



## REVIEW ARTICLE

# Carer-reported measures for a dementia registry: A systematic scoping review and a qualitative study

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## Abstract

**Objectives:** Informal carers play a critical role in supporting people with dementia. We conducted a scoping review and a qualitative study to inform the identification and development of carer-reported measures for a dementia clinical quality registry.

**Methods:** Phase 1—Scoping review: Searches to identify carer-reported health and well-being measures were conducted in three databases (MEDLINE, PsycINFO and Embase). Data were extracted to record how the measures were administered, the domains of quality-of-life addressed and whether they had been used in a registry context. Phase 2—Qualitative study: Four focus groups were conducted with carers to examine the acceptability of selected measures and to identify outcomes that were important but missing from these measures.

**Results:** Phase 1: Ninety-nine carer measures were identified with the top four being the Zarit Burden Interview ( $n = 39$ ), the Short-Form12/36 ( $n = 14$ ), the Brief Coping Orientation to Problems Experienced scale and the Sense of Coherence scale (both  $n = 9$ ). Modes of administration included face-to-face ( $n = 50$ ), postal ( $n = 11$ ), telephone ( $n = 8$ ) and online ( $n = 5$ ). No measure had been used in a registry context. Phase 2: Carers preferred brief measures that included both outcome and experience questions, reflected changes in carers' circumstances and included open-ended questions.

**Conclusions:** Carer-reported measures for a dementia clinical quality registry need to include both outcome and experience questions to capture carers' perceptions of the process and outcomes of care and services. Existing carer-reported measures have not been used in a dementia registry context and adaption and further research are required.

## KEYWORDS

informal caregivers, dementia, quality of health care, quality of life, registries

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## 1 | INTRODUCTION

Dementia is a global public health priority and represents one of the greatest challenges for health and social services across the world.<sup>1</sup> Worldwide, over 55 million people have dementia.<sup>1,2</sup> With population ageing, the number of people living with dementia is estimated to increase significantly, reaching 78 million in 2030 and 139 million in 2050 worldwide.<sup>2</sup>

Informal carers play a critical role in supporting people with dementia and are a key determinant of patient outcomes such as quality of life and entry to residential aged care.<sup>3–6</sup> Informal carers may vary from family members to friends and neighbours, with the former identified as providing the majority of the care.<sup>7–9</sup> A report by Alzheimer's Disease International estimated that worldwide, 84% of people with dementia lived at home and an annual 82 billion hours of informal care were provided to this group, equating to 2089 h per year or 6 h per day per person with dementia.<sup>9</sup> Informal carers provide a wide range of support, such as assisting with activities of daily living including personal care, making decisions about care and treatment options, and organising care and services.<sup>1,7–9</sup> Informal carers typically know the person with dementia well and therefore provide crucial information to help develop effective personalised and need-based interventions and care plans.<sup>1</sup>

There is clear evidence that caring for a person living with dementia can have both positive and negative impacts on carers' lives. The positive aspects of caregiving include strengthening of the relationship, spiritual and personal growth, increasing meaning in life, and experiencing feelings of accomplishment.<sup>10–12</sup> The negative aspects include carer burden or stress, poor psychological or physical health, social isolation and financial hardship.<sup>6,10,13</sup> Compared with carers of people with other diseases, carers of people with dementia report higher levels of stress, burden, depression and anxiety, poorer physical health and greater financial difficulties.<sup>14</sup> Consequently, carers of people with dementia are sometimes referred to as 'the invisible second patients' in recognition of these challenges associated with the care they give.<sup>15</sup>

### 1.1 | Including carer-reported measures in a dementia clinical quality registry

High-quality clinical care can better support people with dementia and their families and improve their quality of life.<sup>6,16,17</sup> Yet, variations in the quality of clinical care for people with dementia are reported frequently.<sup>18</sup>

Clinical quality registries (CQRs), that is, organisations that 'systematically monitor the quality (appropriateness

#### Policy Impact

Existing carer-reported measures have not been used in a dementia clinical quality registry context and adaption and further research are required. Importantly, carer-reported measures for a dementia clinical quality registry need to include both outcome and experience questions to capture carers' perceptions of the process and outcomes of care and services.

and effectiveness) of health care, within specific clinical domains, by routinely collecting, analysing and reporting health-related information',<sup>19</sup> are increasingly recognised worldwide as a valuable tool to reduce variations, and importantly, drive improvements in the provision of clinical care. Several dementia CQRs have been established internationally, such as the Swedish Dementia Registry (SveDem), Norwegian Dementia Registry (NorKog) and the Danish Dementia Registry, with evidence showing that dementia CQRs can drive quality improvements in the diagnosis, management and care of people with dementia and support for their carers, as well as reduce cost of dementia.<sup>20</sup> Against this background, the Australian Dementia Network (ADNeT) Registry has been established at dementia diagnostic services across Australia, to monitor and improve the quality of care and patient outcomes for people with dementia and mild cognitive impairment and their carers.<sup>21</sup>

While the inclusion of patient-reported measures has been emphasised in CQR data collection to provide a patient perspective on the impact and health outcomes of clinical care and to inform patient-centred care,<sup>22–25</sup> less attention has been paid to carer-reported measures. In this paper, a carer-reported measure was defined as a measurement of the carers' health and well-being-related outcomes that are directly reported by the carer. Examples include quality-of-life measures, burden, stress/distress, coping strategies, satisfaction, efficacy, health rating, consequences of care or measures indicating the level of carer function and participation beyond the home. Carer-reported measures do not include proxy-rated measures that are completed by carers but focus on patient outcomes.

Given the vital roles that carers play in supporting people with dementia and the impact of caregiving on carers, the ADNeT Registry also includes carer-reported measures, in addition to patient-reported measures.<sup>21</sup> Including carer-reported measures in dementia CQRs can help to understand the changes in caregiving over the course of disease and the impact of clinical care from carers' perspective. It can also inform the development of interventions that aim at improving outcomes for carers,

which ultimately will help carers to provide better support to people living with dementia.

Although there have been a few reviews on quality of life or well-being measures for informal carers of people with dementia,<sup>26–28</sup> none of these reviews have considered the use of these measures in the context of a dementia CQR. A CQR aims at enrolling an entire population within a clinical domain; therefore, the carer-reported measures need to be able to be used at scale, and by a real-world clinical population. To our knowledge, none of the existing dementia CQRs include carer-reported measures. To inform the identification and/or development of carer-reported measures for the ADNeT Registry, we conducted a systematic scoping review and a qualitative study. The aim of the scoping review was to identify carer-reported measures, which could potentially be used in a dementia CQR. The aim of the qualitative study was to examine the acceptability of carer-reported outcome measures identified from the scoping review and to identify outcomes that were important to carers but missing from identified measures.

## 2 | METHODS

### 2.1 | Phase 1: A systematic scoping review

#### 2.1.1 | Research questions and study design

The key research questions guiding this review were as follows:

1. What carer-reported measures have been used in dementia research?
2. Have the identified measures been used in a dementia CQR?
3. What quality-of-life domains were addressed in identified measures?
4. How were the measures administered?

