



REVIEW ARTICLE

Care partner needs of people with neurodegenerative disorders: What are the needs, and how well do the current assessment tools capture these needs? A systematic meta-review

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Abstract

Objectives: The burden on care partners, particularly once dementia emerges, is among the greatest of all caregiving groups. This meta-review aimed to (1) synthesis evidence on the self-reported needs of care partners supporting people living with neurodegenerative disorders; (2) compare the needs according to care partner and care recipient characteristics; and (3) determine the face validity of existing care partner needs assessment tools.

Methods: We conducted a systematic review of reviews involving a thematic synthesis of care partner needs and differences in needs according to demographic and other characteristics. We then conducted a gap analysis by identifying the themes of needs from existing needs assessment tools specific to dementia and cross-matching them with the needs derived from the thematic synthesis.

Results: Drawing on 17 published reviews, the identified range of needs fell into four key themes: (1) knowledge and information, (2) physical, social and emotional support, (3) care partner self-care, and (4) care recipient needs. Needs may differ according to disease trajectory, relationship to the care recipient, and the demographic characteristics of the care partner and recipient. The 'captured needs' range between 8% and 66% across all the included needs assessment tools.

Conclusions: Current tools do not fully or adequately capture the self-identified needs of care partners of people living with neurodegenerative disorders. Given the high burden on care partners, which has been further exacerbated by the COVID-19 (SARS CoV-2) pandemic, the needs assessment tools should align with the self-reported needs of care partners throughout the caregiving trajectory to better understand unmet needs and target supportive interventions.

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KEYWORDS

Alzheimer's, assessment tool, care partners, caregivers, carers, cognitive impairment, dementia, descriptive system, economic evaluation, instrument, meta-review, needs assessment, neurodegenerative disorders, systematic review

Key points

- This is a synthesis of available research in the area of needs of care partners of people living with neurodegenerative disorders.
- Needs identified by care partners fall into four broad themes (1) knowledge and information, (2) physical, social and emotional support needs, (3) care partner self-care, and (4) care recipient needs.
- This research highlights the mismatch between the care partners' needs and the needs captured by the needs assessment tools.
- This meta-review identified emerging needs that have not been explored by existing needs assessment tools and demonstrated the importance of individualized assessment of the relative importance of needs throughout the caregiving trajectory.

1 | INTRODUCTION

Neurodegenerative disorders (NDD) associated with progressive cognitive impairment include Alzheimer's disease, Parkinson's disease, motor neurone disorder, cerebellar degeneration, Huntington's disease, and the prion disorders. Dementias are responsible for the greatest burden of neurodegenerative diseases, with Alzheimer's representing approximately 60%–70% of dementia cases worldwide. The World Health Organization estimates that, globally, 24.3 million people have dementia, with 4.6 million new cases annually.¹ This number is estimated to double every 20 years.¹

NDD are characterized by a progressive loss of nerve cells and synapses, leading to deficits that affect an individual's ability to perform daily tasks. This loss necessitates reliance on care support, which increases as the disorder progresses. Care provided by informal care partners, usually unpaid and untrained, is an integral aspect of the support provided to the person living with the NDD and accounts for up to 70% of total healthcare costs associated with these conditions.² The negative impact on care partners, particularly once dementia emerges, is among the greatest of all caregiving groups.³ Emerging evidence highlights even further disproportional effect on care partners of people living with dementia caused by the public health restrictions due to the COVID-19 (SARS CoV-2) pandemic.⁴

Here, we use the term 'care partner' to acknowledge the bidirectional partnership and caring relationship between the person receiving care and the person providing it.⁵ Eilers (2013) corroborated this notion and described that the care partnership builds on pillars of trust, equality and shared experience.⁶ The care partner is usually a spouse or an adult child who takes on the responsibility to support and assist a family member unable to take care of themselves and ensure they are safe and well.⁵ Care partners may be in part-time or full-time employment, diminishing their time and energy to provide care. Care partners may also have their own physical and mental health needs, limiting their capabilities to provide care. Consequently, care partners, particularly those with dementia, may have

increased negative feelings, depression, and diminished wellbeing.⁷ They become 'the invisible patients' themselves.⁸

Given the central role of care partners in ensuring health and wellbeing, it is essential to understand their needs, thereby improving the quality of life and the care they provide for individuals with NDD. Tools developed specifically to capture the unmet needs of care partners are necessary to assess this group's unique concerns. We applied the concept of "unmet need" at an individual level instead of its application in large-scale public health surveys.⁹ Needs assessment is an approach that allows individuals to the extent to which their health and social care needs have or have not been met, allowing for estimations of the prevalence of needs and the magnitude of help required.^{10,11} It can assist in identifying care partners who experience higher levels of unmet needs and therefore require greater support. It is crucial to ask care partners directly about the issues they need assistance with to achieve optimal wellbeing as those might differ from healthcare providers' views regarding individuals' needs.^{12,13}

The problem- or symptom-focused approach used by most assessment tools extrapolates respondents' needs based on their endorsement of symptoms.⁹ In contrast, the "needs' assessment" approach measures the discrepancy between the respondents' experiences and their perceived needs or expectations.⁹ It is a valuable means of planning supportive interventions or services based on specific and individualized needs, mainly when clinical presentations are complex, such as in multi-morbidity with dementia.⁹

Several reviews have contributed to our understandings of the needs of care partners^{14–16} and the needs assessment tools available.^{14,17} However, their restricted aims and inclusion criteria have led to a patchwork understanding of these needs. To our knowledge, a broad overview of the literature, including qualitative and quantitative reviews, has not yet been undertaken. Thus, to address this gap, we conducted a meta-review of reviews assessing the needs of care partners of people living with NDD, differences in needs across care partners and care recipients, and how effectively existing needs assessment tools to capture these needs. A comprehensive understanding and assessment of care partners' needs are essential to

supporting the development and enhancement of appropriate interventions. This meta-review addressed the following three research questions:

RQ1 What are the needs of care partners of people living with NDD?

RQ2 Do these needs differ?

RQ3 How well do current needs assessment tools effectively capture these needs?

2 | METHODS

A meta-review (a systematic review of reviews) was undertaken to comprehensively summarize the evidence with more than one review on an important topic.¹⁸ In this meta-review, any type of review was referred to as 'review', while studies within these 'reviews' were referred to as 'primary studies'. The meta-review adhered to the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) Statement^{19,20} and was registered in the PROSPERO database (CRD42021227379). Guidance from the Joanna Briggs Institute informed the development, conduct and reporting of this meta-review.²¹

Any reviews that reported findings from primary studies on the needs of care partners of people with progressive cognitive disorders or NDD such as Alzheimer's, Parkinson's, motor neurone, cerebellar degenerations, Huntington's, and prion disorders were included (see Appendix 1, Table A1 for full search strategy). Care partners in these studies had to be non-paid adults (18 years of age or older) of either sex and any ethnic or geographical origin. The people to whom they provide care could be of any age and at any point along their disease trajectory.

2.1 | Data search and extraction

A qualified medical librarian searched the international literature in January 2021 through Embase, Medline, CINAHL, PsychINFO and Epistemonikos 98 databases. Thorough hand searching of identified articles' reference lists supplemented the database searching. The search was guided by search terms and derivatives related to "literature reviews," care partner needs," cognitive disorders", and "neurodegenerative disorders". Search results were imported into EndNote X7 software, duplicates removed, and imported into Covidence online software.

We conducted data extraction in two stages. In stage 1, we extracted the needs and differences in needs (RQ1 and RQ2 accordingly). After completing stage 1 extraction and identifying the types of NDD, we conducted stage 2 extraction for condition-related needs assessment tools and the themes of needs captured by these tools. We then cross matched the needs derived from the narrative synthesis in stage 1 against the needs captured by the needs assessment tools (RQ3).

Two investigators (LE, IK) independently applied the eligibility criteria outlined above and documented reasons for exclusion. Any discrepancies flagged through Covidence were resolved through discussion. Once all included articles were identified, one investigator (LE) extracted data from each study into an Excel V15.28 spreadsheet on publication year, region and country of origin, review type, NDD, progression, socio-demographic characteristics, results, and authors conclusion. YC, EA, AS, and A-SA conducted secondary data extraction for individually allocated variables.

The needs assessment tools were sourced from the most recent psychometric systematic review by Kipfer S. and Pihet S. (2020),¹⁷ which included 14 needs assessment tools for informal dementia caregivers (Box 1). Four investigators (EA, AA, YC, IK) independently extracted the themes for each identified tool and matched them against the themes of needs derived from the narrative synthesis (stage 1 extraction). The primary investigator (IK) subsequently collated extraction sheets and reviewed the data for all included reviews.

