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Activities of persons with dementia at home and after nursing home admission: A survey study



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ABSTRACT

Objectives: This study compared whether the categories of activities that persons with dementia engage in changed between home and after nursing home admission. Also investigated were the methods for assessing the wishes, needs, and abilities regarding activities, and informal caregivers' satisfaction with the degree of assessment of activities during the transition.

Methods: A cross-sectional survey in which 81 informal caregivers of nursing home residents with dementia participated (37% male, mean age 65.0 years, SD 10.1).

Results: Persons with dementia performed activities in fewer activity categories in the nursing home compared to home ($Z = -3.74, p < .01$). Conversation was the most used assessment method. Informal caregivers rated their satisfaction with the degree of assessment of activities during transition with a median score of 7 (IQR 5–8) on a scale from 0 to 10.

Conclusion: Monitoring the activities for persons with dementia during the transition is essential and activities should be assessed repeatedly over time to prevent potential activity decline.

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Introduction

Engagement in activities is important for the well-being^{1,2} and quality of life of persons with dementia.^{3–5} Persons with dementia living at home report activities as one of the things that matters most to them.⁶ In the nursing home also, activities have been reported as the most important need.⁷ Not meeting these needs can result in boredom, inactivity, and increased affective and psychotic symptoms.^{7–10}

Admission into a nursing home is a life event for both the person with dementia and their informal caregivers.¹¹ Continuation of activities could facilitate adjustment after transition into a nursing home and provide a sense of stability and normality.^{8,12} Nursing home residents with dementia often miss activities they did at home and prefer to continue some of those activities after nursing home admission.^{13,14} For informal caregivers, focusing on continuation of the person with dementia's life and re-establishing their routines, habits, and activities can be a way to cope with negative emotions

after the transfer to a nursing home.¹⁵ Unmet needs of informal caregivers during these transitions may lead to greater levels of burden and negativity regarding the transition.^{11,16}

Healthcare professionals and healthcare organizations can enhance quality of care and person-centered care by providing activities.^{17,18} An adequate assessment of the needs, wishes, and abilities of the person with dementia would contribute to person-centered care, the gold standard in dementia care.¹⁹ Especially during the transition, this assessment is relevant because of the changing situation.²⁰ Even though activities have important benefits for persons with dementia, there is a lack of awareness and attention for activities during transition.^{21,22} A recent systematic review showed that maintaining meaningful activities during transitions is an under-researched area.²² This review showed a decrease of meaningful activities after transition and that systematically collecting information about the person (e.g., what makes them tick, their interests, psychosocial needs, meaningful activities, and wishes) is important to adjust meaningful activities to the person.²²

The first step to ensure that persons with dementia can continue activities in the nursing home is to obtain an overview of what

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categories of activities are performed at home and in the nursing home. This study examined the categories of activities that persons with dementia engaged in at home and in the nursing home. Also examined were the current methods for the assessment of wishes, needs, and abilities of persons with dementia regarding activities, when these assessments were conducted, by whom, and informal caregiver satisfaction with the degree of assessment of activities during transition.

Materials and methods

Design

A cross-sectional survey design was chosen. A survey enables obtaining information from a large group in a relatively short time.²³ The current study was part of a larger survey study about meaningful activities for persons with dementia and how these activities contribute to quality of life. The survey was distributed to informal caregivers, healthcare professionals, and volunteers. The current study used the data provided by informal caregivers as they were the persons who were involved both at home and after nursing home admission. The data were collected between September and October 2021. This manuscript was prepared following the Consensus-Based Checklist for Reporting of Survey Studies (CROSS).²⁴

Setting

In the Netherlands, persons with dementia who live in a nursing home require 24-hour care or supervision and have a high need for medical and nursing care and support.²⁵ Daily care is provided by a multidisciplinary team, including nursing aids, registered nurses, psychologists, elderly care physicians, occupational therapists, and physiotherapists.²⁶ The care vision is person-centered.²⁷ Activities are offered and often organized by activity coordinators. In recent years, hostesses are working in the living rooms to be present for the residents and assist with eating and drinking.

