

RESEARCH ARTICLE

Persons with dementia and informal caregivers prioritizing care: A mixed-methods study

Joost D. Wammes¹ | Nanon H. M. Labrie² | George O. Agogo³ | Joan K. Monin⁴ |
 Esther W. de Bekker-Grob^{5,6} | Janet L. MacNeil Vroomen¹

¹ Department of Internal Medicine, Section of Geriatric Medicine, Amsterdam Public Health Research Institute, Amsterdam UMC, University of Amsterdam, Amsterdam, The Netherlands

² Athena Institute, Vrije Universiteit Amsterdam, Amsterdam, The Netherlands

³ Center for Disease Control and Prevention (CDC), Village Market, Nairobi, Kenya

⁴ Department of Social and Behavioral Sciences, Yale School of Public Health, New Haven, Connecticut, USA

⁵ Erasmus School of Health Policy & Management, Erasmus University Rotterdam, Rotterdam, The Netherlands

⁶ Erasmus Choice Modelling Centre, Erasmus University Rotterdam, Rotterdam, The Netherlands

Correspondence

Joost D. Wammes, Section Geriatrics, Internal Medicine, Amsterdam University Medical Center, Meibergdreef 9, 1105 AZ, Amsterdam, the Netherlands.

Email: j.d.wammes@amsterdamumc.nl

Funding information

Netherlands Organization for Health Research and Development (NWO-ZonMw), Grant/Award Number: 091.619.060; Ben Sajat Centrum (Grant Ministry of Health, Welfare and Sport), Grant/Award Number: 330428

Abstract

Introduction: More persons with dementia are residing in the community as many countries shift from residential care to home and community care. Although there are many forms of care and support available to avoid crisis situations and prolong community living, it remains unclear how these are valued by community-dwelling persons with dementia and their informal caregivers. Understanding perspectives of persons with dementia and informal caregivers on care characteristics is a vital step in valuing care services. This study aims to prioritize care characteristics for community-dwelling persons with dementia and informal caregivers with the use of an innovative mixed-methods approach.

Methods: Six mixed focus groups were conducted in The Netherlands with persons with dementia ($n = 23$) and informal caregivers ($n = 20$), including a quantitative ranking exercise that prioritized seven care and support characteristics from "most important" to "least important," followed by a group discussion about the prioritization. Audio recordings were transcribed and analyzed using thematic analysis.

Results: The ranking exercise and discussion showed that persons with dementia favored in-home care, help with daily activities, and social activities, whereas informal caregivers favored social activities, information about dementia, navigating the health care system, and emotional support.

Discussion: Persons with dementia prioritized day-to-day activities, whereas informal caregivers preferred assistance with organizing care and coping with caregiving. This study created a method to capture the care preferences of persons with dementia and informal caregivers.

KEYWORDS

care preferences, dementia, health services, informal caregivers, mixed-methods study

1 | BACKGROUND

The number of persons with dementia in developed countries is estimated to nearly double to 14.3 million by 2050.¹ Dementia

is one of the most expensive conditions in the world, particularly toward the end-of-life.² The Netherlands is the highest spender on long-term care of all Organisation for Economic Cooperation and Development (OECD) countries.³ The overall costs of

This is an open access article under the terms of the [Creative Commons Attribution-NonCommercial-NoDerivs](https://creativecommons.org/licenses/by-nc-nd/4.0/) License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2021 The Authors. *Alzheimer's & Dementia: Translational Research & Clinical Interventions* published by Wiley Periodicals, Inc. on behalf of Alzheimer's Association.

dementia correspond to 10.3% of the total Dutch health care budget.⁴

In 2015, The Netherlands instituted various policies to reduce the costs of long-term care, including dementia care, by shifting residential care to home and community care.^{5,6} The literature is scant on whether these policies decreased nursing home stays and reduced costs, or if extended in-home stays triggered crises situations, leading to unplanned hospitalizations, institutionalization, and increased costs. To prevent crisis situations of community-dwelling persons with dementia, care services should be tailored to the needs of persons with dementia and their informal caregivers, because unmet needs are associated with lower quality of life^{7,8} and nursing home placement.^{9,10}