BOX 1 Condition specific needs assessment tool included in meta-review (*n* = 14)

- Carers Assessment of Difficulties Index (CADI)²²
- Care Needs Assessment Pack for Dementia (CARENAPD)²³
- Carers' Needs Assessment for Dementia (CNA-D)²⁴
- Caregivers' Needs Checklist for Dementia (CNCD)²⁵
- Echelle d'attentes de consultation (EAC)²⁶
- Johns Hopkins Dementia Care Needs Assessment (JHDCNA)²⁷
- Needs Assessment Survey (NAS)²⁸
- Partnering for Better Health-Living with Chronic Illness: Dementia (PBH-LCI:D)²⁹
- Questionnaire of Carers Needs Evaluation (QCNE)³⁰
- Questionnaire National dementia Programme survey needs and problems of informal caregivers of persons with dementia (QNP)³¹
- Risk Appraisal Measure (RAM)³²
- Scales measuring the Impact of Dementia on CARers (SIDECAR)³³
- Tayside Profile for Dementia Planning (Tayside)³⁴
- Unmet Need Measure (UNM)³⁵

Each assessment tool was scored one point for each need that was 'fully included' in the tool, half a point if a need was 'somewhat included', and zero for the 'not included' need. Each tool received a score estimated by summing the needs included score and dividing the total by the number of applicable fields, and multiplying by 100. A greater percentage score reflects a greater number of needs identified as important to care partners included in each assessment tool. The authors applied this scoring method in past research and customized it for this meta-review.³⁶

2.2 | Data synthesis

Thematic synthesis of the needs was completed in three stages. First, all included reviews were imported into NVivo, and one investigator conducted line-by-line free coding of the perspectives of care partners and their needs (Step 1; LE). Free codes were then organized into descriptive themes (Step 2; LE, IK). Random selection of data extracts and checking of the trustworthiness of the data was carried out by a third independent investigator (SK), and disagreements were resolved through discussion (Step 3). We then conducted a gap analysis by identifying the themes of needs from 14 needs assessment tools specific to dementia (EA, AA, YC, IK) and cross-matching them with the needs derived from the thematic synthesis (EA, IK, YC).

2.3 | Quality assessment

Three investigators (IK, YC, AB) assessed the quality of reviews using a bespoke three-step checklist.³⁷ Step 1: investigators extracted review type, that is, systematic, scoping, integrative, etc., as per the verbatim description provided in each review. Consistent with the previous research, review type was considered a primary quality measure.^{38,39} Step 2: investigators ascertained the use of Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) or any other relevant guidelines. Step 3: investigators assessed whether reviews assessed the quality of primary studies that they had included. If so, how, what tools they used, and what were the results. After the investigators individually assessed all included reviews, they met and resolved discrepancies in their ratings through discussion.

3 | RESULTS

3.1 | Overview

The initial search for reviews in five databases yielded 1940 references for screening. After the removal of duplicates ($n = 810$), 1128 references were screened by title and abstract. The full texts for 121 reviews were retrieved. In total, 17 reviews met the inclusion criteria and were included in a narrative synthesis. Figure 1 shows the search and selection process in detail.

Table 1 offers an overview of the main characteristics of included reviews. In total, 17 reviews included over 528 studies mostly originated from the US ($n = 70$), the UK ($n = 49$), Canada ($n = 25$), Australia ($n = 15$), Netherlands ($n = 11$) and Sweden ($n = 10$) among other countries (not reported in Table 1).

All 17 reviews focused on dementia due to an NDD. Only half specified the type of dementia (9/17; 53%). Most reviews did not report the dementia stage (47%). Four reviews focused on end-of-life needs (24%), and one review on the needs of care partners during the early and moderate stages of dementia. Across all reviews, where

reported, most care partners were female (over 64%) and had mean ages between 55 and 77 years (not reported in Table 1).

3.2 | Research question 1: Identified needs

Overall, 11 types of needs were identified from the 17 reviews and combined into four main themes relating to the needs of care partners of people with NDD: (1) knowledge and information needs, (2) physical, social and emotional support needs, (3) care partner self-care needs, and (4) care recipient needs (see Appendix 2 Table A2 and Supplementary File for details description).

3.2.1 | Theme 1: Knowledge and information needs

Knowledge and information needs included five sub-themes: (1) disease-specific information, (2) healthcare-related information, (3) financial and legal needs, (4) care partner self-care information needs, and (5) information source. Disease-specific information was among the most reported need identified in 82% of reviews ($n = 14$),^{15,16,40,42,43,45,47-54} followed by healthcare-related information needs that reflected the lack of knowledge about the physical needs of care recipients (76%, $n = 13$).^{15,16,40,42,43,45,48-54} The need for instant access to relevant information in one place was reported in 59% of reviews ($n = 10$).^{15,16,40-44,46,49,51} Self-care information needs appeared in 18% of reviews ($n = 3$).^{40,47,53}

3.2.2 | Theme 2: Support needs

Support needs included the following three sub-themes: (1) physical, (2) social, and (3) emotional support needs. Physical support needs were identified by 82% of reviews ($n = 14$),^{15,16,42-47,49-54} followed by social (71%, $n = 12$)^{15,16,41-44,47-49,52-54} and emotional support needs (59%, $n = 10$).^{15,16,42-45,48,50,53,54}

3.2.3 | Theme 3: Care partner self-care needs

Self-care needs were reported in 47% of reviews ($n = 8$).^{15,42-44,49,50,53,54}

3.2.4 | Theme 4: Care recipient needs

Care recipient needs included two sub-themes of (1) collaboration with the health care team and (2) safety. Care partners expressed the need to be included as equal partners in formal and informal care planning. This need was identified in 35% of reviews ($n = 6$).^{15,16,42,44,48,51} The need for ensuring safety was identified in two reviews (12%).^{15,40}

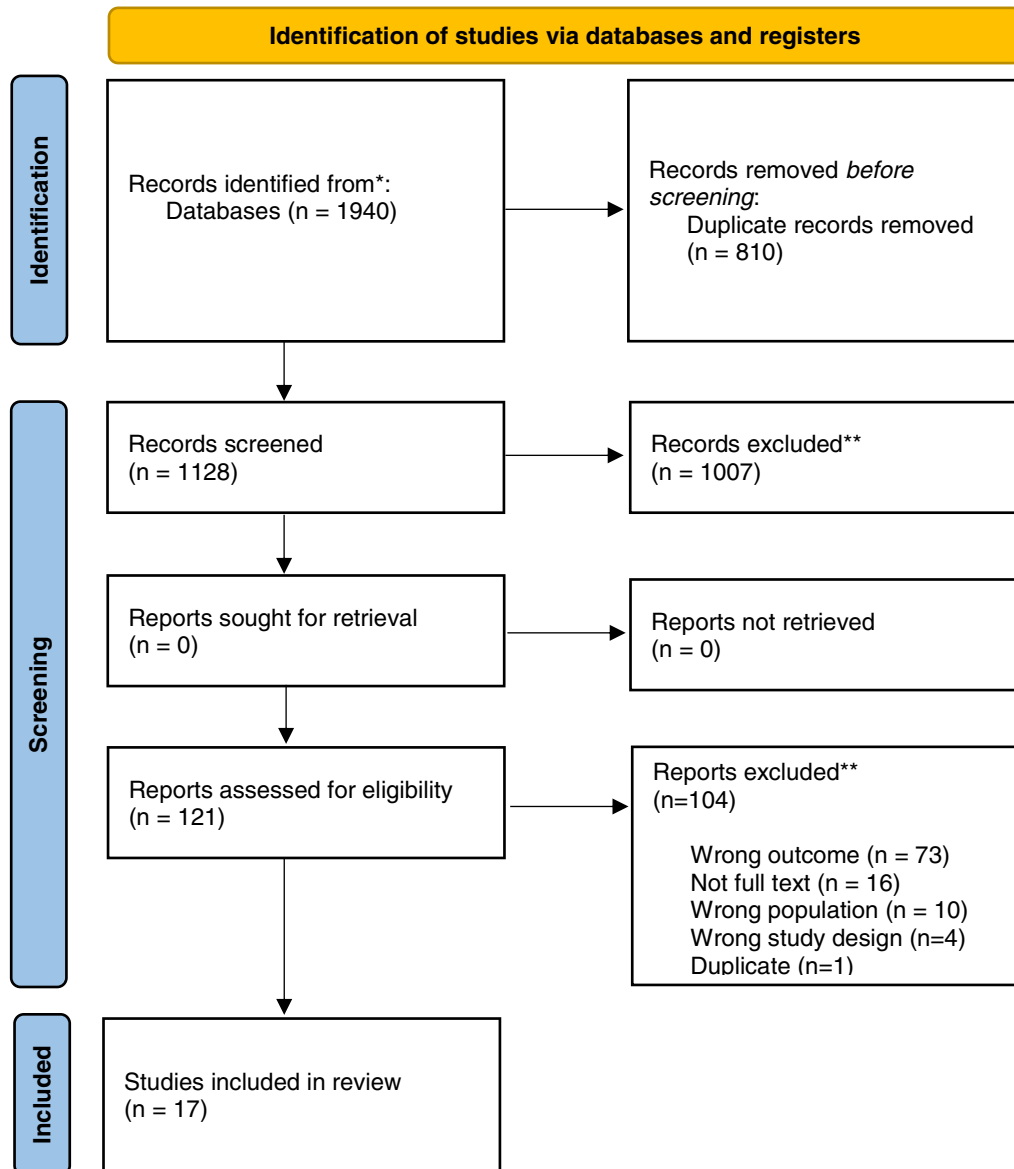


FIGURE 1 PRISMA 2020 flow diagram for new systematic reviews which included searches of databases and registers only

