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Mental health of informal caregivers during the COVID-19 pandemic: a Swiss cohort study

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Summary

AIMS OF THE STUDY: The COVID-19 pandemic and related public health measures have disrupted healthcare systems and may have impacted informal caregivers' mental health due to increased responsibilities and limited access to support services. This study aimed to examine the prevalence of mental distress among caregivers and non-caregivers and identify risk and protective factors for mental distress in caregivers during the COVID-19 pandemic.

METHODS: Data were collected from participants in Specchio-COVID19, a population-based cohort in Geneva, Switzerland. Mental distress was measured using the 12-item General Health Questionnaire (GHQ-12) in June 2021. The prevalence of distress was compared between caregivers and non-caregivers. Risk and protective factors for mental distress among caregivers were explored using logistic regressions.

RESULTS: Among the 5416 participants, 1086 (20%) reported helping someone in a non-professional manner with activities of daily life and were considered caregivers. Mental distress was more frequent in caregivers than in non-caregivers (41% vs 37%, p = 0.010). In caregivers, limited social support (adjusted odds ratio [aOR] = 1.25 [95% confidence interval: 1.10, 1.42]), caring for an individual with a mental condition (aOR = 1.21 [1.05, 1.41]), living over 10 km away from the care recipient (aOR = 1.17 [1.02, 1.34]), feeling more isolated in one's caregiving role (aOR = 1.20 [1.08, 1.32]), worrying about caregiving ability in case of COVID-19 or quarantine (aOR = 1.18 [1.08, 1.28]) and experiencing reduced availability of healthcare professionals (aOR = 1.11 [1.02, 1.22]) were associated with increased odds of mental distress.

CONCLUSION: Informal caregivers experienced higher levels of mental distress than non-caregivers during the COVID-19 pandemic. This study highlights the need for public health policies that enhance both formal and informal support networks and include rapidly implementable solutions for caregiving continuity, benefiting both caregivers and their care recipients.

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Introduction

The COVID-19 pandemic and its associated public health measures disrupted health and care systems [1], impacting clinically vulnerable people and their informal caregivers [2–6]. Informal caregivers (hereafter used interchangeably with caregivers) are family or friends who provide non-professional care. They represent a sizeable part of the general population (5% to 44% of adults across different European countries) [7–11] and are integral to health and care systems [12, 13]. It is well known from pre-pandemic data that the caregiving burden is associated with poorer mental health outcomes [14, 15]. The pandemic unsettled nearly every aspect of informal caregivers' lives and caregiving routines with new challenges such as lockdown, fear of transmitting the virus and restricted access to human and material resources that assist with caregiving. Moreover, caregivers may have taken additional professional adjustments and preventive measures, such as limiting social contacts to avoid transmitting the virus, leading to po-

ABBREVIATIONS

GHQ-12:	General Health Questionnaire – 12-item
OSSS-3:	Oslo Social Support Scale – 3-item
PCR:	Polymerase chain reaction
PSS-10:	Perceived Stress Scale – 10-item
SARS-CoV-2:	Severe acute respiratory syndrome-coronavirus 2
UCLA-3:	UCLA Loneliness Scale – 3-item
WHO-5:	World Health Organisation Well-being Index – 5-item

tential financial consequences, social isolation and a negative impact on their well-being and mental health [5, 6, 16, 17]. The pandemic may have also pushed previously non-caregivers to become new caregivers for their relatives or friends who could no longer assume some of the tasks they used to handle due to restrictions and vulnerability factors. All these factors may have exacerbated the impact of providing care on caregivers' mental health.

During the first few months of the pandemic, informal caregivers reported poorer mental and physical health and an overall lower quality of life than non-caregivers [4, 18–24]. A few studies have examined caregivers' mental and physical health levels compared to pre-pandemic levels. Some highlighted an increase in stress, anxiety, depression, and caregiving burden during the early phases of the pandemic, while others suggested comparable or better caregiver mental health [25, 26]. Caregiving conditions and caregivers' health could widely vary depending on local policies and public health measures.

In Switzerland, caregivers' mental health during the pandemic remains underexplored. Therefore, the purposes of this study were (a) to determine the prevalence of mental distress among caregivers and non-caregivers, (b) to describe the perceived evolution of the caregiving roles and burden during the COVID-19 pandemic and (c) to identify protective and risk factors for mental distress in caregivers in the context of the COVID-19 pandemic.

Material and methods

Study design, setting and sample

Data were drawn from the Specchio-COVID19 cohort study, initiated in December 2020 to follow adults (≥18 years old) who participated in successive SARS-CoV-2 serosurveys between April 2020 and June 2021 [27–31]. Serosurvey participants were randomly selected from the Bus Santé population-based study, from Geneva registries provided by the Swiss Federal Office of Statistics or the Cantonal Office for Population and Migration, and from a convenience sample of essential workers (i.e. those employed in roles considered critical for delivering vital services such as healthcare, transportation, food production and social work, among others) living or working in Geneva [27]. After a serology, they were invited to join the cohort. Participants' sociodemographic, health and lifestyle characteristics were assessed at inclusion in the cohort, and thematic and follow-up health questionnaires were offered regularly through an online digital platform (www.specchio-hub.ch). All participants in the Specchio-COVID19 study provided informed and written consent upon study enrolment.

This study used data from an inclusion questionnaire (completed between December 2020 and June 2021) and four additional questionnaires administered between June and July 2021. The first focused on general and mental health and included the 12-item General Health Questionnaire (GHQ-12). The second centred on well-being and mental health, including measures of stress, depression, and social support; its completion was optional for inclusion in this study. The third included a question assessing caregiver status. Finally, the fourth was exclusively sent to caregivers and explored their caregiving responsibilities and the characteristics of their care recipients. The latest included variables were selected as candidate risk and protective factors for mental distress in caregivers based on existing research and practical considerations from experts in the field. The variables collected in each questionnaire are detailed in table S1 in the appendix.

Participants in the Specchio-COVID19 study were eligible for this analysis if they had completed (a) a questionnaire about general and mental health and (b) a follow-up questionnaire with a question assessing caregiver status (figure 1).

Measures

Caregiving status was the main exposure of this study. Individuals who answered affirmatively to the question *“Since the start of the pandemic, have you regularly helped (in a non-professional role) a person close to you (dependent, elderly, ill or disabled person) with the tasks of daily living (for example, washing or shopping, meals, housework)?”* in June 2021 were categorised as informal caregivers.

The primary outcome was mental distress, measured by the 12-item General Health Questionnaire. This internationally validated scale comprises 12 mental health questions (e.g. concentration, sleep loss, stress, confidence), including six positively and six negatively worded questions. Each item is scored on a four-point Likert system ranging from zero to three points. Its maximum total score is 36 points, with a higher score indicating greater distress. Mental distress was defined as a score of ≥12 points [32, 33].

Additional mental health measures included well-being as measured by the WHO-5 Well-being Index (WHO-5), loneliness as measured by the UCLA Loneliness Scale (UCLA-3), and perceived stress as measured by the 10-item Perceived Stress Scale (PSS-10), with the definitions provided in appendix table S1.

The covariates included caregivers' demographics (e.g. age, sex, birth country, and education) and pre-existing mental and physical health, assessed at inclusion in the cohort. A previous SARS-CoV-2 infection was defined as either (a) a positive serological, antigenic or polymerase chain reaction (PCR) test self-reported at inclusion or in a follow-up questionnaire, (b) a positive serology indicating natural infection (presence of anti-nucleocapsid antibodies) or (c) a positive PCR test according to a database established by regional public health authorities before 1 June 2021 [34].

Potential risk and protective factors for distress among caregivers were assessed at inclusion in the cohort (e.g. demographics), in a questionnaire about well-being and mental health (e.g. social support) and in an optional questionnaire about caregiving responsibilities and care recipient's characteristics. They are defined in table S1 in the appendix and can be summarised as follows: (a) factors related to the caregiver (e.g. age, sex, and pre-existing conditions), (b) factors related to caregiving (e.g. frequency, distance from caregiver to care recipient, type of care, such as help with activities of daily living, and age of the care recipient) and (c) factors related to the COVID-19 pandemic (e.g. increase in caregiving burden and availability of healthcare professionals). If a caregiver cared for more than one individual, the participant was asked to answer a set of questions on caregiving specific to each person (e.g. care recipient's age, reason for care, relationship, distance, and frequency and type of care). For care recipient-related variables, the data was derived from the first reported care recipient unless otherwise specified.

Statistical analyses

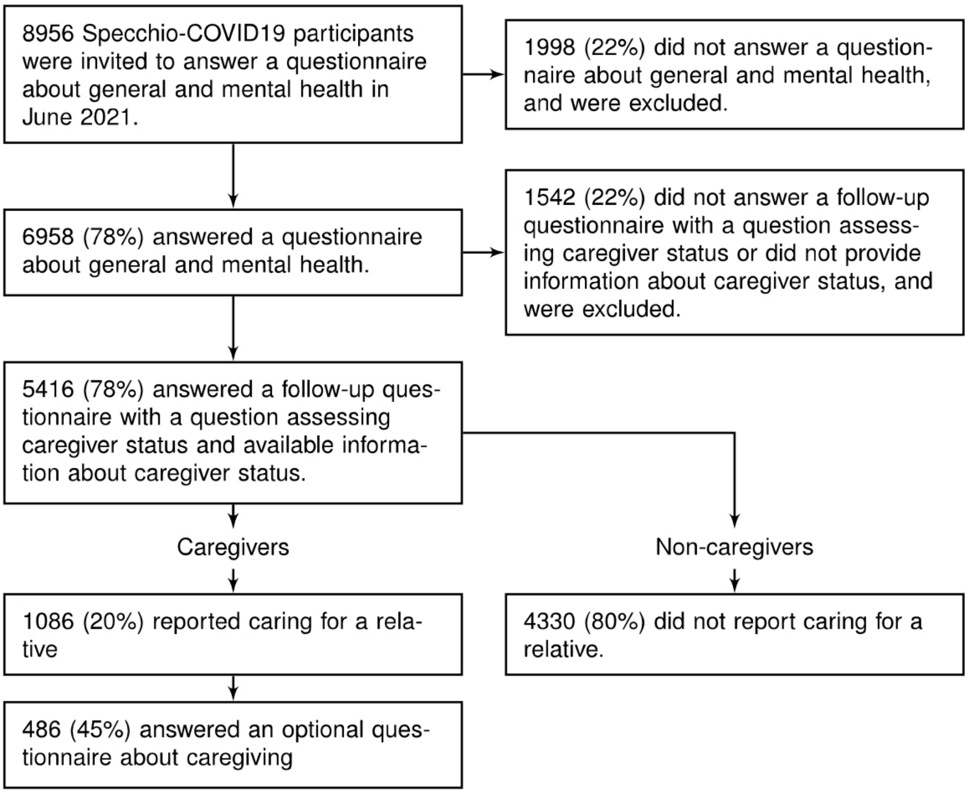
Baseline sociodemographic and mental health characteristics were compared between caregivers and non-caregivers and between caregivers with and without mental distress. Risk and protective factors for mental distress in caregivers were also assessed. All descriptive analyses included absolute numbers with relative percentages for categorical variables and means and standard deviations or medians with interquartile ranges for continuous variables. Hypotheses were tested using the chi-squared tests, Welch's two-sample *t*-test or the Wilcoxon-Mann-Whitney test, as appropriate. The significance level was set at $p<0.05$.

