## RESEARCH



# Identifying the needs of natural caregivers caring for a person with dementia: a mixed method study

Clarisse Dibao-Dina<sup>1,2\*</sup>, Lydia Nasri<sup>2</sup>, Céline Dagot<sup>3</sup>, Jean-Philippe Fouquet<sup>4</sup>, Sophie Rideau<sup>1</sup>, Vincent Dumas<sup>1</sup>, Guillaume Neff<sup>1</sup>, Véronique Payen<sup>1</sup>, Delphine Rube-Millon<sup>1</sup>, Marie Lemaile<sup>5</sup>, Jacques-Alexis Nkodo<sup>5</sup>, Vincent Camus<sup>5,10,11</sup>, Bertrand Fougère<sup>5,7</sup>, Bruno Giraudeau<sup>2,8</sup>, Dominique Beauchamp<sup>9</sup>, Laura Fruchard-Foucault<sup>2,6</sup>, Cécile Renoux<sup>1,7</sup> and Jean Robert<sup>1</sup>

### Abstract

**Background** Many available interventions to reduce challenges of natural caregivers of people living with dementia have limited efficacy since they do not meet the caregiver's individual needs. This study aims to evaluate caregivers' needs with the future goal of developing a tailored, multicomponent intervention to ease caregiver challenges through appropriate caregiver-centred interventions.

**Methods** Mixed method study using a convergent design with quantitative and qualitative data collection and analysis performed at similar times. For the cross-sectional quantitative study, questionnaires were sent to natural adult caregivers of a person with dementia identified by local healthcare professionals and general practitioners exercising in a rural and an urban department. For the qualitative descriptive study, individual caregiver interviews and healthcare professional focus groups were conducted in two primary healthcare territories in both departments. Data about screening for caregiver challenges and any help provided to the caregiver were collected. Quantitative data were analysed using descriptive statistics and qualitative data underwent thematic analysis using the grounded theory approach. Quantitative and qualitative results were described using a narrative discussion approach, then results were combined on a theme-by-theme basis using the weaving approach enabling integrated analysis.

**Results** A total of 199 general practitioners and 67 caregivers participated in the quantitative study. In the qualitative study, 10 caregivers from the urban area and 12 caregivers from the rural area participated in the individual interviews, and 9 healthcare professionals participated in the focus groups. Our broad categories of caregiver needs were identified: awareness and early diagnosis, information and training, practical, coordinated support, and psychological support. The integrated analysis highlighted areas for improvement in meeting these needs, especially a better identification of the caregiver role, caregiver distress, better information about what the caregiver has to expect in terms of the disease's progression and daily management, ways to improve awareness in general population, acceptation of practical support and its coordination and adaptation.

\*Correspondence: Clarisse Dibao-Dina clarisse.dibao-dina@univ-tours.fr

Full list of author information is available at the end of the article



© The Author(s) 2025, corrected publication 2025. **Open Access** This article is licensed under a Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International License, which permits any non-commercial use, sharing, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if you modified the licensed material. You do not have permission under this licence to share adapted material derived from this article or parts of it. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit http://cre ativecommons.org/licenses/by-nc-nd/4.0/. **Conclusions** Identified needs were concordant with those in the literature. The mixed method used enabled expectations to be explored by analysing together the points of view of both patients and healthcare professionals in order to identify ways of improving their care.

Trial registration Not applicable.

Keywords Caregivers, General practitioners, Needs

### Background

More than 47 million people are living with dementia worldwide, and this is predicted to increase to more than 75 million by 2030 [1]. Specifically, in France, more than 800,000 people live with Alzheimer's disease alone and more than 2,000 people younger than 60 years of age are diagnosed with this disease every year [2]. Currently, seven out of ten people with Alzheimer's disease are living at home [2], which is largely made possible through support from their relatives, called natural caregivers. These caregivers provide patient-specific care including supporting their social life, maintaining their autonomy, performing administration, providing psychological support and general domestic help [2].

However, providing this level of care is associated with caregiver challenges [3] and has been shown to have a physical and psychological impact including caregiver exhaustion, increased risk of depression, impaired immunity related to chronic stress, increased rates of cardiovascular disease and increased mortality rates [4, 5]. Furthermore, the caregiver's quality of life is correlated to the quality of life of the person they are caring for. Therefore, it is important that caregivers manage this challenges.

Currently, interventions to reduce caregiver challenges include psychological support, counselling, therapeutic education, information, and respite facilities [6]. However, these interventions have been shown to have limited efficacy due to caregiver heterogeneity, insufficient time for the intervention and improvement objectives that do not correspond to caregiver expectations. Interventions to reduce caregiver challenges will only be effective if they are tailored to the caregiver's individual needs [7], yet caregiver needs are currently poorly understood.

The aim of this study is therefore to evaluate the needs of caregivers caring for a person with dementia with the future goal of developing a tailored, multicomponent intervention to manage caregiver challenges through appropriate caregiver-centred interventions.

### Methods

### Study design

This mixed method study used a convergent design with quantitative and qualitative data collection and analysis being performed at similar times and subsequent integrated analysis [8].

Incorporating both quantitative and qualitative data enables a comprehensive analysis of the complex, multilevel nature of health services and caregiver needs, leading to more nuanced and effective intervention strategies [7, 8].

### Participants and recruitment

The quantitative study involved all registered general practitioners (GPs) and adult caregivers of a person with dementia, and the qualitative study involved healthcare professionals (such as physicians, nurses, physiotherapists, and dieticians) and adult caregivers from in the Cher (rural) and Indre-et-Loire (urban) departments, France. Participants could only be involved in either the quantitative or qualitative study. No participant participated in both studies.

### Cross-sectional quantitative study

Eligible adult caregivers were recruited directly by healthcare professionals from different healthcare settings (local hospitals with geriatric teams, local Alzheimer patient associations, and regional multidisciplinary healthcare networks). Professional caregivers and caregivers younger than 18 years of age were excluded.

Eligible GPs were identified from an exhaustive list of practising GPs obtained from the local medical council of physicians and contacted by email and postal invitation letter. Those GPs who had retired or were not practising in general practice were excluded.

### Qualitative descriptive study

Adults who were the main caregivers of a person with dementia living at home and who were a member of the Asclepios CPTS (urban) or the Cher Est CPTS (rural) were eligible for inclusion. A CPTS (communauté professional lealth community) is a multidisciplinary regional healthcare network which helps healthcare professionals improve access to healthcare in a given region [9]. Caregivers were recruited through direct telephone contact with the researchers (SR and VD) who were members of the Asclepios CPTS and Cher Est CPTS respectively at the time of the study or through another healthcare professional who knew the caregiver or the person with dementia. The researchers explained the study, its objective, and the interview process, and answered any

questions participants might have. The caregivers provided written informed consent to participate. Caregivers were recruited and included between March and April 2019 for Asclepios CPTS (SR) and between September 2019 and March 2020 for Cher Est CPTS (VD).