3.3 | Research question 2: Differences in needs

Just over half (56%) of included reviews reported differences in needs based on disease trajectory (8/47%),^{15,40,43,48,50,51,53,54} relationship to care recipient (4/24%),^{43,44,50,54} location (2/12%),^{48,52} ethnicity (2/12%),^{44,53} sex (2/12%),^{44,53} and age (1/6%).⁴⁴

3.3.1 | Disease trajectories

As the disease progresses, care partners emphasized the need for information on the processes around death and how to prepare for and manage grief and life after caring. Psychological and emotional support needs also emerged, especially when care partners could not enact emotional coping strategies and when their resilience

decreases during the disease trajectory due to the burden of caregiving and lack of support received.

3.3.2 | Relationship

Spouses and adult children care partners reported differences in how frequently they engage in leisure activities, feelings of guilt concerning self-care, failing to meet caregiving challenges, negative feelings towards others, depression, and psychosocial needs and responses.^{50,54} Siblings of persons with dementia uniquely wanted to learn more about heredity aspects of the disease.

Adult children expressed the need for practical information on how to deal with the condition.^{50,54} These care partners experienced guilt, anger and frustration (mid-stage disease), sadness,

TABLE 1 Characteristics of included reviews (n = 17)

	Soong 2020 ⁴⁰	Romero- mas 2020 ⁴¹	Queluz 2020 ⁴²	HoltClemmins 2020 ⁴³	Bressan 2020 ⁴⁵	Waligora 2019 ⁴⁴	Lee 2019 ⁴⁵	Hirt 2019 ⁴⁶	Sousa 2017 ⁴⁷	Barker 2017 ⁴⁸	McCabe 2016 ⁴⁹	Millenaar 2016 ⁵⁰	Khanassov 2016 ¹⁶	Flemming 2016 ⁵¹	Dunn 2016 ⁵²	Afram 2015 ⁵³	Thompson 2014 ⁵⁴	Overall (% out of 17)
Included primary studies (n)	20	46	31	122	34	29	29	24	8	40	12	27	46	35	12	13	NR	528
Type of review																		
Systematic					×	×					×	×	×	×	×	×		7 (41%)
Scoping	×		×	×			×	×										6 (35%)
Integrative		×						×										2 (12%)
Not reported/ unclear															×		×	2 (12%)
Language of review	E	E	E	E	E	E	E	E	P	E	E	E	E	E	E	E	E	-
Regions of primary studies																		
Africa													×					1 (6%)
Asia	×		×	×	×	×	×	×		×	×		×					10 (59%)
Europe	×		×	×	×	×	×	×	×	×	×		×	×				12 (71%)
North America	×		×	×	×	×	×	×	×	×	×		×	×	×			13 (76%)
Oceania	×		×	×	×	×	×	×	×	×	×		×	×				11 (65%)
South America			×	×	×	×	×					×						4 (24%)
Not reported/ unclear		×													×		×	4 (24%)
Type of primary studies																		
Qualitative	×	×	×	×	×	×	×	×		×	×	×	×	×	×	×		14 (82%)
Quantitative	×	×	×	×	×	×	×	×	×	×	×	×	×					10 (59%)
Mixed methods	×		×	×	×	×	×	×	×	×	×	×	×					10 (59%)
Literature review				×			×			×								3 (18%)
Not reported/ unclear									×						×		×	3 (18%)
Condition																		
Dementias (unspecified)	×		×	×	×	×	×	×	×	×	×	×	×	×	×	×	×	13 (76%)
Alzheimer's disease	×	×	×	×	×	×	×	×					×					8 (47%)
Lewy body dementia	×		×	×	×	×	×						×					6 (35%)
Mild cognitive impairment			×	×	×	×	×	×										5 (29%)
Frontotemporal dementia			×	×	×	×	×	×					×					5 (29%)

TABLE 1 (Continued)

	Romero- mas 2020 ⁴¹	Soong 2020 ⁴⁰	Queluz 2020 ⁴²	Holt-Clemmins 2020 ⁴³	Bressan 2020 ⁴⁵	Waligora 2019 ⁴⁴	Lee 2019 ⁴⁵	Hirt 2019 ⁴⁶	Sousa 2017 ⁴⁷	Barker 2017 ⁴⁸	McCabe 2016 ⁴⁹	Millenaar 2016 ⁵⁰	Khanassov 2016 ¹⁶	Flemming 2016 ⁵¹	Dunn 2016 ⁵²	Afram 2015 ⁵³	Thompson 2014 ⁵⁴	Overall (% out of 17)
Vascular dementia		x	x		x								x					3 (18%)
Young/early-onset dementia		x	x	x	x							x	x					6 (35%)
progression																		
Several stages (mild to severe)	x			x	x		x											5 (29%)
Early-stage													x					1 (6%)
Moderate stage													x					1 (6%)
End of life										x				x				4 (24%)
Not reported/unclear			x			x		x	x		x	x			x			8 (47%)

Abbreviations: E, English; NR, Not Reported; P, Portuguese.

longing, and loneliness (late-stage disease). In contrast, married care partners experienced sadness (early and mid-stage disease) followed by anger, confusion, frustration, and feelings of uncertainty (later stages). For spousal care partners, grief increased linearly from early to late stages. Spousal care partners expressed the need for support to maintain continuity in their relationship by enabling shared moments and structuring visits within residential care facilities, and emotional support needs to preserve care partners' feelings of interconnectedness and mutuality with the person with dementia.

3.3.3 | Location

Limited availability and insufficient services for dementia care were reported in rural communities, especially as the disease progresses.^{53,54} Compared to urban and suburban communities, unique unmet needs of rural communities include bathing, dressing, housekeeping, meal preparation, transportation difficulties and lack of resources.^{50,54} Barriers to accessing healthcare in this setting include a shortage of healthcare professionals, inadequate access for physical and mental healthcare coordination, and information required to access healthcare.^{48,52,53} Financial difficulties and transportation issues frequently prohibit follow-up visits.^{15,51}

3.3.4 | Ethnicity

Carers of persons with an African-American ethnic background stated the need for spiritual and religious activities (e.g. praying, attending Church) as a source of strength and emotional support.⁴⁴ They reported the need for community resources (especially for self-care) and support from family members, churches, or communities. They may also not refer to themselves as carers because of the perception that providing care for elders is part of family life and culture. For carers of persons of Asian background, cultural values, such as "filial piety", were central to causing emotional distress when caring for a family member (e.g. when considering the use of nursing homes).⁵³

3.3.5 | Sex

The polarization of male and female roles in caregiving was identified as a potential barrier to self-care in that it emotionally and socially stigmatizes female carers. Gender roles may impact how carers respond to the caregiving situation and whether they sacrifice their own needs. Male carers reported finding caregiving problematic because this required taking over new responsibilities with which they were traditionally unfamiliar and prioritizing the needs of the person they care over their own needs; they may also be insufficiently supported. On the other hand, female carers were more likely

to have worse medication adherence and appointment keeping. For female carers, support networks were essential for sharing care duties and responsibilities, providing self-care advocacy, authenticating their needs to self-care, and helping manage their stress. Female carers acknowledged that the care recipient needs and health took priority over their own self-care needs. Female carers may connect their female identities to caring and feel obligated to fulfil society's gender standards.⁵⁴

Gender differences were also observed within adult children providing care. Engaging in leisure activities was found to reduce depressive symptoms in daughters who experience strong feelings of guilt (but not when they experience low feelings of guilt). There might be societal gender roles with sons referring to their role as care managers and daughters as emotionally supportive personal caretakers.⁵⁰ Such male and female role differences may influence how carers use services.⁵⁰ Daughters were reluctant to accept support because they perceived it as a burden to others or a failure to care properly. At the same time, sons relied heavily on assistance with daily care from formal health care services.⁵⁰

3.3.6 | Age

For older carers, sleep emerged as a vital self-care need. Older age was significantly correlated to several objectively measured sleep variables, including less time in bed spent sleeping, slow-wave and stage 2 sleep, greater stage 1 sleep, time spent in bed, and awake time after sleep onset and total short awakenings.⁴⁴

3.4 | Research question 3: Needs assessment

Table 2 presents results of a gap analysis of the needs derived from the narrative synthesis (RQ1) against the needs extracted from the 14 needs assessment tools (refer to Appendix 3 for further details). The 'captured needs' score ranged from 8% to 66% across all the tools. While the SIDECAR³³ tool captured the most needs (66%), the Tayside³⁴ tool captured the least (8%). None of the tools fully captured the needs as derived from the narrative synthesis. The most frequently captured needs were healthcare and disease-specific knowledge and information, safety, and social support needs. The least captured needs were the need for instant access to relevant information in one place, financial and legal knowledge and information, and the need for better collaboration with the professional healthcare team.

