BMJ Open

Impact of COVID-19 restrictions on behavioural and psychological symptoms in home-dwelling people with dementia: a prospective cohort study (PAN.DEM)

Marie H Gedde ,[1,2] Bettina S Husebo,[2,3] Ipsit V Vahia,[4,5] Janne Mannseth,[6] Maarja Vislapuu,[2] Mala Naik,[1,7] Line I Berge[2,8]

To cite: Gedde MH, Husebo BS, Vahia IV, *et al*. Impact of COVID-19 restrictions on behavioural and psychological symptoms in home-dwelling people with dementia: a prospective cohort study (PAN.DEM). *BMJ Open* 2022;**12**:e050628. doi:10.1136/bmjopen-2021-050628

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (http://dx.doi.org/10.1136/bmjopen-2021-050628).

Received 25 February 2021
Accepted 05 January 2022

For numbered affiliations see end of article.

Correspondence to
Dr Marie H Gedde;
marie.gedde@uib.no

ABSTRACT

Objectives To investigate the impact of the COVID-19 restrictions on behavioural and psychological symptoms of dementia (BPSD).

Design Prospective cohort study (PAN.DEM) nested within the halted parent trial (LIVE@Home.Path).

Setting Households in Norway immediate before and 6–9 weeks into the COVID-19 restrictions.

Participants 104 dyads (persons with mild to moderate dementia aged ≥65 and their informal carers) completed both prepandemic and pandemic assessments, among 237 in the parent trial. Mini-Mental Status Examination score 15–26 or Functional Assessment Staging score 3–7 covered dementia severity.

Main outcome measures Neuropsychiatric Inventory (NPI-12) total (range 0–144), psychosis (range 0–24), hyperactive behaviour (range 0–60) and mood subsyndrome (range 0–48) scores; Cornell Scale for Depression in Dementia (CSDD) total score (range 0–38).

Results We found an overall increase in BPSD by NPI-12 total score comparing prepandemic to pandemic levels (median 16 IQR (4.5–29) to 20 (7–32.5), p=0.03) over a mean of 86 days (SD 19). NPI-12 total score worsened in 57 (55%) of people with dementia and was associated with postponed or averted contacts with healthcare professionals (logistic regression, OR 3.96, 95% CI 1.05 to 14.95). Psychosis subsyndrome levels increased (0 (0–3) to 0.5 (0–6), p=0.01) in 37 (36%) persons; this worsening was associated with partial insight (9.57, 1.14 to 80.71) and reduced informal carer contact (4.45, 1.01 to 19.71). Moreover, depressive symptoms increased as assessed by CSDD total score (5 (3–9) to 7 (4–12), p=0.01) and worsened for 56 (54%), which was inversely associated with psychotropic drugs on-demand (0.16, 0.03 to 0.75).

Conclusions BPSD worsened during the first months of the COVID-19 restrictions, most pronounced for psychosis and depression. These BPSD exacerbations have implications for pandemic policies, emphasising that restrictions must balance COVID-19 morbidity and mortality against dementia deterioration.

Trial registration number NCT04043364; Results.

Strengths and limitations of this study

- ► This is the first prospective cohort study investigating the impact of the COVID-19 restrictions on behavioural and psychological symptoms of dementia (BPSD).
- ► The same informal carers reported BPSD for each home-dwelling person with dementia both before and during the pandemic scenario using validated, well-established instruments.
- ► The COVID-19 restrictions left some informal carers with less basis of observation, as 28% reported reduced contact with the person with dementia.
- ► Our study captures the impact of the initial phase of the outbreak in Norway and does not describe the long-term impact of the COVID-19 restrictions on BPSD.

INTRODUCTION

Dementia is among the most critical risk factors for COVID-19 mortality.[1] In England and Wales alone, 12 869 people with dementia have died, accounting for 26% of the COVID-19 death toll.[2] Until vaccination is widely available globally, hygiene and physical distancing interventions will remain cornerstones of protecting vulnerable populations.[3] The subsequent restrictions have been disrupting for home-dwelling people with dementia as private homes were not accessible to family members and volunteers, day care centres closed and home nursing services were restricted to those most in need. As a result, people with dementia living in the community are not only at risk from COVID-19 morbidity and mortality; they are also threatened from unforeseen effects of the restrictions.[4 5]

Behavioural and psychological symptoms of dementia (BPSD) cover a wide range of

clinical presentation including depression, anxiety, agitation and psychosis. Longitudinally, persistent BPSD may be found in up to 80% of people with dementia.[6] BPSD are best managed with structured, non-pharmacological interventions, placing psychotropic drugs as secondary treatment options.[7] Preliminary evidence indicates that BPSD may be exacerbated under the COVID-19 restrictions. Eight weeks into the Argentinian quarantine, informal carers reported worsening of anxiety, insomnia and depression among persons at different stages of Alzheimer's and related dementias living at home (N=119).[8] In another study, family carers stated worsening BPSD in 60% of Italian outpatients with various stages and aetiologies of dementia 1 month into the pandemic (N=4913).[9] This study also found that 28% required changes in psychotropic medication to address irritability, apathy, agitation and depression. Further, nursing home patients separated from the outside world in France with mild Alzheimer's disease reported increased anxiety and depression when asked to evaluate their own experience of the pandemic retrospectively (N=58).[10]

However, all these studies are cross-sectional and thus far, there is a dearth of longitudinal data tracking changes in BPSD during COVID-19 by comparing prepandemic to pandemic rates.[11] In this study, we aim to address this significant gap in the literature using data from the prospective PAN.DEM study.[12] This study is nested within the ongoing LIVE@Home.Path trial[13] and was launched by our team to investigate the impact of the COVID-19 restrictions (implemented in Norway on 12 March 2020) on home-dwelling people with dementia. Here, we present comparisons of prepandemic and pandemic BPSD, and explore factors associated with worsening BPSD.

METHODS

Study design

This is a prospective cohort study comparing the prepandemic assessment of BPSD of the parent trial, LIVE@Home.Path, to the PAN.DEM assessment.

Setting

The parent trial is a stepped-wedge randomised controlled trial.[13] It compares the cost-effectiveness in resource utilisation of a 6-month multicomponent intervention comprising Learning, Innovation, Volunteers and Empowerment to usual conditions for dyads of home-dwelling people with dementia and their informal carers. Trained data collectors blindly assessed all dyads in direct conversation every 6 months for 2 years (2019–2021). The prepandemic 6-month assessment was close to complete when the COVID-19 restrictions replaced trial protocol (figure 1A). Physical distancing (ie, restrictions on gatherings, public transport closure, stay at home-regulations and limitations on movement) formed the basis for the restrictions,[3] which implied that healthcare was limited to those most in need.[12] In response, we developed the semistructured PANdemic in DEMentia (PAN.DEM) telephone interview for informal carers to capture if, and how, dyads were affected by the outbreak (online supplemental file). This assessment included selected instruments from the parent trial in addition to questions regarding the pandemic. We consecutively invited as many dyads as possible from the parent trial to complete the PAN.DEM assessment from week 6 of restrictions until eased the 9th week (20 April 2020 to 15 May 2020). Potential respondents were considered unreachable when no response was given to two calls and a text message.

