> (2022)	Psychological Interpersonal	Interpersonal	Three overarching themes were identified. Theme 1 highlighted that family carers experienced frequent and overwhelming need to fulfil a family obligation and feelings of guilt to seek help, which acted as barriers to seeking support, in the early stages. In theme 2, family carers rarely received support in the early stages and available resources were limited to self-help materials.	In Theme 3, family carers wanted to receive interpersonal tailored support to seek practical advice and to learn psychological skills to build resilience in the early stages to overcome emotional challenges.
Cotton <i>et al.</i> (2021)	Situational Structural	–	Across all interviews, caregivers spontaneously described common precedents of service use (crisis or accumulation of unmet needs) and a distinct sequence of stages (seeking, initiating, and utilizing) surrounding service engagement. Major themes characterizing caregivers' experiences throughout service engagement highlight the varied influence of personal, familial, health, and social system-related factors.	–

Table 2. Continued

AUTHOR (YEAR)	BARRIERS	ENABLERS	BARRIER FINDINGS	ENABLER FINDINGS
			Findings demonstrate that caregivers may have different service needs as dementia progresses and that gerontological social work practice can facilitate service use.	
Czapka and Sagbakken (2020)	Psychological Structural Cultural	–	Several barriers and facilitators in accessing and using dementia care services were identified, the most important of which were related to lack of knowledge of dementia, lack of awareness of dementia care services, lack of language skills, culturally based differences, the organization of Norwegian dementia care services, and immigrants' socio-economic status. According to the study participants, having health care personnel in the family and further adaptation of dementia services to the needs of people with different cultural and linguistic backgrounds facilitate access to dementia services.	
Ferguson-Coleman <i>et al.</i> (2020)	Structural	–	Deaf PLWD. Findings demonstrate the multifaceted effects of barriers to knowledge and information when the care partner is also deaf, the urgent need for effective support for deaf carers, and unrecognized safeguarding concerns that are a result of lack of access to forms of basic knowledge about living with someone with dementia and potential coping strategies.	
Richardson <i>et al.</i> (2019)	Psychological Cultural	–	Several themes emerged that were qualitatively different across groups, including knowledge about dementia, language barriers, religion and spirituality, and cultural differences in attitudes about caring and formal services.	
Gibson <i>et al.</i> (2015)	Psychological Structural	–	Access to AT was driven by carers, with the majority of benefits being experienced by carers. Barriers to use included perceptions about AT cost; dilemmas about the best time to use AT; and a lack of information and support from formal health and social care services about how to access AT, where to source it and when and how it can be used.	

Table 2. Continued

AUTHOR (YEAR)	BARRIERS	ENABLERS	BARRIER FINDINGS	ENABLER FINDINGS
Giebel <i>et al.</i> (2021)	Psychological Structural	–	Health literacy; having faith and lack of faith; service suitability; structural issues surrounding service provision; and financing care.	–
Giebel <i>et al.</i> (3) (2021)	Psychological Structural	Structural	Four themes emerged from the interviews: (1) getting the ball rolling: the process of diagnosis; (2) balancing the support needs of people with dementia and carers; (3) barriers to accessing support. Inequities existed for both YOD and LOD, with emerging evidence of unequal experiences in accessing care at the beginning of the COVID-19 pandemic.	Identified Facilitators to accessing support in young and late-onset dementia.
Herat-Gunaratne <i>et al.</i> (2020)	Psychological Structural Cultural	–	We identified 4 themes: an expectation and duty to care, expectation and duty as a barrier to accessing formal care (family carer reluctance, care recipient reluctance, and service organization), culturally (in)sensitive care, and the importance of support from informal care networks.	–
Hindley <i>et al.</i> (2017)	Psychological Interpersonal Cultural	Situational –	Barriers to use of traditional and faith healers in rural Tanzania. Relevant barriers include (ii) people with dementia and carer reasons for seeking help and experiences of treatment and the role of prayers, plants and witchcraft in diagnosis and treatment; (iii) willingness to collaborate with allopathic healthcare services. FHs and people with dementia expressed concerns about any collaboration with THs.	–
Holm and Ziguras (2003)	Situational	–	People using the program (respite) were those who experienced barriers utilising center-based programs for older people for a range of reasons including advanced dementia, hearing difficulties, difficulties in social interaction or confusion.	–
Judkins and Roberto (2001)	Psychological Interpersonal	–	Fear of being abandoned in adult day care in two women with AD. Their fears stemmed from two sources: contextual confusion, centered on their inability to grasp the concept of attending an adult day care center,	–

Table 2. Continued

AUTHOR (YEAR)	BARRIERS	ENABLERS	BARRIER FINDINGS	ENABLER FINDINGS
Jutla (2015)	Situational Cultural	–	and imagined barriers between them and their caregivers. One of the women tended to “re-cruit” the other woman into her world of insecurity, and hence their friendship actually may have had a detrimental effect on each other’s days at the center. Findings highlighted that migration experiences and migration identities are important for understanding participants’ experiences of services and experiences of caring for a family member with dementia.	–
Ketchum <i>et al.</i> (2022)	Psychological Structural Cultural	–	Caregivers described their experiences in three stages of seeking, initiating, and utilizing care, and different factors served to hinder or enable the use of care services in each stage. The most important factors included limited knowledge about dementia, challenges interacting with healthcare systems, and how closely formal services met the expectations and needs of caregivers, particularly with regard to accommodating cultural or ethnic/racial identity. Caregivers preferred interacting with service care providers who shared a similar identity to receive information or services.	–
Kyriopoulos <i>et al.</i> (2014)	Situational Structural	–	A total of 25% of chronic patients face geographical barriers while 63.5% and 58.5% of them are in front of economic and waiting list barriers, respectively. Unemployed, low-income and low-educated are more likely to face economic barriers in access. Moreover, women, low-income patients, and patients with lower health status are more likely to be in front of geographical barriers. In addition, the probability of waiting lists occurrence is greater for unemployed, employees and low-income patients.	–
Leong <i>et al.</i> (2001)	Psychological Structural	–	The six most frequently reported barrier (unmet) needs are discussed in this paper. These included the needs: 1) to know that someone will provide care when family carer unable to do	–