The gap analysis identified some emerging needs not captured by the included needs assessment tools. For example, these included the need for a central expert point of contact and help with how to apply for funding to access healthcare services, the need for culturally respectful care from formal support services, and the need for honest conversations in plain language that do not avoid discussion of difficult topics, especially those around dying.

TABLE 2 Gap analysis of needs derived from the narrative synthesis against the needs assessment tools – observation of validity

Theme	Sub-theme	Tool														Overall (% included)
		CADI	CARENAPD	CNA-D	CNCD	EAC	JHDCNA	NAS	PBH-LCID	QCNE	QNP	RAM	SIDECAR	Tayside	UNM	
1. Knowledge and information needs	1.1. Disease specific	0%	30%	50%	40%	50%	20%	20%	50%	20%	30%	30%	100%	0%	50%	34%
	1.2. Healthcare related	0%	40%	50%	50%	30%	20%	80%	30%	60%	10%	100%	0%	50%	39%	
	1.3. Information source	0%	0%	0%	17%	0%	NA	0%	NA	0%	0%	50%	0%	0%	8%	
	1.4. Financial and legal needs	0%	0%	10%	40%	0%	NA	0%	0%	10%	20%	0%	30%	0%	70%	14%
2. Support needs	1.5. Self-care information	0%	0%	0%	100%	50%	NA	0%	0%	0%	50%	0%	0%	100%	25%	
	2.1. Physical	20%	30%	10%	60%	10%	30%	20%	10%	20%	10%	60%	50%	60%	28%	
	2.2. Social	38%	0%	30%	75%	25%	13%	0%	25%	25%	38%	50%	13%	50%	33%	
3. Caregiver self-care needs	2.3. Emotional	25%	0%	25%	25%	25%	8%	0%	0%	42%	0%	58%	8%	42%	21%	
	3.1. Own needs	80%	0%	0%	0%	10%	NA	0%	0%	10%	30%	90%	0%	20%	21%	
4. Needs for care recipient	4.1. Collaboration with the professional healthcare team	25%	0%	0%	0%	38%	NA	25%	0%	38%	0%	63%	0%	0%	13%	
	4.2. Safety	0%	0%	50%	36%	0%	100%	50%	NA	100%	100%	100%	0%	0%	39%	
Overall (% included)		19%	11%	28%	36%	22%	13%	22%	10%	31%	16%	66%	8%	41%		

Note: Carers Assessment of Difficulties Index (CADI)²², Care Needs Assessment Pack for Dementia (CARENAPD)²³, Carers' Needs Assessment for Dementia (CNA-D)²⁴, Caregivers' Needs Checklist for Dementia (CNCD)²⁵, Echelle d'attentes de consultation (EAC)²⁶, Johns Hopkins Dementia Care Needs Assessment (JHDCNA)²⁷, NA – Not able to Access, Needs Assessment Survey (NAS)²⁸, Partnering for Better Health—Living with Chronic Illness: Dementia (PBH-LCID)²⁹, Questionnaire of Carers Needs Evaluation (QCNE)³⁰, Questionnaire National dementia Programme survey needs and problems of informal caregivers of persons with dementia (QNP)³¹, Risk Appraisal Measure (RAM)³², Scales measuring the Impact of Dementia on CARers (SIDECAR)³³, Tayside Profile for Dementia Planning (Tayside)³⁴, and Unmet Need Measure (UNM).³⁵

4 | DISCUSSION

4.1 | Identified needs

This meta-review collated evidence from 17 reviews of different types, including systematic, scoping, and rapid reviews. The results yielded a range of needs expressed by care partners of people living with dementia due to an NDD. These needs were categorized thematically into four major themes related to (1) knowledge and information needs, (2) support needs, (3) care partner self-care needs, and (4) care recipient needs. Quantitative, qualitative, and mixed methods reviews supported all four themes. The overall quality of the evidence supporting the themes was varied but essentially low, predominantly coming from reviews that did not follow a systematic approach or conduct a quality appraisal of included studies.

The most prominent and frequently cited needs were related to knowledge, information, and support. Knowledge and informational needs underpin the learning processes inherent in caregiving⁴² and can affect the other needs, particularly in the case of multimorbidity.⁹ In fact, many of the identified needs could be met at a relatively low cost by providing more information. For example, by addressing knowledge and information needs, a care partner could meet their other needs more effectively by better identifying supports available or by seeking help for self-care. Care partners who do not know what to expect about the disease prognosis or where to access formal support can feel overburdened because they do not have the information necessary to manage care better or to plan for the assistance they may need in the future.^{9,49}

4.2 | Differences in needs

Each person's unique caregiving context prompts different needs that may vary across situations and throughout the caregiving trajectory. Evidence suggests that there are differences in the way men and women are affected by the caregiving experience.^{4,44,53} Women reported greater depression, stress, loneliness, and anxiety compared with men who provide care.⁴ Importantly, these gender differences were seen from early on in the caregiving role. Women are more likely than men to take on the caregiving role and may also be juggling work, family responsibilities, and caregiving. Some men find it challenging to adapt to the caring role and so may be reluctant to access services.^{44,53}

The caregiving context can explain some of the variations among care partners' needs, including the intensity of needs – that is, perceived urgency, level of burden, or clustering of needs over time, and across different types of NDD. These differences highlight the importance of individualized assessments and intervention approaches early in caregiving and ongoing assessment of need.

4.3 | Needs assessment

The gap analysis of the needs derived from the narrative synthesis (RQ1) against the needs extracted from the 14 needs assessment tools revealed that none of the selected tools fully captured the needs identified by care partners, and some emerging needs remain unexplored. Uncaptured needs included a central expert point of contact, assistance in applying for funding to access formal healthcare services, culturally respectful formal support services, and honest, jargon-free conversations with healthcare professionals that do not "divert" from a hard discussion, especially around dying.

While several tools used interviews or focus groups when developing their descriptive systems,^{22,24,25,28,31,34,35} only a few included expert consultations^{27,29,32} and more iterative consultations with carer partners.^{23,30} Only one tool came the closest to a co-design methodology and person-centered approach.³³ The development of SIDECAR³³ included the involvement of two care partner consultants on the research team. It is worth highlighting that SIDECAR³³ also captured the most needs identified in our meta-review. Emerging evidence suggests that research co-design may lead to the development of clearer and more consistent terminology, better reporting of the activities involved and better evaluation.⁵⁵

While each person's unique caregiving context will prompt different needs that may vary across situations and throughout the caregiving trajectory, it is essential to assess needs using a standardized tool co-designed with care partners. Ensuring that needs assessment tools are aligned with the stated needs of care partners throughout the caregiving trajectory will allow for more targeted supportive interventions for those caring for people with NDD.

Another limitation of existing tools was their inability to determine which needs care partners perceived as the most important. Assessment of the relative importance of needs could be instrumental in ensuring that interventions are responsive to the most critical needs as ranked by care partners. Relative importance may be assessed by asking care partners to select, for example, the top five needs which, if they were to be met, would have the most significant impact on their wellbeing. In a research setting, tools that assess relative importance may be used to provide reliable outcome measures to assess the cost-effectiveness of interventions across the spectrum of health and social care interventions.