Participants

Dyads were eligible for inclusion in the parent trial if the persons with dementia were: ≥65 years, diagnosed with dementia (with Mini-Mental Status Examination (MMSE) score 15–26 or Functional Assessment Staging (FAST) score 3–7)[14 15]; home-dwelling in one of three Norwegian municipalities; and had weekly face-to-face contact with the informal carer. Dyads gave informed spoken and written consent for participation in the parent trial as described in the protocol.[13] Informal carers gave additional informed consent to PAN.DEM.[12]

Measurements

The primary outcome was change in BPSD between the prepandemic and pandemic assessments. We administered two informal carer-rated scales at both time points: (1) The Neuropsychiatric Inventory (NPI-12) assesses frequency and severity of delusions, hallucinations, agitation, depression, anxiety, euphoria, apathy, disinhibitions, irritability, aberrant motorial behaviour, sleep disturbances and appetite changes over the four preceding weeks.[16] Each of these 12 domains is scored from 0 (no symptoms) to 12 (very severe symptoms), a score ≥4 is regarded a BPSD with symptom load of clinical relevance.[6] These domains are further aggregated to generate subsyndrome scores for psychosis comprised of delusions and hallucinations (0–24), hyperactive behaviour comprised agitation, euphoria, irritation, disinhibition, aberrant motor behaviour (0–60), mood comprised depression, apathy, sleep disturbances and appetite changes (0–48), and finally, a total NPI-12 score (0–144);[17] (2) The Cornell Scale for Depression in Dementia (CSDD) assesses nineteen items of depressive symptoms during the prior week, each rated from 'absent' to 'severe' (0–2) or 'symptoms not possible to evaluate' (missing).[18] Adding item scores generate the CSDD total score (0–38).[18] A CSDD total score ≥8 indicates depression of clinical relevance.[19] The Norwegian versions of NPI-12 and CSDD have robust psychometric properties.[16 18–20]

In addition to BPSD, we collected the following data at the prepandemic assessment: the persons with dementia's level of functioning in activities of daily living by Physical Self-Maintenance Scale (PSMS)[21] and Instrumental Activities of Daily Living Scale (IADL),[22] health by the General Medical Health Rating Scale (GMHR),[23] possible dementia aetiology following the International Classification of Diseases-10th version,[24] and use of

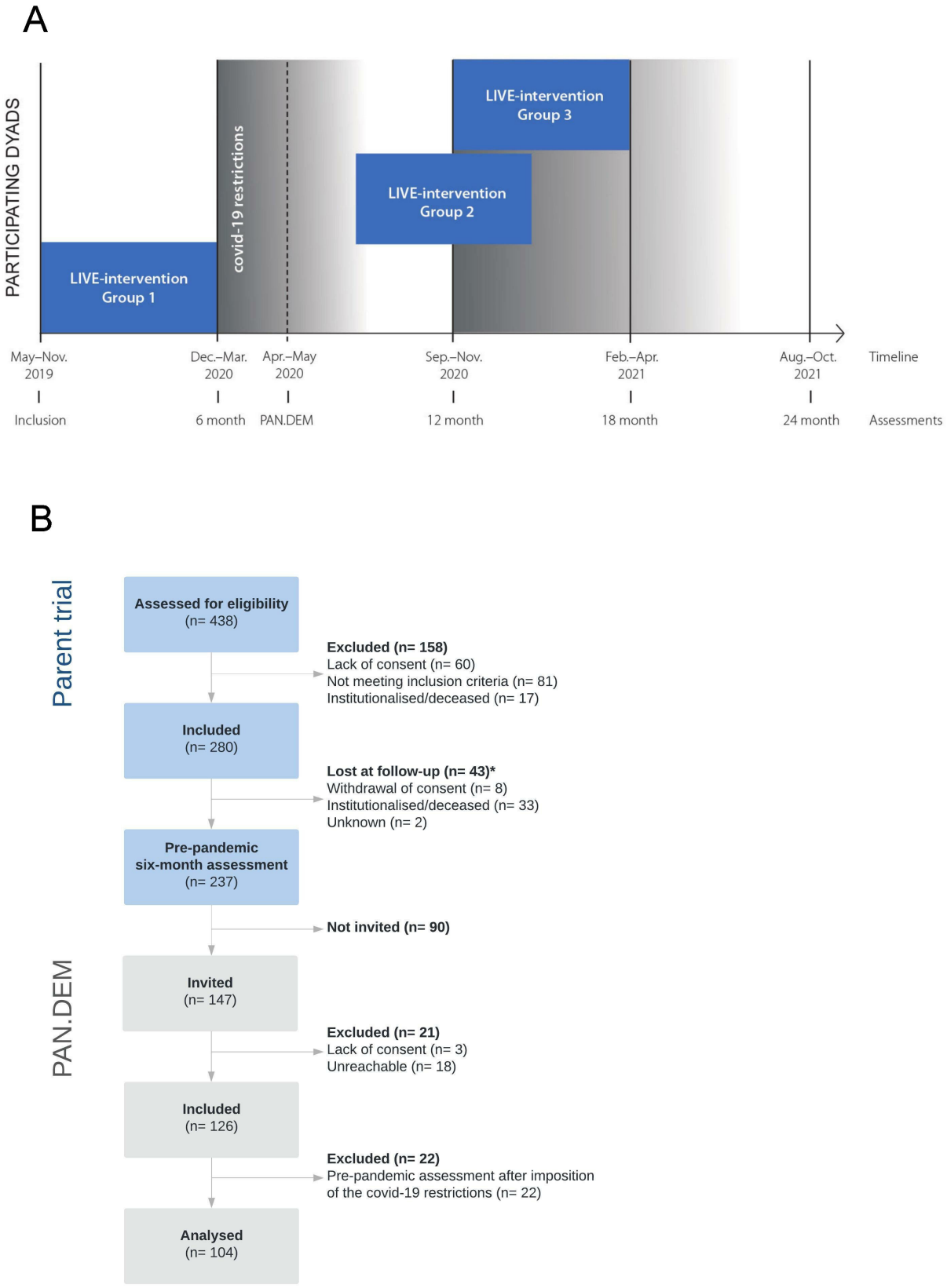

Figure 1 The parent trial, LIVE@Home.Path, including PAN.DEM. The COVID-19 restrictions replaced trial protocol from 12 March to eased on 15 May 2020. None of the dyads (person with dementia and informal carer, n) received the intervention while the PAN.DEM interviews were conducted (20 April 2020 to 15 May 2020). (A) Timeline. Vertical lines indicate assessments. The shaded parts illustrate the COVID-19 restrictions, postponing the Learning, Innovation, Volunteers and Empowerment (LIVE-Intervention) for the dyads of group 2. (B) Flow chart. This study includes the dyads of PAN.DEM completing the prepandemic assessment before the COVID-19 restrictions was implemented on 12 March 2020. *Parent trial attrition: rate within assumptions of lost to follow-up.

healthcare services and medications as specified by the dyads. Drugs catalogued in the Anatomical Therapeutic Chemical Index (ATC) administered in a set schedule were regarded 'regular', whereas all others were documented as 'on demand'.[25] Psychotropic drugs included antipsychotic (N05A), anxiolytic (N05B), hypnotic and sedative (N05C), antidepressant (N06A) and antiementia drugs (N06D) by ATC. Demographical data (age, gender, residency, kinship) were self-reported. We evaluated dementia severity in terms of cognition with MMSE and level of functioning with FAST at inclusion.[14 15]

At the pandemic assessment, the informal carers were also asked to estimate the degree of insight presented by the person with dementia into the COVID-19 situation and change in (1) contact with the informal carer, (2) volunteering services and (3) municipal healthcare services (home nursing services, home help, day-care, and in-home and out-of-home respite care) due to the COVID-19 restrictions.[12] Finally, informal carers stated if contacts with healthcare professionals were postponed or averted.

Study size

This study includes all dyads in PAN.DEM completing the prepandemic assessment before the COVID-19 restrictions were effectuated (figure 1B).

