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Caregivers of people with dementia and mental health during COVID-19: findings from a cross-sectional study

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Abstract

Background: There is sparse evidence on the impact on vulnerable populations of the COVID-19 pandemic. The aim of our study was to explore burden and mental wellbeing (including depressive, anxiety, and stress symptoms) in caregivers of people with dementia during the first wave of the pandemic in Italy and southern Switzerland, two bordering regions severely hit by the COVID-19 pandemic.

Methods: We conducted an online cross-sectional survey with family carers of people with dementia between May and June 2020. We registered socio-demographic characteristics, and information about the relationship with the care recipient, dementia subtype, care inputs from others, and the need of care of the person with dementia. We measured caregiver burden with the Zarit Burden Interview (ZBI), psychological distress with the Depression, Anxiety and Stress Scale (DASS-21), and perceived isolation with the 3-item UCLA Loneliness Scale (UCLALS3).

Results: Caregivers ($N = 571$) reported moderate to severe care-related burden (mean=54.30; SD=18.33), moderate anxiety symptoms (mean=10.04; SD=6.93), mild depressive symptoms (mean=11.79; SD=6.12) and mild stress (mean=12.95; SD=5.53), and 72.3% of participants reported to feel lonely. All scores were significantly more severe in Swiss compared to Italian caregivers (all p values < 0.001).

Conclusions: We found that caregivers' burden, anxiety symptoms, depression and perceived loneliness were marked during the first wave of the COVID-19 pandemic, in two severely hit bordering countries. Regional differences in the impact of the epidemic on caregivers could be due to contextual, societal, and cultural circumstances. As the pandemic endures, support to caregivers of people with dementia should be proportionate and tailored to needs and adapted to contextual factors.

Keywords: Caregivers, Dementia, Mental health, COVID-19, Cross-sectional study

Introduction

Dementia influences those who are affected and the family members who very often care for their relatives at home [1]. Friends and relatives who provide non-professional and un-paid care to help a person, usually with long-term needs are defined as "informal carers" [2].

In 2019, according to the World Health Organization (WHO), informal caregivers worldwide spent over 89 billion hours assisting a family member with dementia in basic personal activities of daily living, with women contributing to 70% of global hours of care [3]. Informal care provision generally reflects more factors, from the scarcity or lack of resources and formal support services for people with dementia, to social and cultural expectations that family members, especially women, have the obligation to take care of a relative in need [4]. Even if there

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is evidence that caring duties can also lead to a sense of personal accomplishment and gratification [5], many informal caregivers deal with social, financial, and psychological strain that increases the likelihood of developing mental and physical distress [6].

Indeed, literature shows that caring for someone with dementia is associated with feelings of burden perceived stress, depression, loneliness, poorer immune function, and cognitive decline [7–10]. The COVID-19 pandemic brought new challenges to caregivers. Worldwide, governments enforced restrictions measures such as physical distancing, stay at home orders and travel restrictions that often limited the access to health-care facilities and caregivers support interventions such as respite services [3]. The disruption or abrupt suspension of social and medical support forced informal caregivers to take over multiple and additional responsibilities to meet the needs of the person with dementia [11]. In addition, since older age and premorbid conditions represent a risk factor for COVID 19 mortality [12], caregivers felt additional pressure to protect themselves from infection to prevent transmission to the person they cared for [13]. Taken together, all the changes imposed by the pandemic have likely exacerbated already taxing caring conditions and may have contributed to increase and worsen psychological distress of caregivers, potentially in the long term.

Longitudinal studies [14, 15] suggest that the impact on mental health on the general population varies through the waves and various phases of the COVID-19 pandemic, from outbreaks to relapses of mitigation public health measures, with marked geographic variations. However, there is scant evidence about caregivers' mental health during the pandemic, particularly during the first wave of the outbreak and lockdown periods. Moreover, evidence on cross-country comparisons in psychological distress of caregivers is extremely thin [16], and inexistent from northern Italy and southern Switzerland, two regions that were very severely hit during the first pandemic outbreak. In addition, most of the few available studies on dementia caregivers during the pandemic, focused only on some psychological outcomes, mainly stress or caregiver burden [17–20] and varied in methods; psychological distress was often not measured using previously validated scales [21–23]. It is indispensable to expand and advance the current knowledge on the impact of the pandemic on caregivers of people with dementia to inform the design and provision of appropriate measures and interventions aimed at supporting this vulnerable population for the current and in view of future pandemic crises.

