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Maud Hevink¹  | Claire Wolfs¹ | Rudolf Ponds^{1,2}  | Shelley Doucet³  |
Carrie McAiney⁴  | Isabelle Vedel⁵  | Maria Maćkowiak⁶  |
Joanna Rymaszewska⁶  | Greta Rait⁷  | Louise Robinson⁸  | Marie Poole⁸  |
Meredith Gresham⁹  | Yun-Hee Jeon¹⁰  | Lyn Phillipson¹¹  | Lee-Fay Low¹²  |
Henry Brodaty⁹  | Marjolein de Vugt¹  | Frans Verhey¹ 

¹Department of Psychiatry and Neuropsychology, School for Mental Health and Neuroscience (MHeNS), Alzheimer Centre Limburg, Maastricht University, Maastricht, The Netherlands

²Department of Medical Psychology, Amsterdam UMC Location VUmc, Amsterdam, The Netherlands

³Department of Nursing and Health Sciences, The Centre for Research in Integrated Care, University of New Brunswick, Saint John, New Brunswick, Canada

⁴School of Public Health Sciences, University of Waterloo and Schlegel-UW Research Institute for Aging, Waterloo, Ontario, Canada

⁵Department of Family Medicine, McGill University, and Lady Davis Institute for Medical Research, and Jewish General Hospital, Montreal, Quebec, Canada

⁶Department of Psychiatry, Wrocław Medical University, Wrocław, Poland

⁷Department of Primary Care and Population Health, Institute of Epidemiology and Health Care, University College London, London, UK

⁸Population Health Sciences Institute, Newcastle University, Newcastle upon Tyne, UK

⁹Centre for Healthy Brain Ageing, Discipline of Psychiatry and Mental Health, University of New South Wales, Sydney, New South Wales, Australia

¹⁰Susan Wakil School of Nursing and Midwifery, Faculty of Medicine and Health, The University of Sydney, Sydney, New South Wales, Australia

¹¹School of Health and Society, Faculty of Arts, Social Sciences and Humanities, University of Wollongong, Wollongong, New South Wales, Australia

¹²Faculty of Medicine and Health, University of Sydney, Sydney, New South Wales, Australia

Correspondence

Claire Wolfs, Department of Psychiatry and Neuropsychology, School for Mental Health and Neuroscience (MHeNS), Alzheimer Centre Limburg, Maastricht University, Maastricht, The Netherlands.

Email: claire.wolfs@maastrichtuniversity.nl

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Abstract

Objectives: The study aims to describe people with dementia and informal caregivers' respective experiences of support after diagnosis and compares these experiences. Additionally, we determine how people with dementia and informal caregivers who are satisfied with support differ from those dissatisfied.

Methods: A cross-sectional survey study in Australia, Canada, the Netherlands, Poland, and United Kingdom was carried out to examine people with dementia and informal caregivers experience with support (satisfaction with information, access to care, health literacy, and confidence in ability to live well with dementia). The separate surveys contained closed questions. Analysis consisted of descriptive statistics and Chi-square tests.

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Results: Ninety people with dementia and 300 informal caregivers participated, and 69% of people with dementia and 67% of informal caregivers said support after diagnosis helped them deal more efficiently with their concerns. Up to one-third of people with dementia and informal caregivers were dissatisfied with information about management, prognosis, and strategies for living positively. Few people with dementia (22%) and informal caregivers (35%) received a care plan. People with dementia were more often satisfied with information, had more often confidence in their ability to live well with dementia, and were less often satisfied with access to care compared to informal caregivers. Informal caregivers who were satisfied with support were more satisfied with information and access to care compared to informal caregivers not satisfied with support.

Conclusions: Experience of dementia support can be improved and people with dementia and informal caregiver differ in their experiences of support.

KEYWORDS

dementia, informal caregivers, international, post-diagnostic support, surveys

Key points

- Support for people with dementia and their informal caregivers can be improved.
- Roughly one-third of people with dementia and informal caregivers indicated that support after the dementia diagnosis had not helped them deal more efficiently with their concerns.
- People with dementia tend to be more satisfied with information and advice and have greater confidence in their ability to live well with dementia compared to informal caregivers.
- Informal caregivers report better health literacy and satisfaction with access to care compared to people with dementia
- Information provision for people with dementia and informal caregivers should be tailored, accessible, evidence-based and it should include a range of strategies individuals can choose to assist them to live positively with dementia.

1 | INTRODUCTION

Dementia is a progressive disease and consequently, people become increasingly dependent on support and care of others. Recent literature emphasizes the need for high-quality care for people with dementia and their informal caregivers as a means of maintaining or increasing quality of life and promoting the concept of living well with dementia.^{1,2} This is in line with the World Health Organization's global action plan on dementia, which states people should receive care aligned with their wishes and preferences.³

Post-diagnostic support is defined as a system of holistic, integrated continuing care in the context of declining function and increasing needs of informal caregivers.⁴ It is an important means to live well with dementia and covers a broad range of services and information that help people with dementia and informal caregivers, both immediately after diagnosis and going forward. Ideally, support is tailored, ongoing, and flexibly adapts to the changing needs as dementia progresses.⁵ According to the National Health Service in the United Kingdom (UK), a goal of early support is providing information and support to access formal support soon after diagnosis.⁶

Support soon after diagnosis is important, as informal caregivers who receive it will cope better over time compared to those that do not.⁷ Early support can potentially increase people with dementia and informal caregivers' confidence in identifying and accessing community support.⁸ However, as highlighted by the informal caregiver need paradox, when caregivers had little acceptance of their role as informal caregiver, they are not open to early support.⁹ At the same time, informal caregivers retrospectively consider that early support tailored to personal needs would have been helpful in accepting dementia, thus highlighting its importance.