Table 2. Continued

AUTHOR (YEAR)	BARRIERS	ENABLERS	BARRIER FINDINGS	ENABLER FINDINGS
			so; 2) a telephone hot-line: 3) time away from caring duties; 4) ways to deal with stress; 5) time for physical rest, and 6) ways to deal with feelings of being trapped.	
Marsack-Topolewski and Brady (2020)	Structural	–	Based on the results from the content analysis of interview responses, four themes emerged: (a) difficulty getting a dementia diagnosis, (b) barriers to obtaining services, (c) caregiving realities and challenges, and (d) rewards of caregiving.	–
Macleod <i>et al.</i> (2017)	Psychological Structural	Psychological Interpersonal Structural	The barriers to service usage were: the inability to find information about relevant services or support, the poor quality or mistrust of the services, the inflexibility of services, caregivers' beliefs about their obligations to the caregiving role, and resistance by the care recipient.	Key facilitators for service usage were: having good communication with the care recipient, having an expert point of contact, and having beliefs about the caregiving role that enabled the use of services.
McHugh <i>et al.</i> (2012)	Structural	–	Examined barriers to use of teleconferencing as a source of support for carers. Themes of “group processes” and “barriers,” containing subcategories of “functions of the group,” “responsibilities of facilitators,” and “barriers to communication” were discussed. According to caregivers, successful teleconferencing support groups should acknowledge the caregiver as the dementia expert, allow participants to meet before the deployment of the support group, provide active facilitation and leadership via the researcher, employ user-friendly technologies, and facilitate for the group to self-maintain following the pilot deployment period.	–
Nielsen <i>et al.</i> (2021)	Psychological Structural Cultural	–	On the service user side, barriers in access to dementia care were related to lacking language proficiency and strong cultural norms, including familial responsibility for the care of older family members and stigma associated with mental illness and dementia. On the care provider side, the available formal services were rarely tailored	–

Table 2. Continued

AUTHOR (YEAR)	BARRIERS	ENABLERS	BARRIER FINDINGS	ENABLER FINDINGS
			to the specific needs of minority ethnic service users and were often considered inadequate or unacceptable.	
Nyman <i>et al.</i> (2017)	Psychological Structural	–	Barriers to using technology to meet social care needs: difficulties were reported with learning to use unfamiliar technology and the cost of visual impairment aids, and for some, the presence of dementia made visual impairment aids unusable and vice versa.	–
Phillipson and Jones (2012)	Situational Psychological	–	Respite day care centers. While service users held positive beliefs, nonusers perceived negative outcomes for the care recipient with dementia or faced barriers associated with the recipient's behavioral or physical needs.	–
Read <i>et al.</i> (2021)	Situational	–	Unmet needs increased over time, especially among those who initially had more functional limitations. The major driver of increased unmet needs was not having a partner (direct effect). Age, sex, and wealth contributed indirectly via the initial level of functional limitations and/or unmet need.	–
Robinson <i>et al.</i> (2012)	Psychological Structural	–	Carers considering day respite care were often overwhelmed by the quantity of information, confused about the process, and worried about the recipient's safety in an unfamiliar environment. They felt anxious about public acknowledgement of the condition leading to fear of embarrassment.	–
Ryan (2021)	Psychological Interpersonal	–	Emotional barriers to community-based care service usage include: reluctance to question general practitioner (GP) authority; embarrassment during level of care requirement reviews; sense of obligation to provide all care; and fear of stigma. Caregivers interviewed were reluctant to communicate concerns with professional healthcare providers (PHPs), thereby reducing the PHP's awareness of these barriers and delaying/preventing use of CBS.	–

Table 2. Continued

AUTHOR (YEAR)	BARRIERS	ENABLERS	BARRIER FINDINGS	ENABLER FINDINGS
Stephan <i>et al.</i> (2018)	Psychological	–	Sixteen categories describing barriers and facilitators were identified, referring to three global themes: Aspects related to 1) individuals involved, 2) the system, or 3) overarching aspects. The attitudes and beliefs of people with dementia and their carers may have a major impact, and they often serve as barriers. Formal care was perceived as a threat to the individual independence of people with dementia and was thus avoided as long as possible.	–
Sun <i>et al.</i> (2014)	Psychological Interpersonal Cultural	–	Similar to previous research, this study identified shortages of culturally competent services, stigma, caregivers' limited knowledge of the health care system, and lack of initiative to seek professional help as service barriers. In contrast to prior work, lack of communication concordance was identified as a major barrier in client–professional interactions, including professionals' insufficient understanding of the Chinese language and culture, patient and family tendencies to minimize issues in the treatment of Alzheimer's disease and related disorders, and incongruent expectations that health professionals and Chinese patients have for one another.	–
Tetley (2013)	Psychological Structural	–	Three main themes were identified from the interview data; barriers to articulation of experiences; finding help and support; and managing and coping.	–
Vickrey <i>et al.</i> (2007)	Psychological Structural Cultural	–	Caregiving roles, concern about the person with dementia, and unmet information and resource needs were expressed similarly. However, perspectives differed across ethnic groups on stigma surrounding dementia, benefits of caregiving, spirituality/religion to ease caregiving burden, and language barriers and discrimination.	–
Winslow (2003)	Situational Psychological	–	Barriers to service use included care receiver resistance,	–

Table 2. Continued

AUTHOR (YEAR)	BARRIERS	ENABLERS	BARRIER FINDINGS	ENABLER FINDINGS
			reluctance of the caregiver, hassles for the caregiver, concerns over quality, and concerns over finances.	
Yiu <i>et al.</i> (2020)	Cultural	Psychological Interpersonal	The content analysis of transcribed audiotaped interviews revealed various barriers related to financial support, service availability and accessibility, life burden, and referral. The culture rooted in Confucianism with a British melioration may play an important role in shaping PwDs' experiences in the use of dementia services in Hong Kong.	Facilitators include family responsibility, perceived benefits, and caring relations.
Zhan (2004)	Cultural	–	Results revealed ethnocultural and structural barriers that Chinese family caregivers experienced, including stigmatization of AD in the Chinese community, a lack of knowledge about AD, a lack of culturally and linguistically appropriate AD services, negative interactions with health-care providers, and difficulty with English.	–

