

Palliative care and impact of the COVID-19 pandemic on nursing home residents with dementia

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Summary. COVID-19 and infection control measures have impacted greatly on nursing homes, with particular concerns about residents with dementia and at the end of life. We examined how three important issues in palliative care in dementia – advance care planning, connecting with family, and challenging behaviour – are affected by the pandemic. We drew on the literature, particularly a systematic review on palliative care in dementia in relation to COVID-19 which identified advance care planning as the most prominent theme. Advance decisions about hospitalization are preferably made with all involved in advance of a pandemic, and to avoid misconceptions, healthcare professionals should explain what palliative care can offer in the nursing home. Additionally, we analysed data on family visits and agitation from a longitudinal study on nursing home residents with dementia in the Netherlands. A first assessment was conducted just before a national visitor lockdown of nursing homes March 20th, 2020. We separately analysed changes with a second assessment during the lockdown period through June 14th (n=44 residents) or outside this period (n=17). We found less agitation during lockdown, while unchanged when assessed outside the lockdown period. Physicians reported COVID-19 impacted on treatment and care of 57% of residents due to limited family visits, less opportunity to go around, staff availability and activities offered, and decreased quality of care. However, impact was highly individual with also cases with no or positive impact, staff having more time for individual support. The findings may inspire further research on how to better individualize palliative dementia care.

Key words. SARS-CoV-2, dementia, nursing homes, end of life, advance care planning.

Cure palliative e impatto della pandemia COVID-19 sui residenti nelle case di cura con demenza.

Riassunto. COVID-19 e le misure di controllo delle infezioni hanno avuto un grande impatto sulle case di cura, con particolare preoccupazione per i residenti con demenza e alla fine della vita. Abbiamo esaminato come tre importanti questioni delle cure palliative nella demenza – pianificazione dell'assistenza avanzata, collegamento con la famiglia e comportamenti difficili – siano influenzate dalla pandemia. Abbiamo attinto alla letteratura, in particolare una revisione sistematica delle cure palliative nella demenza in relazione a COVID-19 che ha identificato la pianificazione delle cure anticipate come il tema più importante. Le decisioni anticipate sull'ospedalizzazione vengono preferibilmente prese con tutti i soggetti coinvolti in anticipo rispetto a una pandemia e, per evitare equivoci, gli operatori sanitari dovrebbero spiegare cosa possono offrire le cure palliative nella casa di cura. Inoltre, abbiamo analizzato i dati relativi alle visite e all'agitazione della famiglia da uno studio longitudinale su residenti in case di cura con demenza nei Paesi Bassi. Una prima valutazione è stata condotta appena prima che venisse introdotto, il 20 marzo 2020, il divieto nazionale delle visite alle case di cura. Abbiamo analizzato separatamente le modifiche con una seconda valutazione durante il periodo di blocco fino al 14 giugno (n = 44 residenti) o al di fuori di questo periodo (n = 17). Abbiamo trovato meno agitazione durante il blocco, mentre è rimasto invariato quando valutato al di fuori del periodo di blocco. I medici hanno riferito che COVID-19 ha avuto un impatto sulle cure e sull'assistenza del 57% dei residenti a causa di visite familiari limitate, minori opportunità di spostarsi, disponibilità del personale e attività offerte e riduzione della qualità delle cure. Tuttavia, l'impatto è stato altamente individuale con anche casi senza impatto o impatto positivo, con personale che ha più tempo per il supporto individuale. I risultati potrebbero ispirare ulteriori ricerche su come individuare meglio le cure per la demenza palliativa.

Parole chiave. SARS-CoV-2, demenza, case di cura, fine vita, piano di cura avanzato.

Introduction

Warned by a collaborator from Northern Italy that COVID-19 could cause up to a devastating 80% mortality of residents in some nursing homes in March 2020, in the months afterwards, nursing homes in

Northern Europe and the US also experienced multiple outbreaks. In many countries, almost half of deaths from COVID-19 occur in nursing homes (24% to 82%; lower in some Asian countries)¹⁻³. Nursing home residents' condition is typically frail and many are older people but this does not fully explain excess mortality. The way care is organized plays a role,

often focused on living, in a partly social and partly medical model, with important related societal issues such as a poor public image of nursing home care and low-wage staff³. However, the extent to which nursing homes have been affected is amazingly diverse; from numerous reports on crisis situations with many acutely ill residents, high mortality, and sick staff adding to panic, to no infections and nursing homes with many infections virtually going unnoticed⁴.

COVID-19 measures to limit spread of the disease in nursing homes (e.g.^{5,6}) differentially affect nursing home residents with dementia. For example, because they may not understand isolation measures or alternative communication via video calls to connect with loved ones, or because they need touch as a language they can understand.⁷ Figures from western countries report that about half of nursing home residents and around 60-80% of decedents have dementia⁸⁻¹⁰. In this contribution, we address how the COVID-19 pandemic affects important palliative care needs in nursing home residents with dementia and their loved ones.

First, we outline the general concept of palliative care in dementia, a progressive incurable condition with people either dying with or from the dementia. Box 1 indicates we should not wait until the advanced

stage – because it may never arrive – to address various and changing needs that arise along a dementia disease trajectory, but adopt a person-centred multidisciplinary palliative approach earlier²⁷. The newly proposed needs-based palliative care definition that still explicitly includes end of life²⁸ fits well with dementia. However, there are clearly special issues in the care of nursing home residents with dementia. Dementia involves considerable uncertainty²⁹. In addition to difficulty predicting the disease trajectory (box 1) and conceptualising palliative care, in view of progressive cognitive impairment, advance care planning and care for family members' changing roles and concerns does require special attention^{27,30}. Further, as with palliative care, person-centred care³¹ and quality of life are core in dementia care. However, to maintain functioning and improve comfort (figure 1), assessing and managing pain and challenging behaviour as related to quality of life³⁴, requires special skill. Such skill may not typically be available among professional caregivers specialized in palliative care, and integration with skill of dementia specialists is helpful, e.g. through collaborations^{27,35}. Importantly, persons with dementia desire relationships and identity maintained at the end of life, but this also requires

Box 1. Dementia disease trajectories: some facts.

