A photograph of two people, an older woman and a younger man, sitting on a light-colored sofa. Both are wearing blue surgical-style face masks. The woman on the left has long grey hair and is looking towards the camera. The man on the right has dark hair tied back and is looking down. The background is a plain, light-colored wall.

Informal caregivers during the SARS-CoV-2 pandemic: profiles, perceptions and preventive measures

Corona Immunitas Ticino Working Group Caregivers

Dr Sara Levati, RN, MSc, PhD

Scuola universitaria professionale
della Svizzera italiana

SUPSI

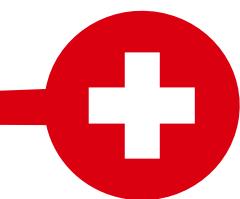
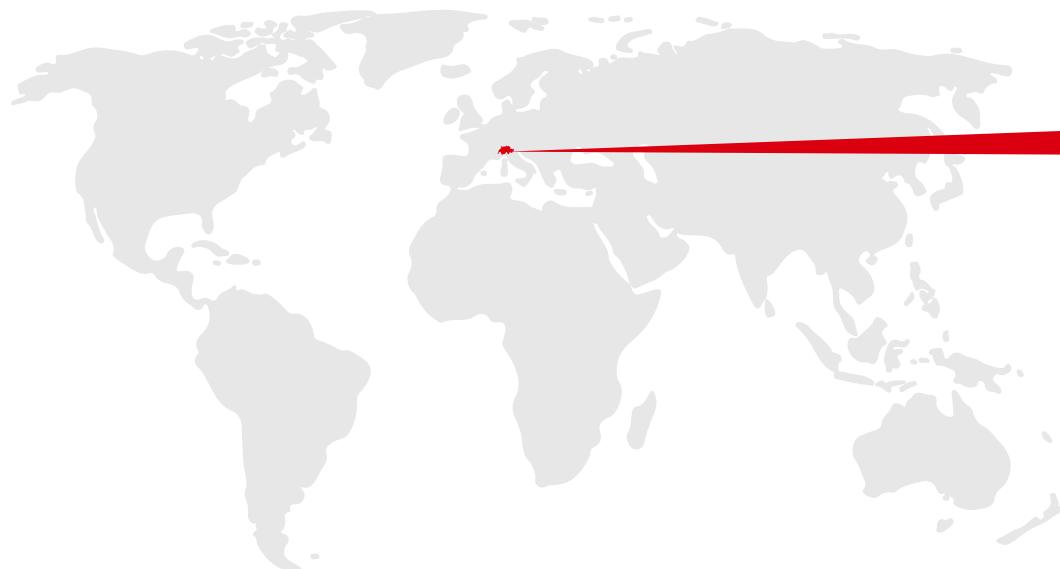


Università
della
Svizzera
italiana

Outline

- Introduction
- Research questions
- Study design
- Results
- Discussions
- Future steps

