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# **Empirical Article**

# Emerging costs in a "hidden" workforce: The longitudinal psychosocial effects of caregiving during the COVID-19 pandemic among Norwegian adults

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During COVID-19 many informal caregivers experienced increased caregiving load while access to formal and informal support systems and coping resources decreased. Little is known about the psychosocial costs of these challenges for an essential yet vulnerable and "hidden" frontline workforce. This study explores and compares changes in psychosocial well-being (psychological well-being, psychological ill-being, and loneliness) before and across up to three stages of the COVID-19 pandemic among caregivers and non-caregivers. We also examine predictors of psychosocial well-being among caregivers during the peak of the pandemic. We use longitudinal data collected online in the Norwegian Counties Public Health Survey (age: 18-92) in four counties and up to four data points (n = 14,881). Caregivers are those who provide care unpaid, continuous ( $\geq$  monthly across all time points) help to someone with health problems. Findings show that levels of psychosocial well-being first remained stable but later, during the peak stages of the pandemic, dropped markedly. Caregivers (13-15% of the samples) report lower psychosocial well-being than non-caregivers both before and during the pandemic. Caregivers seem especially vulnerable in terms of ill-being, and during the peak of the pandemic caregivers report higher net levels of worry (OR = 1.22, p < 0.01) and anxiety (OR = 1.23, p < 0.01) than non-caregivers. As expected, impacts are graver for caregivers who provide more intensive care and those reporting health problems or poor access to social support. Our study findings are valuable information for interventions to support caregivers during this and future pandemics.

Key words: COVID-19, Caregiving, psychosocial well-being, loneliness, Norway, longitudinal analysis.

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# INTRODUCTION

The COVID-19 pandemic has generated immense challenges for health care systems worldwide (Abbas, 2021; Eurofound, 2022). One particularly relevant group for these systems has not received much research attention, namely informal caregivers, who provide unpaid care to individuals with long-term illnesses or other health-related needs. Considered key partners in disease management and care coordination, informal caregivers account for about half of the total care provided in Norway (Opinion, 2021). Even in normal times, evidence suggests that caregivers experience burden and distress that threatens their health and well-being, and in turn, their ability to care for their care recipients (Adelman, Tmanova, Delgado, Dion & Lachs, 2014; Hansen, Slagsvold & Ingebretsen, 2013). However, there is widespread concern among caregiver advocacy groups and others that the pandemic has created new and unique challenges for this vulnerable and "hidden" frontline workforce (Eurocarers, 2021).

There are multiple reasons why caregivers may have experienced higher than usual burden and stress during COVID-19. First, COVID-19 has posed particular threats for vulnerable groups, which may have led to increased worry for the care recipient's health and increased self-isolation and even reluctance to receive care services or admittance to care facilities due to fears about infection or prolonged separation (Onwumere, Creswell, Livingston et al., 2021). This isolation may also include exposure to challenging behavioral problems, for example in adults with dementia or drug-related disorders. Second, many caregivers experienced that much needed services (e.g., respite care and day centers) were severely restricted or closed during periods of high infection rates and lockdown restrictions (Di Novi, Martini & Sturaro, 2023; Eurocarers, 2021). Third, many caregivers were also left without access to their usual support systems (e.g., friends and colleagues, volunteer support), community-based resources (e.g., cafes and swimming pools), and leisure activities (e.g., choir or exercise groups) (Lightfoot, Yun, Moone

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et al., 2021; Onwumere et al., 2021). In sum, the combination of increased caregiver load and reduced access to regular coping resources and respite opportunities may have subjected carers to intense levels of stress during COVID-19.

An emerging literature has begun to document pandemicrelated changes in caregiver burden and distress. These studies are mostly based on data from the beginning of the pandemic, small convenience samples, and cross-sectional retrospective selfreports. First, there is Norwegian and international evidence that caregivers, especially women, reported increased caregiving time and intensity during the pandemic (Eurofound, 2022; Opinion, 2021; Truskinovsky, Finlay & Kobayashi, 2022; Zwar, König & Hajek, 2021, 2023). For example, a pan-European study of long-term carers shows that caregiving time increased in all countries, and that women increased their mean weekly hours of care (from 48 to 57) more than men (from 39 to 45) (Eurocarers, 2021). This study also shows that most caregivers report that the pandemic negatively affected their social participation (79%), well-being (77%), mental health (67%), access to health services for their care recipient (60%), and their care recipient's health (54%), with the impacts more severe for female than for male caregivers (Eurocarers, 2021). Similarly, several studies explore retrospective changes in stress, exhaustion, and mental health among caregivers and find increasing problems from before to during the pandemic especially among women (Altieri & Santangelo, 2021; Canevelli, Valletta, Blasi et al., 2020; Cohen, Kunicki, Drohan & Greaney, 2021; Park, 2021; Truskinovsky et al., 2022). Other studies find that care disruptions and caregiving load increased overall during the pandemic, with these changes associated with worse mental health and well-being (Leggett, Koo, Park & Choi, 2022; Truskinovsky et al., 2022). These reports may be subject to recall bias, and without a comparison group of non-caregivers it is uncertain whether caregivers were affected differently from non-caregivers by the pandemic. In a rare study using panel data, from before and during the beginning of the pandemic, caregivers reported higher psychological distress than non-caregivers at both time points, yet both groups reported about equal absolute levels of increase in distress (Gallagher & Wetherell, 2020).