Recruitment

Participants were recruited nationwide in the Netherlands via the Dutch Alzheimer association, six Dutch collaborative networks in the care for older people which included nursing homes, and Alzheimer cafés. These organizations handed out flyers about the survey to potential participants in person, placed them in information stands, and distributed the flyers via email and newsletters. Furthermore, social media was used. The flyer included a QR code or a URL that forwarded to a website where the participant could leave their email-address and indicate whether they were a volunteer, informal caregiver, or professional caregiver. Next, participants received an email with a link to the online survey. Informal caregivers could participate in the survey if they had weekly contact with their relative with dementia who lives in a nursing home, had sufficient understanding of the Dutch language to fill in a survey, and were ≥ 18 years old. For the current study, an additional inclusion criterion was the involvement of the informal caregiver during the nursing home admission (i.e., knowing which activities the person with dementia performed before and after the transition). This was verified with the question “Were you involved in your relative’s move to the nursing home? Involved means that you have insight into the activities your relative engaged in before and after moving.” Participants who answered “Yes, but it was so long ago that I can’t answer questions about that anymore” and “no” were excluded from the analysis.

Survey development and procedure

The 16 activity categories in the survey were based on a literature search on activities performed by persons with dementia.^{3,28,29} These categories were evaluated on clarity and comprehensibility by the research team, two healthcare professionals, and an informal caregiver. A full description of the categories and examples of activities are presented in Appendix A.

The survey was pilot tested by two healthcare professionals and one informal caregiver to ensure the questions were comprehensible and test the survey completion time. Completing the whole survey took approximately 25 min. The survey was created in the cloud-based electronic platform Castor Electronic Data Capture.³⁰ All questions were mandatory. Participants could move backward and forward through the survey. In addition, it was possible to save and complete the survey at a later time. The survey contained nine topics: (1) consent form; (2) general information about you; (3) information about your relative; (4) relationship to your relative; (5) activities; (6) characteristics and preferences of your relative with dementia; (7) people involved in activities; (8) implementation; (9) move from home to nursing home. The current study used data from topics 1, 2, 3, 4, 6, and 9. Topic 5 was not included because it contained questions about the activities offered in the nursing home and the expected contribution to quality of life.

Topics two, three, and four included questions about the characteristics of the informal caregiver and their relative with dementia, dementia diagnosis, admission date, and the relationship between the informal caregiver and resident. The topic “characteristics and preferences of your relative with dementia” started with the question, “With regard to activities, how are your relative’s wants, needs, and abilities assessed?” Answers included “conversation”, “booklet” (e.g. life story), “collage”, “games”, “physical examination”, “the wishes, needs, and abilities of my relative with dementia were not assessed”, “other”, “don’t know”.

Next, participants could indicate when this method was used: “Before the move to the nursing home”, “Upon admission to the nursing home”, “After several months in the nursing home, namely... months”, “This is not assessed”, “Don’t know”. The number of months could be specified. The follow-up question inventoried how often activities were assessed: “one time”, “regularly”, “don’t know” Regularly had the option to specify how many times per year.

Next, we asked who assessed the activities. Multiple answers were possible and they were merged into certified nurses and nurse assistants, activity coordinators, social care workers and hostesses, physicians and nurse practitioners, therapists, and informal caregivers. Finally, participants were asked to score “the degree to which activities are assessed before the move or just after moving” on a Visual Analogue Scale (VAS) from 0 to 10 (0 very poor–10 very well).

The topic “move from home to nursing home” comprised three questions: 1) a multiple-choice question: “Has there been any change in the activities your relative with dementia engages in after admission to the nursing home?” Possible answers were: “my relative has been doing fewer activities after the move”, “some activities have decreased and other activities have increased”, “activities have remained the same”, “my relative has been doing more activities after the move”, “my relative has been engaging in other activities after admission to the nursing home”, “don’t know”. 2) “What activities did your relative engage in at home?” 3) “What activities does your relative engage in the nursing home?”. For questions 2 and 3, multiple categories could be selected and there were open text fields for any activity that did not fit in any of the categories.