The prevalence of distress was adjusted for confounders and compared among caregivers and non-caregivers. Based on existing literature, potential confounders of the association between caregiver status and mental distress were identified using a directed acyclic graph: sex, age and country of birth (figure S1 in the appendix). The adjusted prevalence of distress was calculated using average adjusted predictions. First, a linear regression model was fitted, including caregiver status as the primary predictor and confounders as covariates, including age, sex and birth country. Then, predictions were made for each individual in the dataset using their observed values for all covariates and averaged within caregiver and non-caregiver groups. This approach estimates the expected prevalence of distress, adjusted for the distribution of other confounders in the study population. A sensitivity analysis was conducted on a subsample of participants exclusively drawn from random samples of the general population (i.e. excluding essential workers).

The risk and protective factors for mental distress in caregivers were assessed using unadjusted and adjusted logistic regressions. The adjustment set included sex, age, education, social support, pre-existing mental condition and pre-existing physical condition. The results are reported as odds ratios (ORs) with 95% confidence intervals (CIs). Sensitivity analyses were conducted to test the robustness of the observed associations. First, the same models were run in a subsample of the caregivers from the general population (i.e. excluding essential workers). Then, when a caregiver reported caring for multiple care recipients, the data relative to the first care recipient was replaced with the data for the second care recipient. This approach allowed for an examination of whether the results were influenced by the characteristics of the care recipient in cases where a caregiver cared for multiple care recipients.

Missing data ranged from 0 to 20% per variable. Multiple imputation by chained equations (MICE) with predictive

Figure 1: Flowchart.



mean matching was used to treat missing data in all models [35].

All analyses were conducted using R (v.4.1.2; R Foundation for Statistical Computing, Vienna, Austria) with packages including dplyr (v.1.1.4), tidyverse (v.2.0), gtsummary (v.1.7.2), marginaleffects (v.0.17), mice (v.3.16), ggplot2 (v.3.4.4), and likert (v.1.3.5). The code is available at: https://gist.github.com/cedricfollonier/052233eb0bb4c8025f400c8fc1289a3e.

Patient and public involvement

Participants were not involved in setting the research questions or outcome measures or designing the study. However, they showed overwhelming support for the study through continuing attendance for follow-up.

Results

Demographic characteristics, physical health and mental health of caregivers and non-caregivers

Among the Specchio-COVID19 participants eligible for this study, 1086 (20%) declared being caregivers (figure 1). Table 1 presents the characteristics of caregivers and non-caregivers. Overall, their mean age was 51 years, 56% were female, and 52% had completed tertiary education. Caregivers were more often female (60% vs 55%, $p = 0.002$), born in Switzerland (70% vs 59%, $p < 0.001$), and had lower household income ($p = 0.002$) than non-caregivers.

The overall observed prevalence of mental distress (GHQ-12 score ≥12 points) was 38% (95% CI: 36–39%) as of June 2021. Caregivers were more frequently affected than non-caregivers (41% vs 37%, $p = 0.009$), even after adjusting for age, sex and country of birth (41% vs 36%, $p = 0.004$). In both groups, the most frequently reported items of the GHQ-12 were feeling under stress and losing sleep (figures S2 and S3). In addition, caregivers reported slightly poorer well-being (64 vs 68 points, $p = 0.048$) and higher levels of perceived stress (23 vs 22 points, $p < 0.001$). There was no significant difference in the prevalence of loneliness (13% vs 13%, $p = 0.905$). The unadjusted and adjusted prevalence of distress remained similar and significantly more frequent among caregivers in a sensitivity analysis conducted on a subsample representative of the general population (appendix table S2).

Caregiving responsibilities and evolution during the pandemic

The characteristics of the responding and non-responding caregivers are detailed in table S3 in the appendix: respondents were older (54 vs 50 years, $p < 0.001$) and more often female (64% vs 58%, $p = 0.040$).

Among caregivers, 7% of the care recipients were spouses or partners, and 64% were first-degree relatives (table 2). Most caregivers cared for a single person (66%, figure S4 in the appendix). When caregivers cared for more than one person, the characteristics of the first and second care recipients they reported are shown in table S4 in the appendix. Care recipients often lived separately from their caregivers but within a 10 km distance. Ageing (78%) was the predominant reason for caregiving, with 63% of care recipients aged 80 years old or above (appendix figure S5). Help with instrumental activities of daily living (96%) and social support (66%) were frequent. Most caregivers (78%) received additional support from another informal (e.g. another caregiver or a volunteer) or formal (e.g. a home care nurse) source (appendix figure S6).

The pandemic appears to have influenced informal caregiving, with 40% of caregivers experiencing decreased healthcare availability, 61% expressing concerns about being unable to help their care recipient in case of COVID-19 or quarantine, and 24% feeling more isolated in their role since the pandemic onset. Among professionally active caregivers, 13% had to make occupational adaptations to accommodate their caregiving responsibilities, including taking paid leave (38%), work schedule flexibility (31%), reduction in working hours (23%) or resignation (6%) (appendix figure S7). In addition, 47% of caregivers experienced an increase in caregiving burden since the pandemic onset, primarily driven by increased care recipient needs (67%), willingness to limit contacts with the care recipient (61%), and reduced availability of other sources of formal support (34%) (appendix figure S8).

Risk and protective factors for distress in caregivers

Risk and protective factors for distress in caregivers are presented in tables 2, 3 and 4. Among caregiver-related factors, older caregivers had a lower likelihood of expressing mental distress, while those with limited social support presented a higher likelihood (table 2).

Among caregiving- and care recipient-related factors, caregivers caring for an individual with a mental condition and those living more than 10 km away from the care recipient had about 20% increased odds of suffering from mental distress. The caregiver and care-recipient's degree of relationship, duration of care relationship, frequency of care, and older age of the care recipient (≥80 years old) were not significantly associated with mental distress, but the confidence intervals were large (table 3).

Among COVID-19 pandemic-related factors, caregivers feeling more isolated in their caregiving role since the pandemic onset, those worrying about the inability to carry the care responsibility due to COVID-19 or quarantine, and those experiencing decreased availability of healthcare workers had significantly higher odds of experiencing mental distress (table 4).

Sensitivity analyses showed similar results in direction and magnitude (tables S5 and S6 in the appendix), suggesting that these results may apply to the general population and are robust regardless of whether the caregiver cared for one or more persons.

Discussion

This study highlights higher mental distress in caregivers compared to non-caregivers 16 months after the onset of the COVID-19 pandemic. Caregivers reported perceiving significant changes in their caregiving responsibilities since the onset of the pandemic, including reduced healthcare access, increased concerns, feelings of isolation, occupational adjustments to meet their caregiving duties, and a greater caregiving burden. Low social support, caring for an individual with a mental condition, living far from the care recipient, feeling more isolated in one’s caregiver role and worrying about the inability to care in case of COVID-19 or quarantine were risk factors for mental distress in caregivers.

The proportion of caregivers varies significantly across countries and its definition tends to be polymorphous. The proportion of caregivers in our sample was 20%, aligning with previous findings in Europe, where between 5% and 44% of the population provide informal care [7–11]. Nonetheless, the open nature of the question used to identify caregivers leaves room for personal interpretation, reflecting each respondent’s own interpretation of their caregiver status. Therefore, it may have favoured the selection of those more deeply engaged in caregiving tasks, such as assistance with bathing or meal preparation, potentially underrepresenting those whose caregiving roles were purely administrative or social.

Both before and during the pandemic, the literature tends to describe poorer mental health in caregivers than in non-caregivers across multiple outcomes such as anxiety, depression, mental distress and suicidal ideation [4, 15, 18–25, 36–39]. These results are nuanced and could be explained by regional, caregiver subgroups (e.g. caregivers of a child with autism or adults with dementia) and measurement variations. In addition, findings in the context of the pandemic emerge from data collected at the beginning

Table 1:
Demographics, physical and mental health of non-caregivers and caregivers.

		Overall, N = 5416*	**Non-caregivers, N = 4330***	**Caregivers, N = 1086***	
		n / N (%)	**n / N (%)**	**n / N (%)**	**p-value****
Sociodemographic characteristics					
Female sex		3052 / 5416 (56%)	2395 / 4330 (55%)	657 / 1086 (60%)	**0.002**
Age (years), mean (SD)		51 (13)	51 (14)	52 (12)	**0.001**
In a relationship		4004 / 5414 (74%)	3217 / 4329 (74%)	787 / 1085 (73%)	0.248
Born in Switzerland		3335 / 5416 (62%)	2574 / 4330 (59%)	761 / 1086 (70%)	**<0.001**
Education					0.183
	Primary	179 / 5414 (3.3%)	145 / 4328 (3.4%)	34 / 1086 (3.1%)	
	Secondary	2423 / 5414 (45%)	1910 / 4328 (44%)	513 / 1086 (47%)	
	Tertiary	2812 / 5414 (52%)	2273 / 4328 (53%)	539 / 1086 (50%)	
Professionally active		4023 / 5413 (74%)	3199 / 4328 (74%)	824 / 1085 (76%)	0.183
Household income					**0.002**
	Low	707 / 4322 (16%)	540 / 3446 (16%)	167 / 876 (19%)	
	Medium	2863 / 4322 (66%)	2276 / 3446 (66%)	587 / 876 (67%)	
	High	752 / 4322 (17%)	630 / 3446 (18%)	122 / 876 (14%)	
Limited social support (OSSS-3)***		735 / 4642 (16%)	589 / 3698 (16%)	146 / 944 (15%)	0.767
Pre-existing physical condition		1214 / 5416 (22%)	957 / 4330 (22%)	257 / 1086 (24%)	0.287
Pre-existing mental condition		110 / 5416 (2.0%)	86 / 4330 (2.0%)	24 / 1086 (2.2%)	0.728
Physical health					
Self-perceived health status					0.062
	Good or very good	4849 / 5416 (90%)	3891 /4330 (90%)	958 / 1086 (88%)	
	Average	517 / 5416 (9.5%)	405 / 4330 (9.4%)	112 / 1086 (10%)	
	Poor or very poor	50 / 5416 (0.9%)	34 / 4330 (0.8%)	16 / 1086 (1.5%)	
Previous SARS-CoV-2 infection		1610 / 5416 (30%)	1282 / 4330 (30%)	328 / 1086 (30%)	0.729
Mental health* **					
Self-perceived mental health status					0.726
	Good or very good	4247 / 5416 (78%)	3404 /4330 (79%)	843 / 1086 (78%)	
	Average	1009 / 5416 (19%)	801 / 4330 (18%)	208 / 1086 (19%)	
	Poor or very poor	160 / 5416 (3.0%)	125 / 4330 (2.9%)	35 / 1086 (3.2%)	
Well-being index (WHO-5), median (IQR)		68 (48–80)	68 (48–80)	64 (48–80)	**0.048**
Well-being index (WHO-5)					0.627
	Well-being (WHO-5 = >50)	3393 / 4642 (73%)	2711 / 3698 (73%)	682 / 944 (72%)	
	Poor well-being (WHO-5 = 29–50)	821 / 4642 (18%)	644 / 3698 (17%)	177 / 944 (19%)	
	Depression (WHO-5 = ≤28)	428 / 4642 (9.2%)	343 / 3698 (9.3%)	85 / 944 (9.0%)	
Loneliness (UCLA-3)		584 / 4642 (13%)	464 / 3698 (13%)	120 / 944 (13%)	0.905
Perceived stress (PSS-10),median (IQR)		22 (17–28)	22 (17–27)	23 (18–28)	**<0.001**
Mental distress (GHQ-12), median (IQR)		10 (8–13)	10 (8–13)	10 (8–14)	**<0.001**
Mental distress (GHQ-12 ≥12), observed prevalence (95% CI)		2044 / 5416 (38% [36–39])	1597 / 4330 (37% [35–38])	447 / 1086 (41% [38–44])	**0.010**
Mental distress (GHQ-12 ≥12), adjusted prevalence**** (95% CI)			36% (35–38)	41% (38–44)	**0.004**

GHQ-12: General Health Questionnaire – 12-item; IQR: interquartile range; OSSS-3: Oslo Social Support Scale – 3-item; PSS-10: Perceived Stress Scale – 10-item; SD: standard deviation; UCLA-3: UCLA Loneliness Scale – 3-item; WHO-5: World Health Organisation Well-being Index – 5-item (WHO-5).