Healthcare professionals (HCP) who were members of the Asclepios CPTS in Indre-et-Loire (urban) were eligible for inclusion. The researchers contacted all the healthcare professionals in Asclepios CPTS by email and phone. HCP were recruited and included between April and May 2019.

### Data collection

### Cross-sectional quantitative study

The caregiver questionnaire was developed by the research team and blind-tested by researchers different from the conceivers and by caregivers different from those who participated in the study. The caregiver questionnaire consisted of 22 binary or multiple-choice questions and one final open-ended question for caregivers to express themselves more freely (Appendix 1). These questions concerned sociodemographic data and information about help the caregiver received from their GP. The study questionnaire was emailed or sent by post to the healthcare professionals responsible for caregiver recruitment in the different healthcare settings along with a cover letter and a consent form. The questionnaire was either self-administrated or administrated by a clinical research associate, a secretary, or a medical student.

The research team developed the GP study questionnaire which was blind-tested by researchers different from the conceivers and four GPs who were not included in the study. The questionnaire consisted of 29 binary or multiple-choice questions. Data collected included sociodemographic data, identifying natural caregivers, screening for caregiver challenges and any help provided to the caregiver. The information letter and questionnaire were sent to the recruited GPs in Cher and Indre et Loire by email, post, or both (Appendix 2). A Google Form questionnaire was used when sent by email. The last questionnaire was received on 22 January 2020.

GP and caregiver data was collected between October 2019 and January 2020. All collected data were anonymised.

### Qualitative descriptive study

The research team constructed the interview guide based on existing literature [6, 7, 10] (Appendix 3). An initial ice-breaker question was asked to make the interviewe feel at ease. The topics addressed during the interview included description of the disease and the caregiver's role, available support for the caregiver and the person with dementia, their relationship with the care network, experience of the disease, difficulties encountered by the caregiver and caregiver expectations. The interviews were adapted as and when themes emerged during the previous interviews. Caregiver interviews took place between April and May 2019 for Asclepios CPTS and between September 2019 and March 2020 for the Cher Est CPTS. A general practitioner intern (SR for Asclepios CPTS and VD for Cher Est CPTS), who had no prior experience in interviewing and a sociologist (CD), who was an experienced interviewer, conducted the semi-structured interviews at the caregivers' homes. Interviews were audio recorded and anonymised. Caregivers provided their consent prior to the interview.

HCP focus groups took place in June 2019 and were conducted by a medical student (SR) and a sociologist (CD). The interview guides (Appendix 4) were developed from the main themes addressed by the caregivers during their interviews and existing literature [6, 7, 10]. The interview started with an icebreaker question and covered topics including identifying caregivers, knowledge about support, feedback from caregivers about this support, perception of the caregiver's role, barriers to helping caregivers, and care coordination within the CPTS. All participants provided consent prior to the focus groups and the focus groups were all audio recorded and anonymised.

The reasons for conducting the research were explained to all participants. Participants were given the opportunity to see the transcripts from their interviews or focus groups and provide feedback.

### Data analysis

Quantitative data were analysed using descriptive statistics with Excel. Data are presented in the form of numbers and percentages for categorical variables and mean (standard deviation) for quantitative variables (respondent characteristics). Verbatim from the caregiver open ended question was included in the qualitative data analysis. All answered questions were included in the analysis even if the questionnaire was incomplete. Missing quantitative data were treated by a complete case analysis.

Qualitative data collected during the interviews and focus groups underwent thematic analysis using the grounded theory approach [11]. This method enables us to use data from the practice as a starting point for inductively determining the needs of caregivers. Verbatim from caregiver interviews was analysed initially to reveal the main themes, followed by analysis of verbatim from the focus groups. Data triangulation was used with two researchers (SR and CD) performing the coding using a coding book when required, and a third researcher (CDD) resolving any discrepancies, if necessary, until data saturation. Interviews were stopped when data saturation was obtained. Verbatim from caregiver interviews was analysed initially to reveal the main themes, followed by analysis of verbatim from the focus groups. Data triangulation was used with two researchers (SR and CD) performing the coding using a coding book when required, and a third researcher (CDD) resolving any discrepancies, if necessary, until data saturation.

### Integrated analysis

Results from the quantitative and qualitative studies were integrated so they could be compared and interpreted together. Data merging was used to enable interpretation. Three researchers (LN, CDD and LFF) described the qualitative and quantitative results using a narrative discussion approach [8] and results were combined on a theme-by-theme basis using the weaving approach [8, 12, 13]. The weaving approach was chosen because "the results were connected to each other thematically, and the qualitative and quantitative data weaved back and forth around similar themes or concepts" [8]. This enabled the possible different elements of a multicomponent tailored intervention to be described.

### **Results** Quantitative results

### Caregivers

A total of 70 questionnaires were collected from caregivers. Three of which were excluded because the consent form was not returned, so that the remaining 67 questionnaires were analysed. Caregiver characteristics are presented in Table 1. Most caregivers were women, were related to the person with dementia and cared for them at home.

Table 2 reports the results of the caregiver questionnaire. Most caregivers had the same GP as the person with dementia that they cared for. Of these, almost all believed that the GP was aware they were a caregiver. In contrast, among those caregivers who had a different GP from the person with dementia fewer felt that their GP knew they were a caregiver.

Table 1	Caregiver	characteristics	included ir	n the quantitative
study				

Caregiver characteristics N = 67	Number (%) for qualitative variables, mean (range) for quantitative variables
Age (years) mean, range	67 (35–91)
Gender: women N(%)	37/66 (56)
Relationship with the person with dementia N(%)	
- Couple	38/66 (58)
- Parent/child	24/66 (36)
- Other	4/66 (6)
PWD place of residence N(%)	
- Individual home	56/64 (88)
- Nursing home	8/64 (13)

GPs mainly provided information about Alzheimer's disease, but little information was given about progression or management. Only half of participating caregivers stated that their GP had approached them about difficulties associated with being a caregiver including psychological difficulties.

Support offered by their GPs varied but only a quarter of caregivers had been referred to support groups or offered a support plan. A third had been referred to the social worker for support and half had been informed about facilities for the person with dementia including day care centres. However, some caregivers declared they found it difficult accepting outside help.