Data analysis

The data were analyzed using SPSS version 25. Descriptive analyses and statistical tests were used to describe the results. Categorical

data were described in percentages, and for continuous variables, the mean (SD) or median (IQR) were reported. To compare the activities reported at home and in the nursing home, McNemar’s test was used. The Wilcoxon Rank test (not normally distributed) was used to test for differences in the total activities categories (sum of all categories of activities per resident) reported at home and in the nursing home. Furthermore, a sensitivity analysis was performed to examine whether there was a difference in the activity categories (chi-squared test and Fisher’s exact test) and the total of activities (Mann-Whitney U test) between residents living shorter (≤ 12 months) vs. longer (> 12 months) in the nursing home. The cut-off score of twelve months was chosen because living in the nursing home longer than 12 months is considered a long-stay admission.³¹

Ethical considerations

Before the survey started, an information letter was shown on the screen and participants were asked to give online consent for participation in the study. The survey started only after online consent was given. The Leiden-The Hague-Delft Medical Ethical committee declared the study exempt from the Dutch Medical Research Involving Human Subjects Act (protocol nr. N21.128)-blinded for peer review-.

Results

Fig. 1 shows a flow diagram of the study. Of the 135 informal caregivers who wanted to participate in the study, 81 were included in the analysis. Table 1 presents the characteristics of the study population. Of the participants, 37 % were male, mean age was 65 (SD 10.1) years, almost 62 % were children (in-law), and 28.3 % were living

Table 1

Characteristics of the informal caregivers and their relative with dementia (n = 81).

Characteristic	n (%)
Gender informal caregiver (male)	30 (37.0 %)
Age informal caregiver in years: mean (SD)	65.0 (10.1)
Relationship to the person with dementia	
Child (in-law)	50 (61.7 %)
Partner	25 (30.9 %)
Sibling	4 (4.9 %)
Other ^a	2 (4.2 %)
Living together with person with dementia before nursing home admission	23 (28.4 %)
Hours spent with person with dementia per week: median (IQR)	5 (3–8)
Gender of person with dementia (male)	27 (33.3 %)
Age of person with dementia in years: mean (SD)	83.5 (9.4)
Type of dementia	
Alzheimer’s disease	40 (49.4 %)
Vascular dementia	18 (22.2 %)
Frontotemporal dementia	7 (8.6 %)
Alzheimer’s and vascular dementia	5 (6.2 %)
Other ^b	5 (6.2 %)
Unknown	6 (7.4 %)
Months Living in a nursing home: median (IQR) ^c	25 (10–42)
≤ 12 months living in a nursing home	23 (29.5 %)
> 12 months living in the nursing home	55 (70.5 %)

SD=standard deviation; IQR=Interquartile Range.

^a former wife and legal representative mentor.

^b other: frontotemporal and vascular, dementia not specified, Lewy-Body dementia (including Parkinson’s dementia).

^c n=78.

together with the person with dementia. Also, 33.3 % of the persons with dementia were male and 40 (49.4 %) had a diagnosis of Alzheimer’s disease.