Despite its' importance, support often fails to adequately meet the needs of people with dementia and informal caregivers.^{10,11} People with dementia report several unmet needs, including having sufficient daytime activities, support to address psychological distress and physical health issues.¹²⁻¹⁴ Additionally, they lack information on dementia and feel emotionally overwhelmed.¹⁵ Informal caregivers also reported a variety of needs including support to help them accept and adapt to their caregiving role.¹⁶ Unsurprisingly, informal caregivers need support to maintain their own well-being.¹² People with dementia and informal caregivers prioritize

different aspects of support. People with dementia prioritize support that maintains or improves quality of life, while informal caregivers prioritize support that helps people with dementia to maintain cognitive functions, their ability to perform activities of daily living and delay disease progression.¹⁷ It is important to tailor support to wishes and needs of people with dementia and informal caregivers.

People with dementia and informal caregivers experience barriers when accessing early support straight after diagnosis¹⁵ such as low health literacy, unfamiliarity with available support options or not knowing how to access them.^{18–21} However, even when informal caregivers are familiar with available support, they are not always open to receiving it in the initial stage, because they feel support is not necessary yet, have difficulty describing their needs, or asking for help.^{9,22}

Despite the body of research, it remains unclear how support helps people with dementia and informal caregivers live well with dementia, and what differentiates those satisfied with support from those less satisfied with support. Knowledge of experiences of early support and its effects on people with dementia and informal caregivers that considers possible differences between their respective experiences of support is needed. This could assist in identifying ways to further improve experiences of support and ultimately reduce unmet needs. The aims of the present study are to (a) describe people with dementia and informal caregivers' experience of support in Australia, Canada, the Netherlands, Poland, and the UK; (b) compare these experiences of support among people with dementia and informal caregivers; (c) determine what factors distinguish those people with dementia and informal caregivers who are satisfied with support from those who are not satisfied with support.

2 | MATERIALS AND METHODS

This cross-sectional survey study among people with dementia and informal caregivers examines their experiences with support. The study is part of the international Co-Designing Dementia Diagnosis and Post-Diagnostic Support project, which focuses on improving support for people with dementia and informal caregivers.

2.1 | Participants

Participants were recruited in Australia, Canada (Ontario, Quebec and New Brunswick), the Netherlands, Poland, and the UK. Each country aimed to include 50 people with dementia and 50 informal caregivers. A broad range of recruitment strategies was used and is described in more detail in Appendix A. People with dementia were eligible if they had received a dementia diagnosis in the previous 24 months and could provide informed consent. Informal caregivers were eligible if they provided self-identified support to a person with dementia. People with dementia and informal caregivers did not have to be a dyad to participate.

2.2 | Procedures

Each country obtained ethical approval. The study was executed according to the Helsinki Declaration.²³ Researchers provided potential participants with study information and they could be contacted in case of additional questions. Postal surveys obtained written informed consent before participation. In online surveys, participants provided written informed consent or ticked a box prior to starting the survey that acted as consent, this was dependent on the country's ethical requirements.

Data collection took place in 2020 (January–July). Surveys were anonymously completed on paper or online, depending on participant capabilities and preferences. People with dementia could be assisted by a family member or researcher if needed. Online surveys were distributed via online survey tools (Google Form, LimeSurvey, RedCAP, and Qualtrics); in accordance with ethical requirements in each country. Codebooks assisted with consistent data collection and analysis across countries.

2.3 | Surveys

The research team, including one person with dementia, identified important topics and developed two surveys—one for people with dementia and one for informal caregivers. Preliminary surveys were tested by five people with dementia and five informal caregivers per country. The surveys were adapted and truncated to improve participant understanding and engagement. The surveys which were developed in English and translated into French, Dutch, and Polish (Appendix B).

The surveys took approximately 30 min to complete. Table 1 shows the topics. Each section included brief instructions on how to answer the items. Questions were single-choice questions and included an '*I don't know*' option. In the surveys, the term 'care plan' was defined as 'a written plan about your health and social care needs relating to dementia, the treatments and services to meet those needs, and who is providing them'. The overarching term 'experiences with support' pertained to experiences and satisfaction with information and advice, health literacy and access to support, and confidence in their ability to live well with dementia.

2.4 | Statistical analysis

Statistical Package for the Social Science (SPSS) version 25 was used for statistical analyses. Each country combined online survey data with a pre-formatted SPSS file that contained manually entered data from postal surveys. The primary author merged data from all countries.

Descriptive statistics were applied to demographic characteristics, and experiences and satisfaction with support of people with dementia and informal caregivers. Percentages of *strongly agree*, *neither disagree nor agree* and *strongly disagree* were examined for

statements regarding our three domains of support. Answer options 'not applicable' and 'I don't know' were excluded from the analysis as exact reasoning behind these options was unknown (participants did not receive this type of support, did not remember receiving it, or did not have an opinion). Appendix C provides an overview of excluded data. Chi-square tests compared people with dementia and informal caregivers on ordinal data on information and advice, access to support, and confidence in the ability to live well with dementia. Additionally, Chi-square tests compared those people with dementia and informal caregivers who were satisfied with support with those who were not. Satisfaction with support was based on the question "Has the support after the diagnosis helped you deal more effectively with your concerns?", and was defined as the answers "Yes, it helped a great deal" and "Yes, it helped somewhat". If sample sizes were too small to justify Chi-square tests (expected count <5), descriptive statistics (% satisfaction) were used. Significance levels were set at 0.05.

3 | RESULTS

Ninety-one people with dementia completed the survey in Australia ($n = 23$), Canada ($n = 4$), the Netherlands ($n = 23$), Poland ($n = 36$), and the UK ($n = 5$). Three hundred informal caregivers completed the survey in Australia ($n = 59$), Canada ($n = 49$), the Netherlands ($n = 134$), Poland ($n = 49$), and the UK ($n = 9$). The majority of people with dementia (61%) and informal caregivers (85%) completed the survey online, and 67% of the people with dementia received help completing the survey. Table 2 reports demographic characteristics of participants. Informal caregivers most often provided care to their

parent (45%) or spouse (43%) and a substantial proportion (29%) experienced mental or physical difficulties. Some informal caregivers (11%) said they could not sustain the current level of care for more than 1 year.