Statistical methods

Initially, we aggregated median and IQR, and calculated NPI-12 subsyndrome scores and total scores for NPI-12 and CSDD if >80% of the scales were answered. We used the Wilcoxon matched-pairs signed-rank test to assess change between the prepandemic and pandemic assessments. Next, we dichotomised those NPI-12 and CSDD sum scores that changed into worsening/not worsening and used multiple logistic regression analysis to explore factors associated. We included the following covariates for persons with dementia: age, gender, residency, dementia aetiology, MMSE, FAST, IADL, PSMS, GMHR, number of psychotropic drugs prescribed regularly and on-demand, and the COVID-19 specific outcomes. We also included age and gender of the informal carers. Covariates were selected based on our expertise in research and clinical dementia care. The Akaike information criterion guided model selection. Selected models were then checked for multicollinearity, robustness and goodness-of-fit by Pearson and Hosmer-Lemeshow test. FAST, IADL and PSMS showed moderate to strong positive correlation, but including all three covariates substantially improved the models. Missing data were handled with listwise deletion, with 14% missing any covariates. Calculations are expressed in OR with 95% CI, and p value. Reported p values are two tailed, and p<0.05 was considered statistically significant. Descriptive statistics are presented by n (%), mean (SD), or median (IQR). We used Stata/IC, release V.16 (StataCorp) for all analyses.

Public and Patient involvement

The conceptualisation, design, assessments and conduct of the parent trial as well as PAN.DEM included close patient/informal carer and public involvement.[12 13] A user-representative participated in the research group's weekly meetings. In PAN.DEM, he consulted with the study team on priorities, length and wording of the interview, and its revisions, with a special focus on the potential burden on informal carers.[12]

RESULTS

Of the 280 dyads participating in the parent trial, 237 completed the prepandemic assessment from December 2019 to March 2020 (figure 1B). This study includes 104 dyads recruited to PAN.DEM completing the prepandemic assessment before the COVID-19 restrictions were effectuated 12 March 2020. Mean time between assessments was 86 days (SD 19).

Table 1 shows that the mean age for people with dementia was 82 years (SD 7), 61% were women, 44% lived alone, and 50% received daily home-nursing services prior to the COVID-19 restrictions. Alzheimer's disease constituted the most common dementia aetiology, while 6% had vascular dementia and 10% reported Lewy-body dementia or Parkinson's disease. Most people with dementia lacked insight into the COVID-19 situation (table 2). The informal carers reported to have less contact with the person with dementia in 28% under the restrictions, and that contacts with healthcare professionals had been postponed or averted in 31%.

From the prepandemic to the pandemic assessment, people with dementia experienced an increase in NPI-12 total score (16 (4.5–29) to 20 (7–32.5), p=0.03) and in numbers of BPSD with symptom load of clinical relevance (2 (0–4) to 3 (1 –5), p<0.001) (table 3). Also, the NPI-12 score worsened for 55% (figure 2). We found an increase in the psychosis subsyndrome (0 (0–3) to 0.5 (0–6), p=0.01), with 36% experiencing more severe symptoms (figure 2). We also found an increase in depressive symptoms measured both by the NPI-12 depression domain (0 (0–3) to 1 (0–6), p=0.04) and CSDD total score (5 (3–9) to 7 (4–12), p=0.01, table 3). Additionally, the CSDD total score worsened for 54% (figure 2).

Table 4 shows the results of the logistic regression models exploring factors associated with worsening BPSD under the restrictions. Worsening NPI-12 total score was associated with postponed or averted contacts with healthcare professionals (OR 3.96, 95% CI 1.05 to 14.95) and impaired cognition as indicated by MMSE (OR 1.19, 95% CI 1.01 to 1.40), while a diagnosis of Alzheimer's disease relative to other dementia aetiologies was associated with lower OR of worsening NPI-12 (OR 0.18, 95% CI 0.05 to 0.63). Worsening psychosis subsyndrome score was associated with partial insight into the COVID-19 situation (OR 9.57, 95% CI 1.14 to 80.71), reduced contact with the informal carer (OR 4.45, 95% CI 1.01 to 19.71), and impaired function as indicated by FAST (OR 2.59,

Table 1 Prepandemic characteristics for the 104 dyads (persons with dementia and informal carers, n)

	N=104
Person with dementia	
Age, mean (SD)	82 (7)
Female gender, n (%)	63 (61)
Residency	
Living alone, n (%)	46 (44)
Coresiding with the reporting informal carer, n (%)	46 (44)
Coresiding with someone else than the informal carer, n (%)	12 (12)
Dementia aetiology	
Alzheimer's disease, n (%)	45 (43)
Vascular dementia, n (%)	6 (6)
Dementia in other diseases classified elsewhere, n (%)	10 (10)
Unspecified dementia, n (%)	43 (41)
MMSE, range 0–30, median (IQR)	21(18–24)
FAST, range 1–7, median (IQR)	4 (4–4)
GMHR, range 1–4, median (IQR)	3 (2–3)
PSMS, range 6–30, median (IQR)	11 (9–14)
IADL, range 8–31, median (IQR)	22 (18–27)
Drugs in general	
Total number, median (IQR)	6 (4–8)
Regularly, median (IQR)	5 (3–7)
Psychotropic drugs	
Total no, median (IQR)	1 (0–2)
Regularly, median (IQR)	1 (0–1)
Antipsychotic drugs (N05A), n (%)	6 (6)
Anxiolytic drugs (N05B), n (%)	3 (3)
Hypnotic/sedative drugs (N05C), n (%)	10 (10)
Antidepressant drugs (N06A), n (%)	19 (18)
Antidementia drugs (N06D), n (%)	52 (50)
On-demand, median (IQR)	0 (0–0)
Antipsychotic drugs (N05A), n (%)	0 (0)
Anxiolytic drugs (N05B), n (%)	5 (5)
Hypnotic/sedative drugs (N05C), n (%)	12 (12)
Antidepressant drugs (N06A), n (%)	0 (0)
Antidementia drugs (N06D), n (%)	0 (0)
Volunteering services, n (%)	8 (8)
Healthcare services	
Daily home nursing, n (%)	52 (50)
Weekly day care, n (%)	29 (28)
Respite care (In-home and out-of-home), n (%)	2 (2)
Informal carer	
Age, mean (SD)	65 (12)
Female gender, n (%)	68 (65)
Kinship to the person with dementia	
Spouse, n (%)	44 (42)
Child, n (%)	58 (56)
Others, n (%)	2 (2)

Drugs were classified by the Anatomical Therapeutic Chemical Index; antipsychotics, anxiolytics, hypnotics/sedatives, antidepressants and antidementia drugs constituted psychotropic drugs.
FAST, Functional Assessment Staging; GMHR, General Medical Health Rating Scale; IADL, Instrumental Activities of Daily Living Scale; ICD-10, International Classification of Diseases10th version; MMSE, Mini-Mental Status Examination; Prepandemic, Six-month assessment of parent trial (12 December 2019 to 11 March 2020); PSMS, Physical Self-Maintenance Scale.

95% CI 1.07 to 6.27). An inverse association occurred for higher dependency in activities of daily living by PSMS and worsening psychosis subsyndrome (OR 0.68, 95% CI 0.51 to 0.91). Worsening depressive symptoms was associated with impaired function by FAST (OR 4.96, 95% CI 1.57 to 15.65), in contrast to lower odds associated with Alzheimer's disease (OR 0.21, 95% CI 0.05 to 0.85) and psychotropic drug use on-demand (OR 0.16, 95% CI 0.03 to 0.75).

