

# Empowering interventions for people living with dementia: A European survey

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## Abstract

**Aims:** We aim to identify existing empowerment interventions for people living with dementia and to explore which used interventions and projects are considered empowering and why.

**Design:** This was an online survey.

**Methods:** We conducted an online survey between May 2018 and July 2018 amongst professionals interested in dementia care in Europe. Interventions were clustered within the ecological model for health promotion. Reasons from respondents as to why they considered interventions to be empowering were analysed and structured according to a recently developed conceptual framework of empowerment for people living with dementia.

**Results:** Seventy-three respondents from 23 countries together mentioned 98 interventions or projects, of which 90 were unique. Interventions focused on the (inter) personal ( $n = 54$ ), organizational ( $n = 15$ ), communal ( $n = 6$ ) and societal ( $n = 15$ ) levels. A broad range of interventions were considered empowering, but no interventions were specifically developed for, nor aimed at, empowerment. Reasons as to why respondents considered these interventions as empowering fitted the framework's domains.

**Conclusion:** This European survey provides insights into interventions considered empowering for people living with dementia. An important step that needs to be taken is to develop and test interventions that specifically aim to promote empowerment for people living with dementia.

**Impact:** Empowerment may encourage people with dementia to live the life they choose, and focus on what is possible, instead of what is no longer possible. Many interventions are considered as empowering for people living with dementia, however no interventions could be identified that were specifically developed for or aimed at empowerment. This study shows that for promoting empowerment, it is necessary to develop and test interventions that specifically aim for empowerment, do this in

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collaboration with relevant stakeholders, and in this way support people living with dementia to live according to their competencies, talents and wishes.

**KEYWORDS**

dementia, psychosocial nursing, quality of life, caregiving

## 1 | INTRODUCTION

The concept of empowerment contributes to the shift from task-oriented care, with a focus on the illness, to person-centred care, with an emphasis on the whole person (Holmstrom & Roing, 2010). Empowerment has received increasing attention, also for people living with dementia (Morris et al., 2020; Prato et al., 2018; Shelton et al., 2018). To encourage them to live the life they choose and focus on what is possible, instead of what is no longer possible, it is considered important to encourage empowerment for people living with dementia (Hage & Lorensen, 2005; Tengland, 2008). Therefore, interventions that promote empowerment for people living with dementia, and that support (in)formal caregivers in this empowerment process, are valuable for care and support.

### 1.1 | Background

Over recent decades, several interventions or projects for people living with dementia addressing the concept of empowerment have been described in the literature (Bhatt et al., 2020; Gould et al., 2008; Pearce et al., 2012). Furthermore, it is possible that additional empowering interventions for people living with dementia may already exist, but cannot be found in the literature as they may only be used in practice without description in the scientific literature, or because they did not specifically use the word 'empowerment'. Nevertheless, there is a lack of clarity around the concept. Literature on what empowerment means and includes for people living with dementia remains scarce, and most literature surrounding empowerment lacks a clear definition or explanation of the concept (van Corven et al., 2021b). Perspectives on empowerment of people with dementia were therefore evaluated and described elsewhere (van Corven et al., 2021a). To gain an overview of empowering interventions for people living with dementia, and thus find opportunities to improve current care and support, a review of scientific literature may not be the best method as this could possibly overlook many empowering interventions.

Therefore, in this study, we performed a European survey aiming to identify existing empowerment interventions for people living with dementia and to find out which applied interventions and projects are considered empowering and why. Results may direct further work on empowerment interventions, and thus provide a basis to promote empowerment for people living with dementia, and to support (in)formal caregivers in this empowerment process.

## 2 | THE STUDY

### 2.1 | Aims

We aim to identify existing empowerment interventions for people living with dementia and to explore which used interventions and projects are considered empowering and why.

### 2.2 | Design and procedure

We performed an online survey between May 2018 and July 2018 amongst professionals interested in dementia care across Europe. The survey was hosted online using the online survey tool, LimeSurvey.

The European Working Group of People With Dementia (EWGPWD) was consulted on the relevance and design of the survey, leading to further specification of the aim and adaptations in terminology. The EWGPWD was set up by Alzheimer Europe in 2012. The group is composed entirely of people living with dementia, who are nominated by their national Alzheimer Association. They work in collaboration with Alzheimer Europe, contributing towards their work and supporting research projects (Alzheimer Europe, 2020).