Caregivers in Switzerland

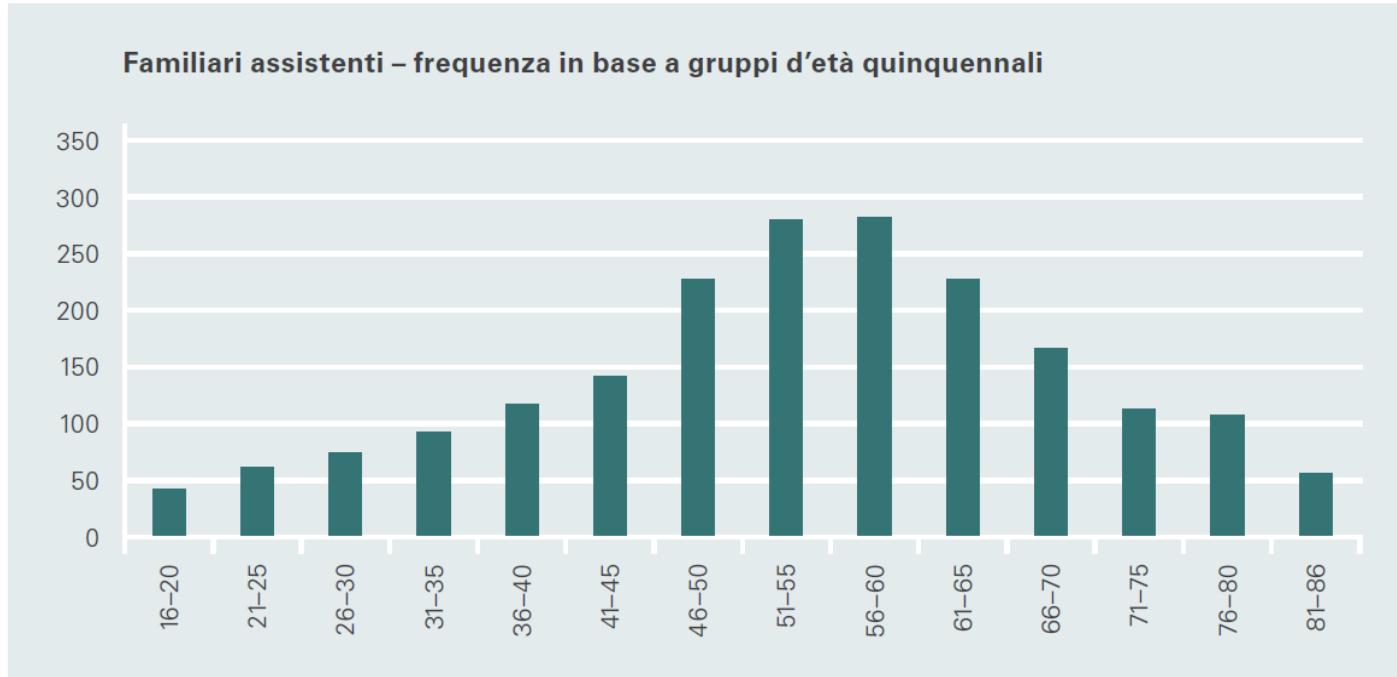


Switzerland

FOPH program
“Supports for family
caregivers”
(2017-2020)

600'000 informal
caregivers

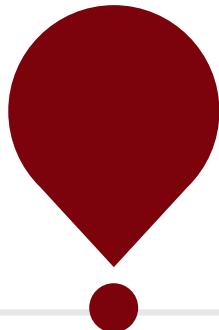
Characteristics of caregivers



N=1997 (età compresa tra i 16 e gli 86 anni) | grafico: UFSP

Source: «Offerte di sgravio per familiari assistenti 2017-2020» Mandato ufficiale UFSU

Characteristics of caregivers



Care recipients

Family caregivers in paid work care predominantly for parents and in-laws

Gender

54% of caregivers 16+ are women

Paid work

Caregivers in paid work by age group
36-49 years: 87%
50-54 years: 79%

Hours

Hours of assistance provided/week
1-10: 63%
10-20: 19%
21-30: 6%
31-40: 4%
24/24: 8%

Source: «Offerte di sgravio per familiari assistenti 2017-2020» Mandato ufficiale UFSU

Characteristics of caregivers

Estimated number of informal caregivers (aged 16+) in Switzerland - according to major regions

Tab. 8: Geschätzte Anzahl betreuende Angehörige (ab 16 Jahren) in der Schweiz – nach Grossregionen

Grossregion	Anteil an der Wohnbevölkerung (in %)	In absoluten Zahlen (gerundet)	Frauenanteil (in %)
Alle Regionen	7.6	543'000	54.5
Genferseeregion	6.5	88'000	57.7
Espace Mittelland	7.6	120'000	55.9
Nordwestschweiz	8.0	78'000	51.8
Zürich	8.0	101'000	54.8
Ostschweiz	8.1	80'000	54.6
Zentralschweiz	7.7	52'000	48.0
Tessin	8.0	24'000	57.4

N=2'036. Wohnbevölkerung nach Zensusdaten 2017

Careum Forschung | gfs.bern

Challenges and opportunities

Socio-economic conditions

Caregivers are more likely to report poorer socio-economic conditions
(Carmichael et al. 2010, Sacco et al. 2018)

Jobs

Informal care responsibilities have an impact on employment opportunities and earnings but it is difficult to draw causal inferences.
(King & Pickard 2013, Carr et al. 2018)

Costs

Family caregivers incur economic costs through effects on their own employment, out-of-pocket expenses and caregiving labor expenses
(Keating et al. 2014)