4.4 | Strengths and limitations

This meta-review has several strengths and limitations. The main strength is its inclusivity of review types. This meta-review integrates different types of reviews and data collection strategies to understand care partners' needs comprehensively. The comprehensive

search by an experienced librarian across several databases with additional hand searching, web searching, and citation tracking ensured that relevant reviews were identified. To reduce subjective bias, the study selection and data extraction were performed independently by several investigators. Transparency of the method and independent analysis by multiple investigators promoted the validity of findings, rigor, and trustworthiness of this meta-review.

Consistent with the exploratory nature, the main aim was not to emphasize methodological inadequacies within the identified reviews, but to present a broad scope of self-identified needs of care partners and match these against the needs captured by existing needs assessment tools. Therefore, the quality assessment results of our meta-review should be used as a guide in interpreting and valuing the findings of included reviews and not as a methodological quality check. The findings are informative on the specific needs of care partners. However, the primary studies included had some limitations. Most of the primary studies were conducted in high-income countries such as the US, UK, Canada and Australia. Thus, findings may have limited generalizability to other geographical regions or even rural areas within these countries. Few reviews focused on or included care partners who belong to racial and ethnic minority groups, regional differences, and lower socio-economic backgrounds.

Only those needs assessment tools that were part of a literature review on psychometric properties were included in our analysis. Other needs assessment tools designed for and with care partners, for example, NAT-CC for care partners of people with a chronic condition that is not cancer⁵⁶ or NAT: PD for care partners of people with progressive disease⁵⁷ could be relevant and warrant investigation with care partners of people with NDD.

4.5 | Implications

The findings of this review highlight the need to better understand needs of care partners as vital to developing and delivering services and resources to alleviate the strain caused by caregiving. This should include the validity of tools used to collect data on care partners' needs, report consistently on dimensions of care partners' experiences, and explore the needs and how, when, and where those needs manifest across the care journey. Future work needs to capture both the relative importance and changes in care partner needs to provide insight into services needed along the caregiving trajectory.

Given the paucity of studies focused on differences in needs of care partners, it is crucial to examine how age, gender, culture – including race, ethnicity, nationality, and other factors – impacts transitions into and experiences of the caregiving role. This knowledge could be crucial to tailoring support for care partners. These factors may be associated with unique needs and may intersect with other dimensions of identity in essential ways and impact the caregiving journey. Moreover, differing circumstances of care partners, including kin relationships, types or progression of NDD, may also affect their needs for support.

5 | CONCLUSION

The results of this meta-review provide a broad framework comprising four themes of carer partners' needs related to (1) knowledge and information needs, (2) physical, social and emotional support needs, (3) care partner self-care needs, and (4) care recipient needs. The needs of care partners are complex and may differ depending on demographics and other socio-economic factors. No existing tool is equipped to capture all needs identified in this meta-review and offer a relative ranking aligned with carers' priorities. A new, interactive, preference-based tool co-designed with care partners is warranted to enable a detailed assessment of needs aligned with carers' values and preferences. Understanding care partners' needs using a person-centered approach is essential when developing and planning interventions to support care partners who care for people living with NDD.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

Data sharing not applicable to this article as no datasets were generated or analyzed during the current study.

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REFERENCES

1. WHO. Neurological Disorders: Public Health Challenges. Chapter 4 Conclusions and Recommendations. 2006.
2. Chai H, Guerriere DN, Zagorski B, Coyte PC. The magnitude, share and determinants of unpaid care costs for home-based palliative care service provision in Toronto, Canada. *Health Soc Care Community*. 2014;22(1):30-39. <https://doi.org/10.1111/hsc.12058>
3. Kim Y, Schulz R. Family caregivers' strains: comparative analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving. *J Aging Health*. 2008;20(5):483-503. <https://doi.org/10.1177/0898264308317533>
4. Grycuk E, Chen Y, Almirall-Sanchez A, et al. Care burden, loneliness, and social isolation in caregivers of people with physical and brain health conditions in English-speaking regions: Before and during the COVID-19 pandemic. *Int J Geriatr Psychiatry*. 2022;37(6):1-13. <https://doi.org/10.1002/gps.5734>

5. Bennett PN, Wang W, Moore M, Nagle C. Care partner: a concept analysis. *Nurs Outlook*. 2017;65(2):184-194. <https://doi.org/10.1016/j.outlook.2016.11.005>
6. Eilers D. What's in a word--caregiver or care partner? *Nephrol Nurs J*. 2013;40(1):61-62.
7. Pinquart M, Sörensen S. Differences between caregivers and non-caregivers in psychological health and physical health: a meta-analysis. *Psychol Aging*. 2003;18(2):250-267. <https://doi.org/10.1037/0882-7974.18.2.250>
8. Brodaty H, Donkin M. Family caregivers of people with dementia. *Dialogues Clin Neurosci*. 2009;11(2):217-228. <https://doi.org/10.31887/dcns.2009.11.2/hbrodaty>
9. Leroi I, Wolski L, Charalambous AP, et al. Support care needs of people with hearing and vision impairment in dementia: a European cross-national perspective. *Disabil Rehabil*. 2021;1-13. <https://doi.org/10.1080/09638288.2021.1923071>
10. Meaney AM, Croke M, Kirby M. Needs assessment in dementia. *Int J Geriatr Psychiatr*. 2005;20(4):322-329. <https://doi.org/10.1002/gps.1284>
11. Bradley SEK, Casterline JB. Understanding unmet need: history, theory, and measurement. *Stud Fam Plann*. 2014;45(2):123-150. <https://doi.org/10.1111/j.1728-4465.2014.00381.x>
12. Pollock K, Wilson E, Porock D, Cox K. Evaluating the impact of a cancer supportive care project in the community: patient and professional configurations of need. *Health Soc Care Community*. 2007;15(6):520-529. <https://doi.org/10.1111/j.1365-2524.2007.00711.x>
13. Osse BHP, Vernooij-Dassen MJFJ, deVree BPW, Schadé E, Grol RPTM. Assessment of the need for palliative care as perceived by individual cancer patients and their families. *Cancer*. 2000;88(4):900-911. [https://doi.org/10.1002/\(sici\)1097-0142\(20000215\)88:4<900::aid-cnrcr22>3.0.co;2-2](https://doi.org/10.1002/(sici)1097-0142(20000215)88:4<900::aid-cnrcr22>3.0.co;2-2)
14. Mansfield E, Boyes AW, Bryant J, Sanson-Fisher R. Quantifying the unmet needs of caregivers of people with dementia: a critical review of the quality of measures. *Int J Geriatr Psychiatr*. 2017;32(3):274-287. <https://doi.org/10.1002/gps.4642>
15. Bressan V, Visintini C, Palese A. What do family caregivers of people with dementia need? A mixed-method systematic review. *Health Soc Care Community*. 2020;28(6):1942-1960. <https://doi.org/10.1111/hsc.13048>
16. Khanassov V, Vedel I. Family physician-case manager collaboration and needs of patients with dementia and their caregivers: a systematic mixed studies review. *Ann Fam Med*. 2016;14(2):166-177. <https://doi.org/10.1370/afm.1898>
17. Kipfer S, Pihet S. Reliability, validity and relevance of needs assessment instruments for informal dementia caregivers: a psychometric systematic review. *JBI Evid Synth*. 2020;18(4):704-742.
18. Smith V, Devane D, Begley CM, Clarke M. Methodology in conducting a systematic review of systematic reviews of healthcare interventions. *BMC Med Res Methodol*. 2011;11(1):15. <https://doi.org/10.1186/1471-2288-11-15>
19. Page MJ, McKenzie JE, Bossuyt PM, et al. Updating guidance for reporting systematic reviews: development of the PRISMA 2020 statement. *J Clin Epidemiol*. 2021;134:103-112. <https://doi.org/10.1016/j.jclinepi.2021.02.003>
20. Moher D, Liberati A, Tetzlaff J, Altman DG, Group P. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *J Clin Epidemiol*. 2009;62(10):1006-1012. <https://doi.org/10.1016/j.jclinepi.2009.06.005>
21. Aromataris E, Munn Z. Chapter 1: JBI systematic reviews. In: Aromataris EMZ, ed. *JBI Manual for Evidence Synthesis*; 2020.
22. Charlesworth GM, Tzimoula XM, Newman SP. Carers Assessment of Difficulties Index (CADi): psychometric properties for use with carers of people with dementia. *Aging Ment Health*. 2007;11(2):218-225. <https://doi.org/10.1080/13607860600844523>
23. McWalter G, Toner H, McWalter A, Eastwood J, Marshall M, Turvey T. A community needs assessment: the care needs assessment pack for dementia (CarenapD)—its development, reliability and validity. *Int J Geriatr Psychiatr*. 1998;13(1):16-22. [https://doi.org/10.1002/\(sici\)1099-1166\(199801\)13:1<16::aid-gps721>3.0.co;2-n](https://doi.org/10.1002/(sici)1099-1166(199801)13:1<16::aid-gps721>3.0.co;2-n)
24. Wancata J, Krautgartner M, Berner J, et al. The carers' needs assessment for dementia (CNA-D): development, validity and reliability. *Int Psychogeriatr*. 2005;17(3):393-406. <https://doi.org/10.1017/s1041610205001699>
25. Vaingankar JA, Abdin E, Chong SA, et al. Validity and reliability of the caregivers' needs checklist for dementia. *Archives Psychol*. 2018;2(1).
26. Laprise R, Dufort F, Lavoie F. Construction et validation d'une échelle d'attentes en matière de consultation auprès d'aïdant(e)s de personnes âgées. *Can J Aging/La Revue canadienne du vieillissement*. 2001;20(2):211-232. <https://doi.org/10.1017/s0714980800012988>
27. Hughes TB, Black BS, Albert M, et al. Correlates of objective and subjective measures of caregiver burden among dementia caregivers: influence of unmet patient and caregiver dementia-related care needs. *Int Psychogeriatrics*. 2014;26(11):1875-1883. <https://doi.org/10.1017/s1041610214001240>
28. Wackerbarth SB, Johnson MMS. Essential information and support needs of family caregivers. *Patient Educ Counsel*. 2002;47(2):95-100. [https://doi.org/10.1016/s0738-3991\(01\)00194-x](https://doi.org/10.1016/s0738-3991(01)00194-x)
29. Sadak T, Korpak A, Borson S. Measuring caregiver activation for health care: validation of PBH-LCI:D. *Geriatr Nurs*. 2015;36(4):284-292. <https://doi.org/10.1016/j.gerinurse.2015.03.003>
30. Dimakopoulou E, Sakka P, Efthymiou A, Karpathiou N, Karydaki M. *Evaluating the Needs of Dementia Patients' Caregivers in Greece: A Questionnaire Survey*; 2015.
31. Peeters JM, VanBeek AP, Meerveld JH, Spreeuwenberg PM, Francke AL. Informal caregivers of persons with dementia, their use of and needs for specific professional support: a survey of the National Dementia Programme. *BMC Nurs*. 2010;9(1):9. <https://doi.org/10.1186/1472-6955-9-9>
32. Czaja SJ, Gitlin LN, Schulz R, et al. Development of the Risk appraisal measure: a brief screen to identify Risk areas and guide interventions for dementia caregivers. *J Am Geriatr Soc*. 2009;57(6):1064-1072. <https://doi.org/10.1111/j.1532-5415.2009.02260.x>
33. Oyeboode JR, Pini S, Ingleson E, et al. Development of an item pool for a needs-based measure of quality of life of carers of a family member with dementia. *Patient - Patient-Centered Outcomes Res*. 2019;12(1):125-136. <https://doi.org/10.1007/s40271-018-0334-4>
34. Gordon DS, Spicker P, Ballinger BR, et al. A population needs assessment profile for dementia. *Int J Geriatr Psychiatr*. 1997;12(6):642-647. [https://doi.org/10.1002/\(sici\)1099-1166\(199706\)12:6<642::aid-gps596>3.0.co;2-p](https://doi.org/10.1002/(sici)1099-1166(199706)12:6<642::aid-gps596>3.0.co;2-p)
35. Gaugler JE, Anderson KA, Leach CR, Smith CD, Schmitt FA, Mendiondo M. The emotional ramifications of unmet need in dementia caregiving. *Am J Alzheimer's Dis Other Dementias*. 2004;19(6):369-380. <https://doi.org/10.1177/153331750401900605>
36. Kinchin I, Mitchell E, Agar M, Trepel D. The economic cost of delirium: a systematic review and quality assessment. *Alzheimers Dement*. 2021;17(6):1026-1041. <https://doi.org/10.1002/alz.12262>
37. Garside R. Should we appraise the quality of qualitative research reports for systematic reviews, and if so, how? *Innovation. Eur J Soc Sci Res*. 2014;27(1):67-79. <https://doi.org/10.1080/13511610.2013.777270>
38. Kinchin I, McCalman J, Bainbridge R, Tsey K, Lui FW. Does Indigenous health research have impact? A systematic review of reviews. *Int J Equity Health*. 2017;16(1):52. <https://doi.org/10.1186/s12939-017-0548-4>
39. Grant MJ, Booth A. A typology of reviews: an analysis of 14 review types and associated methodologies. *Health Inf Libr J*. 2009;26(2):91-108. <https://doi.org/10.1111/j.1471-1842.2009.00848.x>