The Netherlands has many care services available for community-dwelling persons with dementia and their informal caregivers such as day care, home care, and case management. Peeters et al.¹¹ found that 92.6% of Dutch dementia informal caregivers received a form of professional support. However, 67.4% indicated that they needed more additional support. Van Der Roest et al.¹² found that the most frequent unmet care needs of persons with dementia and caregivers were information on dementia, psychological distress, and daytime activities. Utilization of dementia care services can depend on factors such as awareness of services, accessibility, affordability, and appropriateness to the user.¹³ There is an evidence gap on how persons with dementia and informal caregivers value available care services. Providing care packages that include care services that are valued by persons with dementia and their informal caregivers may help prolong community living and avoid crisis situations.

Unfortunately, persons with dementia are frequently excluded from policy development and evaluation because communication is often perceived as challenging. Recent evidence shows that persons with dementia can express their needs well.^{8,12} Other studies showed the importance of including persons with dementia in quality-of-life research.^{14,15} However, methods to include persons with dementia in research valuing care services are lacking. Understanding the perspectives of both persons with dementia and informal caregivers is a vital step in valuing care services. Based on the knowledge and methodology gap, this study aims to prioritize care characteristics for community-dwelling persons with dementia and informal caregivers using an innovative mixed-methods approach.

2 | METHODS

2.1 | Design

A focus group discussion including a quantitative ranking exercise was chosen to prioritize care characteristics for persons with dementia and their informal caregivers. Focus groups create an environment to share experiences that may trigger recall, which can be beneficial for persons with dementia to help overcome verbal communication and memory impairment.^{16,17} Persons with dementia and informal caregivers participated in mixed focus groups. This allowed participants to share and build on each other's knowledge. Informal caregivers could not partic-

RESEARCH IN CONTEXT

1. **Systematic review:** The authors reviewed literature primarily using PubMed. Several publications described care needs of community-dwelling persons with dementia and informal caregivers; however, no studies performed a qualitative study that prioritized care and support of community-dwelling persons with dementia and informal caregivers.
2. **Interpretation:** Our findings led to an in-depth understanding of how persons with dementia and informal caregivers prioritize care and support characteristics differently. Providing care packages that include preferred care and support options of persons with dementia and informal caregivers may prolong community living for persons with dementia.
3. **Future directions:** The use of this innovative approach enabled persons with dementia to be included in research and can be applied in other study settings. Preferences found in this study can inform a future larger study quantifying the care preference of community-dwelling persons with dementia and informal caregivers.

HIGHLIGHTS

- Focus groups can enable persons with dementia to prioritize care options
- Persons with dementia and informal caregivers prioritize care options differently
- Persons with dementia favor options that assist with day-to-day care
- Informal carers favor options that assist with organizing and coping with care

ipate in the same focus group as the person with dementia they cared for participated because we found in a previous interview study¹⁸ that caregivers tended to speak for the person they care for, which can impede free discussion. This study was designed using consolidated criteria for reporting qualitative research (COREQ) guidelines (Appendix A).¹⁹ An ethical waiver was obtained from the ethics committee at the Amsterdam University Medical Centre (W20_001 #20.025).

2.2 | Participant selection

We recruited participants through 5 day-care centers across The Netherlands and a dementia-support organization. Potential participants were informed about the aim of this study with an

information letter and were approached in-person, via telephone, or email by the staff of the day-care or dementia organization. Persons with Alzheimer's disease and other dementias (further referred to as persons with dementia) were eligible if they obtained a diagnosis of Alzheimer's disease or other dementias from a general practitioner or medical specialist (see appendix A), resided at home, were able to understand the consent process, and had the cognitive and verbal ability to participate in a group discussion. No specific test was used to examine cognitive functioning. Eligibility was assessed by the day-care organization staff based on their experiences with the persons with dementia. Informal caregivers were eligible if they were involved in caring for a person with dementia as a family member or friend.