### 2.3 | Participants

This survey targeted European dementia researchers and healthcare providers for people living with dementia residing at home and in nursing homes. The survey was distributed in a variety of ways. First of all, the survey was distributed via several networks and channels of Alzheimer Europe (e.g. its 37 national Alzheimer associations from 33 countries, newsletter and social media). Second, the survey was distributed to people presenting at the Alzheimer Europe conferences of 2017 and 2018 with the word 'empowerment' in their abstract. Third, the survey was distributed to all members of the pan-European, multi-professional clinical research network INTERDEM (Timely Detection and Intervention in Dementia), the United Kingdom's Older People Network and the pan-European Community Occupational Therapy for people with dementia (COTiD) network. Lastly, we sent the survey to Dutch dementia researchers in the professional network of the authors. Respondents were asked to forward the survey to other relevant people in their network or country.

TABLE 1 Characteristics of survey distribution

Way of distribution	Survey sent	Survey forwarded	Total number of people receiving the survey	Completed surveys	Mentioned interventions
Alzheimer Europe network	45	24	69	18	27
INTERDEM network <sup>a</sup>	174	16	173	41	55
COTiD network	18	7	25	5	7
UK Older People Network <sup>b</sup>	3	0	2	0	0
Professional network of authors	31	4	35	9	9
Total	271	51	304	73	98

<sup>a</sup>17 non-responses because of invalid e-mail address ( $n = 14$ ), retirement ( $n = 1$ ) or research outside Europe ( $n = 3$ ).

<sup>b</sup>1 non-response because of invalid e-mail address.

## 2.4 | Data collection

To identify existing empowerment interventions for people living with dementia in Europe, a specific survey was developed, including both open format and multiple-choice questions. Questions covered basic information about the intervention, its goals, target population, involved healthcare professionals, information on the development, evaluation and implementation, and why respondents considered the intervention to be empowering. The questions of the survey can be found in Additional File 1. Respondents could choose between two languages of preference: English or Dutch. If respondents were not aware of the details of the intervention, they could answer some basic questions, only covering the aim of the intervention, a general description and why they considered the intervention to be empowering (see Additional File 1).

## 2.5 | Ethical considerations

The study was conducted in accordance with Dutch law and the Declaration of Helsinki. The study protocol was not reviewed by the local Medical Ethics Review Committee, since the participating professionals were not subjected to actions nor were rules of behaviour imposed on them. By filling in the survey, professionals in dementia care gave their consent for participation.

## 2.6 | Data analysis

Interventions were clustered within the ecological model for health promotion on the (inter)personal, organizational, communal and societal levels (McLeroy et al., 1988). Interventions on the (inter)personal level included all interventions regarding the person living with dementia and/or their social environment. Therefore, these interventions were further clustered based on the person who was targeted (person living with dementia, family caregiver, formal caregiver or a combination). Information about interventions which were mentioned more than once was combined. For each cluster of interventions, all qualitative data were summarized. The quantitative

data of the multiple-choice questions were analysed using descriptive statistics (absolute frequency and relative frequency).

The reasons as to why respondents of this survey considered interventions to be empowering are structured according to the conceptual framework of empowerment for people living with dementia, based on stakeholder perspectives and the scientific literature. This conceptual framework includes: (1) the state of being empowered, (2) the process of empowerment, and (3) contribution of the environment to the empowerment process.

## 2.7 | Validity, reliability and rigour

For this study, a specific English survey was developed by the authors. The survey was piloted by three member associations of Alzheimer Europe (i.e. the national Alzheimer associations of Ireland, Italy and Finland), leading to textual changes of questions (e.g. specification of multiple-choice options), and increased readability and clarity of the introduction text. Afterwards, the survey was also translated to Dutch by the first author (CvC), which was checked by two other authors (AB, DG).

## 3 | RESULTS

In total, 73 people participated in the study. Their responses mentioned a total of 98 interventions that they considered to be empowering. There were 90 unique instances of interventions, as some interventions were mentioned more than once. Detailed questions about the intervention were answered for 69 interventions, whilst for 21 interventions, only basic information was provided.

### 3.1 | Respondent characteristics

Table 1 presents the various methods of survey distribution, the number of people who received the survey (either sent by us or forwarded by respondents), the number of people who completed the survey and the number of interventions mentioned.