We conducted a cross-sectional survey in Italian and Swiss informal caregivers of people with dementia during the first wave of the COVID-19 pandemic

(May- June 2020). We aimed to explore levels of burden, depressive symptoms, stress, anxiety, and perception of loneliness in caregivers of people with dementia during the first peak of the pandemic, in two hardly hit bordering countries, where preventive public health measures, including personal limitations and home confinement were strictly enforced. Public health preventive measures varied in the two countries, but according to the Oxford University's stringency index were almost identical at the time of data collection of the present study [24].

Methods

Study participants and procedures

We conducted an online cross-sectional survey in family caregivers of people with dementia in two bordering, Italian-speaking regions: Italy and southern Switzerland. We used snowball technique to recruit a convenient sample of both Italian and Swiss informal caregivers by advertising our research via three different channels. An invitation message was prepared and circulated in 32 social media pages on Facebook and Instagram related to ageing and/or dementia and Facebook private groups of informal caregivers, and through 53 day-care centres for people with dementia in the two regions. Inclusion criteria were being 18 years of age or older, Italian-speaker, and informal (i.e. non professional) caregiver of a non-institutionalized family member with previously diagnosed dementia. Participants were excluded from the study if they did not match all inclusion criteria.

The online survey, implemented in RedCap (Research Electronic Data Capture), was active between May 25th, 2020 and June 25th, 2020. The estimated compilation time was 15 minutes. All participants received an informed consent to participate prior to filling out the survey, online. All methods were performed in accordance with the relevant guidelines and regulations.

Measures

Sociodemographic variables

We collected socio-demographic data of caregivers, including age, gender, place of residence, level of education, and work. We also asked carers about their relationship with the person with dementia, and inquired whether care provision was their only occupation, and if they received any care inputs from other formal or informal caregiver. Information about the care recipient elicited from the carers included the clinically diagnosed dementia subtype and level of autonomy in activities of daily living. All questions were asked and data collected in Italian.

Psychological measures

All psychological measures were already available in Italian, were previously validated, and have been extensively used in Italian.

We used three main standardized questionnaires. The Italian version of the Zarit Burden Interview (ZBI) [25] to assess the level of caregiver burden. For each of the 22 items, respondents reported their perceived strain associated to the provision of care on a Likert scale ranging between zero (never) and four (nearly always). We computed total scores and applied standard cut-offs of low (<21), mild to moderate ($21 \leq x \leq 40$), moderate to severe ($41 \leq x \leq 60$), and severe burden (>60) [26]. The Italian short version of the Depression, Anxiety and Stress Scale (I-DASS-21) [27], to assess the mental health of caregivers. DASS-21 is commonly used to assess negative emotions in community samples, including in informal caregivers [28]. We changed and extended, from the original questionnaire delivery, the time reference of the items from “the past week” to “the past months of COVID-19 outbreak”. Respondents reported frequency of symptoms on a four-point Likert scale (never; sometimes; often; and almost always), and we calculated the separate scores of depressive, anxiety and stress-related symptoms (mild; moderate; severe; extremely severe) according to standard cut-offs [29]. Finally, we explored the frequency (hardly never; some of the time; often) of feelings of loneliness during the COVID-19 outbreak in the region, with the three items (lack of companionship, exclusion, and isolation) Italian version of the UCLA Loneliness scale (UCLALS3) [30, 31]. This scale has been previously used in population-based studies to measure social isolation, including in caregivers of people with dementia [32], and during the COVID-19 pandemic [33]. We asked participants to answer the items referring to the past months of COVID-19 outbreak. We computed an overall loneliness score, which ranged from three to nine, with higher scores indicating higher perception of loneliness.