Just over half of participating caregivers considered their GP to be a resource. They explained that listening skills and empathy were important and enabled them to establish a trusting relationship. GPs provided advice, support, and comfort. The caregivers who did not consider their GP to be a resource were mostly caregivers who had a different GP to that of the person with dementia.

In total, 733 GPs were contacted (582 in Indre-et-Loire and 151 in Cher). Of those GPs, a total of 199 completed the questionnaire which is a response rate of 17%. In the Indre-et-Loire region, 178 GPs completed the questionnaire, being a response rate of 30.6% and in Cher, 21 GPs responded, being a response rate of 14%. GP characteristics are summarised in Table 3.

Differences were highlighted between GPs who cared for the person with dementia and their caregiver and those who only cared for the person with dementia or the caregiver.

For GPs that cared for the person with dementia and their caregiver, support was mainly provided to the caregiver during a consultation for another reason or during a consultation for the person with dementia. Less than a quarter of GPs routinely screened for caregiver fatigue. When screening was performed, most GPs screened for depression and sleep disorders. Similar numbers of GPs relied on social support bodies and assessed how well caregiver needs were being met. The most common forms of support that these GPs offered the caregivers was respite, support groups, psychotherapy, and training courses.

For GPs who cared for the person with dementia but not the caregiver, identifying the caregiver posed little difficulty. However, just less than half of the GPs routinely recorded the caregiver identity in the person with dementia's medical records. There is also a lack of communication between GPs as around half of GPs who care for the person with dementia stated that they do not contact the caregiver's GP.

For GPs caring for the caregiver but not the person with dementia, almost all found out about the person's

Question	n/N (%)
Do you have the same GP as your loved one?	
Yes	40/67 (60)
No	27/67 (40)
Does your GP know that you are a caregiver?	
Yes	49/65 (75)
No	16/65 (25)
If not, why not?	
He is not the GP for the person I care for	11/16 (69)
I have never spoken to him about it	8/16 (50)
I always come to consultations without the person I care for	8/16 (50)
I rarely see my GP	8/16 (50
It is difficult to discuss with my GP	1/16 (6)
Has your GP informed you about Alzheimer's disease?	
Yes	31/47 (66)
No	16/47 (34)
If yes, you were given information about:	
The disease itself	24/31 (77)
Progression	18/31 (58)
Treatments	11/31 (35)
Support	11/31 (35)
If not, would you have liked information on these subjects?	
Yes	8/16 (50
No	8/16 (50)
Does your GP discuss difficulties you experience in connection with your caregiver role?	
Yes	27/46 (59)
No	19/46 (41)
If you have the same GP as your loved one, these difficulties are discussed	
During a consultation dedicated to your role as a caregiver and its impact on your health	6/25 (24)
During a consultation for another reason	12/25 (48)
During a consultation for your loved one	14/25 (56)
If you have a different GP to your loved one, these difficulties are discussed:	
During a consultation for another reason	5/5 (100)
Never	0/0 (0)
Does your GP check for psychological difficulties?	24/46 (52)
Yes	24/46 (52)
NO	22/46 (48)
Medicines (anviolution cleaning alle antideproceants)	0/24 (20)
Listening and psychological support	9/24 (30) 10/34 (43)
Eistening and psychological support	10/24 (42)
Psychological support from a psychologist	4/24 (17) E/24 (21)
None	7/24 (21)
If not would you like your GP to discuss those difficulties?	//24 (29)
	10/10 (53)
No	0/10 ( <i>1</i> 7)
Did your GP provide information about discussion groups, caregiver support and training?	) (1) (1)
	11/43 (26)
No	32/43 (7/1)
Have you benefited from any of these?	52/15(/7)
Yes	23/47 (49)
No	24/47 (41)
Did your GP inform you about the French Alzheimer's Association in your region?	=
Yes	18/44 (41)

Question	n/N (%)
No	26/44 (59)
Did your GP inform you about facilities for your loved one (day care centres, temporary accommodation etc.)?	
Yes	22/47 (47)
No	25/47 (53)
Did your GP refer you to a social worker for support and assistance?	
Yes	14/45 (31)
No	31/45 (69)
Has your GP offered you a support plan for your loved one?	
Yes	13/46 (28)
No	33/46 (72)
If yes, it includes	
A home nurse	5/16 (31)
Bathing assistance	8/13 (62)
A housekeeper	13/13 (100)
Meal delivery	5/16 (31)
Guardianship/legal protection/family authorisation	1/16 (6)
Temporary accommodation in a respite facility	5/16 (31)
Home nursing services	5/16 (31)
Have you had difficulty accepting outside help in your home?	
Yes	14/63 (22)
No	29/63 (46)
Not applicable	20/63 (32)
If yes, what difficulties did you encounter?	
Your loved one refuses outside help	9/13 (69)
Outsiders coming to the house disturbs your loved one	3/13 (23)
You don't feel you need help	4/13 (31)
The outside help is perceived as an intrusion	7/13 (54)
Financial cost	6/13 (46)
Restrictions associated with the times the helpers can come	4/13 (31)
The guilt of letting someone else take care of your loved one	5/13 (38)
The fear that it will be badly done or that something will happen in your absence	2/13 (15)
It is never the same person who comes to help	4/13 (31)
Other	2/13 (15)
Is you GP a resource to help you with your caring role?	
Yes	35/62 (56)
No	27/62 (44)
N=total number of participants who answered the question $GP=General Practitioners$	

role as a caregiver directly from that person. Anxietydepressive disorders, caregiver challenges, sleep disorders, and caregiver autonomy were the most commonly covered points during consultations. To help with these difficulties, these GPs suggested human help, for example a housekeeper, applying for financial support, respite, and social support. General support included providing information about medico-social and financial support, referral to a local social support structure or a caregiver association, or ensuring the caregiver has a long consultation dedicated to their role as a caregiver (Table 4).

### Phase 2: qualitative results

### Caregiver and healthcare professional characteristics

Semi-structured interviews were conducted with 10 caregivers from Asclepios CPTS in Indre-et-Loire (U1 to U10, U was the code assigned for interviews in urban areas) and 12 caregivers from Cher Est CPTS (R1 to R12, R was the code assigned for interviews in Rural area). Most participants were older than 70 years of age, retired and were married to and lived with the person with dementia that they care for. The caregivers who did not live with the person with dementia were theirs children or niece (Table 5).

Focus groups with HCPs lasted an average of two hours. Only two HCPs were recruited from the 250 professionals contacted by email at the Asclepios CPTS.