3.1 | Overall satisfaction with support

Fifty-three people with dementia (69%) and 177 informal caregivers (67%) indicated that support after the dementia diagnosis helped them deal more efficiently with their concerns. Few people with dementia (22%) and informal caregivers (35%) indicated they received a care plan. People with dementia and informal caregivers did not significantly differ with respect to their overall satisfaction with support and having a care plan. Post-hoc analysis comparing people with young-onset dementia against those with late-onset dementia showed no significant difference in their respective experiences of support (Appendix D).

3.2 | Satisfaction with information and advice

Figure 1 displays information on satisfaction with information and advice. People with dementia and informal caregivers were most often satisfied with information provided about the diagnosis. People with dementia were least often satisfied with strategies provided on how to live a positive life with dementia. People with dementia and informal caregivers differed significantly in their satisfaction with information provided about dementia ($\chi^2 = 15.84$ $p < 0.001$) and

TABLE 1 Number of questions per section for survey for people with dementia and informal caregivers.

| Sections in survey | People with dementia | Informal caregivers |
|---|----------------------|---------------------|
| Demographic characteristics | 7 | 7 |
| Experiences and satisfaction with the diagnostic process | 12 | 11 |
| Quality of life | 1 | 1 |
| Experiences and satisfaction with post-diagnostic support | 9 | 16 |
| Role as caregiver ^a | - | 4 |
| COVID-19 ^b | 3 | 3 |
| Open question | 1 | 1 |

^aSection only presented in informal caregiver survey.

^bQuestions on the impact of COVID-19 were added shortly after data collection began.

TABLE 2 Demographic characteristics of people with dementia and informal caregivers.

| | People with dementia (N = 91) | Informal caregiver (N = 300) |
|--|-------------------------------|------------------------------|
| Age (range) | 48–93 | 22–94 |
| Gender (% female) | 54% | 71% |
| Cultural background (% Caucasian) | 96% | 94% |
| Lives with informal caregiver/person with dementia (%) | 66% | 47% |
| Has an informal caregiver/is the primary caregiver (%) | 76% | 83% |

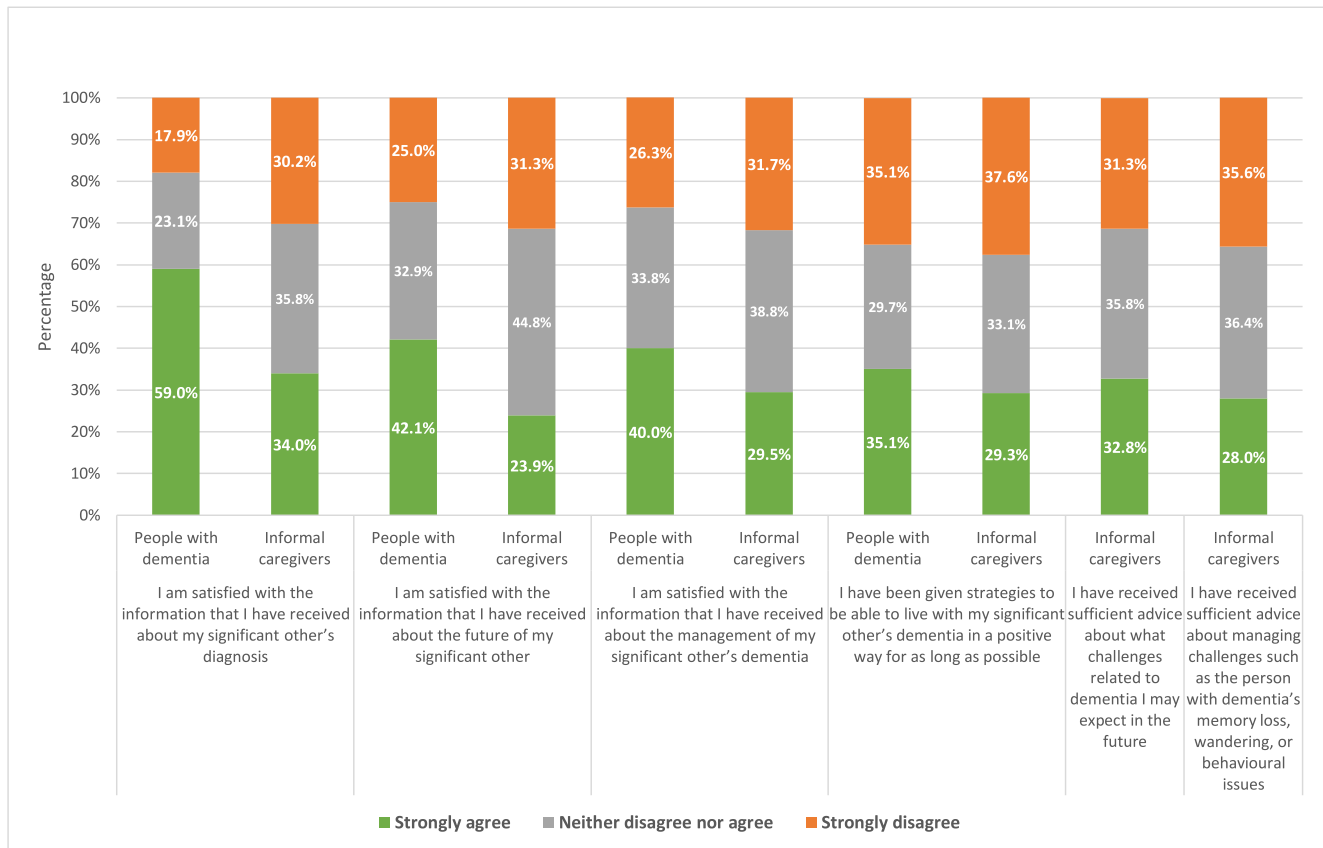


FIGURE 1 Satisfaction of people with dementia and informal caregivers with information and advice. Statements are reported as per informal caregiver survey. Some statements were presented to informal caregivers only.

satisfaction with information about the future with dementia ($\chi(2) = 9.83$, $p = 0.007$), with descriptive statistics indicating people with dementia were more often satisfied than informal caregivers.

