

BMJ Open Assessment of the validity of the Resilience and Strain Questionnaire in Caregivers of People with Dementia (ResQ-Care-Dem): a cross-sectional survey study

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ABSTRACT

Objectives The aim of the present study was to examine the reliability and validity (structural and convergent) of the Resilience and Strain Questionnaire in Caregivers of People with Dementia (ResQ-Care-Dem).

Design Cross-sectional survey study.

Setting Online survey in Germany.

Participants The ResQ-Care-Dem was completed by 243 informal caregivers of people with dementia ($M_{age}=59.7$ years, $SD=10.9$, 84.8% female).

Methods The ResQ-Care-Dem consists of four scales: two resilience scales (psychological aspects and social aspects of resilience) and two burden scales (interpersonal burden and general burden). The reliability of the two resilience and two burden scales was assessed using Cronbach's alpha as a measure of internal consistency. Structural validity was examined using a principal axis factor analysis. Convergent validity was assessed by Pearson's correlations with the Zarit Burden Interview (ZBI-7), the Caregiver Self-Efficacy Scale (CES-8) and the Gain in Alzheimer Care Instrument (GAIN).

Results The ResQ-Care-Dem scales' internal consistencies ranged between 0.65 and 0.81. The factorial structure could partly be confirmed, with the items of the four scales primarily loading on four factors. The burden scales demonstrated high and positive correlations with the score for caregiver burden (ZBI-7, $r=0.51-0.55$) and small to high, negative correlations with the scores for caregiver self-efficacy (CES-8, $r=-0.52-0.56$) and gains from caregiving (GAIN, $r=-0.21-0.22$), supporting construct validity of the scales. The resilience scales showed small to high positive correlations with the scores for caregiver self-efficacy (CES-8, $r=0.50-0.57$) and gains from caregiving (GAIN, $r=0.27-0.50$), as well as moderate negative correlations with the caregiver burden score (ZBI-7, $r=-0.45-0.50$), providing evidence for the scales' construct validity.

Conclusions The reliability and structural validity of the ResQ-Care-Dem were partially confirmed. Evidence supporting its convergent validity suggests that the questionnaire has potential as a tool for assessing caregiver burden and resilience factors among informal caregivers of people with dementia. While these findings

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The construct validity of the Resilience and Strain Questionnaire in Caregivers of People with Dementia was thoroughly examined using several questionnaires on the caregiver situation and caregiver burden.
- ⇒ The recruitment strategy, through the German Alzheimer's Association and social media, allowed for the recruitment of a comparatively large sample of informal caregivers of people with dementia, who are typically difficult to reach.
- ⇒ However, the recruitment strategy and the online mode of the study likely did not yield a representative sample, but rather younger informal caregivers who had already sought information and support on the topic.

indicate potential practical applicability, future studies should investigate its performance in real-world settings and assess changes over time (eg, responsiveness) in longitudinal studies.

INTRODUCTION

In Germany, there are currently an estimated 1.8 million people living with dementia,¹ and globally, the number exceeds 50 million and is expected to rise.² The majority of people with dementia is cared for by family members.³ Informal caregivers can experience significant stress and are at risk of physical or psychological illnesses themselves.⁴⁻⁶ To support the health and well-being of informal caregivers, promote stable care arrangements⁷ and ultimately enhance the well-being of individuals with dementia,⁸ it is essential to recognise early warning signs for timely intervention, identify sources of stress and actively foster resilience in dementia caregivers.



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Stress and resilience in dementia caregivers

To understand how chronic stress affects health, allostatic load is a key concept. Individuals strive for homeostasis, a balanced state in which they can function optimally.⁹ In the face of stress, they respond with adaptive processes, known as allostatic processes, to return to homeostasis. When the challenge surpasses an individual's coping abilities, for example because it occurs chronically, the allostatic system becomes overstimulated. This condition is referred to as allostatic load, and it is associated with poorer health outcomes.¹⁰ Moreover, chronic stress induces the activation of stress-sensitive systems in the body, leading to physiological and psychological strain over time.¹¹ The concepts of strain and burden are closely associated, both referring to the stress experienced by individuals providing care. Specifically, caregiver burden may be defined as 'the extent to which caregivers perceived their emotional or physical health, social life and financial status as suffering as a result of caring for their relative'.¹²

However, there are substantial interindividual differences among caregivers in the extent to which negative health consequences manifest.¹³ While previous research primarily focused on caregiver strain and burden as a result of stress, recent attention has shifted towards factors associated with increased caregiver resilience. Resilience may be defined as 'the process and outcome of successfully adapting to difficult or challenging life experiences, especially through mental, emotional and behavioural flexibility and adjustment to external and internal demands'.¹⁴ Resilience becomes particularly relevant in the face of adversity, as it enables individuals to maintain their well-being despite challenges. Thus, rather than chronic stress per se, it is also the way caregivers cope with stress that may ultimately determine their health outcomes.