A scoping review was undertaken following the methodological framework of Arksey and O'Malley (2005) due to the broad and exploratory nature of the review questions.<sup>29</sup> Scoping reviews are not eligible for registration with PROSPERO; however, the review is reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement.

#### 2.1.2 | Data search and selection

We completed a systematic search of three databases: Ovid MEDLINE, PsycINFO and Embase on 21st August

2018 using a combination of three groups of Medical Subject Headings (MeSH):(1) dementia, Alzheimer's disease, Cognitive dysfunction, Cogniti\*, (2) Carer OR Caregiver OR Care\*, (3) quality of life, well-being, care\*burden, care\*stress. The search was limited to full-text, peer reviewed articles published in English between 2008 and 2018 to identify the most current carer-reported measures.

#### 2.1.3 | Inclusion/exclusion criteria

Inclusion criteria were primary studies that (1) included adult informal carers (i.e. aged  $\geq 18$  years) for people with dementia living in the community (as they require significantly more support from informal carers compared to those living in residential aged care facilities), (2) included a carer-reported measure as an outcome measure, (3) interventional studies that were primarily directed towards the carers (as these would measure carer health and well-being as an outcome) and (4) conducted in Australia and countries that have similar socio-economic status (e.g. the US, Canada, UK, European Union and New Zealand).

Exclusion criteria were (1) studies of informal carers for people with dementia in hospitals, palliative care or residential care, (2) interventional studies that were primarily directed to people with dementia as these were less likely to include carer outcomes as a primary outcome, (3) drug trials, (4) studies examining psychometric properties of a measure, (5) studies focussing on proxy reported 'patient' outcomes and (6) qualitative studies, commentaries, debates or editorials, economic evaluations or systematic reviews.

#### 2.1.4 | Screening

Search results were imported into and managed through Covidence software with duplicates removed. Two researchers (Authors 5 and 12) independently screened titles and abstracts against inclusion and exclusion criteria. Articles meeting the inclusion criteria were assessed for eligibility via full-text review. Disagreements were discussed, with discordant decisions managed by a third reviewer (Author 3).

#### 2.1.5 | Data extraction

Data extracted included study design, country, participant demographics, dementia subtype, carer-reported measures that were used and their administration methods.

## 2.1.6 | Data analysis

Descriptive analysis of the study characteristics was performed. Content analysis was conducted to categorise the key attributes of the measures and the administration methods.

## 2.2 | Phase 2: A descriptive qualitative study

### 2.2.1 | Aims and study design

Following the scoping review, a descriptive qualitative study was conducted via focus groups with people who identified as a carer for someone with dementia.

A descriptive qualitative design<sup>31</sup> was chosen as our focus was on exploring the experience of caregiving and to obtain acceptability information about selected carer-reported outcomes.

### 2.2.2 | Participants and recruitment

Eligible participants were people who self-identified as current informal carers of a family member with dementia and lived either at home or in residential aged care. Recruitment was through an advertisement on the website of consumer organisations, social media, word of mouth and flyers to relevant carer organisations and groups. Ethics approval was obtained from the Monash University Human Research Ethics Committee (Project ID: 16840, Approval date: 15th October 2018).

After receiving expressions of interest from potential participants, a research assistant screened them to confirm eligibility. Four focus groups were conducted to suit the availability and geographical areas of participants. All participants provided verbal consent to participate (as per our ethics approval) and to the recording before the focus group commenced. The focus groups were conducted between November 2018 and March 2019 and were 82–97 min in length.

### 2.2.3 | Data collection

Each focus group started with questions about the participants' experience of caring for someone with dementia (these results will be reported in a separate publication). Participants were then provided with selected carer-reported measures, including the top three

measures identified from the scoping review and two additional measures. These additional measures were included because none of the carer-reported measures identified from the scoping review had been used in the context of a dementia CQR. To address this implementation gap, the researchers contacted colleagues working in the CQR registry field for carer-reported measures that could potentially be used in a dementia CQR. The Cancer Survivors Partners Unmet Needs (CaSPUN) survey and the Carer Experience Survey (CES) were identified through this process. The CaSPUN survey was recommended because it has extensive questions specific to the impact of the disease on the relationship between the person with the disease and the carer.<sup>31</sup> The CES was recommended because it is brief and assesses carer quality of life beyond health.<sup>32</sup> As a result, five carer-reported measures were explored in the qualitative study.

Participants were asked to complete these measures while interacting with other participants and 'thinking aloud'.<sup>33</sup> They discussed (1) whether the questions in the selected measures made sense?, (2) what the questions meant to them?, (3) what they felt was missing from the measures (if anything)? and (4) any questions or words in the measures that they would like to remove or change? The number of carer-reported measures discussed at each focus group ranged from one to three, depending on the size of the focus groups and the time available following the initial phase of the focus group discussion. All focus groups were facilitated by experienced qualitative researchers (*Authors 3, 5, 12 and 14*).

### 2.2.4 | Data analysis

The focus group recording was transcribed verbatim by an author (*Author 9*). As per descriptive qualitative studies,<sup>30</sup> content analysis was conducted using deductive coding processes by two authors (*Authors 9 and 14*). Both authors had extensive experience in qualitative studies.

Specifically, the two authors developed a set of key codes based on the aims of this phase. These key codes included question and response wording, length of measures, instructions for completion, missing questions and overall impressions of the measures. One author (*Author 9*) then went through the transcript, assigned the pre-defined set of key codes to the transcript, and selected quotes. Finally, the two authors met and discussed the assignment of key codes and the selection of quotes until consensus was reached.

### 3 | RESULTS

#### 3.1 | Phase 1: A systematic scoping review

##### 3.1.1 | Study characteristics

The search yielded 2005 papers with 92 meeting inclusion criteria after full-text screening (Figure 1). These papers reported the results of 88 studies with seven papers merged into three studies as they reported data from the same cohort at different time points.<sup>34-40</sup> Twenty-two (25%) of the studies were conducted in the United States, nine were in Spain (20%), eight were multicountry (9%), seven were in Italy (8%) and the remainder were spread across 16 individual countries. Study designs ranged from cross-sectional ( $n = 69$ ), comparative cross-sectional ( $n = 6$ ), longitudinal prospective cohort ( $n = 12$ ), to one retrospective cohort study.

A total number of 19,829 participants (carers) were included in the 88 studies. The ages of the carers ranged from 20 years<sup>41</sup> to 96 years.<sup>42</sup> The descriptors of the people

they cared for included dementia ( $n = 45$ ), Alzheimer's disease ( $n = 29$ ) and frontotemporal dementia ( $n = 4$ ). While most studies included carers of one particular type of dementia, six studies included carers of two types<sup>8,43-47</sup> and three studies included carers of all three types<sup>41,48,49</sup> (Table 1).