Post hoc analysis did not show any association between use of antipsychotic drugs before the restrictions and worsening psychosis subsyndrome using unequal variances t-test (online supplemental table A). Similarly, we found no association between use of antidepressants and worsening depressive symptoms. Neither randomisation

Table 2 Pandemic characteristics for the 104 persons with dementia (n) as perceived by their informal carers

	N= 104
Degree of insight	
Sufficient, n (%)	34 (33)
Partial, n (%)	54 (52)
To no degree, n (%)	16 (15)
Change in contact with the informal carer*	
Reduced, n (%)	29 (28)
No change, n (%)	49 (47)
Increased, n (%)	23 (22)
Ceased volunteering services*, n (%)	8 (8)
Change in healthcare services*, n (%)	42 (40)
Postponed or averted contacts with healthcare professionals*, n (%)	32 (31)

*Relative the prepandemic situation. Healthcare services provided by the municipality: home nursing services, home help, day-care and respite care (in-home and out-of-home).
Pandemic, PAN.DEM assessment (20 April 2020 to 15 May 2020).

Table 3 Prepandemic compared with pandemic behavioural and psychological symptoms for the 104 persons with dementia (n)

	Prepandemic			Pandemic			
	N (%) with symptom load of clinical relevance*	Median	IQR	N (%) with symptom load of clinical relevance*	Median	IQR	P value
Neuropsychiatric inventory (NPI-12)							
Total score, range 0–144		16	4.5–29		20	7–32.5	0.03†
Subsyndromes							
Psychosis‡, range 0–24		0	0–3		0.5	0–6	0.01†
Hyperactive behaviour§, range 0–60		5.5	0–12		4	0–12	0.79
Mood¶, range 0–48		6	0–12		6.5	1–12	0.21
Domain scores, range 0–12							
Delusions	20 (19)	0	0–2	31 (30)	0	0–6	0.04†
Hallucinations	8 (8)	0	0–0	16 (15)	0	0–0	0.23
Agitation	23 (22)	0	0–3	18 (17)	0	0–2	0.45
Depression	25 (24)	0	0–3	40 (38)	1	0–6	0.04†
Anxiety	18 (17)	0	0–2	31 (30)	0	0–4	0.07
Euphoria	8 (8)	0	0–0	4 (4)	0	0–0	0.19
Apathy	35 (34)	0	0–4	30 (29)	0	0–4	0.50
Disinhibitions	9 (9)	0	0–0	15 (14)	0	0–1.5	0.16
Irritability	28 (27)	0	0–4	29 (28)	0	0–4	0.78
Aberrant motor behaviour	23 (22)	0	0–1	24 (23)	0	0–2.5	0.66
Sleep disturbances	25 (24)	0	0–3	28 (27)	0	0–4	0.82
Appetite changes	14 (13)	0	0–1	17 (16)	0	0–1	0.84
No of BPSD with symptom load of clinical relevance*, range 0–12		2	0–4		3	1–5	<0.001†
Cornell Scale for Depression in Dementia (CSDD)							
Total score, range 0–38	34 (33)	5	3–9	41 (39)	7	4–12	0.01†

*NPI domain scores ≥4 indicate BPSD with symptom load of clinical relevance. CSDD total score ≥8 indicates depression of clinical relevance.
†Indicates two-tailed p<0.05.
‡ Psychosis: delusions and hallucinations
§ Hyperactive behaviour: agitation, euphoria, irritation, disinhibition, aberrant motor behaviour
¶ Mood: depression, apathy, sleep disturbances and appetite changes
BPSD, behavioural and psychological symptoms of dementia; P, p value for difference in median between time points by the Wilcoxon matched-pairs signed-rank test; Pandemic, PAN.DEM assessment (20 April 2020 to 15 May 2020); Prepandemic, Six-month assessment of parent trial (12 December 2019 to 11 March 2020).

to the intervention vs control of the parent trial showed associations with worsening NP-12 total score, psychosis subsyndrome nor depressive symptoms (online supplemental table A). To explore if consecutive sampling introduced bias, we compared our study sample to those not included yet still in parent trial at the prepandemic assessment, revealing minimal differences (online supplemental table B).

DISCUSSION

Our primary aim was to compare prepandemic and pandemic levels of BPSD in home-dwelling people with dementia during the two first months of COVID-19 restrictions in Norway. Even though BPSD fluctuates over the dementia course, our study indicates that the COVID-19 restrictions caused an overall increase in BPSD over a mean of 86 days, and that odds of worsening were four times higher with postponed or averted contacts with healthcare professionals. More specifically, the increase was most pronounced for symptoms of psychosis and depression. The odds for worsening psychosis increased 10-fold with partial insight into the COVID-19 situation and 4-fold with reduced contact with informal carers, while as-needed use of psychotropic drugs was associated with fewer depressive symptoms.

Strengths and weaknesses

Our study provides prospective data obtained shortly before and under the COVID-19 restrictions rated by the same informal carer for each subject and based on extensive assessor-blinded interviews with validated, well-established instruments.[12 13] We used established cut-off scores when presenting BPSD with symptom load of clinical relevance.[6 19] The parent trial population was recruited from different municipalities to be representative to the Norwegian demographic in terms of dementia aetiology, severity and symptomatology.[13] As our study

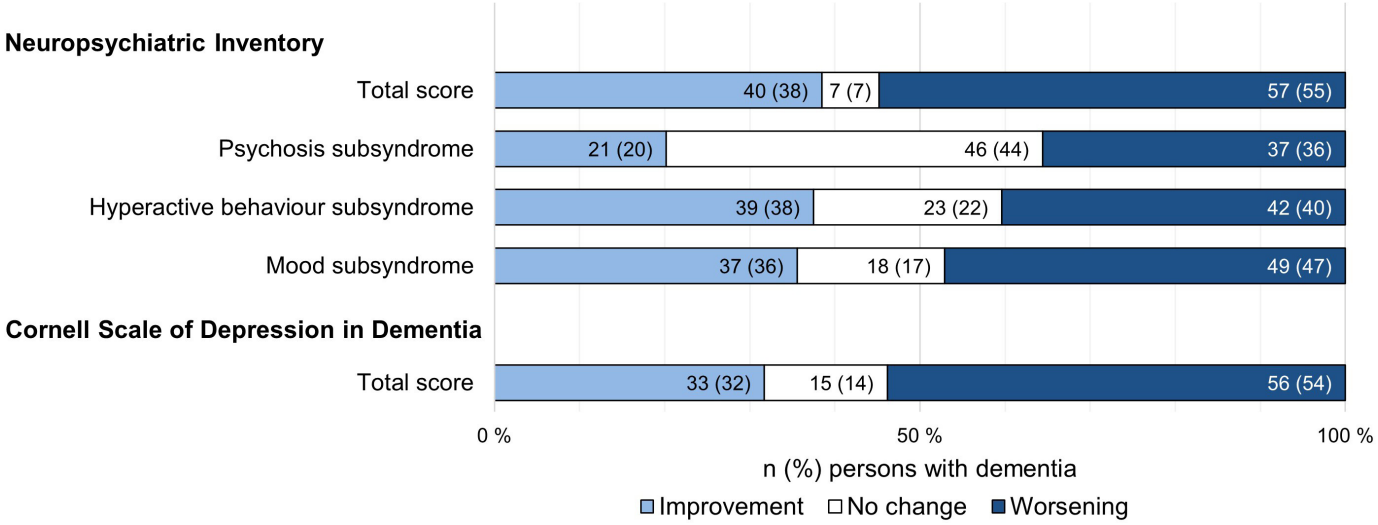

Figure 2 Change in behavioural and psychological symptoms in n (%) persons with dementia from the prepandemic to the pandemic assessment. n: 104. Prepandemic: Six-month assessment of parent trial (12 December 2019 to 11 March 2020). Pandemic: PAN.DEM assessment (20 April 2020 to 15 May 2020). Neuropsychiatric Inventory, subsyndrome score: psychosis (delusions and hallucinations), hyperactive behaviour (agitation, euphoria, irritation, disinhibition, aberrant motor behaviour), mood (depression, apathy, sleep disturbances and appetite changes). Cornell Scale for Depression in Dementia, total score.

sample was fairly similar to those dyads not included from the parent trial, we argue that our study was not biased by selection.