Although a key concept in the health sciences, the literature on resilience lacks conceptual clarity, with ongoing debates regarding its precise definition and dimensional structure.^{15 16} Initially, resilience was understood as a stable personality trait.¹⁷ However, this perspective has evolved into an understanding of resilience as a positive adaptation process that specifically occurs in response to adversity.¹⁸

Accordingly, different approaches to conceptualising and measuring resilience have been proposed.¹⁶ The first main approach conceptualises resilience as a unidimensional, stable trait, reflecting an inherent personal disposition.¹⁷ The second, process-oriented approach conceptualises resilience as a multidimensional construct, encompassing a range of psychological and social resources that can be used in response to adversity.¹⁹ Finally, resilience can also be measured as maintained functioning despite adversity, for example, through indicators of psychological well-being.²⁰

In the context of informal caregiving, the concept of resilience specifically refers to the ability to adapt to the often challenging experience of providing care for a

family member or a friend. More and more studies are now examining what constitutes resilience in dementia caregivers. From a process-oriented perspective, which focuses on resources that facilitate positive adaptation to the caregiving situation, several key factors have been identified; these include biological factors (eg, male gender), psychological factors (eg, higher self-efficacy), social factors (eg, greater social support) and structural factors (eg, financial stability).^{21–24}

Resilience and Strain Questionnaire in Caregivers of People with Dementia (ResQ-Care-Dem)

Caregivers of people with dementia are frequently overlooked within the healthcare system, which is why they are sometimes referred to as the 'invisible second patient'.³ So far, there is no validated instrument that comprehensively assesses burden and resilience factors²⁵ and can serve as a diagnostic tool in practical settings. Wuttke-Linnemann *et al.*²⁶ aimed to develop such an instrument and developed two questionnaires, the Resilience and Strain Questionnaire for informal caregivers (ResQ-Care) as a general measure and the Resilience and Strain Questionnaire in Caregivers of People with Dementia (ResQ-Care-Dem) specifically for informal caregivers of people with dementia.

The ResQ-Care and the ResQ-Care-Dem were designed for use in the counselling context and are intended to serve two functions: first, to identify particularly vulnerable caregivers as early as possible, and second, to derive specific counselling and preventive measures based on the profile of resilience and burden factors. To date, only the ResQ-Care has been evaluated for reliability and validity, with its psychometric quality ranging from moderate to good.²⁷ The ResQ-Care-Dem was additionally developed to address the specific challenges associated with dementia caregiving. Due to the nature of the syndrome, including behavioural symptoms and the gradual loss of the loved one, informal caregivers of people with dementia often report especially high levels of burden and have an elevated rate of depression.^{28 29} Therefore, it seems important to specifically assess the unique challenges faced by this particularly vulnerable group.

The four scales of the ResQ-Care-Dem were developed based on a literature review of predictors of caregiver burden, as well as caregiver resilience.^{26 27} The first two scales ('My strength-givers') measure caregiver resilience in general. In the development process, resilience was understood as a multidimensional construct in the sense of a process-oriented perspective, with a focus on the resources that can be used in response to adversity. A biopsychosocial approach was adopted, based on the classification of resilience factors by Dias *et al.*³⁰ and Joling *et al.*²⁴ The first resilience scale ('My inner attitude') focuses on psychological aspects, emphasising attitudes towards caregiving and the caregiver's personal characteristics associated with lower caregiving burden or buffering its effects. These include factors such as the voluntary decision to provide care,³¹ self-efficacy,³² growth and

maturation through caregiving,²⁴ rapid recovery from stress and a sense of competence in caregiving.³³ The second resilience scale ('My sources of energy') focuses on social aspects of resilience that have been linked to reduced caregiving burden, particularly social support,³⁴ as well as measures of self-care.³⁵

The third and the fourth scale ('My strength-sappers') focus on caregiver burden. The third scale of the ResQ-Care-Dem ('Difficulties in caring for the person with dementia') assesses specific challenges associated with caregiving for a person with dementia. This scale is where the general and the dementia-specific version of the questionnaire differ; the general version of the questionnaire captures difficulties in supporting the person in need of care more broadly, while the ResQ-Care-Dem focuses on typical challenges in caring for a person with dementia. The ResQ-Care-Dem acknowledges the significant contribution of behavioural problems and interpersonal stressors in understanding caregiver burden. Therefore, the items cover, particularly, the occurrence and extent of behavioural problems in accordance with the Neuropsychiatric Inventory,³⁶ as well as coping and subsequent consequences (eg, caregivers' feelings of shame,³⁷ role reversal among caregivers and the person with dementia,³⁸ as well as relationship quality³⁹). The fourth scale ('General burdens of my living situation') captures factors that are associated with a greater caregiver burden due to the caregiver's general life situation, such as personal health problems,⁴⁰ role conflicts⁴¹, but also structural factors like financial concerns.^{42 43}

The interpretation of the ResQ-Care-Dem is conducted in two steps. In the first step, the scales are individually analysed to identify relevant counselling topics. For example, if caregivers score low (sum score <7.5) on the psychological aspects of resilience, suitable counselling topics might include self-care, stress management or problem-solving training. Likewise, if caregivers score high (sum score >7.5) on the burden scales, suitable counselling topics might include psychoeducation on behavioural problems or arrangement of support services. In the second step, burden and resilience factors are considered in relation to each other to derive four caregiver types with distinct needs. More detailed information is available online (<https://www.zqp.de/english/what-we-do/#RESQ-CARE>).

Present study

The psychometric quality of the ResQ-Care-Dem has not yet been examined. The objective of the present study was to assess the reliability, structural validity and convergent validity of the ResQ-Care-Dem using a cross-sectional online survey of caregivers of people with dementia. Convergent validity was evaluated in relation to other instruments measuring the situation of informal caregivers. It was hypothesised that the burden scales of the ResQ-Care-Dem would correlate positively, and the resilience scales would correlate negatively, with a well-validated caregiver burden score. Additionally, the

resilience scales of the ResQ-Care-Dem were hypothesised to correlate positively, and the burden scales negatively, with scores for caregiver self-efficacy and gains from caregiving.