Situational

Nine studies referred to situational factors that acted as barriers to social care access. Economic barriers were identified, due to the financial impact to the carer/person with dementia in accessing care, which was associated with increased experiences of unmet needs over time (Read *et al.*, 2021; Winslow, 2003). Furthermore, economic barriers in England were experienced more frequently in those without a partner providing direct support (Read *et al.*, 2021) and were experienced in Greece from those with a low income, low education, or unemployed (Kyriopoulos *et al.*, 2014). The negative experiences of caregiving, including the perceived hassle of caregiving, and carers' concerns over the quality of care provided, were also found to result in situational barriers to accessing or using social care services (Winslow, 2003).

A further situational barrier identified includes the limiting impact in attending day care centers and respite due to the PLWD's physical and behavioral needs. Advanced dementia, hearing difficulties, difficulties in social interaction, and confusion were

reported to limit engagement with day centers in Australia, Latin America, China, India, and Nigeria (Albanese *et al.*, 2011, Holm and Ziguras, 2003, Phillipson and Jones, 2012). Phillipson and Jones (2012) suggested that improvements to program activities and environments are required to ensure needs are met for those currently unable to access care.

Psychological

A total of 26 studies identified psychological barriers to social care usage, with only three of these studies describing psychological enablers. The nature of these psychological enablers varied depending on the population; for example, PLWD were more likely to use community dementia services if they had a sense of family responsibility and perceived the services as beneficial to them (Yiu *et al.*, 2020). Family carers were more likely to use social care services available to caregivers (respite, home care services, support groups, and planned activity groups) if they believed that carers needed breaks away from the caregiving role and that there is often

Table 3. Stage 1 quality ratings: authors' initial independent quality rating of research papers included in systematic review

RESEARCH PAPER	YEAR OF PUBLICATION	AUTHORS' INDEPENDENT SCORES (%)	
		JW	TF
Albanese <i>et al.</i>	2011	75.0%	94.0%
Armstrong <i>et al.</i>	2022	80.0%	85.0%
Baghirathan <i>et al.</i>	2020	85.0%	80.0%
Bruce and Paterson	2000	60.0%	65.0%
Casado <i>et al.</i>	2015	85.0%	75.0%
Cascioli <i>et al.</i>	2008	75.0%	65.0%
Clarke and Bailey	2016	75.0%	60.0%
Contreras, Mioshi and Kishita	2021	75.0%	
Cotton <i>et al.</i>	2021	75.0%	60.0%
Czapka and Sagbakken	2020	90.0%	80.0%
Ferguson-Coleman <i>et al.</i>	2020	70.0%	50.0%
Richardson <i>et al.</i>	2019	90.0%	95.0%
Gibson <i>et al.</i>	2015	80.0%	60.0%
Giebel <i>et al.</i>	2021	85.0%	80.0%
Giebel <i>et al.</i> (3)	2021	85.0%	80.0%
Herat-Gunaratne <i>et al.</i>	2020	75.0%	80.0%
Hindley <i>et al.</i>	2017	80.0%	60.0%
Holm and Ziguras	2003	70.0%	60.0%
Judkins and Roberto	2001	55.0%	55.0%
Juttla	2015	65.0%	75.0%
Ketchum <i>et al.</i>	2022	90.0%	80.0%
Kyriopoulos <i>et al.</i>	2014	70.8%	
Leong, Madjar and Fiveash	2001	70.0%	
Marsack-Topolewski and Brady	2020	85.0%	
Macleod <i>et al.</i>	2017	75.0%	
McHugh <i>et al.</i>	2012	85.0%	
Nielsen, Nielsen and Waldemar	2021	80.0%	
Nyman, Innes and Heward	2017	80.0%	
Phillipson and Jones	2012	75.0%	
Read <i>et al.</i>	2021	86.4%	
Robinson <i>et al.</i>	2012	90.0%	
Ryan	2021	85.0%	
Stephan <i>et al.</i>	2018	80.0%	
Sun, Mutlu and Coon	2014	75.0%	
Tetley	2013	65.0%	
Vickrey <i>et al.</i>	2007	70.0%	
Winslow	2003	80.0%	
Yiu <i>et al.</i>	2020	90.0%	
Zhan	2004	85.0%	

Appendix I. Stage 2 quality rating: Final agreed quality rating of research papers included in systematic review.

no perfect solution to difficult situations, necessitating the use of such services (Macleod *et al.*, 2017). Carers were also more likely to use services if they had health literacy; that is, they were skilled in proactively seeking out support and information (Giebel *et al.*, 2021).

Numerous psychological barriers to social care usage were identified. One prominent barrier was misunderstandings about available services (Casado

et al., 2015) and perceptions about costs associated with services (Gibson *et al.*, 2015). Confusion and difficulties surrounding the process of using unfamiliar services served as additional psychological barriers in England and Australia (Nyman *et al.*, 2017; Robinson *et al.*, 2012).

Another psychological barrier was stress and anxiety. Both PLWD and carers across eight European countries, who experienced a loss of control,

were less likely to access and use social care services, comprising nursing home care, day care services, community, long-term care medical care, and social care structures such as respite services (Stephan *et al.*, 2018). There were also specific anxieties that were experienced by PLWD and carers, respectively. Studies across America, Singapore, and Europe reported that for PLWD, fears of abandonment (Judkins and Roberto, 2001), stress, and entrapment (Leong *et al.*, 2001) were barriers to service usage. PLWD who felt that service usage would threaten their independence (Stephan *et al.*, 2018; Tetley, 2013) or lead to public acknowledgement of their condition (Robinson *et al.*, 2012) were less likely to engage with services. Finally, PLWD in England who were not living in their own home environment were less comfortable in unfamiliar surroundings and therefore less willing to access services (Clarke and Bailey, 2016).

