**Minimal impact of COVID-19 on the mental health and well-being of people living with dementia:
analysis on matched longitudinal data from the IDEAL study**

Serena Sabatini¹, Holly Q. Bennett^{2*}, Anthony Martyr¹, Rachel Collins¹, Laura D. Gamble², Fiona E. Matthews², Claire Pentecost¹, Eleanor Dawson¹, Anna Hunt¹, Sophie Parker¹, Louise Allan¹, Alistair Burns³, Rachael Litherland⁴, Catherine Quinn⁵, and Linda Clare^{1,6}

- 1 College of Medicine and Health, University of Exeter, UK
- 2 Population Health Sciences Institute, Newcastle University
- 3 Institute of Brain, Behaviour and Mental Health, University of Manchester, UK
- 4 Innovations in Dementia CIC, Exeter, UK
- 5 Centre for Applied Dementia Studies, Bradford University, UK
- 6 NIHR Applied Research Collaboration South-West Peninsula, UK

*Serena Sabatini and Holly Bennett are joint first authors.

Corresponding author: Dr Serena Sabatini; s.sabatini2@exeter.ac.uk

Serena Sabatini - 0000-0002-3618-6949

Holly Q. Bennett - 0000-0002-4085-8023

Anthony Martyr – 0000-0002-1702-8902

Rachel Collins – 0000-0002-3405-7932

Laura D. Gamble – 0000-0001-8496-9705

Fiona E Matthews – 0000-0002-1728-2388

Claire Pentecost – 0000-0003-2048-5538

Eleanor Dawson – 0000-0002-4883-7307

Anna Hunt – 0000-0001-7523-1792

Sophie Parker – 0000-0003-4878-9859

Louise Allan – 0000-0002-8912-4901

Alistair Burns – 0000-0002-9837-0645

Catherine Quinn – 0000-0001-9553-853X

Linda Clare – 0000-0003-3989-5318

ABSTRACT

Objective: Research suggests a decline in the mental health and well-being of people with dementia (PwD) during the COVID-19 pandemic; however few studies have compared data collected pre-pandemic and during the pandemic. Moreover, none have compared this change with what would be expected due to dementia progression. We explored whether PwD experienced changes in mental health and well-being by comparing pre-pandemic and pandemic data, and drew comparisons with another group of PwD questioned on two occasions prior to the pandemic.

Methods: Community-dwelling PwD enrolled in the IDEAL programme were split into two groups matched for age group, sex, dementia diagnosis, and time since diagnosis. Although each group was assessed twice, one was assessed prior to and during the pandemic (pandemic group; n=115) whereas the other was assessed prior to the pandemic (pre-pandemic group; n=230). PwD completed measures of mood, sense of self, well-being, optimism, quality of life, and life satisfaction.

Results: Compared to the pre-pandemic group, the pandemic group were less likely to report mood problems, or be pessimistic, but more likely to become dissatisfied with their lives. There were no changes in continuity in sense of self, well-being, and quality of life.

Discussion: Results suggest the pandemic had little effect on the mental health and well-being of PwD, with any changes observed likely to be consistent with expected rates of decline due to dementia. Although personal accounts attest to the challenges experienced, PwD appear to have been resilient to the impact of lockdown and social restrictions during the pandemic.

CONTRIBUTION TO THE FIELD

Existing research investigating the impact that the COVID-19 pandemic and associated social restrictions had on the mental health and well-being of people living with dementia led to mixed findings. This may be due to the methodological limitations of previous studies. Indeed, many studies were simply based on cross-sectional analyses based on self- and informant reports. Those previous longitudinal studies that identified a decline in the mental health and well-being of people with dementia during the COVID-19 pandemic compared with pre- COVID-19 pandemic information however could not discern whether the observed change was due to the typical course of dementia or to the impact of pandemic-related social restrictions. As an attempt to address this methodological issue, we explored for the first time whether people with dementia experienced changes in six indicators of mental health and well-being (mood, continuity in sense of self, well-

being, optimism, quality of life, and life satisfaction) by comparing pre-pandemic and pandemic data, and drew comparisons with another matched group of people with dementia questioned on two occasions prior to the pandemic.

KEYWORDS

Quality of life, well-being, sense of self, optimism, life orientation

CONFLICT OF INTEREST STATEMENT

The authors have no conflicts of interest to report

AUTHOR CONTRIBUTION STATEMENT

Conception and design – LC, AM, CP, RC, LA, AB, RL, CQ, FM, SS, HB

Analysis and interpretation of data - HB conducted study analysis, SS interpreted the data

Drafting the manuscript – HB drafted the methods and results sections, SS drafted the introduction and discussion sections

Critical appraisal and review of the manuscript – all

Final approval of the manuscript – all

DATA AVAILABILITY STATEMENT

IDEAL data were deposited with the UK data archive in April 2020 and will be available to access from April 2023. Details of how the data can be accessed after that date can be found here:

<http://reshare.ukdataservice.ac.uk/854293/>. INCLUDE data will be archived in connection with the IDEAL dataset in March 2022.

Words =

References =

Tables/Figures = 3 tables, 3 Supplementary Tables, 3 Supplementary figures.

1. INTRODUCTION

The COVID-19 pandemic (hereafter referred to as ‘the pandemic’) and consequent periods of lockdown and social restrictions forced individuals to change their routines, social interactions, and usual ways of accessing health and social care services (Manca et al., 2020; Simonetti et al., 2020; Altieri and Santangelo, 2021). For instance, non-urgent clinical activities were postponed, conducted via phone, or interrupted. People considered clinically vulnerable were strongly advised to stay at home even in those periods when social restrictions were less severe. The category of clinically vulnerable people included some people with dementia (PwD) who also had other health conditions. Social support services for community dwelling PwD and their carers were also interrupted (Giebel *et al.* 2020). Hence PwD living in the community may have been particularly affected by the changes related to the pandemic.

However, existing evidence based on carer reports and self-reports from PwD provided mixed results (Brown et al., 2020; Liu et al., 2021). On the one hand some studies (Boutoleau-Bretonniere et al., 2020; Canevelli et al., 2020; Lara et al., 2020; Rainero et al., 2020; Borelli et al., 2021) found that the pandemic accelerated decline in the cognitive, physical, functional, and mental health of PwD, as well as increased neuropsychiatric symptoms, behavioural problems, and loneliness among PwD (Barguilla et al., 2020; Boutoleau-Bretonniere et al., 2020; Canevelli et al., 2020; Cohen et al., 2020; Lara et al., 2020; Rainero et al., 2020; Vaitheswaran et al., 2020; Altieri and Santangelo, 2021; Azevedo et al., 2021; Borelli et al., 2021; Carlos et al., 2021; Liu et al., 2021; Tam et al., 2021; Tsapanou et al., 2021). On the other hand, some studies found that the pandemic had minimal negative impact or no impact on these outcomes (Canevelli et al., 2020; Cohen et al., 2020; Lara et al., 2020; Thyrian et al., 2020). These inconsistent findings may be due to the methodological limitations of cross-sectional analyses based on self- and informant reports (Boutoleau-Bretonniere et al., 2020).

