CASCADE

Community Areas of Sustainable Care and Dementia Excellence in Europe
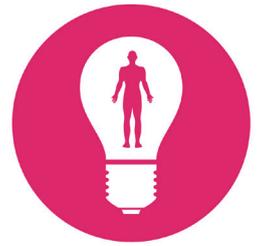
holistic person centred care in the community

Positive public perception

save environment for independent living

Living live to the full

strengths based approach

Dignity
Communication, Autonomy, Respect and Empowerment (CARE)

Final Report
Findings from the Evaluation Study of the CASCADE Model at Two Implementation Sites in Belgium

Canterbury Christ Church University

Ten Kerselaere
woonzorg
emmaüs

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HZ UNIVERSITY
OF APPLIED SCIENCES

Interreg
2 Seas Mers Zeeën
CASCADE
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Preface

Community Areas of Sustainable Care and Dementia Excellence in Europe (CASCADE) was a cross-border partnership involving health and care service providers, dementia experts and academics from Belgium, France, the Netherlands and United Kingdom. The CASCADE project took place between April 2017 and March 2023. The CASCADE project comprised of four implementation sites two of which are located in Belgium and the other two in the United Kingdom. In Belgium, Holy Hart Elderly Care in the municipality of Kortrijk and Emmaüs (Ten Kerselaere residential care home) in the municipality of Heist-op-den-Berg implemented the CASCADE model.

This report presents Outputs 2.2, 2.3, 2.4 and 2.5 of Work Package 3 'Evaluation', focussing on the implementation sites in Belgium.

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Executive Summary

The prevalence of dementia in Europe, including early onset dementia, has increased in the last decade (Alzheimer Europe, 2022) with matching demand for skilled labour and good standards of care. Dementia is poorly understood within existing models of care and the needs of people living with dementia are often left unmet (Smith et al, 2021). The CASCADE partnership, including health and care providers, academics and dementia experts, co-created a community integrated model to address the challenges in care provision and to promote the autonomy of people living with dementia. This report presents the evaluation study of process and outcomes of implementing the CASCADE model in two residential care settings in Belgium. A mixed methods strategy incorporating proxy questionnaires, self-reported questionnaires, focus groups and interviews was used to capture data at baseline and two follow-up timepoints.

Key findings indicated improvements in residents', staff and family carers' outcomes, particularly:

- Residents receiving care tailored to the CASCADE model (intervention group) experienced more improvements in health-related quality of life compared to the control group.

- This positive change in residents was reflected in improvements in levels of depression and a reduction in the concurrent use of medications.

- The safety and quality of care indicators revealed good standards of care for the intervention and control groups.

- Training resources developed by the CASCADE partners was linked to behavioural changes in staff and the communities surrounding the two residential homes.

- The CASCADE training programme for staff was highly commendable and perceived to have greater effect when incorporating a practice-oriented approach with inhouse facilitation.

- Staff reported a recognisable shift to a targeted focus on person-centred care and improvements in their emotional reactions.

- Staff largely valued the use of technology to support care but also perceived the warmth of a human touch as irreplaceable.

- Chronic staff shortages reflected in the labour market and fragmented information systems across home, hospital and residential care settings were ongoing challenges.

- Community views indicated improvements in dementia awareness. More community engagements are required to enhance the commitment to creating dementia-friendly communities.

1. Introduction

The report provides insights into the effectiveness of the CASCADE model as implemented in Belgium. Staff who delivered the CASCADE model received training, which preceded implementation. Four stakeholder groups took part in the evaluation study employing a mixed approach to capture quantifiable intervention outcomes and qualitative 'lived' experiences of the CASCADE programme implementation. Baseline data were collected prior to staff core training tailored to the CASCADE model, entitled 'You and Me, Together we are Human'. The evaluation also considered elements of staff learning and development, social economic outcomes and the acceptance of technology in dementia care.

In the following sections, we present a brief description of the evaluation methodology, key findings, conclusions and recommendations.

2. Evaluation Methodology

2.1 Design and methods of data collection

The evaluation strategy constituted a mixed methods approach including quantitative measures of health, wellbeing and service improvements as well as qualitative methods exploring lived experiences of staff during the implementation of the CASCADE model. A quasi-experimental design in which care home residents were assigned to intervention and control groups was used to assess the influence of the model on outcomes for people living with dementia. The intervention group received care tailored to the CASACADE model while the control group received routine care. The theory of change (De Silva et al., 2014) underpinned the quasi-experimental design was on the assumption that care tailored to the CASCADE model results in measurable outcomes for residents, staff and family carers. The COVID-19 pandemic affected the evaluation plan, causing unavoidable delays in data collection. Data were collected between September 2021 and July 2022 with three timepoints including baseline (T0), first follow-up (T1) and second follow-up (T2). Each participant was assigned a unique code used consistently throughout the evaluation study to anonymise data about individuals.

Table 1 shows the methods used for collecting data and the evaluation study participant groups. Detailed information about the tools for data collection is included in Appendix 1.

Table 1. Methods of collecting data and participant groups

Measures	T0		T1		T2		Area of change	Completed by
People living with dementia (N=36) Intervention group (I) =20 Control group (C) = 16								
Review medical records for:	I	C	I	C	I	C		
• Falls	✓	✓	✓	✓	✓	✓	Quality of care and service improvements	Nominated clinical staff at project delivery site
• Urinary tract infection	✓	✓	✓	✓	✓	✓		
• Polypharmacy	✓	✓	✓	✓	✓	✓		
• Unintended weight loss	✓	✓	✓	✓	✓	✓		
Resource utilisation in dementia scale	✓	✓	✓	✓	✓	✓	Wellbeing	Proxy questionnaire
Cornell Scale for Depression in Dementia (CSDD)	✓		✓		✓		Wellbeing	Project delivery site clinical staff
Quality of Life-Alzheimer's Disease (QOL-AD)	✓		✓		✓		Quality of life	Proxy completed by staff
EQ-5D-5L	✓	✓	✓	✓	✓	✓	Health-related quality of life	Proxy completed by staff
Quality of Interactions schedule			✓		✓		Service improvements	Researcher with staff
Family carers (intervention group only) (N=8)								
Adult carer quality of life scale (Ac-QoL)	✓		✓		✓		Wellbeing	Self-completed
Focus Group Discussions			✓		✓		Overall experiences	Researcher facilitated
Staff (N=16)								
Person Centred Practice index for staff (PCPI-S)			✓		✓		Person centred relationships	Self-completed
Strain and emotional reaction in dementia care scale			✓		✓		Staff attitudes and wellbeing	Self-completed
Contact form	Throughout implementation ← →						Acceptability of technology	Staff
Online survey	✓						Reactions and learning	Self-completed
Normalisation questionnaire			✓		✓		Behavioural change post training	Self-completed
Interviews			✓		✓		Experiences of delivering CASCADE	Researcher facilitated
Focus Group Discussions			✓		✓		Overall experiences	Researcher facilitated
Local community surrounding residential homes (N=27)								
Online survey	Throughout implementation ← →						Awareness & behavioural change	Self-completed

Quantitative data were analysed using SPSS v.26 and Microsoft Office Excel (2016). Participants with more than 20% of missing data were removed from statistical analyses. Nonparametric tests were used to compare differences between timepoints and between the intervention and control groups. A 5% significance level was set for all statistical analyses, and test results were reported using means, medians, standard deviations, and exact p-values. Template analysis (Brooks et al., 2015) was used to code and analyse textual data collected using qualitative methods. A coding template constituting broad a priori codes including context, implementation and mechanisms (Moore et al., 2015) guided charting of data. Appendix 1 includes more details about the evaluation study tools.

3. Findings

This section includes demographic characteristics of participant groups. Residents' characteristics are presented in more detail incorporating gender distribution, age distribution, dementia diagnoses and changes in the sample size. Outcomes presented under the socioeconomic evaluation aspect include change in health and general living conditions and service improvements. Findings about the change in health and general living conditions cover resident's outcomes of health-related quality of life, levels of depression, polypharmacy, resource utilisation in dementia and family carers' quality of life. Service improvements encompass safety and quality of care, quality of interactions in care and user satisfaction. The behavioural change in stakeholders covers the learning and development for staff and local communities. Findings also include the acceptance of technology, which is part of the CASCADE model.

Demographic characteristics of participant groups
- All (n=16) staff identified as female ranging between 31 – 60 years old (mean age 40).
- All family carers (6 females and 2 males) were residents' children ranging between 53 – 69 years (mean age 60.25).
- The majority (92%) of the community survey respondents identified as female with age ranging from 24 to 83 years (mean age 43.96).
- There were 36 residents at baseline split between the intervention (n=20) and control (n=16) groups.
- The majority (81%) of residents were female as illustrated in Figures 1a & 1b. This gender breakdown reflects wider incidence rates of dementia in the general population worldwide which are greater in women compared to men (Beam et al.,2018).
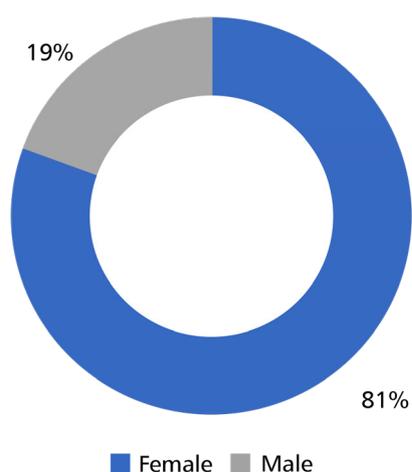

Figure 1a. Residents' gender distribution at baseline (T0)
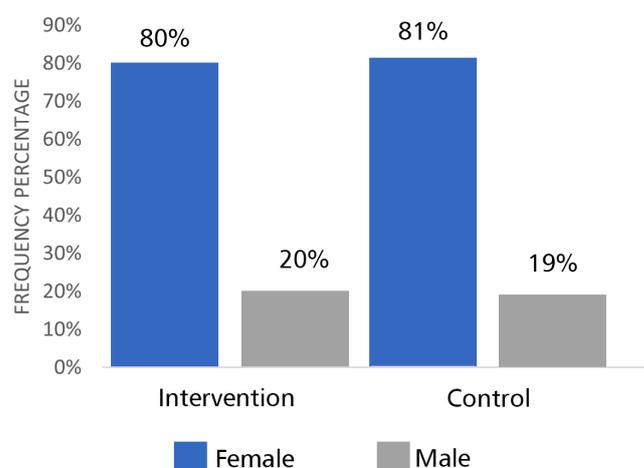
Figure 1b. Residents' gender distribution at baseline (T0) by intervention and control group