METHODS

Participants and procedures

The data collection was conducted in collaboration with the German Alzheimer Society (Deutsche Alzheimer Gesellschaft e.V.), a German self-help organisation for people living with dementia and their informal caregivers. In the December 2022 issue of the members' magazine, a questionnaire for informal caregivers of people with dementia, along with a QR code leading to an online version with a more extensive caregiver survey, was published. Furthermore, the questionnaire was promoted through the Alzheimer Society's newsletter and on social media platforms. All the questions in the survey were presented in German. For the present analyses, the survey participants who reported currently caring for a person with dementia and who had fully completed the ResQ-Care-Dem were selected.

Measures

Resilience and Strain Questionnaire in Caregivers of People with Dementia (ResQ-Care-Dem)

The ResQ-Care-Dem questionnaire comprises four scales, two of which are resilience scales that assess psychological aspects ('My inner attitude', for example, self-efficacy, growth) and social aspects ('My sources of energy', for example, social support) of caregiver resilience.^{26 27} Two further scales assess aspects of caregiver burden. The first one measures interpersonal burden ('Difficulties in caring for the person with dementia', for example, aggressive behaviour, wandering), while the other burden scale focuses on the caregiver's life situation (eg, health issues or role conflicts). Each scale consists of five items. In addition, there is a basic scale with sociodemographic questions, which was not used in this questionnaire as sociodemographic information had already been collected in the survey. Respondents answered the items on a four-point scale ranging from 0 ('no') to 3 ('yes'). A sum score was calculated for each scale, with values ranging from 0 to 15. Higher scores on the resilience scales indicated higher resilience, while higher scores on the burden scales indicated higher caregiver burden. The questionnaire was developed and employed in German. The German name of the questionnaire is 'Fragebogen zur Angehörigen-Resilienz und -Belastung bei Demenz (FARBE-DEM)'.

Further caregiver questionnaires for investigating convergent validity

Zarit Burden Interview (ZBI-7)

The ZBI-7 is a 7-item short version^{44 45} of the original questionnaire.⁴⁶ It includes items such as whether the caregiver feels they do not have enough time for themselves,

experiences stress balancing caregiving tasks and other responsibilities or notices negative health effects. Caregiver burden was assessed on a five-point Likert scale ranging from 0 (never) to 4 (nearly always). The mean was computed as the total score, with higher values indicating higher burden.

The long version of the German Zarit Burden Interview was psychometrically evaluated in a sample of caregivers of people with dementia⁴⁷ and demonstrated high convergent validity with depressive symptoms and life satisfaction. A comparative validity study indicated that the 7-item short version is also well-suited for assessing caregiver burden among dementia caregivers.⁴⁸ A good internal consistency for the seven-item version in caregivers of people with dementia (Cronbach's $\alpha=0.86$)⁴⁴ was reported.

Caregiver Self-Efficacy Scale (CSES-8)

The CSES-8 is an 8-item questionnaire designed to assess self-efficacy in caregiving. An example item is: 'How sure or confident are you that you can cope with unexpected or new situations that may come up with your care partner?' The response scale ranged from 0 (not at all confident) to 9 (totally confident). The total score was calculated as the mean, with higher values indicating higher self-efficacy. In the original publication, the questionnaire demonstrated good internal consistency, with Cronbach's α ranging from 0.88 to 0.89.⁴⁹ The questionnaire has not yet been validated in German; it was translated for the present study by the author team.⁴⁹

Gain in Alzheimer Care Instrument (GAIN)

The GAIN questionnaire was used to assess positive outcomes in dementia caregiving, including personal gains (eg, 'Providing care has made me stronger and more resilient'), gains in relationships (eg, 'Providing care has helped to bond my family closer') and higher-level gains (eg, 'Providing care has given me deeper insights into the meaning of life'). The questionnaire consists of 10 items and the response scale ranged from 0 (disagree a lot) to 4 (agree a lot). In the original publication, the questionnaire showed good internal consistency, with Cronbach's α of 0.89.⁵⁰ The total score was calculated as the mean of the answered items, with higher values indicating higher gains in caregiving. The questionnaire has not yet been validated in German. For this study, it was translated by the author team.⁵⁰

Data analysis

Reliability

The reliability of the four subscales was assessed using Cronbach's alpha as an indicator of internal consistency.

Structural validity

The dimensional structure of the ResQ-Care-Dem was examined using an exploratory factor analysis. As the goal was to examine the underlying factors of the scales, a principal axis factor analysis was conducted. Since it was assumed that the scales are correlated with each other, an

oblique rotation was performed and Promax was chosen as the rotation method. For factor extraction, the Kaiser criterion,⁵¹ a scree plot⁵² and a parallel analysis⁵³ were employed.

Convergent validity

Pearson's correlations between the four scales of the ResQ-Care-Dem with the ZBI-7, CSES-8 and GAIN were examined. The strength of the correlations was evaluated based on Cohen's classification guidelines,^{54 55} where correlations below 0.3 are considered small, below 0.5 moderate and above 0.5 large.

Handling of missing data

Using Little's test, it was examined which missingness mechanism underlies missing values. Analysis methods were chosen to maximise the utilisation of the available data.

Patient and public involvement

Patients and/or the public were not involved in this study.