##### 3.1.2 | What carer-reported measures were used in dementia research?

Ninety-nine carer-reported measures were administered in these studies. The five most commonly used scales were as follows: the Zarit Burden Interview (ZBI) ( $n = 39$ ), the Short-Form 12 or 36 (SF-12/36) ( $n = 14$ ), the Brief Coping Orientation to Problems Experienced scale (Brief COPE) ( $n = 9$ ), the Sense of Coherence scale (SOC) ( $n = 9$ ) and the Caregiver Burden Inventory (CBI) ( $n = 8$ ). The remaining measures were utilised across one to five studies (Figure 2).

None of the measures identified have been used as a carer-reported measure in a dementia CQR context.

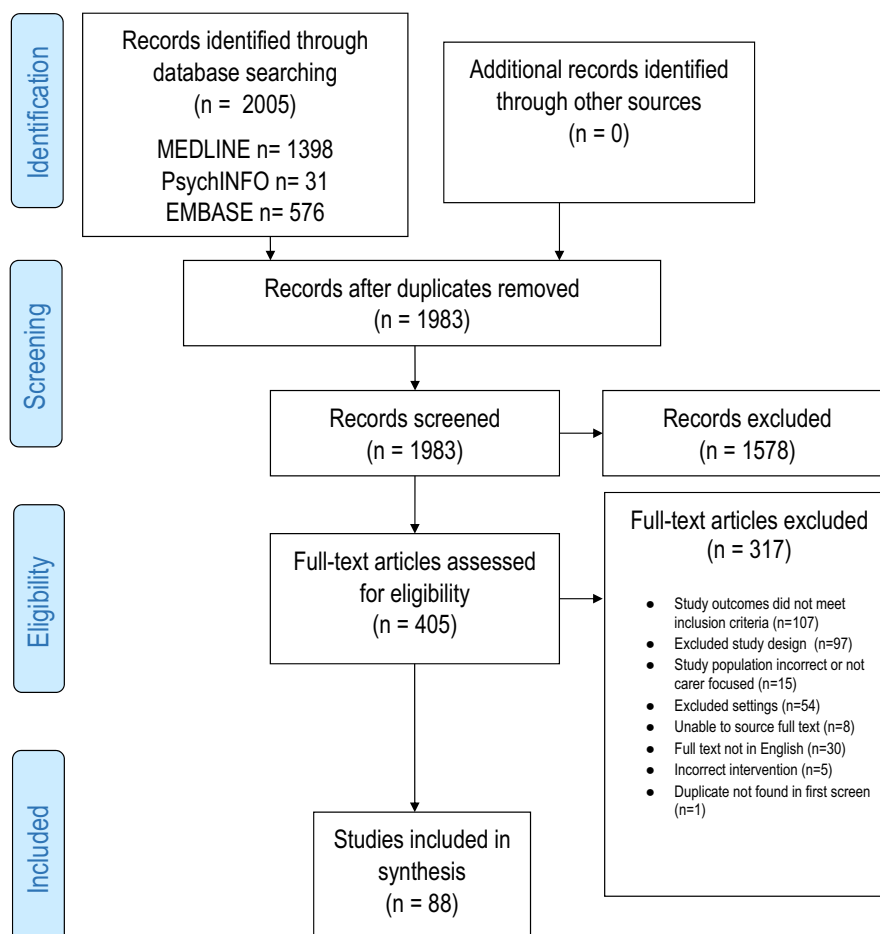


FIGURE 1 PRISMA flow diagram

TABLE 1 Demographics/characteristics of studies ( $n = 88$ , total participants 19,829)

Author, year	Country	Sample size	Carer age mean (SD); range	Study design	Carer-reported measure used	Diagnosis of person being cared for:			Delivery method
						Dementia	AD	FTD	
Alwin et al., 2010	Sweden	110	67.3 (12.0)	CS	SF-12; WHOQoL-5; EQ-5D; COPE Index	✓			F2F or telephone interviews by the project research team
Andrén & Elmståhl, 2008	Sweden	130	61 (NS) 27–90	CS	CBS; SOC; NHP - Swedish translation; EQ-5D	✓			F2F at home by geriatric registered nurse
Armstrong et al., 2013	US	102	NS	CS	ZBI	✓		✓	NS
Bakker et al., 2014	Netherlands	205	58.4 (9.3) 20–88	CS	SSCQ	✓		✓	F2F interviews by trained researchers and research assistants
Bednarek et al., 2016	Netherlands	205	58.4 (9.3) 25–88	CS	ZBI	✓		✓	F2F interviews
Bekhet, 2014	US	73	57.46 (NS) 25–87	CS	ZBI	✓			Delivered and collected by research assistant
Bergvall et al., 2011	Spain, Sweden, UK and US	866	60.6 (14.2) Sp 70.2 (12.2) Sw 71.3 (11.7) UK 66.9 (13.6) US	CS	ZBI; SF-12; WHOQoL-Brief			✓	F2F interview with physician or a research nurse
Borsje et al., 2016	Netherlands	117	67.3 (13.3) 32–92	Prospective cohort study	SCQ; GHQ-12	✓			F2F interviews at home by trained research assistant
Bremer et al., 2015	Estonia, Finland, France, Germany, Netherlands, Sweden, Spain and UK	1029	64.6 (13.6)	CS	GHQ-12; EQ-VAS (from EQ-5D)	✓			F2F interviews
Bristow et al., 2008	England	61	Carers 62.9 (5.9) Controls 63.3 (5.4)	Comparative CS	GHQ-30; PSS-10; SOS; CBS; WCQ-R; SACL			✓	Questionnaire packs handed out
Brodady et al., 2014	Australia	732	78.3 (7.4)	Prospective cohort study	ZBI	✓		✓	F2F interviews
Campbell et al., 2008	England	74	67.76 (12) 37–90	CS	ZBI; MSQPOP	✓			Measures handed to carers at clinic, posted back
Chen et al., 2013	US	87	NS	CS	ASA; GSS; CDS; LEE	✓			Postal with phone interview
Chen et al., 2014	US	91	55 (7.1)	CS	CMAI; PSS; CDS; CSS-6	✓			Postal

(Continues)

TABLE 1 (Continued)