Although some studies examined changes in the mental health and well-being of PwD by using data collected both prior to and during the pandemic (Barguilla et al., 2020; Canevelli et al., 2020; Thyrian et al., 2020; Altieri and Santangelo, 2021; Clare et al., 2021), they lacked a matched comparison group providing data on changes in mental health and well-being over time prior to the pandemic. Because of this they could not determine whether a decline in the mental health and well-being of PwD was due to the pandemic or to the normal progression of dementia. Studies such as that conducted by Tondo et al. (2021) found that during the pandemic PwD experienced a greater cognitive decline compared to what was expected for people in their same stage of the illness. However, to the best of our knowledge, no study undertook a similar approach to that of Tondo et al. (2021) to explore the effects of the pandemic on the mental health and well-being of PwD.

Using longitudinal data from the IDEAL (Improving the experience of Dementia and Enhancing Active Life) cohort, we found that during the pandemic PwD were more likely to report discontinuity in sense of self, poorer quality of life, and lower life satisfaction, but also better mood, greater optimism, and similar levels of physical health, when compared to mean scores for the cohort prior to the pandemic, but we could not establish whether the observed changes were attributable to conditions during the pandemic (Clare et al., 2021).

Building on our earlier findings and on longitudinal data from the IDEAL programme, the current study investigated the mental health and well-being of PwD by comparing longitudinal change seen in a group of participants assessed both prior to and during the pandemic with that seen in a matched comparison group of PwD assessed on two occasions prior to the pandemic. To capture mental health and well-being, measures assessing mood, continuity/discontinuity in sense of self, well-being, optimism, quality of life, and life satisfaction were employed. We hypothesised that, compared to the experience of their matched counterparts prior to the pandemic, PwD during the pandemic were more likely to be anxious or depressed, perceive discontinuity in sense of self, report lower psychological well-being, be less optimistic, have poorer quality of life, and be dissatisfied with their life. We also expected that the changes in mental health and well-being experienced by PwD during the pandemic would be greater than the changes over time experienced by a matched group of PwD whose data were collected during two assessment waves prior to the pandemic.

2. MATERIALS AND METHODS

2.1. DESIGN

We report a comparison of data from two matched groups of PwD, each assessed on two occasions. One group was assessed prior to and during the pandemic, and the other group was assessed on two occasions prior to the pandemic.

This study is embedded in the ongoing IDEAL programme. The IDEAL programme centres on a longitudinal cohort study following a large group of PwD and their carers for up to 6 years (Clare et al., 2014; Silarova et al., 2018). PwD were recruited for baseline interviews (T1) through 29 National Health Service (NHS) sites in England, Scotland, and Wales between 2014 and 2016. Participants lived in the community, and had a clinical diagnosis of dementia and a Mini-Mental State Examination (MMSE) (Folstein et al., 1975) score ≥ 15 at baseline. For those who agreed to participate, trained researchers conducted structured interviews during home visits. Follow-up interviews occurred 12 (T2) and 24 (T3) months later. A follow-up study (IDEAL-2) began in 2018 and aimed to comprise three further waves of data collection (T4-T6); the T4 interviews were scheduled

two years after T3. T4 was due to end in July 2020 and T5 was due to end 12 months later but data collection for both waves was interrupted by the COVID-19 pandemic. The INCLUDE (Identifying and mitigating the individual and dyadic impact of COVID-19 and life under physical distancing on people with dementia and carers) study was introduced at this point to understand the impact of COVID-19 on the IDEAL cohort. Those who had participated in IDEAL and IDEAL-2 were invited to take part in INCLUDE. Interviews for INCLUDE were conducted remotely by trained researchers between September 2020 and April 2021, see (Clare et al.) for details.

2.2. PARTICIPANTS

Two matched groups of participants were identified from the INCLUDE and IDEAL datasets:

- The 'pandemic group' (n=115) comprised PwD who were assessed for both IDEAL T3 and INCLUDE.
- The 'pre-pandemic group' (n=230) comprised PwD who were assessed for IDEAL T1 and T3 but did not take part in INCLUDE.

Participants in the pre-pandemic group were matched 2:1 to participants in the pandemic group. Matching was based on age group, sex, dementia diagnosis, and time since dementia diagnosis. The pool of participants from which the matched pre-pandemic group was chosen consisted of those who took part in IDEAL T1 and T3 but not INCLUDE (as described above, n=736). Two participants from this pool were matched to each participant from the pandemic group. However, using these criteria it was not possible to identify two exact matches for every participant in the pandemic group. Therefore, for the first match, 70 out of 115 of the pandemic group were matched exactly on age group (<65, 65-69, 70-74, 75-79, 80+), sex, dementia subtype (Alzheimer's disease, vascular dementia, mixed Alzheimer's and vascular dementia, frontotemporal dementia, Parkinson's disease dementia, dementia with Lewy bodies, unspecified/other) and time since diagnosis (<1 year, 1-2 years, 3-5 years, 6+ years). Another 14 out of 115 of the pandemic group were matched exactly on age group, sex, binary dementia subtype (Alzheimer's disease, vascular dementia, mixed, versus other), and time since diagnosis. Seven out of 115 had exact first matches on age group, sex, binary dementia subtype, and binary time since diagnosis (≤ 2 years, ≥ 3 years). The remaining 24 from the pandemic group had exact first matches on age group, sex, and binary dementia diagnosis. For second matches 113 out of 115 matched on age group, sex, and binary dementia diagnosis, and 2 out of 115 matched only on age group, and sex.

There were two 'waves' of data available for each group:

- Wave 1 (W1) refers to IDEAL T1 for the pre-pandemic group and IDEAL T3 for the pandemic group.
- Wave 2 (W2) refers to IDEAL T3 for the pre-pandemic group and INCLUDE data collection for the pandemic group.

These time-points were selected as the time between assessments was the nearest match we could achieve for the two groups.

2.3. MEASURES

Single items from standardised measures were used to assess self-reported mood (depressed or anxious; not depressed or anxious) (The EuroQol Group, 1990), continuity in sense of self (discontinuity; continuity) (Clare et al., 2020), well-being (high; moderate; low) (Bech, 2004), optimism (optimistic; pessimistic or neutral) (Scheier et al., 1994), quality of life (poor or fair; good; excellent) (Logsdon et al., 2000), and life satisfaction (satisfied; dissatisfied) (Diener et al., 1985); see Supplementary Table 1.