Statistical analyses

We computed means and proportions for descriptive statistics of the sociodemographic variables, Chi squared tests for all socio-demographic variables, and the main scales. We tested assumptions of normality and linearity, and we calculated correlations between the psychological distress measures, education, and years of caregiving experience using Pearson's correlation coefficient and univariate and multivariate ANOVA regressions, setting statistical significance at 0.05. We assessed differences in ZBI, DASS-21, and UCLALS3 scores by country and sociodemographic characteristics using independent

samples t-test. Finally, in a set of sensitivity analysis we ran linear regressions to model the effect of study site (i.e. Switzerland/ Italy) separately on each of the psychological distress scores adjusting for relevant socio-demographic and care characteristics. We used SPSS 25.0 statistical software for Windows for all statistical analyses.

Results

Sociodemographic characteristics

Of the 646 caregivers contacted, 571 completed the survey and formed the analytic sample (response rate 87%). Table 1 shows the sociodemographic characteristics of the overall study sample, and by country. Of the 571 caregivers, 425 were Italian (74.4%) and 146 (25.6%) were Swiss, with a mean age of 53 years ($SD=11.99$) and a range of 24 to 89. The majority of caregivers were female (81.6%), and the mean number of years spent in caregiving was 6 ($SD=3.95$). Most participants cared for a family member affected by Alzheimer's Disease (55.3%), followed by Vascular (16.6%), Parkinson's (12.6%), Frontotemporal dementia (7.7%), Lewy-Body dementia (3.3%), and other or unspecified types of dementia (4.5%). Most caregivers were children (71.8%), or spouse of the person with dementia (20.7%) and referred to care for a person not autonomous in most daily life activities (79.9%). Almost two thirds of participants admitted getting help from others in caring (58.7%), especially from other family members (32.2%) or professional carers (22.8%). More than half of participants had at least higher secondary education (56.4%), and almost half of the caregivers were employed with a full time or part-time job (49.6%).

Psychological measures

Overall, caregivers had a mean Zarit burden score of 54.3 ($SD=18.3$), which corresponds to “moderate to severe”. Mean scores from DASS-21 showed mild depression (mean=11.79; $SD=6.12$), moderate anxiety (mean=10.04; $SD=6.93$), and mild stress (mean=12.95; $SD=5.53$), according to standard cut-offs [29]. However, the severity of reported symptoms was more pronounced for anxiety, intermediate for depression, and less marked for stress (Fig. 1). According to past categorizations of the UCLALS3 scale [34], 72.3% of caregivers fell into the ‘lonely’ category, 99.3% among Swiss and 63.1% in Italian caregivers.

All psychological variables were positively correlated to each other (r^2 values ranging from 0.59 to 0.85, all p values <0.001) (Table 2). Correlations did not vary between countries and are presented for the full sample. More specifically, multiple linear regressions showed that stress were significantly associated with depression levels ($\beta=0.52$; $p<0.001$) and burden ($\beta=0.43$;

Table 1 Sociodemographic characteristics of informal caregivers by country (N = 571)