Given the challenges and concerns caregivers faced during the COVID-19 pandemic, coupled with the limitations of current research predominantly based on initial pandemic data and small samples, there is a pressing need for longitudinal, population-based studies to assess caregiver distress throughout various stages of the pandemic. Importantly, we lack knowledge about how the population reacted to the second (during the fall of 2020) and later waves of the pandemic, when Norway and many other countries witnessed a dramatic increase in infection rates and issued stronger infection control measures (Nørgaard, Vestergaard, Nielsen *et al.*, 2021).

Furthermore, while caregivers are a heterogenous group with varied risk profiles and thus likely to react differently to COVID-19, there has been little attention to subgroup differences and risk factors. For example, the research on gender differences is still sparse and needs further investigation. While early evidence suggested that female caregivers were disproportionately affected, this expectation is not a given, as women may have more access to social support and higher resilience and coping ability as

caregivers than men (Cohen *et al.*, 2021; Gaugler, Kane & Newcomer, 2007; Merlani, Verdon, Businger, Domenighetti, Pargger & Ricou, 2011). Also, as most studies either focus on older adults or fail to stratify by age, little is known about age-differences in the reactions and especially the impacts among young carers (for an exception, see Blake-Holmes & McGowan, 2022).

Moreover, the reactions may vary according to access to social, socioeconomic, and other relevant resources. Grounded in stresscoping frameworks for caregiving (Pearlin, Mullan, Semple & Skaff, 1990; Pinquart & Sörensen, 2003), caregiving distress is influenced by both the nature and intensity of caregiving and the availability of coping resources. These resources include social support systems, formal support services, socioeconomic advantages, optimal health conditions, and minimized role conflicts, such as those arising between employment and caregiving duties. Hence, more adverse impacts are likely - for example, among individuals with limited social support, lower educational attainment, concurrent employment, or those with compromised health themselves, as has been shown during "normal" times (Hansen & Slagsvold, 2015; Pinquart & Sörensen, 2003). Finally, extant studies are confined to a few countries and there is little evidence from the Nordic countries. Pandemic-related impacts of caregiving may differ across countries due to an interplay between COVID-19 restrictions and cultural and institutional frameworks. Norway is characterized by relatively comprehensive formal care services (Colombo, 2011; Hansen et al., 2013), high levels of gender equality, fairly good health among older adults (Skirbekk, Dieleman, Stonawski, Fejkiel, Tyrovolas & Chang, 2022), and low pandemic-related infection and mortality rates. These patterns likely mitigate risks for female caregivers in particular. Conversely, the pandemicrelated restrictions could lead to a drastic change of habitual arrangements and thus cause immense distress to caregivers usually relying on formal structures to support them, especially regarding the more intimate and comprehensive personal care tasks (Daatland, Herlofson & Lima, 2011; Di Novi et al., 2023).

This study extends prior work by examining gender-stratified longitudinal change in psychological and social (i.e., psychosocial) well-being by caregiver status in a large probability-based sample of adults. Participants were surveyed before and up to three times during the pandemic, including periods with high infection rates (autumns of 2020 and 2021), recognized as pandemic peaks (The Norwegian Government, 2022; WHO, 2022). To grasp the pandemic's full impact on informal caregiving, it is essential to include data from these critical periods (Zwar et al., 2021). Our analysis centers on two main research questions: (i) How did the COVID-19 pandemic differentially affect the psychosocial well-being of caregivers versus non-caregivers?; and (ii) What factors predicted caregivers' psychosocial well-being during the height of the pandemic? With the latter question we aim to identify heterogeneity in the impacts of the COVID-19 pandemic among caregivers and under-supported groups in need of more attention in future pandemics. The predictors include sociodemographic factors, health variables, and care-related factors such as frequency of caregiving and heightened caregiving demands during the pandemic.

#### **METHODS**

# Data

We use data from the Norwegian Counties Public Health Survey (NCPHS), an online cross-sectional study of a probability sample of community-dwelling individuals aged 18+ (Hansen *et al.*, 2021). In response to the COVID-19 outbreak, two counties (Agder and Nordland), in which data were collected just prior to the outbreak, were selected for a COVID follow-up survey. Altogether, data collections were fielded four times. Pre-pandemic data (t1) was collected in Agder September 23 to October 18, 2019 (N=28,015, response rate [RR] = 46%) and in Nordland January 27 to February 16, 2020 (N=24,199, RR = 47%). A random sample of 20,196 individuals from these counties was invited to participate in three follow-ups, during June 4–18, 2020 (t2; N=11,953, RR = 59%), November 18–December 4, 2020 (t3; N=11,029, RR = 55%), and December 6–20, 2021 (t4; N=10,220, RR = 52%).

In addition, we use data from two counties (Oslo and Vestland) that were invited to participate in the COVID survey at t3 (N=15,134, RR = 39%) and t4 (N=12,588, RR = 33%), for which we lack prepandemic data. These counties, encompassing Norway's two largest cities Oslo and Bergen, were harder hit by the pandemic and had stricter COVID-19 restrictions than rural Agder and Nordland (the location can be seen in Fig. 1). Despite missing pre-pandemic data, their inclusion could reveal unique pandemic effects in denser, stricter-regulated regions. After listwise deletion (also known as complete case analysis), the four-counties panel sample comprises data from 14,881 individuals. We opted for listwise deletion because: (i) imputation for caregiving variables was not

feasible since these questions were exclusive to t4 (see below); and (ii) the base sample of our analyses contained very limited (<5%) missing values (Allison, 2001).