The majority of residents were aged between 81 and 90 years (Figure 2) and had been widowed at the time they were recruited in the study. The majority (97.2%) had received a clinical diagnosis of dementia at baseline except one resident who exhibited symptoms consistent with dementia at the time of data collection without a formal diagnosis.
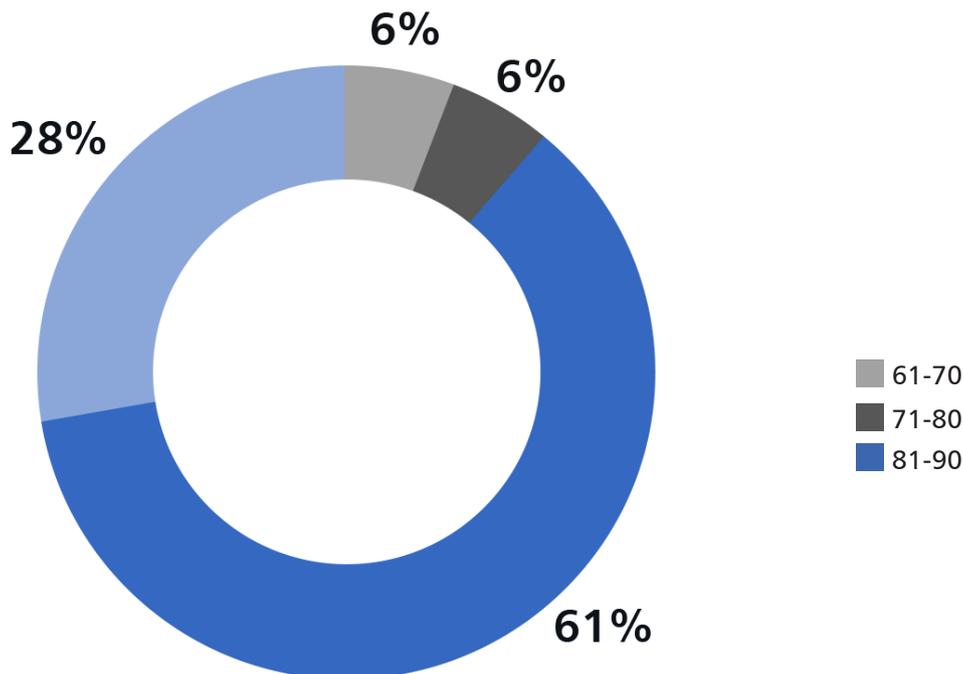
Figure 2. Residents' age distribution at baseline (T0)

Alzheimer's disease (AD) was the most frequent diagnosis accounting for 56% of all cases followed by unspecified dementia (25%). Mixed and vascular dementia each accounted for 6% of the total sample of residents (Figure 3). This is consistent with global estimates that AD is the most common type of dementia in older adults suggesting that the study sample was representative of the broader population.
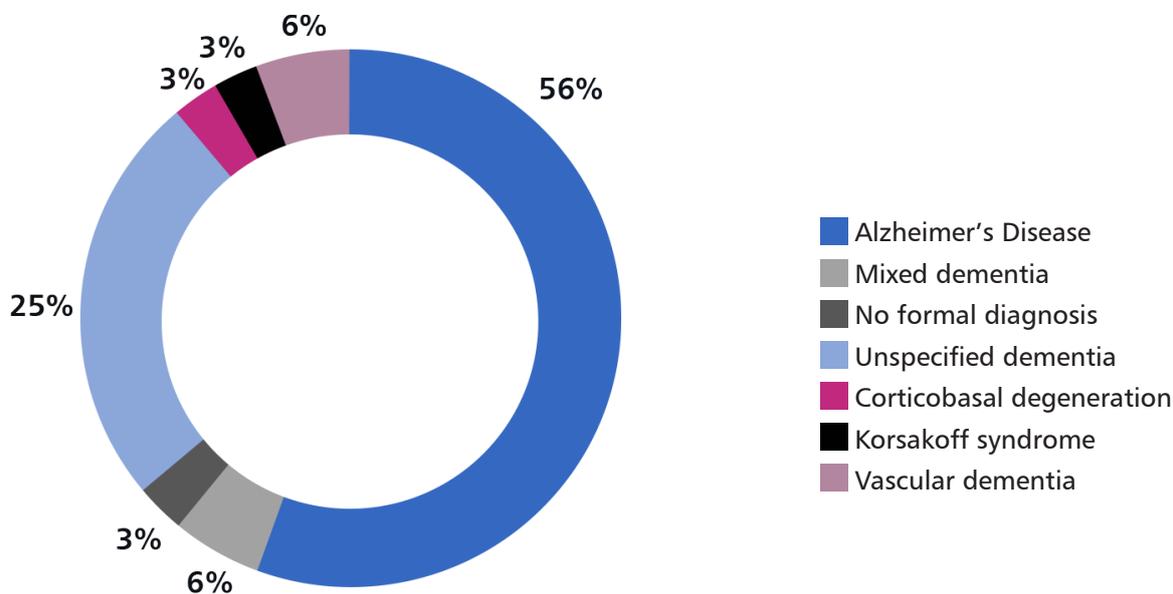
Figure 3. Residents' type of dementia diagnosis at baseline

Attrition

- 25 residents participated in the study at all three timepoints out of the 36 residents recruited at baseline (Figure 4).
- 11 residents died during the study resulting in a 31% level of attrition between T0 to T2.
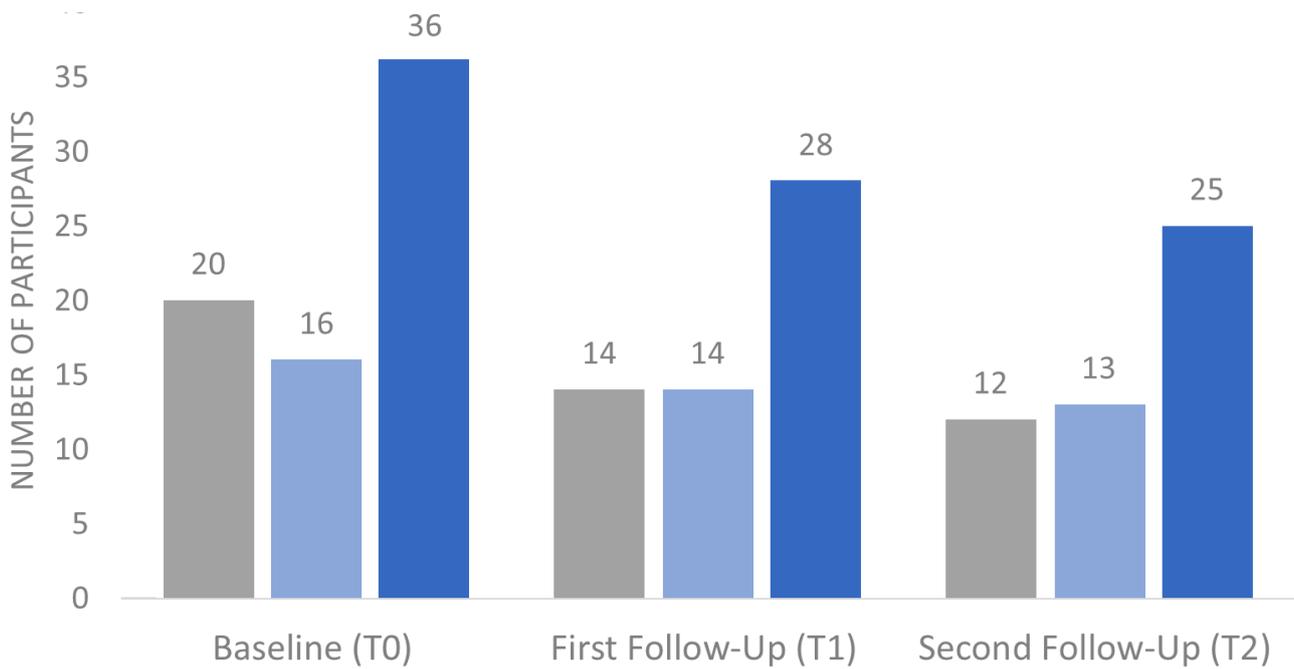
Figure 4. Resident headcount at baseline (T0), (T1) and (T2)

3.2 Socioeconomic outcomes

Improved health and general living conditions

Health-related quality of Life

The EQ-5D-5L questionnaire was used to assess the residents' changes in health-related quality of life. The Paretian Classification of Health Change (PCHC) analysis identified that residents in the intervention group experienced improvements (18%) and mixed changes (27%) more often than the control group (12% and 14% respectively) (Figure 5). The frequency of worsening was comparable between the intervention (24%) and the control groups (25%). However, residents in the control group were observed to experience 'no changes' more frequently (49%) than the intervention group (31%).
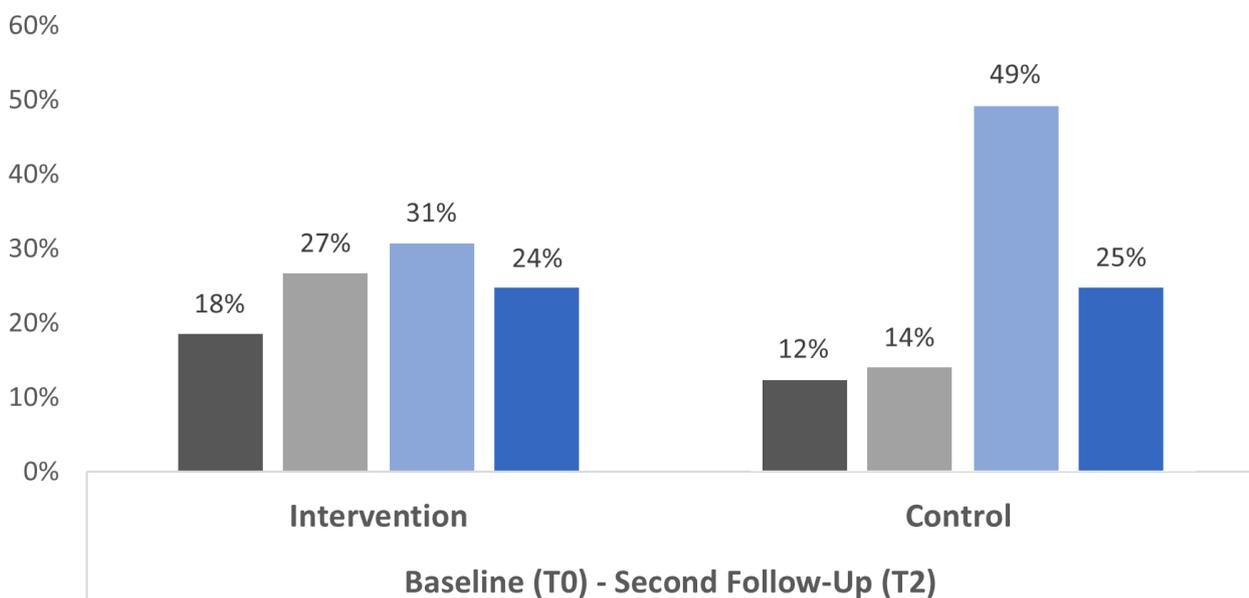
Figure 5. Residents' health-related quality of life