Health

Caregiving can have negative effects on symptoms of depression and quality of life (Potocnik & Sonnentag 2013), sleep (Sacco et al. 2018), cardiovascular diseases (Mortensen et al. 2017) and self-rated health (Vlachantoni et al. 2016)

Social consequences

Negative social consequences include isolation, less time for friends or hobbies;
positive social consequences include satisfaction, affection, learning new skills

Caregivers and the COVID-19 pandemic

- Compared to non-caregivers, informal caregivers:
 - Report more negative effects from the pandemic (more likely to experience social isolation, anxiety and depression, fatigue, sleep disturbance, etc.)
 - Are more likely to report taking precautions, and to worry about becoming ill or infecting the care recipient
- The pandemic has increased caregiving responsibilities and providing care has become more emotionally, physically, and financially difficult. Caregivers are providing more care because the needs of the person they care for have increased or because of reductions (or closures) in local services.

Sources:

Effects of COVID-19 on Family Caregivers A Community Survey from the University of Pittsburgh (July 2020)

Carersuk.org (October 2020) Caring behind closed doors: six months on The continued impact of the coronavirus (COVID-19) pandemic on unpaid carers

Caregivers and the COVID-19 pandemic

- Almost two thirds of carers (64%) have not been able to take any breaks from their caring role during the COVID-19 pandemic. While one in five (19%) said that they had not been able to take as many breaks as they felt they needed.
- Juggling work and care was challenging before the pandemic – with a reduction in services and the shift to working from home, caregivers had to adapt fast. For some working carers this has been beneficial, but a minority of caregivers reduced their hours to manage their caring responsibilities or had given up work altogether.

Sources:

Effects of COVID-19 on Family Caregivers A Community Survey from the University of Pittsburgh (July 2020)

Carersuk.org (October 2020) Caring behind closed doors: six months on The continued impact of the coronavirus (COVID-19) pandemic on unpaid carers

Our research questions

- Do caregivers in Southern Switzerland differ from non-carers in terms of sociodemographic factors and their health profile?
- How has the COVID-19 pandemic influenced the lives of caregivers?

Corona Immunitas Ticino

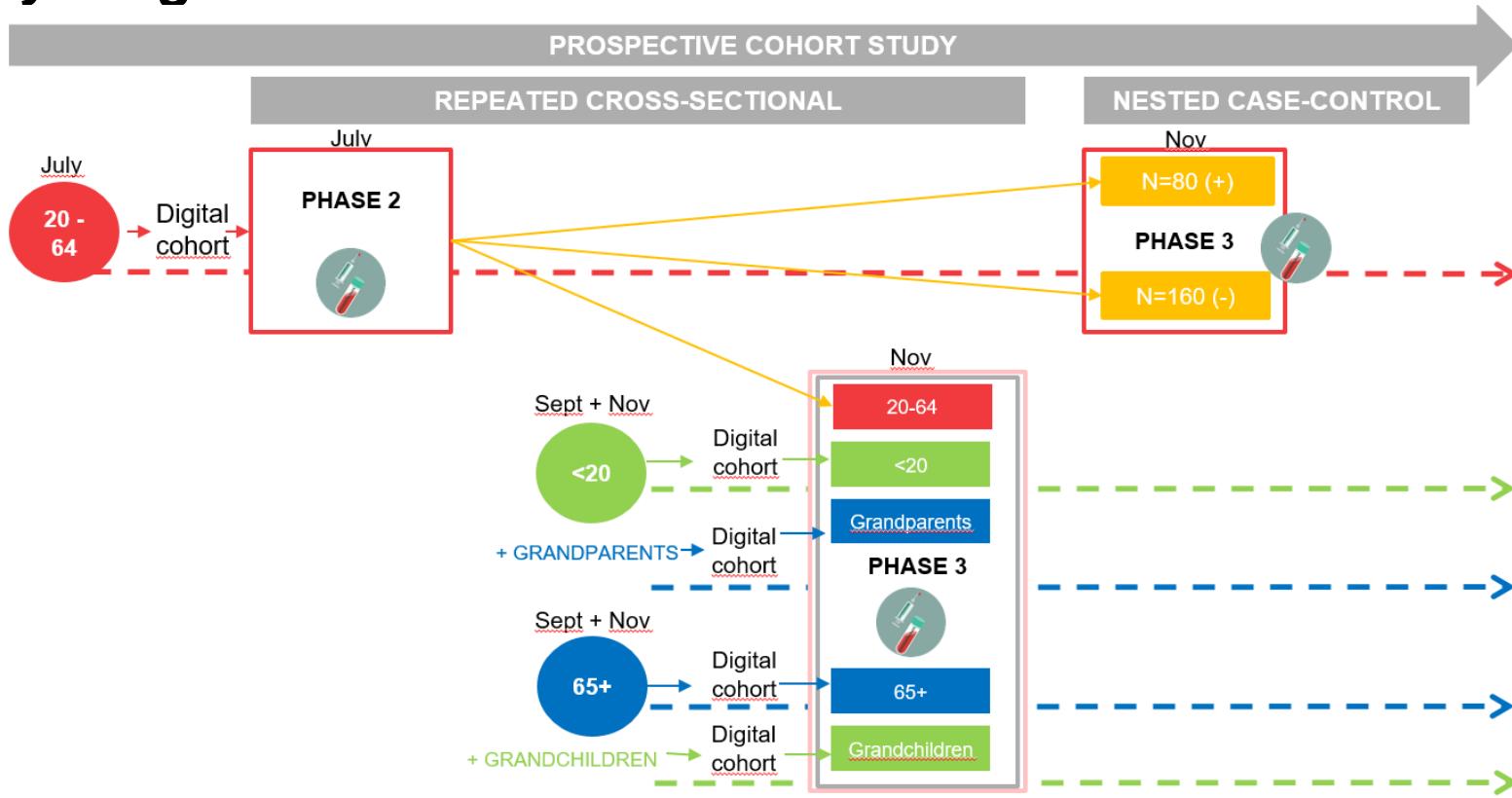
- Prospective, population-based study that is part of the national Corona Immunitas initiative
- Launched by the Swiss School of Public Health SSPH+ in March 2020 and supported by the Federal Office of Public Health