# Caregiving variables

Information about caregiving was included only in the last (t4) data collection, and we thus asked retrospectively about caregiving around the time of the previous data collections. Caregiver status questions were introduced by the following question: "Did you, during the whole or part of the period since March 2020, provide regular unpaid help or supervision to someone in need of help due to health problems or old age (e.g., housework, personal care, or supervision)? Please disregard work through a volunteer organization." Response categories were "no," "yes, to person(s) in the household," and "yes, to person(s) outside of the household." Caregivers (both resident and non-resident) were probed about the frequency of caregiving ("How often do/did you provide such help") with reference to currently and at the time of t1 through t3," and with five response categories ("daily," "weekly or more often,", "monthly or more often," "less than monthly," and "not at this time"). We categorize caregivers as those who provide care at least "monthly or more often" across all available time points. This categorization was guided both by the need for statistical power (ensuring a substantial sample size of caregivers) and by substantive considerations about the level of care that can be expected to influence daily life and well-being. By omitting the lowest level of frequency (less than monthly), we focus on caregiving levels that are likely more demanding and impactful. Although caregiving

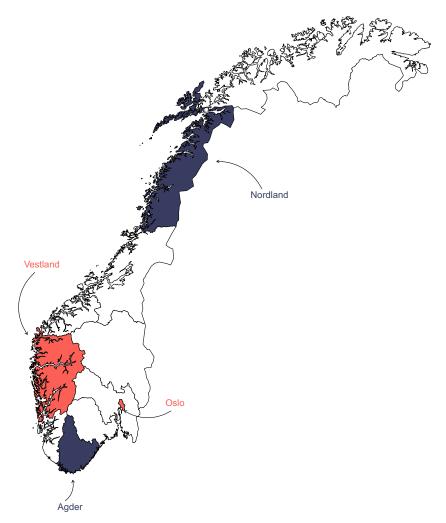


Fig. 1. Map of included counties. Counties with two (red) or four (blue) assessments.

literature use varied thresholds, several studies adopt a "weekly" benchmark (e.g., Cohen *et al.*, 2021). Consequently, in supplementary analyses, we explored our findings using the "weekly or more often" criterion (see Appendix S1).

Extra caring (and its appraisal in terms of added stress) was assessed by: "Did your caregiving load increase due to changes in the health and social services (e.g., home services, respite care, or day care centers) during the fall 2020 lockdown." Response categories include "No," "Yes, and it was challenging for me," and "Yes, but I could handle it."

# Well-being variables

The NCHPS includes a range of indicators of psychological and social well-being. Most are measured by a list of items measuring emotions: "Think about the past 7 days, to what degree did you feel\_\_\_?" on a scale from 0 (not at all) to 10 (very much). The response format and selection of items conform to conventions and OECD-guidelines in the subjective well-being literature (Nes, Hansen & Barstad, 2018; OECD, 2013).

Psychological well-being refers to how people experience and evaluate their lives, that is, their emotional and evaluative well-being (Diener, 2012). Based on the above items we have constructed an index termed *psychological ill-being*, measured by the mean of three items: *worried*, *anxious*, and *down or sad* ( $\alpha$  = 0.74). The three selected items reflect inter-related aspects of psychological distress (OECD, 2013) and represent commonly experienced emotional responses among caregivers (Pinquart & Sörensen, 2003). In supplementary analyses we also use the five-item Hopkins Symptom Checklist, which measures psychological distress (depressive symptoms and anxiety; Strand, Dalgard, Tambs & Rognerud, 2003).

Based on the mean of the item *happy* and a single 0–10 *life satisfaction* question (r=0.80), we constructed the index *psychological well-being*. By merging these items, we capture both the affective (happy) and cognitive (satisfaction) components of psychological well-being (OECD, 2013). Combining these components provides a more comprehensive measure, covering both the day-to-day emotional experiences and the overarching evaluation of life.

Social well-being can be defined as an appraisal of one's social interaction and social relationships, and loneliness is one of its core indicators (Aartsen & Hansen, 2020). *Loneliness* is measured with a single item that asks about the degree to which one has felt "lonely" (0–10).

Beyond mean levels, we also explore "low" levels of psychosocial well-being. "Low" refers to scores at the undesirable end of the scales, that is, scores ≥6 for negatively worded items (e.g., lonely) and ≤4 for positively worded items (e.g., happy). These operationalizations and cutoffs are suggested in guidelines on measuring subjective well-being (Nes *et al.*, 2018; OECD, 2013).

# Controls and predictors of psychosocial well-being

Demographic variables include *gender*, *age* (measured in 10-year intervals), *education* (tertiary [college/university or compulsory/high-school/tertiary] = 1, otherwise non-tertiary 0), *partner status* (married/cohabiting or in a relationship = 1, otherwise 0), *employment status* (full/part time, self-employed, or sickness leave = 1, otherwise 0). *Self-rated health* is measured by a single item recoded into poor (1–2), fair (3), and good (4–5). *Social support* is measured with the three-item (e.g., "How many people are you so close to that you can count on them if you have great personal problems") Oslo Support Scale (OSS-3) ( $\alpha$  = 0.60) (Meltzer, 2003). Scores are categorized into poor (score 3–8), moderate (9–11), and strong (12–14) (Bøen, Dalgard & Bjertness, 2012). All independent variables are measured at t1 for Agder/Nordland, and t3 for Oslo/Vestland.