* Data are presented as n / N (%), mean (SD) or median (IQR).

** P-values were calculated using Pearson’s Chi-squared test, Welch’s two-sample t-test or the Wilcoxon rank sum test.

*** Secondary mental health measures (i.e. social support [OSSS-3], well-being index [WHO-5], loneliness [UCLA-3], and perceived stress [PSS-10]) were assessed in an additional and optional well-being and mental health questionnaire; they were missing for 774 participants who did not answer the latter.

**** Adjusted prevalences are expressed as percentages and were calculated as means of each level of distress status averaged across each level of covariates, including sex, age and birth country.

and/or at the height of the pandemic, and it remains unknown whether this effect will last over time. In this study, caregivers experienced more instances of mental distress and stress and a slightly lower level of well-being than non-caregivers. This result supports pre-pandemic research showing that caring for someone, while rewarding, can be stressful and burdensome, leading to adverse physical and mental effects, such as increased stress, depression, emotional and cognitive impairments, and decreased subjective well-being [14, 15, 40]. This burden arises from the demanding nature of caregiving responsibilities, which can limit the time caregivers have available to attend to their own health needs and directly affect physical health [41].

Among caregivers, several factors may contribute to depression, stress, and low subjective well-being. Caregiver-related factors such as sex, education or socioeconomic status were not significantly associated with mental distress in this study. This finding is contradictory to previous studies, which showed that females experience more negative impacts of caregiving on their mental health [42, 43]. There were no associations but wide confidence intervals for factors such as the degree of relationship, duration of the care relationship and frequency of care, which had been previously linked with poorer mental health among caregivers [15, 42, 43]. Other factors, including the caregiver's responsibility for a care recipient with a mental condition and living at a distance, both adding stress and demands, were identified. These results partly support previous studies, which highlighted that mental health was negatively impacted by the presence of cognitive-behavioural disorders in care recipients [15, 42, 43]. Finally, limited social support was shown to be associated with poorer mental health among caregivers, as previously suggested [44].

The COVID-19 pandemic is thought to have exacerbated the regular emotional, physical and financial strains associated with caregiving [45] and introduced a distinct set of challenges for caregivers. Accordingly, in this study, approximately 40% of caregivers experienced a decrease in the availability of healthcare professionals who might have had difficulty maintaining routine health services due to the surge of patients with COVID-19 and restrictive public health measures. Consequently, caregivers had to assume additional responsibilities, including tasks typically performed by professional caregivers, and experienced increased workload, task complexity, and time commitment dedicated to caregiving, with potential financial implications. Given this context, nearly half of the caregivers reported that the burden of care had increased since the onset of the pandemic, primarily due to increased care recipient needs, limited contact with other individuals involved in caregiving and reduced availability of formal support systems. This finding is consistent with a trend reported throughout Europe [38, 46]. Over half of the caregivers reported concerns about being unable to help their care recipient due to COVID-19 or quarantine, and about a quarter felt more isolated in their role; they were more likely to suffer from mental distress, as previously identified [47]. Ultimately, the association between decreasing healthcare professional availability, not receiving any external support during the pandemic, and increased mental distress underscores the importance of formal and informal support networks in the context of caregiving. These networks are essential in preserving caregiver's well-being and enhanc-

Table 2:
Association of factors related to the caregiver with mental distress in a subsample of 486 informal caregivers who completed an additional questionnaire about caregiving.

	Descriptive				**Unadjusted**			**Adjusted** $^{\#}$		
	Overall, N = 486*	**No mental distress, N = 284***	**Mental distress, N = 202***		**Mental distress vs no distress**			**Mental distress vs no distress**		
	n / N (%)	**n / N (%)**	**n / N (%)**	**p-value****	**OR**	**95% CI**	**p-value*****	**aOR**	**95% CI**	**p-value*****
Female sex (ref. male sex)	311 / 486 (64%)	176 / 284 (62%)	135 / 202 (67%)	0.315	1.24	0.85, 1.81	0.272	1.05	0.96, 1.15	0.263
Age (per 5 years)$^{\#\#}$, mean (SD)	54 (11)	55 (11)	53 (12)	0.055	0.92	0.85, 1.00	0.053	0.98	0.96, 1.00	**0.034**
In a relationship (ref. not in a relationship)	348 / 486 (72%)	207 / 284 (73%)	141 / 202 (70%)	0.521	0.86	0.58, 1.28	0.458	0.96	0.87, 1.06	0.462
Born in Switzerland (ref. not born in Switzerland)	355 / 486 (73%)	207 / 284 (73%)	148 / 202 (73%)	>0.999	1.02	0.68, 1.53	0.926	1.01	0.91, 1.11	0.861
Completed tertiary education (ref. no tertiary education)	241 / 486 (50%)	140 / 284 (49%)	101 / 202 (50%)	0.951	1.03	0.72, 1.48	0.878	1.02	0.94, 1.11	0.624
Professionally active (ref. not professionally active)	361 / 486 (74%)	206 / 284 (73%)	155 / 202 (77%)	0.348	1.25	0.82, 1.90	0.298	1.02	0.91, 1.15	0.681
Low household income (ref. mid or high household income)	67 / 390 (17%)	40 / 230 (17%)	27 / 160 (17%)	>0.999	0.99	0.59, 1.66	0.968	0.99	0.87, 1.13	0.926
Limited social support (OSSS-3) (ref. strong social support)	68 / 463 (15%)	27 / 270 (10%)	41 / 193 (21%)	**0.001**	2.45	1.45, 4.12	**<0.001**	1.25	1.10, 1.42	**<0.001**
Pre-existing mental condition (ref. no pre-existing mental condition)	11 / 486 (2.3%)	3 / 284 (1.1%)	8 / 202 (4.0%)	0.070	3.86	1.01, 14.8	**0.049**	1.30	0.97, 1.75	0.077
Pre-existing physical condition (ref. no pre-existing physical condition)	128 / 486 (26%)	68 / 284 (24%)	60 / 202 (30%)	0.188	1.34	0.89, 2.02	0.157	1.08	0.98, 1.19	0.121

aOR: adjusted odds ratio; OR: odds ratio; IQR: interquartile range; OSSS-3: Oslo Social Support Scale – 3-item; SD: standard deviation; ref.: reference category.

* Data are presented as n / N (%), mean (SD) or median (IQR).

** P-values were calculated using Pearson's Chi-squared test or Welch's two-sample t-test, as appropriate.

*** P-values were calculated for logistic regression coefficients.

$^{\#}$ Adjusted for sex, age, education, social support, pre-existing mental condition and pre-existing physical condition.

$^{\#\#}$ Odds ratio for age is presented for each five-year increase.

ing their capacity for providing optimal care to their recipients.

This study screened mental distress using the GHQ-12, scored with the Likert method (0–1–2–3), considering a threshold of 12 points. This scoring method is more reliable for screening depressive disorders than the binary

Table 3:
Association of factors related to the care recipient and the act of caregiving with mental distress in a subsample of 486 informal caregivers who completed an additional questionnaire about caregiving.

		Descriptive				**Unadjusted**			**Adjusted** [#]		
		Overall, N = 486*	**No mental distress, N = 284***	**Mental distress, N = 202***		**Mental distress vs no distress**			**Mental distress vs no distress**		
		n / N (%)	**n / N (%)**	**n / N (%)**	**p-value****	**OR**	**95% CI**	**p-value*****	**aOR**	**95% CI**	**p-value*****
Cared for ≥2 care recipients (ref. 1 care recipient)		164 / 486 (34%)	88 / 284 (31%)	76 / 202 (38%)	0.153	1.34	0.92, 1.97	0.128	1.05	0.96, 1.15	0.270
Older care recipient (≥80 years, ref. younger care recipient)		307 / 485 (63%)	184 / 284 (65%)	123 / 201 (61%)	0.476	0.86	0.59, 1.26	0.441	1.01	0.92, 1.10	0.907
Condition of the care recipient	*Ageing*	380 / 486 (78%)	224 / 284 (79%)	156 / 202 (77%)	0.748	0.91	0.59, 1.41	0.665	0.99	0.89, 1.10	0.823
	Physical health condition	188 / 486 (39%)	107 / 284 (38%)	81 / 202 (40%)	0.656	1.11	0.76, 1.60	0.589	1.03	0.94, 1.13	0.491
	Mental health condition	46 / 486 (9.5%)	18 / 284 (6.3%)	28 / 202 (14%)	**0.008**	2.38	1.27, 4.44	**0.007**	1.21	1.05, 1.41	**0.011**
Relationship between the care recipient and caregiver					0.271						
	Spouse or partner	32 / 486 (6.6%)	23 / 284 (8.1%)	9 / 202 (4.5%)		—	—		—	—	
	First degree relative	311 / 486 (64%)	180 / 284 (63%)	131 / 202 (65%)		1.86	0.83, 4.16	0.130	1.13	0.94, 1.35	0.198
	Other	143 / 486 (29%)	81 / 284 (29%)	62 / 202 (31%)		1.96	0.84, 4.53	0.118	1.13	0.93, 1.37	0.213
Duration of the care relation					0.651						
	Less than a year	120 / 485 (25%)	66 / 284 (23%)	54 / 201 (27%)		—	—		—	—	
	One to five years	239 / 485 (49%)	142 / 284 (50%)	97 / 201 (48%)		0.84	0.54, 1.30	0.431	0.99	0.89, 1.10	0.855
	More than five years	126 / 485 (26%)	76 / 284 (27%)	50 / 201 (25%)		0.81	0.49, 1.34	0.407	0.97	0.86, 1.10	0.654
Frequency of care					0.850						
	Daily or almost daily	72 / 440 (16%)	42 / 256 (16%)	30 / 184 (16%)		—	—		—	—	
	3–5 days a week	46 / 440 (10%)	24 / 256 (9.4%)	22 / 184 (12%)		1.16	0.57, 2.35	0.678	1.01	0.85, 1.20	0.940
	1–2 days a week	196 / 440 (45%)	115 / 256 (45%)	81 / 184 (44%)		0.92	0.55, 1.56	0.762	0.98	0.86, 1.11	0.699
	A few times a month or less	126 / 440 (29%)	75 / 256 (29%)	51 / 184 (28%)		0.88	0.50, 1.54	0.649	0.96	0.83, 1.10	0.513
Distance between the care recipient and caregiver					0.161						
	Same home or building	104 / 472 (22%)	68 / 278 (24%)	36 / 194 (19%)		—	—		—	—	
	10 km or less	272 / 472 (58%)	160 / 278 (58%)	112 / 194 (58%)		1.35	0.84, 2.16	0.212	1.06	0.95, 1.19	0.268
	More than 10 km	96 / 472 (20%)	50 / 278 (18%)	46 / 194 (24%)		1.81	1.03, 3.20	**0.040**	1.17	1.02, 1.34	**0.021**
Type of care	*Social support (ref. no social support)*	323 / 486 (66%)	186 / 284 (65%)	137 / 202 (68%)	0.661	1.11	0.76, 1.63	0.592	1.02	0.93, 1.12	0.622
	Help with instrumental activities of daily living (IADL, ref. no help with IADL) [##]	468 / 485 (96%)	274 / 284 (96%)	194 / 201 (97%)	>0.999	1.01	0.38, 2.71	0.983	0.98	0.78, 1.25	0.895
	Help with activities of daily living (ADL, ref. no help with ADL) [###]	53 / 485 (11%)	26 / 284 (9.2%)	27 / 201 (13%)	0.180	1.55	0.87, 2.74	0.136	1.15	1.00, 1.32	0.050
Other support from formal or informal networks, including other caregivers (ref. no other support from formal or informal networks)		380 / 485 (78%)	232 / 284 (82%)	148 / 201 (74%)	**0.044**	0.63	0.40, 0.97	**0.035**	0.91	0.82, 1.01	0.089

aOR: adjusted odds ratio; IQR: interquartile range; OR: odds ratio; ref.: reference category; SD: standard deviation.