RESULTS

Participants

243 caregivers of people with dementia participated in the study. Their average age was 59.7 years (SD: 10.9, range: 27 to 92). The majority of caregivers, 84.8%, were female. The majority of the respondents took care of their parent (47.3%) or their partner (42.3%), and a small percentage took care of their mother- or father-in-law (3.3%). The majority of the respondents had a job, 25.5% full-time and 37.5% part-time. Across all levels of education (school, vocational school, further education, university), respondents had invested an average of 15.2 years (SD: 4.1) into their education. The people with dementia who were cared for by their family members had an average age of 78 years (SD: 10.5, range: 45 to 97). The majority of those receiving care, 59.3%, were female. According to the caregivers, the majority of those receiving care had moderate dementia (52.7%), followed by severe dementia (26.7%), mild dementia (17.3%) and mild cognitive impairment (2.9%).

Missing data

The number of missing values was very low, with two missing values in the GAIN and one missing value in the CSES-8. Data were missing at random according to Little's test ($\chi^2(5) = 2.397, p=0.792$).

Reliability

Table 1 displays Cronbach's alpha as a measure of internal consistency of the ResQ-Care-Dem scales. Reliability of the scales was moderate and ranged from 0.65 ('Difficulties in caring for the person with dementia') to 0.81 ('General burdens of my living situation').

Structural validity

According to the Kaiser-Meyer-Olkin criterion,⁵⁶ KMO=0.81, the data were deemed suitable for this

Table 1 Descriptive statistics, reliability estimates, and bivariate correlations of the different questionnaires of the caregiver perspective in dementia care

	n	M	SD	Min	Max	1	2	3	4	5	6	7
ResQ-Care-Dem dimensions												
1 Resilience: My inner attitude	243	9.53	2.76	2.00	15.00	(0.68)						
2 Resilience: My sources of energy	243	8.92	3.07	0.00	15.00	0.36**	(0.70)					
3 Burden: Difficulties in caring for the person with dementia	243	7.02	3.18	0.00	15.00	-0.49**	-0.33**	(0.65)				
4 Burden: General burdens of my living situation	243	8.27	3.76	0.00	15.00	-0.39**	-0.50**	0.37**	(0.81)			
5 ZBI-7	243	2.26	0.77	0.43	4.00	-0.50**	-0.45**	0.51**	0.55**	(0.88)		
6 CSES-8	242	4.10	1.89	0.00	9.00	0.57**	0.50**	-0.56**	-0.52**	-0.62**	(0.86)	
7 GAIN	241	2.04	0.73	0.00	3.89	0.50**	0.27**	-0.21**	-0.22**	-0.27**	0.36**	(0.83)

n=241–243 due to missing values on some items in the CSES-8 and GAIN, (pairwise deletion). **p<0.01. Reliability estimates (Cronbach's alpha) are reported in parentheses in the diagonal.
CSES, Caregiver Self-Efficacy Scale; GAIN, Gain in Alzheimer Care INstrument; ResQ-Care-Dem, Resilience and Strain Questionnaire in Caregivers of People with Dementia; ZBI, Zarit Burden Interview.

analysis ('meritorious' according to Kaiser and Rice⁵⁷). Regarding the number of factors, different criteria for factor extraction yielded different results. Six factors met the Kaiser criterion of an eigenvalue greater than one. The Scree plot⁵² was ambiguous, showing inflections that could justify both four or six factors. In the parallel analysis,⁵³ five factors were above the intersection point of the line representing the sample and the one derived from random data. Based on these conflicting information, the more conservative Kaiser criterion was chosen, and all six factors with eigenvalues greater than one were extracted.

Table 2 displays the rotated factor loadings (pattern matrix) for all six factors with eigenvalues greater than 1, and the variance explained by each factor. The first factor can be interpreted as caregiver burden related to the general living situation, as all items from the scale 'General burdens of my living situation' show high loadings on it. Additionally, two resilience items (quick recovery from stress and pursuing personal interests) load highly negatively on this factor. The second factor represents burden related to caregiving for the person with dementia, with all items from the scale 'Difficulties in caring for the person with dementia' loading on it, except for the item that asks about difficulties in assisting with activities of daily living. The third factor represents social resilience, items from the scale 'My sources of energy' assessing, among others, support from the social environment and joy in everyday life, load highly on this factor. On the fourth factor, three items from the psychological resilience scale 'My inner attitude', which assesses positive experiences in caregiving and the voluntary decision to take on caregiving responsibilities, show moderate to high loadings. The fifth factor is formed by additional items from this scale that assess self-efficacy and competence in caregiving. On the sixth factor, particularly one item from the scale 'Difficulties in caring for the person

with dementia', assessing difficulties due to the high demand of assistance with activities of daily living shows a high factor loading.

Convergent validity

Table 1 displays the correlations of the ResQ-Care-Dem scales with other instruments assessing the situation of informal caregivers of people with dementia. The resilience scales 'My inner attitude' and 'My sources of energy' showed small to high correlations with scales measuring caregiver self-efficacy (CSES-8) and positive outcomes in caregiving (GAIN), which supports the convergent validity of the two resilience scales. There were particularly strong positive correlations between the resilience scale 'My inner attitude' and caregiver self-efficacy (CSES-8) as well as positive outcomes in caregiving (GAIN). These subconstructs of psychological resilience in caregiving are also specifically captured by the scale. At the same time, both resilience scales showed a moderate negative correlation with caregiver burden as assessed by the ZBI-7. The two burden scales correlated highly with caregiver burden as assessed by the ZBI-7, supporting convergent validity of the burden scales. In addition, the two burden scales showed negative and small to high correlations with the scales that assess aspects of resilience, namely caregiver self-efficacy (CSES-8) and positive outcomes in caregiving (GAIN).