Observable changes indicated an improvement in 'mobility' among residents in the intervention group receiving the CASCADE model of care between T1 and T2 (Figure 6). A similar trend was observed in the 'self-care' dimension from T0 to T1. Conversely, observable differences revealed that participants in the control group experienced a deterioration in 'mobility' from T0 to T1 and in 'self-care' from T1 to T2. Comparison between the intervention and control groups revealed that residents in the control group who received routine care had worse 'mobility', 'self-care' and 'usual activities' at all timepoints compared to their intervention counterparts. The difference in mobility scores was statistically significant at T2 (p = 0.02*). Figure 6 shows the changes in all domains of the EQ-5D-5L.
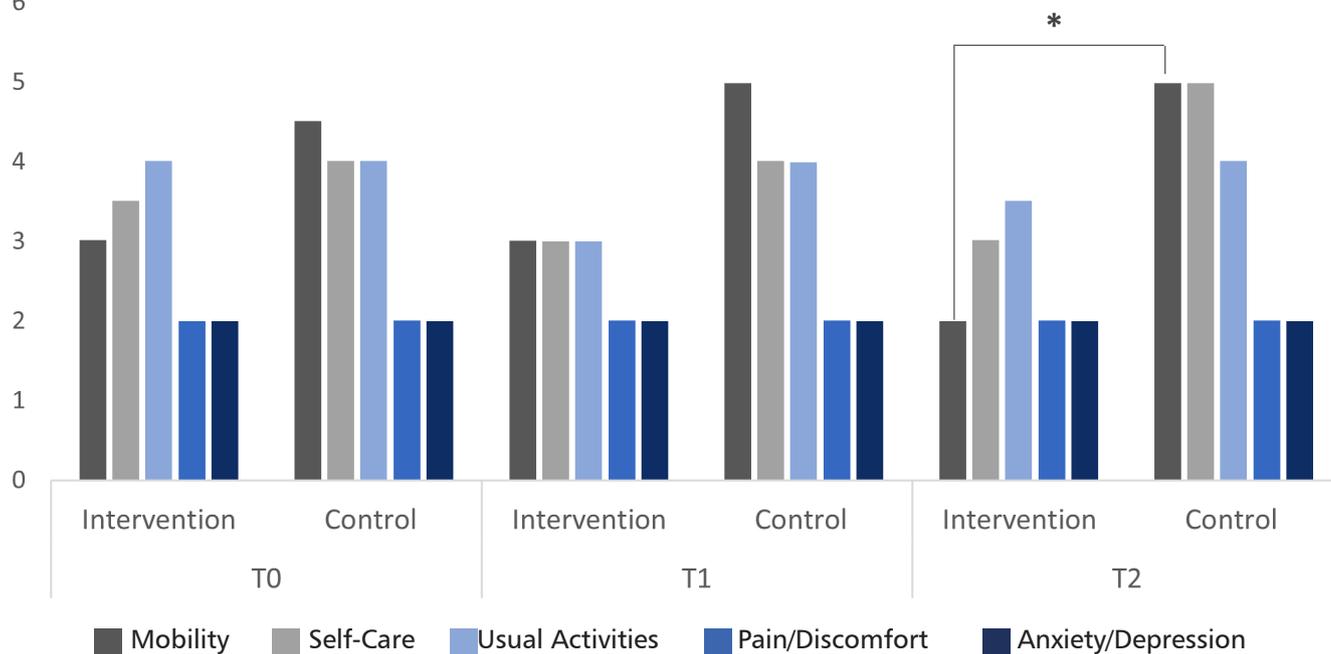
Note: Lower scores represent better quality of life along a particular dimension

Figure 6. Residents' EQ-5D-5L scores by group and study timepoint

Residents in the intervention group had statistically significant higher EQ-5D-5L health scores at T1 (p = 0.01*) and T2 (p = 0.04*) compared to those in the control group. As indicators of health are more obvious and therefore more likely to be objectively assessed, these results suggest an improvement in the health-related quality of life of the residents who received the CASCADE intervention compared to the control group (Figure 7).
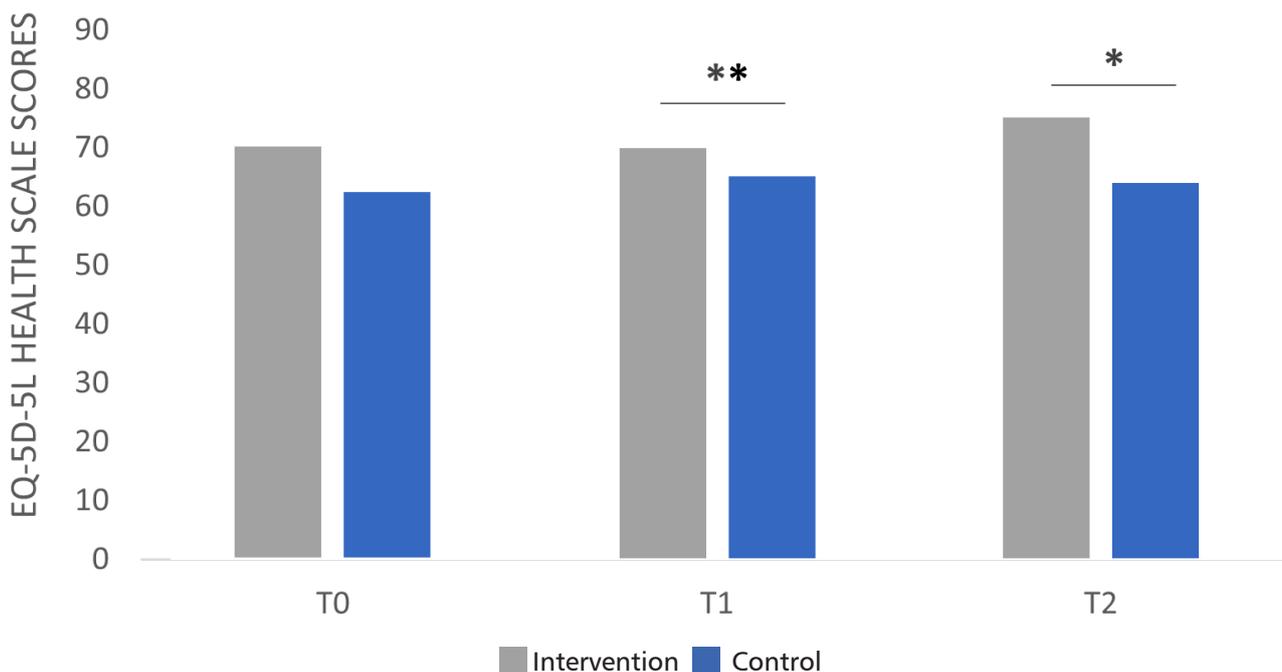
Figure 7. Residents' health scores by group and study timepoint

Depression and wellbeing

The wellbeing of residents in the intervention group was assessed by examining the prevalence of symptoms of depression (Figure 8). At baseline, anxiety and sadness were the most frequently reported symptoms (60% and 85%, respectively), while early morning awakenings and weight loss were the least reported (5% and 5%, respectively). Notably, anxiety and sadness remained the most reported symptoms of depression at both T1 (83% and 91%, respectively) and T2 (67% and 67%, respectively). Assessing the severity of dementia was not as part of the evaluation study. However, it is likely that participating residents presented with moderate to severe dementia considering Belgium's eligibility for entry into long-term residential care. Weight loss was among the symptoms least experienced at T0 and T2 (5.3% and 8.3%). At T1, 33% of residents experienced unintended weight loss greater than 15% of total bodyweight.
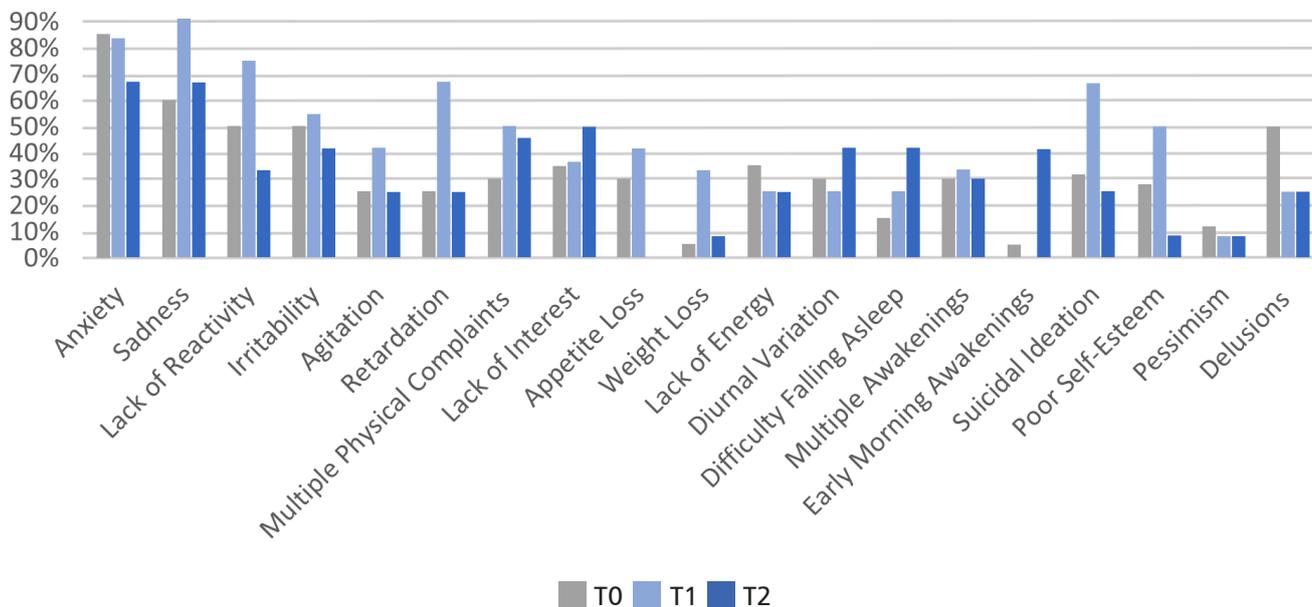
Figure 8. Prevalence of symptoms of depression in the intervention group measured on the Cornell Scale for Depression in Dementia (CSDD)

The number of residents with clinical depression (mean > 0.42) fluctuated throughout the study timepoints. At baseline, seven participants presented with clinical depression. By T1, four of the seven residents had passed away. The proxy EQ-5D-5L scores of these four residents indicated severity in the mobility, 'self-care' and 'usual activities' domains. Residents presenting with clinical depression decreased to five for both T1 and T2.