There are weaknesses to address. Despite efforts, we were not able to invite all potential respondents through consecutive sampling before the restrictions were eased for the first time, explaining the limited sample size. CSDD is not validated for telephone interviews[18] yet our findings using CSDD were consistent with the depression domain of NPI-12, which can be used as a telephone interview instrument.[16] Previous work has shown that carer psychosocial factors such as sense of competence, guilt and relationship quality account for up to 56% of the variance in BPSD-related distress.[26] In the case of the pandemic, stress-related symptoms were experienced by two-thirds of family carers soon after the outbreak hit Italy (N=4913) and were associated with incident or worsening BPSD.[9] The authors conclude that they could not determine whether increased BPSD were the cause or consequence of carer distress, as both counterparts were exposed to similar conditions during quarantine. Even though we did not assess such domains, these considerations apply to our study. Another point is that 28% of the informal carers reported reduced contact with the person with dementia, leaving them with less clinical observation. As 44% of the dyads were not living together, we suggest that some violated the restrictions to visit their loved ones and keep their obligations as careers, possibly mitigating the impact on BPSD. These weaknesses should be considered when interpreting the results, along with the wide CIs of the covariates associated with worsening BPSD. Notably, our data capture the impact of the initial phase of the outbreak in Norway and can therefore not answer longer-term consequences from either reimposition or lengthening of invasive restrictions.

Comparison with other studies

This study provides data on the negative mental health consequences of the COVID-19 restrictions for people with dementia. Using a non-randomised, non-controlled design to evaluate causations may be reasonable in the pandemic scenario as no other way of assessing the impact of the COVID-19 restrictions exist. However, our results should be interpreted with caution. The deterioration in BPSD could in theory be caused by the progression of the dementia syndrome itself, rather than being exacerbated by the pandemic restrictions. Arguing against this, change in BPSD over 4 months was substantially lesser in an observational cohort of nursing home residents of which the majority had dementia than what we demonstrate comparing prepandemic and pandemic symptom levels.[27]

Our findings echo a small body of the existing literature on this topic. A study from Spain noted increases in levels of agitation, apathy, and aberrant motor behaviour 5 weeks into lockdown in outpatients with mild cognitive impairment and Alzheimer's disease (N=40), but no increase in psychotic symptoms.[28] A cross-sectional study from Italy (N=139) describes exacerbation of psychotic symptoms in a small percentage of subjects with subjective cognitive decline, mild cognitive impairment and dementia.[29] This study, in part, used self-assessments, that may have led to underreporting of delusions and hallucinations. Even though other studies are equivocal on whether psychosis worsened,[8 9] UK registry data indicate higher antipsychotic prescription rates to people with dementia during the pandemic, and the authors speculate that this increase may be the result of worsened agitation and psychosis.[30] Meanwhile, our study revealed no associations between psychotropic drugs and psychosis, likely given that very few patients used antipsychotics

Table 4 Factors associated with worsening in behavioural and psychological symptoms of dementia from the prepandemic to the pandemic assessment

	NPI-12 total score				NPI-12 psychosis subsyndrome				CSDD total score			
		95% CI				95% CI				95% CI		
Covariates	OR	Lower	Upper	P value	OR	Lower	Upper	P value	OR	Lower	Upper	P value
Prepandemic characteristics												
Person with dementia												
Age	1.01	0.92	1.11	0.79	0.91	0.82	1.01	0.16	1.09	0.97	1.22	0.16
Female gender	0.51	0.13	1.98	0.34	0.36	0.09	1.52	0.09	0.19	0.03	1.31	0.09
Living alone	0.20	0.04	1.01	0.05	2.69	0.41	17.80	0.31	0.55	0.07	4.18	0.57
Alzheimer's disease*	0.18	0.05	0.63	0.01¶¶	0.84	0.23	3.08	0.79	0.21	0.05	0.85	0.03¶¶
MMSE†	1.19	1.01	1.40	0.04¶¶	0.97	0.82	1.14	0.68	0.96	0.80	1.15	0.65
FAST‡	0.98	0.45	2.16	0.97	2.59	1.07	6.27	0.04¶¶	4.96	1.57	15.65	0.01¶¶
IADL§	0.96	0.80	1.15	0.64	1.19	0.98	1.45	0.08	0.84	0.67	1.07	0.16
PSMS¶	1.00	0.79	1.28	0.99	0.68	0.51	0.91	0.01¶¶	0.99	0.76	1.29	0.96
GMHR**	0.91	0.36	2.32	0.84	2.06	0.72	5.88	0.18	0.84	0.28	2.50	0.76
Psychotropic drugs††												
Regularly	1.16	0.54	2.48	0.71	0.67	0.31	1.47	0.32	1.11	0.49	2.53	0.80
On-demand	0.35	0.09	1.46	0.15	2.95	0.69	12.66	0.15	0.16	0.03	0.75	0.02¶¶
Informal carer												
Age	0.97	0.92	1.03	0.40	1.04	0.98	1.12	0.21	0.99	0.93	1.06	0.87
Female gender	1.81	0.50	6.49	0.36	0.70	0.18	2.80	0.62	0.82	0.16	4.27	0.82
Pandemic characteristics, person with dementia												
Insight to the COVID-19 situation‡‡												
Partial	0.61	0.10	3.69	0.60	9.57	1.14	80.71	0.04¶¶	0.67	0.10	4.44	0.68
Sufficient	1.14	0.15	8.82	0.90	3.69	0.33	40.93	0.29	2.70	0.26	28.27	0.41
Contact with the informal carer§§												
Reduced	1.88	0.48	7.44	0.37	4.45	1.01	19.71	0.049¶¶	1.40	0.27	7.27	0.69
Increased	2.41	0.61	9.49	0.21	3.21	0.71	14.55	0.13	0.30	0.07	1.23	0.10
Ceased volunteering services	0.30	0.04	2.24	0.24	0.20	0.02	2.11	0.18	0.59	0.04	7.91	0.69
Change in healthcare services	0.48	0.13	1.78	0.28	0.48	0.11	2.08	0.33	1.16	0.28	4.83	0.84
Postponed or averted contacts with healthcare professionals	3.96	1.05	14.95	0.04¶¶	1.55	0.45	5.42	0.49	3.37	0.70	16.08	0.13