Covariates included marital status (spouse/partner; single; widowed), education (no qualifications; school leaving certificate at age 16; school leaving certificate at age 18; university), social class (high; intermediate; low), living alone (yes; no), cognition (MMSE score (Folstein et al., 1975) 0-21, 22-25, 26-30), diagnosed depression (depressed; not depressed) and months between waves. Number of health conditions other than dementia was a count of heart problems (heart attack or congestive heart failure), hypertension, peripheral vascular disease, stroke or hemiplegia, transient ischaemic attack, chronic bad chest, inflammation of the joints, peptic/stomach ulcer disease, skin ulcer, diabetes, moderate or severe kidney disease, cancer, and liver disease. The count was categorised into 0-1 or 2+.

2.4. STATISTICAL METHODS

Binary outcomes (anxiety or depression, continuity in sense of self, optimism, life satisfaction) were analysed using mixed effect logistic regression models with waves grouped within participant as a random intercept to account for correlation over waves within a participant. For outcomes with more than two categories (well-being, quality of life) mixed effect multinomial logistic regression models were used, again with the random intercept grouping waves within participants. Due to low participant numbers the random intercept was constrained to be equal for all outcome categories instead of having separate random intercepts for each category of the outcome. To understand the

difference in trends over time (waves) in the outcome between the pre-pandemic group and the pandemic group, an interaction between the pandemic group indicator variable and wave variable was included in the model. All models were adjusted for the matching variables (age group, sex, dementia subtype, time since dementia diagnosis) and for other covariates that were important to the model. A sensitivity analysis was conducted for the mood model where diagnosed depression was included as a covariate to control for long-term depression.

3. RESULTS

In the whole sample (n=345) the average age was 72.6 years and 48.7% were women. As participants were matched for age group rather than age, mean age was 72.7 years in the pre-pandemic group and 72.4 years in the pandemic group. In the whole sample the majority of participants had a partner, had education to age 18 or university level, were in the higher social class group, and had Alzheimer's disease (Table 1). Average time between waves was 24.9 months for the pre-pandemic group and 39.1 months for the pandemic group. Including time between waves as a covariate or interaction with pandemic group in the model did not lead to significantly different results, so this was excluded.

--Please insert Table 1--

Number and proportions of participants in each category of mental health and well-being indicators are reported in Table 2. Results from the mixed effect models are shown in Table 3.

--Please insert Tables 2 and 3--

In the pre-pandemic group 34.5% at W1 and 32.6% at W2 were depressed or anxious. At W1 38.3% of the pandemic group were depressed or anxious, decreasing to 25.4% at W2; the trend for this decrease in feeling depressed or anxious in the pandemic group differed to the trend between W1 and W2 in the pre-pandemic group; interaction odds ratio (OR): 0.4, 95% confidence interval (CI): 0.1 – 1.0 (Table 3, Supplementary Figure 1). The results were robust when adjusted for diagnosed depression in the sensitivity analysis (Supplementary Table 2).

In the pre-pandemic group (W1: 30.5%, W2: 32.3%) and pandemic group (W1: 33.0%, W2: 34.5%) there was no evidence of change in the proportion of participants reporting discontinuity in sense of self and no evidence of any difference in trends between groups (interaction OR: 1.1, 95% CI: 0.4 – 2.6) (Table 3, Supplementary Figure 2).

At W1 67.3% of the pre-pandemic group had a high level of well-being; by W2 this had dropped to 61.7%. In the pandemic group the proportion of participants reporting high levels of well-being was similar at W1 (63.2%) and W2 (61.1%). There was some evidence to suggest an increase in the proportion reporting moderate well-being by W2 in the pre-pandemic group (OR: 1.5, 95% CI: 0.8 – 2.6) with no difference in trend for the pandemic group (interaction OR: 0.8, 95% CI: 0.3 – 2.1, Table 3).

Most (73.9%) of the pre-pandemic group were optimistic at W1, reducing to 68.0% at W2. At W1 67.8% of the pandemic group were optimistic, increasing to 74.3% at W2 (Supplementary Figure 3). The models provided some evidence to suggest a difference in trends between the two groups (interaction OR: 0.5, 95% CI: 0.2 – 1.2) (Table 3, Supplementary Figure 3).

The proportion of those reporting good quality of life decreased for the pre-pandemic group (W1: 56.1%, W2: 52.9%) and pandemic group (W1: 60.0%, W2: 47.8%). Whereas in the pre-pandemic group there was some evidence to suggest an increase in the proportion feeling their quality of life was poor or fair (OR: 1.6, 95% CI: 0.9 – 2.9), in the pandemic group there was some evidence to suggest an increase in the proportion feeling quality of life was excellent (interaction OR: 1.8, 95% CI: 0.7 – 4.6), as well as in the proportion feeling quality of life was poor or fair (Table 3).

The proportion reporting they were satisfied with life in the pre-pandemic group was similar at W1 (83.9%) and W2 (85.0%). At W1, 91.3% of the pandemic group were satisfied with life, decreasing to 85.8% at W2. There was some evidence to show the trend over waves differed between the pre-pandemic and pandemic group (interaction OR: 3.3, 95% CI: 0.9 – 13.0, Supplementary Table 3). However, these results should be interpreted with caution as, due to low numbers of those dissatisfied with life, the estimate for the interaction was inflated when adjusting for matching variables. Adjustment for further covariates did not improve the estimates (Supplementary Table 3).

4. DISCUSSION

This study investigated whether the experience of living through the pandemic and associated social restrictions affected the mental health and well-being of PwD living in the community in Britain. Contrary to our hypotheses, COVID-19 restrictions appeared to have little negative impact on whether PwD experienced continuity in sense of self and on how PwD appraised their well-being and quality of life, and in the case of mood and optimism, COVID-19 restrictions appeared to have a positive impact. Although the hypothesis that, compared to pre-COVID-19, PwD during COVID-19

were more likely to be dissatisfied with their lives was partially supported, estimations were inflated. Overall, findings for six outcomes capturing different facets of mental health and well-being consistently suggest that, when considering PwD enrolled in the IDEAL cohort as a group, the pandemic was associated with minimal negative change in mental health and well-being and with an improvement in mood and optimism.