* Data are presented as n / N (%), mean (SD) or median (IQR).

** P-values were calculated using Pearson's Chi-squared test or Welch's two-sample t-test, as appropriate.

*** P-values were calculated for logistic regression coefficients.

[#] Adjusted for sex, age, education, social support, pre-existing mental condition and pre-existing physical condition.

[##] Instrumental activities of daily living (IADL) consist of tasks allowing an individual to live independently and include using the telephone, managing medications, preparing meals, managing money and bills, shopping for groceries and necessities, cleaning and maintaining the house and using transportation (e.g. using public transport).

[###] Activities of daily living (ADL) consist of basic self-care tasks and include bathing and showering, maintaining personal hygiene, dressing, toileting, transferring (e.g. moving from the bed to a chair), controlling continence and feeding.

method, where responses are scored as 0–0–1–1 [48], but results in a higher prevalence of mental distress (38% vs 20% using the binary method) by including individuals with milder symptoms of distress. Nonetheless, the high prevalence of mental distress underscores the difficult times encountered during the study period due to the disruptions caused by the health crisis.

Implications for public health policies and research

This study identified modifiable risk factors for distress in caregivers during a pandemic. In the event of a future pandemic or any events leading to disruption in healthcare systems, measures should be implemented to ensure that caregivers receive appropriate social support, including from formal and informal support networks. We also highlighted a need for rapidly implementable solutions when regular caregivers temporarily cannot provide care due to unforeseen personal or societal circumstances, including developing contingency plans, such as identifying backup caregivers, arranging temporary home nursing care or utilising temporary placement facilities. These measures would benefit both caregivers, who have particular needs, and their care recipients through continuity of care.

Mental health improved in the general population after the early stages of the pandemic [49]. However, the trajectory of caregiver mental health during the subsequent stages of the pandemic remains unknown, making it challenging to discern whether the impact of the pandemic is transient or long-lasting in this population. Longitudinal investigations are warranted to follow the evolution of informal caregivers' well-being and mental health and provide insights into the possible lasting consequences of this global health crisis.

Strengths and limitations

This study had several strengths, including comprehensive data regarding sociodemographic status, mental health and caregiving responsibilities during the pandemic, derived from a cohort primarily composed of individuals randomly selected from the general population. While previous studies have mainly focused on specific populations of caregivers and care recipients, often suffering from severe conditions such as autism or dementia, this study included a wide range of caregivers and care recipients and thus might be more representative of real-life caregiving. Indeed, this approach allows the identification of shared characteristics and challenges they might face collectively.

Several limitations should be acknowledged. Including both a population-based sample and a sample of essential workers may have limited the representativeness of our findings. However, the results were similar when the analysis was restricted to participants from the population-based sample. Self-selection bias may have occurred at different levels: older, better-educated, and more health-conscious people are more likely to enrol in research studies and maintain participation over time, as commonly observed in cohort studies [50]. Caregivers may have been both more and less likely to answer the caregiving questionnaire, depending on their willingness to share their experiences and their exhaustion level. Unfortunately, the absence of pre-pandemic data prevented a direct comparison of mental health status and caregiving responsibilities change. Mental distress was measured when public health measures were progressively being eased in Switzerland, and its prevalence may have been lower than during the height of the pandemic but higher than in the post-pandemic period. Finally, caregiving responsibilities are influenced by societal, political, health and care settings, and these results should be generalised cautiously.

Table 4:
Association of factors related to the COVID-19 pandemic with mental distress in a subsample of 486 informal caregivers who completed an additional questionnaire about caregiving.

	Descriptive				Unadjusted			Adjusted****		
	Overall, N = 486[1]	No mental distress, N = 284*	Mental distress, N = 202*		Mental distress vs no distress			Mental distress vs no distress		
	n / N (%)	n / N (%)	n / N (%)	p-value**	OR	95% CI	p-value***	aOR	95% CI	p-value***
Previous SARS-CoV-2 infection (ref. no previous SARS-CoV-2 infection)	144 / 486 (30%)	81 / 284 (29%)	63 / 202 (31%)	0.593	1.14	0.77, 1.69	0.526	1.04	0.95, 1.14	0.422
Increased caregiving burden (ref. stable or decreased caregiving burden)	229 / 485 (47%)	134 / 284 (47%)	95 / 201 (47%)	>0.999	1.00	0.69, 1.43	0.982	0.99	0.91, 1.08	0.840
Professional adaptations due to caregiver duties (ref. no professional adaptations)	48 / 376 (13%)	20 / 216 (9.3%)	28 / 160 (18%)	**0.027**	1.86	0.98, 3.52	0.056	1.14	0.98, 1.34	0.086
Feeling more isolated in one's caregiving role since the pandemic onset (ref. not feeling more isolated in one's caregiving role)	114 / 485 (24%)	49 / 284 (17%)	65 / 201 (32%)	**<0.001**	2.29	1.49, 3.51	**<0.001**	1.20	1.08, 1.32	**<0.001**
Worrying about the inability to care due to COVID-19 or quarantine (ref. not worrying about the inability to care)	297 / 485 (61%)	155 / 284 (55%)	142 / 201 (71%)	**<0.001**	2.01	1.37, 2.96	**<0.001**	1.18	1.08, 1.29	**<0.001**
Experiencing decreased availability of healthcare professionals (ref. not experiencing decreased availability of healthcare professionals)	311 / 486 (64%)	176 / 284 (62%)	135 / 202 (67%)	0.315	1.68	1.16, 2.43	**0.006**	1.11	1.02, 1.22	**0.017**

aOR: adjusted odds ratio; COVID-19: coronavirus disease 2019; OR: odds ratio; ref: reference category; SARS-CoV-2: severe acute respiratory syndrome-coronavirus 2

* Data are presented as n / N (%), mean (SD) or median (IQR).

** P-values were calculated using Pearson's Chi-squared test or Welch's two-sample *t*-test, as appropriate.

*** P-values were calculated for logistic regression coefficients.

**** Adjusted for sex, age, education, social support, pre-existing mental condition and pre-existing physical condition.

Conclusion

Sixteen months after the onset of the COVID-19 pandemic, most caregivers reported an increase in their caregiving burden. Compared to non-caregivers, they faced additional mental health challenges, which could be attributed to increased caregiving responsibilities and reduced support. Public health policies should ensure caregivers receive additional support and resources, such as social support, and continuity of care from formal caregivers, and include rapidly implementable solutions to maintain caregiving continuity, especially during pandemics.

Data availability

Data will be shared upon reasonable request.

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Appendix

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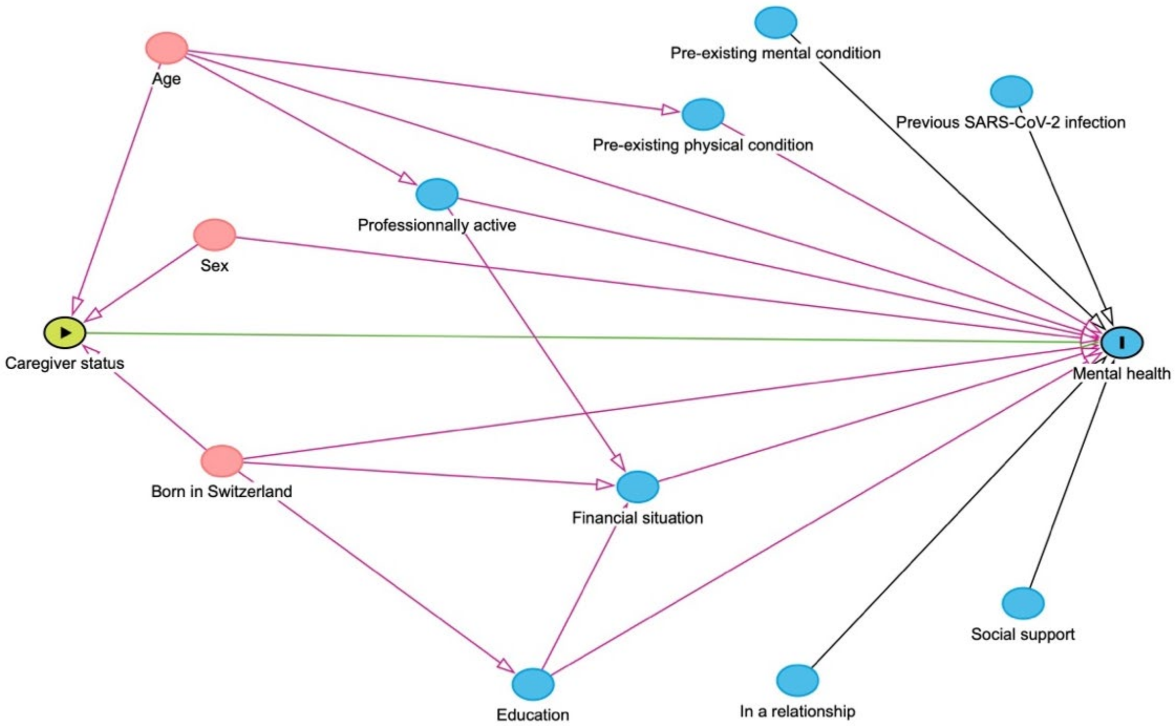
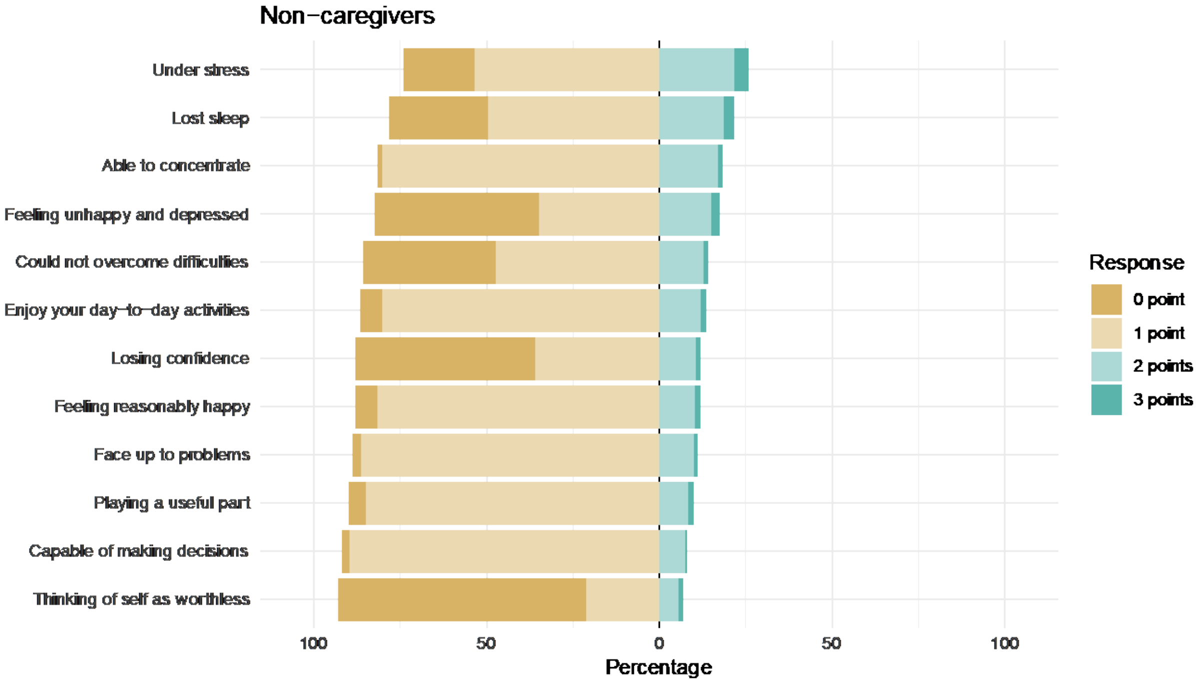
Supplementary Figures