Carers had their own anxieties, some of which centered around their PLWD and some were general anxieties. Carers who were worried about being separated from their PLWD (Stephan *et al.*, 2018) and concerned about the safety of their PLWD in an unfamiliar environment (Hindley *et al.*, 2017; Robinson *et al.*, 2012; Vickrey *et al.*, 2007; Winslow, 2003) were less likely to engage with services. Finally, carers were reluctant to use support if it came at a cost of feeling diminished as a person (Baghirathan *et al.*, 2020) and if they lacked trust in the services (Armstrong *et al.*, 2022; Macleod *et al.*, 2017; Phillipson and Jones, 2012; Winslow, 2003).

PLWD and carers experienced several other psychological barriers to using social care services. Some people were generally reluctant or resistant to using services in England and California (USA) (Herat-Gunaratne *et al.*, 2020; Winslow, 2003) while a study of Chinese-American caregivers found that participants were simply not motivated to seek professional help (Sun *et al.*, 2014). Timing was another important psychological barrier, with some people feeling unsure of when to initiate support (Gibson *et al.*, 2015) or delaying support until crisis point (Tetley, 2013). PLWD with communication difficulties and who had little insight into their condition often found it difficult to articulate their support needs (Clarke and Bailey, 2016; Tetley, 2013) and were less likely to recognize the need for supportive services (Stephan *et al.*, 2018). Furthermore, carers who felt a sense of duty, expectation, or responsibility to care for their PLWD (Contreras *et al.*, 2022; Herat-Gunaratne *et al.*, 2020; Leong *et al.*, 2001; Macleod *et al.*, 2017; Nielsen *et al.*, 2021; Ryan, 2021; Yiu *et al.*, 2020) or felt that relinquishing care to services was a personal failure (Stephan *et al.*, 2018) were less likely to access services.

Interpersonal

Interpersonal factors referred to relationships and interactions between PLWD, carers, and informal and formal supports. Eight studies referred to interpersonal factors that acted as barriers to social care usage, with three of these studies describing interpersonal enablers. Enabling interpersonal factors included carers' willingness to receive interpersonal tailored support (Contreras *et al.*, 2022), strengthening of relationships and trust (Armstrong *et al.*, 2022), and high-quality communication between PLWD and social care workers (Yiu *et al.*, 2020).

Conversely, a lack of communication was a prominent interpersonal barrier to social care usage. Some carers in Ireland were reluctant to communicate their concerns with community-based care providers, thus preventing and delaying support (Ryan, 2021). A lack of communication concordance and incongruent expectations that carers and community based and other formal service providers have for one another were both major barriers to support (Sun *et al.*, 2014). Indeed, carers in the USA and Germany were less likely to interact with service providers if they believed that they did not share a similar identity with themselves (Ketchum *et al.*, 2022).

For PLWD in the USA, the stress and anxiety associated with social care services was exacerbated by perceived barriers between themselves and social care workers (Judkins and Roberto, 2001). Carers who questioned the suitability of collaborating with social care services in Africa, or believed that there were no good or trustworthy African social care workers, were less likely to use their services (Hindley *et al.*, 2017).

Structural

Twenty studies referred to structural factors, which primarily reported barriers through lack of awareness. Several studies showed how carers lacked any knowledge of available formal dementia services (Armstrong *et al.*, 2022; Ketchum *et al.*, 2022; Macleod *et al.*, 2017), while others reported that too little information was provided about the dementia diagnosis, or how to initiate post-diagnostic dementia care, including but not limited to, carer support groups, respite and day care centers, transport, befriending, and clinical support (Bruce and Pateron, 2000; Giebel *et al.*, 2021c; Ketchum *et al.*, 2022; Macleod *et al.*, 2017). In addition, for those PLWD with additional needs, such as deafness and poor language skills, information sources were harder to find (Czapka and Sagbakken, 2020; Ferguson-Coleman *et al.*, 2020). Where carers/PLWD were unable to find accessible information, they were unable to access available support (Tetley, 2013;

Gibson *et al.*, 2015). In contrast, too much information (which for many people is provided at the point of diagnosis [Robinson *et al.*, 2012]) was found to be overwhelming to carers.

A further barrier included the structure of dementia organizations and services that were deemed unfit for purpose. Herat-Gunaratne (2020) described poorly organized services in England, whereby high levels of family carer presence in the person with dementia's home led to paid care workers coming out to the home less frequently, assuming the family carer would take on greater care responsibilities. In addition, Giebel *et al.* (2021d) further identified how many forms of post-diagnostic services in England were not adapted to the needs of those with rarer subtypes of dementia. In particular, Young Onset Dementia (YOD) and Lewy Body Dementia (LBD) were impacted by unsuitable service design (Giebel *et al.*, 2021d). The use of technology, which was found to be unfamiliar to many English service users, was particularly unsuitable to those with preexisting visual impairments (Nyman *et al.*, 2017).

An additional structural barrier included the difference in care needs between the PLWD and the caregiver (Cotton *et al.*, 2021; Leong *et al.*, 2001), further illustrating services that are not specific to individuals' needs. Leong *et al.* (2001) reported that carers in the USA in their study required time away from caring duties for physical rest but are unable to access respite services at short notice, suggesting that current services should aim to be more flexible where possible to encourage user engagement.

The final structural barrier identified from this review included the geographical factors that impeded access to services, due to the location of the providers and facilitators and the costs associated with attending services. In Greece, it was found that geographical barriers were most likely to affect women, low-income patients, and patients with lower health status (Kyriopoulos *et al.*, 2014). In addition, the COVID-19 pandemic was also found to exacerbate unequal access to formal care, as further physical limitations were put in place to curb the spread of the virus, which were found to be unequal nationally (Giebel *et al.*, 2021d).