The small decline in the proportion of PwD who reported mood problems in both the pre-pandemic and pandemic groups is consistent with previous evidence (Clare et al., 2021; Leung et al., 2021). This effect was larger in the pandemic group, suggesting that some circumstances related to COVID-19 led to a reduction in the proportion of PwD having mood problems. It may be that during lockdown carers provided greater social support to PwD, or, as qualitative studies have found, PwD perceived the home environment as a safe place where they could enjoy quiet time, learn new skills, or return to past hobbies without fearing failure or comparison with peers (O'Rourke et al.; Talbot and Briggs, 2021). The engagement of PwD in activities such as reading and playing computer games during the lockdown is documented in other studies (Canevelli et al., 2020; Clare et al., 2021). Due to stigma, embarrassment or awareness of being less able to engage in activities in normal times PwD may experience social anxiety and, as a consequence, withdraw from social activities (Sabat, 2008; Seignourel et al., 2008; Aldridge et al., 2017; Alsawy et al., 2017; Hackett et al., 2019), so in this sense restrictions may have had positive aspects. Nonetheless, further understanding of the mechanisms through which pandemic experiences decreased the likelihood of mood problems in PwD could help to identify ways of promoting better mood in PwD post-pandemic.

This was the first study exploring whether the pandemic had an influence on continuity in sense of self in PwD. We found that COVID-19 restrictions had no impact on how continuity in self of self in PwD. Again, it may be that during the lockdown PwD engaged in a range of activities and hobbies that contributed to the experience of continuity in sense of self.

The pandemic did not influence the well-being and quality of life of PwD and only marginally influenced their optimism. Indeed, although PwD in the pandemic group were more likely to be optimistic about the future compared to those in the pre-pandemic group, differences between groups were minimal. Moreover, PwD who were more optimistic about the future prior to the pandemic maintained this optimistic outlook during the pandemic. This pattern of results suggests that the pandemic may not have influenced pre-existing levels of optimism. This may be due to optimism being a relatively stable trait among older people (Armbruster et al., 2015).

There was some evidence to support the hypothesis in relation to life satisfaction, as during the pandemic PwD were more likely to feel dissatisfied with their lives. However, the number of PwD expressing dissatisfaction with their lives was low both before and during the pandemic, and

this significant effect is due to only six people becoming dissatisfied with their lives during COVID-19. Moreover, comparison of baseline levels of life satisfaction between the pandemic group and the pre-pandemic group shows that the proportion of PwD feeling dissatisfied with their lives was lower in the pandemic group and, despite a significant increase in the number of PwD becoming unsatisfied with their life during COVID-19, the number of PwD feeling dissatisfied with their life during COVID-19 remained lower than that in the pre-pandemic group.

Compared to previous evidence (Liu et al., 2021) this study provides a more positive picture of the mental health and well-being of PwD during COVID-19. This disparity with previous studies on the topic may be due to several major methodological differences. First, although previous longitudinal studies identified a decline in the mental health and well-being of PwD during the pandemic compared with pre-pandemic information (Aalten et al., 2005; Tatsumi et al., 2009; Brodaty et al., 2015; Trigg et al., 2015; Van De Beek et al., 2019; Barguilla et al., 2020), they could not discern whether the observed change was due to the typical course of dementia or to the impact of pandemic-related social restrictions. In contrast, by using longitudinal data to compare the change experienced by PwD during the pandemic with that experienced by a matched sample of PwD whose data were collected prior to COVID-19, our results suggest that most of the negative changes experienced by PwD during the pandemic are parallel to those that would be expected in a group of PwD with similar demographic characteristics under normal conditions. For instance, although the current analyses confirmed some of the previous results from the IDEAL cohort (e.g., a decrease in mood problems) that were based on comparison of pre-pandemic and pandemic data without a matched comparison group (Clare et al., 2021) it did not confirm others (e.g., poorer quality of life). The methodological advancements of this study suggest that the previously-described increase in the proportion of PwD reporting discontinuity in sense of self, poorer quality of life, and dissatisfaction with their life may have been due to the progress of dementia rather than to the pandemic.

Second, another possible reason for the disparity between our findings and those of previous studies is that previous studies relied on informant ratings provided by carers (Cagnin et al., 2020; Canevelli et al., 2020; Carpinelli Mazzi et al., 2020; Cohen et al., 2020; Borelli et al., 2021; Manini et al., 2021; Tsapanou et al., 2021) whereas this study considered the self-ratings of PwD. As carer ratings differ from self-ratings (Wu et al., 2020) and the subjective perceptions of people with mild-to-moderate dementia are widely accepted as valid (Woods et al., 2014), our study may have produced more reliable results than existing research. Third, whereas many previous studies collected data at the beginning of the pandemic and therefore during the period of strict lockdown (Liu et al., 2021), data collection for this study started in September 2020. Hence, the more positive

results found in this study may be due to participants having had the time to overcome the initial shock caused by the pandemic, adapt to a new lifestyle, and cope with changes related to the pandemic (O'Rourke et al., 2021).

Fourth, as those IDEAL participants who could not use telephones and/or had deteriorated markedly since their previous assessment were underrepresented in INCLUDE, study analyses are based on a self-selected group of PwD who may have been well-positioned to adapt to the lockdown and social restrictions. Hence, our positive results may not generalise to all PwD. Fifth, many individual effects of the pandemic on the mental health and well-being of PwD may have remained hidden in our analyses that considered PwD as a group. Indeed, qualitative studies suggest a heterogeneous picture in relation to the mental health and well-being of PwD during the pandemic (O'Rourke et al., 2021). For instance, the majority of our sample lived with someone else. However, those PwD who live alone found it harder to cope with some of the changes related to the pandemic, such as increased loneliness, and were therefore more likely to experience poorer mental health and well-being (O'Rourke et al., 2021).

Overall, study results suggest that COVID-19 did not have a negative impact on the mental health and well-being of our sample of PwD. Instead, it may have had a small beneficial effect particularly in relation to mood. Qualitative interviews conducted during the pandemic with 11 PwD participating in the IDEAL study and their carers suggest that in some cases the resilience shown by PwD may reflect positive social circumstances and use of previously-learned coping strategies (O'Rourke et al., 2021). Despite our positive pattern of results, we should be mindful that some negative feelings and experiences, such as the perception of being abandoned by services, have been reported by PwD (Clare et al., 2021; O'Rourke et al., 2021). These should be addressed as they may lead to poorer mental health and well-being in the long term.