A descriptive comparison revealed that people with dementia who find support helpful more often reported a higher degree of satisfaction with information and advice. For informal caregivers, overall support satisfaction was associated with satisfaction with information on the diagnosis ($\chi(2) = 25.31$, $p < 0.001$), information on the future of their loved one ($\chi(2) = 29.89$, $p < 0.001$), information on management of dementia ($\chi(2) = 39.49$, $p < 0.001$), the offering of strategies to live a positive life with dementia ($\chi(2) = 14.36$, $p < 0.001$), advice about dementia-related challenges ($\chi(2) = 52.02$, $p < 0.001$), and advice on managing dementia-related behavior ($\chi(2) = 44.50$, $p < 0.001$), with descriptive statistics indicating that informal caregivers who said support was helpful were more often satisfied with the available information and advice.

3.3 | Experiences with health literacy and accessing support

Figure 2 displays information on health literacy and access to support. The majority of people with dementia and informal caregivers expressed confidence to ask for professional help. People with dementia and informal caregivers differed significantly with regard to

the level of confidence to ask for professional help ($\chi(2) = 7.15$, $p = 0.028$) and their capabilities to find information on available support ($\chi(2) = 6.55$, $p = 0.038$), with descriptive statistics indicating people with dementia were more often dissatisfied than informal caregivers.

A descriptive comparison revealed that people with dementia who find support helpful more often had the confidence to ask for professional help (76% vs. 22%) compared with people with dementia who didn't find support helpful. For informal caregivers, overall support satisfaction was associated with the level of confidence to ask for professional help ($\chi(2) = 6.19$, $p = 0.045$), awareness of available services ($\chi(2) = 27.44$, $p < 0.001$), awareness of available service to provide support ($\chi(2) = 27.35$, $p < 0.001$), knowledge on accessing community services ($\chi(2) = 16.95$, $p < 0.001$), and knowledge on whom to turn to get answers ($\chi(2) = 32.14$, $p < 0.001$) with descriptive statistics indicating that informal caregivers who said support was helpful were more often health literate and had fewer problems in accessing support.

3.4 | Confidence in the ability to live well with dementia

Figure 3 displays information on the confidence of people with dementia and informal caregivers in their ability to live well with

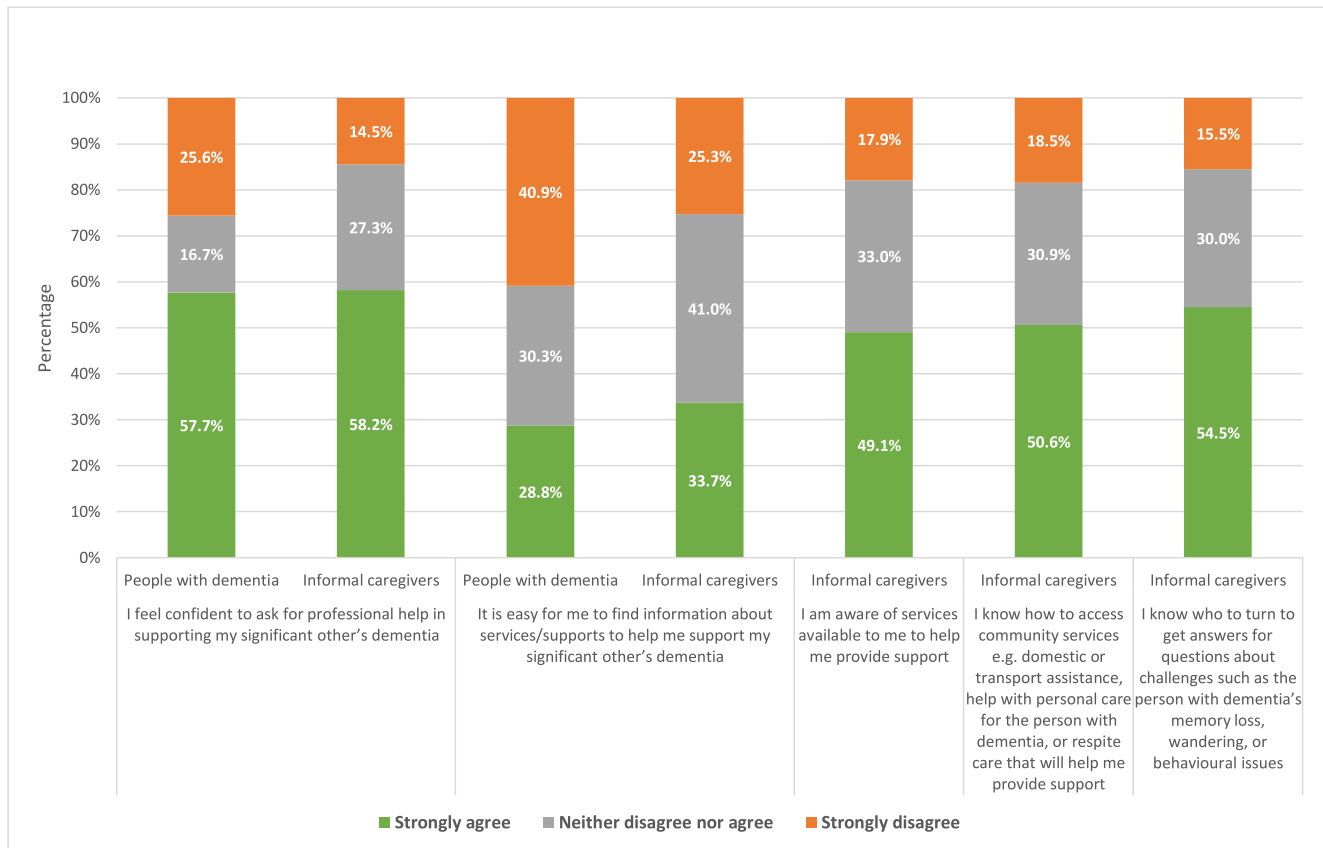


FIGURE 2 Experiences of people with dementia and informal caregivers with health literacy and access to support. Statements are reported as per informal caregiver survey. Some statements were presented to informal caregivers only.