Change dichotomised into worsening/not worsening. OR explored by multiple logistic regression, estimates adjusted for all other factors in the models.
*Alzheimer's disease, reference: all other dementia aetiologies.
†MMSE, range 0–30, higher scores indicate better cognition, reference: 30.
‡FAST, range 1–7, lower scores indicate better functioning, reference: 1.
§IADL, range 8–31, lower scores indicate better functioning, reference: 8.
¶PSMS, range 6–30, lower scores indicate better functioning, reference 6.
**GMHR, range 1–4, lower score indicate higher comorbidity burden, reference 4.
††Number of psychotropic drugs according to the Anatomical Therapeutic Chemical Index: antipsychotics (N05A), anxiolytics (N05B), hypnotics/sedatives (N05C), antidepressants (N06A) and anti-dementia drugs (N06D), reference: 0.
‡‡Degree of insight into the COVID-19 situation as perceived by the informal carer, reference: no insight.
§§Change in contact with the informal carer, reference: no change.
¶¶P: two-tailed p<0.05
CSDD, Cornell Scale of Depression in Dementia ; FAST, Functional Assessment Staging, at inclusion; GMHR, General Medical Health Rating Scale; IADL, Instrumental Activities of Daily Living Scale; MMSE, Mini-Mental Status Examination, at inclusion; n, 89 dyads (person with dementia and informal carer); NPI-12, Neuropsychiatric Inventory, twelve item version, with psychosis subsyndrome constituting delusions and hallucinations; Pandemic, PAN.DEM assessment (20 April 2020 to 15 May 2020); Prepandemic, Six-month assessment of parent trial (12 December 2019 to 11 March 2020); PSMS, Physical Self-Maintenance Scale.

before the pandemic, in addition to the lack of real-time prescription data throughout the outbreak. Because this is a nascent area of research, discrepancies may be attributed to heterogeneity in design, as well as dementia severity and aetiology.

Early findings suggest that older adults at group level are more resilient to the mental health effects of the pandemic than younger ones.[11] Nonetheless, our study adds to the cross-sectional reports calling attention to deteriorating depressive symptoms among people with dementia.[8–10] For better communication within and between dyads and their formal caregivers, digital devices may enhance individual support.[12] Further, anxiolytics and hypnotics/sedatives were associated with fewer depressive symptoms when used as-needed in our sample. These drugs are known to temporarily alleviate some

of the symptoms assessed by the CSDD, such as anxiety, irritability and agitation. However, in line with national guidelines, we rather recommend that antidepressants are considered if severe symptoms persist.[31]

Our study supports the WHO's concerns that the pandemic would negatively impact the mental health of people with cognitive impairments.[5] Even though way of life varies globally, the policies implemented in response to COVID-19 are likely equally disruptive to the environment of home-dwelling people with dementia across nations.[3] We, therefore, argue that our findings are generalisable to other countries. Furthermore, they emphasise that non-pharmacological approaches still should be the first-line treatment to avoid BPSD deterioration regardless of context.

Unanswered questions and future research

Future research should explore the long-term impact of the COVID-19 restrictions on BPSD, and whether moderations or service innovations can mitigate worsening. Less than 5% of trials on COVID-19 involve behavioural and mental health interventions,[32] emphasising the need for knowledge to adapt restrictions and navigate the unforeseeable consequences for persons with dementia and informal caregiver of the current, and future, pandemics.

Author affiliations
[1]Haraldsplass Deaconess Hospital, Bergen, Norway
[2]Centre for Elderly and Nursing Home Medicine, Department of Global Public Health Primary Care, Faculty of Medicine, University of Bergen, Bergen, Norway
[3]Bergen Municipality, Bergen, Norway
[4]McLean Hospital, Belmont, Massachusetts, USA
[5]Harvard Medical School, Boston, Massachusetts, USA
[6]Section for Epidemiology and Medical Statistic, Department of Global Public Health and Primary Care, Faculty of Medicine, University of Bergen, Bergen, Norway
[7]Department of Clinical Science, Faculty of Medicine, University of Bergen, Bergen, Norway
[8]NKS Olaviken Gerontopsychiatric Hospital, Askøy, Norway

Acknowledgements Renira Angeles (postdoctoral fellow, NORCE) and Nathalie Puaschitz (postdoctoral fellow, Western Norway University of Applied Sciences) contributed to data collection. Rune Samdal secured public and patient involvement. The motivation and willingness of dyads and municipal personnel in Bergen, Bærum and Kristiansand made this study possible.

Contributors BSH was primary investigator. MHG, BSH, MV and LIB designed and planned the study. MHG, MV and LIB collected data. MHG did the data analysis, supervised by JM. MHG and LIB wrote the first draft of the manuscript. MHG, BSH, IVV, JM, MV, MN and LIB were actively involved in interpreting the results, revising the manuscript and approving the final version. LIB is responsible for the overall content as guarantor. The corresponding author attests that all listed authors meet the authorship criteria and that no others fulfilling authorship criteria are omitted.

Funding This work was supported by the Research Council of Norway (grant number 273581). The Norwegian Government and the G.C. Rieber Foundation supports the Centre for Elderly and Nursing Home Medicine, University of Bergen, organising the conduction of LIVE@Home.Path and PAN.DEM. The research was designed, conducted, analysed, interpreted and written by the authors independently of the funding sources. All authors had access to the data in the study and can take responsibility for the integrity of the data and the accuracy of data analysis.

Competing interests All authors have completed the ICMJE uniform disclosure form at www.icmje.org/coi_disclosure.pdf and declare: MHG, MV, JM and LIB had financial support from the Research Council of Norway (grant number 273581), for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years; IVV reports receiving honorarium as editor of the American Journal of Geriatric Psychiatry.

Patient consent for publication Not applicable.

Ethics approval This study was approved by the Regional Committee for Medical and Health Research Ethics North Norway (reference number 2019/385 for the parent trial and 10861 for PAN.DEM).

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available on reasonable request. Relevant anonymised data are available at reasonable request. Data are fully available to collaborators and affiliated researchers.

ORCID iD
Marie H Gedde http://orcid.org/0000-0002-8423-6402

REFERENCES

1 Atkins JL, Masoli JAH, Delgado J, *et al*. Preexisting comorbidities predicting COVID-19 and mortality in the UK Biobank community cohort. *J Gerontol A Biol Sci Med Sci* 2020;75:2224–30.
2 Suárez-González A, Livingston G, Low L-F. Impact and mortality of COVID-19 on people living with dementia: cross-country report, 19 August 2020. Available: https://ltccovid.org/wp-content/uploads/2020/08/International-report-on-the-impact-of-COVID-19-on-people-living-with-dementia-19-August-2020.pdf [Accessed Aug 2021].
3 Islam N, Sharp SJ, Chowell G, *et al*. Physical distancing interventions and incidence of coronavirus disease 2019: natural experiment in 149 countries. *BMJ* 2020;370:m2743.
4 Wang H, Li T, Barbarino P, *et al*. Dementia care during COVID-19. *Lancet* 2020;395:1190–1.
5 World Health Organization. Mental health and psychosocial considerations during the COVID-19 outbreak. Available: https://apps.who.int/iris/handle/10665/331490 [Accessed 18 Mar 2020].
6 Vik-Mo AO, Giil LM, Borda MG, *et al*. The individual course of neuropsychiatric symptoms in people with Alzheimer's and Lewy body dementia: 12-year longitudinal cohort study. *Br J Psychiatry* 2020;216:43–8.
7 Bessey LJ, Walaszek A. Management of behavioral and psychological symptoms of dementia. *Curr Psychiatry Rep* 2019;21:66.
8 Cohen G, Russo MJ, Campos JA, *et al*. COVID-19 epidemic in argentina: worsening of behavioral symptoms in elderly subjects with dementia living in the community. *Front Psychiatry* 2020;11:866.
9 Cagnin A, Di Lorenzo R, Marra C, *et al*. Behavioral and psychological effects of coronavirus disease-19 quarantine in patients with dementia. *Front Psychiatry* 2020;11:578015.
10 El Haj M, Altintas E, Chapelet G, *et al*. High depression and anxiety in people with Alzheimer's disease living in retirement homes during the covid-19 crisis. *Psychiatry Res* 2020;291:113294.
11 Vahia IV, Jeste DV, Reynolds CF. Older adults and the mental health effects of COVID-19. *JAMA* 2020;324:2253–2235.
12 Gedde MH, Husebo BS, Erdal A, *et al*. Access to and interest in assistive technology for home-dwelling people with dementia during the COVID-19 pandemic (PAN.DEM). *Int Rev Psychiatry* 2021;33:404–11.
13 Husebo BS, Allore H, Achterberg W, *et al*. LIVE@Home.Path—innovating the clinical pathway for home-dwelling people with dementia and their caregivers: study protocol for a mixed-method, stepped-wedge, randomized controlled trial. *Trials* 2020;21:1–16.