This study has some limitations. Exact matches on all variables could not be found for everyone in the pandemic group. However, all matching variables were included as covariates in the models, and in an effort to mitigate this limitation, the pre-pandemic group included two matches for each PwD in the pandemic group. Mental health and well-being were assessed with single-item measures that, although reducing the burden for participants (Clare et al., 2021), may not have adequately captured the constructs. There was also a longer timeframe between assessments for the pandemic group. However, the models controlling for the difference between timepoints led to the same results as those models not controlling for this difference between timepoints, suggesting that the difference between timepoints did not influence study findings. Moreover, there was generally little effect from COVID-19 on the mental health and well-being of PwD so it was unlikely

that the longer gap between assessments for the pandemic group affected the results, especially as the expectation was for a greater effect from COVID-19 on this group.

Despite these limitations, our unique study design made it possible to investigate whether observed changes in mental health and well-being were due to the pandemic and concomitant social restrictions rather than reflecting the typical course for PwD. In this sample of PwD the COVID-19 pandemic appears to have had little to no negative effect on mental health and well-being, and little impact on continuity and discontinuity in sense of self, well-being, quality of life, and life satisfaction. If anything, there was a small positive impact on mood and optimism. Future research is needed to understand the mechanisms behind this unexpected positive effect as it may help to identify ways to address mood disturbance in PwD. The remarkable resilience showed by PwD in this study adds to understanding of what is possible in adjusting to the diagnosis and living with the condition and offers hope that it is possible to “live well” with dementia. Although this study found that the radical changes imposed by the pandemic did not have a negative effect on the mental health and well-being of PwD as a group, some PwD may have been less resilient than others. Indeed, previous studies documented how some people with dementia had negative experiences of the pandemic (Clare et al., 2021; O’Rourke et al., 2021). Future research could therefore focus on identifying the characteristics of those PwD who found it harder to adapt to the pandemic and that, because of this, would benefit the most from post-pandemic support. Finally, as the social support provided by carers may be one of the reasons why PwD showed resilience in being able to maintain their mental health and well-being against the radical changes imposed by the pandemic, future work with the IDEAL dataset will explore whether carers’ mental health and well-being have instead been affected during the pandemic.

FUNDING

‘Identifying and mitigating the individual and dyadic impact of COVID19 and life under physical distancing on people with dementia and carers (INCLUDE)’ was funded by the Economic and Social Research Council (ESRC) through grant ES/V004964/1. Investigators: Clare, L., Victor, C., Matthews, F., Quinn, C., Hillman, A., Burns, A., Allan, L., Litherland, R., Martyr, A., Collins, R., & Pentecost, C. ESRC is part of UK Research and Innovation (UKRI).

‘Improving the experience of Dementia and Enhancing Active Life: living well with dementia. The IDEAL study’ was funded jointly by the Economic and Social Research Council (ESRC) and the National Institute for Health Research (NIHR) through grant ES/L001853/2. Investigators: L. Clare, I.R. Jones, C. Victor, J.V. Hindle, R.W. Jones, M. Knapp, M. Kopelman, R. Litherland, A. Martyr, F.E. Matthews, R.G. Morris, S.M. Nelis, J.A. Pickett, C. Quinn, J. Rusted, J. Thom. IDEAL data were deposited with the UK data archive in April 2020 and will be available to access from April 2023.

Details of how the data can be accessed after that date can be found here:

<http://reshare.ukdataservice.ac.uk/854293/>

‘Improving the experience of Dementia and Enhancing Active Life: a longitudinal perspective on living well with dementia. The IDEAL-2 study’ is funded by Alzheimer’s Society, grant number 348, AS-PR2-16-001. Investigators: L. Clare, I.R. Jones, C. Victor, C. Ballard, A. Hillman, J.V. Hindle, J. Hughes, R.W. Jones, M. Knapp, R. Litherland, A. Martyr, F.E. Matthews, R.G. Morris, S.M. Nelis, C. Quinn, J. Rusted.

L. Clare and L. Allan acknowledge support from the NIHR Applied Research Collaboration South-West Peninsula.

The views expressed are those of the author(s) and not necessarily those of the ESRC, UKRI, NIHR, the Department of Health and Social Care, the National Health Service, or Alzheimer’s Society. The support of ESRC, NIHR and Alzheimer’s Society is gratefully acknowledged.

ACKNOWLEDGEMENTS

We acknowledge the support of NIHR Dementias and Neurodegeneration Specialty (DeNDroN) and Health and Care Research Wales with IDEAL cohort recruitment and data collection. We gratefully acknowledge the local principal investigators and researchers involved in participant recruitment and assessment within these networks. We are grateful to the IDEAL study participants for their participation in the IDEAL and INCLUDE studies, to the wider group of IDEAL programme researchers, and to members of the ALWAYS group and the Project Advisory Group for their support.