40. Soong A, Au ST, Kyaw BM, Theng YL, Tudor Car L. Information needs and information seeking behaviour of people with dementia and their non-professional caregivers: a scoping review. *BMC Geriatr.* 2020;20(1):61. <https://doi.org/10.1186/s12877-020-1454-y>
41. Romero-Mas M, Gómez-Zúñiga B, Cox AM, Ramon-Aribau A. Designing virtual communities of practice for informal caregivers of Alzheimer's patients: an integrative review. *Health Inf J.* 2020;26(4):2976-2991. <https://doi.org/10.1177/1460458220950883>
42. Queluz F, Kervin E, Wozney L, Fancey P, McGrath PJ, Keefe J. Understanding the needs of caregivers of persons with dementia: a scoping review. *Int Psychogeriatr.* 2020;32(1):35-52. <https://doi.org/10.1017/s1041610219000243>
43. Holt Clemmensen T, Hein Lauridsen H, Andersen-Ranberg K, Kaae Kristensen H. Informal carers' support needs when caring for a person with dementia – a scoping literature review. *Scand J Caring Sci* 2021;35(3):685-700. <https://doi.org/10.1111/scs.12898>
44. Waligora KJ, Bahouth MN, Han HR. The self-care needs and behaviors of dementia informal caregivers: a systematic review. *Gerontol.* 2019;59(5):e565-e583.
45. Lee K, Puga F, Pickering CEZ, Masoud SS, White CL. Transitioning into the caregiver role following a diagnosis of Alzheimer's disease or related dementia: a scoping review. *Int J Nurs Stud.* 2019;96:119-131. <https://doi.org/10.1016/j.ijnurstu.2019.02.007>
46. Hirt J, Burgstaller M, Zeller A, Beer T. Needs of people with dementia and their informal caregivers concerning assistive technologies. *Pflege.* 2019;32(6):295-304. <https://doi.org/10.1024/1012-5302/a000682>
47. Sousa L, Sequeira C, Ferré-Grau C, Martins D, Neves P, Lleixà-For tuño M. Necessidades dos cuidadores familiares de pessoas com demência a residir no domicílio: revisão integrativa. *J Mental Health Nursing/Revista Portuguesa de Enfermagem de Saude Ment.* 2017;45-50. (Special Issue). <https://doi.org/10.19131/rpesm.0166>
48. Barker S, Lynch M, Hopkinson J. Decision making for people living with dementia by their carers at the end of life: a rapid scoping review. *Int J Palliat Nurs.* 2017;23(9):446-456. <https://doi.org/10.12968/ijpn.2017.23.9.446>
49. McCabe M, You E, Tatangelo G. Hearing their voice: a systematic review of dementia family caregivers' needs. *Gerontologist.* 2016;56(5):e70-e88. <https://doi.org/10.1093/geront/gnw078>
50. Millenaar JK, Bakker C, Koopmans RCTM, Verhey FRJ, Kurz A, deVugt ME. The care needs and experiences with the use of services of people with young-onset dementia and their caregivers: a systematic review. *Int J Geriatr Psychiatry.* 2016;31(12):1261-1276. <https://doi.org/10.1002/gps.4502>
51. Flemming KAK, Ward C, Watt I. Adult family carers' perceptions of their educational needs when providing end-of-life care: a systematic review of qualitative research [version 1; peer review: 3 approved with reservations]. *AMRC Open Res.* 2019;1(2). <https://doi.org/10.12688/amrcopenres.12855.1>
52. Dunn D, Price D, Neder S. Rural caregivers of persons with dementia: review of the literature guided by rogers' science of unitary human beings. *J Rogerian Nurs Sci.* 2016;22(2):16-24.
53. Afram B, Verbeek H, Bleijlevens MHC, Hamers JPH. Needs of informal caregivers during transition from home towards institutional care in dementia: a systematic review of qualitative studies. *Int Psychogeriatrics.* 2015;27(6):891-902. <https://doi.org/10.1017/s1041610214002154>
54. Thompson GN, Roger K. Understanding the needs of family caregivers of older adults dying with dementia. *Palliat Support Care.* 2014;12(3):223-231. <https://doi.org/10.1017/s1478951513000461>
55. Slattery P, Saeri AK, Bragge P. Research co-design in health: a rapid overview of reviews. *Health Res Pol Syst.* 2020;18(1):17. <https://doi.org/10.1186/s12961-020-0528-9>
56. Careresearch. NAT-CC – Caring for You. Accessed 17 July, 2021. <https://www.eldac.com.au/Portals/12/Forms/Toolkits/NAT-CC%20%28chronic%29.pdf>
57. Careresearch. Needs Assessment Tool : Progressive Disease (NAT: PD). Accessed July 17, 2021. <https://www.caresearch.com.au/caresearch/Portals/0/Documents/PROFESSIONAL-GROUPS/General-Practitioners/NeedsAssessmentTool-ProgressiveDiseaseCHERP.pdf>