# Analytical strategy

Utilizing data from all four counties, we conducted two sets of analyses. First, we describe and compare change in well-being variables for

caregivers and non-caregiver at the time of the data collections, adjusting for controls. Hence, for Agder/Nordland we use data from before and at three stages of the pandemic (t1 through t4). For Oslo/Vestland we lack pre-pandemic data and use data from late 2020 and late 2021 (the timing of t3 and t4 for Agder/Nordland). Trajectories were calculated as fixed-effects panel regression models, adjusting for gender, age, employment, education, and partner status. Standard errors were clustered at the individual level. We calculated marginal effects and plotted the adjusted point estimates for caregivers and non-caregivers in Agder/Nordland and Oslo/Vestland separately, with 95% confidence intervals. To shed additional light on the substantive importance of the observed changes (i.e., how many are "suffering?"), we also show rates of "low" well-being across the three time points.

Second, we concentrate on caregivers and examine predictors of well-being variables. We analyze dependent variables both cross-sectionally (at t3/t4) and longitudinally (at t3/t4 with control for respective dependent variables at t1; only for Agder/Nordland). We focus on three sets of predictors: (i) background factors (age, marital status, education, employment status, and health); (ii) caregiving factors (resident vs. non-resident caregiving, frequency of caregiving); and (iii) added caregiving load during the pandemic. All analyses are stratified by gender and performed using Stata v.15.

#### **RESULTS**

# Descriptive statistics

About 15% in Agder/Nordland and 13% in Oslo/Vestland provided care monthly or more often during all available time points. Respectively 77% and 80% in these regions did not provide any care at any time point (excluded from the analysis were the 8% and 7%, respectively, that provided care on at least one time point but not monthly or more often throughout). There was significant within-person consistency and change in the frequency of caregiving over time (see transition plot in Fig. S1). Across data collections, among those defined as caregivers (≥ monthly in all waves), 29–36% reported to provide care monthly, 53–57% weekly, and 11–16% daily. We observed a trend towards increasing frequency among the caregivers, and that more individuals entered than exited the caregiver role during the pandemic.

We also found that most (70.6%) caregivers cared for someone outside of the household, while 29.4% cared for a person in their household. Furthermore, more than one-fourth (27.2%) of caregivers reported that their caregiving load increased during lockdown. Among them, 28.0% – representing 7.6% of all caregivers – reported that they found this heightened load challenging (data not presented).

Table 1 shows the distribution of caregivers and non-caregivers on independent variables. As shown, caregivers were generally slightly more likely than non-caregivers to be older, partnered, and non-employed, to have non-tertiary education, and to report poor health and poor social support. Patterns were quite similar for men and women and across the regions, except that the Oslo/ Vestland sample was markedly younger and had more employed and higher education individuals. Of note, some caregivers, and slightly more female (8–12%) than male (5–8%) caregivers, reported being in poor health. Conversely, while some caregivers indicated poor social support, the percentage was slightly higher for male caregivers (11–18%) than their female counterparts (9–14%). Furthermore, about one third of male caregivers and one

Table 1. Descriptive statistics (N [%]) of caregivers and non-caregivers

|                         | Agder/Nordland (t1)      |                 |                              |                     | Oslo/Vestland (t3) |                 |                                |                     |  |
|-------------------------|--------------------------|-----------------|------------------------------|---------------------|--------------------|-----------------|--------------------------------|---------------------|--|
|                         | Caregivers $(n = 1,022)$ |                 | Non-caregivers $(n = 5,167)$ |                     | Caregivers (n =    | = 1,255)        | Non-caregivers ( $n = 7,437$ ) |                     |  |
|                         | Men $(n = 493)$          | Women (n = 529) | Men $(n = 2,452)$            | Women $(n = 2,715)$ | Men $(n = 548)$    | Women (n = 707) | Men $(n = 3,291)$              | Women $(n = 4,146)$ |  |
| Age 18–39               | 24 (4.9)                 | 32 (6.0)        | 281 (11.5)                   | 544 (20.1)          | 49 (9.0)           | 87 (12.2)       | 944 (28.7)                     | 1,479 (35.6)        |  |
| Age 40–59               | 243 (49.3)               | 308 (58.1)      | 1,025 (41.8)                 | 1,252 (46.1)        | 306 (55.8)         | 379 (53.7)      | 1,370 (41.6)                   | 1,680 (40.5)        |  |
| Age 60–92               | 226 (45.8)               | 189 (35.7)      | 1,146 (46.8)                 | 919 (33.8)          | 193 (35.3)         | 241 (34.1)      | 977 (29.7)                     | 987 (23.8)          |  |
| Tertiary education      | 232 (47.1)               | 289 (54.6)      | 1,294 (52.8)                 | 1,627 (59.9)        | 343 (62.6)         | 453 (64.1)      | 2,217 (67.4)                   | 3,004 (72.5)        |  |
| Partner                 | 437 (88.6)               | 419 (79.2)      | 2,081 (84.9)                 | 2,158 (79.5)        | 462 (84.3)         | 522 (73.8)      | 2,633 (80.0)                   | 3,084 (73.5)        |  |
| Employed                | 314 (63.7)               | 368 (69.6)      | 1,576 (64.3)                 | 1,845 (68.0)        | 405 (73.9)         | 501 (70.9)      | 2,546 (77.4)                   | 3,169 (76.4)        |  |
| Poor health             | 38 (7.7)                 | 63 (11.9)       | 145 (5.9)                    | 202 (7.4)           | 28 (5.1)           | 57 (8.1)        | 158 (4.8)                      | 256 (6.2)           |  |
| Fair health             | 103 (20.9)               | 108 (20.4)      | 370 (19.2)                   | 484 (17.8)          | 100 (18.3)         | 105 (14.9)      | 488 (14.8)                     | 626 (15.1)          |  |
| Good health             | 352 (71.4)               | 355 (67.1)      | 1,834 (74.8)                 | 2,025 (74.6)        | 419 (76.5)         | 543 (76.8)      | 2,633 (80.0)                   | 3,257 (78.6)        |  |
| Poor social support     | 55 (11.1)                | 49 (9.3)        | 218 (8.9)                    | 253 (9.3)           | 101 (18.4)         | 96 (13.6)       | 547 (16.6)                     | 538 (13.0)          |  |
| Moderate social support | 220 (44.6)               | 226 (42.7)      | 1,206 (49.2)                 | 1,154 (42.5)        | 293 (53.5)         | 327 (46.3)      | 1,815 (55.2)                   | 2,095 (50.5)        |  |
| Strong social support   | 212 (43.0)               | 251 (47.5)      | 1,016 (41.4)                 | 1,292 (47.6)        | 153 (27.9)         | 277 (39.2)      | 903 (27.4)                     | 1,497 (36.1)        |  |
| Resident caregiving     | 161 (32.7)               | 132 (25.0)      |                              |                     | 197 (36.0)         | 179 (25.3)      |                                |                     |  |
| Increased care load     | 112 (22.7)               | 136 (25.7)      |                              |                     | 157 (28.7)         | 214 (30.3)      |                                |                     |  |