dementia. People with dementia more often reported confidence in their ability to live a positive life with dementia as opposed to their ability to handle future changes. Informal caregivers more often expressed confidence in their ability to deal with the challenges of caregiving than confidence in their ability to manage dementia-related behaviours. People with dementia and informal caregivers differed significantly with regard to the level of confidence in a positive life with dementia ($\chi^2 = 8.56$ $p = 0.014$), with descriptive statistics indicating people with dementia were more confident in living well with dementia than informal caregivers.

A descriptive comparison revealed that people with dementia who find support helpful more often had confidence in their ability to handle future changes (53% vs. 13%). Informal caregivers who were satisfied with support did not significantly differ from those dissatisfied with support in confidence in their ability to live well with dementia.

4 | DISCUSSION

This study aimed to describe people with dementia and informal caregivers' experiences of support and compare their respective experiences. We highlight that although more than half of people with dementia and informal caregivers were satisfied with the

support received, there still was a significant proportion who indicated they were not satisfied with support. This is consistent with how patients with other neurodegenerative and life-threatening diseases such as cancer, perceive support.^{24,25}

We demonstrate moderate satisfaction rates on dementia-specific information for people with dementia and informal caregivers. Information is an important component of support and often the first support people access, these findings emphasize the need for improving information provision about dementia. Our findings are consistent with previous studies that showed people with dementia and informal caregivers perceive a lack of information upon diagnosis.^{15,26} Information and advice about managing behavioural issues are important in addressing unmet informal caregiver needs; however, our findings highlight that the majority are not satisfied with this type of information.²⁷ These results support findings by Steiner, Pierce²⁸ whereby informal caregivers indicated needing information on dementia-related behavioural changes.

Our results suggest information is not readily accessible to people with dementia and informal caregivers as health literacy and information-seeking preferences may play a vital role in access to information. Informal caregivers preferably receive information from their healthcare professional who knows them and is familiar with their needs and preferences and often expect them to direct toward trustworthy and relevant information.²⁶ At the same time, informal

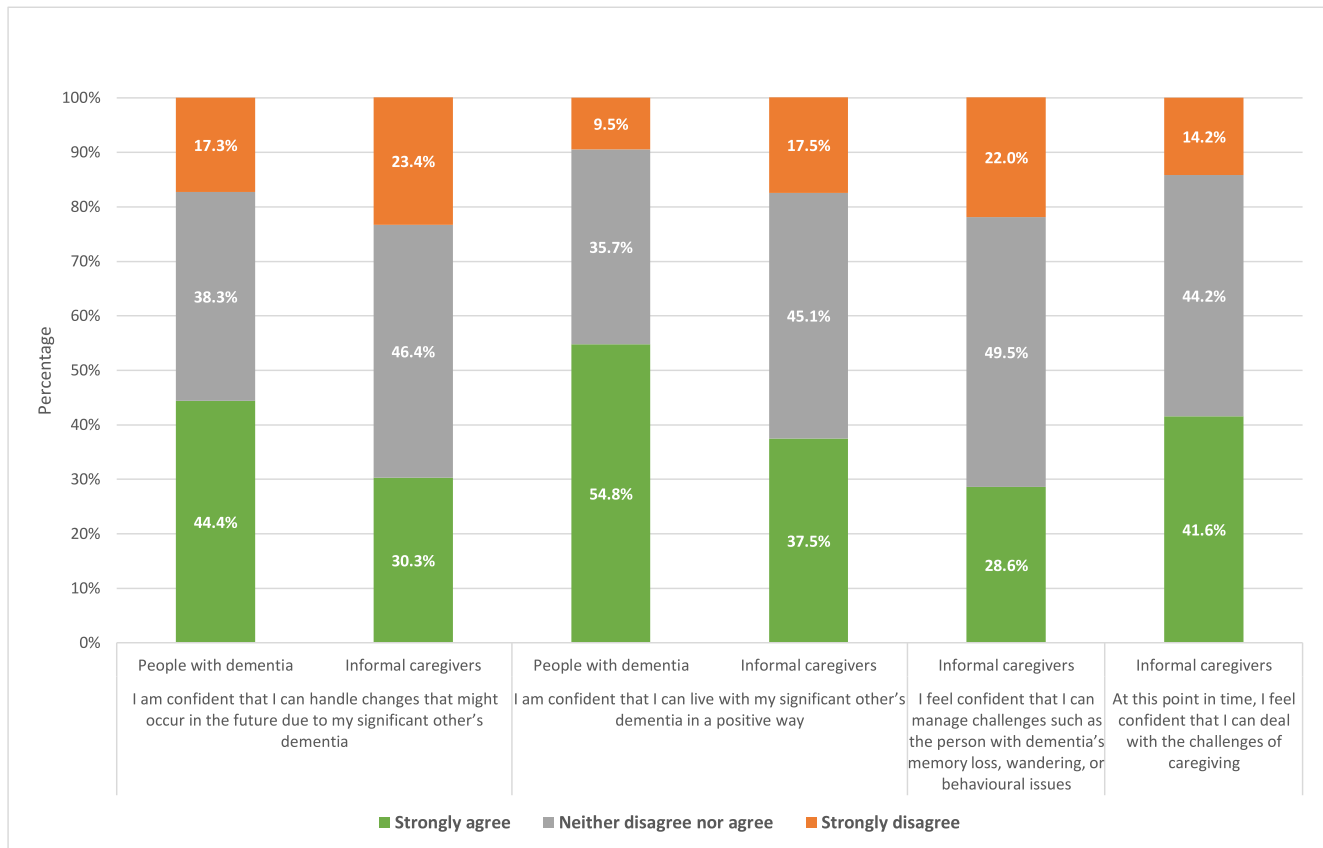


FIGURE 3 Confidence of people with dementia and informal caregivers in their ability to live well with dementia. Statements are reported as per informal caregiver survey. Some statements were presented to informal caregivers only.