No statistically significant differences in residents' symptoms of depression across the three study timepoints were identified. This may be due to the small sample size. However, observable differences indicated an overall decrease in residents' 'mood-related signs', 'physical signs' and 'ideational disturbance' between T0 and T2 (Figure 9).
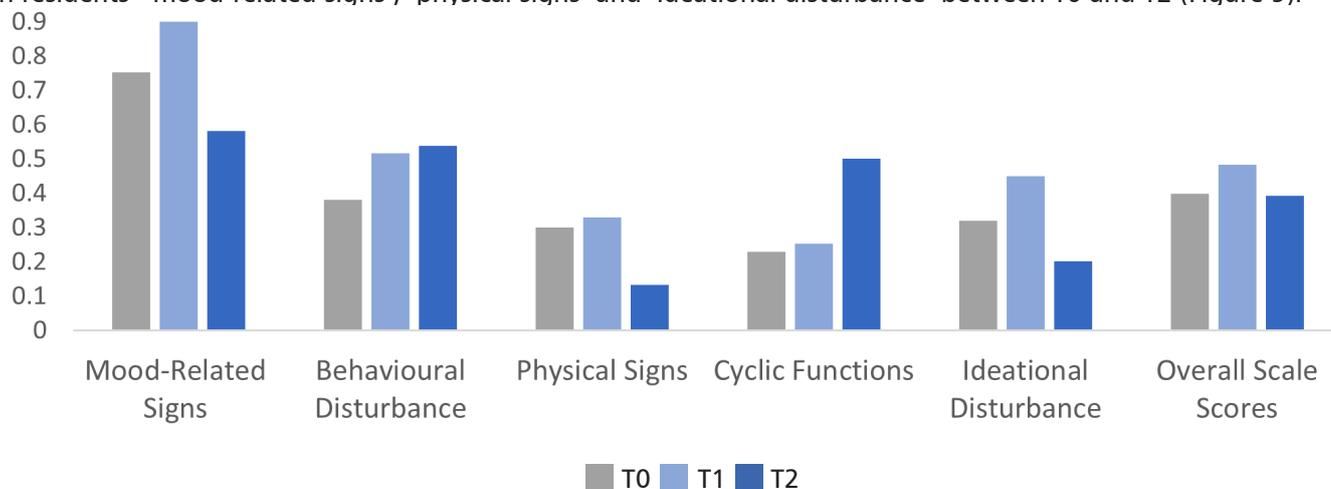
Figure 9. Intervention group residents' CSDD scores by domain and study timepoint

Correlation analyses between residents' CSDD and Quality of life in Alzheimer's Disease (QoL–AD) scores identified statistically significant inverse relationships between the two at T0 (p=0.026*) and T2 (p=0.009**). That is,

residents in the intervention group experienced lower quality of life when symptoms of depression were more prevalent. These results demonstrate validity of the measures used in the evaluation, which align with previous research linking depression and impaired quality of life in people living with dementia (Chan et al., 2011; Stensvik et al., 2021).

Quality of life of residents in the intervention group

Some noteworthy improvements in most of the intervention group residents' scores were observed on the QoL-AD scale (Figure 10). For example, scores for the 'energy' domain gradually improved between baseline and T2. A modest improvement in residents' overall quality of life was noted between baseline and T2. These results are consistent with the health-related quality of life of the intervention group. Improvements were also observed in residents' 'ability to do household chores', 'mood' and 'living situation' between baseline and T2. There was a noticeable decline in residents' memory scores between T0 and T2, which is expected in a condition characterised by progressive decline in cognitive functions.
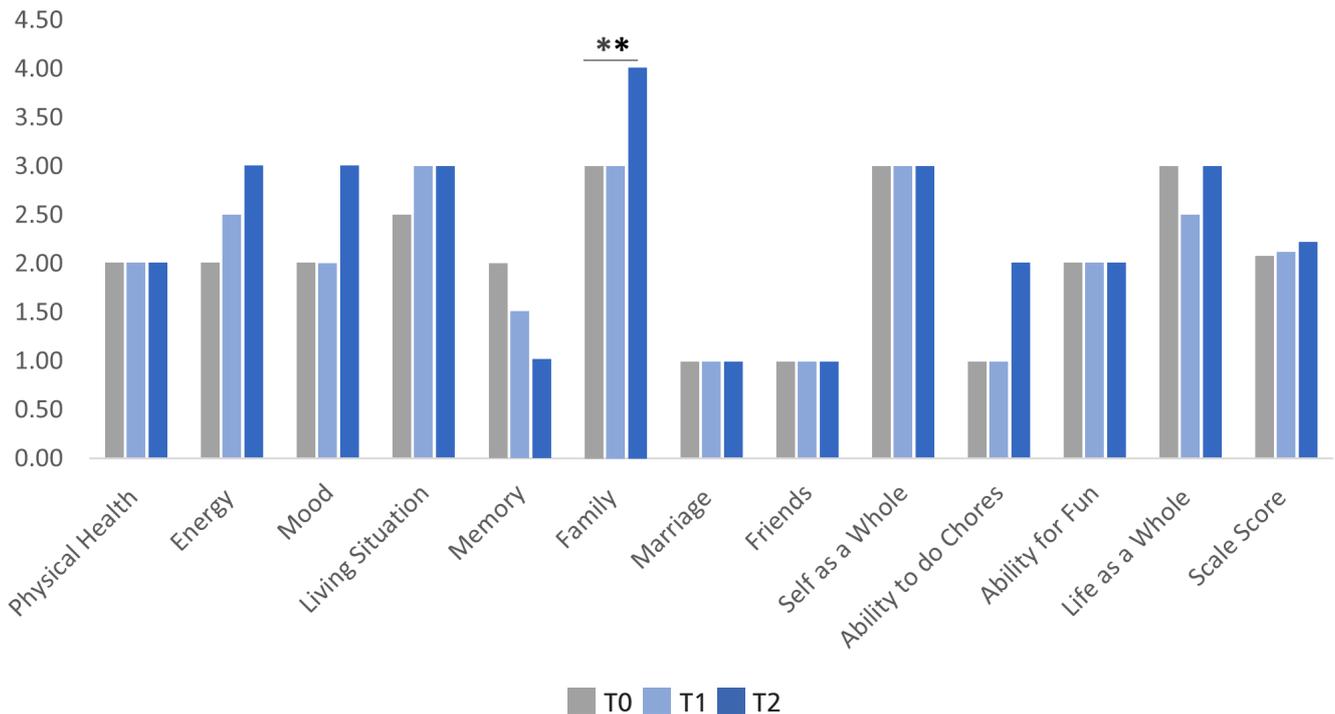
Figure 10. Residents' scores on the QoL-AD scale by study timepoint

Comparative analyses identified statistically significant improvements in the residents' 'family' life from T0 to T2 and between T1 and T2. This dimension of the QoL-AD scale is an important measure the influence of dementia on the individual's family and their ability to provide care and support. Improvements in this area are also indicative of enhanced social support, reduced caregiver burden, and improved relationships between people living with dementia and family carers. Process evaluation findings revealed that family carers valued residents' daily structure and social interactions that offered meaningful living in a lively and safe environment as a family carer commented:

> *Well, she is with people and that was important to her because she never sat in her room. She was always in the living room talking to people. She joined in with activities…for our mother that was a salvation* **[Daughter of a resident].**

The concurrent use of medications (polypharmacy)

On average, both the intervention and control groups used more than five medications concurrently at all timepoints of the evaluation study, indicative of polypharmacy. This is not uncommon among older adults in long-term residential care (Cioltan et al., 2017). At baseline residents in the intervention group used more medications of various types compared to the control group and this difference was statistically significant ($p < 0.01$) (Figure 11). However, the use of medications decreased by 30.83% in the intervention group by T2 compared to baseline.
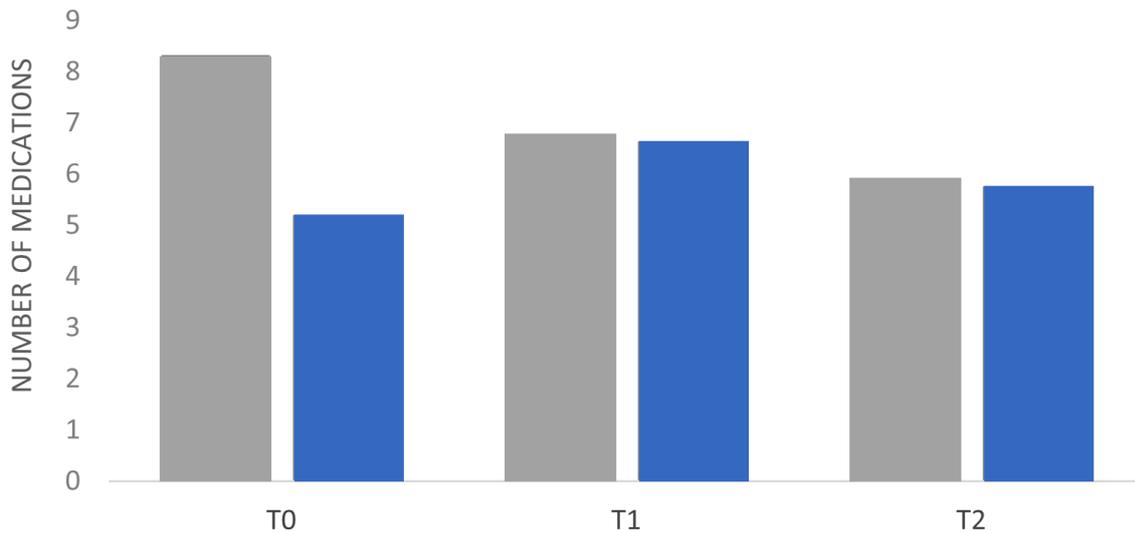
Figure 11. Number of medications used by resident group and study timepoint