fourth of female caregivers provided care to someone in their household, and between 23% and 30% of caregivers reported that their caregiving responsibilities increased during the pandemic due to changes in the formal health and social services.

# Change in psychosocial well-being

Figure 2 presents estimated levels of psychosocial well-being across the data points for caregivers and non-caregivers. Mean levels, confidence intervals, and tests are provided in Table S1. First, it is evident that the overall trajectory of psychosocial well-being among all groups and across all outcomes was quite consistent: first characterized by stability, followed by a marked decline before plateauing or slightly improving in the later stage of the pandemic. Specifically, in Agder/Nordland, all groups (by sex and caregiver status) showed a significant decline in psychosocial outcomes from t2 to t3 (p < 0.05) but remained steady from t1 to t2 and t3 to t4. In Oslo/Vestland, changes from t3 to t4 were mostly non-significant, except a significant increase in well-being and decrease in loneliness for male and female non-caregivers, and reduced loneliness for female caregivers (p < 0.05). As can also be seen, reported psychosocial well-being was generally lower in Oslo/Vestland than in Agder/Nordlandiii.

Furthermore, psychological *well-being* tended to be slightly, but not significantly, higher among non-caregivers than caregivers both before and during the pandemic. This caregiver disadvantage was significant (P < 0.05) only among men at t4 in Oslo/Vestland (difference: -0.25, p < 0.05). Regarding *ill-being*, we see that caregivers reported higher levels than non-caregivers both before and during the pandemic. However, the differences, ranging from 0.26 to 0.30 (p < 0.05), were significant only for men during t3 and t4 in Oslo/Vestland and

at t3 in Agder/Nordland. Women (irrespective of caregiver status) reported higher levels of ill-being than men (p < 0.05); in fact, men's level during the peak of the pandemic was like that experienced by women before the pandemic. A similar pattern emerged also for *loneliness*, but only among men (significant only among men at t4 in Oslo/Vestland; 0.33, p < 0.05). Among women, levels of loneliness were almost identical for caregivers and non-caregivers. These patterns explored care provided "monthly or more often;" however, virtually identical patterns emerged when considering care provided "weekly or more often" (see Fig. S2).

The most notable caregiver disadvantage was observed for illbeing, with caregivers reporting significantly higher levels of worry, anxiety, and sadness than their non-caregiving counterparts. The NCPHS included also the five-item Hopkins Symptom Checklist, which measures psychological distress (Strand *et al.*, 2003). Analyzing change in this measure showed a similar pattern as that observed for ill-being (see Fig. S3), corroborating the plight of caregivers during COVID-19.

We observed similar results in sensitivity analyses including all available respondents (even if they only participated in one of the rounds). In these analyses caregivers were defined as giving care at least monthly at each given time point, meaning they could change from being caregivers and non-caregivers (see Fig. S4).

We have in auxiliary analyses (see Table S2) also analyzed the odds of reporting "low" well-being during the peak of the pandemic (net of controls). We found that caregivers at t3 (November 2020) were more likely than non-caregivers to report being worried (OR = 1.22, p < 0.01), anxious (OR = 1.23, p < 0.01), and depressed/sad (OR = 1.10, p < 0.05). Differences were not significant (p > 0.10) for happy (OR = 1.06), satisfied (OR = 1.13), or lonely (OR = 0.94). There were no significant sex differences in these results.