One way to address structural issues, and thus enable improved access to care, was the use of care navigators, or a dedicated link person, who can help to overcome barriers to accessing dementia care (Giebel *et al.*, 2021c). However, where the care services were situated outside the care navigator's reach, they were unable to support the service user. The benefits of care navigators are corroborated by Macleod *et al.* (2017), as good communication between services and the PLWD, and having an expert point of contact for the family carer, were

reported as key facilitators to service usage. Although the use of technology has been reported previously as a structural barrier for PLWD, establishing a telephone hotline to support carers enabled carers to seek additional advice and information when needed.

Cultural

Thirteen studies reported cultural barriers to accessing care, relating to language barriers, cultural stigmas associated with dementia and/or mental illness, and their cultural identities not being addressed in current service delivery.

Culturally insensitive care was described where care workers did not speak the same language as the service user (Sun *et al.*, 2014; Herat-Gunaratne, 2020; Nielsen *et al.*, 2021). In a study including Chinese family carers, a lack of culturally and linguistically appropriate services were noted. Where language barriers exist, negative interactions have been found between the service user and the care providers (Zhan, 2004). Furthermore, Jutla (2015) reported on the importance of understanding carers' experiences of migration, which are closely related to their experiences of inequalities and institutionalized racism, from their study interviewing 12 carers from the Sikh community. It was recommended that person-centered dementia care models highlight the importance of understanding life histories to better support carers and their family members with dementia (Jutla, 2015).

Cultural identity plays an important part in the access to dementia care and support services. Armstrong *et al.* (2022) identified a perceived lack of person-centered and culturally sensitive care from care professionals, in their study of carers and PLWD from South Asian and Black communities.

The stigma of dementia was experienced by different cultures, including African American, Chinese American, and Hispanic American caregivers (Vickrey *et al.*, 2007). Chinese family carers reported stigmatization of dementia in their community to stem from a lack of knowledge about the disease (Sun *et al.*, 2014; Zhan, 2004). The lack of knowledge, and feelings of shame associated with mental illness in this culture that can lead to secrecy of the condition within the family, subsequently prevented the carer or PLWD from obtaining a dementia diagnosis and accessing support services (Sun *et al.*, 2014; Zhan, 2004).

Cultural facilitators identified from this review relate to the benefits of faith and family values/responsibility to care. Strong cultural norms of familial responsibility for the care of older family members encourages carers to engage with services to ensure the PLWD receives the necessary care

(Nielsen *et al.*, 2021; Yiu *et al.*, 2020). In addition, Vickrey *et al.* (2007) reported that faith/spirituality can play a role in easing carer burden and provide an increased sense of purpose in supporting the PLWD.

Finally, Hindley *et al.* (2017) described post-diagnostic dementia care in the form of faith healers, in their qualitative study interviewing Tanzanian healers and PLWD. Faith healers referred people with dementia to allopathic services when diagnosis and treatment was needed, acknowledging the limitations of their own practice such as prayers and plant extracts.

Discussion

This appears to be the first systematic review to comprehensively explore the evidence base on the barriers and facilitators of accessing and using community-based social care and support services for dementia, by focusing on multilevel inequalities as opposed to selecting a single factor. Overall, this review showed a large number of intersectional barriers faced by people with dementia when trying to access social care, and only a few enablers.

Numerous structural barriers, and thus system-based inequalities to accessing social care were evidenced, including lack of knowledge and availability of services, lack of suitable services based on dementia subtype and carer and people with dementia needs, as well as geographical availability of and accessibility to services. One way to overcome structural barriers and facilitate service uptake are Dementia Care Navigators. Care Navigators are employed in some countries under different names, with evidence emerging primarily from the US and to some degree from England and the Netherlands (Bass *et al.*, 2013; Giebel *et al.*, 2021c; Nowaskie *et al.*, 2020). At the core of this role is the supportive navigation of the PLWD and carer through the care system from the point of diagnosis, to connect them with services in the community and necessary information and provide a listening support as a single point of contact about any queries related to the diagnosis. However, as evidence highlighted in this review showed, not all structural barriers can be overcome via this solution, and particularly geographical barriers can remain. Accessing dementia care in rural areas, for example, can be attempted to be facilitated via rural and remote memory clinics, as piloted in rural Canada (Morgan *et al.*, 2009). With the digitalization of dementia care, particularly since the pandemic, geographical barriers can be overcome more easily. However, the digitalization of care generates new inequalities, such as digital illiteracy particularly in the older population (Choudrie

et al., 2020), digital infrastructure and financing, as well as the limited benefits of remote versus in-person care. Hence, a multidimensional approach to tackling structural barriers needs to be employed.

Care navigators or similar link persons could also provide a crucial link to facilitate improved communication between service users (carers, people with dementia) and service providers, to address and overcome interpersonal barriers in accessing care. Another way to address communication specifically, as opposed to linkage between users and providers, could be proposed by van Manen *et al.* (2021). The authors developed the Contac-d model, which provides a comprehensive overview of factors in the communication between nursing staff and people with dementia, including factors attributed to people with dementia, such as behavior and values, factors attributed to nursing staff, including individual experiences and nonverbal communication skills, as well as contextual factors, i.e. organization of care. This generated starting points for discussion to facilitate improved communication, such as respect for needs, a flexible and adapted communication approach, and longer duration of interaction. This model could be adapted or directly implemented in social care and social support services and translated for non-nursing staff.

Improved communication from services and service providers could also aid in the reduction of the myriad of psychological barriers experienced, including lack of trust in services. Addressing the wider personal barriers to accessing care services requires a multidimensional approach by tackling the misconceptions of services threatening independence, abandonment, and strong feelings of guilt from carers. Accessing social support services in the community enables independence, as opposed to threatening it, as some recent evidence from the US using Medicaid data confirms (Wang *et al.*, 2021). This and many other advantages of accessing community-based social care and support for dementia need to be communicated more clearly to people with dementia and carers, to also alleviate any potential guilt which carers might experience, as this review has indicated. Feelings of guilt are common in carers and are not restricted to community-based care but also extend to residential long-term care (Giebel *et al.*, 2022c; Statz *et al.*, 2022). This suggests that in addition to clearer communication, more readily available psychological support needs to be accessible for carers, but also potentially for people with dementia, to overcome any feelings of guilt, or other psychological experiences including stress and anxiety.