2.3 | Setting

Six focus groups were conducted between December 2019 and March 2020 that lasted between 90 and 120 minutes. All focus groups were facilitated by JW, who has a background in physical therapy, experience in working with persons with cognitive impairments, and extensive experience in conducting focus groups. The focus groups took place at the recruitment locations to ensure a safe and familiar environment. A second researcher was present to record field notes. Participants answered a short questionnaire with demographic questions and signed informed consent before participating. In addition, we continuously reminded participants during the focus groups that they were participating in research to ensure participants remained informed of the principles of the research and were happy to continue to be involved in the focus group.²⁰

2.4 | Data collection

The content of the focus group was based on previously published work that investigated the views of informal caregivers and persons with dementia living at home about components of care they considered enhance living at home safely.¹⁸ From this article, we identified seven care characteristics that were important to maximize time at home for persons with dementia while avoiding crisis situations: (1) help with daily activities, (2) in-home care, (3) social activities, (4) emotional support, (5) information about dementia, (6) navigating the health system, and (7) in-home adaptations and tools. We created cards of each characteristic containing easy to understand visual and written information. We developed a focus group guide including three rounds to structure the focus group discussion: (1) an introduction round to explain the seven care characteristics using the cards; (2) persons with dementia and informal caregivers all received a set of the seven cards, which they used to individually rank the care characteristics on a ranking format from one "most important" to seven "least important"; and (3) discussion to understand the rationale of the ranking, and detect any other additional care characteristics (see focus group design in Appendix B). Piloting the focus group protocol and the ranking cards included discussions with informal caregivers, geriatricians, physiotherapists,

health economists, and dementia care support organization staff. All focus groups were audio recorded and transcribed verbatim.

2.5 | Data analysis

Transcripts were analyzed through thematic analysis as proposed by Braun and Clarke²¹ "to systematically identify, organize, and offer insights into patterns of meaning across the written data." A coding scheme was developed to deductively code the seven care characteristics. Inductive coding was used to understand the rationale behind the importance of each care characteristic. JW analyzed all transcripts, whereas NL and JMV independently analyzed the first three transcripts. Coding and analyses were discussed to enhance investigator triangulation. All data were analyzed using MAXQDA 2018 V.18.2.0.

To cross validate the qualitative results, sum scores of the ranking exercise per care characteristic were created. To determine if there was a group difference in the ranking between persons with dementia and informal caregivers a Mann-Whitney *U* test was used. SPSS version 25.0 was used for analysis.

3 | RESULTS

Background characteristics of the study participants are presented in Table 1.

3.1 | Ranking of care characteristics

No new care characteristics were added by participants to the seven initial care characteristics. Table 2 shows that persons with dementia significantly ranked all care characteristics differently compared to informal caregivers except for social activities. Persons with dementia found in-home care, help with daily activities, and social activities more important than the other care characteristics. Informal caregivers found social activities, information about dementia, navigating the health care system, and emotional support more important than the other care characteristics.

3.1.1 | In-home care

In-home care was ranked as most important by persons with dementia compared to the other care characteristics (see Table 2). Most informal caregivers and persons with dementia indicated that they received home care, which aided with activities of daily living such as washing, cleaning, or dressing. Often informal caregivers performed several of these care tasks themselves; however, due to the increased dementia symptoms of the person they cared for, whereas their own physical fitness decreased over time, assistance with activities of daily living was needed. Participants also indicated that the home care workers helped with medication compliance and safe drug intake because