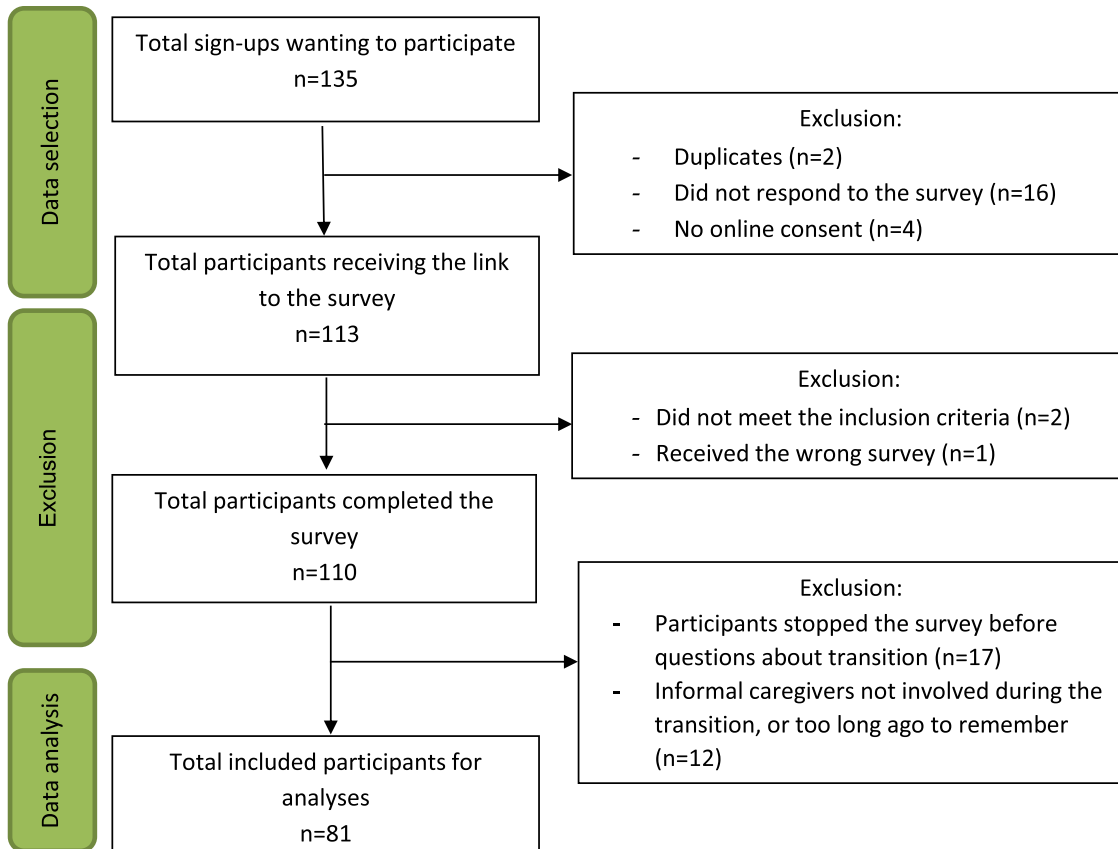


Fig. 1. Flowchart of the study.

Activities at home and in the nursing home

Thirty-nine (48.1 %) participants indicated that the person with dementia performed less activities after nursing home admission compared to at home. By contrast, 12.3 % ($n = 10$) indicated that the person with dementia performed more activities in the nursing home than at home; 13.6 % reported ($n = 11$) that their relative engaged in other activities; and 17.3 % ($n = 14$) stated that some activities declined, but other activities increased. Only 3.7 % ($n = 3$) reported that activities remained the same after admission into a nursing home and 5.0 % ($n = 4$) indicated not knowing.

Table 2 shows the categories of activities persons with dementia performed at home and in the nursing home. The total number of activity categories per person was significantly lower in the nursing home (median 5 (IQR 3–7)) compared to at home (median 7 (IQR 5–9); $Z = -3.744$, $p = <0.01$, $n = 79$). This implies there is less variation in activity categories that residents engage in at the nursing home compared to at home.

The most frequently performed activity categories at home were family and social activities (74.1 %), household activities (70.4 %), and music and entertainment activities (69.1 %). In the nursing home, the most frequently reported categories included music and entertainment activities (87.7 %), exercise (67.9 %), and family and social activities (49.4 %). Six of the 16 activity categories were significantly less often performed in the nursing home compared to at home, i.e., household activities, activities focused on daily rituals, family and social activities, activities focused on personal care, activities focused on holiday and events, and cognitive stimulation. Music and entertainment activities ($n = 71$; 87.7 % vs. $n = 56$; 69.1 %; $p = .011$) and activities including dolls ($n = 0$; 0.0 % vs. $n = 7$; 8.6 %; $P = .016$) were engaged in significantly more in the nursing home than at home.

A sensitivity analysis was performed to examine differences in activities for residents who lived relatively short (≤ 12 months) compared to residents who lived longer (> 12 months) in the nursing home. The total amount of activities performed in the nursing home did not significantly differ between the two groups ($n = 78$; $Z = -4.20$, $p = .674$). Comparison per category of activities showed significantly

Table 2

Categories of activities performed by persons with dementia at home and in the nursing home, including a comparison between the two settings.