caregivers perceive that healthcare providers sometimes lack dementia-specific knowledge, indicating that they are not the best accessible information source.²⁹ Additionally, informal caregivers report encountering several barriers when accessing information, such as not knowing where to find information or not being aware of the available information on support options.^{18,20} Additionally, our findings indicate that people with dementia may have even more difficulty accessing information than informal caregivers. Most information sources target informal caregivers.³⁰ Our findings reinforce the notion that current information is not fulfilling people with dementia's need for easily accessible information. There is a need for enhancing the connection between healthcare providers and accessible information sources as well as designing information specifically for people with dementia.

Information and access to information are often seen as a gateway to increasing or maintaining quality of life and confidence in their ability to live well with dementia. Despite moderately satisfactory rates of information after diagnosis, most people with dementia and informal caregivers expressed a lack of strategies to live a positive life. It is worth noting that less than half of informal caregivers are confident in their caregiving skills and fewer informal caregivers are confident in their abilities to handle dementia-related challenges. These findings tie into the low number of people who received a care plan to plan their future or manage dementia.

Providing people with strategies to live a positive life with dementia and a care plan could potentially increase their confidence in their ability to handle dementia or live a positive life. Our findings reinforce Quinn and Toms³¹ notion that early-stage support for informal caregivers is needed to help develop a more positive experience of caregiving, improve psychological health and prepare for future challenges, which may ultimately increase well-being. Positive health, including social health, can assist in promoting a more positive view of dementia and caregiving.³²

We demonstrate that people with dementia and informal caregivers differ in their experiences of support despite their overall satisfaction being rather similar. People with dementia tend to be more satisfied with information and advice and have greater confidence in their ability to live well with dementia while informal caregivers report better health literacy and satisfaction with access to care. This suggests that if we want to improve their respective experience of support, different aspects should be targeted for people with dementia and informal caregivers. People with dementia sometimes self-stigmatize in the early stages of dementia, making it harder to actively seek support due to fear of being stigmatized.³³ These findings suggest that people with dementia need to be empowered to ask for help and the provision of information on support should be tailored to people with dementia. However, more research is needed to elaborate on these initial findings.

Compared to people with dementia, informal caregivers are less satisfied with information and advice and are less confident in their ability to live well with dementia. Additionally, informal caregivers' confidence in their ability to live well with dementia is not associated with overall support satisfaction. These results suggest that information and advice could serve as a means to further increase overall satisfaction with support for informal caregivers. Increased overall satisfaction with support has the potential to improve quality of life and decrease caregiver burden as this has been associated with fewer unmet needs.³⁴ Numerous studies have also underpinned the importance of information provision for informal caregivers.^{27,35} Further studies should investigate whether there is a relationship between satisfaction with information and advice and informal caregivers' confidence in their ability to live well with dementia.

While most research focuses on informal caregivers' experiences and proxy reports of experiences of people with dementia, our study was unique by including both perspectives. We were able to demonstrate that their experiences do not always align. Our study has a rich data set as it collected data from five countries across three continents. We have successfully utilized online surveys, allowing us to continue data collection during the first wave of the COVID-19 pandemic, we maintained flexibility by offering postal surveys to those with limited digital skills.

Our sample primarily included people who had been diagnosed before the onset of the COVID-19 pandemic. After the data collection had started, we added questions on the impact of COVID-19 on dementia. We do not report on them as they fall outside the scope of this paper. However, it has been well documented that COVID-19 has had a negative effect on people with dementia and the support for them and informal caregivers.^{36,37}

This study encountered some limitations as COVID-19 impacted our study in several ways. Some countries had delays in securing ethical approval or trouble recruiting participants. In the UK, recruitment was completely paused for a while. Therefore, the number of people with dementia who participated was lower than initially expected. We were statistically unable to examine cross-country differences and caution is advised in terms of generalizability of our findings, in particular those findings incorporating data from people with dementia. In addition, we planned to recruit an ethnically diverse sample. The majority of our sample had a Caucasian background as we were limited in our recruitment strategies due to COVID-19. Future research should take into account the recent recommendations on the inclusion of minority populations in dementia research by Brijnath, Croy.³⁸

A concise survey was created to minimize participant distress. Potentially relevant information might not have been included such as dementia severity. We acknowledge support needs and thus experiences of support may change over time as dementia severity increases.¹⁶ The inclusion criteria aimed to include people with mild to moderate dementia, but it cannot be guaranteed that all participants had mild to moderate dementia. Additionally, our analysis is unable to provide the strength of significant results. Future research

should consider including dementia severity as a measure and the option of multivariate tests to provide detailed and in-depth information.

In summary, our findings imply that experiences of support for people with dementia and informal caregivers can be improved and that information should specifically address and distinguish between people with dementia and informal caregivers. Future research should focus on accessible online, evidence-based information that includes a range of strategies individuals can choose to adopt that can assist them to live positively with dementia and has the potential to improve quality of life.³⁹ Having this information available online is of particular value as Internet searches are already part of current information-seeking behaviour among people with dementia and informal caregivers.⁴⁰ It should take a positive approach to allow people with dementia and informal caregivers to improve their attitude toward a future with dementia.

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CONFLICT OF INTEREST STATEMENT

The authors declare that there is no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ETHICS STATEMENT

The study received ethical approval by the local research council in each country.