Comparative analyses also revealed a statistically significant reduction (37.42%) in using central nervous modulating medication in the intervention compared to the control group from T1 to T2 ($p < 0.01$). In contrast, the control group experienced a slight increase of using central nervous modulating medication at T2 which was not statistically significant (Figure 12). The significant reduction in using medications in the intervention group suggests that a targeted model of care may reduce unnecessary medication use and promote safer prescribing practices for people living with dementia.
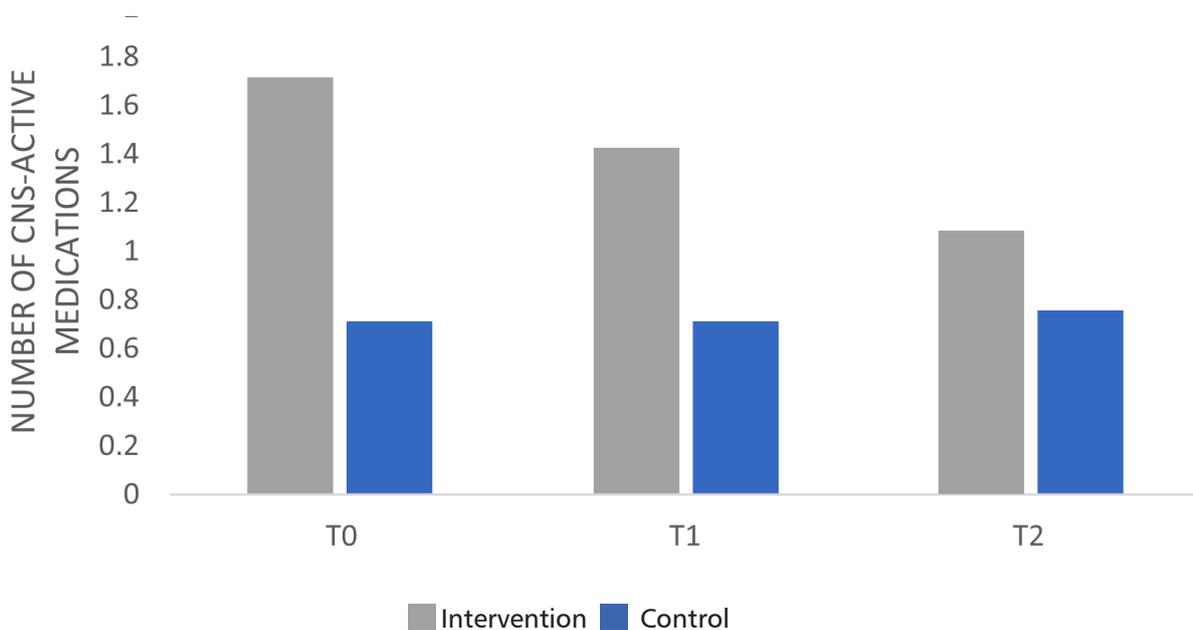
Figure 12. Number of central nervous modulating medication used by resident group and study timepoint

Resource utilisation in dementia

No outstanding changes were observed between baseline and follow-up timepoints in hospital admissions and urgent care visits. The use of these services remained low in both groups throughout the study. No visits were made to the geriatrician, neurologist, psychiatrist, social worker or psychologist. However, visits to the General Practitioner (GP) decreased by more than half (55.03%) from baseline to T2 in the intervention group. Conversely, an increase of 120.75% was noted among control group residents between baseline and T2 (Figure 13). Comparative analyses revealed that this increase was statistically significant. It was not possible to analyse differences in occupational therapy use between groups across the timepoints of the evaluation study due to variations in scoring.
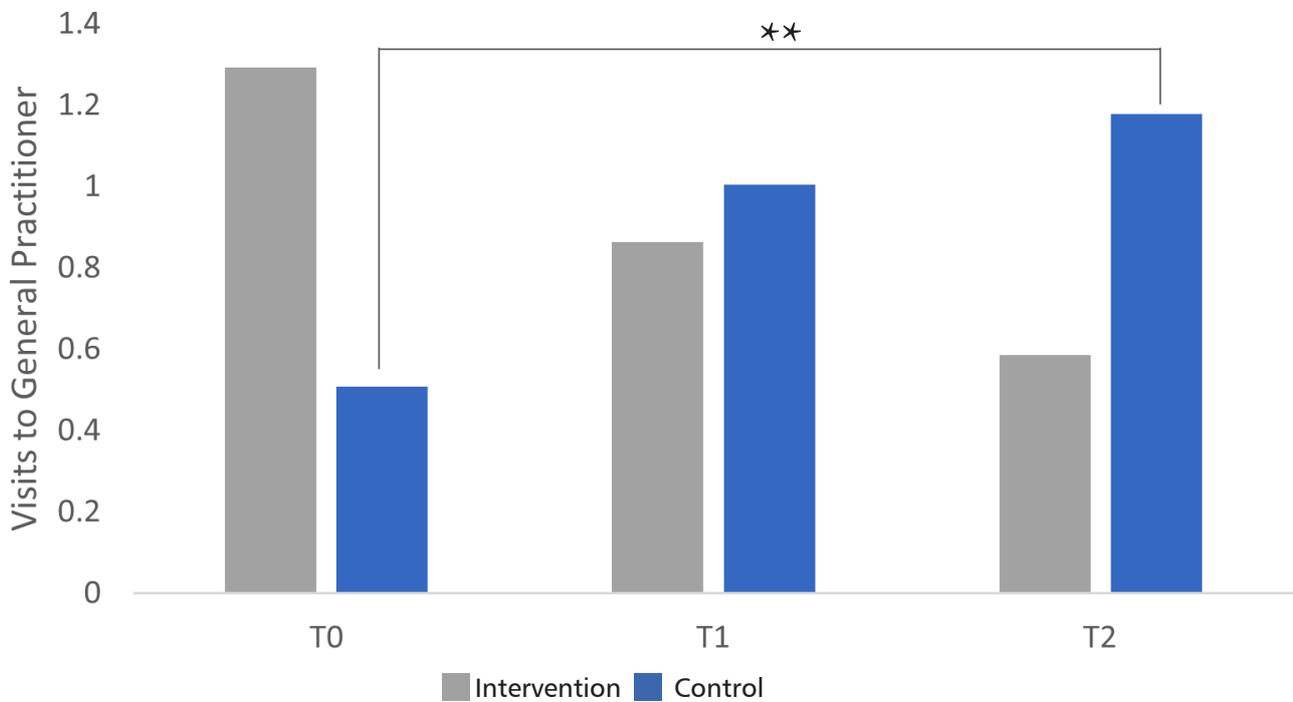
Figure 13. Residents' General Practitioner visits by group and study timepoint

Family carers' quality of life

Family carers' scores on the Adult Carer Quality of Life (AC-QoL) scale are illustrated in Figures 14a and 14b. The 'caring stress' and 'caring choice' subscales were rated lowest at both T0 and T1. The 'support for caring' dimension was rated as 'moderate' at all timepoints indicating that family carers perceived that they received average levels of emotional, practical and professional support. These results are reflected in the qualitative findings where family carers identified less support from staff particularly at weekends when limited staff presence was apparent. A family carer echoed:

> *What I miss is a contact point for the family or staff to talk about our concerns and …, well…worries and fears. And, how you are doing. That doesn't get much attention…people need it sometimes* [**Daughter of a resident**]**.**

Finally, family carers' overall scale scores improved notably between baseline and T2. This suggests the CASCADE ways of working had a positive effect on the family carers' well-being and overall quality of life. It is worth noting that the actual factors contributing to this improvement cannot be concretised without further investigations preferably based on a larger sample.
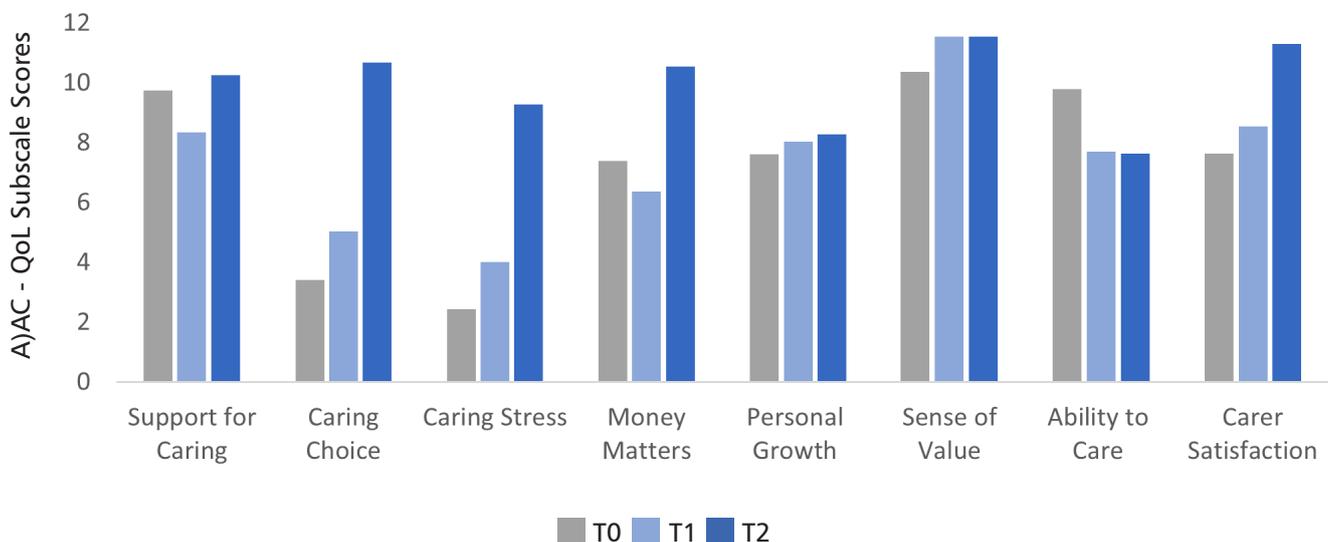
Figure 14a. Family carers' scores on the AC-QoL scale domains by study timepoints
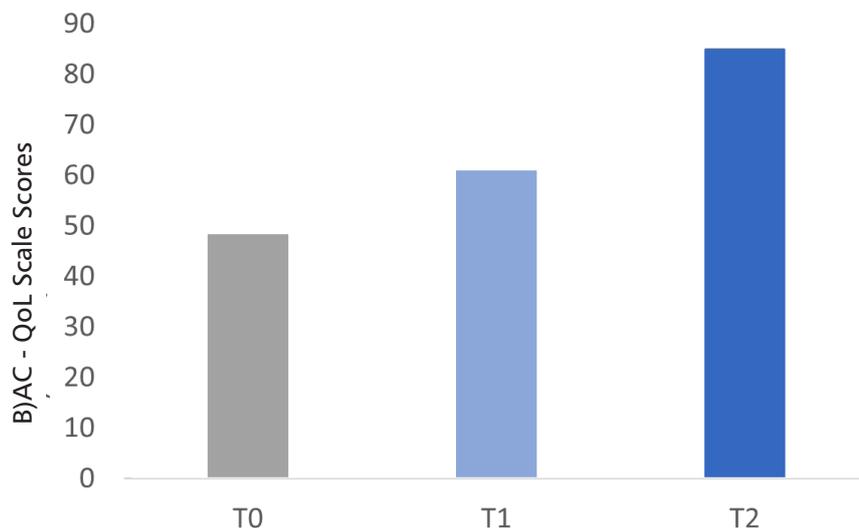
Figure 14b. Overall changes in family carers' AC-QoL scores across the study timepoints

Family carers' self-reported scores were not statistically significant between the evaluation study timepoints. However, the small sample size likely affected the study's ability to detect significant effect sizes.