Author, year	Country	Sample size	Carer age mean (SD); range	Study design	Carer-reported measure used	Diagnosis of person being cared for:			Delivery method
						Dementia	AD	FTD	
Conde-Sala et al., 2014	Spain	330	59.7 (0.8) at baseline	Prospective cohort study	ZBI; SF-12	✓	✓		F2F interview
Contador et al., 2012	Spain	130	58.62 (12.4)	CS	BEEGC-20; ZBI	✓			F2F interviews
Cooper, et al., 2008 and Cooper, Owens et al., 2008	England	93 (83)	63.9 (14.8) 64.2 (15.4)	CS of a longitudinal study at TP1: 1-year; TP2: 3.5 year	TP1: Brief COPE; HSQ-12; SRRS; ZBI; QoL-AD; TP2: AQ; Brief COPE; ZBI		✓		F2F interviews
Creese et al., 2008	Canada	60	73.65 (9.3) 49–93	CS	PSQI – modified; SF-12; HPLP; S-ZBI		✓		Telephone interviews
DeFazio et al., 2015	Italy	150	NS 94 > 50 years	CS	CBI	✓			F2F Interviews by physicians
DeLabra et al., 2015	Spain, Poland, Denmark	101	61.25 (12.6) 25–88	CS	ZBI; CCS; SSQRS; RCSS	✓			-
Di Mattei et al., 2008	Italy	112	58.94 (12.05) 32–81	CS	CBI; COPE - Italian	✓			F2F on-ward inferred, from research assistants
Diehl-Schmid et al., 2013	Germany	94	59.11 (11.7) 24–78	CS	CSI	✓		✓	Pack posted, follow-up phone call
Ducharme et al., 2016	Canada	96	YOD 53.06 (10.2) OOD 63.88 (13.0)	Comparative descriptive	PCS; RSCSE; CAMI; FCCS; PDI; PFCNS; ISSB	✓		✓	F2F by trained interviewers
Epstein-Lubow et al., 2008	US	33	No persisting burden: 65.5 (14.0) Persisting: 60.7 (8.4)	Longitudinal cohort	ZBI	✓			F2F at home 6 and 12 months
Ferrara et al., 2008	Italy	100	Male 59.4 (14.3) Female 56.1 (13.3)	Retrospective	CBI		✓		F2F interviews at clinic
Fonereva et al., 2012	US	41	Carers 66.4 (7.8) Non-carers 66.4 (7.9)	Comparative CS	PSS	✓		✓	Personal digital Assistant (PDA) – collected 3–4 times during the day at random
Gallagher et al., 2011	Ireland	102	64.4 (14) 31–87	CS	RUD-Lite; Carers' checklist; DIS; ZBI; Brief COPE; SES		✓		F2F questionnaire
Galvin et al., 2010	US	962	55.9 (12)	CS	ZBI; informal questions	✓			Internet-based survey monkey

TABLE 1 (Continued)

Author, year	Country	Sample size	Carer age mean (SD); range	Study design	Carer-reported measure used	Diagnosis of person being cared for:			Delivery method
						Dementia	AD	FTD	
García-Alberca et al., 2012	Spain	80	62.15 (10.4)	CS	ZBI; STAI-S; CSI	✓	✓		F2F interviews by authors (psychiatrist, neuropsychologist, neurologist)
Garre-Olmo et al., 2016	Spain	306	61.2 (13.9)	CS multi centre	ZBI	✓	✓		F2F at clinic visit by physician or psychologist
George & Steffen, 2014	US	53	62.61 (10.5)	Longitudinal cohort	CSE- R; SF-12; RSCSE	✓			Phone interviews 12 and 18 months after intervention
Giebel & Sutcliffe, 2018	England	272	67 (12)	CS	AC-QOL; GHQ – 12	✓			F2F or hand/postal of questionnaires (research team attended carer support groups)
González-Abrales et al., 2013	Spain	33	57.6 (11.3) 35–82	CS	ZBI – Spanish version	✓			Postal
Gusi et al., 2009	Spain	110	60.6 (6.6) Non-carers 62.6 (5.6)	Comparative CS	SF-12	✓			F2F interview at home by a trained interviewer
Harmell et al., 2011	US	100	73.8 (8.1)	CS	CSE – 13		✓		F2F interview at home
Haro et al., 2014	France, Germany, UK	1497	67.3 (12)	Prospective cohort (multi centre)	ZBI; EQ-5D; RUD		✓		—
Holley & Mast, 2009	US	80	60.53 (12.7)	CS	MM-CGI; AGS; ZBI-SF	✓			F2F or postal, chosen by participant
Janssen et al., 2017	Germany, Ireland, Italy, Netherlands, Norway, Portugal, Sweden, UK	453	66.4 (13.3)	Prospective cohort	RSS; SOC-13; LOCBS; CarerQoL	✓			—
Kaizik et al., 2017	Australia	90	Children (mild) 32.2 (9.7) Spouses (mild) 62.5 (11) Children (severe) 30.7 (10.1) Spouses (severe) 61.9 (9)	CS	ZBI; SNI; IBM; DASS-21			✓	Online survey

(Continues)



TABLE 1 (Continued)

Author, year	Country	Sample size	Carer age mean (SD); range	Study design	Carer-reported measure used	Diagnosis of person being cared for:			Delivery method
						Dementia	AD	FTD	
Kaufman et al., 2010	US	141	White 53.5 (11.8) African American 49.4 (11.9)	CS	SPMSQ; ISEL; CCI; QoLI	✓			Telephone interviews by trained interviewers
Kowalska et al., 2017	Poland	58	54.7 (12.6) 21–78	CS	CBS; BSSS; SWLS	✓			F2F interview by psychologist
Lo Sterzo & Orgeta, 2017	UK	155	NS 26–82	CS	BIPO; SOC	✓			Handed out then completed at home and returned to researcher
Luchsinger et al., 2015	US	139	59.29 (10.4)	CS	ZBI	✓	✓		—
Majoni & Oremus, 2017	Canada	200	Retired 68–80 Employed 51–62	CS	EQ-5D-3L		✓		F2F by trained interviewers
Marziali et al., 2010	Canada	232	NS	CS	EPQ-R; RSCSE; MSPSS; HSQ-12	✓			F2F Interview from trained graduate and senior undergrad allied health students
Maseda et al., 2015	Spain	58	56.3 (1.5) 28–82	CS	ZBI – Spanish version; STAI	✓			Postal
Mausbach et al., 2011	US	108	73.88 (8)	CS	PANAS; PES-AD; WCC-R; CSE		✓		F2F at home
McLennon et al., 2011	US	84	73.3 (10.5) 49–96	CS	ZBI; SF-36; FMTCG	✓			F2F at location and time chosen by carer - by chief investigator
Melo et al., 2011	Portugal	109	67.0 (12.5)	CS	ZBI; NEO-FFI - Portuguese	✓			F2F in own home by trained interviewer
Melo et al., 2017	Portugal	98	66.8 (12.7)	CS	ZBI; NEO-FFI - Portuguese	✓			F2F at home by trained nurse
Millenaar et al., 2016	Holland	328	YOD 59.02 (9.3) OOD 64.3 (12.4)	Longitudinal cohort	SSCQ	✓			NS 6 monthly follow-ups over 2years
Miller et al., 2010	US	421	63.0 (15.5) 22–89	CS	CDS; ZBI;		✓		—
Molinuevo & Hernández, 2011	Spain	249	59.9 (14.9)	Prospective multicentre study	SF-36; ZBI		✓		—

TABLE 1 (Continued)