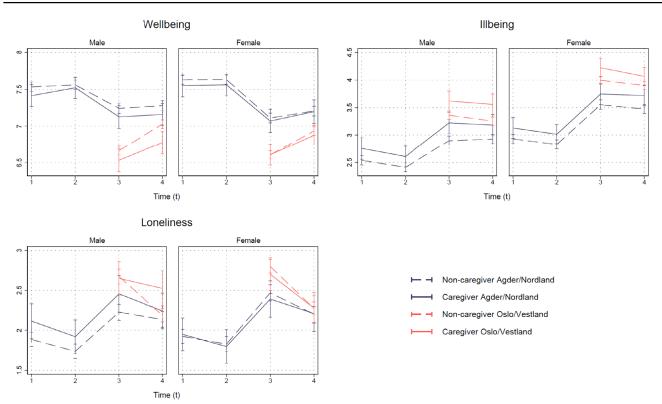


Fig. 2. Trajectories of psychosocial indicators among caregivers and non-caregivers, adjusted for age, partner status, education, and employment status, and stratified by gender and county. Significant caregivers (vs. non-caregivers) (p < 0.05) associations are found only among males, for well-being/Oslo-Vestland/t4, ill-being/Agder-Nordland/t3, ill-being/Oslo-Vestland/both t3 and t4, and loneliness/Oslo-Vestland/t4 (see Table S1).

Predictors of caregiver psychosocial well-being during the pandemic

Table 2 shows the results of analyses of predictors of (change in) psychosocial well-being among caregivers. Patterns were generally quite similar for men and women. Older age, better health, and strong social support were associated with better psychosocial wellbeing across all indicators, although some of the especially longitudinal associations failed to reach statistical significance. Notably, poor access to social support (compared with strong access) was associated with 1.41-1.88 lower well-being, 0.99-1.69 higher ill-being, and 2.04-2.74 higher loneliness (ps < 0.01). Having a partner consistently related to higher well-being (0.37-0.64, p < 0.05) and reduced loneliness (-1.43 to 1.90, p < 0.01) but had no effect on ill-being. Educational level and employment status were mainly unrelated to all outcomes, except that being employed related to slightly beneficial outcomes among women. These patterns of associations were quite similar among noncaregivers (see Table S3). The only difference was that access to social support had a slightly less pronounced impact on the psychosocial well-being of non-caregivers compared to caregivers.

Turning to care-related factors, the analysis showed that residential caregiving (caring for someone within the household) was associated with slightly but not statistically significantly lower psychosocial well-being. Predictably, increased caregiving load during COVID-19 was associated with compromised psychosocial well-being along all indicators, also in longitudinal analyses. Notably, the longitudinal analyses show that increased caregiving load predicted 0.49 (women) and 0.62 (men) from before to during the peak of the pandemic (ps < 0.01).

We were interested in whether both trajectories and predictors of caregivers' psychosocial well-being varied across age groups (Fig. S4 and Table S4). We found no substantial age differences in the change in psychosocial well-being among caregivers. Similarly, age did not moderate associations between outcomes and caregiving factors (residential caregiving and increased caregiving load).

# DISCUSSION

To our knowledge, this is the first longitudinal study of trajectories in caregivers' psychosocial well-being from before and during different stages of the COVID-19 pandemic. Clarifying how the intensity and psychosocial costs of informal caregiving have changed during COVID-19 is a critical step toward building the case for increasing public health surveillance and enhancing formal support for this vulnerable yet invaluable workforce (Kent, Ornstein & Dionne-Odom, 2020). Our study demonstrates that levels of psychosocial well-being first remained stable but later dropped markedly during the peak stages of the pandemic. With some variations, and in line with previous research (Gallagher & Wetherell, 2020), caregivers report lower levels compared with non-caregivers both before and during the pandemic. While the magnitude of the declines in psychosocial well-being is similar across the two groups, the declines affect caregivers more: "a falling tide sinks all boats," yet the implications are graver for those lower on the well-being ladder.

Regarding psychological ill-being (i.e., negative emotionality), caregivers fare worse than non-caregivers both before and during

Table 2. Regressing well-being indicators on background characteristics and care-related factors (data from t3/t4)