| Variable | Total sample (N = 571) N (%) | Italy (N = 425) N (%) | Switzerland, Ticino (N = 146) N (%) | p-value* |
|---|---------------------------------|--------------------------|--|-----------|
| Gender | | | | |
| Female | 466 (81.6) | 381 (89.6) | 85 (58.2) | p<0.001 |
| Male | 104 (18.2) | 43 (10.1) | 61 (41.8) | |
| Not specified | 1 (0.2) | 1 (0.2) | | |
| Age Mean (SD) | | | | |
| | 53.54 (11.99) | 51.85 (10.72) | 58.49 (13.99) | p<0.001 |
| Years of caregiving Mean (SD) | | | | |
| | 6.07 (3.95) | 5.08 (3.68) | 8.83 (3.31) | p<0.001 |
| Caregiver as sole occupation | | | | |
| Yes | 292 (51.1) | 176 (41.4) | 116 (79.5) | p<0.001 |
| No | 279 (51.1) | 249 (58.6) | 30 (20.5) | |
| Employment Status | | | | |
| Unemployed/Housewife | 202 (35.4) | 132 (31.1) | 70 (47.9) | p<0.001 |
| Full-time Job | 253 (44.3) | 228 (53.6) | 25 (17.1) | |
| Part-time Job | 30 (5.3) | 25 (5.9) | 5 (3.4) | |
| Retired | 86 (15.1) | 40 (9.4) | 46 (31.5) | |
| Relationship with the care-recipient | | | | |
| Child | 410 (71.8) | 328 (77.2) | 82 (56.2) | p<0.001 |
| Spouse | 118 (20.7) | 59 (13.9) | 59 (40.4) | |
| Other | 43 (7.5) | 38 (8.9) | 5 (3.4) | |
| Education | | | | |
| Compulsory education | 107 (18.7) | 70 (16.5) | 37 (25.3) | p<0.001 |
| Higher Secondary education | 322 (56.4) | 231 (54.4) | 91 (62.3) | |
| University education | 142 (24.9) | 124 (29.2) | 18 (12.3) | |
| Care recipient type of dementia | | | | |
| Alzheimer | 316 (55.3) | 247 (58.1) | 69 (47.3) | p<0.001 |
| Vascular dementia | 95 (16.6) | 82 (19.3) | 13 (8.9) | |
| Parkinson's Disease | 72 (12.6) | 24 (5.6) | 48 (32.9) | |
| Frontotemporal dementia | 44 (7.7) | 44 (10.4) | 0 | |
| Dementia with Lewy Bodies | 19 (3.3) | 17 (4.0) | 2 (1.4) | |
| Other | 25 (4.5) | 11 (2.6) | 14 (9.6) | |
| Autonomy in basic function of the care recipient | | | | |
| Yes | 116 (20.3) | 105 (24.7) | 11 (7.5) | p<0.001 |
| No | 455 (79.7) | 320 (75.3) | 135 (92.5) | |
| Help from others | | | | |
| Yes | 335 (58.7) | 285 (67.1) | 50 (34.2) | p = 0.197 |
| Relative | 184 (32.2) | 159 (55.8) | 25 (50.0) | |
| Professional carers (nurse/domestic worker) | 130 (22.8) | 106 (37.2) | 24 (48.0) | |
| Friends/neighbours | 21 (3.7) | 20 (7.0) | 1 (2.0) | |
| No | 236 (41.3) | 140 (32.9) | 96 (65.8) | |

P values were calculating using *Chi Squared tests, and **Independent t-test, as appropriate

p<0.001); depression explained a significant proportion of variance in perception of loneliness (β=0.49; p<0.001), anxiety (β=0.42; p<0.001), and stress scores (β=0.53; p<0.001); anxiety was significantly associated with depression (β=0.33; p<0.001), loneliness (β=0.27;

p<0.001) and stress (β=0.26; p<0.001); perception of loneliness was significantly associated with symptoms of depression (β=0.17; p<0.001) and anxiety (β=0.12; p<0.001). In addition, higher levels of education and years of experience in caregiving slightly predicted