TABLE 1 Characteristics of participants in frequencies

	Total	Group 1	Group 2	Group 3	Group 4	Group 5	Group 6
Total (N):	43	9	6	5	8	7	8
Persons with dementia (N):	23	2	3	2	5	3	8
Age (mean, SD):	80.6 (7.5)	70.5 (10.6)	84.0 (10.4)	81.5 (10.6)	80.4 (7.4)	79.0 (4.2)	82.2 (5.9)
Sex (N):							
Male	5	1	0	1	1	2	0
Female	18	1	3	1	4	1	8
Has informal caregiver	23	2	3	2	5	3	8
Informal caregivers (N):	20	7	3	3	3	4	0
Age (mean, SD) :	69.0 (11.1)	63.3 (10.1)	76.6 (13.7)	67.0 (13.1)	69.3 (3.2)	73.0 (13.3)	-
Sex (N):							
Male	5	2	1	1	1	0	-
Female	15	5	2	2	2	4	
Relation to persons with dementia (N):							
Partner	10	2	2	2	1	3	-
Child	7	5	0	0	1	1	
Relative	2	0	0	1	1	0	
Close friend	1	0	1	0	0	0	
Expect persons with dementia to stay home until (N):							
Death	10	2	2	2	2	2	-
Several more years from now	6	2	1	0	1	2	
Less than a year	2	1	0	1	0	0	
Already in care facility or deceased	2	2	0	0	0	0	

TABLE 2 Care characteristic ranking scores of persons with dementia and informal caregivers

Care characteristic	Persons with dementia (n = 23) sum of ranks ^a	Informal caregivers (n = 20) sum of ranks ^a	Group differences P-value ^b
In-home care	69	93	.002
Help with daily activities	70	92	.005
Social activities	71	53	.403
In-home adaptations	101	130	.009
Information about dementia	105	59	.015
Navigating the health care system	109	62	.017
Emotional support	116	71	.001

^aSum scores of ranked care characteristic, stratified for persons with dementia and informal caregivers. Lower scores indicate greater importance, and higher scores indicate lower importance. Results are ordered by the ranking scores of persons with dementia.

^bMann-Whitney *U* test: between-group differences in ranking of persons with dementia versus informal caregivers.

many persons with dementia had co-morbidities that required complex drug regimens.

“I receive home care for my husband because he is very heavy and does not cooperate with me when I try to wash him. When I need help, I can call, and they will come right away. I cannot wash him myself. If we did not receive this care, he could not live at home anymore. It would be too burdensome.”

(Informal caregiver, female, 84-years-old)

3.1.2 | Help with daily activities

Help with daily activities was ranked as important compared to other care characteristics by persons with dementia, whereas informal caregivers ranked it less important. Many participants indicated that they received assistance with instrumental activities of daily living (IADLs) like groceries, finances, and household tasks. Even though informal caregivers mentioned they performed many of these tasks themselves, they indicated that without regular assistance of a professional, the

person with dementia would not live at home. Older caregivers increasingly experienced performing IADLs as burdensome because their own health and physical fitness was decreasing over time. Furthermore, informal caregivers explained that assistance with IADLs enabled them to do other activities instead of only caring for the person with dementia. Persons with dementia who were living alone indicated that help with IADLs was indispensable to them because performing these tasks themselves was too difficult.

“Once a week I receive help with household activities. She cleans the toilet, vacuums, mops the floor, cleans the kitchen, and occasionally cleans the window and all other tasks that need to be done. I cannot perform those tasks anymore. It’s necessary that someone comes to help.”

(Person with dementia, female, 87-years-old)

3.1.3 | Social activities

Social activities were prioritized as the most important care characteristic by informal caregivers. Persons with dementia also frequently scored social activities as important. Preferences of social activities varied between formal social activities like day-care centers, and informal social activities like walking groups, gymnastics, and music-related groups. Social activities were found essential for persons with dementia because it helped structuring the day, stimulated active behavior, and provided social interactions with peers.

“What I enjoy the most is that we all get along well. [...] Yes, socializing with other people, you really get to know each other here.”

(Person with dementia, male, 82-years-old)

Day-care centers were helpful for informal caregivers because they provided a form of respite care. When the person with dementia was at the day-care center, informal caregivers could do other activities that would be impossible to do if the person they cared for was around. Furthermore, day-care centers provided valuable opportunities for care-recipient–informal caregiver involvement, and opportunities for caregiver peer support.

“I asked many times if my partner could come more often to the day care center so I have more time for myself. Sometimes I feel that I need to do something for myself without worrying about caring for him. Drinking a cup of coffee with a friend, simple things that I need recharge my batteries.”