### Table 3 Characteristics of the general practitioners included in the quantitative study

General practitioner (GP) characteristics (n = 199)	Number (%) for categorical variables Mean (Standard deviation) for quantitative variable for quantita-		
	tive variables		
Age (years)	48.1 (11.3)		
Male gender	101 (50.8%)		
Time practising as a GP			
More than 10 years	126 (63.3%)		
Between 5 and 10 years	40 (20.1%)		
Less than 5 years	33 (16.6%)		
Practice type			
Group practice	93 (46.2%)		
Multiprofessional group practice	69 (34.2%)		
Sole practice	37 (18.6%)		
Further training			
Geriatrics-gerontology (University diploma or inter-university diploma)	13 (6.5%)		
Continuing professional education	18 (9%)		
University diploma in nutrition	1 (0.5%)		
Postgraduate diploma in emergency care	1 (0.5%)		
None	166 (83.4%)		
Medical work in addition to working as a GP			
None	131 (65.8%)		
At least 1 additional role	68 (34.2%)		
<ul> <li>Work in a residential care facility for the elderly</li> </ul>	14 (7%)		
Hospital work	12 (6%)		
Medico-social work	9 (4.5%)		
<ul> <li>Teaching (faculty, university supervisor)</li> </ul>	7 (3.5%)		
• Other	26 (13.1%)		

Subsequent direct contact resulted in a further 7 HCPs being recruited for the focus groups. Two focus groups were formed. The first consisted of a GP, 2 nurses, a physiotherapist, and a pharmacist. The second was made up of 2 GPs, a nurse, and a dietitian. The participants were all very active within the CPTS with six being members of the executive board and five being working group leaders.

### **Identified categories**

Four categories of caregiver needs were identified: awareness, information, practical support and psychological support.

### Awareness

Caregivers and HCPs all described the need to improve awareness about dementia in the general population: "As a caregiver, they explain the disease to us, they give us little books that we keep, that we read but it should be given to healthy people so that they learn what it is. Because it can affect anyone" (U4).

### Information

Caregivers highlighted the need for information about the disease as soon as possible after the diagnosis because they found that the *"doctor didn't tell me much" (U7)*. However, both caregivers and GPs described caregiver denial about the diagnosis as one of the main barriers to accessing this information: "we find ourselves in this ambivalence", "Perhaps there was denial" (U5). Caregivers also reported the need for information about disease progression and what to expect so they could prepare themselves and adapt their homes accordingly. Both caregivers and HCPs described the need for information about support in the area such as practical support or regional associations. The main barrier to providing this information was a lack of time during consultations: "I have a number of things to check [during a consultation]. The person comes with a certain number of requests, and we do not necessarily have free time or a clear mind to ask about anything else" (Focus Group no. 1).

### Practical support

Caregivers reported the need for trained professional caregivers to help them and provide respite when they need it. They also described the need for support facilities, such as respite centres, but access can be difficult, particularly in rural areas: *"I have to travel 40 km one way, 40 km return, it's a long day" (R12).* Caregivers highlighted the lack of responsiveness in adapting support to disease progression. They also described barriers to support including financial difficulties associated with affording support and the person with dementia refusing

 Table 4
 GP guestionnaire results

GPs who care for the nerson with dementia and the caregiver	n/N (%)
When do you look after the caregiver?	11/14 (70)
During a consultation with the person with dementia	132/197 (67.0)
During a long consultation with the caregiver dedicated to their role as a caregiver	41/197 (20.8)
During a consultation with the caregiver for another reason	1/9/107 (20.0)
During a long evaluation visit of the nationt-caregiver duad at home	71/107 (36.0)
At the explicit request of the caregiver caregiver dyad at nome	05/107 (48.2)
No you screen for caregiver exhaustion?	93/197 (40.2)
	26/107(192)
Offen	92/107 (40.1)
Samatimas	65/19/ (42.1) 45/107 (22.9)
Sometimes	45/19/ (22.8)
	33/19/ (16.8)
If yes, do you use evaluation tools?	F (100 (2 c)
ZAKIT MINI-SCAIE	5/190 (2.6)
None	185/190 (97.4)
Do you assess the unmet needs of the caregiver and person with dementia in terms of support?	
Routinely	36/196 (18.4)
Often	/9/196 (40.3)
Sometimes	58/196 (29.6)
No	23/196 (11.7)
Do you rely on social structures to help you and coordinate care?	
Routinely	39/196 (19.9)
Often	82/196 (41.8)
Sometimes	57/196 (29.1)
No	18/196 (9.2)
What support do you offer the caregivers?	
Individual or group psychoeducation	36/199 (18.1)
Telephone or internet support	7/199 (3.5)
Individual or family psychotherapy	45/199 (22.6)
Support group with other families or caregivers	75/199 (37.7)
Caregiver training course	39/199 (19.6)
Referral to respite	174/199 (87.4)
None	11/199 (5.5)
Do you screen for depression?	
Routinely	26/197 (13.2)
Often	77/197 (39.1)
Sometimes	70/197 (35.5)
No	24/197 (12.2)
Do you screen for sleep disorders?	
Routinely	31/197 (15.7)
Often	80/197 (40.6)
Sometimes	66/197 (33.5)
No	20/197 (10.2)
Do you screen for caregiver autonomy?	
Routinely	35/197 (17.8)
Often	60/197 (30.5)
Sometimes	55/197 (27.9)
No	44/197 (22.3)
Do you screen the nutritional status of the caregiver?	
Routinely	14/196 (7.1)
Often	34/196 (17.3)
Sometimes	65/196 (33.2)
No	83/196 (42.3)
GPs caring for the person with dementia but not the caregiver	