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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APPENDIX 1

TABLE A1 Search strategy

Search strategy	
Data sources	Embase, Medline, CINAHL, PsychINF, Epistemonikos 98 databases
Search terms	
Care partner	Caregiver/caregiv* Care giver Carer* Care partner Dyad Spouse Famil* Wife Husband
Cognition	Neurocognitive Disorders Cognitive defect Cognition/Cogniti* Neuropsychological Neurocognitive Executive Brain Impairment Impaired Defect Function Dysfunction Process Symptom Factor* Deficit Disorder
Neurodegenerative	Neurodegenerative disease Degenerative disease Huntington's disease Dementia Motor neuron disease OR motorneurone disease Cerebellum degeneration Degenerative disease Neurodegenerative disease Alzheimer Parkinson Prion disease Transmissible dementia Cerebellar degeneration/cerebellum degeneration Subacute cerebellar degeneration
Needs	Need Wellbeing/wellbeing Support Training Education Assistance Help Intervention Require Wish* Demands Guidance Advice Caregiver Burden Carer support Caregiver Stressors Caregiver Well-Being Caregiver Role Strain
Setting	No limit

(Continues)

Study design	Meta-analysis Meta-analysis Systematic* Review Systematic review Systematic overview Cochrane Database of Systematic Reviews Synthesis Meta-analy*/metaanaly*
Time frame	No limit
Inclusion and exclusion criteria	
Inclusion criteria	Any review, e.g., systematic, scoping, rapid, literature reviews etc. Reports on the needs of care partners who support people with NDD Care partners must be non-paid (relatives, or members of the person's community), adults (18 years of age or older), of either sex, and of any ethnic or geographical origin. The people for which they provide care can be of any age, at any time during the disease trajectory. NDD included Alzheimers', Parkinson's, motor neurone, cerebellar degenerations, Huntington's, and prion. Full text available electronically Published in any language Published in a peer-reviewed journal
Exclusion criteria	Studies that primarily reported on the needs of the patient, care partner burden, care partners of people in full-time care (e.g. nursing home, palliative care, in-patient setting etc.) or care partners of people without NDD or cognitive impairments (e.g. cancer) were excluded. Studies that did not included qualitative data within a review, protocols, primary research papers, conference abstracts, posters, studies without full text available were excluded.

APPENDIX 2

TABLE A2 Needs identified

Needs identified	Type of need (or description)	Key aspects	Frequency (%)	References
Knowledge and information needs	Disease specific information	<ul style="list-style-type: none"> • Receive tailored information about disease, progression and ongoing management • Receive tailored information throughout caregiving role – information sharing should be seen as an ongoing process and not just at the time of diagnosis • Receive information regarding treatment options, current research and medications. • To know that care partners have the option to refuse treatment • Receive information regarding advance care planning, the process around dying and how to manage bereavement and a life after caring 	14 (82%)	15,16,40,42,43,45,47-54
	Healthcare related information	<ul style="list-style-type: none"> • Information on how to provide general day-today care to CR including general care, basic first aid, personal care including bathing, food and nutritional information, physical exercise and how to make their home safe • Knowledge on how to manage care recipient symptoms and behaviors • Information on where they can improve much needed skills to aide them in their caregiving role, especially for providing physical care (e.g. how to prevent and manage incontinence) as well as communication skills and non-pharmacological strategies to manage behavior 	13 (76%)	15,16,40,42,43,45,48-54

TABLE A2 (Continued)

Needs identified	Type of need (or description)	Key aspects	Frequency (%)	References
		<ul style="list-style-type: none"> Information on available formal care options including respite and home help, and how to access these services Early information on advance care planning and to involve care recipient on these directives 		
	Information source	<ul style="list-style-type: none"> Timely access to accurate information to plan for future needs opposed to researching information in response to addressing current needs Information that is understandable and digestible A forum for information sharing so care partners can share personal experiences and learn from other care partners in similar stages of caregiving 	10 (59%)	15,16,40-44,46,49,51
	Financial and legal needs	<ul style="list-style-type: none"> To receive information about what financial support is available to them and how to obtain Help with navigating insurance policies and payouts Help with how to apply for funding to access formal healthcare services Professional support to educate, understand and access both disease specific planning and legal issues Information on helping care partners balance paid work and the role of caregiving 	8 (47%)	15,16,40,43,50-53
	Care partner self-care information needs	<ul style="list-style-type: none"> To know how to take care of their own mental and physical health whilst being a caregiver Knowledge of care partner burden and how to identify and manage symptoms early on to reduce adverse effects of caring 	3 (18%)	40,47,53
Support needs	Physical support	<ul style="list-style-type: none"> Assistance with care recipient activity of daily living such as feeding, mobility, toileting and instrumental activities of daily living such as meal preparation, housework and financing Timely access to respite services Transport assistance High-quality, familiar and culturally respectful care from formal support services Tailored care plans developed by healthcare professionals to outline how to provide care for care recipient 	14 (82%)	15,16,42-47,49-54
	Social support	<ul style="list-style-type: none"> To remain part of the society Receive support from family members and friends; have someone to talk to and share healthcare related tasks and decisions To have a central expert point of contact Access community support groups which gives care partner an opportunity to exchange information and knowledge, and reducing feelings of isolation 	12 (71%)	15,16,41-44,47-49,52-54
	Emotional support	<ul style="list-style-type: none"> To learn how to accept and use respite services without feelings of guilt and worry To receive mental healthcare assistance and timely access to counseling services 	10 (59%)	15,16,42-45,48,50,53,54

(Continues)

TABLE A2 (Continued)

Needs identified	Type of need (or description)	Key aspects	Frequency (%)	References
		<ul style="list-style-type: none"> • Access to coping strategies to help feel in control of their life (e.g. have a sense of control, stability and security of their own lives; develop a sense of self-esteem; cope with anxiety, stress and worries) • Interventions (both pharma and non-pharma) for stress management • Find time for themselves to help with ease the stress that comes with the role of caregiving • Maintaining attendance (if applicable) at spiritual and religious 		
Care partner self-care needs	Own health	<ul style="list-style-type: none"> • To be take care of their own physical and mental health first • To address their physical health to prevent the worsening of old chronic conditions, onset of acute health challenges, and development of new chronic conditions • Continue to participate in leisure activities and hobbies • To maintain healthy sleeping habits • To allow themselves to take a break, to accept help and to talk to people who could understand the situation, immediately recognizing their needs 	8 (47%)	15,42-44,49,50,53,54
Needs for care recipient	Collaboration with the professional healthcare team	<ul style="list-style-type: none"> • To be part of the healthcare team when making decisions for the care recipient • Trust and positive relationships HCP • Honest conversations in a language that consumers understand and not to "divert" from hard discussion especially around dying • Improved care coordination 	6 (35%)	15,16,42,44,48,51
	Safety	<ul style="list-style-type: none"> • To ensure the safety of the care recipient 	2 (12%)	15,40

APPENDIX 3

Analysis of needs derived from the narrative synthesis against the needs captured by the needs assessment tools