Respondents of the survey had a range of occupations, with employment at research universities ( $n = 22$ ), Alzheimer or other patient organizations ( $n = 17$ ), healthcare organizations ( $n = 13$ ), universities of applied sciences ( $n = 9$ ), university medical centres ( $n = 9$ ), governmental organizations ( $n = 2$ ) or other employment ( $n = 9$ ), including consultancy, information research organizations, knowledge centres, national centres for research, education and service development, NGOs, professional scientific societies, research and engagement programs and research institutes. These numbers add up to more than the total number of respondents as some were employed at multiple organizations.

The respondents were from 23 countries. An overview of the number of participants and interventions per country is found in Table 2. Three respondents filled in the survey, but indicated that empowering interventions or projects might exist, but that they or their organization did not know this information ( $n = 2$ ), or indicated that to the best of their knowledge, this type of intervention or project did not exist in their country ( $n = 1$ ). These respondents came from Finland, Greece and Bulgaria.

### 3.2 | Empowering interventions

#### 3.2.1 | Baseline characteristics

Baseline characteristics were provided for 69 interventions. Interventions targeted people living with dementia residing at home ( $n = 58$ , 84%), attending a day care centre ( $n = 31$ , 45%) or in a care home or nursing home ( $n = 35$ , 51%). Percentages add up to over 100% as some interventions were applied in multiple settings. The majority of the interventions did not specify age of dementia onset ( $n = 56$ , 81%), however some interventions were specifically for people living with young onset dementia ( $n = 3$ , 4%) or late-onset dementia ( $n = 10$ , 15%). Furthermore, the majority of interventions targeted all types of dementia ( $n = 66$ , 96%), whereas some interventions specifically targeted Alzheimer's disease ( $n = 3$ , 4%). Most interventions were specifically for people living with mild ( $n = 35$ , 51%) or moderate ( $n = 23$ , 33%) dementia. Three interventions were tailored to people living with severe dementia (4%). Severity was not specified for the other interventions ( $n = 30$ , 44%). These percentages add up to over 100% as some interventions focused on multiple categories of dementia severity.

A diverse range of healthcare professionals were involved in the interventions: elderly care physicians, geriatricians, general practitioners, psychiatrists, psychologists, dementia case managers, nurses, nursing assistants, care assistants, social workers, physiotherapists, occupational therapists, speech therapists, volunteers and many more.

The reach of the interventions ranged from regional ( $n = 25$ , 36%), national ( $n = 28$ , 41%) and international ( $n = 15$ , 22%), with the range of one intervention marked as unknown (1%). Most interventions had benefited between 1 and 100 people living with dementia ( $n = 28$ , 41%), others indicated having benefited 100–500 ( $n = 12$ ,

17%), 500–2000 ( $n = 7$ , 10%) or more than 2000 people ( $n = 8$ , 12%). For 14 interventions (20%), respondents indicated that they did not know how many people living with dementia had benefited from the intervention so far.

#### 3.2.2 | Description of empowering interventions

The four levels of the ecological model (McLeroy et al., 1988) for health promotion were represented: interventions were on either an (inter)personal ( $n = 54$ ), organizational ( $n = 15$ ), communal ( $n = 6$ ) or societal ( $n = 15$ ) level. Interventions on an (inter)personal level targeted the person living with dementia ( $n = 30$ ), the person living with dementia and their family caregiver ( $n = 13$ ), the family caregivers ( $n = 7$ ) or the healthcare professional ( $n = 4$ ). Lastly, interventions for people living with dementia regarded a range of categories, such as physical health ( $n = 9$ ), music and art ( $n = 9$ ), interaction ( $n = 9$ ) or physical environment ( $n = 3$ ). Table 2 displays the clustering of interventions, an overview of the type of interventions and their effective or useful elements.

#### 3.2.3 | Reasons for interventions to be considered empowering

The reasons as to why respondents considered interventions as empowering were clustered according to the domains of a recently developed framework of empowerment for people living with dementia (van Corven et al., 2021b). The total amounts to more than the number of interventions, as some respondents mentioned multiple reasons as to why they considered an intervention to be empowering. However, none of the interventions focused on all of the domains of empowerment.