### Table 4 (continued)

Do you contact the caregiver directly?	
Routinely	58/191 (30.3)
Often	65/191 (34.0)
Sometimes	46/191 (24.1)
No	22/191 (11.5)
Do you have difficulty identifying the caregiver of the person with dementia?	
Routinely	1/192 (0.5)
Often	11/192 (5.7)
Sometimes	87/192 (45.3)
No	91/192 (47.4)
Do you record the identity of the caregiver in the medical records of the person with dementia?	
Routinely	88/192 (45.8)
Often	53/192 (27.6)
Sometimes	28/192 (14.6)
No	23/192 (12.0)
When the caregiver is cared for by another GP, do you think this makes it more difficult to provide support?	
Yes	101/192 (52.6)
No	91/192 (47.4)
Do you contact the caregiver's GP to advise them about the caregiver's situation?	
Routinely	4/192 (2.1)
Often	15/192 (7.8)
Sometimes	65/192 (33.9)
No	108/192 (56.3)
GPs caring for the caregiver but not the person with dementia	
How do you identify the caregiver	
From the patient directly	192/199 (96.5)
From the person with dementia 's GP	3/199 (1.5)
From the'person with dementia s specialist	3/199 (1.5)
Other	1/199 (0.5)
What support do you most commonly offer?	
A long consultation dedicated to the caregiver's role	51/168 (30.4)
A long evaluation visit of the patient-caregiver dyad at home	28/168 (16.7)
Referral to a nearby social organisation	66/168 (39.3)
Referral to a patient or family support group	51/168 (30.4)
Information about financial and medical-social support	86/168 (51.2)
What are the main points covered during a consultation with the caregiver?	
Caregiver nutrition	15/194 (7.7)
Caregiver sleep	104/194 (53.6)
Cardiovascular risk factors	13/194 (6.7)
Anxiety and depression	163/194 (84.0)
Joint disorders	0 (0)
Caregiver autonomy	95/194 (49.0)
Caregiver challenges	151/194 (77.8)
What support do you most often offer for these difficulties?	
Human support (housekeeper, nurse)	167/188 (88.8)
Financial support	128/188 (68.1)
Psychological support	19/188 (10.1)
Respite	118/188 (62.8)
Social support	81/188 (43.1)
Caregiver training	6/188 (3.2)
Medication (anxiolytic, antidepressant)	12/188 (6.4)

Caregiver code	Gender	Age (years)	Family link to person with dementia	Living with person with dementia	Place of residence	Professional status	Member of Cher Est (Rural) or Asclepios (Urban) CPTS
U1	Female	76	Spouse	Yes	Urban	Retired	Asclepios
U2	Male	85	Spouse	Yes	Urban	Retired	Asclepios
U3	Female	59	Child	Yes	Urban	Employed	Asclepios
U4	Male	85	Spouse	Yes	Urban	Retired	Asclepios
U5	Male	64	Child	No	Urban	Retired	Asclepios
U6	Female	84	Spouse	Yes	Rural	Retired	Asclepios
U7	Male	48	Child	No	Rural	Employed	Asclepios
U8	Female	79	Partner	Yes	Rural	Retired	Asclepios
U9	Female	68	Spouse	Yes	Rural	Retired	Asclepios
U10	Female	55	Niece	No	Urban	Employed	Asclepios
R1	Male	84	Spouse	Yes	Rural	Retired	Cher Est
R2	Male	88	Spouse	Yes	Rural	Retired	Cher Est
R3	Male	86	Spouse	Yes	Rural	Retired	Cher Est
R4	Male	85	Spouse	Yes	Rural	Retired	Cher Est
R5	Female	76	Spouse	Yes	Rural	Retired	Cher Est
R6	Male	73	Spouse	Yes	Rural	Retired	Cher Est
R7	Female	80	Spouse	Yes	Rural	Retired	Cher Est
R8	Female	83	Spouse	Yes	Rural	Retired	Cher Est
R9	Female	80	Spouse	Yes	Rural	Retired	Cher Est
R10	Female	91	Spouse	Yes	Rural	Retired	Cher Est
R11	Female	50	Child	No	Rural	Employed	Cher Est
R12	Male	47	Child	No	Rural	Employed	Cher Est

Tab	le 5	Characteristics of	f caregivers	participating	in t	he qua	litative stud	y
-----	------	--------------------	--------------	---------------	------	--------	---------------	---

U=for interviews in Urban area. R=for interviews in Rural area

practical support at home: "My wife has never accepted having someone clean our house" (R2).

HCPs also described these support needs. The main identified barriers included a lack of coordination between hospitals, outpatient care, and social services, a lack of effective communication tools and difficulties identifying all the HCPs monitoring the person with dementia. They also mentioned caregiver denial about theirs challenges making them unreceptive to offers of support or information about support: "Caregivers are in denial about their exhaustion, no matter how much we point it out to them", "We tell them that they need to get a bit of help to keep going a bit longer but they say 'no, no, everything's fine'. They often deny that they are exhausted. I still have quite a few patients who have failed to take advantage of the respite offered to them" (Focus group no. 2). HCPs suggested improving coordination by providing a single telephone number to access social services with a coordinator who would be the main contact person for the caregiver and multiprofessional consultations: "We need a case manager who helps them with regional support" (Focus group no. 1), "There are plans for multiprofessional consultations around the patient" (Focus group no. 2).

### **Psychological support**

Caregivers expressed their need for psychological support, particularly from their GP: "My attending physician is an obvious resource because he listens to the difficulties I am facing" (U1). They reported needing support to deal with losses from their old life such as a change of home or a different relationship with the person with dementia, and help accepting their new life including their loved ones' state of health, professional caregivers at home, respite or nursing homes: "It's really painful to see a person like that, it destroys you", "He was like a zombie. He had a blank stare, was absent, no longer there. It was so hard for me, I wanted to leave home" (R5). They also reported needing help to deal with the stigma, social isolation and difficulties maintaining their social life: "they no longer invite us to certain meetings and gatherings, because there are people from outside and we mustn't give the impression that there's something wrong with the family.(R9).

HCPs also described this need for psychological support. They described difficulties identifying caregivers in distress and caregivers putting the person with dementia first leading to a delay in providing appropriate support to the caregiver: *"The caregiver gives all their time to their loved one and no longer has time for themselves, there is* 

Integrated data the	emes			
Awareness	Information and	Practical and	Psychological	
	training	coordinated	support	
		support		
Identified needs				
Early diagnosis of	About the what	Support plan	Listening skills	
dementia	the Alzheimer	with referral to	and empathy	
	disease is	social workers	from the GP	
Improvement need	led			
To be identified	About the	Acceptation from	To identify	
as a caregiver by	progression of	the caregiver/	caregiver's	
the HCPs,	the disease	the person with	distress	
escpecially the	About the	dementia/the		
GP	management in	family		
To improve	daily life	Communication		
awareness in the	About the	and coordination		
general	different support	between GPs,		
population	and associations	between		
		healthworkers		
		(outpatient and		
		hospital) and		
		social workers		
		Tailored and		
		evolutive		
		approach		

Fig. 1 Integrated data themes

*therefore problems with their well-being" (Focus group no. 2).* 

### Integrated quantitative and qualitative results

The main caregiver needs revealed in both the quantitative and qualitative data could be gathered in the same four themes identified in the qualitative analysis: awareness, information and training about Alzheimer's disease, practical and coordinated support and psychological support. Quantitative data revealed similar themes and analysis of both quantitative and qualitative data using weaving approach gave some interesting insights to better understand those needs and how to improve their caring (Fig. 1).