- **Many die before reaching an advanced stage.** About half of nursing home residents with dementia die before they reach an advanced stage of the disease with full ADL dependency¹¹⁻¹³ and even fewer (14%) reach an end stage with total impairment (lost ability to even sit upright) and death often following problems in food and fluid intake¹⁴.
- **The trajectory may last years, even if the advanced stage is reached.** The disease trajectory typically lasts years (1 to 9 or more), with more years of life lost with onset at young age¹⁵. Prospective nursing home studies show that even nursing home residents enrolled when already in the advanced stage for some time, typically live with that condition for another year (62% alive after 9 months in the UK¹⁶; 80% after 6 months in Italy¹⁷; 75% after 6 months in the US, with more than half living longer than a year¹⁸). Indeed, those living to the advanced stage belong to a group with "persistent severe disability"¹⁹.
- **Survival is difficult to predict.** Despite strong predictors such as male gender and ADL-dependency, and age in (community) samples with more varied age, survival is inherently difficult to predict. This is because the predictions include risk for frequent immediate causes of death, which may be pneumonia, or a result from prolonged food and fluid intake problems, a cardiovascular event, or consecutive intercurrent disease²⁰⁻²³.
- **Mortality risk with respiratory infection depends on frailty rather than dementia.** Pneumonia-related mortality is predicted by frailty rather than the dementia or dementia severity itself^{13,24}, also in the case of COVID-19²⁵.
- **However, risk of contracting it might differ.** Community-dwelling persons with dementia are more likely to be tested COVID-19 positive and the dementia may increase risk through behaviour²⁶. This finding needs to be confirmed in future studies in different lockdown situations.

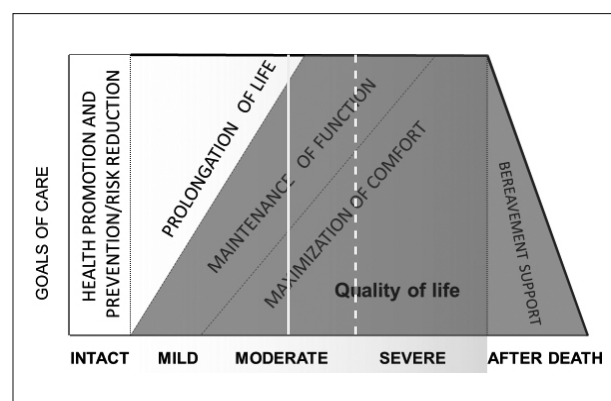


Figure 1. Dementia progression and suggested prioritising of care goals.

A mixture of goals is possible, with the goals of "Maintenance of function" and "Maximization of comfort" being compatible with quality of life, and therefore, palliative goals of care. The white lines show, as an example, stage of dementia for a typical nursing home resident with dementia in the Netherlands upon admission (left, solid line) and when dying (right, dotted line). Upon admission, prolongation of life might still be a (and even a dominant) care goal for some, but maintenance of function and maximization of comfort are more important (in fact, we found that in nursing home practice in the Netherlands, for most, comfort dominates already upon admission). Over time, with more severe dementia, care goals shift to comfort as the dominant goal, and no life prolongation near the severe stage (inferred from Hendriks et al.³² and van Soest-Poortvliet et al.³³).

The figure was adapted to add quality of life and lines to indicate mixture of care goals and reproduced, from van der Steen JT, Radbruch L, Hertogh CM, de Boer ME, Hughes JC, Larkin P, Francke AL, Jünger S, Gove D, Firth P, Koopmans RT, Volicer L; European Association for Palliative Care (EAPC). White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care, Palliative Medicine, Copyright (© The Authors, 2013)²⁷.

increased effort on the part of family and professional caregivers³⁶.

Many studies have shown that persons with dementia are at risk for overtreatment, undertreatment or suboptimal treatment, and in this respect, COVID-19 puts them at risk for significant harm⁷. COVID-19 and the measures taken to control the pandemic influence a number of issues that are specific to palliative care in dementia, especially persons living in nursing homes and their families. In this contribution, we focus on goals of care in the context of advance care planning, family visits, and challenging behaviour.

Methods

In our systematic review on palliative care in dementia related to the pandemic, we identified recommendations for nursing care from research and policy documents³⁷. Even at 14 July 2020, the most intuitive all-text word search in PubMed (“dementia and (palliative or end of life) and (COVID-19 or SARS-CoV-2)”) resulted in only one hit, an editorial on use of technology in end-of-life planning³⁸. Therefore, we searched publications about long-term or nursing home care for content about palliative or end-of-life care or dementia. The two most prominent themes in the literature up to May 18 were advance care planning and psychosocial aspects of care. We summarize the literature on advance care planning, adding more recent publications.

We address family visits during nursing home visitor lockdown and changes in agitation as an important challenging behaviour in dementia, and even key driver of costs in advanced dementia³⁹. We analysed data from an ongoing, multiple-cohorts longitudinal data collection in nursing homes in the Netherlands. No family visits were allowed except for in the terminal phase. There was no exception for dementia such as in the UK, but residents were allowed to go outside their room^{5,6}. During outbreaks, zoning into COVID-19 positive and negative areas was implemented^{6,40}.

Resident-level data are collected in the context of mandatory evidence-based medicine (EBM) courses⁴¹ that are part of a 3-year residency internship of the elderly care physician training program⁴² at Leiden University Medical Center (LUMC). Physicians in training contribute to a fixed large data collection, since 2018, on pain and discomfort in nursing home residents with cognitive impairment. For this EBM training study, they attend classes on how to collect the data, enter in an online Castor EDC module, develop a proper research question, analyse the data, and report and present the results. Data are collected mostly on psychogeriatric units which are closed departments with 24/7 oversight for, almost exclusively, persons with a physician diagnosis of dementia who typically stay for the rest of their life (different from Dementia Special Care

Units – DSCU – in the US designed for those with no severe dementia to improve functioning with behavioural problems or wandering^{3,43}). The dataset expands as the physicians each collect data on 5 nursing home residents they care for in homes mostly in the west and south of the country. Two the same assessments about 2 months apart allow for assessing changes over time.