|  | Agder/Nordland |           |         | Agder/Nordland, with control for t1 |                |                 | Oslo/Vestland |           |         |
|--|----------------|-----------|---------|-------------------------------------|----------------|-----------------|---------------|-----------|---------|
|  | Well-being     | Ill-being | Lonely  | Well-being                          | Ill-being      | Lonely          | Well-being    | Ill-being | Lonely  |
| Men (N)  | 467            | 472       | 452     | 467                                 | 472            | 451             | 539           | 535       | 518     |
| Age 40-59  | 0.07           | -0.41     | -0.58   | -0.00                               | -0.31          | -0.39           | 0.43          | -0.32     | -0.18   |
| Age 60+  | 0.48           | -0.95*    | -0.48   | 0.10                                | -0.58          | -0.23           | 1.11**        | -1.10**   | -0.72   |
| Partner  | 0.64**         | -0.04     | -1.49** | 0.18                                | 0.13           | -0.77**         | 0.50*         | -0.13     | -1.90** |
| Tertiary education                                 | -0.21          | 0.05      | 0.04    | -0.28**                             | 0.03           | -0.02           | -0.04         | 0.04      | -0.06   |
| Employed   | 0.13           | -0.33     | 0.16    | -0.05                               | -0.19          | 0.11            | 0.32          | -0.31     | -0.47   |
| Good health  | 0.90**         | -0.71**   | -0.69** | 0.35*                               | -0.25          | -0.35           | 1.36**        | -1.04**   | -0.70** |
| Poor support                                       | -1.19**        | 1.19**    | 1.79**  | -0.50*                              | 0.50           | 0.58            | -0.94**       | 0.61**    | 1.40**  |
| Strong support                                     | 0.50**         | -0.50**   | -0.72** | 0.08                                | -0.17          | -0.28           | 0.50**        | -0.59**   | -0.64** |
| Resident caregiving                                | -0.07          | 0.26      | 0.07    | 0.05                                | 0.18           | -0.12           | -0.06         | 0.14      | 0.01    |
| Increased careload                                 | -0.19          | 0.67**    | 0.47    | -0.31*                              | 0.69**         | 0.62**          | -0.08         | 0.38*     | 0.41    |
| Psychosocial wb t1 <sup>a</sup>                    |                |           |         | 0.54**                              | 0.41**         | 0.49**          |               |           |         |
| Women (N)  | 513            | 516       | 495     | 512                                 | 516            | 492             | 672           | 673       | 643     |
| Age 40–59  | 0.59           | -1.34**   | -1.13*  | 0.26                                | -1.00**        | -0.92           | 0.50**        | -0.90**   | -0.92** |
| Age 60+  | 1.08**         | -1.51**   | -1.23*  | 0.59                                | -0.93**        | -0.83           | 0.80**        | -1.09**   | -1.52** |
| Partner  | 0.37           | 0.30      | -1.43** | 0.16                                | 0.31           | -1.20**         | 0.59**        | 0.20      | -1.73** |
| Tertiary education                                 | 0.00           | -0.30     | -0.12   | -0.05                               | -0.28          | -0.07           | -0.07         | -0.22     | 0.14    |
| Employed   | 0.28           | -0.55**   | -0.21   | 0.39*                               | -0.43*         | -0.21           | -0.01         | -0.08     | -0.49*  |
| Good health  | 0.26           | -0.18     | -0.05   | -0.20                               | 0.03           | 0.11            | 1.32**        | -0.92**   | -0.46*  |
| Poor support                                       | -1.35**        | 0.61      | 1.64**  | -0.70**                             | 0.18           | 0.69            | -0.80**       | 0.59**    | 0.88**  |
| Strong support                                     | 0.53**         | -0.54**   | -1.10** | 0.13                                | -0.12          | -0.65**         | 0.61**        | -0.39*    | -1.20** |
| Resident caregiving                                | -0.27          | 0.07      | -0.26   | -0.12                               | -0.08          | -0.22           | -0.18         | 0.07      | 0.04    |
| Increased careload Psychosocial wb t1 <sup>a</sup> | -0.20          | 0.38      | 0.48    | -0.14<br>0.42**                     | 0.32<br>0.39** | 0.49*<br>0.38** | -0.27*        | 0.58**    | 0.42*   |

Notes: wb = well-being Reference categories: age 18-39, unpartnered, non-tertiary education, non-employed, moderate support, non-residential care, and stable careload.

the pandemic. However, caregivers are at higher risk of reporting severe emotional reactions as indicated by high levels of worry, anxiety, or sadness during the pandemic. These findings echo those of previous cross-sectional studies from the beginning of the pandemic, documenting increased caregiver burden and distress (Altieri & Santangelo, 2021; Canevelli *et al.*, 2020; Cohen *et al.*, 2021; Truskinovsky *et al.*, 2022; Zwar *et al.*, 2021). In contrast to this literature, which finds more serious impacts among women, we find similar impacts for men and women. This difference likely reflects the relatively high access to formal care and gender equality in caregiving roles in Norway, mitigating risks for female caregivers in particular.

Against a background literature which portrays caregiving as detrimental for loneliness and well-being (e.g., Pinquart & Sörensen, 2006; Vasileiou, Barnett, Barreto *et al.*, 2017), it is noteworthy that this and prior Norwegian studies (Hansen & Slagsvold, 2015; Hansen *et al.*, 2013) find no such overall impacts. Across all time points, caregivers report similar levels of evaluative (life satisfaction) and experienced (joy) well-being compared with non-caregivers. Our findings are consistent with notions that caregiving, including in the COVID-era, may confer gains as well as strains (Hansen *et al.*, 2013). As noted, patterns likely also mirror that caregiving is relatively less demanding in Norway and other countries with comprehensive formal care services and generous social welfare protections (Colombo, 2011; Hansen *et al.*, 2013). Similarly, Norway had relatively low

pandemic-related infection and mortality rates (WHO, 2022), potentially explaining fewer COVID-era psychological impacts than in countries with greater infection rates and more stringent social distancing measures. These notions are supported by the fact that few (28%) caregivers in our sample report that their caregiving load increased due to changes in the health and social services during the peak of the pandemic, of which less than one third reported the changes as "challenging." By contrast, a broad pan-European study reported that 60% of caregivers experienced negative impacts on their access to health services for those they cared for during the pandemic (Eurocarers, 2021).

The somewhat surprising finding that caregiving seems inconsequential for men and women's cognitive well-being, even during lockdown when caregiving can be extra challenging, may attest to the highly cognitive nature of satisfaction judgments. These appraisals may be detached from, or even enhanced by, emotionally taxing and burdensome experiences (Hansen, 2010). The near-zero effects also suggest that, although aspects of caregiving may reduce satisfaction and joy, other aspects (e.g., helping others, feeling useful and needed, receiving appraisal) may promote positive self-evaluations. Similar predictions can be made also regarding loneliness. While caregiving can limit engagement in social activities, it can also, especially during a time of crisis and isolation, improve a sense of continuity, social connection, and purpose, potentially helping to stave off loneliness. Finally, the near-zero findings likely mirror that

p < 0.05, p < 0.01.