ORCID

Maud Hevink  <https://orcid.org/0000-0001-9914-7341>
 Rudolf Ponds  <https://orcid.org/0000-0002-9748-4659>
 Shelley Doucet  <https://orcid.org/0000-0003-4420-8199>
 Carrie McAiney  <https://orcid.org/0000-0002-7864-344X>
 Isabelle Vedel  <https://orcid.org/0000-0002-6873-1681>
 Maria Maćkowiak  <https://orcid.org/0000-0003-4002-6902>
 Joanna Rymaszewska  <https://orcid.org/0000-0001-8985-3592>
 Greta Rait  <https://orcid.org/0000-0002-7216-7294>
 Louise Robinson  <https://orcid.org/0000-0003-0209-2503>
 Marie Poole  <https://orcid.org/0000-0001-8379-7462>
 Meredith Gresham  <https://orcid.org/0000-0002-8717-4964>
 Yun-Hee Jeon  <https://orcid.org/0000-0003-2031-9134>
 Lyn Phillipson  <https://orcid.org/0000-0003-2173-0291>
 Lee-Fay Low  <https://orcid.org/0000-0001-9283-3525>
 Henry Brodaty  <https://orcid.org/0000-0001-9487-6617>
 Marjolein de Vugt  <https://orcid.org/0000-0002-2113-4134>
 Frans Verhey  <https://orcid.org/0000-0002-8307-8406>

REFERENCES

- Martyr A, Nelis SM, Quinn C, et al. Living well with dementia: a systematic review and correlational meta-analysis of factors associated with quality of life, well-being and life satisfaction in people with dementia. *Psychol Med*. 2018;48(13):2130-2139. <https://doi.org/10.1017/S0033291718000405>
- Wong G, Knapp M. Should we move dementia research funding from a cure to its care? *Expert Rev Neurother*. 2020;20(4):303-305. <https://doi.org/10.1080/14737175.2020.1735364>
- Organization WH. Global Action Plan on the Public Health Response to Dementia 2017-2025; 2017.
- Prince M, Comas-Herrera A, Knapp M, Guerchet M, Karagiannidou M. World Alzheimer Report 2016: Improving Healthcare for People Living with Dementia: Coverage, Quality and Costs Now and in the Future; 2016.
- Kokorelias KM, Gignac MAM, Naglie G, et al. A grounded theory study to identify caregiving phases and support needs across the Alzheimer's disease trajectory. *Disabil Rehabil*. 2020;44(7):1-10. <https://doi.org/10.1080/09638288.2020.1788655>
- Fife N. Dementia Post Diagnostic Support Service [Webpage]; 2020. [updated 08 October 2020; cited 2022 07-02-2022]. Dementia Post Diagnostic Support Service]. <https://www.nhsfife.org/services/all-services/dementia/dementia-post-diagnostic-support-service/>
- Brooker D, Dröes R.-M, Evans S. Framing Outcomes of Post-diagnostic Psychosocial Interventions in Dementia: The Adaptation-Coping Model and Adjusting to Change; 2017. <http://www.emeraldinsight.com/doi/abs/10.1108/WWOP-12-2016-0039%20Working%20with%20Older%20People>
- Stockwell-Smith G, Moyle W, Kellett U. The impact of early psychosocial intervention on self-efficacy of care recipient/carer dyads living with early-stage dementia—a mixed-methods study. *J Adv Nurs*. 2018;74(9):2167-2180. <https://doi.org/10.1111/jan.13710>
- Boots LM, Wolfs CA, Verhey FR, Kempen GI, de Vugt ME. Qualitative study on needs and wishes of early-stage dementia caregivers: the paradox between needing and accepting help. *Int Psychogeriatr*. 2015;27(6):927-936. <https://doi.org/10.1017/s1041610214002804>
- Francis N, Hanna P. Informal carer experiences of UK dementia services-A systematic review. *J Psychiatr Ment Health Nurs*. 2020; 29(1):116-129. <https://doi.org/10.1111/jpm.12698>
- Laakkonen M.-L, Raivio MM, Eloniemi-Sulkava U, et al. How do elderly spouse care givers of people with Alzheimer disease experience the disclosure of dementia diagnosis and subsequent care? *J Med Ethics*. 2008;34(6):427-430. <https://doi.org/10.1136/jme.2007.021956>
- Bamford C, Wheatley A, Brunskill G, et al. Key components of post-diagnostic support for people with dementia and their carers: a qualitative study. *PLoS One*. 2021;16(12):e0260506. <https://doi.org/10.1371/journal.pone.0260506>
- Miranda-Castillo C, Woods B, Galboda K, Oomman S, Olojugba C, Orrell M. Unmet needs, quality of life and support networks of people with dementia living at home. *Health Qual Life Outcomes*. 2010;8(1):132. <https://doi.org/10.1186/1477-7525-8-132>
- Miranda-Castillo C, Woods B, Orrell M. People with dementia living alone: what are their needs and what kind of support are they receiving? *Int Psychogeriatrics*. 2010;22(4):607-617. <https://doi.org/10.1017/S104161021000013X>
- Stephan A, Bieber A, Hopper L, et al. Barriers and facilitators to the access to and use of formal dementia care: findings of a focus group study with people with dementia, informal carers and health and social care professionals in eight European countries. *BMC Geriatr*. 2018;18(1):131. <https://doi.org/10.1186/s12877-018-0816-1>
- de Vugt ME, Verhey FRJ. The impact of early dementia diagnosis and intervention on informal caregivers. *Prog Neurobiol*. 2013;110:54-62. <https://doi.org/10.1016/j.pneurobio.2013.04.005>
- Maki Y, Ohashi W, Hattori H, Suzuki T. Discrepancies in persons with dementia, family members, and physician perspectives of dementia treatment: a descriptive study. *Psychogeriatrics*. 2021;21(4):596-604. <https://doi.org/10.1111/psyg.12710>
- Kerpershoek L, Wolfs C, Verhey F, et al. Optimizing access to and use of formal dementia care: qualitative findings from the European Actifcare study. *Health Soc Care Community*. 2019;27(5):e814-e23. <https://doi.org/10.1111/hsc.12804>
- Kerpershoek L, de Vugt M, Wolfs C, et al. Access to timely formal dementia care in Europe: protocol of the Actifcare (ACcess to Timely Formal Care) study. *BMC Health Serv Res*. 2016;16(1):423. <https://doi.org/10.1186/s12913-016-1672-3>
- Zwaanswijk M, Peeters JM, van Beek AP, Meerveld JH, Francke AL. Informal caregivers of people with dementia: problems, needs and support in the initial stage and in subsequent stages of dementia: a questionnaire survey. *Open Nurs J*. 2013;7:6-13. <https://doi.org/10.2174/1874434601307010006>
- Górska S, Forsyth K, Irvine L, et al. Service-related needs of older people with dementia: perspectives of service users and their unpaid carers. *Int Psychogeriatrics*. 2013;25(7):1107-1114. <https://doi.org/10.1017/S1041610213000343>
- Dam AEH, Boots LMM, van Boxtel MPJ, Verhey FRJ, de Vugt ME. A mismatch between supply and demand of social support in dementia care: a qualitative study on the perspectives of spousal caregivers and their social network members. *Int Psychogeriatrics*. 2018;30(6):881-892. <https://doi.org/10.1017/S1041610217000898>
- World Medical A. World Medical Association Declaration of Helsinki. Ethical principles for medical research involving human subjects. *Bull World Health Organ*. 2001;79(4):373-374.
- Miele G, Lavorgna L, De Mercanti SF, et al. Source of medical information and behavioral seeking patterns in patients affected with Friedreich's ataxia and their caregivers: a survey study. *Neurol Sci*. 2022;43(5):3223-3229. <https://doi.org/10.1007/s10072-021-05738-6>
- Martins JCA. Patients' satisfaction with information on disease and morbidity. *Rev Latino-Am Enferm*. 2009;17(3):335-340. <https://doi.org/10.1590/s0104-11692009000300009>
- Peterson K, Hahn H, Lee AJ, Madison CA, Atri A. In the Information Age, do dementia caregivers get the information they need? Semi-