##### *The state of being empowered*

Firstly, corresponding to the empowerment theme 'having a sense of personal identity', respondents considered interventions as empowering when the intervention was person centred and focused on the needs and wishes of the person living with dementia and their family caregivers ( $n = 25$ ). Secondly, in line with the theme 'having a sense of choice and control', interventions that promoted choice, control and autonomy were considered to be empowering ( $n = 28$ ), which also included promoting independence and exerting an influence on everyday life activities. Thirdly, fitting into the theme 'using abilities and being needed', interventions were considered empowering by respondents if people living with dementia were encouraged to stay active, take part in activities and had the opportunity to make a contribution ( $n = 22$ ). Moreover, interventions enabling the person living with dementia to actively live in the community for a longer period were mentioned ( $n = 8$ ), or if they focused on remaining or preserving abilities ( $n = 11$ ), for example, by training cognitive abilities. Lastly, fitting with the empowerment theme 'retaining a sense of worth', respondents

TABLE 2 Types of interventions that were considered empowering, and their effective or useful elements

Intervention types	Intervention goal
Interpersonal (n = 54)	
<i>The person living with dementia</i>	
Physical health	
Cognitive rehabilitation or stimulation (n = 4)	To achieve personally meaningful goals
Management of medication (n = 1)	-
Nutritional guidance (n = 1)	To improve health-related quality of life
Physical activity (n = 2)	To enable people with dementia to participate in physical activities and to benefit from physical activity
Health coach (n = 1)	To improve health-related quality of life.
Experiences	
Music (n = 2)	To create an inclusive participatory music environment and focus on the person behind the dementia
Art (n = 2)	To touch people through art and to share experiences
Reminiscence (n = 3)	To gain insight into life stories and positive memories and to increase well-being
Peer support or education for people living with dementia (n = 2)	To inform people about living with dementia, provide a sense of community and find ways to live with dementia
Physical environment	
Mobility (n = 3)	To maintain mobility
Assistive technologies at home (n = 6)	To turn the home of the person living with dementia into a personalized 'coaching assistant', to support memory and structure in everyday life and to support social participation, self-management and independence
Interaction	
Communication with caregivers (n = 2)	To support the dialogue with (in)formal caregivers, assist in creating better insight into what support is needed to uphold independent living and support the needs and wishes of the person living with dementia
Promotion of social contacts (n = 1)	To promote social networks, improve skills and obtain support for regular activities
<i>Person living with dementia and their family caregiver</i>	
Peer support (n = 2)	Aims for social activation, new friendships, mastery over one's own life, to share experiences, improve quality of life and raise awareness about dementia
Multicomponent interventions (n = 10)	Aims for active ageing, reducing neuropsychiatric symptoms, retaining independence, participating in meaningful activities, improving quality of life, reducing burden on the family caregiver, providing individual counselling, giving direction in care pathways and seeking possibilities to adapt the environment or activities
Promote interaction between person living with dementia and their family caregiver (n = 1)	To make contact, improve comfort, improve or preserve quality of life and increase the positive experiences of the family caregiver
<i>Family caregiver</i>	
Education (n = 2)	To provide better support in caring for the person living with dementia and improving self-management of the family caregiver to stay in balance
Care relief (n = 5)	To delay long-term institutionalization, prevent overload and increase social support
<i>Healthcare professional (and family caregiver)</i>	
Education (n = 4)	To provide a practical approach to communication, that helps caregivers pause, reflect and connect to people living with dementia, teaches general practitioners on communicating about what is important for people living with dementia and their family caregiver and improves quality of communication about end-of-life care and care wishes
Organization (n = 15)	
Care approach (n = 5)	To engage in activities that fit personal wishes and ideas, provide a home, provide help in summarizing thoughts about end-of-life care, create a culture of palliative care and promote respect for dignity

TABLE 2 (Continued)

Intervention types	Intervention goal
Day support facilities ( $n = 10$ )	To slow down the process of dementia, provide some structure to the day, promote coping, train cognitive or physical functioning, provide psychological support, information about the disease, meaningful daytime activities, support in one place and cater to varied needs of people living with dementia
Community ( $n = 6$ )	
Dementia-friendly community ( $n = 6$ )	To increase community awareness and understanding of dementia, turn places into memory-friendly areas, reduce barriers and involve people living with dementia in their communities, so they have the opportunity to continue to engage in their usual activities
Society ( $n = 15$ )	
Dementia-friendly society ( $n = 6$ )	To raise awareness of dementia, share stories, run national campaigns and bring together national organizations to connect and take practical action on dementia
Research and policy involvement ( $n = 4$ )	To stimulate people with dementia to talk about what they need and want
Knowledge generation ( $n = 5$ )	To gain knowledge about living with dementia and appropriate care and support and to support autonomy and agency

considered interventions empowering if these promoted self-worth and confidence ( $n = 12$ ). This included people living with dementia being considered as resourceful human beings and being proud of themselves.