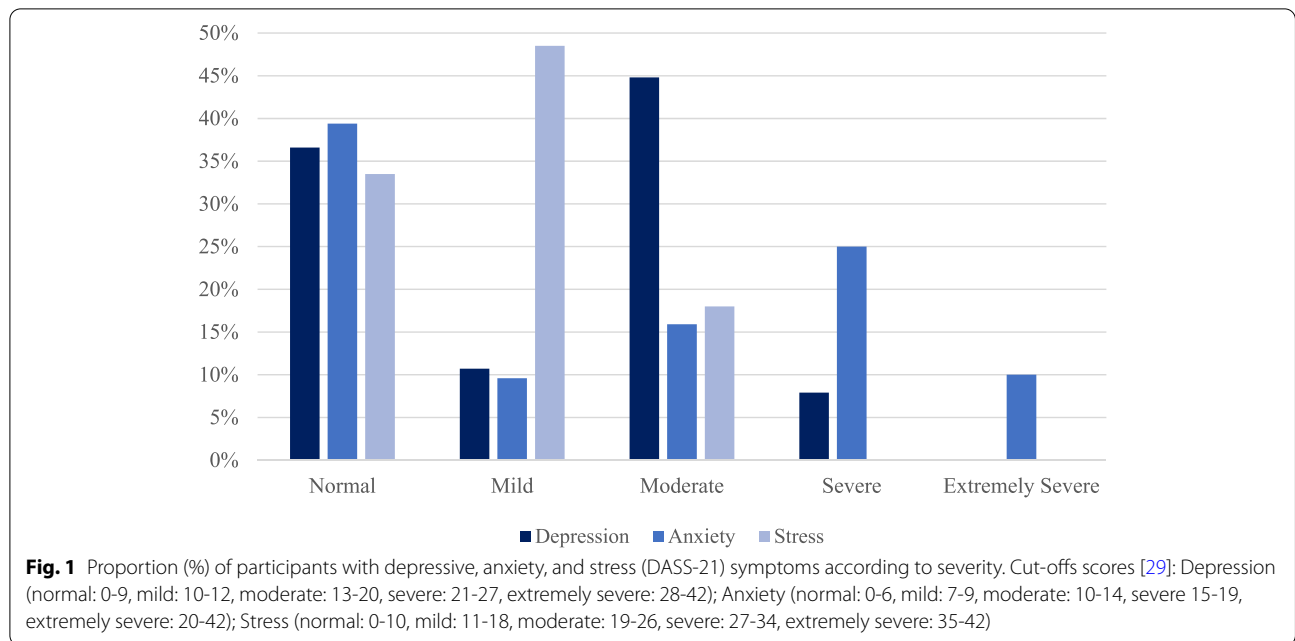


Table 2 Multiple linear regressions for psychological variables

| Variable | R | R ² (p-value) | Caregiver burden | Depression | Anxiety | Stress | Loneliness | Education | Years of experience |
|------------------|------|--------------------------|------------------|----------------|----------------|----------------|----------------|----------------|---------------------|
| Caregiver burden | 0.79 | 0.62 (<0.001) | | 0.08 (0.20) | 0.20 (0.16) | 0.43 (0.20)*** | 0.02 (0.36) | -0.09 (0.31)** | 0.11 (0.13)*** |
| Depression | 0.92 | 0.85 (<0.001) | 0.03 (0.01) | | 0.33 (0.03)*** | 0.52 (0.04)*** | 0.17 (0.07)*** | -0.00 (0.06) | -0.25 (0.03) |
| Anxiety | 0.90 | 0.82 (<0.001) | 0.10 (0.01)** | 0.42 (0.05)*** | | 0.30 (0.05)* | 0.12 (0.09)*** | -0.07 (0.08)** | 0.05 (0.03)* |
| Stress | 0.91 | 0.84 (<0.001) | 0.19 (0.01)* | 0.53 (0.03)*** | 0.26 (0.03)*** | | 0.00 (0.07) | 0.06 (0.06)** | 0.02 (0.03) |
| Loneliness | 0.77 | 0.59 (<0.001) | 0.03(0.00)*** | 0.49 (0.02)*** | 0.27 (0.02)*** | 0.01 (0.02) | | -0.02 (0.04) | 0.01 (0.02) |

Beta standardized coefficients (β) are reported with Beta standard errors in parentheses

*, **, *** indicates p values <0.05, <0.005, <0.001, respectively

better mental health on all outcomes (all p values <0.001) (Table 2).

Independent t-test showed that all psychological symptoms were more pervasive in Swiss caregivers with higher scores for burden depression, stress, anxiety, and loneliness than the Italian counterparts (all p values < 0.001) (Table 3).

The linear regression models of the effect of country of residence on the psychological distress measures confirmed that anxiety, depression, stress, and burden were, respectively, 55% (β=0.547), 44% (β=0.438), 42% (β=0.418), and 52% (β=0.517) higher in Switzerland compared to Italy (all p values < 0.001). All associations remained significant also after we adjusted for relevant covariates (all p values < 0.001).

We also found significant differences for social support, with caregivers who got help from others showing lower levels of burden (mean=49.27; SD=16.41),

depression (mean=10.66; SD=6.02), loneliness (mean=6.34; SD=2.08) and anxiety (mean=8.65; SD=6.65) than caregivers who took care of their relatives alone (mean=13.40; SD=5.89); (mean=7.39; SD=1.85); (mean=12.02; SD=6.84) (all p values < 0.001). Similarly, spouses' caregivers reported significantly higher scores in all psychological outcomes than children caregivers (all p values < 0.001).