Author, year	Country	Sample size	Carer age mean (SD); range	Study design	Carer-reported measure used	Diagnosis of person being cared for:		
						Dementia	AD	FTD
Mougias et al., 2015	Greece	197	59.18 (13.9)	CS	ZBI	✓		—
O'Dwyer et al., 2013	Australia and US	120	58.76 (10.7)	CS	SES; SF-12; ZBI; Brief COPE; BHS; ADKS; LOT; DSSI; SBQ-R	✓		Online survey using LimeSurvey
O'Dwyer et al., 2016	Australia	566	Non-suicidal 64.14 (11.3) Suicidal 56.60 (10.1)	CS	SES; SF-12; ZBI; Brief COPE; BHS; ADKS; LOT; DSSI; SBQ-R; BRLL	✓		Online survey or in hard copy
Orgeta & Lo Sterzo, 2013	UK	170	62.42 (11.2) 24–88	CS	SOC; RSS; EQ-VAS	✓		—
Papastavrou et al., 2015	Greece	208	Reported in age brackets and %	Comparative CS	SCQ-G; ZBI;	✓		F2F interviews by trained research assistant nurse graduates at home
Papastavrou et al., 2014	Greece	76	Reported in age brackets and %	CS	QOL-AD; ZBI	✓		—
Papastavrou et al., 2012	Greece	410	AD 56.8 (13.3) Schiz. 56 (15.0) Cancer 50.6 (13.4)	Comparative CS	ZBI		✓	F2F interviews at home/ clinic
Papastavrou et al., 2011	Greece	172	56.8 (13.4) 25–88	CS	ZBI; WCQ- Greek	✓		F2F in own home
Pertl et al., 2017	Ireland	253	69.64 (7.8) 50–90	CS	PSS-4; SES; BIPAQ	✓		—
Quinn et al., 2012	UK	447	68 (12.5)	CS	MECS; PAI; CCS; MICS	✓		Postal
Raggi et al., 2015	Italy	73	64 (IQR 52–72)	CS	CBI		✓	F2F in clinic
Raivio et al., 2015	Finland	728	PWB mod/good 77.7 (5.9) Poor 78.7 (7.1)	CS	PWB		✓	Postal
Riedijk et al., 2008 and Riedijk et al., 2009	Holland	63	60.7 (9.6)	CS	SF-36; SCQ; UCL; SSL; SCL-90-R		✓	Telephone interview by trained psychologists
Roche et al., 2015	Holland	46	59.11	CS	CSI; QoL-AD; Brief COPE		✓	Postal or handed out
Roepke et al., 2009	US	73	Carers 72.16 (9.6) Non-carers 68.41 (6.7)	CS	MFSI-SF; PM		✓	—

(Continues)

TABLE 1 (Continued)

Author, year	Country	Sample size	Carer age mean (SD); range	Study design	Carer-reported measure used	Diagnosis of person being cared for:			
						Dementia	AD	FTD	
Romero-Moreno et al., 2011	Spain	167	59.88	CS	RSCSE; ZBI; POMS	✓			F2F interview at social or health centre
Rosa et al., 2010	Italy	112	55 (10)	CS	CBI; STAI	✓			F2F interview
Rosness et al., 2011	Norway	49	AD 60.8 (5.3) Non-AD 58.5 (8.3)	CS	QoL-AD – Norwegian Version	✓	✓		F2F interviews in memory clinic
Salgado-García et al., 2015	US	642	Smoker 57.02 (12.7) Non-Smoker 62.84 (13.2)	CS	ZBI; SF-36; PAC; Brief RCOPE		✓	✓	F2F interview at home
Savundranayagam & Orange, 2011	Canada/US	84	65.64 36–90	CS	PCI-DAT		✓		—
Scholzel-Dorenbos et al., 2009	Netherlands	97	73.5 (7.2)	CS	SEIQoL; ZBI; SRB; SPPIC		✓		F2F interviews – same person
Simonelli et al., 2008	Italy	100	55–85	CS	CBI		✓		F2F interview at clinic
Skarupski et al., 2010	US	396	Blacks 56.9 (13.3) Whites 61.2 (13.6)	Longitudinal cohort	Caregiver burden (Lawton); MSPSS; PA; CSS-5		✓		F2F or phone interviews 3 monthly over 4 years
Stensletten et al., 2016	Norway	97	79 65–96	CS	RSS; SPS – Norwegian; SOC	✓			Handed out in community clinic
Sun et al., 2010	US	141	52	CS	CCI; QoLI; COPE	✓			Telephone surveys
Sutcliffe et al., 2017	Estonia, Finland, France, Germany, Netherlands, Spain, Sweden, UK	1223	64.7 (13.4)	CS	ZBI; RUD	✓			F2F interviews
Svendsboe et al., 2016	Norway	186	74.9 (7.8)	CS	RSS		✓		F2F by clinician/nurse
Torrissi et al., 2017	Italy	27	76.2 (7.1)	CS	CBI	✓			F2F with psychologist
Välimäki et al., 2009 and Välimäki et al., 2014 and Välimäki et al., 2016	Finland	236	71.6 (7.2) (48–85)	CS	Study1: SOC; HRQoL-VAS; GHQ; Study2: SOC Study3: HRQoL-VAS		✓		F2F trained psychologist
von Känel et al., 2014	US	126	74.2 (7.9)	Longitudinal cohort	PANAS; PSQI		✓		F2F in-home by trained research staff up to 4 years

TABLE 1 (Continued)

Author, year	Country	Sample size	Carer age mean (SD); range	Study design	Carer-reported measure used	Diagnosis of person being cared for:			Delivery method
						Dementia	AD	FTD	
Wawrzyniczny et al., 2017	France	150	67.2 (6.5)	CS	CRA; PFCNS; KSS; SF-36; ISSB; FCCS; PDI; RSCSE	✓			F2F at home or clinic (Choice of carer)
Wilks & Croom, 2008	US	229	45	CS	PSS; S-PSSS; S-RS	✓			Surveys done at conferences
Wilks et al., 2011	US	419	61	CS	CITS; RS	✓			Postal
Zucchella et al., 2012	Italy	126	56.11 (12.4)	CS	CBI; COPE	✓			F2F interviews by clinicians
Zvěřová, 2014	Czech Republic	30	NS	Longitudinal cohort	ZBI	✓			F2F interviews 0, 4, 8, months