#### *The process of empowerment*

Corresponding to the process of empowerment, which takes place within the interaction of the person living with dementia and their environment, respondents designated interventions as empowering if they improved relationships or social participation, actively involved familial caregivers or improved communication between the person living with dementia and their family caregiver or healthcare professionals ( $n = 17$ ).

#### *Contribution of the environment to the empowerment process*

A number of respondents noted that they considered interventions to be empowering when they focused on the contribution of the environment to the empowerment process.

Firstly, on an (inter)personal level, interventions were thought to be empowering by respondents if they trained and informed healthcare professionals and family caregivers on different topics of dementia, and on how to communicate with the person living with dementia ( $n = 4$ ). In this way, family caregivers could provide better care and support for the person living with dementia.

Secondly, on an organizational level, several care approaches were thought to be empowering by respondents ( $n = 3$ ) as they offered solutions before moving to a nursing home, such as respite care for informal caregivers.

Thirdly, on a societal level, dementia friendliness, low stigma, participation in society and social inclusion were mentioned by respondents as contributions from the environment to the empowerment process ( $n = 16$ ). They argued that people living with dementia would feel more integrated and could remain included in society. It was thought to be empowering by respondents to create communities where there is complete acceptance and inclusion of people living with dementia, and where people living with dementia are

supported to continue to live fulfilling lives for as long as possible. This necessitates a community that is aware of the challenges faced by people living with dementia and their partners, families and close friends. Moreover, respondents considered an intervention that promoted advocacy for people living with dementia as empowering ( $n = 1$ ), for example, the opportunity to be a spokesperson for people living with dementia. In other interventions, people living with dementia could share their story ( $n = 3$ ), for example, in a film or outreach campaign, and, through this, give a face to dementia. In these interventions, people living with dementia were encouraged to speak openly about their condition. Furthermore, respondents thought that generating knowledge about the condition and providing information about available services was empowering ( $n = 6$ ). Lastly, it was considered empowering by respondents for people living with dementia to have a leading role in research projects or the design of services ( $n = 7$ ).

#### *Effects of empowerment on other variables*

Some of the mentioned reasons as to why an intervention was considered empowering could not be clustered to the domains of the empowerment framework. This entailed that there were possible effects of empowerment on other variables. Multiple respondents considered various interventions designed for people living with dementia as empowering when they aimed to improve the quality of life, mood or well-being of people living with dementia, or supported people to have a good life alongside their dementia ( $n = 23$ ).

## 4 | DISCUSSION

This European survey gave an interesting overview of interventions for people living with dementia that were considered to be empowering by different stakeholders in dementia care and research. It showed that many different types of interventions, with wide-ranging aims, are considered empowering by professionals interested in dementia care. Yet, most interventions appeared to fit

within the conceptual framework of empowerment for people living with dementia. The majority of shared interventions (60%) focused on the (inter)personal level, that is, the person living with dementia, their family caregivers or the healthcare professional.

Respondents of the survey suggested, proposed or implied that interventions were empowering, but not one of the reported interventions specifically aimed to empower people living with dementia. Interventions identified in this survey may therefore contribute to good care and support for people living with dementia, but the question remains as to whether these are empowerment interventions, or interventions that may promote empowerment as a side effect. It could be, as seen in our integrative review, that people use the word 'empowerment' in contexts where it is possibly not always the most suitable concept. An important step in promoting empowerment amongst people living with dementia is to develop and test interventions that specifically aim to promote empowerment, and to support (in)formal caregivers in this empowerment process. For this purpose, clarity around the concept of empowerment is needed. Our recently developed conceptual framework, based on stakeholders' perspectives and the scientific literature (van Corven et al., 2021b), articulates the state of empowerment, the process of empowerment and the role of the environment therein, thus providing a structure for the development of effective interventions specifically aimed at promoting empowerment for people living with dementia. The framework suggests that empowering interventions should focus on a sense of identity, usefulness, control and self-worth for people living with dementia, whilst supporting (in)formal caregivers in promoting the empowerment process (van Corven et al., 2021b).