Supplementary Figure S1. Directed acyclic graph (DAG) for the relationship between caregiver status and mental health



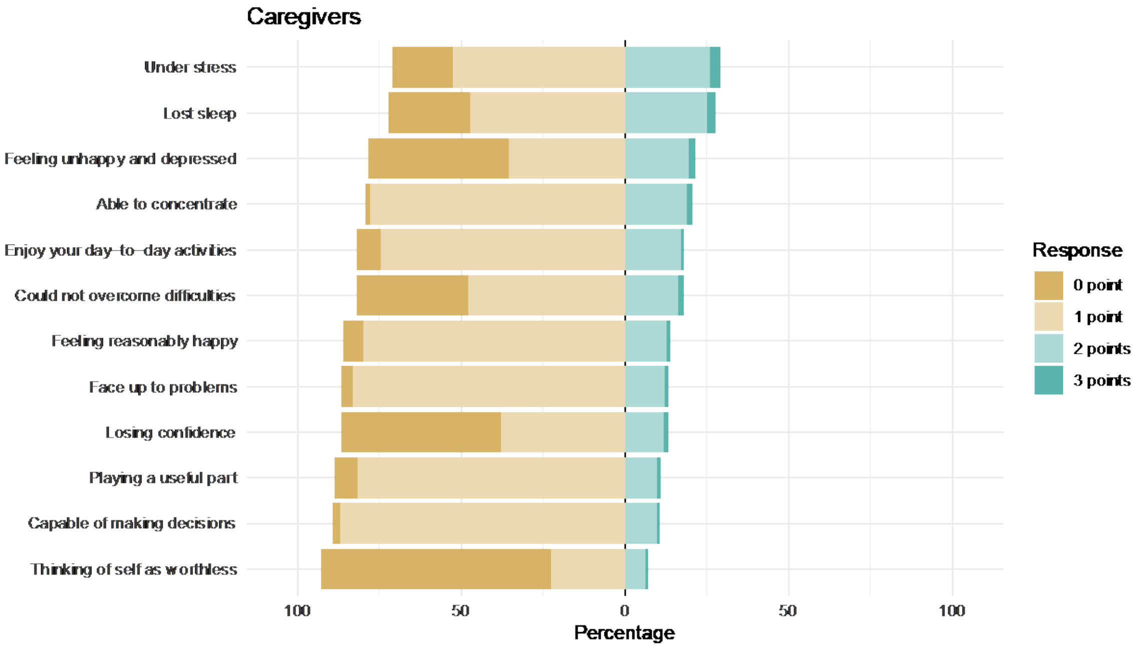
Legends: green node with a triangle = exposure, blue node with a line = outcome, blue node = ancestor of the outcome, red node = ancestor of exposure and outcome, green path = causal path, purple path = biasing path, black path = other path.

Supplementary Figure S2. Likert plot of the response to each item of the GHQ-12 score in non-caregivers



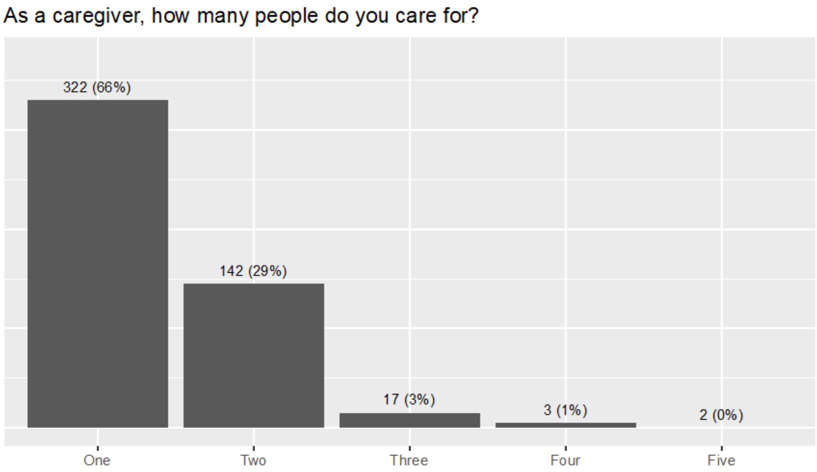
Fewer points indicate a usual or better than usual feeling (0 or 1 point, yellow-brown colour) for a given item. Conversely, more points indicate a worse or much worse feeling than usual (2 or 3 points, blue-green colour). Overall, a smaller score indicates better mental health. The items are ranked in descending order of response, i.e., the top items are those in which the participants are doing worst.

Supplementary Figure S3. Likert plot of the response to each item of the GHQ-12 score in caregivers

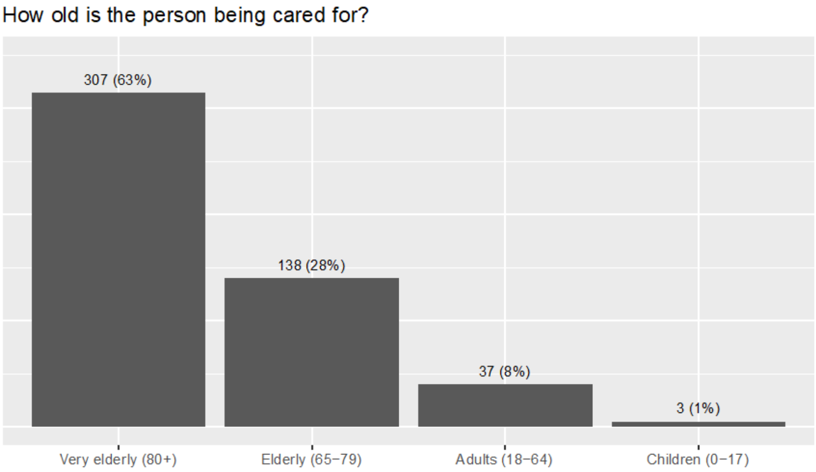


Fewer points indicate a usual or better than usual feeling (0 or 1 point, yellow-brown colour) for a given item. Conversely, more points indicate a worse or much worse feeling than usual (2 or 3 points, blue-green colour). Overall, a smaller score indicates better mental health. The items are ranked in descending order of response, i.e., the top items are those in which the participants are doing worst.

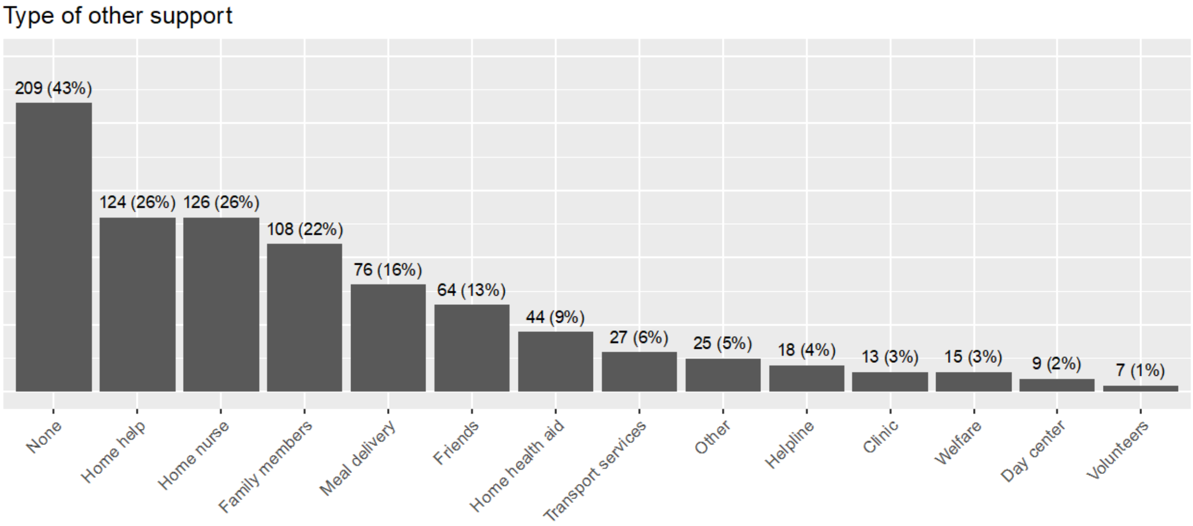
Supplementary Figure S4. Number of care recipients per caregiver



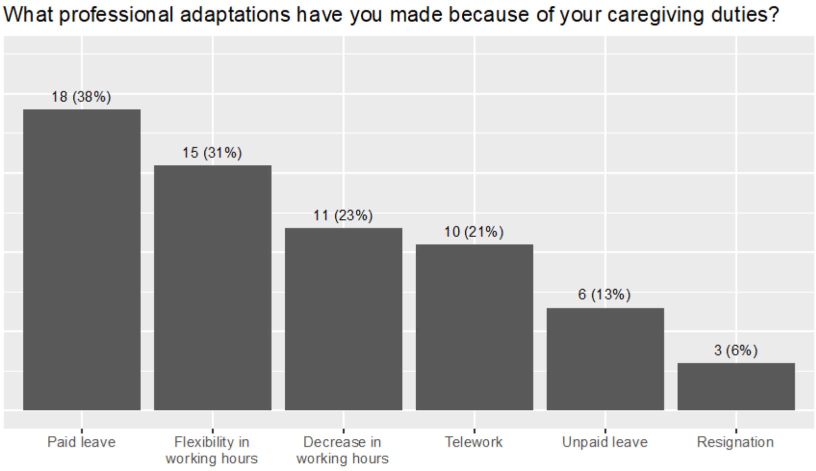
Supplementary Figure S5. Age distribution of care recipients



