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

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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 State 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.

INTRODUCTION

Dementia is among the most critical risk factors for COVID-19 mortality.1 In England and Wales alone, 12869 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. BPSD are best managed with structured, non-pharmacological interventions, placing psychotropic drugs as secondary treatment options. 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). In another study, family carers stated worsening of anxiety, insomnia and depression among persons at different stages of Alzheimer’s and related dementias living at home and depression among persons at different stages of informal carers reported worsening of anxiety, insomnia and depression when asked to evaluate their own experience of the pandemic retrospectively (N=58).

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. In this study, we aim to address this significant gap in the literature using data from the prospective PAN.DEM study. This study is nested within the ongoing LIVE@Home.Path trial 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. 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 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, which implied that healthcare was limited to those most in need. 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 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 ≥26 years, diagnosed with dementia (with Mini-Mental Status Examination (MMSE) score 15–26 or Functional Assessment Staging (FAST) score 3–7), 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. Informal carers gave additional informed consent to PAN.DEM.

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. 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. These domains are further aggregated to generate subsyndrome scores for psychosis comprised of delusions and hallucinations (0–24), hyperactive behaviour comprised agitation, euphoria, irritation, disinhibitions, irritability, aberrant motorial behaviour, sleep disturbances and appetite changes (0–48), and finally, a total NPI-12 score (0–144). (2) The Cornell Scale for Depression in Dementia (CSDD) assesses nine items of depressive symptoms during the prior week, each rated from ‘absent’ to ‘severe’ (0–2) or ‘symptoms not possible to evaluate’ (missing). Adding item scores generate the CSDD total score (0–38). A CSDD total score ≥8 indicates depression of clinical relevance. The Norwegian versions of NPI-12 and CSDD have robust psychometric properties.

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) and Instrumental Activities of Daily Living Scale (IADL), and health by the General Medical Health Rating Scale (GMHR), possible dementia aetiology following the International Classification of Diseases-10th version, 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 ‘on demand’.25 Psychotropic drugs included antipsychotic (N05A), anxiolytic (N05B), hypnotic and sedative (N05C), antidepressant (N06A) and antiemetic 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 pre-pandemic 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 pre-pandemic 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 pre-pandemic assessment from December 2019 to March 2020 (figure 1B). This study includes 104 dyads recruited to PAN.DEM completing the pre-pandemic 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 pre-pandemic 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,
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

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

| Person with dementia | N=104 |
|----------------------|-------|
| **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) |
| Other dementia 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 number, median (IQR) | 1 (0–2) |
| Regularly, median (IQR) | 1 (0–1) |
| Antipsychotics (N05A), n (%) | 6 (6) |
| Anxiolytics (N05B), n (%) | 3 (3) |
| Hypnotics/sedatives (N05C), n (%) | 10 (10) |
| Antidepressants (N06A), n (%) | 19 (18) |
| Antidementia drugs (N06D), n (%) | 52 (50) |
| On-demand, median (IQR) | 0 (0–0) |
| Antipsychotics (N05A), n (%) | 0 (0) |
| Anxiolytics (N05B), n (%) | 5 (5) |
| Hypnotics/sedatives (N05C), n (%) | 12 (12) |
| Antidepressants (N06A), n (%) | 0 (0) |
| Antidementia drugs (N06D), n (%) | 0 (0) |
| Volunteering services, n (%) | 8 (8) |
| Healthcare services |       |
| Daily home nursing, n (%) | 52 (50) |
| Weekly home care, n (%) | 29 (28) |
| Respite care (In-home and out-of-home), n (%) | 2 (2) |
| **Informal carer** |       |
| Age, mean (SD) | 65 (12) |

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**Table 1** Continued

| Gender, n (%) | 68 (65) |
|---------------|---------|
| **Kinship to the person with dementia** |       |
| Spouse, n (%) | 44 (42) |
| Child, n (%)  | 58 (56) |
| Others, n (%) | 2 (2) |

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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).
to the intervention vs control of the parent trial showed associations with worsening NP-12 total score, psychosis subsyndrome nor depressive symptoms (online supplementary 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 supplementary 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. We used established cut-off scores when presenting BPSD with symptom load of clinical relevance. The parent trial population was recruited from different municipalities to be representative to the Norwegian demographic in terms of dementia aetiology, severity and symptomatology. As our study

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

| Neuropsychiatric inventory (NPI-12) | Prepandemic | Pandemic | P value |
|------------------------------------|-------------|----------|---------|
| N (%) with symptom load of clinical relevance* | Median | IQR | N (%) with symptom load of clinical relevance* | Median | IQR | |
| 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, PANDEM assessment (20 April 2020 to 15 May 2020); Prepandemic, Six-month assessment of parent trial (12 December 2019 to 11 March 2020).
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 yet our
findings using CSDD were consistent with the depres-
sion domain of NPI-12, which can be used as a telephone
interview instrument. 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. 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 wors-
ening BPSD. 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 consider-
ations 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 observa-
tion. 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 reimposi-
tion 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 exacer-
bated 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 demon-
strate comparing prepandemic and pandemic symptom
levels.

Our findings echo a small body of the existing litera-
ture 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 cogni-
tive impairment and Alzheimer’s disease (N=40), but no
increase in psychotic symptoms. A cross-sectional study
from Italy (N=139) describes exacerbation of psychotic
symptoms in a small percentage of subjects with subjec-
tive cognitive decline, mild cognitive impairment and
dementia. This study, in part, used self-assessments, that
may have led to underreporting of delusions and hallu-
cinations. Even though other studies are equivocal on
whether psychosis worsened, UK registry data indicate
higher antipsychotic prescription rates to people with
dementia during the pandemic, and the authors specu-
late that this increase may be the result of worsened agita-
tion and psychosis. Meanwhile, our study revealed no
associations between psychotropic drugs and psychosis,
likely given that very few patients used antipsychotics.
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. Nonetheless, our study adds to the cross-sectional reports calling attention to deteriorating depressive symptoms among people with dementia. For better communication within and between dyads and their formal caregivers, digital devices may enhance individual support. Further, anxiolytics and hypnotics/sedatives were associated with fewer depressive symptoms when used as-needed in our sample.
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.3 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 modifications 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.

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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, IVW, 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.

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Competing interests
All authors have completed the ICMJE uniform disclosure form at www.icmje.org/col1_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).

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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.

Supplemental material
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