Abbreviations: AC-QoL, Adult Carer Quality of Life; AD, Alzheimer's disease; ADKS, Alzheimer's Disease Knowledge Scale; AGS, Anticipatory Grief Scale; AQ, Attachment Questionnaire; ASA, Attachment Assessment; BEGEC-20, Battery of Generalized Expectancies of Control Scales (also known as GEC20); BHS, Beck Hopelessness Scale; BIPAQ, Brief International Physical Activity Questionnaire; BIPQ, Brief Illness Perception Questionnaire; BRLI, Brief Reasons for Living Inventory; BSSS, Berlin Social Support Scale; CAMI, Carers' Assessment of Managing Index; CarerQoL, Care-related Quality of Life scale; CBI, Caregiver Burden Inventory (Novak); CBS, Caregiver Burden Scale; CCI, Consequences of Care Index; CCS, Caregiver Competence Scale; CDS, Caregiving Distress Scale (from the NPI); CITS, Coping in Task Situations questionnaire; CMAI, Cohen-Mansfield Agitation Inventory; COPE Index, Coping Orientations to Problems Experienced scale (Brief); CRA, Caregiver Reaction Assessment; CS, cross-sectional; CSE, Coping Self-efficacy scale; CSI, Coping Strategies Inventory; CSS, Caregiver Satisfaction Scale (6-items, 5-items); DASS 21, Depression, Anxiety and Stress Scale-21; DJS, Desire to Institutionalize Scale; DSSI, Duke Social Support Index; EPQ-R, Eysenck Personality Questionnaire Revised; EQ-5D, Euro-Quality of Life; EQ-VAS, EuroQol-Visual Analogue Scale; F2F, face-to-face; FCCS, Family Caregiver Conflict Scale; FMTCG, Finding Meaning Through Care-Giving; FTD, frontotemporal dementia; GHQ-12, General Health Questionnaire 12-item version; 30-item version; GSS, Gillette Strain Scale; HPLP, Health Promoting Lifestyle Profile; HSQ-12, Health Status Questionnaire; IBM, Intimate Bond Measure; ISEL, Interpersonal Support Evaluation List; ISSB, Inventory of Socially Supportive Behaviours; KSS, Knowledge of Services Scale; LEE, Level of Expressed Emotion scale; LOCBS, Locus of Control of Behaviour Scale; LOT, Life Orientation Test; MECS, Motivations in Elder Care Scale; MFSI-SF, Multidimensional Fatigue Symptom Inventory-Short Form; MM-CGI, Marwit-Meuser Caregiver Grief Inventory; MSPSS, Multidimensional Scale of Perceived Social Support; MSQFOP, Marital Satisfaction Questionnaire For Older Persons; NEO-FFI, NEO Five Factor Inventory (personality traits); NHP, Nottingham Health Profile; NS, not stated; OOD, Older Onset Dementia; PA, Positive Affect; PAC, Positive Aspects of Caregiving; PAI, Positive Affect Index; PANAS, Positive And Negative Affect Scale; PCI-DAT, Perception of Conversation Index – Dementia of the Alzheimer's Type; PCS, Preparedness for Caregiving Scale; PDI, Psychological Distress Index; PES-AD, Pleasant Events Schedule - Alzheimer's Disease; PFCNS, Planning for Future Care Needs Scale; PM, Pearlin Mastery scale; POMS, Profile Of Mood States (Tension Subscale); PSQI, Pittsburgh Sleep Quality Index; PSS, Perceived Stress Scale; PSSS, Perceived Social Support Scale (-S, Short); PWB, Psychological Well-Being (scale); QoL-AD, Quality of Life – Alzheimer's Disease; QoL-I, Quality of Life Inventory; RCOPE, Religious Coping measure; RCSS, Revised Caregiving Satisfaction Scale; RS, Resilience Scale (S-short); RSCSE, Revised Scale for Caregiving Self-Efficacy (Steffen); RSS, Relative Stress Scale; RUD, Resource Utilisation in Dementia (-Lite); SACL, Stress Arousal Checklist; SBQ-R, Suicidal Behaviours Questionnaire (-R, Revised); SCL-90-R, Revised Symptom Checklist; SCQ - G, Social Capital Questionnaire-Greek version; SCQ, Sense of Competence Questionnaire (-S, Short); SEIQoL, Schedule for the Evaluation of Individual Quality of Life; SES, Self-Efficacy Scale (Fortinsky); SF-12; SF-36, Short Form 12; 36 questions; SNI, Social Network Index; SOC, Sense of Coherence scale (-13 item); SOS, Significant Others Scale; SPMSQ, Short Portable Mental Status Questionnaire; SPPIC, Self-Perceived Pressure from Informal Care; SPS, Social Provision Scale; SRB, Self-Rated Burden scale; SRRS, Social Readjustment Rating Scale; SSL, Social Support List; SSQRS, Social Support Questionnaire; Short form Revised; STAI, State-Trait Anxiety Inventory; SWLS, Satisfaction With Life Scale; TP, Timepoint; UCL, Utrecht Coping List; UK, United Kingdom; US, United States; WCC, Ways of Coping Checklist (-R Revised); WCCQ, Ways of Coping Questionnaire (-R Revised); YOD, Younger Onset Dementia; ZBI, Zarit Burden Interview (S-ZBI Short version).

### 3.1.3 | What quality-of-life domains were addressed in identified measures?

The five most used measures were mapped across health and well-being domains to identify similarities and differences (Table 2). Four measures collected data on emotional and social status, and three on physical and stress/burden status. Additional areas covered by these measures included coping, financial impact, motivation, pain, role functioning and time dependence. Most of these areas were covered in the remaining measures, which ranged from stress-related, to personality coping, to emotional, mood and sleep scales.

### 3.1.4 | How were the measures administered?

The mode of delivery for the identified carer-reported measures varied from face-to-face ( $n = 50$ ), to postal ( $n = 11$ ), telephone ( $n = 8$ ) and online ( $n = 5$ ). Thirteen did not state the collection method and four used more than one method.

## 3.2 | Phase 2: A descriptive qualitative study

### 3.2.1 | Participant characteristics

Four focus groups were conducted with a total of 15 participants (focus group 1:  $n = 2$ ; focus group 2:  $n = 3$ ; focus group 3:  $n = 7$ ; focus group 4:  $n = 3$ ). Most of the participants were female ( $n = 10$ ) and lived in metropolitan Melbourne ( $n = 8$ ). Thirteen participants reported being

the spouse or partner of the person living with dementia, and of them, 12 lived at home with the person with dementia and the remaining carer's spouse lived in a residential aged care facility. The other two participants were adult children caring for a parent with dementia who lived in residential aged care facilities.

### 3.2.2 | Carer Experience Scale

Three groups (i.e. Groups 1 to 3) reviewed the CES. Participants liked the measure because it was brief and easy to complete:

It's very easy...it's more comprehensive...this one gives you an opportunity to add anything.

They also liked the inclusion of a question on activities they enjoy outside their caring role. They commented that this measure can be improved by a more personal approach, for example, the use of 'I' instead of 'You' statements.

### 3.2.3 | CaSPUN

Two groups (i.e. Groups 2 and 3) reviewed the CaSPUN. The overall comment was that the measure was too long and that the wording required significant revision:

By the time somebody gets to 35 questions, they are going to be exhausted, it's a bit long.

I just find the language up the top, like, "No unmet need is currently unmet". I find I never like having to answer things in the negative...