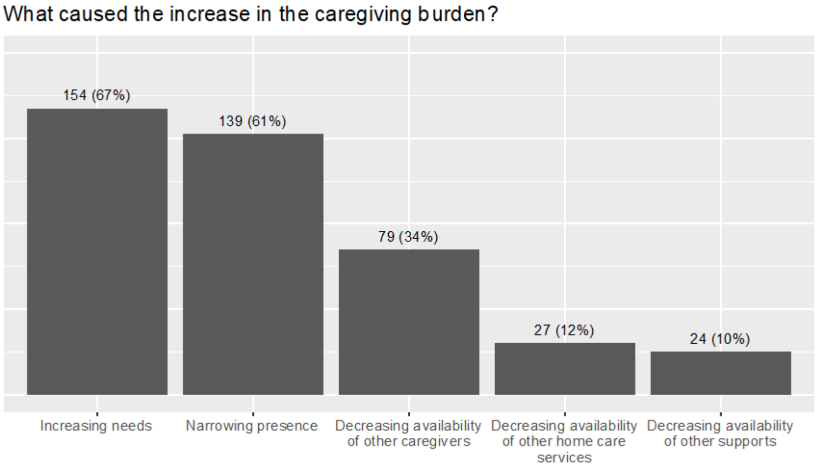
Supplementary Figure S6. Type of formal and informal support in providing care to the care recipient



Supplementary Figure S7. Type of professional adaptation among the 48 caregivers who reported having made a professional adaptation in connection with their caregiving status



Supplementary Figure S8. Causes of increased caregiving burden



Supplementary Tables

Supplementary Table S1. Data sources, ranges/possible answers and additional definitions

Variable	Questionnaire/data source	Range / possible answers	Definition
Female sex	Inclusion questionnaire	True, false	
Age	Inclusion questionnaire	18-100	
In a relationship	Inclusion questionnaire	True, false	
Born in Switzerland	Inclusion questionnaire	True, false	
Education	Inclusion questionnaire	Primary, secondary, tertiary	Classified according to the highest level of education achieved. Primary education was defined as mandatory schooling; secondary as either professional or specialized maturity (general culture and business schools) gymnasial maturity, or vocational education (certified, non-certified and advanced); tertiary as universities, universities of applied sciences, and polytechnic schools or higher. No participant reported having received no education.
Professionnaly active	Inclusion questionnaire	True, false	
Household income	Inclusion questionnaire	Low, mid, high	Classified as low (below the first quartile), medium (between the first and third quartiles) or high (above the third quartile) based on self-reported household income and household composition, and according to household income statistics for the same household composition categories within the canton of Geneva
Household size	Inclusion questionnaire	One, two, three or more	
Limited social support	Well-being and mental health questionnaire	True, false	Defined as a score ≤8 on the 3-item Oslo social support scale (OSSS-3)
Pre-existing physical disease or disability	Inclusion questionnaire	True, false	Defined as any chronic disease that may require regular care or treatment (e.g., cardiovascular, respiratory, endocrine, infectious, inflammatory, musculoskeletal, auto-immune, neoplasia)
Pre-existing mental disease or disability	Inclusion questionnaire	True, false	Defined as any mood, anxiety, psychotic disorders, addictions, or any other mental disorders
Self-perceived health status	General and mental health questionnaire	Good or very good, average, poor or very poor	

Previous SARS-CoV-2 infection	Inclusion questionnaire, regular follow-up questionnaires, regional public-health database	True. false	Defined as either (1) a positive serological, antigenic, or PCR test self-reported at inclusion or in a follow-up questionnaire, (2) a positive serology indicating natural infection (presence of anti-nucleocapsid antibodies) at baseline or follow-up, or (3) a positive PCR test according to a database established by regional public health authorities before June 1, 2021. The methods of blood sampling and serological analysis for the various anti-SARS-CoV-2 antibodies carried out in Specchio-COVID19 serosurveys were detailed in previous studies. [1-7]
Self-perceived mental health status	General and mental health questionnaire	Good or very good, average, poor or very poor	
Well-being (WHO-5 scale)	Well-being and mental health questionnaire	0-100	Assessed using the World Health Organization 5 items (WHO-5) well-being index, a self-reported questionnaire with five items assessing vitality, mood, and general interest. Scores range from 0 (worst well-being) to 100 (best well-being). [8]
Well-being (WHO-5 scale with 28 and 50 points cutoffs)	Well-being and mental health questionnaire	Wellbeing, poor well-being, depression	Wellbeing was defined as a score >50 points on the WHO-5 scale, poor as ≤50 and depression as ≤28. [8]
Loneliness (UCLA-3)	Well-being and mental health questionnaire	3-9	Measured using the UCLA loneliness scale, consisting of three questions rated on a 3-point Likert scale (total score: 3-9, with higher scores indicating higher loneliness levels). Loneliness was defined as a score ≥6.
Mental distress (GHQ-12 score)	General and mental health questionnaire	0-36	Measured using the 12-item general health (GHQ-12) score, an internationally validated scale comprising 12 mental health questions (e.g., concentration, sleep loss, stress, confidence), including six positively and six negatively worded questions. Each item is scored on a four-point Likert system ranging from zero to three points. The maximum total score is 36 points, and a higher score indicates greater distress.
Mental distress (GHQ-12 with 12-point cutoff)	General health questionnaire	True, false	Defined as ≥12 points on the GHQ-12 score [9, 10]
Cared for ≥2 care recipients	Caregiving questionnaire	True, false	
Older care recipient (≥80 years old)	Caregiving questionnaire	True, false	

Condition of the care recipient: ageing	Caregiving questionnaire	True, false	Defined as answering "Ageing" to the question "What are the causes of autonomy loss of the care recipient?"
Condition of the care recipient: somatic disease or disability	Caregiving questionnaire	True, false	Defined as answering "Physical disease" or "Physical handicap" to the question "What are the causes of autonomy loss of the care recipient?"
Condition of the care recipient: mental disease or disability	Caregiving questionnaire	True, false	Defined as answering "Mental disease" or "Mental handicap" to the question "What are the causes of autonomy loss of the care recipient?"
Relationship between the care recipient and caregiver	Caregiving questionnaire	Spouse or partner, first-degree relative, other	Categorized as spouses or partners, first-degree relative (Mother/father, daughter/son, sister/brother), or other (mother/father-in-law, grandmother/grandfather, aunt/uncle, granddaughter /grandson, friend, neighbor)
Duration of the care relation	Caregiving questionnaire	Less than a year, one to five years, more than five years	
Frequency of care	Caregiving questionnaire	Daily or almost daily, 3-5 days a week, 1-2 days a week, a few times a month or less	
Distance between the care recipient and caregiver	Caregiving questionnaire	Same home or building, less than 10km, more than 10km	
Type of care: social support	Caregiving questionnaire	True, false	
Type of care: IADL (instrumental activities of daily living)	Caregiving questionnaire	True, false	Defined as any help with any instrumental activity of daily living (IADL) such as meal preparation, managing finances, housekeeping, transportation, medication management, shopping for groceries or other essential items
Type of care: ADL (activities of daily living)	Caregiving questionnaire	True, false	Defined as any help with an activity of daily living (ADL) such as bathing or showering, dressing, eating, toileting (using the toilet), transferring (moving from one position to another, such as from bed to chair), continence management (controlling bladder and bowel functions)
Other support from formal or informal networks, including other caregivers	Caregiving questionnaire	True, false	Defined as help from a third party such as home nursing, therapeutic day centre, home meal delivery, home volunteers, transportation services, social assistance, assistance from family members, or assistance from friends or neighbors.

Increased caregiving burden	Caregiving questionnaire	True, false	Defined as the answer “my number of hours dedicated to caregiving increased” to the question: "To what extent has the pandemic led to a change in the number of hours of care or assistance you usually provide?"
Professional adaptations due to caregiver duties		True, false	Defined as a positive answer to the question “Because of your caregiving duties, have you made at least one special arrangement concerning your paid employment (leave, cessation of activity, etc.) since the start of the pandemic?"
Felt more isolated in one’s caregiving role	Caregiving questionnaire	True, false	Defined as the answers "strongly agree" or "agree" (among the answers: "strongly agree", "agree", "neither agree nor disagree", "disagree", "strongly disagree") to the statement "I feel more isolated and alone in my role as a caregiver since the start of the pandemic"
Worried about the inability to care due to COVID-19 or quarantine	Caregiving questionnaire	True, false	Defined as the answers "strongly agree" or "agree" (among the answers: "strongly agree", "agree", "neither agree nor disagree", "disagree", "strongly disagree") to the statement "I worry about how the people I care for will fare if I become isolated or ill from COVID-19."
Experienced decreased availability of healthcare professionals	Caregiving questionnaire	True, false	Defined as the answers "significant decrease" or "slight decrease" (among the answer options: "significant decrease," "slight decrease," "stable," "slight increase," and "significant increase") to either of the following questions: "To what extent has the pandemic led to an increase or decrease in the availability of healthcare professionals in the event of an emergency?" or "To what extent has the pandemic led to an increase or decrease in the possibility of exchanging information with healthcare professionals?"

Supplementary Table S2. Sensitivity analysis of the prevalence of distress in a subsample of participants exclusively drawn from a random sample of the general population (i.e., excluding a subsample of mobilized workers)

	Overall **N = 3597**[1]	**Non-caregivers** **N = 2893**[1]	**Caregivers** **N = 704**[1]	
	n / N (%)	n / N (%)	n / N (%)	p-value[2]
General Health Questionnaire 12-items (GHQ-12), median (IQR)	10 (8, 13)	10 (8, 12)	10 (8, 14)	**<0.001**
Distress (GHQ-12≥12)	1323 / 3597 (37%)	1032 / 2893 (36%)	291 / 704 (41%)	**0.006**
Distress (GHQ-12≥12), adjusted prevalence[3], 95% CI		35% (34-37)	41% (38-45)	**0.003**

[1] Data are presented as n / N (%) or median (IQR).

[2] P-values were calculated using Pearson's Chi-squared test, Welch Two Sample t-test or Wilcoxon rank sum test.

[3] Adjusted prevalences are expressed as percentages and were calculated as means of each level of distress status averaged across each level of covariates including sex, age, and birth country.

Abbreviations: GHQ-12 = General Health Questionnaire 12-items

Supplementary Table S3. Demographics, physical and mental health in caregivers who answered and did not answer an additional questionnaire about caregiving.