(Informal caregiver, female, 63-years-old)

3.1.4 | In-home adaptations and tools

Informal caregivers and persons with dementia ranked in-home adaptation less important compared to other care characteristics. Participants noted that the need for in-home adaptations and tools increased over time, and was based on the physical condition of the person with dementia and living situation (e.g., residing in an age-friendly apartment). Most participants indicated that they already had home adaptations and used tools designed for persons with dementia. Installing age-friendly bathrooms, chairlifts, and grips in the house were needed to ensure safety and increase autonomy in daily living activities like toileting. Participants found tools like GPS systems and emergency buttons helpful, as they promoted independence for persons with dementia. Persons with dementia explained that using these tools increased their own feeling of safety.

“Grips and a GPS system so my husband can bike or walk on his own. I do not always have to accompany him because I can trace him. And of course, grips to prevent falls and an emergency button around his neck. I use them for him to remain independent.”

(Informal caregiver, female, 74-years-old)

3.1.5 | Information about dementia

Information about dementia was prioritized as important by informal caregivers and less important by persons with dementia, compared to other care characteristics. Persons with dementia found it important to know what the diagnose dementia entailed and how it develops over time. Informal caregivers viewed information as a requirement to care for someone with dementia. Because dementia symptoms increase over time, they indicated there was a continuous need for information provision. In the early stage, information was needed about diagnoses and symptom development. In the middle stage, information on receiving assistance with daily living, behavioral changes, care options, and coping strategies was needed. In the late stage, information was needed about extensive assistance with daily living and the procedures of transferring to a long-term care facility. Many participants indicated the preferred source of information was the case manager. Some participants indicated they followed a course about dementia offered by the day-care center or case manager.

“The moment after all the medical examinations, when they told me I have dementia, I wanted to know everything about it. What is dementia and what is going to happen with me? How does this develop over time?”

(Person with dementia, female, 63-years-old)

"I wanted to know everything about dementia. From there I can react on the things that need to be done. The moment you have knowledge you can act on it."

(Informal caregiver, male, 82-years-old)

3.1.6 | Navigating the health care system

Navigating the health care system was ranked as important by informal caregivers and less important by persons with dementia compared with other care characteristics. Navigating the health care system was mostly the responsibility of the informal caregiver. Informal caregivers stated that the health care system was too complex for a layperson, and difficulties were experienced with organizing care and financial matters such as reimbursements. Furthermore, many laws and regulations of dementia care changed regularly, which made navigating the health care system a persistent challenge.

"It is like jumping in the deep end. You have no clue where to start with arranging everything."

(Person with dementia, female, 72-years-old)

"It means that you have the tools to know where to go, for example where I have to go to arrange care. I think then you make a big step providing care for your partner. In my case, it eases my mind that if I cannot figure out what to do, there is someone there for you like a case manager."

(Informal caregiver, male, 78-years-old)

Participants indicated that their case manager helped solve some of their difficulties; however, the case manager was only available for a limited amount of time. Some participants contacted a telephone helpdesk of a patient federation, but the information provided was too general and not tailored to their local and personal situations.

3.1.7 | Emotional support

Informal caregivers prioritized emotional support, whereas persons with dementia ranked it less important. Persons with dementia mentioned that they needed emotional support when they received the dementia diagnosis and realized how dementia would influence their life. Informal caregivers expressed their need for emotional support because caring for a person with dementia was experienced as mentally challenging. They explained that emotional support helped to relieve care-related stress and provided recognition of their caregiver burden.

"I have the feeling that I am taking care of a little child. My wife was diagnosed two years ago. I continuously must care for her, keep her active, maintain her personal hygiene, prepare meals, you name it. She is also very stubborn which makes it very burdensome. It is important that there is someone who understands you, who tells you this is normal, and listens to your concerns."