Services improvements

Safety and quality of care

The incidence of safety and quality of care indicators assessed included weight loss, falls and urinary tract infections (UTIs). Incidences of weight loss were lower among residents in the intervention group compared to the control group at T1 (21% and 42%, respectively) and T2 (25% and 9%, respectively). The overall rates of weight loss remained relatively low in both groups.

The intervention group had a higher percentage of residents who experienced falls at baseline compared to the control group (44% and 31%, respectively). While the incidence of falls decreased over time in both groups, the intervention group experienced more improvements with lower incidences compared to the control group at T1 (21% and 25%) and T2 (8% and 18%). The intervention group also had a lower incidence of UTIs compared to the control group at T2 (0% and 18%, respectively). Overall, the data suggest service improvements related to the CASCADE model and good standards of care provided to both groups. Residents in the intervention group experienced some positive effects on incidences of weight loss, falls and UTIs (Table 2). However, the small sample size makes it difficult to draw definitive conclusions from these findings.

Table 2. The incidence of care safety and quality indicators by resident group and study timepoint

	Intervention Group			Control Group		
	T_0 (n = 16)	T_1 (n = 14)	T_2 (n = 12)	T_0 (n = 16)	T_1 (n = 12)	T_2 (n = 11)
Weight Loss	1 (6%)	3 (21%)	3 (25%)	4 (25%)	5 (42%)	1 (9%)
Falls	7 (44%)	3 (21%)	1 (8%)	5 (31%)	3 (25%)	2 (18%)
UTIs	3 (33%)	2 (18%)	0 (0%)	1 (9%)	4 (33%)	2 (18%)

Quality of Interactions in Care

A total of 28 and 22 observations were recorded at T1 and T2, respectively at one study site only using the Quality of Interactions Schedule (QUIS) for observing communication between staff and residents. Data from the second implementation site in Belgium were not available at the time of the analysis. The nature of the

interactions observed was predominantly verbal at both study time points (89.29% and 81.82%, respectively). The overwhelming majority of interactions were rated as 'positive social care' at T1 (Figure 15) indicating that staff frequently employed a person-centred approach involving empathy, dignity, respect and inclusion. At T2, 50% of the interactions observed were rated as 'positive social care', followed by 'positive care' (36.36%). Positive care interactions enhanced residents' feelings of importance and safety. A few interactions were scored as neutral (indifferent) at T1 and T2. However, there were no negative interactions reported.
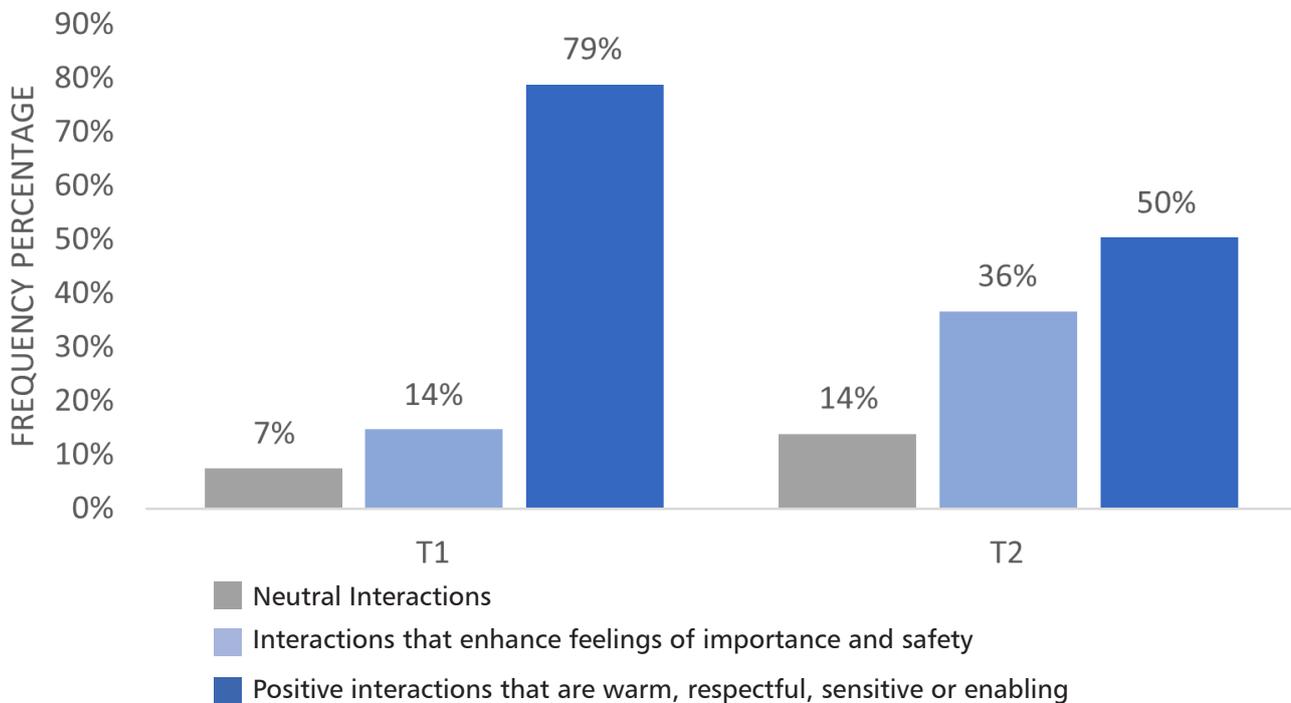

Figure 15. Quality of interactions in care ratings by study timepoint

The QUIS ratings showed a slight decline in the quality of interactions at T2 compared to T1. This result may be linked to staff experiences of implementing the CASCADE model within challenges of staff shortages, which were exacerbated by the COVID-19 pandemic. Staff stated:

I think… one staff per four residents would be ideal so you can be even more person-centred in that way, because, uh, we already do a lot, but still, somewhere you are also caught up in the fact that people must be cared for. Someone may take an hour to eat a meal in the afternoon. Everyone wants to support that with the best will in the world, but it does mean that your whole pattern of care is compromised [**Staff member**].

A number of people [staff] left due to COVID and we had to replace them quickly, but you don't feel the click with dementia care … and then you feel that it takes a lot of energy to get those new people [staff] on board with the vision in which dementia care is different from just caring for someone without dementia [**Staff member**].

Changes in health and care systems made around the globe to prevent and control the spread of COVID-19 had little consideration for people living with dementia (Martin, 2022). Some of the staff trained to deliver the CASCADE model shared their experiences of constraints on person-centred care during the COVID-19 pandemic and how the CASCADE model facilitated overcoming these constraints. While care delivery shifted from person-centredness to task oriented care, refocusing processes to what works well in dementia care was more acceptable in implementation sites with existing provisions than new establishments (Martin & Hatzidimitriadou, 2022). Workplace cultures were notably flexible in existing provisions where COVID-19 stimulated improvements in multidisciplinary working (Martin, 2022).

Emmaüs extended the long-term residential care service to offer holiday with care for people living with dementia with services tailored to the CASCADE model. The evaluation of this service is based on the 11 responses received. On average, users of the Emmaüs tourism suite rated all aspects of the service close to 'excellent' [a rating of 4] (Figure 16). 'Communication' scored highest followed by the quality of service and friendliness and helpfulness.
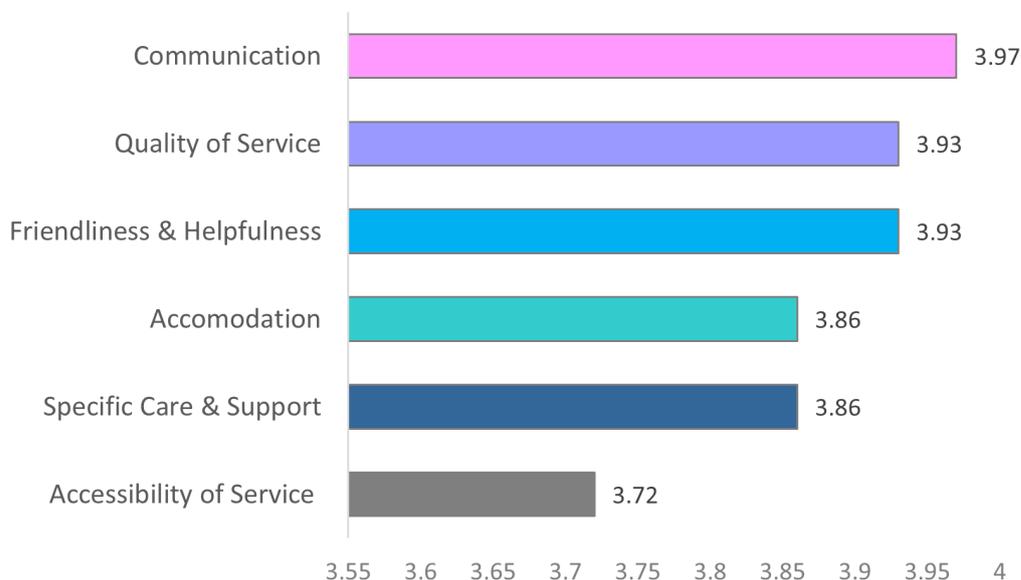
Note: Response options included 1 (bad), 2 (mediocre), 3 (good), 4 (excellent) with a 'does not apply' (5) option
Figure 16. User feedback on the holiday with care service at Emmaüs

The extra holiday with care component was a service improvement for people living with dementia frequently excluded from society's designs of luxury recreational facilities.

3.3 Behavioural change in stakeholders

The behavioural change in staff was evaluated using the 'strain and emotional reactions in dementia care', person-centred practice index and normalisation scales. Community attitudes were assessed through an online survey.