The notion of building trust in the system weaves through the identified barriers, as cultural barriers are similarly characterized by a lack of trust in

services and service providers. This is compounded by dementia being a heavily stigmatized condition, which creates a personal barrier to accessing the care and support people require. The systemic inequalities can be addressed by providing targeted education and training to care providers on diverse and individual cultural needs, with this review extending a recent report by a European working group on the topic of cultural equity in dementia diagnosis and care (Gove *et al.*, 2021). Services need to be adapted to the dietary, religious, and linguistic needs of people with dementia, which can be difficult in the diverse societies that we live in today. However, a general approach of being mindful of and assessing the people with dementia's needs, including cultural and noncultural needs, should be engrained into care delivery.

If systemic barriers were removed and adequate and suitable services existed, people with dementia and carers may still experience situational barriers in accessing services, as individual's personal circumstances may inhibit them from accessing care, including financial barriers. Coming from a lower socioeconomic background can hinder people from accessing vital care (Czapka and Sagbakken, 2020), unless they get needs tested and receive financial support. However, in England, for example, currently, the cap of care costs is £23,250, with any savings or income above this cap requiring people to pay for their own care. Care systems are financed differently in each country, and the US for example has no requirement for medical insurance, leaving many from lower socioeconomic backgrounds worse off in accessing any care (Dwyer-Lindgren *et al.*, 2017). Thus, wider system changes need to be implemented, with learning from different countries, to address this layer of barriers.

Limitations

This systematic review was conducted rigorously to avoid limitations in quality. However, limitations of the evidence were identified and should be noted. The criteria for this review included mixed-methods studies, although in principle only one quantitative paper was identified. This is likely due to the nature of research exploring lived experiences and perceptions, but this review thus highlights a gap in the literature. The included evidence was also mostly limited to providing a generic assessment of inequalities in accessing social care and social support services for dementia, as opposed to focusing on specific services, such as day care or peer support groups. This review included international studies, however, which produced rich data around barriers and enablers to accessing dementia care globally, although the

variation in individual cultures and social care systems across nations should be considered. In relation to these differences in care systems and also funding structures in different countries, it is important to highlight that we tried to be as inclusive as possible in our inclusion criteria to account for different types of social care and support services. This is evidenced by having included studies from lower and middle-income countries (LMICs). However, there may be services which have not been captured, which are more utilized in LMIC settings for example. Finally, we found mainly barriers with relatively few enablers to access and use of social care and support services. This does not necessarily mean that few enablers exist, but that research has understandably focused more on the barriers. Future research should aim to identify both barriers *and* enablers so that we know what hinders but also what helps people with dementia and their carers.

Conclusions

People with dementia and unpaid carers severely struggle in accessing suitable dementia care after a diagnosis across the globe. While barriers, and the few enablers, to accessing and using community-based social care for dementia were categorized into situational, psychological, interpersonal, structural, and cultural factors, these factors overlapped in many instances. In order to address inequalities in service utilization and ultimately improve health and well-being outcomes for people with dementia and their carers, future research and implementation should attempt to be cross-country and generate cross-country policy learning, such as via Alzheimer's Europe, Alzheimer's Disease International or WHO, all of which generate cross-country policy and care recommendations.

Conflicts of interest

CG is Guest Editor for this Special Issue and is not involved in any review or editorial decisions of this manuscript.

Source of funding

CG is funded by the National Institute for Health and Care Research Applied Research Collaboration North West Coast (ARC NWC). The views expressed in this publication are those of the author(s) and not necessarily those of the National Institute for Health Research or the Department of Health and Social Care.