The Medical Ethics Review Committee of the LUMC (now called METC-LDD) reviewed the protocol (no P18.100, 24 September 2018) and judged the study to be exempt from the Medical Research Involving Human Subjects Act (WMO) and therefore the Board of directors of LUMC declared they had no objection to perform the research.

Fifteen physician trainees scheduled to conduct the first assessment around January 2020 each enrolled 5 residents (88%; 75 of sample of 85 at alphabetical order of names, 1 not asked because asked for other study, 3 family unreachable; remaining 81 asked—mostly family-informed consent: 2 late responses, 2 refused, and 2 no response). Two of 75 had cognitive impairment but no dementia and were excluded from the analysis. Of 73 residents with dementia, 12 (16%) died before the second assessment (figure 2). The physicians managed to complete the second assessment for 21 residents between 28 February and 17 April 2020. March 20, a national lockdown of nursing homes was implemented, with no access to family, and sometimes restricted access for physicians for direct observation for research purposes. Therefore, in April, we modified the program to offer a substantially reduced second assessment dropping direct observation of pain and discomfort. We kept agitation frequency¹² anticipating this might increase during lockdown, while adding a few COVID-19-related items. This assessment was completed for the other 40 residents between 30 April and 30 June 2020 (figure 2).

In the analyses, we made use of natural changes and different timing that occurred as in a quasi-experimental design. We distinguished between second assessments during and outside the lockdown period, while 5 of these second assessments were before the nursing home lockdown and 12 at or after the national reopening at June 15 (with locally-paced reopening stepwise between May 25 and June 15, mandated between June 15 and 30 if the home and staff had been COVID-19 free). This resulted in 44 paired assessments during the lockdown period available for analysis, of which 16 full and 28 reduced assessments. We present descriptive statistics for the first assessment (with SPSS version 25, IBM, 2017). We did not compare the first assessment between the two groups with differently timed second assessments as differences were not expected, but we compared resident-level change data separately for second assessments during and outside the lockdown period. Differences in agitation frequency were tested with the non-parametric paired Wilcoxon test.

January	February	March	April	May	June
Lockdown period					
1 st assessment: 73 residents	Died before the 2 nd assessment: 12 residents				
		Regular 2 nd assessment in full: 21 residents	No assessments	Shortened 2 nd assessment with COVID-19 items: 40 residents	
		5 residents		28 residents (at lockdown)	12 residents

Figure 2. Timeline first six months of 2020 and selection of nursing home residents with dementia.

Lockdown period: 20 March to 15 June. None of the nursing home was part of 26 selected nursing homes for a national pilot with relaxed visiting restrictions that started May 11. Nationally there were no new cases in the pilot homes and between 25 May and 15 June, nursing homes were to relax the visiting restrictions to allow one visitor once a week if COVID-19 free for 14 days. More specifically, of the 44 resident assessments during lockdown, 31 (70%) were conducted in the full-lockdown period before 25 May (assessed between March 25 and May 11). Of the 14 other assessments, 5 were in a nursing home with one of the assessments performed with a resident with COVID-19 still at 12 June and therefore still in lockdown, and 5 in a nursing home that reopened only at the deadline of 15 June. In all, only 3 of 44 residents would normally have been allowed one visitor once or twice at the end of the almost 3-month lockdown period.

Results

LITERATURE ON ADVANCE CARE PLANNING IN DEMENTIA, PARTICULARLY IN COVID-19 TIMES

COVID-19 may involve rapid deterioration with acute onset of respiratory distress even after a relatively benign onset of the illness^{44,45}. Advance care planning is relevant as it avoids decisions made in crisis; it can reduce decisional uncertainty and decision regret^{27,30,46,47}. It has social elements⁴⁸ as healthcare professionals may prepare resident and family emotionally for future decisions anticipating changes in condition. With dementia, “advance” is not just in advance of loss of capacity, or death, as assumed in generic definitions of advance care planning⁴⁹. It is better conceived as a continuous process of multiple conversations while prioritization of care goals may change over time (figure 1)²⁷. However, the literature is replete with barriers to initiate it in dementia; just one example: difficulty projecting a future. In Dutch practice, advance care planning is often initiated only upon nursing home admission when elderly care physicians typically prioritize care goals and decide with family – and the resident if still able – about hospitalization and resuscitation (CPR)^{32,33,45}. Care goals typically change shortly before death to comfort if comfort had not been prioritized already upon admission (figure 1).

The relevance of advance decisions about hospitalization and CPR, also in dementia has become more obvious through COVID-19 and coverage in the news^{5,45,50}. The literature recommends discussing realistic scenarios. This should include discussions about how COVID-19 may cause residents to become critically unwell, risks and benefits of hospitalization and what they and their families would wish if their health deteriorates. Advance care planning is helpful for preference-sensitive decisions, but in the case of COVID-19, informed assent with no choice in regards CPR or hospital or ICU admission makes sense in

case of multimorbidity and a poor prognosis^{45,48}. It is not so much that the dementia itself predicts adverse hospitalization outcomes, which depends on frailty as for anyone else⁵¹. Rather, there are well-documented elevated risks including confusion, delirium and distress. For example, earlier ethnographic fieldwork found the environment distressing, with hospital nursing staff feeling unskilled to provide psychosocial care for the person with dementia and the caring as not prestigious⁵².

In crisis situations, however, informed assent to not hospitalize may be (mis)conceived to serve to decrease infection risk for healthcare professionals or to triage and allocate hospital beds based on survival prediction⁴⁸. Initiated only during a pandemic for all, it may impress as unjust withholding of care⁴⁰. Conversations only at the time of COVID-19 may be more difficult because it mixes shared decision making with disclosures of bad news⁴⁸. Also, face-to-face family involvement in decision making is often preferable but may need to be preplaced by supportive technology³⁸.