(Informal caregiver, male, 69-years-old)

Informal caregivers and persons with dementia explained that they discussed most of their concerns with their case manager. However, the case manager's availability was often limited. Informal caregivers also appreciated peer support groups as a form of emotional support because it provided the opportunity to share their experiences with other caregivers. Furthermore, informal caregivers mentioned they contacted a telephone support number of a dementia patient federation. This was seen as useful because they received immediate counseling while staying anonymous; however, others experienced this as impersonal. Several informal caregivers visited a psychologist but felt that the professional was not specialized enough to support them with stressors specific to coping with dementia caregiving.

4 | DISCUSSION

This study created a mixed-methods approach that enabled persons with dementia and informal caregivers to prioritize care characteristics and elicit the rationale behind their ranking decisions. Persons with dementia favored care characteristics that assisted with day-to-day activities, whereas informal caregivers favored characteristics that assisted with organizing care and psychological support.

Our study showed that informal caregivers and persons with dementia have different preferences regarding care services. This is consistent with Monin et al.⁸ who found that perceptions on unmet needs differed between informal caregivers and persons with dementia. A possible explanation for differences in care preferences found in this study may be that organizing care is mainly done by the informal caregiver, and therefore the complexity and burden thereof is experienced by caregivers. In addition, informal caregivers have to cope with disruptive behaviors of the person with dementia, which is a known driver leading to caregiver distress.²² This is in line with the findings of Peeters et al.¹¹ who found that informal caregivers in The Netherlands report that they need additional support with organizing care and coping with caregiving. Regarding emotional support, caregivers mentioned that specific knowledge on dementia caregiving of the person providing the support is important to help with caregiver-related distress. Therefore, emotional support should be provided by professionals such as the case manager, or peer support groups, that are familiar with dementia caregiving. These findings imply that care packages for informal caregivers require services that address support with organization of care and caregiver related emotional support.

Informal caregivers might have scored support with day-to-day activities as less important because they viewed this as their own responsibility, which they wanted to perform themselves for as long as possible. Furthermore, most informal caregivers that participated in this study already received services that supported with day-to-day activities. However, performing ADL and IALD tasks were still perceived as burdensome, consuming most time of the day. Aging and decreased physical fitness of the informal caregiver contributed to higher care burden. These results are in accord with recent reports indicating that many informal caregivers are of older age themselves,^{23,24} and their decreasing health can impede caregiving abilities.²⁵ Services that are flexible and tailored to the needs of informal caregivers might leave room for activities other than caregiving, contributing to their lives in a meaningful way.

Similarities in care preferences between informal caregivers and persons with dementia were also found in this study. Both preferred social activities above most other care characteristics. Social activities especially in day-care centers were perceived beneficial for the informal caregiver (ie, reduce caregiver burden, information provision) and the care recipient (ie, increase of socialization, reduce passive behavior). These findings are consistent with previous studies that found that day-care centers were associated with reducing caregiver burden and improved the competence of caring by information provision.^{26,27} Moreover, higher perceived social support by dementia family caregivers is associated with higher levels of quality of life.²⁸

The ranking results of our study are comparable with those of Teahan et al.,²⁹ an Irish study establishing priorities of support services for dementia informal caregivers. They found that social activities in the form of day care was preferred over most other support services. Inconsistent with our results, Teahan et al.²⁹ found that services related to organizing and coordinating care were ranked as less important by informal caregivers. This discrepancy might be attributed to differences in health care systems, and available care services in each country.

Previous efforts quantifying care preferences of community-dwelling persons with dementia and informal caregivers used discrete choice experiments.^{30,31} Discrete choice experiments are a method commonly used to quantify a target groups' care preferences.³² Previous discrete choice experiments reported consistent with our study results that informal caregivers preferred respite care, emotional support, and information about coping with dementia while persons with dementia preferred social activities^{30,31} despite the discrete choices occurring in other countries that might have a different status quo to available care. However, these studies did not include detailed analysis of differences in care preferences between persons with dementia versus informal caregivers. Our study implies that considering group differences is needed as care preferences between persons with dementia and informal caregivers can vary. Furthermore, some care characteristics of the selection used in these previous studies like memory aids and relaxation therapy^{30,31} were found irrelevant by participants of our study, whereas other important care options like navigating the health care system were not included. This implies that care characteristics used in the quantification of care preferences should be selected

carefully, taking into consideration the context of participants. Preferences found in this study can inform a future larger study, quantifying care preferences of community-dwelling persons with dementia and informal caregivers.