14 Folstein MF, Folstein SE, McHugh PR. "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *J Psychiatr Res* 1975;12:189–98.
15 Reisberg B. Functional assessment staging (FAST). *Psychopharmacol Bull* 1988;24:653–9.
16 Cummings J. The neuropsychiatric inventory: development and applications. *J Geriatr Psychiatry Neurol* 2020;33:73–84.
17 Aalten P, de Vugt ME, Lousberg R, *et al*. Behavioral problems in dementia: a factor analysis of the neuropsychiatric inventory. *Dement Geriatr Cogn Disord* 2003;15:99–105.
18 Alexopoulos GS, Abrams RC, Young RC, *et al*. Cornell scale for depression in dementia. *Biol Psychiatry* 1988;23:271–84.
19 Barca ML, Engedal K, Selbaek G. A reliability and validity study of the Cornell scale among elderly inpatients, using various clinical criteria. *Dement Geriatr Cogn Disord* 2010;29:438–47.
20 Selbaek G, Kirkevold O, Sommer OH, *et al*. The reliability and validity of the Norwegian version of the neuropsychiatric inventory, nursing home version (NPI-NH). *Int Psychogeriatr* 2008;20:375–82.
21 Lawton MP, Brody EM. Assessment of older people: self-maintaining and instrumental activities of daily living. *Gerontologist* 1969;9:179–86.
22 Lawton MP. Aging and performance of home tasks. *Hum Factors* 1990;32:527–36.
23 Lyketsos CG, Galik E, Steele C, *et al*. The general medical health rating: a bedside global rating of medical comorbidity in patients with dementia. *J Am Geriatr Soc* 1999;47:487–91.
24 World Health Organization. *The ICD-10 classification of mental and behavioural disorders: clinical descriptions and diagnostic guidelines*. Geneva, Switzerland, 1992.
25 World Health Organization Collaborating Centre for Drug Statistics Methodology Norwegian Institute of Public Health. ATC/DDD index, 2015. Available: https://www.whocc.no/atc_ddd_index/
26 Feast A, Orrell M, Russell I, *et al*. The contribution of caregiver psychosocial factors to distress associated with behavioural and psychological symptoms in dementia. *Int J Geriatr Psychiatry* 2017;32:76–85.
27 Gedde MH, Husebo BS, Mannseth J, *et al*. Less is more: the impact of deprescribing psychotropic drugs on behavioral and psychological symptoms and daily functioning in nursing home patients. results from the cluster-randomized controlled Cosmos trial. *Am J Geriatr Psychiatry* 2021;29:304–15.
28 Lara B, Carnes A, Dakterzada F, *et al*. Neuropsychiatric symptoms and quality of life in Spanish patients with Alzheimer's disease during the COVID-19 lockdown. *Eur J Neurol* 2020;27:1744–7.
29 Canevelli M, Valletta M, Toccaceli Blasi M, *et al*. Facing dementia during the COVID-19 outbreak. *J Am Geriatr Soc* 2020;68:1673–6.
30 Howard R, Burns A, Schneider L. Antipsychotic prescribing to people with dementia during COVID-19. *Lancet Neurol* 2020;19:892.
31 The Norwegian Directorate of Health. Nasjonal faglig retningslinje for demens [National professional guidelines on dementia], 2020. Available: https://www.helsedirektoratet.no/retningslinjer/demens [Accessed 4 Sep 2021].
32 Jones CW, Woodford AL, Platts-Mills TF. Characteristics of COVID-19 clinical trials registered with ClinicalTrials.gov: cross-sectional analysis. *BMJ Open* 2020;10:e041276.

The PAN.DEM assessment

Respondents: informal carers in the LIVE@Home.Path trial

1 **Date of birth:** mm.dd.yyyy

2 **Are you temporarily laid off due to the covid-19 restrictions?**

- ☐ Yes
- ☐ No
- ☐ Not applicable

3 **During the last month, have you been quarantined due to covid-19?**

- ☐ Yes
- ☐ No

If yes, please specify:

_____

4 **Does the person with dementia have insight into the covid-19 situation?**

- ☐ To no degree
- ☐ Partial
- ☐ Sufficient

5 **To what degree are you concerned that the person with dementia will be infected with covid-19?**

Tick a number on the scale from 0-10 (0=not at all; 10=as much as possible):

0 1 2 3 4 5 6 7 8 9 10

6 **To what degree are you concerned that you yourself will be infected with covid-19?**

Tick a number on the scale from 0-10 (0=not at all; 10=as much as possible)

0 1 2 3 4 5 6 7 8 9 10

Gedde MH, *et al. BMJ Open* 2022; 12:e050628. doi: 10.1136/bmjopen-2021-050628

7 **To what degree are you concerned that you yourself will be infected with covid-19?**

Tick a number on the scale from 0-10: (0=not at all; 10=as much as possible):

0 1 2 3 4 5 6 7 8 9 10

8 **To what degree are your concern for own infection sourced from your responsibilities as carer?**

Tick a number on the scale from 0-10:(0=not at all; 10=as much as possible):

0 1 2 3 4 5 6 7 8 9 10

9 **As a response to the covid-19 pandemic, did you discuss advanced care planning with the person with dementia?** If yes, please specify below.

_____

10 **Did the covid-19 restrictions have any consequences for the healthcare services provided by the municipality for the person with dementia** (e.g. home nursing services, activity groups, day care centre, respite care).

☐ Yes
☐ No

If yes, specify per Resource Utilization in Dementia Version 4 section A2.2.5 [1 2]

11 **Have you avoided or postponed contacts with health care professionals due to the COVID-19 pandemic and the restrictions?**

☐ Yes
☐ No

If yes, please specify:

_____

12 **Informal care time assessed by Resource Utilization in Dementia Version 4 section B1.2** [1 2]

13 **Has the food habits and appetite of the person with dementia changed under to the covid-19 restrictions?**

- ☐ Yes
- ☐ No

If yes, please specify: Tick one or several items.

- ☐ Eats/drinks less
- ☐ Loss of appetite
- ☐ Eats more
- ☐ Eats mote unhealthy food
- ☐ Has stopped preparing food him/herself
- ☐ Heats prepared food
- ☐ Is unable to maintain diet without help from informal or formal carers

14 **Neuropsychiatric inventory (12 item version)** [3]

15 **Cornell Scale of Depression in Dementia** [4]

16 **Has the pandemic had any consequences for services provided by volunteers?**

- ☐ Yes
- ☐ No

If yes, specify as applicable:

_____

17 **Has the covid-19 restrictions increased your interest in assistive technology?**

- ☐ Yes
- ☐ No

If yes, specify as applicable including complaint/need, type of technology, if acquired, including privately financed or municipally funded:

_____

18 **Compared to pre-pandemic levels, what sort of contact have you had with the person with dementia?** Tick one or several items.