Needs		Tool													
		CADI	CARENAP D	CNA-D	CNCD	JHDCNA	NAS	PBH-LCI:D	RAM	QCNE	EAC	QNP	SIDECAR	Tayside	UNM
Knowledge and information needs	1	1.1	Red	Yellow	Green	Green	Yellow	Yellow	Green	Green	Yellow	Green	Green	Red	Green
		1.2	Red	Yellow	Yellow	Red	White	Red	Red	Red	White	Yellow	Red	Red	Yellow
		1.3	Red	Yellow	Green	Green	Yellow	Yellow	Green	Yellow	White	Green	Red	Red	Green
		1.4	Red	Red	Red	Red	White	Red	Red	Red	White	Red	Red	Green	Red
		1.5	Red	Red	Red	Red	White	Red	Red	Yellow	White	Red	Red	Red	Red
	2	2.1	Red	Yellow	Yellow	Yellow	White	Yellow	Green	Yellow	White	Green	Green	Red	Green
		2.2	Red	Yellow	Yellow	Green	White	Yellow	Green	Yellow	White	Green	Green	Red	Green
		2.3	Red	Yellow	Yellow	Red	White	Yellow	Red	White	Yellow	Red	Green	Red	Yellow
		2.4	Red	Yellow	Yellow	Green	White	Yellow	Green	Yellow	White	Red	Green	Red	Red
		2.5	Red	Yellow	Yellow	Red	White	Yellow	Red	White	White	Red	Green	Red	Red
	3	3.1	Red	Red	Red	Red	White	Yellow	Red	White	White	Red	Yellow	Red	Red
		3.2	Red	Red	Red	Red	White	Yellow	Red	White	White	Red	Yellow	Red	Red
		3.3	Red	Red	Red	Yellow	White	Yellow	Red	White	White	Red	Yellow	Red	Red
	4	4.1	Red	Red	Yellow	Green	White	Yellow	Red	Yellow	White	Red	Green	Red	Green
		4.2	Red	Red	Red	Red	White	Yellow	Red	White	White	Red	Red	Red	Green
		4.3	Red	Red	Red	Red	White	Yellow	Red	White	White	Red	Red	Red	Yellow
		4.4	Red	Red	Red	Yellow	White	Yellow	Red	White	White	Red	Yellow	Red	Green
		4.5	Red	Red	Red	Yellow	White	Yellow	Red	White	White	Red	Yellow	Red	Red
	5	5.1	Red	Red	Red	Green	White	Yellow	Yellow	White	Yellow	Red	Red	Red	Green
	Support needs	6	6.1	Green	Yellow	Yellow	Green	White	Red	Green	Yellow	White	Green	Green	Red
6.2			Red	Yellow	Red	Yellow	White	Red	Red	White	White	Red	Yellow	Red	Green
6.3			Red	Yellow	Red	Green	White	Red	Red	White	White	Red	Red	Yellow	Green
6.4			Red	Red	Red	Red	White	Red	Red	White	White	Red	Yellow	Red	Red
6.5			Red	Red	Red	Yellow	White	Red	Red	White	White	Red	Yellow	Red	Red
7		7.1	Yellow	Red	Yellow	Green	White	Yellow	Red	White	White	Red	Yellow	Red	Red
		7.2	Green	Red	Green	Green	Yellow	Green	Green	Yellow	Green	Yellow	Green	Red	Green
		7.3	Red	Red	Red	Red	White	Red	Red	White	White	Red	Red	Red	Red
		7.4	Red	Red	Yellow	Green	White	Green	Red	Yellow	White	Yellow	Yellow	Red	Green
8		8.1	Red	Red	Yellow	Red	White	Red	Red	White	White	Red	Yellow	Red	Red
		8.2	Red	Red	Yellow	Green	Yellow	Yellow	Red	White	White	Red	Green	Green	Green
		8.3	Red	Red	Red	Red	White	Yellow	Red	White	White	Red	Yellow	Red	Yellow
		8.4	Red	Red	Red	Red	White	Red	Red	White	White	Red	Yellow	Red	Yellow
	8.5	Green	Red	Yellow	Yellow	White	Red	Red	White	White	Red	Green	Red	Red	
	8.6	Yellow	Red	Red	Red	White	Red	Red	White	White	Red	Red	Red	Yellow	
Caregiver self-care needs	9	9.1	Green	Red	Yellow	Red	White	Red	Yellow	White	Red	Yellow	Green	Red	Green
		9.2	Yellow	Red	Yellow	Red	White	Red	Red	White	White	Red	Green	Red	Red
		9.3	Green	Red	Yellow	Red	White	Yellow	Red	White	White	Red	Green	Red	Red
		9.4	Green	Red	Red	Red	White	Red	Green	White	White	Red	Green	Red	Red
		9.5	Yellow	Red	Yellow	Red	White	Red	Red	White	White	Red	Yellow	Red	Red
Needs for care recipient	10	10.1	Yellow	Red	Red	Red	White	Red	Yellow	White	Red	Green	Green	Red	Red
		10.2	Red	Red	Red	Red	White	Red	Red	White	White	Yellow	Green	Red	Red
		10.3	Red	Red	Red	Red	White	Red	Red	White	White	Red	Red	Red	Red
		10.4	Red	Red	Red	Red	White	Red	Red	White	White	Yellow	Green	Red	Red
	11	11.1	Red	Red	Yellow	Yellow	Green	Red	Yellow	Green	White	Red	Green	Red	Red

Index:

	Included
	Somewhat included
	Not included
	Unable to assess

1. Disease specific information
 - 1.1. Receive tailored information about disease, progression and ongoing management
 - 1.2. Receive tailored information throughout caregiving role – information sharing should be seen as an ongoing process and not just at the time of diagnosis
 - 1.3. Receive information regarding treatment options, current research, and medications.
 - 1.4. To know that caregivers have the option to refuse treatment
 - 1.5. Receive information regarding advance care planning, the process around dying and how to manage bereavement and a life after caring
2. Healthcare related information
 - 2.1. Information on how to provide general day-today care to CR including general care, basic first aid, personal care (including bathing), food and nutritional information, physical exercise and how to make their home safe
 - 2.2. Knowledge on how to manage care recipient symptoms and behaviors
 - 2.3. Information on where they can improve much needed skills to aide them in their caregiving role, especially for providing physical care (e.g. how to prevent and manage incontinence) as well as communication skills and non-pharmacological strategies to manage behavior
 - 2.4. Information on available formal care options including respite and home help, and how to access these services
 - 2.5. Early information on advance care planning and to involve care recipient on these directives
3. Information source
 - 3.1. Timely access to accurate information to plan for future needs opposed to researching information in response to addressing current needs
 - 3.2. Information that is understandable and digestible
 - 3.3. A forum for information sharing so caregivers can share personal experiences and learn from other caregivers in similar stages of caregiving
4. Financial and legal needs
 - 4.1. To receive information about what financial support is available to them and how to obtain
 - 4.2. Help with navigating insurance policies and payouts
 - 4.3. Help with how to apply for funding to access formal healthcare services
 - 4.4. Professional support to educate, understand and access both disease specific planning and legal issues
 - 4.5. Information on helping caregivers balance paid work and the role of caregiving
5. Caregiver self-care information needs
 - 5.1. To know how to take care of their own mental and physical health whilst being a caregiver Knowledge of caregiver burden and how to identify and manage symptoms early on to reduce adverse effects of caring
6. Physical
 - 6.1. Assistance with care recipient ADLS such as feeding, mobility, toileting and IADLS such as meal preparation, housework and financing
 - 6.2. Timely access to respite services
 - 6.3. Transport assistance
 - 6.4. High-quality, familiar and culturally respectful care from formal support services
 - 6.5. Tailored care plans developed by healthcare professionals to outline how to provide care for care recipient
7. Social
 - 7.1. To remain part of the society
 - 7.2. Receive support from family members and friends; have someone to talk to and share healthcare related tasks and decisions
 - 7.3. To have a central expert point of contact
 - 7.4. Access community support groups which gives caregiver an opportunity to exchange information and knowledge, and reducing feelings of isolation
8. Emotional
 - 8.1. To learn how to accept and use respite services without feelings of guilt and worry
 - 8.2. To receive mental healthcare assistance and timely access to counseling services
 - 8.3. Access to coping strategies to help feel in control of their life (e.g. have a sense of control, stability and security of their own lives; develop a sense of self-esteem; cope with anxiety, stress and worries)
 - 8.4. Interventions (both pharma and non-pharma) for stress management
 - 8.5. Find time for themselves to help with ease the stress that comes with the role of caregiving
 - 8.6. Maintaining attendance (if applicable) at spiritual and religious
9. Own health
 - 9.1. To be take care of their own physical and mental health first
 - 9.2. To address their physical health to prevent the worsening of old chronic conditions, onset of acute health challenges, and development of new chronic conditions
 - 9.3. Continue to participate in leisure activities and hobbies
 - 9.4. To maintain healthy sleeping habits
 - 9.5. To allow themselves to take a break, to accept help and to talk to people who could understand the situation, immediately recognizing their needs
10. Collaboration with the professional healthcare team
 - 10.1. To be part of the healthcare team when making decisions for the care recipient
 - 10.2. Trust and positive relationships HCP
 - 10.3. Honest conversations in a language that consumers understand and not to "divert" from hard discussion especially around dying
 - 10.4. Improved care coordination
11. Safety