Category of activities	Home n (%)	Nursing home n (%)	p-value
Total categories of activities per person: median (IQR)	5 (IQR 5–7)	7 (IQR 5–9)	<0.001*
Art activities	20 (24.7 %)	19 (23.5 %)	1.000
Animal activities	8 (9.9 %)	14 (17.3 %)	.359
Activities including dolls	0 (0.0 %)	7 (8.6 %)	.016*
Exercise	52 (64.2 %)	55 (67.9 %)	.523
Sensory stimulation	11 (13.6 %)	12 (14.8 %)	1.000
Music and entertainment	56 (69.1 %)	71 (87.7 %)	.011*
Cognitive stimulation	38 (46.9 %)	25 (30.9 %)	.045*
Reminiscence	37 (45.7 %)	33 (40.7 %)	.486
Outside activities	39 (48.1 %)	27 (33.3 %)	.091
Family and social activities	60 (74.1 %)	40 (49.4 %)	.002*
Household activities	57 (70.4 %)	23 (28.4 %)	<0.001*
Religious activities	22 (27.2 %)	15 (18.5 %)	.092
Activities focused on personal care	53 (65.4 %)	36 (44.4 %)	<0.001*
Activities focused on holiday and events	53 (65.4 %)	36 (44.4 %)	.003*
Aromatherapy	2 (2.5 %)	2 (2.5 %)	1.000
Activities focused on daily rituals	39 (48.1 %)	16 (19.8 %)	<0.001*
Other	2 (2.5 %) ^b	0 (0.0 %)	.500

$n = 80$ for home and nursing home; one participant selected 'I don't know' for activities at home and one participant selected 'don't know' regarding activities in the nursing home. For the comparison between settings, these two participants were not included in the analyses ($n = 79$).

^b day care, lovemaking.

* Significant at $p < .05$.

more engagement in the category music and entertainment activities of the group of residents who lived > 12 months in the nursing home ($n = 77$, $p = .039$). For details, see Appendix B. The other categories of activities showed no significant differences between both groups.

Assessment of activities

Informal caregivers rated their satisfaction with the degree of assessment of activities before or just after nursing home admission with a median score of 7 (IQR 5–8). Informal caregivers indicated that multiple persons assessed the activities. Certified nurses and nurse assistants ($n = 53$, 65.4 %) were most frequently mentioned, followed by activity coordinators, social care workers and hostesses ($n = 35$, 43.2 %), physicians, and nurse practitioners ($n = 35$, 43.2 %), therapists ($n = 34$, 42 %), and informal caregivers ($n = 33$, 40.7 %).

Table 3 shows the moment and frequency of the assessment of wishes, needs, and abilities related to activities for the person with dementia per assessment method. The most frequently used method was conversation ($n = 56$), followed by physical examination ($n = 26$). The assessment took place mostly "upon admission to the nursing home".

Discussion

This study compared categories of activities performed by persons with dementia at home and after admission into a nursing home. In general, residents engaged in fewer activity categories in the nursing home compared to at home. Also, we examined by whom, how, and when the wishes, needs, and abilities with regard to activities of persons with dementia were assessed. This assessment was often conducted by certified nurses and nurse assistants in a conversation during admission. Informal caregivers' satisfaction with the assessment of activities during transition was rated 7 (out of 10).

The decline of activities was related to the categories household activities, activities focused on daily rituals, activities focused on holidays and events, cognitive stimulation, and activities focused on personal care. Music and entertainment, and activities including dolls were the only two categories which increased after nursing home admission. The decline of activity categories in our study is in line with findings in other studies.^{22,32} These studies found a decline in physical activities, activities related to lifestyle and habits,²² and

Table 3

Moment and frequency of the assessment of wishes, needs, and abilities related to the activities of the person with dementia per assessment method ($n = 78$)^a.

	Conversation	Booklet	Games	Physical examination
Methods^b	56	8	9	26
Moment of assessment: n				
Before move to the nursing home	9	1	2	1
Upon admission to the nursing home	35	2	2	14
After several months in the nursing home	10	1	2	3
This is not assessed	0	0	0	1
Don't know	2	4	3	7
Frequency of assessment: n				
One time only	7	2	2	4
Regularly (more than once a year)	35	3	3	13
Don't know	14	3	4	9

^a 3 participants were excluded due to missing data.

^b "collage" ($n = 0$) "This is not assessed" ($n = 8$) "I don't know" ($n = 0$), and "other" ($n = 5$), which included: We (daughters) have tailored the clubs and activities to how our mother was active at home; Through an app; Observation; As they get to know her, they look what activities fit; The activities are supply oriented; Customization must be provided by family; Life book and collage was already there.

household activities.³² Watching television is often reported as an activity in nursing homes.^{33,34} This may explain the increase in the music and entertainment category after nursing home admission, as watching television was included in this category. However, it is difficult to compare categories of activities between studies due to variations in the categorization of activities. Moreover, it must be considered that the decrease or increase of activities was evaluated based on the count of categories of activities at home and in a nursing home. Possibly, persons compensated by frequent activities in other categories. Therefore, it is necessary to include frequency of activities in future studies in addition to categories of activities.