The strengths of this study include being one of the first studies that included both persons with dementia and informal caregivers in a focus group design, ranking care characteristics. By providing an easy-to-understand focus group design using visual and written information to give guidance in communicating with persons with dementia, persons with dementia were enabled to formulate and express their own preferences. Our study had limitations. Because no cognitive screening tests were used, there was no information on participants' cognitive level. We expect that participants were more likely to be in early to mid-stage dementia than in late-stage dementia. Furthermore, we did not adjust for co-variables in the between-group analysis due to the small sample size. However, we created a template for other studies to use and further develop this ranking method.

This study showed that using an innovative approach of already existing research methods such as focus groups can enable persons with dementia to participate in research. More effort should be made to develop methods that include persons with dementia in research, incorporating their valuable ideas and preferences. Future studies could focus on quantifying preferences for dementia care and support on a larger scale. Research should consider that preferences are context dependent and differ between informal caregivers and persons with dementia.

ACKNOWLEDGMENTS

This work was supported by the Netherlands Organization for Health Research and Development (NWO-ZonMw Veni, 091.619.060), and the Ben Sajat Centrum (Ministry of Health, Welfare and Sport, Grant: 330428). The authors would like to thank all participants who invested their time. Furthermore, we would like to thank the health care professionals and the informal caregiver that we consulted in the design phase of the focus group.

DECLARATIONS OF INTEREST

None

REFERENCES

1. Prince M, Wimo A, Guerchet M, Ali GC, Wu YT, Prina M. *The global impact of dementia. An analysis of prevalence, incidence, cost and trends*. London: Alzheimer's Disease International (ADI); 2015.
2. Kelley AS, McGarry K, Gorges R, Skinner JS. The burden of health care costs for patients with dementia in the last 5 years of life. *Ann Int Med*. 2015;163:729-736.
3. Organisation for Economic Cooperation and Development. long-term care expenditures. 2017. Accessed: March 29, 2021. https://www.oecd-ilibrary.org/social-issues-migration-health/data/oecd-health-statistics_health-data-en
4. RIVM. kosten van ziekten 2017. RIVM statline 2017. Accessed: March 29, 2021. <https://statline.rivm.nl/#/RIVM/nl/dataset/50050NED/table?ts=1579773109899>
5. Maarse JA, Jeurissen PP. The policy and politics of the 2015 long-term care reform in the Netherlands. *Health Policy (Amsterdam, Netherlands)*. 2016;120:241-245.