REFERENCES

- Aalten, P., De Vugt, M.E., Jaspers, N., Jolles, J., and Verhey, F.R.J. (2005). The course of neuropsychiatric symptoms in dementia. Part I: Findings from the two-year longitudinal Maasbed study. *International Journal of Geriatric Psychiatry* 20, 523-530.
- Aldridge, H., Fisher, P., and Laidlaw, K. (2017). Experiences of shame for people with dementia: An Interpretative Phenomenological Analysis. *Dementia* 18, 1896-1911.
- Alsawy, S., Mansell, W., Mcevoy, P., and Tai, S. (2017). What is good communication for people living with dementia? A mixed-methods systematic review. *International Psychogeriatrics* 29, 1785-1800.
- Altieri, M., and Santangelo, G. (2021). The psychological impact of COVID-19 pandemic and lockdown on caregivers of people with dementia. *The American Journal of Geriatric Psychiatry* 29, 27-34.
- Armbruster, D., Pieper, L., Klotsche, J., and Hoyer, J. (2015). Predictions get tougher in older individuals: A longitudinal study of optimism, pessimism and depression. *Social Psychiatry and Psychiatric Epidemiology* 50, 153-163.
- Azevedo, L., Calandri, I.L., Slachevsky, A., Graviotto, H.G., Vieira, M.C.S., Andrade, C.B., Rossetti, A.P., Generoso, A.B., Carmona, K.C., Pinto, L.a.C., Sorbara, M., Pinto, A., Guajardo, T., Olavarria, L., Thumala, D., Crivelli, L., Vivas, L., Allegri, R.F., Barbosa, M.T., Serrano, C.M., Miranda-Castillo, C., and Caramelli, P. (2021). Impact of social isolation on people with dementia and their family caregivers. *Journal of Alzheimer's Disease* 81, 607-617.
- Barguilla, A., Fernandez-Lebrero, A., Estragues-Gazquez, I., Garcia-Escobar, G., Navalpotro-Gomez, I., Manero, R.M., Puente-Periz, V., Roquer, J., and Puig-Pijoan, A. (2020). Effects of COVID-19 pandemic confinement in patients with cognitive impairment. *Frontiers in Neurology* 11, 589901.
- Bech, P. (2004). Measuring the dimension of psychological general well-being by the WHO-5. *Quality of Life Newsletter* 32, 15-16.
- Borelli, W.V., Augustin, M.C., De Oliveira, P.B.F., Reggiani, L.C., Bandeira-De-Mello, R.G., Schumacher-Schuh, A.F., Chaves, M.L.F., and Castilhos, R.M. (2021). Neuropsychiatric symptoms in patients with dementia associated with increased psychological distress in caregivers during the COVID-19 pandemic. *Journal of Alzheimer's Disease* 80, 1705-1712.
- Boutoleau-Bretonniere, C., Pouclet-Courtemanche, H., Gillet, A., Bernard, A., Deruet, A.L., Gouraud, I., Mazoue, A., Lamy, E., Rocher, L., Kapogiannis, D., and El Haj, M. (2020). The effects of confinement on neuropsychiatric symptoms in Alzheimer's disease during the COVID-19 crisis. *Journal of Alzheimer's Disease* 76, 41-47.
- Brodaty, H., Connors, M.H., Xu, J., Woodward, M., Ames, D., and Group, P.S. (2015). The course of neuropsychiatric symptoms in dementia: A 3-year longitudinal study. *Journal of the American Medical Directors Association* 16, 380-387.
- Brown, E.E., Kumar, S., Rajji, T.K., Pollock, B.G., and Mulsant, B.H. (2020). Anticipating and mitigating the impact of the COVID-19 pandemic on Alzheimer's disease and related dementias. *The American Journal of Geriatric Psychiatry* 28, 712-721.
- Cagnin, A., Di Lorenzo, R., Marra, C., Bonanni, L., Cupidi, C., Lagana, V., Rubino, E., Vacca, A., Provero, P., Isella, V., Vanacore, N., Agosta, F., Appollonio, I., Caffarra, P., Pettenuzzo, I., Sambati, R., Quaranta, D., Guglielmi, V., Logroscino, G., Filippi, M., Tedeschi, G., Ferrarese, C., Rainero, I., Bruni, A.C., and Group, S.I.C.-S. (2020). Behavioral and psychological effects of Coronavirus disease-19 quarantine in patients with dementia. *Frontiers in Psychiatry* 11, 578015.
- Canevelli, M., Valletta, M., Toccaceli Blasi, M., Remoli, G., Sarti, G., Nuti, F., Sciancalepore, F., Ruberti, E., Cesari, M., and Bruno, G. (2020). Facing dementia during the COVID-19 outbreak. *Journal of the American Geriatrics Society* 68, 1673-1676.
- Carlos, A.F., Poloni, T.E., Caridi, M., Pozzolini, M., Vaccaro, R., Rolandi, E., Cirrincione, A., Pettinato, L., Vitali, S.F., Tronconi, L., Ceroni, M., and Guaita, A. (2021). Life during COVID-19 lockdown

- in Italy: The influence of cognitive state on psychosocial, behavioral and lifestyle profiles of older adults. *Aging & Mental Health*.
- Carpinelli Mazzi, M., Iavarone, A., Musella, C., De Luca, M., De Vita, D., Branciforte, S., Coppola, A., Scarpa, R., Raimondo, S., Sorrentino, S., Lualdi, F., and Postiglione, A. (2020). Time of isolation, education and gender influence the psychological outcome during COVID-19 lockdown in caregivers of patients with dementia. *European Geriatric Medicine* 11, 1095-1098.
- Clare, L., Martyr, A., Gamble, L., Pentecost, C., Collins, R., Dawson, E., Hunt, A., Parker, S., Allan, L., Burns, A., Hillman, A., Litherland, R., Quinn, C., Matthews, F., and Victor, C. (2021). Impact of COVID-19 on 'living well' with mild-to-moderate dementia in the community: Findings from the IDEAL cohort. *Journal of Alzheimer's Disease*.
- Clare, L., Martyr, A., Morris, R.G., and Tippet, L.J. (2020). Discontinuity in the subjective experience of self among people with mild-to-moderate dementia is associated with poorer psychological health: findings from the IDEAL cohort. *Journal of Alzheimer's Disease* 77, 127-138.
- Clare, L., Nelis, S.M., Quinn, C., Martyr, A., Henderson, C., Hindle, J.V., Jones, I.R., Jones, R.W., Knapp, M., Kopelman, M.D., Morris, R.G., Pickett, J.A., Rusted, J.M., Savitch, N.M., Thom, J.M., and Victor, C.R. (2014). Improving the experience of dementia and enhancing active life - living well with dementia: study protocol for the IDEAL study. *Health and Quality of Life Outcomes* 12.
- Cohen, G., Russo, M.J., Campos, J.A., and Allegri, R.F. (2020). COVID-19 Epidemic in Argentina: Worsening of Behavioral Symptoms in Elderly Subjects With Dementia Living in the Community. *Frontiers in Psychiatry* 11, 866.
- Diener, E., Emmons, R.A., Larsen, R.J., and Griffin, S. (1985). The Satisfaction With Life Scale. *Journal of Personality Assessment* 49, 71-75.
- Folstein, M.F., Folstein, S.E., and McHugh, P.R. (1975). "Mini-Mental State" A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatry Research* 12.
- Hackett, R.A., Steptoe, A., Cadar, D., and Fancourt, D. (2019). Social engagement before and after dementia diagnosis in the English Longitudinal Study of Ageing. *PLoS One* 14, e0220195.
- Lara, B., Carnes, A., Dakterzada, F., Benitez, I., and Piñol-Ripoll, G. (2020). Neuropsychiatric symptoms and quality of life in Spanish patients with Alzheimer's disease during the COVID-19 lockdown. *European Journal of Neurology* 27, 1744-1747.
- Leung, D.K.Y., Chan, W.C., Spector, A., and Wong, G.H.Y. (2021). Prevalence of depression, anxiety, and apathy symptoms across dementia stages: A systematic review and meta-analysis. *International Journal of Geriatric Psychiatry*.
- Liu, K.Y., Howard, R., Banerjee, S., Comas-Herrera, A., Goddard, J., Knapp, M., Livingston, G., Manthorpe, J., O'Brien, J.T., and Paterson, R.W. (2021). Dementia wellbeing and COVID-19: Review and expert consensus on current research and knowledge gaps. *International Journal of Geriatric Psychiatry* 36, 1597-1639.
- Logsdon, R.G., Gibbons, L.E., Mccurry, S.M., and Teri, L. (2000). "Quality of life in Alzheimer's disease: patient and caregiver reports," in *Assessing quality of life in dementia*, eds. S.M. Albert & R.G. Logsdon. (New York: Springer), 17-30.
- Manca, R., De Marco, M., and Venneri, A. (2020). The impact of COVID-19 infection and enforced prolonged social isolation on neuropsychiatric symptoms in older adults with and without dementia: A review. *Frontiers in Psychiatry* 11, 585540.
- Manini, A., Brambilla, M., Maggiore, L., Pomati, S., and Pantoni, L. (2021). The impact of lockdown during SARS-CoV-2 outbreak on behavioral and psychological symptoms of dementia. *Neurological Sciences* 42, 825-833.
- O'rourke, G., Pentecost, C., Van Den Heuvel, E., Victor, C., Quinn, C., Hillman, A.E., Litherland, R., and Clare, L. (2021). Living with dementia under COVID-19 restrictions: coping and support needs among people with dementia and carers from the IDEAL cohort. . *Ageing and Society*.