DISCUSSION

This study is the first to assess the reliability and validity of the ResQ-Care-Dem, a new tool to assess burden and resilience in caregivers of people with dementia. The reliability of the ResQ-Care-Dem scales was moderate, and its four-scale structure was partially confirmed. The results indicate good convergent validity, with the scales

Table 2 Items, means, standard deviations and factor loadings of the ResQ-Care-Dem

				Rotated factor loadings					
Dimension / Item		M	SD	1	2	3	4	5	6
Resilience scales: 'My strength-givers'									
My inner attitude									
1	I voluntarily and deliberately chose to take on the caregiving.	2.31	0.88	−0.08	0.06	−0.03	0.65	0.04	−0.05
2	Through caregiving, I am discovering new, positive sides of myself, of the person I care for, and/or of our relationship with each other.	1.68	0.97	0.04	−0.14	0.12	0.67	−0.04	0.07
3	I recover quickly from stress.	1.25	0.87	−0.48	−0.07	0.01	0.22	0.09	−0.20
4	I feel competent in the care I provide. For example, I have gathered information about the condition of the person I care for and about support services.	2.07	0.78	−0.04	−0.02	−0.07	−0.05	0.88	0.08
5	I am able to rely on my abilities in difficult situations.	2.21	0.64	0.12	−0.02	0.11	0.12	0.52	−0.11
My sources of energy									
6	Despite the increased demands, I manage to pursue my own interests, for example, hobbies, sport.	1.42	0.87	−0.43	−0.01	0.27	−0.13	0.05	−0.10
7	I use support for the caregiving, for example, from family members, friends, professional support.	1.71	1	−0.08	−0.03	0.69	−0.07	−0.02	0.35
8	I receive supportive feedback for the care I provide.	1.41	0.96	−0.17	−0.06	0.42	0.11	0.07	0.13
9	I have people I can always rely on.	2.11	0.89	0.14	−0.06	0.67	0.06	−0.02	−0.15
10	I experience joy in my everyday life, for example, when I pursue pleasant activities.	2.26	0.82	−0.21	0.24	0.49	0.07	0.02	−0.15
Burden scales: 'My strength-sappers'									
Difficulties in caring for the person with dementia									
11	The person I care for has physical limitations. He/she needs support in everyday life that is difficult for me to provide, for example, with getting dressed, washing, eating or mobility.	1.42	1.01	0.10	0.11	0.04	0.00	0.02	0.53
12	The person with dementia shows difficult behaviours that are burdensome for me, for example, he/she has hallucinations, is aggressive, wanders away, is restless (at night), lacks drive	1.70	1.12	0.07	0.61	0.04	0.17	0.00	0.28
13	I find it difficult to be in public with the person with dementia, for example, due to fear of embarrassing situations, lack of understanding from others, loss of control.	0.63	0.78	−0.21	0.37	−0.22	−0.16	0.07	0.13
14	It weighs heavily on me to see the person with dementia change, and that I have to take on more responsibilities as a result.	1.92	0.96	0.03	0.48	0.08	−0.25	−0.04	−0.07
15	I experience a lot of conflict and arguments with the person with dementia.	1.34	1.01	0.00	0.79	0.03	−0.02	−0.05	−0.05
General burdens of my living situation									
16	Besides the caregiving tasks, I am additionally burdened in my everyday life, for example, due to my own health, worries about other family members, reconciling caregiving, family and job.	2.07	0.93	0.76	−0.13	0.16	−0.16	0.08	0.00
17	I suffer from physical complaints on a daily basis, for example, pain, shortness of breath, heart palpitations, dizziness.	1.53	1.11	0.71	−0.13	−0.03	−0.04	0.02	0.02
18	I am worried about my financial situation.	1.11	1.00	0.47	−0.02	−0.12	0.16	−0.13	0.03

Continued

Table 2 Continued

Dimension / Item		M	SD	Rotated factor loadings					
				1	2	3	4	5	6
19	I neglect my own health, for example, I do not take care of my nutrition, getting enough sleep or attending medical check-ups.	1.76	0.94	0.65	0.19	-0.14	0.15	0.12	0.05
20	I feel like I cannot keep up with the many demands in my everyday life. This can express itself, for example, in a lack of drive, sleep problems, joylessness or irritability.	1.79	0.98	0.85	0.12	0.08	-0.07	0.01	-0.08
Eigenvalues				4.2	3	2.8	2.2	1.9	1.1
% of variance				20.9	15.2	14.1	11.1	9.4	5.4

EFA: Factor loadings for the principal axis factor analysis with Promax rotation (pattern matrix) color-coded by the strength of the loadings. ResQ-Care-Dem, Resilience and Strain Questionnaire in Caregivers of People with Dementia.

correlating as hypothesised with a well-validated scale for caregiver burden and with scales measuring resilience factors such as caregiver self-efficacy and gains from caregiving.

Reliability and structural validity

Cronbach's alpha, used as a measure of internal consistency for the scales, ranged from the lower to upper moderate range, consistent with the validation of the ResQ-Care.²⁷ Factors contributing to the observed moderate reliability include the brevity of the scales and the varying difficulty levels of the items, which reduce interitem correlations and lower Cronbach's alpha.^{58 59} Another key factor is the heterogeneity of item content, as the ResQ-Care-Dem captures a broad range of resilience and burden factors to ensure a comprehensive representation of the caregiver's situation.