Only 3.7 % of the informal caregivers indicated that activities stayed the same after admission into a nursing home and almost half of the participants indicated a decline in activities. Therefore, it is important that healthcare professionals monitor the activities per resident, ideally starting before nursing home admission or -if this is not possible- shortly after admission. A recent developed model (TRANSCIT model), based on the needs of older people and informal caregivers making the transition from home to nursing home, advises to exchange information between the informal caregiver and healthcare professionals on habits, needs, and course of life of the person with dementia during the mid-transition phase which starts when persons decide to move to a nursing home until the actual move.²⁰

The wishes, needs, and abilities of persons with dementia were mainly assessed in a conversation during nursing home admission. Even though the assessment was repeated at least once a year and informal caregivers were relatively satisfied with the assessment, the decline in certain activity categories after nursing home admission warrants further investigation and suggests there is room for improvement. For example, the ratings of activities by informal caregivers can be used to ensure that nursing homes offer a variety of activities for the residents. Thereby, it is important that activities that are offered are tailored and meaningful to the person with dementia.³ This requires knowledge of the resident and highlights the importance of a repeated structured assessment of their wishes, abilities, and needs, as these can change over time.^{19,35} Also, the assessment could facilitate healthcare professionals getting to know the resident better, and help them select meaningful activities for residents, something healthcare professionals find challenging.³⁶

In addition to regular assessments of the residents' wishes, needs, and abilities, several factors are described in previous studies that could contribute to maintaining meaningful activities including the use of preserved abilities³⁷ and making small adjustments in daily care routines which may provide opportunities to enhance, for example, household activities.^{21,38} Furthermore, international and local differences in the organization and available healthcare professionals in nursing homes could influence the availability of activities and assessment methods. However, doing an assessment may help nursing homes to gain insight into which activities they should offer for their residents. Future research could focus on how, how often, and by whom assessment of activities during transitions should ideally take place, and on the potential beneficial effects on preventing activity decline. Furthermore, the perspectives of persons with dementia themselves on engaging in activities at home and in the nursing home and the (dis)continuation of activities could be investigated in a future study with a longitudinal design.

Strengths and limitations

This study is one of the first studies to explicitly investigate categories of activities performed by persons with dementia at home and in the nursing home. It includes the perspectives of informal caregivers on the assessment of the wishes, needs, and abilities in relation to activities, and on activities performed by their relatives with dementia. A limitation of this study is the retrospective design, which

can lead to recall bias. Although the informal caregivers were involved before and after nursing home admission, we cannot rule out that their picture of the activities of the person with dementia was incomplete. The COVID-19 pandemic, with restricted visits for informal caregivers, may have further negatively affected this. Also, a considerable number of persons with dementia had already been living in the nursing home for quite a long time. However, the sensitivity analysis showed no differences between the groups living shorter (≤ 12 months) in the nursing home compared to residents who lived longer (> 12 months) in the nursing home, except on, the category music and entertainment. Another limitation is the small sample size, especially for the subgroup analysis. Caution should therefore be exercised in generalizing these findings.

Conclusion

Activities differed between home and the nursing home. Individual assessment of the resident's wishes, needs, and abilities with regard to activities is needed during the transition from home to nursing home and should be repeated over time to prevent potential activity decline after nursing home admission. This knowledge can be used to ensure activities can be maintained while also providing valuable insight into the needs of persons with dementia and informal caregivers regarding activities.

Declaration of competing interest

The authors declare that they have no known financial or personal relationship that could cause a conflict of interest regarding this article.

CRediT authorship contribution statement

Mari Groenendaal: Writing – original draft, Methodology, Investigation, Formal analysis, Conceptualization. **Hanneke J.A. Smaling:** Writing – review & editing, Supervision, Methodology, Formal analysis, Conceptualization. **Wilco P. Achterberg:** Writing – review & editing, Supervision, Methodology, Formal analysis, Conceptualization. **Monique A.A. Caljouw:** Writing – review & editing, Supervision, Methodology, Formal analysis, Data curation, Conceptualization.

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Supplementary materials

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