	Overall N = 1086[1]	**Did not answer caregiving questionnaire N = 600**[1]	**Answered caregiving questionnaire N = 486**[1]	
	n / N (%)	n / N (%)	n / N (%)	p-value[2]
Sociodemographic characteristics				
Female sex	657 / 1086 (60%)	346 / 600 (58%)	311 / 486 (64%)	**0.040**
Age (years), mean (SD)	52 (12)	50 (12)	54 (11)	**<0.001**
In a relationship	787 / 1085 (73%)	439 / 599 (73%)	348 / 486 (72%)	0.583
Born in Switzerland	761 / 1086 (70%)	406 / 600 (68%)	355 / 486 (73%)	0.063
Education				0.655
Primary	251 / 1086 (23%)	140 / 600 (23%)	111 / 486 (23%)	
Secondary	133 / 1086 (12%)	78 / 600 (13%)	55 / 486 (11%)	
Tertiary	702 / 1086 (65%)	382 / 600 (64%)	320 / 486 (66%)	
Professionally active	824 / 1085 (76%)	463 / 599 (77%)	361 / 486 (74%)	0.278
Household income				0.344
Low	167 / 876 (19%)	100 / 486 (21%)	67 / 390 (17%)	
Medium	587 / 876 (67%)	316 / 486 (65%)	271 / 390 (69%)	
High	122 / 876 (14%)	70 / 486 (14%)	52 / 390 (13%)	
Limited social support (OSSS-3)	146 / 944 (15%)	78 / 481 (16%)	68 / 463 (15%)	0.576
Pre-existing physical condition	257 / 1086 (24%)	129 / 600 (22%)	128 / 486 (26%)	0.073
Pre-existing mental condition	24 / 1086 (2.2%)	13 / 600 (2.2%)	11 / 486 (2.3%)	>0.999
Physical health				
Self-perceived health status				0.123
Good or very good	958 / 1086 (88%)	540 / 600 (90%)	418 / 486 (86%)	
Average	112 / 1086 (10%)	53 / 600 (8.8%)	59 / 486 (12%)	
Poor or very poor	16 / 1086 (1.5%)	7 / 600 (1.2%)	9 / 486 (1.9%)	
Previous SARS-CoV-2 infection	328 / 1086 (30%)	184 / 600 (31%)	144 / 486 (30%)	0.761
Mental health[3]				
Self-perceived morale status				0.859
Good or very good	843 / 1086 (78%)	462 / 600 (77%)	381 / 486 (78%)	
Average	208 / 1086 (19%)	118 / 600 (20%)	90 / 486 (19%)	
Poor or very poor	35 / 1086 (3.2%)	20 / 600 (3.3%)	15 / 486 (3.1%)	
Well-being index (WHO-5), median (IQR)	64 (48, 80)	64 (44, 80)	68 (48, 78)	0.398

Well-being index (WHO-5)				0.262
Well-being (WHO-5 >50)	682 / 944 (72%)	339 / 481 (70%)	343 / 463 (74%)	
Poor well-being (WHO-5 29-50)	177 / 944 (19%)	100 / 481 (21%)	77 / 463 (17%)	
Depression (WHO-5 ≤28)	85 / 944 (9.0%)	42 / 481 (8.7%)	43 / 463 (9.3%)	
Loneliness (UCLA-3)	120 / 944 (13%)	68 / 481 (14%)	52 / 463 (11%)	0.214
Perceived stress (PSS-10), median (IQR)	23 (18, 28)	23 (18, 29)	23 (19, 28)	0.715
Mental distress (GHQ-12), median (IQR)	10 (8, 14)	10 (8, 14)	11 (8, 14)	0.552
Mental distress (GHQ-12≥12)	447 / 1086 (41%)	245 / 600 (41%)	202 / 486 (42%)	0.856

[1] Data are presented as n / N (%) mean (SD) or median (IQR)

[2] P-values were calculated using Pearson's Chi-squared test Welch Two Sample t-test or Wilcoxon rank sum test

[3] Secondary mental health covariates and outcomes (i.e., social support [OSSS-3], well-being index [WHO-5], loneliness [UCLA-3], and perceived stress [PSS-10]) were assessed in an optional well-being and mental health questionnaire and were missing for 142 participants who did not answer the latter.

Abbreviations: OSSS-3 = Oslo Social Support Scale 3 items, WHO-5 = World Health Organisation five items well-being index (WHO-5), UCLA-3 = UCLA loneliness scale version 3, PSS-10 = Perceived Stress Scale 10-items, GHQ-12 = General Health Questionnaire 12-items

Supplementary Table S4. First and second care recipient-related variables in 164 caregivers who reported caring for more than one care recipient.

	First care recipient N = 164[1]	**Second care recipient N = 164**[1]	
	n / N (%)	n / N (%)	p-value[2]
Relation			0.151
Spouse or partner	2 / 164 (1.2%)	1 / 164 (0.6%)	
First degree relative	117 / 164 (71%)	102 / 164 (62%)	
Other	45 / 164 (27%)	61 / 164 (37%)	
Care-recipient condition			
Ageing	128 / 164 (78%)	129 / 164 (79%)	>0.999
Physical condition	67 / 164 (41%)	55 / 164 (34%)	0.209
Mental condition	19 / 164 (12%)	20 / 164 (12%)	>0.999
Frequency of care			0.181
Daily	16 / 154 (10%)	13 / 158 (8.2%)	
3-5 days a week	19 / 154 (12%)	12 / 158 (7.6%)	
1-2 days a week	79 / 154 (51%)	76 / 158 (48%)	
Few times a month or less	40 / 154 (26%)	57 / 158 (36%)	
Distance			0.776
More than 10km	25 / 159 (16%)	21 / 153 (14%)	
Less than 10km	106 / 159 (67%)	101 / 153 (66%)	
Respondent home or same building	28 / 159 (18%)	31 / 153 (20%)	
Elderly care recipient (>=65 y.o.)	97 / 164 (59%)	88 / 164 (54%)	0.373
Duration			0.356
Less than a year	50 / 164 (30%)	61 / 164 (37%)	
One to five years	81 / 164 (49%)	69 / 164 (42%)	
More than five years	33 / 164 (20%)	34 / 164 (21%)	
Type of care			
Help with activities of daily living (ADL)	10 / 164 (6.1%)	10 / 164 (6.1%)	>0.999
Help with instrumental activities of daily living (IADL)	158 / 164 (96%)	150 / 164 (91%)	0.106
Social support	110 / 164 (67%)	99 / 164 (60%)	0.251
Other support from any formal or informal networks, including other caregivers	127 / 164 (77%)	127 / 164 (77%)	>0.999
Increased caregiving burden since the pandemic	90 / 164 (55%)	80 / 164 (49%)	0.320

[1] Data is represented as n / N (%)

[2] P-values were calculated using Pearson's Chi-squared test

[4] Instrumental activities of daily living (IADL) consist of tasks allowing an individual to live independently and include using the telephone, managing medications, preparing meals, managing money and bills, shopping for groceries and necessities, cleaning and maintaining the house, using transportation (e.g., using public transport)

[5] Activities of daily living (ADL) consist basic of self-care tasks and include bathing and showering, maintaining personal hygiene, dressing, toileting, transferring (e.g., move from bed to chair), controlling continence and feeding.

Abbreviations: IADL = instrumental activities of daily living, ADL = activities of daily living

Supplementary Table S5. Sensitivity analysis of the association of factors related to the caregiver, the care recipient, the act of caregiving, and the COVID-19 pandemic with mental distress in a subsample of 327 informal caregivers drawn from a random sample of the general population

	Descriptive				Unadjusted			Adjusted[4]		
	Overall, N = 486[1]	No mental distress, N = 284[1]	Mental distress, N = 202[1]		Mental distress vs. no distress			Mental distress vs. no distress		
	n / N (%)	n / N (%)	n / N (%)	p-value[2]	OR	95% CI	p-value[3]	aOR	95% CI	p-value[3]
Caregiver-related factors										
Female sex (ref. male sex)	203 / 327 (62%)	113 / 194 (58%)	90 / 133 (68%)	0.108	1.50	0.94, 2.39	0.086	1.09	0.98, 1.22	0.114
Age (per 5 years), mean (SD)	55 (12)	56 (12)	54 (13)	0.051	0.98	0.96, 1.00	**0.049**	1.00	0.99, 1.00	**0.044**
In a relationship (ref. not in a relationship)	228 / 327 (70%)	136 / 194 (70%)	92 / 133 (69%)	0.954	0.96	0.59, 1.55	0.857	1.00	0.89, 1.13	0.942
Born in Switzerland (ref. not born in Switzerland)	245 / 327 (75%)	148 / 194 (76%)	97 / 133 (73%)	0.577	0.84	0.50, 1.39	0.492	0.96	0.85, 1.08	0.493
Completed tertiary education (ref. no tertiary education)	174 / 327 (53%)	102 / 194 (53%)	72 / 133 (54%)	0.869	1.06	0.68, 1.66	0.782	1.02	0.92, 1.13	0.707
Professionally active (ref. not professionally active)	208 / 327 (64%)	119 / 194 (61%)	89 / 133 (67%)	0.361	1.27	0.80, 2.03	0.304	1.05	0.92, 1.19	0.506
Low household income (ref. mid or high household income)	39 / 262 (15%)	21 / 159 (13%)	18 / 103 (17%)	0.441	1.39	0.71, 2.73	0.336	1.07	0.91, 1.26	0.401
Limited social support (OSSS-3) (ref. strong social support)	37 / 311 (12%)	15 / 183 (8.2%)	22 / 128 (17%)	**0.026**	2.30	1.14, 4.66	**0.021**	1.24	1.05, 1.46	**0.013**
Pre-existing mental condition (ref. no pre-existing mental condition)	8 / 327 (2.4%)	3 / 194 (1.5%)	5 / 133 (3.8%)	0.364	2.49	0.58, 10.6	0.219	1.24	0.88, 1.75	0.222
Pre-existing physical condition (ref. no pre-existing physicial condition)	76 / 327 (23%)	43 / 194 (22%)	33 / 133 (25%)	0.672	1.16	0.69, 1.95	0.578	1.05	0.93, 1.20	0.423
Caregiving and care recipient-related factors										
Cared for ≥2 care recipients (ref. 1 care recipient)	97 / 327 (30%)	48 / 194 (25%)	49 / 133 (37%)	**0.026**	1.77	1.10, 2.87	**0.020**	1.13	1.01, 1.27	**0.037**

Older care recipient (≥80 years, ref. younger care recipient)	223 / 326 (68%)	139 / 194 (72%)	84 / 132 (64%)	0.160	0.70	0.44, 1.12	0.140	0.94	0.84, 1.06	0.332
Condition of the care recipient										
Ageing	250 / 327 (76%)	152 / 194 (78%)	98 / 133 (74%)	0.399	0.77	0.46, 1.30	0.330	0.94	0.83, 1.07	0.365
Physical health condition	134 / 327 (41%)	75 / 194 (39%)	59 / 133 (44%)	0.360	1.27	0.81, 1.98	0.304	1.07	0.96, 1.20	0.198
Mental health condition	31 / 327 (9.5%)	11 / 194 (5.7%)	20 / 133 (15%)	**0.008**	2.94	1.36, 6.39	**0.006**	1.28	1.07, 1.54	**0.007**
Relationship between the care recipient and caregiver				0.363						
Spouse or partner	25 / 327 (7.6%)	18 / 194 (9.3%)	7 / 133 (5.3%)		—	—		—	—	
First degree relative	204 / 327 (62%)	117 / 194 (60%)	87 / 133 (65%)		1.91	0.76, 4.80	0.166	1.13	0.91, 1.39	0.267
Other	98 / 327 (30%)	59 / 194 (30%)	39 / 133 (29%)		1.70	0.65, 4.47	0.281	1.09	0.87, 1.36	0.470
Duration of the care relation				0.920						
Less than a year	72 / 326 (22%)	42 / 194 (22%)	30 / 132 (23%)		—	—		—	—	
One to five years	165 / 326 (51%)	100 / 194 (52%)	65 / 132 (49%)		0.91	0.52, 1.60	0.736	1.00	0.88, 1.15	0.955
More than five years	89 / 326 (27%)	52 / 194 (27%)	37 / 132 (28%)		1.00	0.53, 1.87	0.988	1.02	0.88, 1.19	0.766
Frequency of care										
Daily or almost daily	53 / 300 (18%)	31 / 175 (18%)	22 / 125 (18%)		—	—		—	—	
3-5 days a week	33 / 300 (11%)	18 / 175 (10%)	15 / 125 (12%)		1.16	0.50, 2.71	0.724	0.99	0.81, 1.23	0.957
1-2 days a week	131 / 300 (44%)	77 / 175 (44%)	54 / 125 (43%)		0.97	0.52, 1.82	0.926	0.99	0.85, 1.15	0.865
A few times a month or less	83 / 300 (28%)	49 / 175 (28%)	34 / 125 (27%)		0.98	0.49, 1.94	0.949	0.97	0.82, 1.15	0.707
Distance between the care recipient and caregiver				0.215						
Same home or building	78 / 319 (24%)	51 / 190 (27%)	27 / 129 (21%)		—	—		—	—	
10km or less	189 / 319 (59%)	113 / 190 (59%)	76 / 129 (59%)		1.29	0.74, 2.24	0.361	1.05	0.92, 1.20	0.454
More than 10km	52 / 319 (16%)	26 / 190 (14%)	26 / 129 (20%)		1.99	0.97, 4.08	0.060	1.20	1.01, 1.43	**0.034**