For instance, consider the scale which assesses burden related to caring for a person with dementia. All items capture typical challenges in the caregiving of people with dementia, such as difficult behaviours of the person with dementia, functional impairments or discomfort in public, which, conceptually, supports their inclusion within a single scale. However, caregivers may not experience all challenges simultaneously or to the same degree. For example, a caregiver might struggle primarily with the functional impairments of the person with dementia but not necessarily feel uncomfortable in public or encounter difficult behaviours, and vice versa. These challenges may occur together but do not necessarily have to, which psychometrically suggests a multidimensional or even a formative construct.

Unlike reflective constructs (eg, intelligence), where indicators represent a common underlying property and strong interitem correlations are expected, formative items capture distinct, non-interdependent aspects of a broader concept and do not necessarily need to be highly correlated.^{60 61} In the case of formative constructs, content validity becomes paramount, ensuring that the scale reflects the complexity of the construct it aims to

measure, which was a key focus during the development of the ResQ-Care-Dem.^{25 26}

The examination of structural validity revealed the emergence of additional factors within the scales with lower reliability ('My inner attitude' and 'Difficulties in caring for the person with dementia'). Within the 'My inner attitude' scale, in addition to a factor primarily reflecting voluntary caregiving and perceived gains, another factor emerged that is more closely related to competence experience and self-efficacy. This suggests that it may represent a meaningful subdimension of resilience in informal caregivers. Similarly, in the 'Difficulties in caring for the person with dementia' scale, a second factor emerged that captures challenges specifically related to the physical impairments of the person with dementia. This factor appears distinct from other challenges measured by the scale, which primarily capture behavioural changes in the person with dementia. The physical impairments of the person with dementia thus seem to represent an additional, meaningful burden for caregivers. These findings indicate the presence of important subdimensions within these scales, which aligns with their moderate internal consistency.

Convergent validity

Convergent validity was assessed through associations with other instruments measuring the caregiver's situation. As hypothesised, the resilience scales were correlated with scales measuring aspects of resilience, namely caregiver self-efficacy and gains from caregiving, supporting convergent validity of the scales. At the same time, the resilience scales were negatively associated with the ZBI,⁴⁴ a well-validated questionnaire and one of the most widely used instruments to assess caregiver burden. As expected, the burden scales demonstrated high and positive correlations with the caregiver burden score from the ZBI, supporting the convergent validity of the burden scales. At the same time, the burden scales were negatively associated with aspects of resilience in informal caregivers, namely scores for caregiver self-efficacy and gains from

caregiving. These anticipated associations support the construct validity of the questionnaire and its scales.

Practical use and future directions

The focus of this study was on the psychometric quality of the ResQ-Care-Dem, but its practical application in counselling or support settings was not examined. However, the questionnaire was developed for use in these settings, and this is where the ResQ-Care-Dem may hold significant potential. It could serve as a valuable tool to structure conversations, act as a screening instrument to identify vulnerable individuals and help to detect individual caregiver needs in order to provide targeted counselling and support services. In addition to further psychometric evaluation and refinement of the ResQ-Care-Dem, future studies should focus on systematically assessing its practical utility in these real-world settings. Insights gained from practical application may inform future refinements and enhance the questionnaire's relevance for both research and applied contexts.

Limitations

Due to the nature of the data collection—being a non-probability sample, with the questionnaire promoted through the members' magazine of the German Alzheimer's Society and social media, and conducted online—a self-selection bias is likely present. The data collection method likely attracted slightly younger informal caregivers and caregivers who had already sought information and support on the topic, which is also reflected in higher scale scores on the resilience than on the burden scales. This means that the sample used for these analyses is not representative of informal caregivers of people with dementia in Germany, which limits the generalisability of the results. Moreover, the generalisability to other countries still needs to be investigated. Additionally, the sample consisted of individuals who self-reported that they are caring for a person with dementia, but we cannot be certain that this was actually the case. However, since many participants became aware of the questionnaire through the members' magazine of the German Alzheimer's Society, it is likely that the vast majority were indeed caregivers who subscribed to the magazine for this reason. Notwithstanding, one strength of the study is that we were able to study a comparatively large number of caregivers of people with dementia, a group that is difficult to reach for studies due to their levels of burden.

Another limitation is that data collection was conducted as a one-time online survey, which did not allow for longitudinal descriptions or the assessment of test-retest reliability or responsiveness of the scales. Finally, not all of the questionnaires used to examine construct validity have been validated in a sample of dementia caregivers or in their German versions. However, the questionnaires were selected by the author team because they assess relevant aspects of caregiver burden and resilience and demonstrated very satisfactory psychometric properties in their original publications.

Conclusions

The reliability and structural validity of the ResQ-Care-Dem were partially confirmed, while the results indicate a high level of convergent validity with respect to other measures of the caregivers' situation. The findings suggest that the ResQ-Care-Dem has potential as a tool for assessing caregiver burden and resilience, particularly in clinical and counselling settings where it may serve as a screening instrument or aide-mémoire for staff. However, further research is needed to refine the questionnaire, evaluate its practical application and assess its responsiveness in longitudinal studies.