- ☐ Unchanged
- ☐ Increased
- ☐ Reduced
- ☐ No contact at all
- ☐ More digital contact

19 **Have you implemented measures and restrictions to prevent transmission of covid-19 to the person with dementia?** Please specify as applicable:

_____

20 **Compared to immediately before the pandemic, how would you rank your own total situation as a carer?** [5]

Tick a number from -5 (much worse) to 5 (much better), via 0 (no change).

-5 -4 -3 -2 -1 0 1 2 3 4 5

21 **Do you have any additional comments?** Please specify as applicable:

_____

References

1. Wimo A, Gustavsson A, Jonsson L, et al. Application of Resource Utilization in Dementia (RUD) instrument in a global setting. *Alzheimers Dement* 2013;9(4):429-35 e17. doi: 10.1016/j.jalz.2012.06.008 [published Online First: 2012/11/13]
2. Wimo A, Jonsson L, Zbrozek A. The Resource Utilization in Dementia (RUD) instrument is valid for assessing informal care time in community-living patients with dementia. *J Nutr Health Aging* 2010;14(8):685-90. [published Online First: 2010/10/06]
3. Cummings J. The Neuropsychiatric Inventory: Development and Applications. *Journal of Geriatric Psychiatry and Neurology* 2020;33(2):73-84.
4. Alexopoulos GS, Abrams RC, Young RC, et al. Cornell Scale for Depression in Dementia. *Biol Psychiatry* 1988;23(3):271-84. doi: 10.1016/0006-3223(88)90038-8 [published Online First: 1988/02/01]
5. Guy W. ECDEU assessment manual for psychopharmacology: U.S. Dept. of Health, Education, and Welfare, Public Health Service, Alcohol, Drug Abuse, and Mental Health Administration, National Institute of Mental Health, Psychopharmacology Research Branch, Division of Extramural Research Programs 1976.

Supplementary table A: Post-hoc analysis of associations between worsening in behavioural and psychological symptoms (from the pre-pandemic to the pandemic assessment) and pre-pandemic traits for the 104 persons with dementia.

	mean (SD)	P
NPI-12 total score		
Use of psychotropic drugs (N05A, N05B, N05C, N06A, N06D)		
Yes	0.58 (0.50)	0.36
No	0.47 (0.51)	
Use of antidementia drugs (N06D)		
Yes	0.58 (0.50)	0.85
No	0.48 (0.50)	
Receiving the LIVE-intervention[#]		
Yes	0.57 (0.51)	0.81
No	0.54 (0.40)	
NPI-12 psychosis subsyndrome		
Use of antipsychotic drugs (N05A)		
Yes	0.33 (0.52)	0.92
No	0.36 (0.48)	
Receiving the LIVE-intervention[#]		
Yes	0.29 (0.46)	0.45
No	0.37 (0.49)	
CSDD total score		
Use of antidepressant drugs (N06A)		
Yes	0.63 (0.50)	0.88
No	0.61 (0.49)	
Receiving the LIVE-intervention[#]		
Yes	0.62 (0.50)	0.97
No	0.61 (0.49)	

Table legend:

Pre-pandemic: Six-month assessment of the parent trial (12 Dec 2019 to 11 Mar 2020). Pandemic: PAN.DEM assessment (20 Apr. to 15 May 15 2020). SD: standard deviation. P: P values for difference between groups by unequal variances t-test, * indicates two-tailed P<.05. NPI-12: Neuropsychiatric Inventory, twelve item version: with psychosis subsyndrome constituting delusions and hallucinations. CSDD: Cornell Scale of Depression in Dementia. Change dichotomised into worsening/not worsening. Drugs classified by the Anatomical Therapeutic Chemical Index. [#]21 (20%) received the LIVE-intervention: Multicomponent intervention of the parent trial comprising Learning, Innovation, Volunteers, and Empowerment.

Supplementary table B: Comparison of PAN.DEM study sample to those not included yet still in parent trial.

	Pre-pandemic six-month assessment of parent trial (n=237)		
	PAN.DEM study sample (n=104)	Not included in PAN.DEM study sample (n=133)	P
Person with dementia			
Age, mean (SD)	82 (7)	83 (7)	0.38
Female gender, n (%)	63 (61)	86 (65)	0.47
Residency			0.93
Living alone, n (%)	46 (44)	54 (41)	
Coresiding with the reporting informal carer, n (%)	46 (44)	59 (44)	
Coresiding with someone else than the informal carer, n (%)	12 (12)	16 (12)	
Dementia aetiology by ICD-10			0.003*
Alzheimer's Disease, n (%)	45 (43)	43 (32)	
Vascular Dementia, n (%)	6 (6)	2 (2)	
Dementia in other diseases classified elsewhere, n (%)	10 (10)	4 (3)	
Unspecified Dementia, n (%)	43 (41)	82 (62)	
MMSE, range 0-30, median [IQR]	21 [18, 24]	21 [18, 23]	0.83
FAST, range 1-7, median [IQR]	4 [4, 4]	4 [4, 5]	0.15
GMHR, range 1-4, median [IQR]	3 [2, 3]	3 [3, 4]	<0.001*
PSMS, range 6-30, median [IQR]	11 [9, 14]	11 [9, 14]	0.40
IADL, range 8-31, median [IQR]	22 [18, 27]	22 [16, 27]	0.65
Drugs in general, total number, median [IQR]	6 [4, 8]	4 [2, 7]	0.002*
Psychotropic drugs			
Total number, median [IQR]	1 [0, 1]	1 [0, 2]	0.02*
Regularly, median [IQR]	1 [0, 1]	1 [0, 1]	0.07
On-demand, median [IQR]	0 [0, 0]	0 [0, 0]	0.06
Health care services			
Daily Home Nursing, n (%)	52 (50)	46 (35)	0.02*
Weekly Day Care, n (%)	29 (28)	37 (28)	0.99

Respite Care (In-Home and Out-of-Home), n (%)	2 (2)	9 (7)	0.08
Volunteering services, n (%)	8 (8)	22 (17)	0.14
Behavioural and psychological symptoms of dementia			
NPI-12 total score, range 0-144, median [IQR]	16 [4.5, 29]	12.5 [4, 28]	0.74
CSDD total score, range 0-38, median [IQR]	5 [3, 9]	6 [2, 12]	0.32
Informal carer			
Age, mean (SD)	65 (12)	68 (12)	0.17
Female gender, n (%)	68 (65)	83 (62)	0.64
Kinship to the person with dementia			0.06
Spouse, n (%)	44 (42)	58 (44)	
Child, n (%)	58 (56)	63 (47)	
Others, n (%)	2 (2)	12 (9)	

Table legend:
n: dyads (person with dementia and informal carer). IQR: Interquartile range. SD: standard deviation. P: P values for difference between groups by two sample t-test, Wilcoxon-Mann-Whitney test, or Pearson chi-squared test, * indicates P<.05 ICD-10: International Statistical Classification of Diseases and Related Health Problems. MMSE: Mini-Mental Status Examination, at inclusion. FAST, Functional Assessment Staging, at inclusion. GMHR: General Medical Health Rating Scale. PSMS: Physical Self-Maintenance Scale. IADL: Instrumental Activities of Daily Living Scale. NPI-12: Neuropsychiatric Inventory. CSDD: Cornell Scale for Depression in Dementia. Drugs were classified by the Anatomical Therapeutic Chemical Index; antipsychotics, anxiolytics, hypnotics/sedatives, antidepressants, and anti-dementia drugs constituted psychotropic drugs.