Ideally, healthcare professionals can fall back upon pre-pandemic conversations and use digital communication to just reconfirm or adjust decisions. In any case, conversations can be enhanced greatly when healthcare professionals explain exactly what *can* be offered in terms of palliative care (box 2, “intensive individualized comfort care”⁵⁰). This may help build relationships of trust⁴⁸. Nurses can introduce the subject³⁷, if available, supported by information brochures about palliative care⁵³ while multidisciplinary advance decision making is preferred⁵.

NURSING HOME RESIDENTS WITH DEMENTIA IN COVID-19 TIMES: FAMILY VISITING, AGITATION AND DIFFERENT IMPACT

Table 1 describes the participating nursing homes with typically, over 100 beds of which over half dementia (psychogeriatric) care beds, the relatively

Box 2. Intensive Individualized Comfort Care: putting into words an offer as a meaningful alternative to treatment and care aimed at life prolongation.

Another option is to keep your loved one here in the nursing home, and we will provide Intensive Individualized Comfort Care (IICC). IICC is a type of care in which our entire team, including the physician and nurse practitioner, work together to ensure that [name of resident] is comfortable and has the best quality of life for as long as possible. We will treat any condition that interferes with [name of resident]'s comfort.

We will:

- address physical aspects of care, including treating symptoms such as pain, shortness of breath, and nausea
- encourage [name of resident] to eat and drink by offering frequent meals, snacks, and beverages
- address psychological aspects of care, including anxiety, depression, and confusion
- provide sensory stimulation, such as music, therapeutic touch, massage, and aromatherapy
- will keep [name of resident] with familiar surroundings and with familiar staff
- address spiritual aspects of care by including clergy or prayer.

From: Lopez RP. Comment on: Coronavirus 2019 in Geriatrics and Long-Term Care: The ABCDs of COVID-19. *J Am Geriatr Soc* 2020; 68⁵⁰. Reproduced with permission from John Wiley and Sons, License number 4858660719480, 30 June 2020.

young physicians in training and the nursing home residents they cared for. The mean time in-between the first assessment around January 2020 with no COVID-19 in the country, and second assessment of the 61 included residents was 3.6 months (figure 2). Of the older, predominantly female nursing home population, only a minority had advanced dementia; over half could still walk or eat independently. Almost 80% answered when asked about pain in the last week, and almost half who answered, self-reported pain.

At any assessment (mostly by the physician her or himself), slightly over one-third to two-thirds were agitated (total at first assessment, 59%, 36/61; table 2) with frequency ranging between rarely to almost daily. Agitation was included in the care and treatment plan for about one-third of residents. Figure 3a shows that when assessed during the lockdown period (n=44) most residents had unchanged or somewhat lower agitation frequency than before, with overall a significant decrease ($p=0.025$). Agitation frequency for those assessed outside the lockdown period (n=17; figure 3b) was mostly unchanged ($p=0.68$).

Table 3 shows that at the lockdown period assessment, one-third (10/28) had some intercurrent disease. Three had COVID-19 at the assessment and 2 had had it before. All family was confronted with visiting limitation measures, with two-thirds (68%) of residents not receiving visitors at all. In most cases (16/28, 57%), the physician felt that the situation impacted on treatment and care of the resident. The physicians reported fewer family visits and freedom

restrictions in addition to fewer staff visits to impact treatment and care; occasionally, approaching the end of life, with detrimental consequences (table 4). However, in some cases, physicians felt it had no impact, or a positive impact, for example when staff could spend more time to connect with the resident. Quality of care and activities offered were mentioned as having decreased, but in some cases, these also improved. In a few cases, the physician felt there was no impact because the resident was not aware of any changes.

Discussion

Advance care planning in dementia was a hot topic in research before the COVID-19 pandemic, and remained an important topic in the literature covering aspects of palliative care in dementia in COVID-19 times. Media reports have contributed to awareness about the need to consider preferences for hospitalization in advance. It has also led to concerns about unrightful rationing of care for frail persons including those with dementia. Explaining what palliative care can do and providing it, is paramount.

In the Netherlands, during and around visitor lockdown of almost 3 months, physicians collected follow-up data about 61 residents and they reported impact on treatment and care for more than half of the residents. Many missed connecting with family and activities with family or staff, and quality of care decreased in some cases. However, there were also accounts of no or little impact, and even positive impact such as staff spending more time with residents. Initial agitation frequency was similar as in an earlier prospective study (57-71%, often persistent¹²), but contrary to our expectations, we found a decrease in agitation during COVID-19 lockdown, compared with no change outside the lockdown period.

Other research on changes of challenging behaviour in nursing home residents in the Netherlands so far is limited to surveying nursing staff about changes in residents' behaviour more generally or family^{54,55}. Decreases were nearly as frequent as increases⁵⁴, and concerns about impact more generally were greater for those without dementia⁵⁵. There are very few resident-level professional reports and our longitudinal EBM training study with clear denominators provided a unique opportunity to obtain prospective data directly from physicians with probably no interest in overreporting, and they had known the residents for at least several months around the time of lockdown. In an Italian study, over half of family caregivers of community-dwelling persons with dementia reported increased neuropsychiatric symptoms, and only for a few percent, it decreased⁵⁶. The situation in the community may be quite different, with distressed family around, or perhaps lower pre-lockdown agitation. For persons with dementia, a balance between sensory-stimulating and sensory-calming activity is important⁵⁷.

Table 1. Characteristics of the samples of nursing home residents with dementia who survived up to the second assessment, their physicians in training, and the nursing homes at first assessment by timing of second assessment.