References

- Albanese, E. et al.** (2011). Equity in the delivery of community healthcare to older people: findings from 10/66 Dementia Research Group cross-sectional surveys in Latin America, China, India and Nigeria. *BMC Health Services Research*, 11, 153–153.
- Alzheimer's Disease International (ADI).** (2022). *World Alzheimer Report 2022 – Life after diagnosis: Navigating treatment, care and support*. London: ADI.
- Armstrong, M. et al.** (2022). Trust and inclusion during the Covid-19 pandemic: perspectives from Black and South Asian people living with dementia and their carers in the UK. *International journal of geriatric psychiatry*, 37.
- Baghirathan, S., Cheston, R., Hui, R., Chacon, A., Shears, P. and Currie, K.** (2020). A grounded theory analysis of the experiences of carers for people living with dementia from three BAME communities: balancing the need for support against fears of being diminished. *Dementia (London, England)*, 19, 1672–1691. <https://doi.org/10.1177/1471301218804714>.
- Bass, D. M. et al.** (2013). Caregiver outcomes of partners in dementia care: effect of a care coordination program for veterans with dementia and their family members and friends. *Journal of the American Geriatrics Society*, 61, 1377–1386.
- Bodryzlova, Y. et al.** (2022). Social class and the risk of dementia: a systematic review and meta-analysis of the prospective longitudinal studies. *Scandinavian Journal of Public Health*, 14034948221110019. <https://doi.org/10.1177/2F14034948221110019>.
- Bruce, D. G. and Paterson, A.** (2000). Barriers to community support for the dementia carer: a qualitative study. *International Journal of Geriatric Psychiatry*, 15, 451–457.
- Casado, B. L., Lee, S. E., Hong, M. and Hong, S.** (2015). The experience of family caregivers of older Korean Americans with dementia symptoms. *Clinical Gerontologist: The Journal of Aging and Mental Health*, 38, 32–48.
- Cascioli, T. R., Al-Madfai, H., Osborne, P. and Phelps, S.** (2008). An evaluation of the needs and service usage of family carers of people with dementia. *Quality in Ageing*, 9, 18–27.
- Choudrie, J., Pheeraphuttrangkoon, S. and Davari, S.** (2020). The digital divide and older adult population adoption, use and diffusion of mobile phones: a quantitative study. *Information Systems Frontiers*, 22, 673–695.
- Clarke, C. L. and Bailey, C.** (2016). Narrative citizenship, resilience and inclusion with dementia: on the inside or on the outside of physical and social places. *Dementia (London, England)*, 15, 434–452.
- Contreras, M., Mioshi, E. and Kishita, N.** (2022). What are the educational and support needs of family carers looking after someone in the early stages of Alzheimer's disease? A qualitative retrospective approach. *Health & Social Care in the Community*, 30, 1726–1734.
- Cooper, C., Tandy, A. R., Balamurali, T. B. S. and Livingston, G.** (2010). A systematic review and meta-analysis of ethnic differences in use of dementia treatment, care, and research. *American Journal of Geriatric Psychiatry*, 18, 193–203.
- Cotton, Q. D. et al.** (2021). Dementia caregivers' experiences engaging supportive services while residing in under-resourced areas. *Journal of Alzheimer's Disease*, 84, 169–177.
- Czapka, E. A. and Sagbakken, M.** (2020). It is always me against the Norwegian system: barriers and facilitators in accessing and using dementia care by minority ethnic groups in Norway: a qualitative study. *BMC Health Services Research*, 20, 954–954.
- Dwyer-Lindgren, L. et al.** (2017). Inequalities in life expectancy among US counties, 1980 to 2014 – temporal trends and key drivers. *JAMA Internal Medicine*, 177, 1003–1011.
- Ferguson-Coleman, E., Johnston, A., Young, A., Brown, F., de Sainte Croix, R. and Redfern, P.** (2020). How do we know what we don't know? Exploring Deaf people's experiences of supporting their Deaf family member living with dementia. *Dementia (London, England)*, 19, 1381–1396. <https://doi.org/10.1177/1471301218798993>.
- Gibson, G., Dickinson, C., Brittain, K. and Robinson, L.** (2015). The everyday use of assistive technology by people with dementia and their family carers: a qualitative study. *BMC Geriatrics*, 15, 89–89. <https://doi.org/10.1186/s12877-015-0091-3>.
- Giebel, C. et al.** (2021a). Impact of COVID-19 related social support service closures on people with dementia and unpaid carers: a qualitative study. *Ageing & Mental Health*, 25, 1281–1288.
- Giebel, C. et al.** (2021b). A UK survey of COVID-19 related social support service closures and their effects on older people, people with dementia, and carers. *IJGP*, 36, 393–402.
- Giebel, C. et al.** (2021d). Health inequities in the care pathways for people living with young- and late-onset dementia: from pre-COVID-19 to early pandemic. *International Journal of Environmental Research and Public Health*, 18, 686.
- Giebel, C. et al.** (2022a). The early impacts of COVID-19 on people living with dementia: part I of a mixed-methods systematic review. *Ageing & Mental Health*, 27, 533–546. <https://doi.org/10.1080/13607863.2022.2084509>.
- Giebel, C. et al.** (2022b). The early impacts of COVID-19 on unpaid carers of people living with dementia: part II of a mixed-methods systematic review. *Ageing & Mental Health*, 27, 547–562. <https://doi.org/10.1080/13607863.2022.2084510>.
- Giebel, C. et al.** (2022c). Guilt, tears and burnout – impact of UK care home restrictions on the mental well-being of staff, families and residents. *Journal of Advanced Nursing*, 78, 2191–2202.
- Giebel, C., Robertson, S., Beaulen, A., Zwakhalen, S., Allen, D. and Verbeek, H.** (2021c). “Nobody seems to know where to even turn to”: barriers in accessing and utilising dementia care services in England and The Netherlands. *International Journal of Environmental Research and Public Health*, 18, 12233.
- Gove, D. et al.** (2021). The challenges of achieving timely diagnosis and culturally appropriate care of people with dementia from minority ethnic groups in Europe. *IJGP*, 36, 1823–1828.