- Rainero, I., Bruni, A.C., Marra, C., Cagnin, A., Bonanni, L., Cupidi, C., Lagana, V., Rubino, E., Vacca, A., Di Lorenzo, R., Provero, P., Isella, V., Vanacore, N., Agosta, F., Appollonio, I., Caffarra, P., Busse, C., Sambati, R., Quaranta, D., Guglielmi, V., Logroscino, G., Filippi, M., Tedeschi, G., Ferrarese, C., and Group, S.I.C.-S. (2020). The impact of COVID-19 quarantine on patients with dementia and family caregivers: A nation-wide survey. *Frontiers in Aging Neuroscience* 12, 625781.
- Sabat, S.R. (2008). "A bio-psycho-social approach to dementia," in *Excellence in dementia care: Research into practice.*, 70-84.
- Scheier, M.F., Carver, C.S., and Bridges, M.W. (1994). Distinguishing optimism from neuroticism (and trait anxiety, self-mastery, and self-esteem): a reevaluation of the Life Orientation Test. *Journal of Personality and Social Psychology* 67, 1063-1078.
- Seignourel, P.J., Kunik, M.E., Snow, L., Wilson, N., and Stanley, M. (2008). Anxiety in dementia: A critical review. *Clinical Psychology Review* 28, 1071-1082.
- Silarova, B., Nelis, S.M., Ashworth, R.M., Ballard, C., Bienkiewicz, M., Henderson, C., Hillman, A., Hindle, J.V., Hughes, J.C., Lamont, R.A., Litherland, R., Jones, I.R., Jones, R.W., Knapp, M., Kotting, P., Martyr, A., Matthews, F.E., Morris, R.G., Quinn, C., Regan, J., Rusted, J.M., Van Den Heuvel, E.A., Victor, C.R., Wu, Y.T., and Clare, L. (2018). Protocol for the IDEAL-2 longitudinal study: following the experiences of people with dementia and their primary carers to understand what contributes to living well with dementia and enhances active life. *BMC Public Health* 18, 1214.
- Simonetti, A., Pais, C., Jones, M., Cipriani, M.C., Janiri, D., Monti, L., Landi, F., Bernabei, R., Liperoti, R., and Sani, G. (2020). Neuropsychiatric symptoms in elderly with dementia during COVID-19 pandemic: Definition, treatment, and future directions. *Front Psychiatry* 11, 579842.
- Talbot, C.V., and Briggs, P. (2021). 'Getting back to normality seems as big of a step as going into lockdown': The impact of the COVID-19 pandemic on people with early to middle stage dementia. *Age and Ageing* 50, 657-663.
- Tam, M.T., Dosso, J.A., and Robillard, J.M. (2021). The impact of a global pandemic on people living with dementia and their care partners: Analysis of 417 lived experience reports. *Journal of Alzheimer's Disease* 80, 865-875.
- Tatsumi, H., Nakaaki, S., Torii, K., Shinagawa, Y., Watanabe, N., Murata, Y., Sato, J., Mimura, M., and Furukawa, T.A. (2009). Neuropsychiatric symptoms predict change in quality of life of Alzheimer disease patients: A two-year follow-up study. *Psychiatry and Clinical Neurosciences* 63, 374-384.
- The Euroqol Group (1990). EuroQol - a new facility for the measurement of health-related quality of life. *Health Policy* 16, 199-208.
- Thyrian, J.R., Kracht, F., Nikelski, A., Boekholt, M., Schumacher-Schonert, F., Radke, A., Michalowsky, B., Vollmar, H.C., Hoffmann, W., Rodriguez, F.S., and Kreisel, S.H. (2020). The situation of elderly with cognitive impairment living at home during lockdown in the Corona-pandemic in Germany. *BMC Geriatrics* 20, 540.
- Tondo, G., Sarasso, B., Serra, P., Tesser, F., and Comi, C. (2021). The Impact of the COVID-19 pandemic on the cognition of people with dementia. *International Journal of Environmental Research and Public Health* 18.
- Trigg, R., Jones, R.W., Knapp, M., King, D., and Lacey, L.A. (2015). The relationship between changes in quality of life outcomes and progression of Alzheimer's disease: Results from the dependence in AD in England 2 longitudinal study. *International Journal of Geriatric Psychiatry* 30, 400-408.
- Tsapanou, A., Papatriantafyllou, J.D., Yiannopoulou, K., Sali, D., Kalligerou, F., Ntanasi, E., Zoi, P., Margioti, E., Kamtsadeli, V., Hatzopoulou, M., Koustimpi, M., Zagka, A., Papageorgiou, S.G., and Sakka, P. (2021). The impact of COVID-19 pandemic on people with mild cognitive impairment/dementia and on their caregivers. *International Journal of Geriatric Psychiatry* 36, 583-587.

- Vaitheswaran, S., Lakshminarayanan, M., Ramanujam, V., Sargunan, S., and Venkatesan, S. (2020). Experiences and needs of caregivers of persons with dementia in India during the COVID-19 pandemic-A qualitative study. *The American Journal of Geriatric Psychiatry* 28, 1185-1194.
- Van De Beek, M., Van Steenoven, I., Ramakers, I.H.G.B., Aalten, P., Koek, H.L., Olde Rikkert, M.G.M., Manniën, J., Papma, J.M., De Jong, F.J., and Lemstra, A.W. (2019). Trajectories and determinants of quality of life in dementia with Lewy bodies and Alzheimer's disease. *Journal of Alzheimer's disease* 70, 389-397.
- Woods, R.T., Nelis, S.M., Martyr, A., Roberts, J., Whitaker, C.J., Markova, I., Roth, I., Morris, R., and Clare, L. (2014). What contributes to a good quality of life in early dementia? Awareness and the QoL-AD: A cross-sectional study. *Health and Quality of Life Outcomes* 12, 1-11.
- Wu, Y.-T., Nelis, S.M., Quinn, C., Martyr, A., Jones, I.R., Victor, C.R., Knapp, M., Henderson, C., Hindle, J.V., Jones, R.W., Kopelman, M.D., Morris, R.G., Pickett, J.A., Rusted, J.M., Thom, J.M., Litherland, R., Matthews, F.E., Clare, L., and On Behalf of the Ideal Programme Team (2020). Factors associated with self- and informant ratings of quality of life, well-being and life satisfaction in people with mild-to-moderate dementia: Results from the Improving the experience of Dementia and Enhancing Active Life programme. *Age and Ageing* 49, 446-452.