Discussion

Our study aimed to explore psychological distress in carers of people with dementia during the first wave of COVID-19 pandemic in two severely hit bordering countries. We found that levels of burden, anxiety, depression, and perception of loneliness were marked in caregivers of people with dementia. All psychological symptoms, including loneliness were positively correlated to each

Table 3 Comparison of psychological variables between Swiss ($N = 146$) and Italian ($N = 425$) caregivers

| Variable | All sample Mean (SD) [min/max] | Italians Mean (SD) [min/max] | Swiss Mean (SD) [min/max] | T statistics* (df) | P-value |
|------------------|--------------------------------|------------------------------|---------------------------|--------------------|---------|
| ZBI | | | | | |
| Caregiver burden | 54.30 (18.33) [6-88] | 48.75 (16.90) [6-88] | 70.46 (11.48) [33-88] | -14.41 (569) | <0.001 |
| DASS-21 | | | | | |
| Depression | 11.79 (6.12) [0-21] | 10.23 (6.17) [0-21] | 16.36 (2.76) [10-21] | -11.61 (569) | <0.001 |
| Anxiety | 10.04 (6.93) [0-21] | 7.82 (6.48) [0-21] | 16.50 (3.05) [4-21] | -15.59 (569) | <0.001 |
| Stress | 12.95 (5.53) [0-21] | 11.60 (5.60) [0-21] | 16.89 (2.71) [8-21] | -10.97 (569) | <0.001 |
| UCLALS3 | | | | | |
| Loneliness | 6.77 (2.06) [3-9] | 6.29 (0.10) [3-9] | 8.20 (0.79) [5-9] | -10.62 (569) | <0.001 |

ZBI Zarit Burden Interview (possible range, 6 to 88), DASS-21 Depression Anxiety and Stress Scale (possible range, 0-21), UCLALS3 UCLA Loneliness Scale 3 items version (possible range, 3-9)

* Students' t test for independent samples

P values were calculated using *Chi Squared tests, and *Independent t-test, as appropriate

other, and were more pervasive in Swiss compared to Italian caregivers, and in spouse compared to children caregivers. Education, employment status and social support were inversely associated with psychological distress.

Previous evidence suggested that providing care for a person with dementia can cause strain and can affect both the psychological and physical health of the carer [8]. Caregivers generally report higher levels of perceived stress, depression, loneliness, burden and lower levels of self-efficacy and well-being compared to the general population [7]. Our results on the inverse association between educational level, social support, employment status, and psychological distress are consistent with those of pre-pandemic studies [35]. Nevertheless, disruption of healthcare facilities and social restriction measures imposed by the pandemic altered care routines and practices, with plausible detrimental consequences on caregivers' physical and mental health [11]. Direct comparisons with literature are not straightforward because few studies have been conducted on caregivers of people with dementia since the beginning of the pandemic, and in particular during the lockdown, in spring 2020 [36]. However, previous studies [37–39] found that high variations in social support services were associated with increased levels of anxiety, burden, and depression in samples of caregivers from Italy and the UK respectively.

We found some variations in the reported psychological symptoms. While severe levels of reported burden and anxiety were common, more than half of the caregivers in our sample reported only mild to moderate levels of stress and depressive symptoms. The COVID-19

pandemic may affect caregivers' mental health on multiple levels. The disruption of health care services may lead to a sudden and unexpected increase in responsibility. Caregivers had to provide more types of care inputs and for longer hours, with a consequent lower sense of competence and mastery [40], which in turn are associated to a greater experience of burden [41]. Suspension of respite care and breaks may have altered coping mechanisms and pre-pandemic recover opportunities, contributing to "chronic stressor felt by caregiver with respect to physical and emotional well-being, family relations and financial status" [42], rather than the more transitory experience of stress to which caregivers can adapt over time. In addition, fear of infecting a loved one can trigger worry and anxiety [43]. Moreover, the uncertainties about infection risks and the very limited knowledge about COVID-19, especially during the first wave of the pandemic, were likely responsible of increases in cognitive alertness, which may shadow or counterbalance depressive symptoms or their perception. Indeed, depression rates in the general population increased during the second wave of the pandemic compared to the first wave, probably because of the prolonged psychological distress and long-term social dislocations [44].