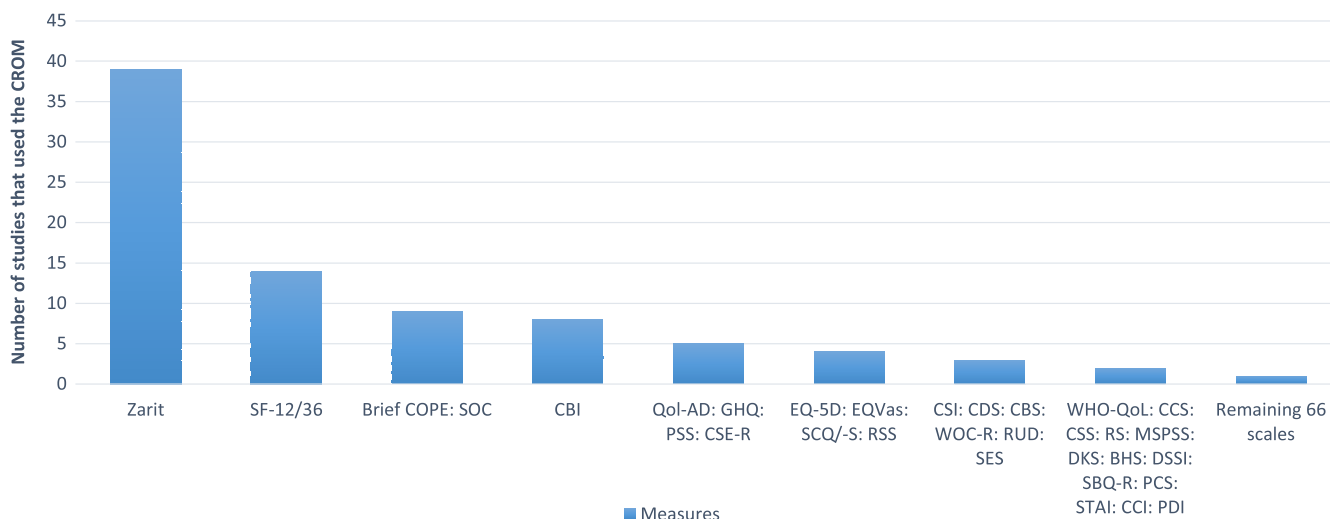


FIGURE 2 Number of studies for each carer measure

You finish up with a double negative and you are not sure what you have answered.

### 3.2.4 | Zarit Burden Interview

Two groups (i.e. Groups 3 and 4) reviewed the ZBI. The ZBI had the most positive feedback. Participants found it to be clearer and more comprehensive than the other measures presented in the focus groups. They also felt that the questions helped to capture the changes in their circumstances:

These sorts of questions change depending on the stage you are at. So, in my case I've seen these questions before when [person they care for] was at home. Now he's not at home, he's in care [a residential aged care]. It becomes a totally different set of answers but yes, they are all relevant.

Participants did not like the use of the word 'burden' in the survey title and suggested using a more neutral term:

Dementia Questionnaire for Carers...Yeah, it's loaded you know, "Burden" ... I like the Zarit with a different title.

### 3.2.5 | Short-Form 12 or 36

One group (i.e. Group 4) reviewed the SF-12/36. The group felt that it was not a preferred tool for carers because it did not ask the right questions and was difficult to follow:

This would not be asking the questions that I would want to be asked...I think the other surveys get more information than this one would ... This is difficult to follow and read and to work with using underlines and so on. There's nowhere where you can write additional stuff, additional "Do you have any notes to add".

### 3.2.6 | Brief COPE

One group (i.e. Group 4) reviewed the Brief COPE. Participants felt that the response options were unclear in terms of the subjective interpretation of the terms and that positively framed responses were easier to understand:

We've got the first scale questions, the one to four, "I haven't been doing this at all" is clear. "I've been doing this a little bit" and "a

medium amount" aren't quite as clear. Maybe "I do this sometimes" or "I do this often" and then "I do this all the time" might be a better way of putting that. Do not have the negative.

Participants also suggested using present tense in the sentences so participants can relate better to the questions:

I would make it more in the present, like "I return to work to just take my mind off things" and make the person think about it more. Like I'm doing...or "currently".

### 3.2.7 | Carer outcomes missing from the measures

Participants were asked to identify outcomes that were important to them but missing from the pretend measures. Participants proposed outcomes in three domains: (1) carer's social needs, (2) carer health needs and (3) access to and use of services for people with dementia and their carers (see Table 3). Carers also felt that it was important to include open-ended questions to enable the opportunity to share additional information if desired.

## 4 | DISCUSSION

Informal carers play a vital role in supporting people with dementia and are integral to the quality of life of people with dementia.<sup>3,4,6,7,9,10</sup> Given this, it is important to include carer-reported measures in a dementia CQR, where the key objective is to monitor the quality of care and service and to drive quality improvement initiatives. This paper reports the results of a systematic scoping review and a descriptive qualitative study that were conducted to inform the identification and/or development of carer-reported measures for a dementia CQR.

This scoping review included 88 studies, in which 99 carer-reported measures were identified. None had been utilised in the context of a dementia CQR. Most of the identified measures were administered via face-to-face, followed by postal and phone administration. The five most used scales reported included the ZBI, the SF-12/36, the Brief COPE, the SOC, and the CBI, with four collecting data on emotional and social health and three on physical health and stress/burden.

The qualitative study explored the acceptability of five carer measures, including three measures identified from the review (i.e. the ZBI, the SF-12/36 and the Brief COPE) and two measures used in CQRs for other diseases (i.e. the CaSPUN and the CES). Of the five measures, carers

TABLE 2 Health domains covered in the five most used carer-reported measures (from Scoping review)

CROM	Main focus	Description	Validation	Emotional	Physical	Social	Stress / Burden	Other
ZBI	Carer Burden	22-item self-report. Rated from 0 (never) to 4 (nearly always) summed to an overall score. A score of $\leq 20$ indicates little or no burden, mild–moderate burden 21–40, moderate–severe burden 41–60, and 61–88 indicates severe burden	High internal consistency ( $\alpha = 0.85$ ) and construct validity with carers of elderly people with dementia (Van Durme et al., 2012).	✓	✓	✓	✓	Coping Financial impact
SF-12/ SF-36	Health status	12 Items. Scorings range from yes/no, to limited a lot/limited a little, all the time/none of the time, to not all/ extremely. Summative scores are created and compared with normative data.	Reliability for the US population was stated as 0.89, and the UK as 0.88 (Ware, Kosinski, & Keller, 1996).	✓	✓	✓		Pain Role functioning
Brief COPE	Coping style	28-item self-reported scale comprising of 14 subscales with two domains in each. Scoring incorporates a Likert scale from 1 (not doing it at all) to 4 (doing it a lot).	Moderate to high psychometric properties have previously been reported with carers of people living with dementia (internal validity $\alpha = 0.72, 0.84, 0.75$ , and test–retest reliability emotion-focussed $r = 0.58$ , problem-focussed $r = 0.72$ , dysfunctional $r = 0.68$ ; $p < 0.001$ ) (C. Cooper et al., 2008).	✓	✓	✓		
SOC	Purpose/ Meaning in life	Self-reported 29-item scale. Scoring is from 1 (never have this feeling) to 7 (always have this feeling), with a higher overall score (summed and ranging from 29 to 203 points) indicating stronger coherence.	High reliability has been reported with Cronbach $\alpha = 0.83$ (Orgeta & Sterzo, 2013). A shorter version SOC-13 scale has been developed (Antonovsky, 1987) where summative scores range from 13 to 91 points with a higher score indicating a more successful adaptation to a stressful situation (Janssen et al., 2017).					Comprehensibility (cognitive) Manageability (behavioural) Meaningfulness (motivational)
CBI	Carer Burden	Self-reported 24-item scale of burden. Scoring incorporates a 5-point Likert scale ranging from 0 (never/not at all disruptive) to 4 (nearly always/very disruptive).	Internal consistency reliability is reported with a Cronbach $\alpha = 0.85$ (factors 1,2), 0.86, 0.73 and 0.77 (factors 3,4,5) with all factors displaying equal importance (Novak & Guest, 1989).	✓	✓	✓	✓	Time dependence

Abbreviations: Brief COPE Index, Coping Orientations to Problems Experienced scale; CBI, Caregiver Burden Inventory (Novak); SF-12, Short Form 12; SF-36, Short Form 36; SOC, Sense Of Coherence scale; ZBI, Zarit Burden Interview.