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REFERENCES

- 1 Blotenberg I, Hoffmann W, Thyrian JR. Dementia in Germany: epidemiology and prevention potential. *Dtsch Arztebl Int* 2023;120:470–6.
- 2 World Health Organization. Global status report on the public health response to dementia. Geneva. Licence: CC BY-NC-SA 3.0 IGO. 2021.
- 3 Brodaty H, Donkin M. Family caregivers of people with dementia. *Dialogues Clin Neurosci* 2022.

- 4 Sörensen S, Duberstein P, Gill D, et al. Dementia care: mental health effects, intervention strategies, and clinical implications. *Lancet Neurol* 2006;5:961–73.
- 5 Etters L, Goodall D, Harrison BE. Caregiver burden among dementia patient caregivers: a review of the literature. *J Am Acad Nurse Pract* 2008;20:423–8.
- 6 Thyrian JR, Boekholt M, Biernitzky O, et al. Informal caregivers of people with dementia in Germany: psychosocial characteristics and unmet needs. *J Alzheimer's Dis* 2024;99:1235–42.
- 7 Köhler K, Dreyer J, Hochgraeber I, et al. Towards a middle-range theory of “Stability of home-based care arrangements for people living with dementia” (SoCA-Dem): findings from a meta-study on mixed research. *BMJ Open* 2021;11:e042515.
- 8 Blotenberg I, Boekholt M, Michalowsky B, et al. What influences life expectancy in people with dementia? Social support as an emerging protective factor. *Age Ageing* 2024;53:afae044.
- 9 McEwen BS. Stress, adaptation, and disease. Allostasis and allostatic load. *Ann N Y Acad Sci* 1998;840:33–44.
- 10 Guidi J, Lucente M, Sonino N, et al. Allostatic load and its impact on health: a systematic review. *Psychother Psychosom* 2021;90:11–27.
- 11 McEwen BS. Neurobiological and systemic effects of chronic stress. *Chronic Stress (Thousand Oaks)* 2017;1:2470547017692328.
- 12 Zarit SH, Todd PA, Zarit JM. Subjective burden of husbands and wives as caregivers: a longitudinal study. *Gerontologist* 1986;26:260–6.
- 13 Tuithof M, ten Have M, van Dorsselaer S, et al. Emotional disorders among informal caregivers in the general population: target groups for prevention. *BMC Psychiatry* 2015;15:23.
- 14 American Psychological Association. Resilience. In: *APA Dictionary of Psychology*. Washington, DC: APA, 2025. Available: <https://dictionary.apa.org/resilience>
- 15 Hiebel N, Rabe M, Maus K, et al. Resilience in adult health science revisited-A narrative review synthesis of process-oriented approaches. *Front Psychol* 2021;12:659395.
- 16 Troy AS, Willroth EC, Shallcross AJ, et al. Psychological resilience: an affect-regulation framework. *Annu Rev Psychol* 2023;74:547–76.
- 17 Block J, Kremen AM. IQ and ego-resiliency: conceptual and empirical connections and separateness. *J Pers Soc Psychol* 1996;70:349–61.
- 18 Bonanno GA, Romero SA, Klein SI. The temporal elements of psychological resilience: an integrative framework for the study of individuals, families, and communities. *Psychol Inq* 2015;26:139–69.
- 19 Schetter CD, Dolbier C. Resilience in the context of chronic stress and health in adults. *Soc Personal Psychol Compass* 2011;5:634–52.
- 20 Mancini AD, Bonanno GA. Predictors and parameters of resilience to loss: toward an individual differences model. *J Pers* 2009;77:1805–32.
- 21 Cherry MG, Salmon P, Dickson J, et al. Factors influencing the resilience of carers of individuals with dementia. *Rev Clin Gerontol* 2013;23:251–66.
- 22 Joling KJ, Windle G, Dröes R-M, et al. Factors of resilience in informal caregivers of people with dementia from integrative international data analysis. *Dement Geriatr Cogn Disord* 2016;42:198–214.
- 23 Teahan A, Lafferty A, McAuliffe E, et al. Resilience in family caregiving for people with dementia: A systematic review. *Int J Geriatr Psychiatry* 2018;33:1582–95.
- 24 Joling KJ, Windle G, Dröes R-M, et al. What are the essential features of resilience for informal caregivers of people living with dementia? A Delphi consensus examination. *Aging Ment Health* 2017;21:509–17.
- 25 Windle G, MacLeod C, Algar-Skaife K, et al. A systematic review and psychometric evaluation of resilience measurement scales for people living with dementia and their carers. *BMC Med Res Methodol* 2022;22:298.
- 26 Wuttke-Linnemann A, Halsband C-A, Fellgiebel A. *Fragebogen zur Angehörigen-Resilienz und -Belastung (FARBE) - Manual für die professionelle Beratung*. Berlin: Zentrum für Qualität in der Pflege (ZQP), 2020.
- 27 Wuttke-Linnemann A, Palm S, Scholz L, et al. Introduction and psychometric validation of the Resilience and Strain Questionnaire (ResQ-Care) - a scale on the ratio of informal caregivers' resilience and stress factors. *Front Psychiatry* 2021;12:778633.
- 28 Wuttke-Linnemann A, Baake R, Fellgiebel A. Dyadic wind of change: new approaches to improve biopsychological stress regulation in patients with dementia and their spousal caregivers. *J Alzheimer's Dis* 2019;68:1325–37.