6. Alders P, Schut FT. The 2015 long-term care reform in the Netherlands: getting the financial incentives right?. *Health Policy (Amsterdam, Netherlands)*. 2019;123:312-316.
7. MacNeil Vroomen J, Bosmans JE, van Hout HP, de Rooij SE. Reviewing the definition of crisis in dementia care. *BMC Geriatr*. 2013;13:10.
8. Monin JK, Jorgensen TD, MacNeil Vroomen JL. Self-Reports and caregivers' proxy reports of unmet needs of persons with dementia: implications for both partners' health-related quality of life. *Am J Geriatr Psychiatry*. 2019.
9. Black BS, Johnston D, Morrison A, Rabins PV, Lyketsos CG, Samus QM. Quality of life of community-residing persons with dementia based on self-rated and caregiver-rated measures. *Quality Life Res*. 2012;21:1379-1389.
10. Gaugler JE, Yu F, Krichbaum K, Wyman JF. Predictors of nursing home admission for persons with dementia. *Medical Care*. 2009;47:191-198.
11. Peeters JM, Van Beek AP, Meerveld JH, Spreeuwenberg PM, Francke AL. Informal caregivers of persons with dementia, their use of and needs for specific professional support: a survey of the National Dementia Programme. *BMC Nurs*. 2010;9:9.
12. van der Roest HG, Meiland FJ, Comijs HC, et al. What do community-dwelling people with dementia need? A survey of those who are known to care and welfare services. *Int Psychogeriatr*. 2009;21:949-965.
13. Ward-Griffin C, Hall J, Deforge R, et al. Dementia home care resources: how are we managing?. *J Aging Res*. 2012;2012:590724.
14. Bruvik FK, Ulstein ID, Ranhoff AH, Engedal K. The quality of life of people with dementia and their family carers. *Dement Geriatr Cogn Disord*. 2012;34:7-14.
15. Moyle W, Venturto L, Griffiths S, et al. Factors influencing quality of life for people with dementia: a qualitative perspective. *Aging & mental health*. 2011;15:970-977.
16. Bamford C, Bruce E. Successes and challenges in using focus groups with older people with dementia. London: Aging and Society; 2002. p. 139-64.
17. Hubbard G, Downs MG, Tester S. Including older people with dementia in research: challenges and strategies. *Aging Mental Health*. 2003;7:351-362.
18. Vullings IL NHM, Wammes JD, de Bekker-Grob EW, MacNeil-Vroomen JL. Important components for Dutch in-home care based on qualitative interviews with persons with dementia and informal caregivers. *Health Expect*. 2020.
19. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19:349-357.
20. McKeown J, Clarke A, Ingleton C, V Clacke. Using thematic analysis in psychology. *Qual Res Psychol*; 2006:77-101.
21. Braun v, Clacke V. Using thematic analysis in psychology. *Quali Res Psychol*. 2006: 77-101.
22. Cheng ST. Dementia Caregiver Burden: a Research Update and Critical Analysis. *Curr Psychiatry Rep*. 2017;19:64.
23. Alzheimer's Association. 2021 Alzheimer's Disease Facts and Figures. 2021;3:37-39.
24. Alzheimer Nederland. Factsheet cijfers en feiten over dementie. 2021. Accessed: April 10, 2021. <https://www.alzheimer-nederland.nl/factsheet-cijfers-en-feiten-over-dementie>
25. Potier F, Degryse JM, Bihin B, et al. Health and frailty among older spousal caregivers: an observational cohort study in Belgium. *BMC geriatrics*. 2018;18:291.
26. Tretteteiga S, Vatneb A, Rokstadab D. The influence of day care centres for people with dementia on family caregivers: an integrative review of the literature. 2015, *Aging and Mental Health*; 2015.
27. Gitlin LN, Reever K, Dennis MP, Mathieu E, Hauck WW. Enhancing quality of life of families who use adult day services: short- and long-term effects of the adult day services plus program. *Gerontologist*. 2006;46:630-639.
28. Pothiban L, Srirat C, Wongpakaran N, Pankong O. Quality of life and the associated factors among family caregivers of older people with dementia in Thailand. *Nurs Health Sci*. 2020;22:913-920.
29. Teahan A, Carney P, Cahill S, O'Shea E. Establishing priorities for psychosocial supports and services among family carers of people with dementia in Ireland. *Dementia*. 2021:1471301220984907. London.
30. Chester H, Clarkson P, Davies L, et al. People with dementia and carer preferences for home support services in early-stage dementia. *Aging Ment Health*. 2018;22:270-279.
31. Kampanellou E, Chester H, Davies L, et al. Carer preferences for home support services in later stage dementia. *Aging Ment Health*. 2019;23:60-68.
32. de Bekker-Grob EW, Ryan M, Gerard K. Discrete choice experiments in health economics: a review of the literature. *Health Eco*. 2012;21:145-172.

SUPPORTING INFORMATION

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

How to cite this article: Wammes JD, Labrie NHM, Agogo GO, Monin JK, de Bekker-Grob EW, MacNeil Vroomen JL. Persons with dementia and informal caregivers prioritizing care: A mixed-methods study. *Alzheimer's Dement*. 2021;7:e12193. <https://doi.org/10.1002/trc2.12193>