### Discussion

Four broad categories of caregiver needs were identified: awareness and early diagnosis, information and training, practical, coordinated support, and psychological support.

These results are encouraging as they are consistent with recommendations about Alzheimer's disease which have been recently produced by the French Health Authority. These recommendations explain that caregivers have the right to be informed about the disease and its consequences, to be listened to and supported, to be helped by professionals and to access solutions for support and respite [14].

# Comparison with existing literature *Awareness and early diagnosis*

The importance of raising awareness is echoed in existing literature. Raising awareness helps to reduce stigmatic beliefs, optimise early diagnosis, and support cognitive health [15]. One way of raising awareness is through Alzheimer's Awareness Months which are held in different months in different countries around the world [16]. Traditionally awareness campaigns used television, print media and radio. However, social media has recently become the main platform [15].

The awareness could also be enhanced in the primary care setting. The GP is identified as a key healthcare professional to early diagnose a person with dementia [17]. It has been suggested that the GP could identify 'target situations' (such as a spontaneous memory complaint or a behaviour change noticed by the family) in which dementia should be detected to allow, secondarily, a diagnosis of dementia [17]. Information may also be available in primary care setting, as suggested by U4 in our study, to increase awareness.

### Information and training for caregivers

The French Health Authority recommends that caregivers receive information about Alzheimer's and its symptoms, available support, and how to take care of themselves and the person they care for [14].

Providing interventions including support and training, with or without information, are important as they have been shown to improve caregiver challenges [18]. However, authors have concluded that the efficacy of these interventions may depend on the nature and availability of the usual services in the study settings.

However, our results revealed that caregiver denial is one of the main barriers to being given the dementia diagnosis and relevant information. This denial can relate to the cognitive decline of the person they care for, and its impact on their own health and needs. This finding is consistent with existing literature [19]. Denial can also be a barrier to identifying the person with dementia and their caregiver. Potential solutions discussed in the literature included improving relationships with the person with dementia and their caregiver, educating patients and families with a tailored explanation about how the diagnosis was reached, encouraging family approaches including meeting with family members prior to delivering the diagnosis and involving the caregiver in the discussion [19].

Another barrier to giving the diagnosis and information is GP and caregiver lack of time. Possible solutions include improved collaboration between HCPs, depending on the region. For example, a mobile extramural unit could be useful, especially in rural areas where access to care is difficult [20].

### Practical, coordinated support

This theme revealed in our study is consistent with existing literature which revealed that caregivers need a contact person, a care plan, written information on available services, and support [21]. HCPs participating in our study expressed the importance of having a contact person for social support who can adapt support according to caregiver requirements. These adaptations may require coordination between social and medical support, which the GP or a general practice team could lead. However, participating caregivers did not expect practical support information from their GP which contrasts with what the GPs thought they expected.

However, participating caregivers did not expect practical support information from their GP which contrasts with what the GPs thought they expected. This information could be useful to GPs so that they can concentrate on what caregivers expect of them, i.e. listening, understanding and support adapted to their needs. In fact, it had already been reported in the literature that GPs felt that there were many obstacles to caring for carers, including a lack of resources, time and knowledge of the help available [22], understanding what caregivers really expect from their GPs could enable GPs to feel more useful, and thus increase the effectiveness of their care.

### **Psychological support**

It is well known that caregivers have a psychological challenge which increases further when the person with dementia has five or more chronic conditions [23]. Psychological support is therefore particularly important and is discussed in the French Health Authority recommendations. Caregivers have the right to be listened to and supported so that they can express their needs and difficulties, avoid isolation, and improve their relationships with the person they care for and other people [14].

Face-to-face cognitive-behavioural-therapy for caregivers is one possible solution which has been to shown to effectively support caregivers. However, lack of time can be a barrier to attending regular sessions so internet or telephone delivery could also be offered [24].

These themes have also been identified in studies about tailored and effective interventions to support caregivers. Multicomponent interventions have been shown to improve caregiver ability, knowledge, well-being, challenges, depression, and anxiety [25]. The most effective interventions described in the literature are psychoeducation and multicomponent interventions, as they affected most outcomes, whereas other interventions are domain-specific [25]. Furthermore, tailored interventions aim to increase the effectiveness of these interventions by systematically identifying barriers and facilitators [26].

### Perspectives

The next step in this project is to develop a tailored, multicomponent intervention according to Medical Research Council Guidance [27]. The intervention should allow caregivers to access existing support systems and to choose them according to their expectations and their healthcare region. A list of intervention proposals will be developed from this exploratory study and completed with an updated literature review on the subject [21]. The intervention proposals will focus on four main areas:

- 1/ Awareness and early diagnosis: providing information to the general population to raise awareness through different media. This information will be prepared with help from patient representatives and associations to reach the target population. Access to diagnostic tests could be facilitated through the practice nurse, access to community memory assessment clinics, or a local number for the CPTS to help find where the tests can be done.
- 2/ Information and training: Local associations and organisations could provide training about the caregiver role. Their contact details could be available in GP waiting rooms and in pharmacies.
- 3/ Practical, coordinated support: Social support could be accessed through a regional coordinator who can be contacted using a number provided to all HCPs. GPs would coordinate the tailored medical support.
- 4/ Psychological support: provided individually or in groups in combination with financial support.

This list of intervention proposals will then be proposed to a panel of experts using a Delphi consensus method. This technique will help us to find multicomponent and complex interventions that could be adapted to the healthcare context and tailored to the caregiver's identified needs.

### Strengths and limitations

The strength of our study was that the main needs of caregivers in predetermined urban and rural areas were identified using a weaving approach to integrate both quantitative and qualitative data. This approach provides a fairly comprehensive overview of caregiver needs. Participants from both rural and urban areas were included since the rural-urban status has been shown to impact the caregiver challenges differently; rural caregivers are more likely to provide long-term care, and experience poorer general and mental health than urban caregivers [28]. The INSEE (the National Statistical Office) [29] definitions of rural and urban were used. Furthermore, in the quantitative part of the study, response rate from

the general practitioners was sufficient to expect good generalisability of our results with 199/733 respondents; however, we could not estimate the total population of caregivers, so that we do not know whether our caregivers' sample is representative.

Some other limitations exist. One such limitation is that only caregivers from the Cher Est CPTS were recruited for the qualitative study, not HCPs. This meant no focus groups were run with HCPs from the rural region. However, we do not believe this has had a large impact on the study as our results are comparable with existing literature [30].

Some limitations were due to the study design: analysing quantitative and qualitative data together in the same time does not allow to adapt the rest of the method to the initial results, unlike a sequential mixed method [8]. A sequential method would have made it possible to investigate certain results in greater depth, such as the difference in perceived expectations of patients and GPs regarding practical support information. However, the choice of a convergent design was relevant as it enabled us to discover those results, that may be explored more in depth in a later step.