	Second assessment happened during lockdown period		Second assessment happened outside lockdown period	
Nursing homes	Mean or %	n=12 *	Mean or %	n=4
Beds total, mean (SD)	128 (67)	12	197 (103)	4
Beds psychogeriatric unit, mean (SD)	72 (48)	12	113 (68)	4
Any use of observational instruments for pain, discomfort, quality of life or behaviour				
yes, routinely †	33%	4	1 of 4	0
yes, occasionally or when indicated †	50%	6	2 of 4	0
no	17%	2	1 of 4	0
Physicians	Mean or %	n=11 *	Mean or %	n=4
Sex, female	82%	9	2 of 4	4
Age	32 (5)	11	30 (4)	4
Clinical experience in the nursing home before training residency, mean number of years (SD)	2.1 (1.2)	11	1.5 (1.6)	4
Any experience with use of observational instruments	18%	2	1 of 4	4
Any experience with doing research (not including just collecting data for others)	55%	6	3 of 4	4
Residents (first assessment)	Mean or %	n=44	Mean or %	n=17
Type of department of residence				
psychogeriatric (closed, almost all dementia)	98%	43	100%	17
for physical disability	2%	1	0	0
Age, mean (SD)	86.2 (7.0)	44	83.8 (8.3)	17
Female	73%	32	59%	10
Dementia type				
Alzheimer only	48%	21	71%	12
mixed Alzheimer and vascular	23%	10	12%	2
vascular only	11%	5	12%	2
Lewy Body or Parkinson dementia	9%	4	6%	1
not specified mixed or single type	9%	4	0	0
Dementia severity, BANS-S ‡				
mean (SD)	13.9 (4.6)	44	12.5 (4.2)	17
17 and higher	32%	14	12%	2
Global deterioration scale (GDS)				
mean (SD)	5.6 (0.9)	44	5.7 (0.8)	17
score 7	16%	7	6%	1
Eating dependency				
fully dependent	7%	3	6%	1
needs help	34%	15	35%	6
independent	59%	26	59%	10
Walking				
fully dependent	32%	14	6%	1
needs help	18%	8	18%	3
independent	50%	22	76%	13
Any pain last week, self report resident				
yes	39%	17	35%	6
no	41%	18	47%	8
no response	20%	9	18%	3
Acute intercurrent disease during first assessment				
COVID-19 (not yet in the country)	0	0	0	0
decubitus ulcers	5%	2	0	0
infection (urinary tract interaction, norovirus)	5%	2	0	0
falls with head or hip/back pain	5%	2	0	0
other	5%	2	6%	1
none	82%	36	94%	16

* One of the physicians assessed residents in two nursing homes.

† Mostly pain observations scales such as Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC) or behaviour observation scales such as the Neuropsychiatric Inventory (NPI), rarely quality of life or discomfort.

‡ Bedford Alzheimer Nursing Severity-Scale (BANS-S) score 17 and higher indicates severe dementia.

References to NPI and GDS can be found in Kromhout et al.⁴¹, to BANS-S in Hendriks et al.²⁴, to NPI and PACSLAC in van der Steen et al.²⁷.

Table 2. Agitation frequency past week at first and second assessment by timing of second assessment (see figure 3 for resident-level changes).

	Second assessment happened during lockdown period (n=44)		Second assessment happened outside lockdown period (n=17)	
	First assessment, % (n)	Second assessment, % (n)	First assessment, % (n)	Second assessment, % (n)
Agitation frequency last week				
never, no treatment	30% (13)	45% (20)	65% (11)	47% (8)
never, due to effective treatment	2% (1)	5% (2)	0	0
rarely (≤ 1 day)	20% (9)	16% (7)	6% (1)	18% (3)
sometimes (2-3 days)	18% (8)	14% (6)	6% (1)	12% (2)
often (4-5 days)	5% (2)	7% (3)	6% (1)	18% (3)
almost daily (6-7 days)	25% (11)	14% (6)	18% (3)	6% (1)
Agitation frequency assessed by				
the physician	70% (30)	85% (33)	100% (17)	100% (17)
nurses	0	8% (3)	0	0
nurse assistants or aids	21% (9)	0	0	0
physicians with nurses together	0	0	0	0
physicians with nurse assistants or aids together	9% (4)	0	0	0
physicians with others (profession not specified)	0	8% (3)	0	0
missing	1	5	0	0
Agitation and care planning				
agitation included in care or treatment plan	39% (17)	38% (6)	29% (5)	0 (5)
missing	0	28 (item not included in shortened assessment)	0	12 (item not included in shortened assessment)

For some, the balance during nursing home lockdown may have improved, as we personally experienced a more peaceful atmosphere in the nursing home in the absence of a continuously ringing doorbell. However, missing family was reported and increased loneliness and sadness has been reported around the world² and may relate to a lack of physical closeness⁷.

Unfortunately, we did not assess change in wellbeing or apathy or advance care planning. Also, we did not assess family perspectives regarding visiting and impact, while media report on enormous frustrations and even envying or blaming risk-taking nursing staff who *are* allowed to touch their loved ones. Further, the literature we found on COVID-19 in relation to palliative care including advance care planning in dementia may be immature and mostly opinion-based at this point, with little empirical data.

We found that the literature also reports positive aspects regarding advance care planning. The COVID-19 situation has been called an opportunity to discuss more openly and “increase death literacy in the population, hopefully culminating in more authentic advance care planning in the future”⁴⁵. It has been suggested that nursing homes include social and spiritual (meaning) aspects in advance care planning³⁷. Living and dying well in a nursing home obviously requires good medical and social care, with opportunities for palliative care. Physicians on site such as in the Netherlands⁴² and on site or on call in Lombardy¹⁷ offer great advantages in terms of opportunity to advance care planning, and hospitalization rates were only a few percent before the pandemic^{11,17}. The option to provide medical care in the nursing home including subcutaneous fluids and oxygen may obviate the need for hospital admission⁴⁰. From the