<sup>&</sup>lt;sup>a</sup>Control for each indicator's respective t1 level.

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reactions are highly heterogenous: some caregivers may be frustrated by limitations on daily routines and access to formal supports, others experienced few major changes to their already solitary and home-based lifestyle (Savla, Roberto, Blieszner, McCann, Hoyt & Knight, 2021).

Which subgroups of caregivers were the most vulnerable? We assessed a handful of potential risk and protective factors for negative (change in) psychosocial well-being during the peak of the pandemic. Key risk factors are younger age, poorer health, being unpartnered, lacking social support, resident (in-household) caregiving, and experiencing more care responsibility during the pandemic, although some of the longitudinal associations fail to reach statistical significance. Of note, the analysis highlights the importance of social support. A sizeable percentage of caregivers (10-15%), and more among those with low psychosocial wellbeing, report having poor access to social support during the pandemic. A similar percentage of caregivers report health problems themselves, and may find caregiving particularly challenging due to their own COVID-19 exposure risks (MacLeod, Tkatch, Kraemer, 2021). Another noteworthy finding is the lack of a social gradient in caregivers' psychosocial wellbeing, again potentially reflecting the idea of equal access to health services under the Norwegian welfare system. As expected, caregiver distress is higher among those providing the most intensive care, that is, to someone in the household, and among those experiencing increasing care responsibility during the pandemic.

This study has several strengths, most notably within-person data from different stages of the pandemic, the scope of variables, and the large sample size, providing rich possibilities for capturing the complexities of caregiving, over time, and for different subgroups. There are some weaknesses to note. For example, we lack details about type of care (e.g., personal care vs. instrumental care), relation to the care recipient, and the care recipient's health. We are thus unable to do more subgroup analyses of caregivers, or to assess whether it is caregiving in itself or deteriorating health of a close relative that is most impactful. Over the study period of up to 27 months, many care recipients are likely to experience increased health problems with negative psychological implications, irrespective of the pandemic, also for their caregiver. Furthermore, there are potential weaknesses related to the use of single-item measures and unvalidated scales. Although our individual single-item measures are commonly used and recommended measurements in the field (OECD, 2013), the composite indexes should be validated in future research. First, findings should be interpreted in light of Norway's relatively low COVID-19 morbidity and mortality rates and relaxed infection control measures. Of note, our two counties with pre-pandemic data (Agder and Nordland) were among the counties least impacted by COVID-19 in Norway. Coupled with the comparatively extensive welfare supports in Norway, pandemic-related caregiver distress is likely greater in other countries.

To conclude, while psychosocial well-being declined overall during the pandemic, the impacts seem somewhat more serious for caregivers who reported lower psychosocial well-being already before the pandemic. The psychosocial costs of COVID-19 for caregivers were especially notable in terms of elevated negative emotions such as worries and distress. These costs were

also more pronounced in urban regions with more pandemic-related infections and restrictions, and among caregivers who provide more intensive care, have their own health problems, or lack social support. That said, the impacts seem milder than suggested by prior research (e.g., Eurocarers, 2021). The contrast could reflect that our within-person design avoids some of the bias in earlier cross-sectional and retrospective subjective data (e.g., recall bias). It could also stem from country differences, thus highlighting the need to replicate our analysis in countries with fewer social protections, a greater age-specific disease burden, higher mortality rates, and more stringent social restrictions during the pandemic.

Understanding how caregivers reacted to the difficulties imposed by the pandemic is essential to support at-risk caregivers, and, by extension, their care recipients, during future pandemics or times of crisis. It is also key to future balancing of health protective measures against their unintended consequences for the well-being and health of vulnerable groups. The importance is highlighted also by the well-established consequences of compromised psychosocial well-being on physical and mental health (e.g., Steptoe, Shankar, Demakakos & Wardle, 2013). These effects in turn impact on their ability to provide care and increase the risk of institutionalization and additional health and social costs (Gallagher & Wetherell, 2020). Attempts to reduce caregiver burden, especially during times of crisis, thus has clear implications for the health and functioning of people in and around the care relationships, as well as for wider society.

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# **ENDNOTES**

<sup>i</sup> The WHO declared COVID-19 a public health emergency of international concern in January, 2020, and later declared it a pandemic on March 11, 2020 (WHO, 2020). "Pre-pandemic" refers here to the time before March 11, 2020.

ii Respondents in Oslo and Vestland were asked retrospectively only about November–December, 2020.

 $^{
m iii}$  Comparable groups based on sex and caregiver status showed lower well-being and higher ill-being in Oslo/Vestland than in Agder/Nordland (ps < 0.05), but loneliness levels were consistent.

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# SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article:

Figure S1. Transition plot.

Figure S2. Trajectories of weekly or more often caregivers.

Figure S3. Hopkins Symptom Checklist as outcome.

Figure S4. Trajectories including full sample.

Figure S5. Age and wellbeing.

Table S1. Significance tests for Fig. 2.

**Table S2.** Low values of wellbeing.

**Table S3.** Predictors of well-being among non-caregivers.

Table S4. Wellbeing predictors for various age groups.

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