- 29 Cuijpers P. Depressive disorders in caregivers of dementia patients: A systematic review. *Aging Ment Health* 2005;9:325–30.
- 30 Dias R, Santos RL, Sousa MFB de, et al. Resilience of caregivers of people with dementia: a systematic review of biological and psychosocial determinants. *Trends Psychiatry Psychother* 2015;37:12–9.
- 31 Campbell P, Wright J, Oyeboode J, et al. Determinants of burden in those who care for someone with dementia. *Int J Geriatr Psychiatry* 2008;23:1078–85.
- 32 Gallagher D, Ni Mhaolain A, Crosby L, et al. Self-efficacy for managing dementia may protect against burden and depression in Alzheimer's caregivers. *Aging & Mental Health* 2011;15:663–70.
- 33 Zauszniewski JA, Bekhet AK, Suresky MJ. Indicators of resilience in family members of adults with serious mental illness. *Psychiatr Clin North Am* 2015;38:131–46.
- 34 Adelman RD, Tmanova LL, Delgado D, et al. Caregiver burden: a clinical review. *JAMA* 2014;311:1052–60.
- 35 Pinquart M, Sörensen S. Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychol Aging* 2003;18:250:250–67.
- 36 Cummings JL, Mega M, Gray K, et al. The Neuropsychiatric Inventory: comprehensive assessment of psychopathology in dementia. *Neurology (Econicon)* 1994;44:2308–14.
- 37 Martin Y, Gilbert P, McEwan K, et al. The relation of entrapment, shame and guilt to depression, in carers of people with dementia. *Aging Ment Health* 2006;10:101–6.
- 38 Eloniemi-Sulkava U, Notkola I-L, Hämäläinen K, et al. Spouse caregivers' perceptions of influence of dementia on marriage. *Int Psychogeriatr* 2002;14:47–58.
- 39 Tough H, Brinkhof MW, Siegrist J, et al. Subjective caregiver burden and caregiver satisfaction: the role of partner relationship quality and reciprocity. *Arch Phys Med Rehabil* 2017;98:2042–51.
- 40 Richardson TJ, Lee SJ, Berg-Weger M, et al. Caregiver health: health of caregivers of Alzheimer's and other dementia patients. *Curr Psychiatry Rep* 2013;15:367:1–7.
- 41 Gräbel E. Häusliche-Pflege-Skala. *Manag Care* 2004;3:15.
- 42 Zarit SH, Orr NK, Zarit JM. *The hidden victims of Alzheimer's disease: families under stress*. NYU press, 1985.
- 43 Zank S, Schacke C, Leipold B. Berliner Inventar zur Angehörigenbelastung - Demenz (BIZA-D). *Z Klin Psychol Psychother* 2006;35:296–305.
- 44 Higginson IJ, Gao W, Jackson D, et al. Short-form Zarit caregiver burden interviews were valid in advanced conditions. *J Clin Epidemiol* 2010;63:535–42.
- 45 Kühnel MB, Ramsenthaler C, Bausewein C, et al. Validation of two short versions of the Zarit Burden Interview in the palliative care setting: a questionnaire to assess the burden of informal caregivers. *Support Care Cancer* 2020;28:5185–93.
- 46 Zarit SH, Reeve KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. *Gerontologist* 1980;20:649–55.
- 47 Braun M, Scholz U, Hornung R, et al. The burden of spousal caregiving: A preliminary psychometric evaluation of the German version of the Zarit Burden Interview. *Aging Ment Health* 2010;14:159–67.
- 48 Yu J, Yap P, Liew TM. The optimal short version of the Zarit Burden Interview for dementia caregivers: diagnostic utility and externally validated cutoffs. *Aging Ment Health* 2019;23:706–10.
- 49 Ritter PL, Sheth K, Stewart AL, et al. Development and evaluation of the eight-item Caregiver Self-Efficacy Scale (CSES-8). *Gerontologist* 2022;62:e140–9.
- 50 Yap P, Luo N, Ng WY, et al. Gain in Alzheimer care INstrument--a new scale to measure caregiving gains in dementia. *Am J Geriatr Psychiatry* 2010;18:68–76.
- 51 Kaiser HF. The application of electronic computers to factor analysis. *Educ Psychol Meas* 1960;20:141–51.
- 52 Cattell RB. The scree test for the number of factors. *Multivariate Behav Res* 1966;1:245–76.
- 53 Horn JL. A rationale and test for the number of factors in factor analysis. *Psychometrika* 1965;30:179–85.
- 54 Cohen J. A power primer. *Psychol Bull* 1992;112:155–9.
- 55 Cohen J. *Statistical power analysis for the behavioral sciences*. 2nd edn. Hillsdale, NJ: Lawrence Erlbaum Associates, 1988.
- 56 Kaiser HF. A second generation little Jiffy. *Psychometrika* 1970;35:401–15.
- 57 Kaiser HF, Rice J. Educational and psychological measurement. *Educ Psychol Meas* 1974;34:111–7.
- 58 Schmitt N. Uses and abuses of coefficient alpha. *Psychol Assess* 1996;8:350–3.
- 59 Cortina JM. What is coefficient alpha? An examination of theory and applications. *J Appl Psychol* 1993;78:98–104.
- 60 Blotenberg I, Schang L, Boywitt D. Should indicators be correlated? Formative indicators for healthcare quality measurement. *BMJ Open Qual* 2022;11:e001791.
- 61 Bollen K, Lennox R. Conventional wisdom on measurement: a structural equation perspective. *Psychol Bull* 1991;110:305–14.