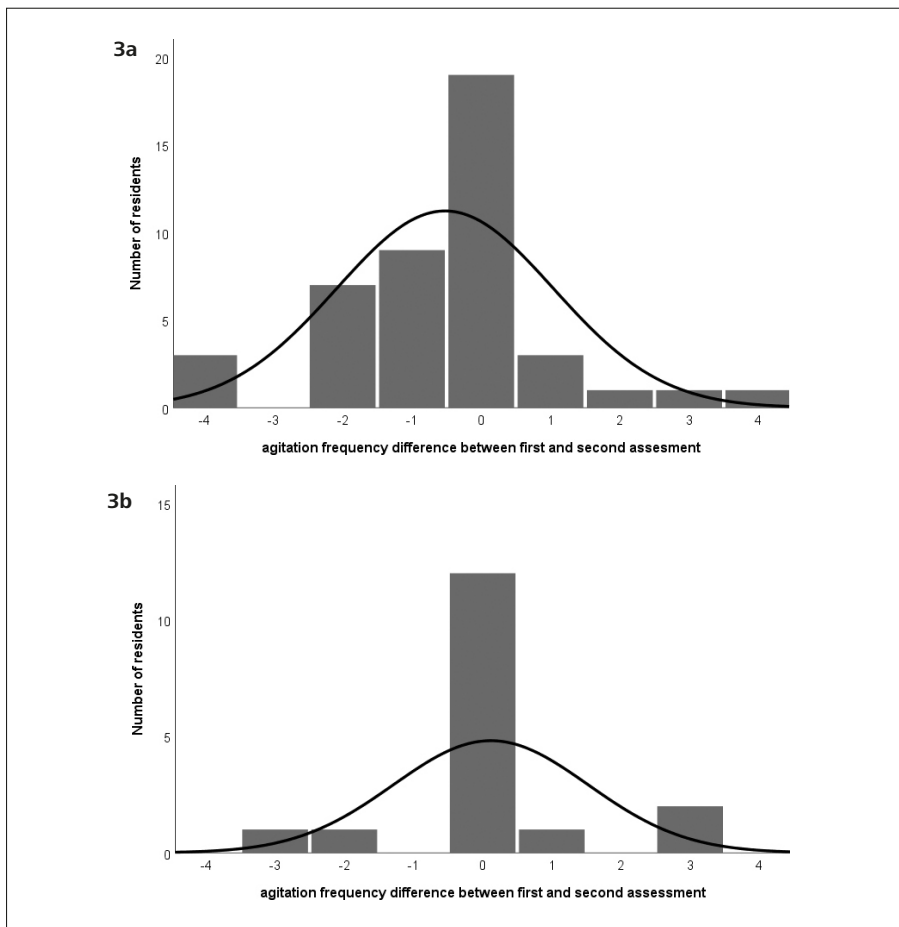


Figure 3. Distribution of difference in agitation frequency between second and first assessment for those with the second assessment during the lockdown period (3a, n=44; p=0.025) and outside the lockdown period (3b, n=17; p = 0.68). Moving 3 residents who may have received a visitor allowed once or twice at the end of the lockdown period did not affect findings (p=0.024 and p=0.78 respectively). Note: 0 means unchanged, 1 means one category increase, -1 one category decrease, etc. (categories according to table 2)

Table 3. Situation during COVID-19 lockdown (n=28 residents with adapted second assessment during lockdown period—between 30 April and 15 June 2020).

Acute intercurrent disease at assessment	
COVID-19	11% (3)
decubitus ulcers	11% (3)
metastatic carcinoma terminal phase	4% (1)
pneumonia	4% (1)
infection with intake problems	4% (1)
falls with backpain	4% (1)
none	64% (18)
Any COVID-19 test	
tested positive	18% (5)
tested negative	25% (7)
not tested, probably no COVID-19	57% (16)
not tested, yet probably COVID-19	0
Family allowed to visit	
yes, unlimited	0
yes, limited	32% (9)
no	68% (19)
Any impact on treatment and care of the particular resident due to the Corona crisis	
yes	57% (16)
definitely	29% (8)
probably	29% (8)
no	43% (12)
probably not	11% (3)
definitely not	32% (9)
do not know (presented as a valid response option)	0

Table 4. COVID-19 crisis impact on treatment and care of the particular resident as perceived by the physician (a total of 34 explanations for 28 residents;* combined double explanations; categorized and shown by intensity of impact).

	Probably or definitely impact (n=16 residents)	Probably or definitely no impact (n=12 residents)
Family not visiting	Resident was not visited (some because exposed to confirmed COVID-19)	No COVID-19 outbreak, however, less visitors
	Resident misses or needs family	Resident however missed family who visited daily
	Resident socially isolated because family and volunteer not visiting	Little impact of receiving less visits because resident received few visits before
	Resident less active, under stimulated	
Little opportunity to go around	Resident sometimes went out with family which was not possible anymore	
	Resident needs freedom, going outside	
Staff availability	Resident with carcinoma in pre-terminal phase delayed visit and pain management	No major impact of less frequent visiting of physician observed
	Less staff available and isolation measures	Physiotherapist visiting resident less often
	Less connection with nursing staff	There was more time for connecting with the resident
	Resident desired to see familiar staff	
Quality of care	Resident moved to other department with suboptimal care	Transfer to COVID zone unit with just a few not very ill residents and therefore resident received more individual support
	Inadequate staffing and some insufficiently trained staff that did not warn physician timely when resident got sicker	
	Department closed because of COVID-19 outbreak. In the beginning, when all residents were still alive, there was not enough time for proper care	
Activities offered	Fewer activities offered on top of family not undertaking activities with resident	No replacement of activities offered
	Resident missed daily activities outside small-scale living group, although medical care not limited	No major impact observed of fewer activities offered
No impact reasons	N/A	Not aware of changes
		Not aware of situation and isolation

* Similar patterns of impact reported in retrospect for 7 of 12 residents (5 missing for the last 5 assessments between 24 and 30 June) assessed at the time the lockdown was being relaxed, except for additionally, *more* activities offered to explain probably or definitely no impact.

current data, with half reporting pain, consistent with previous studies, however, effect of in-house medical care on self-reported pain levels, if any, is somewhat disappointing, and also physician-reported agitation was not always part of care planning.

Conclusions

COVID-19 outbreaks have caused crises in nursing homes and impacted care of persons with dementia, their family and staff. However, our resident-level data suggest impact of COVID-19 on agitation and more gen-

erally to be highly individual, resembling highly variable courses of the dementia and after acute illness also in the absence of a pandemic. Cases of positive impact perhaps resulting from more balanced sensory input need further study, as an opportunity to learn how to better individualize (palliative) dementia care. The general public being more familiar with advance decisions about medical care is also fertile soil to further implement advance care planning in dementia, a proactive approach fully consistent with the adage of palliative care.