In our study, we also focused on perceived loneliness. We found that most caregivers reported to feel lonely. This may be explained by the almost complete lack of social interactions imposed by restriction measures, which was abrupt and unprecedented. The reported feeling of being alone and trapped at home with few external support was probably consequent to an actual condition of forced confinement [45]. These findings suggest that

caregivers of people with dementia are likely vulnerable to lockdown and social restriction measures, and could suffer remarkable loneliness, which may compromise their ability to provide care [46]. Next, psychological measures correlated to each other, correlations between depression and anxiety were particularly strong, and with higher scores in reported anxiety, predicting higher scores in depression and vice versa. Since a third of our sample reported from severe to extremely severe levels of anxiety, there is a concrete risk of increasing levels of depression in caregivers as the pandemic endures.

We investigated mental health in caregivers during the pandemic in two different countries and Swiss caregivers reported significantly higher distress in all mental health outcomes than their Italian counterparts did. During the first wave, the Italian Government adopted slightly stricter public health measures to contain the pandemic compared to the Swiss Confederation [24]. The extent to which and potential causal role of preventive measures on caregivers' mental health are not easy to disentangle. However, the variation in the timing and severity of the restriction measures adopted in the two countries may have contributed, at least to some extent, to explain the differences we found between Swiss and Italian caregivers. The presence of prompt preventive measures to reduce the risk of infection, especially for the elderly and vulnerable populations, may have contributed to lessen the anxiety and fear of contagion in Italian caregivers of people with dementia. On the other hand, the latency and minor severity of restrictions adopted by the Swiss Federal Council may have triggered a sense of personal unsafety for both the caregiver and the care-recipient. Nonetheless, other socio-cultural and contextual factors may contribute to explain the fact that Swiss caregivers reported significantly higher distress in all mental health outcomes than Italian carers did. Evidence suggests that social support is a protective factor towards burden and psychological distress in dementia caregivers [47, 48]. Since in our study Italian caregivers reported to receive more help in caring duties compared to Swiss caregivers (Table 1), the differences in use and availability of emotional and practical forms of support during the pandemic may lead the burden due to the disruption of services and the additional care responsibilities. A further investigation on specific restrictive measures and services available during the lockdown for caregivers of people with dementia in the two different countries is needed to clarify the differences.

The present study is not free from limitations. The lack of longitudinal or pre-pandemic data on the burden, mental health, and loneliness of caregivers limits causal inference. However, we found exceptionally high levels of burden and psychological distress according

to commonly used and standardized scales. Further, although the sample of our study was large it was not representative of the target population. We cannot exclude selection bias also because only caregivers who had access to the internet and to our recruitment channels could participate in the survey. Nevertheless, the study population had a broad sociodemographic spectrum, which provides support at least to some extent to the external validity of our results. We measured psychological distress using robust and valid measures, and participants self-reported a wide range of their socio-demographic and care characteristics. However, people with dementia were less thoroughly characterised. We did not measure behavioural and psychological symptoms of dementia (BPSD), and we used a binary question to measure autonomy and not a standard measure of activities of daily living (ADL). BPSD and ADL impairments are associated with strain and psychological distress in caregivers [49, 50], and may have worsened because of self-sheltering, quarantine, and other personal and social restrictive measures [51].

Our results confirmed that people with dementia and their caregivers have faced serious challenges during the pandemic. Local authorities must consider, locally adapt, and apply the recommendations of issued by the Technical Advisory Board on Mental Health in the WHO European region to reduce the impact of COVID-19 crisis on mental health in vulnerable populations [52].

Conclusions

The present study showed that family caregivers of people with dementia have experienced psychological distress during the first wave of COVID-19 pandemic. Since we found severe feelings of burden and anxiety, rapid and targeted measures are required to enable carers to continue provide care and cope with uncertainty, while maintaining their own well-being. Further interventions should address feelings of loneliness accounting for contextual and cultural circumstances.

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Authors' contributions

Conceptualization: ML; Data curation: ML; Formal analysis: AM; Investigation: ML; Methodology: ML, MF; Supervision: MF, EA; Writing and original draft: AM; Writing, review & editing: ML, MF, EA. All authors read and approved the final manuscript.

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Availability of data and materials

The dataset generated and analysed during the current study are available in the Zenodo open access repository, DOI:10.5281/zenodo.4748652.

Declarations

Ethics approval and consent to participate

We received from both the Italian and Swiss Cantonal ethics committee, the right to proceed, since our study did not fall within the scope of Art. 2 and Art 3 of the law on human research and did not require any ethical approval. All participants gave informed consent to participate prior to filling out the survey, online.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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