Table 1*Demographic profiles of the pre-pandemic and pandemic groups.*

		Pre-pandemic		Pandemic	
		N	%	N	%
Age group	<65	38	16.5	19	16.5
	65-69	44	19.1	22	19.1
	70-74	56	24.4	28	24.4
	75-79	40	17.4	20	17.4
	≥80	52	22.6	26	22.6
		Mean:	72.7	Mean:	72.4
Sex	Men	118	51.3	59	51.3
	Women	112	48.7	56	48.7
Marital status	Spouse/partner	184	80.0	84	73.0
	Single	17	7.4	22	19.1
	Widowed	29	12.6	9	7.8
Education	No qualifications	64	27.8	23	20.4
	Qualification at 16	39	17.0	17	15.0
	Qualification at 18	78	33.9	49	43.4
	University	49	21.3	24	21.2
Social class	High	90	41.7	52	47.7
	Intermediate	96	44.4	36	33.0
	Low	30	13.9	21	19.3
Living situation	Living with others	191	83.4	91	79.1
	Living alone	38	16.6	24	20.9
Health condition count in addition to dementia	0-1	144	63.7	64	56.6
	2+	82	36.3	49	43.4
Diagnosed depression	Not depressed	189	83.6	93	82.3
	Depressed	37	16.4	20	17.7
Dementia subtype	Alzheimer's disease	142	61.7	61	53.0
	Vascular dementia	16	7.0	15	13.0
	Mixed (Alzheimer's and vascular)	38	16.5	21	18.3
	Frontotemporal dementia	13	5.7	8	7.0
	Parkinson's disease dementia	6	2.6	4	3.5
	Lewy body dementia	7	3.0	0	0.0
	Unspecified/Other	8	3.5	6	5.2
Length of time since diagnosis	< 1 year	93	42.5	0	0.0
	1-2 years	83	37.9	51	47.2
	3-5 years	37	16.9	43	39.8
	≥6 years	6	2.7	14	13.0
Average time (months) between W1 and W2		mean	range	mean	range
		24.9	18-38	39.1	27-51

Table 2

Outcomes at Wave 1 and Wave 2 in the pre-pandemic and pandemic groups.

		Pre-pandemic				Pandemic			
		Wave 1		Wave 2		Wave 1		Wave 2	
		N	%	N	%	N	%	N	%
Mood	Depressed or anxious	79	34.5	73	32.6	44	38.3	29	25.4
	Not depressed or anxious	150	65.5	151	67.4	71	61.7	85	74.6
Sense of self	Discontinuity	69	30.5	71	32.3	38	33.0	39	34.5
	Continuity	157	69.5	149	67.7	77	67.0	74	65.5
Well-being	Low	25	10.9	26	12.2	13	11.4	13	12.0
	Moderate	50	21.8	56	26.2	29	25.4	29	26.9
	High	154	67.3	132	61.7	72	63.2	66	61.1
Optimism	Pessimistic or neutral	59	26.1	70	32.0	37	32.2	29	25.7
	Optimistic	167	73.9	149	68.0	78	67.8	84	74.3
Quality of life	Poor or fair	37	16.2	51	23.1	25	21.7	31	27.4
	Good	128	56.1	117	52.9	69	60.0	54	47.8
	Excellent	63	27.6	53	24.0	21	18.3	28	24.8
Life satisfaction	Dissatisfied with life	36	16.1	33	15.0	10	8.7	16	14.2
	Satisfied with life	188	83.9	187	85.0	105	91.3	97	85.8

Table 3

Odds ratios from mixed effect logistic regression models and multinomial logistic regression models with 95% confidence intervals.

		Pandemic vs. pre-pandemic at Wave 1		Wave 2 vs. Wave 1 for pre-pandemic group		Interaction between pandemic group and Wave	
		OR	95% CI	OR	95% CI	OR	95% CI
Mood ¹	Depressed or anxious	Ref.		Ref.		Ref.	
	Not depressed or anxious	1.1	0.5 – 2.8	0.8	0.5 – 1.4	0.4	0.1 – 1.0
Sense of self ²	Discontinuity	1.1	0.5 – 2.4	1.1	0.7 – 1.9	1.1	0.4 – 2.6
	Continuity	Ref.		Ref.		Ref.	
Well-being ³	Low	1.1	0.4 – 3.1	1.2	0.6 – 2.4	1.0	0.3 – 3.4
	Moderate	1.0	0.4 – 2.4	1.5	0.8 – 2.6	0.8	0.3 – 2.1
	High	Ref.		Ref.		Ref.	
Optimism ⁴	Pessimistic or neutral	1.4	0.7 – 2.8	1.5	0.9 – 2.4	0.5	0.2 – 1.2
	Optimistic	Ref.		Ref.		Ref.	
Quality of life ⁵	Poor or fair	1.4	0.7 – 3.1	1.6	0.9 – 2.9	0.9	0.3 – 2.3
	Good	Ref.		Ref.		Ref.	
	Excellent	0.7	0.3 – 1.4	0.9	0.6 – 1.6	1.8	0.7 – 4.6

Note: Results for main effects and interaction between pandemic group indicator variable and wave variable. Main effect of wave gives the odds ratio (OR) comparing the pandemic groups to the pre-pandemic group at wave 1. Main effect for Wave compares Wave 2 to Wave 1 for the pre-pandemic group. The interaction compares the trend over waves in the pandemic group to the trend over waves in the pre-pandemic group. 95% confidence interval (95% CI); Ref. indicates reference category for the outcome. All models adjusted for age group, sex, binary time since diagnosis, and binary dementia diagnosis.

¹Additionally adjusted for education, health condition count, and MMSE group

²Additionally adjusted for education, marital status, health condition count, depression diagnosis, and MMSE group

³Additionally adjusted for social class, and marital status

⁴Additionally adjusted for education, marital status, health condition count, and depression diagnosis

⁵Additionally adjusted for education, social class, marital status, health condition count, depression diagnosis, and MMSE group