TABLE 3 Additional domains suggested by carers (from Qualitative Study)

Domain	Proposed topic	Quotes
Carer social needs	<ul style="list-style-type: none"> <li>• Time for yourself</li> <li>• Activities outside the caring role</li> <li>• Quantitative data on hours on different types of social activities</li> </ul>	<ul style="list-style-type: none"> <li>• About not looking after yourself or not caring as much about your own health and wellbeing and how much exercise you are getting</li> <li>• Another good question would be about social connections. So “I’ve been more isolated since the diagnosis” or “My circle of friends has changed”</li> <li>• Do you get enough support from family?</li> <li>• Do you get enough support from friends?</li> <li>• How many hours per week do you spend doing X, Y, Z and get a bit of a view of during a day and then over a whole week in terms of rest, sleep, activities, time out with other friends and family, for yourself ... to give a picture.</li> <li>• Is the carer having regular holidays?</li> </ul>
Carer health needs	<ul style="list-style-type: none"> <li>• Help with own health problems</li> <li>• Carer’s mental health</li> <li>• Carers’ sexual health</li> <li>• Change in the way that carers look after themselves</li> </ul>	<ul style="list-style-type: none"> <li>• How tired and exhausted are you? And maybe about diet and sleep and “I’m getting enough sleep”, “I’m taking supplements”, “I’m doing meditation”</li> <li>• How much longer before you totally collapse and burnout?</li> <li>• None of these questions refer to sexuality or your sex life, “Do you feel that you have any sex life at all?” That might be important for people...also maybe the other way around, that your partner is interested, and you aren’t ... Intimacy</li> </ul>
Services for people with dementia and their carers	<ul style="list-style-type: none"> <li>• Service and support for people with dementia</li> <li>• Service and support for carers</li> <li>• Unmet needs of carers</li> </ul>	<ul style="list-style-type: none"> <li>• What are the things that could make life better for me, the carer?</li> <li>• Could ask how easy it is to deal with a number of different services and maybe break them up into government services, things like Centrelink [government welfare], ..., and then other care and respite services – maybe on a scale.</li> <li>• Due to my family member’s dementia, I/we need help accessing legal services</li> <li>• I’d also consider adding “Getting help and advice from professional organisations”</li> <li>• Are you getting assistance from organisations? Are you getting assistance from the government?</li> <li>• Is the carer getting enough respite?</li> </ul>

preferred the ZBI and the CES. The ZBI was preferred because it was clear and comprehensive, and the questions helped to capture the changes in carers’ circumstances. However, carers did not like the term ‘burden’ in the title and suggested using a more neutral term. The CES was preferred because it was brief and easy to complete, and it included a question on activities enjoyed outside their caring role. However, carers suggested using a more personal approach in the questions, such as using ‘I’ instead of ‘You’ in the statements. Carers did not like the remaining three measures (i.e. the SF-12/36, the Brief COPE and the CaSPUN) because the measures were too long, did not ask the right questions, or were difficult to complete. Overall, carers preferred a brief measure that captured activities outside of the caring roles, could be used to understand changes in carers’ circumstances and included open-ended questions for carers to provide additional information on carer outcomes and experiences.

Carers also felt that questions relating to their social and health needs and service access/usage were important to understand the impact of caregiving on carers’ lives, but these were missing in some carer measures. Such questions are important to understand the impact of care and services utilisation among patients and carers and their experience of care and services, allowing a more complete picture of the patients’ and carers’ perceptions of both the process and the outcomes of care and services.<sup>23,50</sup>

Taken together, the results from the scoping review and the qualitative study suggested that the ZBI and the CES are two carer-reported measures that could potentially be used in a dementia CQR; however, adaption and further research exploring feasibility and acceptability via focus groups, interviews or surveys of when and how the carer-reported measure is administered is required before being used in a dementia CQR.



## 4.1 | Limitations and strengths

Our study has addressed an important gap in the literature in what carer-reported measures could be implemented into dementia CQRs. The combination of a scoping review and a qualitative study provided information based on existing research evidence and reflected the end-user's perspective.

Nonetheless, the results of this study should be considered in the light of its limitations. First, we have conducted only a scoping review, which did not include specific assessment of the quality of reviewed studies. Second, different numbers of measures were reviewed across the four focus groups and two measures (i.e. SF-12/36 and Brief COPE) were reviewed by only one focus group. This meant that there was limited feedback from the two measures, and future studies need to consider having relatively equal number of participants and measures across focus groups to ensure that all measures had similar opportunities for consumer feedback. Third, the number of participants in the focus groups was relatively small; however, analysis indicated that 90% of themes from a study are evident in three to six focus groups.<sup>51</sup> The focus groups did not explore the needs of carers for people with different types of dementia or the needs of groups such as people from the Aboriginal and Torres Strait Islander communities or Culturally and Linguistically Diverse communities. Future research leveraging the dementia registry data can identify population groups at different sites to inform sampling for interviews and focus groups to explore carer needs for these specific groups. Of the two preferred measures, the ZBI has undergone linguistic validation for several languages<sup>52</sup>; however, the CES has not been validated in languages other than in English.<sup>53</sup>

## 5 | CONCLUSIONS

There has been a growing interest in and use of CQRs around the globe to drive continuous quality improvements in clinical care. The inclusion of carer-reported measures is important for a dementia CQR to reflect carers' perspectives on the quality and outcomes of care and services. Our scoping review identified nearly 100 carer-reported measures from earlier dementia research, but none have been used in a registry context. Our qualitative study found that carers prefer brief measures that include questions related to their social and health needs and use of services. Additionally, the measures need to reflect changes in carers' circumstances, take a personal approach when asking questions and include an open-ended question.

Our studies suggest that the ZBI and the CES are two carer-reported measures that potentially could be used in a dementia CQR; however, adaptation and further exploration

is required. Future carer-reported measures for a dementia registry need to include both outcome and experience measures to help present a more complete picture of carers' perceptions on the process and outcomes of care and services.

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### CONFLICTS OF INTEREST

No conflicts of interest declared.

### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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