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Bibliography

- Comas-Herrera A, Zalakaín J, Litwin C, Hsu AT, et al. Mortality associated with COVID-19 outbreaks in care homes: Early international evidence. LTCcovid.org, International Long-Term Care Policy Network, CPEC-LSE, update 21 May 2020.
- Trabucchi M, De Leo D. Nursing homes or besieged castles: COVID-19 in Northern Italy. *Lancet Psychiatry* 2020; 7: 387-8.
- Lau-Ng R, Caruso LB, Perls TT. COVID-19 deaths in long term care facilities - a critical piece of the pandemic puzzle. *J Am Geriatr Soc* 2020; June 5, epublished.
- Goldberg SA, Pu CT, Thompson RW, et al. Asymptomatic spread of COVID-19 in 97 patients at a skilled nursing facility. *J Am Med Dir Assoc* 2020; May 29, epublished.
- British Geriatrics Society. COVID-19: Managing the COVID-19 pandemic in care homes for older people, 30 March 2020. Version 3, update June 2 2020. www.bgs.org.uk/resources/covid-19-managing-the-covid-19-pandemic-in-care-homes Accessed July 9, 2020.
- Schols JMGA, Poot EP, Nieuwenhuizen NM, et al. Dealing with COVID-19 in Dutch nursing homes. *J Nursing Home Res* 2020; 6:30-4.
- Brown EE, Kumar S, Rajji TK, et al. Anticipating and mitigating the impact of the COVID-19 pandemic on Alzheimer's disease and related dementias. *Am J Geriatr Psychiatry* 2020; 28: 712-21.
- Honinx E, van Dop N, Smets T, et al.; PACE. Dying in long-term care facilities in Europe: the PACE epidemiological study of deceased residents in six countries. *BMC Public Health* 2019; 19(1): 1199.
- Harrison SL, Lang C, Whitehead C, et al. Trends in prevalence of dementia for people accessing aged care services in Australia. *J Gerontol A Biol Sci Med Sci* 2020; 75: 318-25.
- Ng R, Lane N, Tanuseputro P, et al. Increasing complexity of new nursing home residents in Ontario, Canada: A serial cross-sectional Study. *J Am Geriatr Soc* 2020; 68: 1293-1300.
- van der Steen JT, Ribbe MW, Deliëns L, et al. Retrospective and prospective data collection compared in the Dutch End Of Life in Dementia (DEOLD) study. *Alzheimer Dis Assoc Disord* 2014; 28: 88-94.
- Hendriks SA, Smalbrugge M, Galindo-Garre F, et al. From admission to death: prevalence and course of pain, agitation, and shortness of breath, and treatment of these symptoms in nursing home residents with dementia. *J Am Med Dir Assoc* 2015; 16: 475-81.
- Miranda R, van der Steen JT, Smets T, et al.; PACE. Comfort and clinical events at the end of life of nursing home residents with and without dementia: The six-country epidemiological PACE study. *Int J Geriatr Psychiatry* 2020; March 3, epublished.
- Koopmans RT, van der Sterren KJ, van der Steen JT. The 'natural' endpoint of dementia: death from cachexia or dehydration following palliative care? *Int J Geriatr Psychiatry* 2007; 22: 350-5.
- Brodaty H, Seeher K, Gibson L. Dementia time to death: A systematic literature review on survival time and years of life lost in people with dementia. *Int Psychogeriatr* 2012; 24: 1034-45.
- Sampson EL, Candy B, Davis S, et al. Living and dying with advanced dementia: A prospective cohort study of symptoms, service use and care at the end of life. *Palliat Med* 2018; 32: 668-81.
- Toscani F, van der Steen JT, Finetti S, et al.; End of Life Observatory-Prospective Study on DEmentia Patients Care (EoLO-PSODEC) Research Group. Critical decisions for older people with advanced dementia: a prospective study in long-term institutions and district home care. *J Am Med Dir Assoc* 2015; 16: 535.e13-20.
- Mitchell SL, Teno JM, Kiely DK, et al. The clinical course of advanced dementia. *N Engl J Med* 2009; 361: 1529-38.
- Gill TM, Gahbauer EA, Han L, et al. Trajectories of disability in the last year of life. *N Engl J Med* 2010; 362: 1173-80.
- van der van der Steen JT, Heymans MW, Steyerberg EW, et al. The difficulty of predicting mortality in nursing home residents. *Eur Geriatr Med* 2011; 2: 79-81.
- Todd S, Barr S, Passmore AP. Cause of death in Alzheimer's disease: a cohort study. *QJM* 2013; 106: 747-53.
- Manabe T, Fujikura Y, Mizukami K, et al. Pneumonia-associated death in patients with dementia: A systematic review and meta-analysis. *PLoS One* 2019; 14(3): e0213825.
- Foley NC, Affoo RH, Martin RE. A systematic review and meta-analysis examining pneumonia-associated mortality in dementia. *Dement Geriatr Cogn Disord* 2015; 39: 52-67.
- Hendriks SA, Smalbrugge M, van Gageldonk-Lafeber AB, et al. Pneumonia, intake problems, and survival among nursing home residents with variable stages of dementia in the Netherlands: Results from a prospective observational study. *Alzheimer Dis Assoc Disord* 2017; 31: 200-8.
- De Smet R, Mellaerts B, Vandewinckele H, et al. Frailty and mortality in hospitalized older adults with COVID-19: Retrospective observational study. *J Am Med Dir Assoc* 2020, June 9, epublished.
- Atkins JL, Masoli JAH, Delgado J et al. Preexisting comorbidities predicting severe covid-19 in older adults in the uk biobank community cohort. *medRxiv* 2020, May 8, pre-print.
- van der Steen JT, Radbruch L, Hertogh CM, et al.; European Association for Palliative Care (EAPC). White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. *Palliat Med* 2014; 28: 197-209.
- Radbruch L, De Lima L, Knäul F, et al. Redefining palliative care-A new consensus-based definition. *J Pain Symptom Manage* 2020; May 6, epublished.
- Goodman C, Froggatt K, Amador S, et al. End of life care interventions for people with dementia in care homes: Addressing uncertainty within a framework for service delivery and evaluation. *BMC Palliat Care* 2015; 14: 42.
- Wendrich-van Dael A, Bunn F, Lynch J, et al. Advance care planning for people living with dementia: An umbrella review of effectiveness and experiences. *Int J Nurs Stud* 2020; 107: 103576.
- Terkelsen AS, Petersen JV, Kristensen HK. Mapping empirical experiences of Tom Kitwood's framework of person-centred care for persons with dementia in institutional settings: A scoping review. *Scand J Caring Sci* 2020; 34: 6-22.
- Hendriks SA, Smalbrugge M, Hertogh CMPM, et al. Changes in care goals and treatment orders around the occurrence of health problems and hospital transfers in dementia: A prospective study. *J Am Geriatr Soc* 2017; 65: 769-76.
- van Soest-Poortvliet MC, van der Steen JT, de Vet HC, et al. Factors related to establishing a comfort care goal in nursing home patients with dementia: A cohort study among family and professional caregivers. *J Palliat Med* 2014; 17: 1317-27.
- Klapwijk MS, Caljouw MA, Pieper MJ, et al. Characteristics associated with quality of life in long-term care residents with dementia: A cross-sectional study. *Dement Geriatr Cogn Disord* 2016; 42: 186-197.