### Conclusion

Understanding needs of caregivers of persons living with dementia is a key to better respond to them. Four broad categories of caregiver needs were identified through the research: awareness and early diagnosis of dementia, information and training about the disease definition and management, practical and coordinated support, and psychological support of the caregiver. The integrated analysis highlighted areas for improvement in meeting those needs, especially a better identification of the caregiver role and caregiver distress, better information about what the caregiver has to expect in terms of disease's progression and daily management, ways to improve awareness in general population and acceptation of practical support and its coordination and adaptation. This indepth exploration of caregivers' needs will facilitate the development of a tailored, multicomponent intervention to help ease caregiver challenges.

### Abbreviations

- CPTS Communauté professionnelle territoriale de santé (territorial professional health community)
- GP General practitioners

HCP Healthcare professionals

### Supplementary Information

The online version contains supplementary material available at https://doi.or g/10.1186/s12875-025-02724-1.

Supplementary Material 1

Supplementary Material 2

Supplementary Material 3
Supplementary Material 4

### Acknowledgements

This article is supported by the French network of University Hospitals HUGO ('Hôpitaux Universitaires du Grand Ouest'). Editing and critical revision of the manuscript were performed by Speak the Speech Consulting.

### Author contributions

Each author participated to the study design, revised the work critically for important intellectual content, gave his/her final approval of the version to be published and agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. CDD, CD, JPF, VC, BF, DB, CR, JR conceived the study. SR, VD, GNG, VP, CD, LN, LFF participated to the acquisition and analysis of the data. CDD, LN, LFF interpreted data. CDD, LN drafted the work.All authors (CDD, SR, VD, GN, VP, CD, JPF, DRM, ML, JAN, VC, BF, BG, DB, CR, JR, LN, LFF) reviewed the manuscript.

### Funding

The study was funded by the University Hospital of Tours. We confirm that the sponsor had no role in the study design; in the collection, analysis, and interpretation of data; in the writing of the report; and in the decision to submit the article for publication. We also confirm the independence of researchers from funders and that all authors, external and internal, had full access to all the data (including statistical reports and tables) in the study and can take responsibility for the integrity of the data and the accuracy of the data analysis.

### Data availability

All data generated or analysed during this study are included in this article and in its online supplementary material.

### Declarations

### Ethics approval and consent to participate

A declaration has been made to the Data Protection Board (commission nationale informatique et libertés) CNIL (Receipt n°2019\_009 on 11 April 2019). The study was approved by the Ethics Committee of Tours university (Groupe Ethique Clinique), Tours, France, on 30th April 2019, reference number 2019-021. The caregivers provided written informed consent to participate. The research was conducted in accordance with the Declaration of Helsinki. All methods were carried out in accordance with relevant guidelines.

### Consent for publication

Not applicable.

### **Competing interests**

The authors declare no competing interests.

### **Transparency declaration**

As a lead author, Clarisse Dibao-Dina affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted; and that any discrepancies from the study as originally planned (and, if relevant, registered) have been explained.

### Patient and public involvement statement

France Alzheimer Touraine 37, a local association representing persons living with dementia and their caregivers was involved in the design, interpretation, reporting and dissemination plans of our research.

### Author details

<sup>1</sup>Department of General Practice, Département Universitaire de Médecine Générale, Faculté de Médecine, University of Tours, 10 Boulevard Tonnellé cedex 1, B.P. 3223, Tours, France

<sup>2</sup>University of Tours, University of Nantes, INSERM, SPHERE U1246, Tours, France

<sup>3</sup>CETU-ETIcS, University of Tours, Tours, France

 <sup>4</sup>UMR CNRS CITERES 7324, University of Tours, Tours, France
 <sup>5</sup>Division of Geriatric Medicine, Tours University Hospital Tours France, Tours, France
 <sup>6</sup>CHU Tours, Pharmacy, Tours, France
 <sup>7</sup>Education, Ethics, Health Tours University, Tours 7505, EA, France
 <sup>8</sup>INSERM CIC1415, CHRU of Tours, Tours, France

<sup>9</sup>France Alzheimer Touraine 37, Tours, France

<sup>10</sup>Division of Psychiatric Medicine, Tours University Hospital Tours France, Tours, France

<sup>11</sup>INSERM U1253, Tours, France

### Received: 21 February 2024 / Accepted: 24 January 2025 Published online: 21 February 2025

### References

- 1. World Health Organization. The epidemiology and impact of neurocognitive disorder: current state and future trends. 2015.
- Rocher P, Lavallart B. Le plan Alzheimer 2008–2012. Gérontologie et Société. 2009;32:13–31.
- Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. Gerontologist. 1980;20(6):649–55. https://doi.or g/10.1093/geront/20.6.649. PMID: 7203086.
- Badia Llach X, Lara Suriñach N, Roset Gamisans M. Calidad De Vida, Tiempo De dedicación Y Carga Percibida Por El cuidador principal informal del enfermo de Alzheimer [Quality of life, time commitment and burden perceived by the principal informal caregiver of Alzheimer's patients]. Aten Primaria. 2004;34(4):170–7. https://doi.org/10.1016/s0212-6567(04)78904-0. Spanish. PMID: 15388064; PMCID: PMC7668642.
- Schulz R, Beach SR. Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. JAMA. 1999;282(23):2215-9. https://doi.org/10.1001/jam a.282.23.2215. PMID: 10605972.
- Sörensen S, Pinquart M, Duberstein P. How effective are interventions with caregivers? An updated meta-analysis. Gerontologist. 2002;42(3):356–72. http s://doi.org/10.1093/geront/42.3.356. PMID: 12040138.
- Pinquart M, Sörensen S. Helping caregivers of persons with dementia: which interventions work and how large are their effects? Int Psychogeriatr. 2006;18(4):577–95. doi: 10.1017/S1041610206003462. Epub 2006 May 11. PMID: 16686964.
- Fetters MD, Curry LA, Creswell JW. Achieving integration in mixed methods designs-principles and practices. Health Serv Res. 2013;48(6 Pt 2):2134–56. h ttps://doi.org/10.1111/1475-6773.12117. Epub 2013 Oct 23. PMID: 24279835; PMCID: PMC4097839.
- De Fontgalland C, Rouzaud-Cornabas M. De la territorialisation des pratiques de santé aux communautés professionnelles territoriales de santé [Identifying professional and territorial health communities by analyzing healthcare spatial realities]. Sante Publique. 2020 Mar Apr May Jun;32(2–3):239–246. French. https://doi.org/10.3917/spub.202.0239. PMID: 32989953.
- Bismuth S, Bismuth M, Villars H, Oustric S, Andrieu S. Les « aidants naturels » du patient atteint de maladie d'Alzheimer. Le médecin généraliste peut-il les aider? Brève revue de la littérature. Médecine. 2010;6(10):470–4.
- 11. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative Res Psychol. 2006;3:77–101. https://doi.org/10.1191/1478088706qp063oa
- Fetters MD, Molina-Azorin JF. Rebuttal-conceptualizing integration during both the data collection and data interpretation phases: a response to David Morgan. J Mixed Methods Res. 2019;13(1):12–4. https://doi.org/10.1177/1558 689818780596
- Creswell JW, Plano Clark V. Designing and conducting mixed methods research. 3 ed. London: Sage; 2018. https://doi.org/10.1111/j.1753-6405.2007. 00096.x
- Haute Autorité de santé. 2012. Available at: https://www.has-sante.fr/jcms/r\_ 1501551/fr/alzheimer-ou-d-une-maladie-apparentee-faites-le-point-avec-vot re-medecin-traitant-document-pour-les-aidants
- Bacsu JD, Cammer A, Ahmadi S, Azizi M, Grewal KS, Green S, Gowda-Sookochoff R, Berger C, Knight S, Spiteri RJ, O'Connell ME. Examining the Twitter discourse on Dementia during Alzheimer's awareness Month in Canada: Infodemiology Study. JMIR Form Res. 2022;6(10):e40049. https://doi.org/10.21 96/40049. PMID: 36287605; PMCID: PMC9647466.
- World Health Organization. Towards a dementia inclusive society. 2021. [2022-05-18]. https://www.who.int/publications/i/item/9789240031531