- Herat-Gunaratne, R. et al.** (2020). “In the Bengali vocabulary, there is no such word as care home”: caring experiences of UK Bangladeshi and Indian family carers of people living with dementia at home. *The Gerontologist*, 60, 331–339.
- Hindley, G. et al.** (2017). The role of traditional and faith healers in the treatment of dementia in Tanzania and the potential for collaboration with allopathic healthcare services. *Age and Ageing*, 46, 130–137.
- Holm, S. and Ziguras, S.** (2003). The host-homes program: an innovative model of respite for carers of people with dementia. *Australasian Journal on Ageing*, 22, 141–145.
- Judkins, W. and Roberto, K. A.** (2001). Abandonment fears of persons with Alzheimer’s disease attending adult day care. *American Journal of Alzheimer’s Disease and Other Dementias*, 16, 247–250.
- Jutla, K.** (2015). The impact of migration experiences and migration identities on the experiences of services and caring for a family member with dementia for Sikhs living in Wolverhampton. *UK Ageing and Society*, 35, 1032–1054.
- Ketchum, F. B. et al.** (2022). Pathways of care: a qualitative study of barriers and facilitators to engaging dementia care among underserved and minority populations in the US and Germany. *Ageing & Mental Health*, 27, 389–398. <https://doi.org/10.1080/13607863.2022.2033695>.
- Kmet, L. M., Lee, R. C. and Cook, L. S.** (2004). Standard quality assessment criteria for evaluating primary research papers from a variety of fields. Edmonton: Alberta Heritage Foundation for Medical Research (AHFMR). AHFMR – HTA Initiative #13.
- Kyriopoulos, I.-I. et al.** (2014). Barriers in access to healthcare services for chronic patients in times of austerity: an empirical approach in Greece. *International Journal for Equity in Health*, 13, 54–54.
- Leong, J., Madjar, I. and Fiveash, B.** (2001). Needs of family carers of elderly people with dementia living in the community. *Australasian Journal on Ageing*, 20, 133–138.
- Macleod, A., Tatangelo, G., McCabe, M. and You, E.** (2017). There isn’t an easy way of finding the help that’s available. Barriers and facilitators of service use among dementia family caregivers: a qualitative study. *International Psychogeriatrics*, 29, 765–776.
- Marsack-Topolewski, C. N. and Brady, A. M.** (2020). Experiences of family caregivers of individuals with ID and dementia. *Journal for ReAttach Therapy and Developmental Diversities*, 3, 54–64.
- McHugh, J. E., Wherton, J. P., Prendergast, D. K. and Lawlor, B. A.** (2012). Teleconferencing as a source of social support for older spousal caregivers: initial explorations and recommendations for future research. *American Journal of Alzheimer’s Disease and Other Dementias*, 27, 381–387.
- Millenaar, J. K., Bakker, C., Koopmans, R. T. C. M., Verhey, F. R. J., Kurz, A. and de Vugt, M. E.** (2016). The care needs and experiences with the use of services of people with young-onset dementia and their caregivers: a systematic review. *IfGP*, 31, 1261–1276.
- Morgan, D. G. et al.** (2009). Improving access to dementia care: Development and evaluation of a rural and remote memory clinic. *Ageing & Mental health*, 13, 17–30.
- Nielsen, T. R., Nielsen, D. S. and Waldemar, G.** (2021). Barriers in access to dementia care in minority ethnic groups in Denmark: a qualitative study. *Ageing & Mental Health*, 25, 1424–1432.
- Nowaskie, D. et al.** (2020). Care coordinator assistants: job satisfaction and the importance of teamwork in delivering person-centered dementia care. *Dementia*, 19, 1560–1572.
- Nyman, S. R., Innes, A. and Heward, M.** (2017). Social care and support needs of community-dwelling people with dementia and concurrent visual impairment. *Ageing & Mental Health*, 21, 961–967.
- Phillipson, L. and Jones, S. C.** (2012). Use of day centers for respite by help-seeking caregivers of individuals with dementia. *Journal of Gerontological Nursing*, 38, 24–34.
- Rainero, I. et al.** (2020). The impact of COVID-19 quarantine on patients with dementia and family caregivers: a nation-wide survey. *Frontiers in Aging Neuroscience*, 12, 625781.
- Read, S., Hu, B., Wittenberg, R., Brimblecombe, N., Robinson, L. and Banerjee, S.** (2021). A longitudinal study of functional unmet need among people with dementia. *Journal of Alzheimer’s Disease*, 84, 705–716.
- Richardson, V. E. et al.** (2019). At the intersection of culture: ethnically diverse dementia caregivers’ service use. *Dementia (London, England)*, 18, 1790–1809. <https://doi.org/10.1177/1471301217721304>.
- Rising, K. L., Salcedo, V. J. and Amadio, G.** (2022). Living through the pandemic: the voices of persons with dementia and their caregivers. *Journal of Applied Gerontology*, 41, 30–35.
- Robinson, A. et al.** (2012). Seeking respite: issues around the use of day respite care for the carers of people with dementia. *Ageing and Society*, 32, 196–218.
- Roes, R. M., van Rijn, A., Rus, E., Dacier, S. and Meiland, F.** (2019). Utilisation, effect, and benefit of the individualized Meeting Centers Support Program for people with dementia and caregivers. *Clinical Interventions in Ageing*, 14, 1527–1553.
- Ryan, L.** (2021). Accessing community dementia care services in Ireland: emotional barriers for caregivers. *Health & Social Care in the Community*, 29, 1980–1989. <https://doi.org/10.1111/hsc.13342>.
- Samsi, K., Cole, L., Orellana, K. and Manthorpe, J.** (2022). Is it worth it? Carers’ views and expectations of residential respite for people living with dementia during and beyond the COVID-19 pandemic. *IfGP*, 37. <https://doi.org/10.1002/gps.5680>.
- Statz, T. L. et al.** (2022). We moved her too soon: navigating guilt among adult child and spousal caregivers of persons living with dementia following a move into residential long-term care. *Couple and Family Psychology: Research and Practice*, 11, 300–314.
- Stephan, A. et al.** (2018). Barriers and facilitators to the access to and use of formal dementia care: findings of a focus group study with people with dementia, informal carers and health and social care professionals in eight European countries. *BMC Geriatrics*, 18, 131–131.
- Sun, F., Mutlu, A. and Coon, D.** (2014). Service barriers faced by Chinese American families with a dementia relative: perspectives from family caregivers and service professionals. *Clinical Gerontologist*, 37, 120–138.
- Tetley, J.** (2013). Articulation, service use, managing and coping: understanding the needs of older people and carers

- living with dementia. *International Practice Development Journal*, 3, 1–17.
- Van Manen, A. S., Aarts, S., Metzelthin, S. F., Verbeek, H., hamers, J. P. H. and Zwakhalen, S. M. G.** (2021). A communication model for nursing staff working in dementia care: results of a scoping review. *International Journal of Nursing Studies*, 113, 103776.
- Vickrey, B. G., Strickland, T. L., Fitten, L. J., Adams, G. R., Ortiz, F. and Hays, R. D.** (2007). Ethnic variations in dementia caregiving experiences: insights from focus groups. *Journal of Human Behavior in the Social Environment*, 15, 233–249.
- Wang, S., Yan, D., Temkin-Greener, H. and Cai, S.** (2021). Nursing home admissions for persons with dementia: role of home- and community-based services. *Health Services Research*, 56, 1168–1178.
- Watson, J., Giebel, C., Green, M., Darlington-Pollock, F. and Akpan, A.** (2021). Use of routine and cohort data globally in exploring dementia care pathways and inequalities: a systematic review. *International Journal of Geriatric Psychiatry*, 36, 252–270.
- Winslow, B. W.** (2003). Family caregivers' experiences with community services: a qualitative analysis. *Public Health Nursing (Boston, Mass.)*, 20, 341–348.
- Yiu, H. C., Zang, Y. and Chau, J. P. C.** (2020). Barriers and facilitators in the use of formal dementia care for dementia sufferers: a qualitative study with Chinese family caregivers in Hong Kong. *Geriatric Nursing (New York)*, 41, 885–890.
- Zhan, L.** (2004). Caring for family members with Alzheimer's disease: perspectives from Chinese American caregivers. *Journal of Gerontological Nursing*, 30, 19–29.