Type of care										
Social support (ref. no social support)	216 / 327 (66%)	123 / 194 (63%)	93 / 133 (70%)	0.269	1.34	0.84, 2.16	0.223	1.05	0.94, 1.18	0.398
Help with instrumental activities of daily living (IADL, ref. no help with IADL)[5]	315 / 326 (97%)	188 / 194 (97%)	127 / 132 (96%)	0.977	0.81	0.24, 2.73	0.734	0.96	0.72, 1.30	0.810
Help with activities of daily living (ADL, ref. no help with ADL)[6]	35 / 326 (11%)	19 / 194 (9.8%)	16 / 132 (12%)	0.628	1.27	0.63, 2.58	0.504	1.10	0.92, 1.31	0.280
Other support from formal or informal networks, including other caregivers (ref. No other support from formal or informal networks)	261 / 326 (80%)	159 / 194 (82%)	102 / 132 (77%)	0.369	0.75	0.43, 1.30	0.307	0.96	0.84, 1.10	0.568
COVID-19 pandemic-related factors										
Previous SARS-CoV-2 infection (ref. no previous SARS-CoV-2 infection)	95 / 327 (29%)	54 / 194 (28%)	41 / 133 (31%)	0.644	1.16	0.71, 1.88	0.559	1.05	0.93, 1.18	0.428
Increased caregiving burden (ref. stable or decreased caregiving burden)	151 / 326 (46%)	89 / 194 (46%)	62 / 132 (47%)	0.935	1.03	0.66, 1.61	0.885	1.00	0.90, 1.11	0.997
Professional adaptations due to caregiver duties (ref. no professional adaptations)	28 / 225 (12%)	12 / 129 (9.3%)	16 / 96 (17%)	0.147	1.67	0.71, 3.96	0.239	1.13	0.92, 1.40	0.253
Feeling more isolated in one’s caregiving role since the pandemic onset (ref. not feeling more isolated in one’s caregiving role)	79 / 326 (24%)	35 / 194 (18%)	44 / 132 (33%)	**0.002**	2.27	1.35, 3.80	**0.002**	1.18	1.05, 1.34	**0.007**
Worrying about the inability to care due to COVID-19 or quarantine (ref. not worrying about the inability to care)	196 / 326 (60%)	106 / 194 (55%)	90 / 132 (68%)	**0.019**	1.80	1.13, 2.86	**0.014**	1.16	1.04, 1.29	**0.009**
Experiencing decreased availability of healthcare professionals (ref. not experiencing decreased availability of healthcare professionals)	112 / 326 (34%)	59 / 194 (30%)	53 / 132 (40%)	0.089	1.55	0.97, 2.47	0.064	1.11	0.99, 1.24	0.067

[1] Data are presented as n / N (%), mean (SD) or median (IQR). Age is shown as mean (SD), and mental health scores as median (IQR).

[2] P-values were calculated using Pearson's Chi-squared test or Welch Two Sample t-test as appropriate

[3] P-values were calculated for logistic regression coefficients

[4] Adjusted for sex, age, education, social support, pre-existing mental condition and pre-existing physical condition

[5] Instrumental activities of daily living (IADL) consist of tasks allowing an individual to live independently and include using the telephone, managing medications, preparing meals, managing money and bills, shopping for groceries and necessities, cleaning and maintaining the house, using transportation (e.g., using public transport)

[6] Activities of daily living (ADL) consist basic of self-care tasks and include bathing and showering, maintaining personal hygiene, dressing, toileting, transferring (e.g., move from bed to chair), controlling continence and feeding.

Abbreviations = ADL = activities of daily living; aOR = adjusted odds ratio; COVID-19 = coronavirus disease 2019; IADL = instrumental activities of daily living; OR = odds ratio; OSSS-3 = Oslo Social Support Scale 3 items; SARS-CoV-2 = severe acute respiratory syndrome coronavirus 2, ref. = reference category

Supplementary Table S6. Sensitivity analysis of the association of factors related to the care recipient, the act of caregiving, and the COVID-19 pandemic with mental distress in a subsample of 486 informal caregivers using data from the second care recipient in care a caregiver who cared for multiples care recipients.

In case the caregiver cared for two or more people, the data relative to the first reported care recipient was replaced by the data from the second care recipient reported (i.e., care recipient age, care recipient condition, the relationship between the care recipient and caregiver, duration, care frequency, distance, type of care, other support).

	Descriptive				Unadjusted			Adjusted[4]		
	Overall, N = 486[1]	No mental distress, N = 284[1]	Mental distress, N = 202[1]		Mental distress vs. no distress			Mental distress vs. no distress		
	n / N (%)	n / N (%)	n / N (%)	p-value[2]	OR[3]	95% CI[3]	p-value[3]	aOR[3]	95% CI[3]	p-value
Caregiving and care recipient-related factors										
Older care recipient (≥80 years) (*, ref. younger care recipient)	298 / 485 (61%)	176 / 284 (62%)	122 / 201 (61%)	0.850	0.96	0.66, 1.38	0.808	1.03	0.94, 1.13	0.523
Care recipient’s condition										
Ageing (*)	381 / 486 (78%)	226 / 284 (80%)	155 / 202 (77%)	0.523	0.85	0.55, 1.31	0.453	0.98	0.88, 1.09	0.749
Pyhsical condition (*)	176 / 486 (36%)	99 / 284 (35%)	77 / 202 (38%)	0.521	1.15	0.79, 1.68	0.462	1.03	0.94, 1.13	0.523
Mental condition (*)	47 / 486 (9.7%)	21 / 284 (7.4%)	26 / 202 (13%)	0.063	1.85	1.01, 3.40	**0.047**	1.15	0.99, 1.33	0.069
Relationship between the care recipient and caregiver (*)				0.146						
Spouse or partner	31 / 486 (6.4%)	22 / 284 (7.7%)	9 / 202 (4.5%)		—	—		—	—	
First degree relative	296 / 486 (61%)	177 / 284 (62%)	119 / 202 (59%)		1.64	0.73, 3.70	0.230	1.12	0.93, 1.35	0.235
Other	159 / 486 (33%)	85 / 284 (30%)	74 / 202 (37%)		2.13	0.92, 4.92	0.077	1.19	0.98, 1.44	0.083
Duration of the care relation (*)				0.959						
Less than a year	131 / 485 (27%)	77 / 284 (27%)	54 / 201 (27%)		—	—		—	—	
One to five years	227 / 485 (47%)	134 / 284 (47%)	93 / 201 (46%)		0.99	0.64, 1.53	0.960	1.03	0.92, 1.14	0.623
More than five years	127 / 485 (26%)	73 / 284 (26%)	54 / 201 (27%)		1.06	0.64, 1.73	0.832	1.03	0.91, 1.16	0.653

Frequency of care				0.908						
Daily	69 / 444 (16%)	41 / 260 (16%)	28 / 184 (15%)		—	—		—	—	
3-5 days a week	39 / 444 (8.8%)	21 / 260 (8.1%)	18 / 184 (9.8%)		1.20	0.57, 2.55	0.630	1.02	0.85, 1.23	0.819
1-2 days a week	193 / 444 (43%)	112 / 260 (43%)	81 / 184 (44%)		1.05	0.61, 1.79	0.872	1.01	0.89, 1.15	0.885
Few times a month or less	143 / 444 (32%)	86 / 260 (33%)	57 / 184 (31%)		0.94	0.53, 1.66	0.831	0.97	0.85, 1.12	0.689
Distance between the care recipient and caregiver (*)				0.323						
Same home or building	100 / 466 (21%)	64 / 275 (23%)	36 / 191 (19%)		—	—		—	—	
Less than 10km	267 / 466 (57%)	158 / 275 (57%)	109 / 191 (57%)		1.23	0.77, 1.98	0.390	1.05	0.94, 1.17	0.414
More than 10km	99 / 466 (21%)	53 / 275 (19%)	46 / 191 (24%)		1.58	0.90, 2.80	0.113	1.14	0.99, 1.30	0.061
Type of care (*)										
Social support (ref. no social support)	312 / 486 (64%)	180 / 284 (63%)	132 / 202 (65%)	0.727	1.09	0.75, 1.59	0.656	1.03	0.94, 1.13	0.560
Help with instrumental activities of daily living (IADL, ref. no help with IADL)[4]	460 / 485 (95%)	271 / 284 (95%)	189 / 201 (94%)	0.635	0.76	0.34, 1.70	0.499	0.95	0.78, 1.15	0.597
Help with activities of daily living (ADL, ref. no help with ADL)[5]	53 / 485 (11%)	26 / 284 (9.2%)	27 / 201 (13%)	0.180	1.54	0.87, 2.73	0.140	1.13	0.98, 1.30	0.082
Other support from formal or informal networks, including other caregivers (*)	380 / 485 (78%)	229 / 284 (81%)	151 / 201 (75%)	0.180	0.73	0.47, 1.12	0.152	0.95	0.85, 1.06	0.349
COVID-19 pandemic-related factors										
Increased caregiving burden (*,ref. No other support from formal or informal networks)	219 / 485 (45%)	129 / 284 (45%)	90 / 201 (45%)	0.961	0.97	0.67, 1.39	0.858	0.99	0.90, 1.08	0.744

[1] Data are presented as n / N (%), mean (SD) or median (IQR). Age is shown as mean (SD), and mental health scores as median (IQR).

[2] P-values were calculated using Pearson's Chi-squared test or Welch Two Sample t-test as appropriate

[3] P-values were calculated for logistic regression coefficients

[4] Adjusted for sex, age, education, social support, pre-existing mental condition and pre-existing physical condition

[5] Instrumental activities of daily living (IADL) consist of tasks allowing an individual to live independently and include using the telephone, managing medications, preparing meals, managing money and bills, shopping for groceries and necessities, cleaning and maintaining the house, using transportation (e.g., using public transport)

[6] Activities of daily living (ADL) consist basic of self-care tasks and include bathing and showering, maintaining personal hygiene, dressing, toileting, transferring (e.g., move from bed to chair), controlling continence and feeding.

Abbreviations = ADL = activities of daily living; aOR = adjusted odds ratio; COVID-19 = coronavirus disease 2019; IADL = instrumental activities of daily living, OR = odds ratio, ref. = reference category

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