Many of the reasons as to why respondents of this study considered interventions as empowering appeared to fit within the conceptual framework of empowerment (van Corven et al., 2021b). Reasons that fell outside the framework's domains regarded the possible effects of empowerment on other variables, for example, outcomes of empowerment. Several outcomes were also identified in our integrative literature review, but were subsequently not included in the framework as relationships of empowerment with the suggested outcomes were not well described nor empirically studied. Additional research is needed to provide more clarity as to the effects of empowerment on concepts such as a person's well-being.

Moreover, no new themes on the state of being empowered emerged from the current study, which further confirms the framework's relevance and appropriateness for professionals interested in dementia care. Some aspects of empowerment were more prominent in certain interventions than others. The sense of identity, usefulness and control were each addressed in about a quarter of the interventions, whilst much fewer interventions addressed a sense of self-worth. Furthermore, interventions which targeted the process of empowerment by improving interaction and relationships were scarce. We propose that all interventions may benefit from focusing on the four themes of empowerment for interaction. The fact that none of the interventions addressed all aspects of empowerment, and that the importance of interaction and relationships was not always highlighted, suggests the need for specific empowerment interventions. For example, an intervention which promotes

feelings of usefulness may help the person to feel empowered, but may not be empowering on its own. Nevertheless, the interventions or projects identified by this survey add to practical details on how to promote the different aspects of empowerment, and may provide a basis for the development of interventions specifically aimed at empowerment.

### *Strengths and limitations*

To our knowledge, this is the first study performing a European survey aimed at identifying existing interventions that are considered empowering for people living with dementia, and going beyond what can be found in the literature. In this way, we also identified interventions that do not specifically use the concept of empowerment, and interventions that are only used in applied practices. The results provide suggestions on how to promote empowerment for people living with dementia in Europe and support (in)formal caregivers in this empowerment process.

A limitation of this study is that responding professionals and researchers suggested, proposed or implied that interventions were empowering, but these effects on empowerment were not yet studied. We did not consult people living with dementia to validate if they found these interventions empowering. As the EWGPWD highlighted in their consultation, many services that might be described as empowering may not necessarily be considered as such by the people living with dementia. Therefore, it is important that people living with dementia are included in all phases of the development of interventions targeted specifically at empowerment. Furthermore, future studies on how the impact of empowerment can be measured would be valuable.

In addition, there could be a potential selection bias with motivated respondents who were willing to share their time and opinions by filling in the survey, who were familiar with English or Dutch and who could be reached by addressing the networks of Alzheimer Europe, INTERDEM, COTID, the UK's Older People Network and the professional network of the authors. Moreover, as we included the professional network of the authors, there was an overrepresentation of Dutch interventions. It is possible that other empowering interventions exist that were not identified in this study. What may add to this is that the reliability and validity of the survey was not tested beforehand. Lastly, it would be interesting to involve people from various minority and marginalized groups in future discussions about what constitutes empowerment and what improvements are needed.

## 5 | CONCLUSION

This European survey provides insight into interventions that are considered empowering for people living with dementia by different stakeholders in dementia care and research. A broad range of interventions were considered empowering, however none of the interventions were specifically developed for nor aimed at empowerment. An important step in promoting empowerment is to develop and test interventions that specifically aim to promote empowerment in collaboration with people living with dementia, and to investigate how to best measure their impact on feelings of empowerment.

## AUTHOR CONTRIBUTIONS

Made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data: CvC, AB, ADP, DG, JG, MG, DG. Involved in drafting the manuscript or revising it critically for important intellectual content: CvC, AB, ADP, DG, JG, MG, DG. Given final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content: CvC, AB, ADP, DG, JG, MG, DG. 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: CvC, AB, ADP, DG, JG, MG, DG. Charlotte van Corven developed the survey, collected the data, analysed and interpreted the data and wrote the paper. Annemiek Bielderman developed the survey, collected the data, interpreted the data and co-wrote the paper. Dianne Gove and Ana Diaz Ponce developed the survey, collected the data, interpreted the data and assisted in writing the paper. Jean Georges assisted in writing the paper. Debby Gerritsen developed the survey, interpreted the data, supervised the data collection and assisted in writing the paper. All authors have agreed on the final version and meet at least one of the following criteria: (1) substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data, (2) drafting the article or revising it critically for important intellectual content.

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## CONFLICT OF INTEREST

No conflict of interest has been declared by the authors.

## PEER REVIEW

The peer review history for this article is available at <https://publons.com/publon/10.1111/jan.15385>.

## DATA AVAILABILITY STATEMENT

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

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