- structured interviews to determine informal caregivers' education needs, barriers, and preferences. *BMC Geriatr.* 2016;16(1):164. <https://doi.org/10.1186/s12877-016-0338-7>
27. Queluz FNFR, Kervin E, Wozney L, Fancey P, McGrath PJ, Keefe J. Understanding the needs of caregivers of persons with dementia: a scoping review. *Int Psychogeriatrics.* 2020;32(1):35-52. <https://doi.org/10.1017/S1041610219000243>
 28. Steiner V, Pierce LL, Salvador D. Information needs of family caregivers of people with dementia. *Rehabil Nurs.* 2016;41(3):162-169. <https://doi.org/10.1002/rnj.214>
 29. Allen F, Cain R, Meyer C. Seeking relational information sources in the digital age: a study into information source preferences amongst family and friends of those with dementia. *Dementia.* 2018;19(3):766-785. <https://doi.org/10.1177/1471301218786568>
 30. Lauriks S, Reinersmann A, Van der Roest HG, et al. Review of ICT-based services for identified unmet needs in people with dementia. *Ageing Res Rev.* 2007;6(3):223-246. <https://doi.org/10.1016/j.arr.2007.07.002>
 31. Quinn C, Toms G. Influence of positive aspects of dementia caregiving on caregivers' well-being: a systematic review. *Gerontologist.* 2019;59(5):e584-e96. <https://doi.org/10.1093/geront/gny168>
 32. Huber M, Knottnerus JA, Green L, et al. How should we define health? *BMJ.* 2011;343(jul26 2):d4163. <https://doi.org/10.1136/bmj.d4163>
 33. Lohmeyer JL, Alpinar-Sencan Z, Schicklanz S. Attitudes towards prediction and early diagnosis of late-onset dementia: a comparison of tested persons and family caregivers. *Aging Ment Health.* 2021;25(5):832-843. <https://doi.org/10.1080/13607863.2020.1727851>
 34. Park M, Choi S, Lee SJ, et al. The roles of unmet needs and formal support in the caregiving satisfaction and caregiving burden of family caregivers for persons with dementia. *Int Psychogeriatr.* 2018;30(4):557-567. <https://doi.org/10.1017/s104161021700196x>
 35. Ringer TJ, Wong-Pack M, Miller P, et al. Understanding the educational and support needs of informal care-givers of people with dementia attending an outpatient geriatric assessment clinic. *Ageing Soc.* 2020;40(1):205-228. <https://doi.org/10.1017/S0144686X18000971>
 36. Numbers K, Brodaty H. The effects of the COVID-19 pandemic on people with dementia. *Nat Rev Neurol.* 2021;17(2):69-70. <https://doi.org/10.1038/s41582-020-00450-z>
 37. Wheatley A, Poole M, Robinson L. 211 - Changes to post-diagnostic dementia support in England and Wales during the COVID-19 pandemic. *Int Psychogeriatrics.* 2021;33(S1):13. <https://doi.org/10.1017/S1041610221001447>
 38. Brijnath B, Croy S, Sabates J, et al. Including ethnic minorities in dementia research: recommendations from a scoping review. *Alzheimer's and Dementia: Translational Research & Clinical Interventions.* 2022;8(1):e12222. <https://doi.org/10.1002/trc2.12222>
 39. Corbett A, Stevens J, Aarsland D, et al. Systematic review of services providing information and/or advice to people with dementia and/or their caregivers. *Int J Geriatr Psychiatry.* 2012;27(6):628-636. <https://doi.org/10.1002/gps.2762>
 40. Soong A, Au ST, Kyaw BM, Theng YL, Tudor Car L. Information needs and information seeking behaviour of people with dementia and their non-professional caregivers: a scoping review. *BMC Geriatr.* 2020;20(1):61. <https://doi.org/10.1186/s12877-020-1454-y>

SUPPORTING INFORMATION

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

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