The strain and emotional reactions in dementia care scale comprises three domains including attitudes towards behavioural experiences, strain in providing care and emotional reactions in care.
Attitudes towards behavioural experiences: staff views of residents' behavioural experiences were mostly positive with observable improvements at T2 compared to T1 (Figure 17). Staff considered residents less aggressive (76.92% vs. 61.53%), less anguished (76.92% vs. 66.66%) and more rewarding to work with (100% vs. 90.90%). Overall, median scores for staff attitudes towards behavioural experiences remained consistent between T1 and T2.
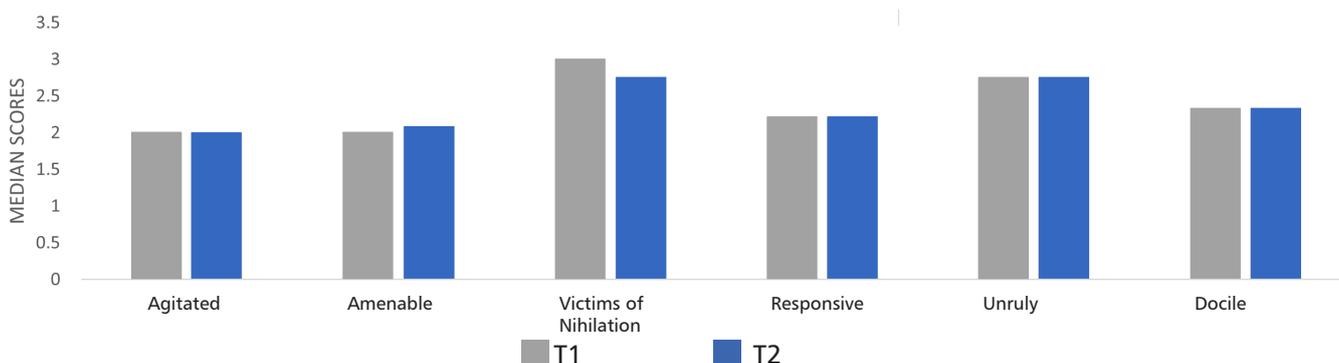
Note: Lower scores indicate higher agreement
Figure 17. Staff's scores on the attitude towards behavioural experiences

Strain in providing care: Staff perceived 'wilfulness' as a notable source of strain in providing care and the difference between T1 and T2 scores was statistically significant (Figure 18). Results of the process evaluation identified a high rate of staff turnover and staff shortages at both implementation sites. These factors challenged consistency in providing care tailored to the CASCADE model as well as allocating appropriate staff caseloads because care needs are not generalisable. The perceived difficulty in handling 'agony' decreased slightly between the two timepoints, while handling 'obedience', 'emptiness', 'evaluation', and 'responsiveness' behaviours remained stable. These findings suggest that the staff may require repeat training and continuous support.
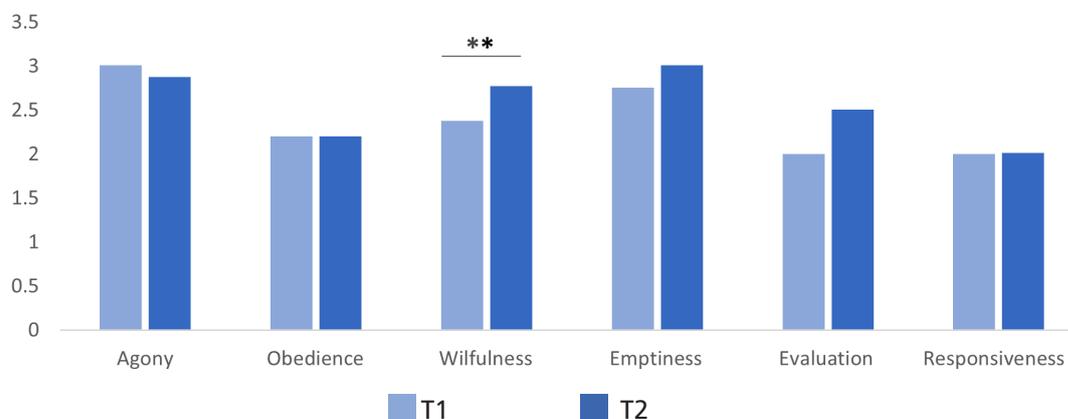
Note: Higher scores indicate higher levels of perceived difficulty in handling the behaviour
Figure 18. Staff scores on the strain in providing care domain

Emotional reactions in care: Findings indicate improvements in staff' experiences of emotions in dementia care (Figure 19). Self-reported scores showed an increase in feelings of 'love' and 'tenderness' towards residents between timepoint T1 and T2. Results also point towards a reduced occurrence of reactions such as 'rejection' and 'defeat'. Additionally, perceptions of negative emotions such as feeling 'unimportant', 'rejected', and 'superior' decreased from 'once in a while' at T1 to 'never' at T2. Figure 19 illustrates improvements in perceptions of the different emotions. Some staff were present at only one timepoint, resulting in a sample of only 10 participants at both timepoints across the two evaluation study sites.
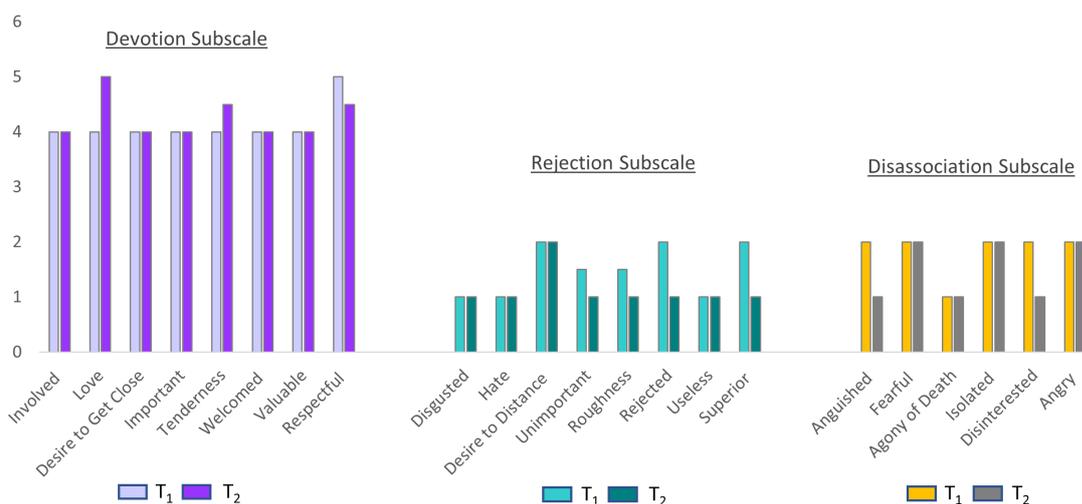
Figure 19. Staff scores on the emotional reactions in care domain

Person-centred Practice

The person- centred practice index (PCPI) was used to assess practice in interpersonal relations and systems of support in care. Sixteen staff completed the survey, with nine of them (56.25%) present at both T1 and T2.

Participating staff included care assistants (44%), logistics /home assistants (25%), floor coordinators (13%), a music therapist (6%), occupational therapist (6%) and nurse (6%).

Slight improvements on the prerequisites for the person-centredness domain were observed in nearly all areas except for professional competence, which decreased at T2 compared to T1 (Figure 20). A decline was observed across 75% of the care environment domain. However, there were improvements in skills mix and working with residents' values at T2. Improvements were also registered across elements constituting the care processes domain.


THE CARE ENVIRONMENT

■ T1   ■ T2
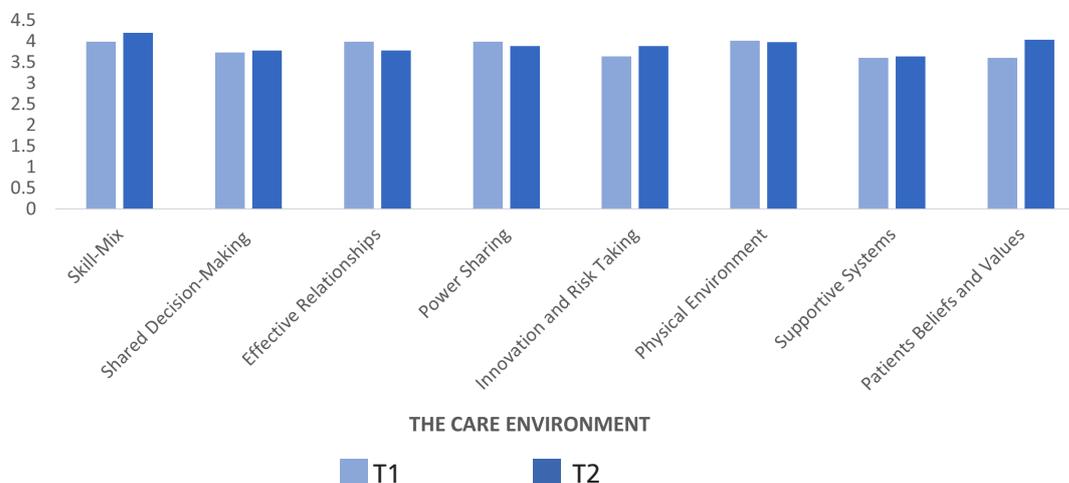
Figure 20. Staff scores on the Person-Centred Practice Index by domain and timepoints

Implementing new practices

Staff completed a normalisation questionnaire to assess the likelihood of embedding the training in daily practice. Overall, staff reported high levels of familiarity with the CASCADE training and perceived it as a valuable tool for improving care processes with the potential to become a normal part of their work. The findings suggest that CASCADE training was well-received and has the potential for long-term integration into care practices.

In terms of understanding of the model, over 50% of the staff could see how CASCADE differs from usual ways of working, and approximately two-thirds felt that they had a shared understanding of the model and were generally open to working with colleagues in new ways. Staff felt management was adequate in supporting the model. However, a little over a third raised some concerns about the insufficient resources available to support the CASCADE model of care. Qualitative findings identified other mechanisms that facilitated positive outcomes including:

- the life story booklet providing information about the resident,
- the wish tree and attention person contributing to the fulfilment of residents' aspirations and
- the tranquil and homely environment providing a sense of belonging as well as reassurance of good standards of care.

Community views

The survey assessing the influence of the CASCADE information materials developed on the attitudes towards people living with dementia showed that good understanding of dementia developed in local communities. All respondents (n=27) agreed that a diagnosis helps planning, people living with dementia should be involved in decision making and that a range of strategies can help them in everyday life. The majority (81%) of respondents knew someone with dementia and an equal percentage believed people living with dementia can contribute significantly to the

community. 96% of the respondents correctly identified that people living with dementia do not need assistance all the time while 78% agreed that maintaining independence was helpful. A notable proportion (41%) of the respondents could communicate with people living with dementia while 26% were not sure they could improve the lives of people living with dementia. Further community engagements may be necessary to improve community responses to people living with dementia particularly communication skills and the commitment to supporting dementia friendly communities.

Technology acceptance

Using technology in dementia care was more established at the Emmaüs tourism suite than elsewhere in the long-term residential care facilities. A smart lamp is used to monitor guests to optimise their independence and safety. Other examples of technology used in the long-term residential care facilities included:

- Portable devices with GPS tracker such as wearables and phones used to maintain independence and residents' safety.
- Access controls such as two-step latches and magnetic keys used to enhance privacy and security.
- Magic table for stimulating meaningful interactions.
- Automated alerts for necessary top ups such as money cards and phone allowances.
- Motion sensors for detecting wandering.