- Villars H, Oustric S, Andrieu S, et al. The primary care physician and Alzheimer's disease: an international position paper. J Nutr Health Aging. 2010;14(2):110–20. https://doi.org/10.1007/s12603-010-0022-0
- González-Fraile E, Ballesteros J, Rueda JR, Santos-Zorrozúa B, Solà I, McCleery J. Remotely delivered information, training and support for informal caregivers of people with dementia. Cochrane Database Syst Rev. 2021;1(1):CD006440. https://doi.org/10.1002/14651858.CD006440.pub3. PMID: 33417236; PMCID: PMC8094510.
- Wollney EN, Armstrong MJ, Bedenfield N, Rosselli M, Curiel-Cid RE, Kitaigorodsky M, Levy X, Bylund CL. Barriers and best practices in disclosing a dementia diagnosis: a clinician interview study. Health Serv Insights. 2022;15:11786329221141829. https://doi.org/10.1177/11786329221141829. PMID: 36506598; PMCID: PMC9729996.
- Collignon J, Rouch I, Gonthier R, Corbin-Seguin A, Combe L, Trombert-Paviot B, Laurent B, Girtanner C. Refus du recours aux soins dans la maladie d'Alzheimer et les maladies apparentées: place d'une unité mobile extrahospitalière [Refusal of application to care in Alzheimer's disease and related diseases: establishment of a mobile unit hospital extra]. Geriatr Psychol Neuropsychiatr Vieil. 2013;11(1):49–55. French. https://doi.org/10.1684/pnv.2 013.0390. PMID: 23508319.
- Khanassov V, Rojas-Rozo L, Sourial R, Yang XQ, Vedel I. Needs of patients with neurocognitive disorder and their caregivers in primary care: lessons learned from the Alzheimer plan of Quebec. BMC Fam Pract. 2021;22(1):186. https://d oi.org/10.1186/s12875-021-01528-3. PMID: 34525960; PMCID: PMC8441033.
- Brunton S, Pruzin JJ, Alford S, Hamersky C, Sabharwal A, Gopalakrishna G. Perspectives of patients, care partners, and primary care physicians on management of mild cognitive impairment and mild Alzheimer's disease dementia. Postgrad Med. 2023;135(5):530–8. Epub 2023 May 29. PMID: 37219410.
- Zhang J, Wang J, Liu H, Wu C. Association of dementia comorbidities with caregivers' physical, psychological, social, and financial burden. BMC Geriatr. 2023;23(1):60. https://doi.org/10.1186/s12877-023-03774-9. PMID: 36721085; PMCID: PMC9890694.

- 24. Töpfer NF, Wrede N, Wilz G. Pragmatic effectiveness of Face-to-face cognitivebehavioral therapy for family caregivers of people with dementia. Clin Gerontol 2022;10:1–12. https://doi.org/10.1080/07317115.2022.2156828. Epub ahead of print. PMID: 36495078.
- Walter E, Pinquart M. How Effective Are Neurocognitive disorder Caregiver Interventions? An Updated Comprehensive Meta-Analysis. Gerontologist. 2020;60(8):609–619. https://doi.org/10.1093/geront/gnz118. PMID: 33226434.
- Baker R, Camosso-Stefinovic J, Gillies C, Shaw EJ, Cheater F, Flottorp S, Robertson N, Wensing M, Fiander M, Eccles MP, Godycki-Cwirko M, van Lieshout J, Jäger C. Tailored interventions to address determinants of practice. Cochrane Database Syst Rev. 2015;2015(4):CD005470. https://doi.org/10.1002/1465185 8.CD005470.pub3. PMID: 25923419; PMCID: PMC7271646.
- Skivington K, Matthews L, Simpson SA, Craig P, Baird J, Blazeby JM, Boyd KA, Craig N, French DP, McIntosh E, Petticrew M, Rycroft-Malone J, White M, Moore L. A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance. BMJ. 2021;374:n2061. ht tps://doi.org/10.1136/bmj.n2061. PMID: 34593508; PMCID: PMC8482308.
- Cohen SA, Ahmed N, Brown MJ, Meucci MR, Greaney ML. Rural-urban differences in informal caregiving and health-related quality of life. J Rural Health. 2022;38(2):442–56. https://doi.org/10.1111/jrh.12581. Epub 2021 May 6. PMID: 33956360.
- INSEE. La ruralité en Centre-Val de Loire. Novembre 2021:1–8. Available on: ht tps://www.insee.fr/fr/statistiques/fichier/5763776/ce\_dp\_2021\_fiche\_rural.p df
- Teel CS. Rural practitioners' experiences in dementia diagnosis and treatment. Aging Ment Health. 2004;8(5):422-9. https://doi.org/10.1080/1360786041000 1725018. PMID: 15511740.

### Publisher's note

Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.