35. Sawatzky R, Porterfield P, Lee J, et al. Conceptual foundations of a palliative approach: A knowledge synthesis. *BMC Palliat Care* 2016; 15: 5.
36. Nishimura M, Harrison Denning K, Sampson EL, et al. Cross-cultural conceptualization of a good end of life with dementia: A meta-qualitative study. Abstract accepted for presentation at ADI 2020. A full paper is under review.
37. Bolt SR, van der Steen JT, Mujezinović I, et al. Practical nursing recommendations for palliative care for people with dementia living in long-term care facilities during the COVID-19 pandemic: A rapid scoping review. *Int J Nurs Stud* 2020, accepted pending minor changes.
38. Edelman LS, McConnell ES, Kennerly SM, et al. Mitigating the effects of a pandemic: Facilitating improved nursing home care delivery through technology. *JMIR Aging* 2020; 26; 3(1): e20110.
39. Buylova Gola A, S Morris S, Candy B, et al. Healthcare utilization and monetary costs associated with agitation in uk care home residents with advanced dementia: A prospective cohort study. *Int Psychogeriatr* 2020; 32: 359-70.
40. Gordon AL, Goodman C, Achterberg W, et al. Commentary: COVID in care homes-challenges and dilemmas in healthcare delivery. *Age Ageing* 2020; May 13, epublihed.
41. Kromhout MA, van Eijk M, Pieper MJC, et al. BeCaf study: caffeine and behaviour in nursing homes, a study protocol and EBM training program. *Neth J Med* 2018; 76: 138-40.
42. Koopmans RT, Lavrijsen JC, Hoek F. Concrete steps toward academic medicine in long term care. *J Am Med Dir Assoc* 2013; 14: 781-3.
43. Gruneir A, Lapane KL, Miller SC, et al. Does the presence of a Dementia Special Care Unit improve nursing home quality? *J Aging Health* 2008; 20: 837-54.
44. Shahid Z, Kalayanamitra R, McClafferty B, et al. COVID-19 and older adults: What we know. *J Am Geriatr Soc* 2020; 68: 926-9.
45. Lapid MI, Koopmans R, Sampson EL, et al. Providing quality end-of-life care to older people in the era of COVID-19: Perspectives from five countries. *Int Psychogeriatr* 2020; May 11, epublihed.
46. Brazil K, Carter G, Cardwell C, et al. Effectiveness of advance care planning with family carers in dementia nursing homes: A paired cluster randomized controlled trial. *Palliat Med* 2018; 32: 603-12.
47. Kermel Schiffman I, Werner P. Willingness of family caregivers of people with dementia to undertake advance care planning: Examining an extended model of the theory of planned behavior. *Dementia* 2020, May 11, epublihed.
48. Jacobsen JC, Tran KM, Jackson VA, et al. Case 19-2020: A 74-year-old man with acute respiratory failure and unclear goals of care. *N Engl J Med* 2020; 382: 2450-7.
49. Rietjens JAC, Sudore RL, Connolly M, et al.; European Association for Palliative Care. Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. *Lancet Oncol* 2017; 18: e543-51.
50. Lopez RP. Comment on: Coronavirus 2019 in Geriatrics and Long-Term Care: The ABCDs of COVID-19. *J Am Geriatr Soc* 2020; 68: 1166-7.
51. Zekry D, Herrmann FR, Grandjean R, et al. Does dementia predict adverse hospitalization outcomes? A prospective study in aged inpatients. *Int J Geriatr Psychiatry* 2009; 24: 283-91.
52. Cowdell F. Care of older people with dementia in an acute hospital setting. *Nursing standard* 2010; 24: 42-8.
53. van der Steen JT, Arcand M et al. Multiple international publications on family booklet on palliative care in dementia. Italian version of the booklet: Cure Palliative alla fine della vita: Una guida per chi si prende cura di persone con malattia di Alzheimer o altre patologie cerebrali degenerative. AIMA, www.alzheimer-aima.it/manuale/manuale.htm. Accessed July 13, 2020.
54. Gerritsen D, Leontjevas R, Bakker C et al. [Probleemgedrag bij verpleeghuisbewoners en COVID-19 maatregelen Voorlopige resultaten landelijke enquête.] Nijmegen: UKON, May 2020. [in Dutch]
55. van der Roest H, Prins M, van der Velden C et al. [De impact van sociale isolatie onder bewoners van verpleeg- en verzorgingshuizen ten tijde van het nieuwe coronavirus.] Utrecht: Trimbos, June 2020. [in Dutch].
56. Canevelli M, Valletta M, Toccaceli Blasi M, et al. Facing dementia during the COVID-19 outbreak. *J Am Geriatr Soc* 2020, June 9, epublihed.
57. Kovach CR. Sensoristasis and imbalance in persons with dementia. *J Nurs Scholarsh* 2000; 32: 379-84.

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