Overall, staff at both implementation sites in Belgium largely agreed that the technology used was user friendly, time saving and worked as expected. However, qualitative results identified that staff believed the warmth of living beings was more valuable in dementia care than the contribution of technology as indicated in the quotations below:

I have my reservations about that [technology supporting better care] *because …it does not retain that warm character. We do have these robot dogs and all, but that is still a robot dog that moves a bit… They try to do a lot, but it remains something artificia*l **[Staff member].**

… there is nothing like a human relationship and a human connection. For example, the experience table is nice, but what makes it extra? … it is not the experience table itself but who people connect with. The experience table offers the means and not the goal... it comes down to the ambiance you create where people are chatting to each other…and that there is interaction **[Staff member].**

4. Conclusion

Findings suggest that the CASCADE model is generally effective in improving dementia care and staff understood it well. Following the CASCADE training programme 'you and me, together we are human', staff obtained individual confidence in dementia care as well as team effectiveness. While disparities existed in the settings of the two implementation sites, the value of respecting people living with dementia beyond the neurological losses of the condition was shared. Family carers appreciated the respect, autonomy and choice residents experience and the liveliness of the care environment demonstrated with the CASCADE ways of working. The evaluation study examined short-term outcomes within limitations of small sample sizes and interruptions underpinned by the COVID-19 pandemic. Similarly, implementation of the CASCADE model occurred amidst several challenges. The evaluation study sites experienced a high staff turnover rate during the pandemic and chronic shortages in the labour market limited opportunities of choosing staff competent in dementia care. Fragmented information and communication systems in community and hospital care were reported to deter advance care planning and understanding the care needs of people living with dementia. Staff and family carers suggested some measures to improve the effectiveness of the CASCADE model and sustainability of good standards of care:

CASCADE training

- Expand dementia care training across organisations providing care to create common values.
- Ongoing staff training should be embedded in discussing real cases, which requires inhouse trainers for a practice-oriented approach to learning.
- Dementia care training and education must be provided in institutions of learning to improve awareness and minimise prejudices students on placement carry.
- Delivery of care
- Integrated information sharing systems are necessary for effective liaison between home and residential care.
- A visual display of staff roles is advised to enable family carers to address queries concerning residents to the right members of staff.
- Organisations should provide sufficient staff resources to support the model of care.
- More engagements facilitating the wider spread of dementia-friendly communities may enhance the magnitude of impact of the CASCADE model.

The CCCU project team leading CASCADE Work Package 3: Evaluation, has so far published 6 peer-reviewed articles in international journals. The publications with over 65 citations informed CASCADE Work Packages and other programmes aimed at improving the care and support of people living with dementia. Some of the areas of impact include informing curriculum development for interprofessional dementia care in the United States; influencing the design of effective community care and support pathways; and stimulating the re-evaluation of the resilience of national health systems in responding to global health crises.

Below is an up-to-date list of WP3 peer-reviewed academic publications:

Martin, A. (2022). Overcoming COVID-19 constraints on person centered Dementia Care: a narrative inquiry of lived experiences of residential care staff in Belgium. Journal of Long-Term Care.

Martin, A., & Hatzidimitriadou, E. (2022). Optimising health system capacity: a case study of community care staff's role transition in response to the coronavirus pandemic. Health & Social Care in the Community, 30(5), e2147-e2156.

Smith, R., Martin, A., Wright, T., Hulbert, S. and Hatzidimitriadou, E., (2021). Integrated dementia care: A qualitative evidence synthesis of the experiences of people living with dementia, informal carers and healthcare professionals. Archives of Gerontology and Geriatrics, 97, pp.104471

Smith, R., Wright, T., Martin, A., & Hatzidimitriadou, E. (2020). The CASCADE project: exploring a 'guesthouse' concept. Journal of Dementia Care, 28(5), 20-21.

Martin, A., O'Connor, S. J., & Jackson, C. (2018). A scoping review of gaps and priorities in dementia care in Europe. Dementia: The International Journal of Social Research and Practice.

Wright, T., & O'Connor, S. (2018). Reviewing challenges and gaps in European and global dementia policy. Journal of Public Mental Health.

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https://www.alzheimer-europe.org/policy/national-dementia-strategies/belgium-flanders

Martin, A. "Overcoming COVID-19 Constraints on Person Centered Dementia Care: A Narrative Inquiry of Lived Experiences of Residential Care Staff in Belgium." *Journal of Long-Term Care* (2022).

Martin, A., and Hatzidimitriadou, E. "Optimising health system capacity: a case study of community care staff's role transition in response to the coronavirus pandemic." *Health & Social Care in the Community 30(5)*, (2022): e2147-e2156.

Moore, G. F., et al. "Process evaluation of complex interventions: Medical Research Council guidance." *BMJ 350* (2015).

Smith, R., Martin, A., Wright, T., et al. "Integrated dementia care: A qualitative evidence synthesis of the experiences of people living with dementia, informal carers and healthcare professionals". *Archives of Gerontology and Geriatrics 97*, (2021): 104471.

Stensvik, Geir-Tore, et al. "Cornell's Depression for Dementia Scale: A psychometric study among Norwegian nursing home residents." *Archives of Gerontology and Geriatrics 93*, (2021): 104325.

Appendices

Appendix 1. Evaluation data collection tools

EQ – 5D – 5L
The EQ-5D-5L is a brief instrument measuring five dimensions of health-related quality of life, including mobility, self-care, pain/discomfort, usual activities, anxiety/depression. Five response items are provided for each item ranging from (1) 'no', (2) 'slight', (3) 'moderate', (4) 'severe', and (5) 'extreme problems/unable to'. The questionnaire includes a visual analogue scale (VAS) to rate a person's current health, anchored at 0 for "the worst health you can imagine" and 100 for "the best health you can imagine". EQ-5D-5L scores were obtained by proxy.

Cornell Scale for Depression in Dementia
The Cornell Scale for Depression in Dementia (CSDD) is a reliable and valid screening tool for depression in people living with dementia. The scale has 19 items and scores range from 0 (absent) to 2 (severe), with higher scores indicating greater depressive symptomatology. The five factors in the CSDD scale are emotion-related symptoms, abnormal behaviours, body symptoms, rhythm function disorders, and thinking disorders. Residents' symptoms of depression were proxy-rated by healthcare professionals.

Quality of Life in Alzheimer's Disease

The Quality of Life in Alzheimer's Disease (QoL-AD) measures quality of life across 13 domains using a four-point Likert scale (poor to excellent) including physical health, energy, mood, living situation, memory, family, marriage, friends, self, ability to do chores, ability to do things for fun, money, and life as a whole. Scores range from 13 to 52, with higher values indicating better quality of life. The QoL-AD measure was chosen as it robustly encapsulates all life aspects of people living with dementia and may provide complementary insights into their perceived health and wellbeing at the time of measurement.

Polypharmacy

Polypharmacy, as defined by the World Health Organisation, refers to the administration of multiple or an excessive number of drugs at the same time. The most used criterion for polypharmacy is the administration of five or more drugs per day for a specific duration. Polypharmacy in dementia is associated with several negative outcomes, including mortality. Psychotropic medications specifically carry risks of adverse drug reactions.

Adult Carer Quality of Life Scale

The Adult Carer Quality of Life Questionnaire (AC-QoL) is a brief, validated tool measuring overall quality of life across eight domains: support for caring, caring choice, caring stress, money, personal growth, value, ability to care, and satisfaction. Scores on each of the eight subscales have a possible range of 0 to 15. Subscale scores of 0 – 5 indicate a low reported quality of life, 6 – 10 indicate a mid-range reported quality of life, while 11+ indicate a high reported quality of life. Scores on the overall questionnaire have a possible range of 0 to 120 with higher scores indicating greater quality of life. These can range from low (0 – 40), mid-range (41 - 80) to high (81+).

Quality of Interactions Schedule

The Quality of Interactions Schedule (QUIS) is a tool used to evaluate the quality of interactions between individuals with dementia and their caregivers in a care setting. It consists of 16 items that measure different aspects of interaction quality. Each item is rated on a 5-point scale with higher scores indicating better interaction quality.

User Satisfaction: Tourism Evaluation

Tourism-related activities may offer a promising approach for enhancing the well-being and the community engagement of people living with dementia. The holiday with care service provider obtained direct feedback from guests after their stay. Aspects evaluated included: communication, quality of service, friendliness and helpfulness, accommodation, care and support and accessibility of service.

Resource Utilisation in Dementia

The Resource Utilisation in Dementia (RUD) questionnaire is a quantitative battery for evaluating the use of healthcare resources and social services as well as the time spent by professionals on various activities related to dementia care. The RUD questionnaire has several sections, including questions about healthcare utilisation (e.g., hospital admissions, outpatient visits), informal care (e.g., assistance with activities of daily living), and other costs (e.g., equipment, transportation).

Strain & Emotional Reactions in Dementia Care

The Strain and Emotional Reactions in Dementia Care (SRDC) measure was used to measure staff' perceptions and adaptations was used. The SRDC has three domains: (1) staff attitude towards residents' behaviours, (2) perceived burden of care strain, and (3) emotions evoked in caregiving. Domain 1 and 2 responses were measured on a four-point Likert scale, with response options ranging from 'agree' to 'don't agree' for the Attitude domain, and 'very easy' to 'very difficult' for the Strain domain. Domain 3 consisted of 18 pairs of bipolar emotions, measured on a five-point scale where a score of 3 suggests that the negative dimension is as common as its positive opposite and 5 implies a mainly positive dimension.

Person Centred Practice Index

The Person-centred Practice Inventory – Staff (PCPI-S) is a tool used to measure the degree to which staff in health and care settings engage in person-centred practices. It consists of 17 items that are rated on a 5-point Likert scale, ranging from "strongly disagree" to "strongly agree". The items are designed to assess six key domains of person-centred practice: knowing the person, communication and information sharing, involving the person, staff attitudes and behaviours, organisational support and the care environment. The PCPI-S can be used to identify areas for improvement in person-centred practice, as well as to evaluate the impact of interventions aimed at promoting person-centred care.

Normalisation Questionnaire

Successful implementation of new practices requires coordinated and collective behaviour among staff working in health and care settings. To understand the integration of the CASCADE module and subsequent learning in the new model of dementia care, the Normalisation Questionnaire was designed. Respondents were asked to rate their agreement with statements that probed their familiarity with the CASCADE learning, as well as the efficiency and value of integrating the learning into new ways of working. Response options for general questions about the CASCADE learning ranged from 0 ('still feels very new') to 10 ('feels completely familiar'), while all other response options ranged from 'strongly agree' to 'strongly disagree'.

Community Survey

A local community survey was conducted to evaluate the effectiveness of CASCADE education and training materials in raising dementia awareness and perceived benefits of dementia care facilities in the area. The survey included questions to gauge the level of knowledge and understanding of dementia among community members. It also asked about their perceptions of the dementia care facilities available in the localities and how they have benefitted the community.

Technology Evaluation

To evaluate the technology used in the context of the project, a contact form was designed to assess its functionality and user-friendliness. This form was used to gather feedback from staff on their experiences with the technology, including its ease of use and effectiveness in supporting their work. The responses were used to assess the acceptance and overall user-friendliness and effectiveness of the technology, with a view to improving it as necessary to better meet the needs of the end-users.

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