Aims

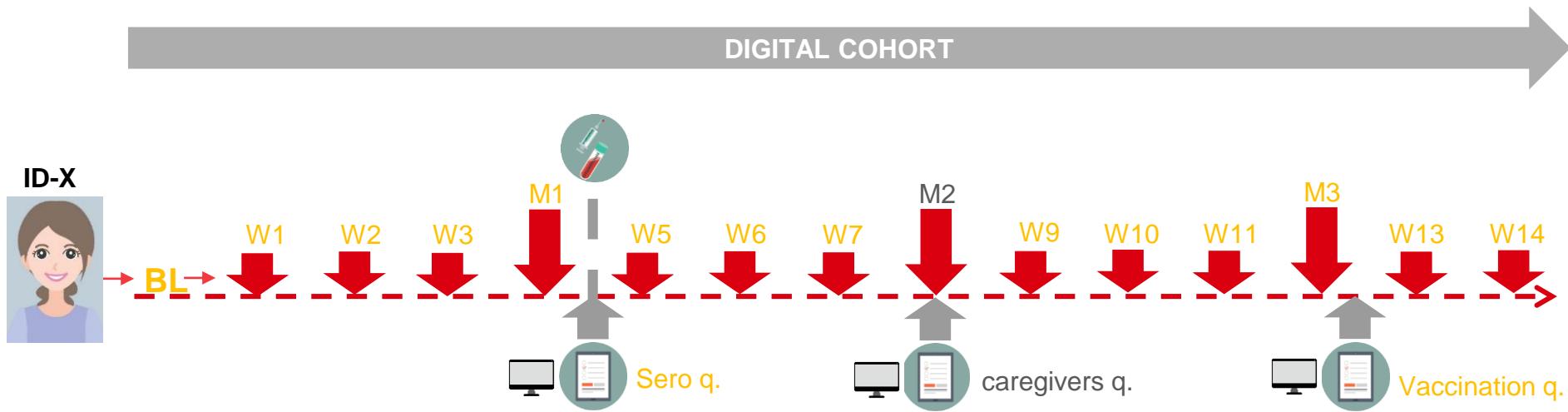
1. to assess the seroprevalence (spread) of anti-SARS-CoV-2 antibodies
2. to assess the impact of the COVID-19 pandemic in Ticino



Study design



Digital follow-up



Data collection

- Questions asked in BL + ad hoc questionnaire administered to the adult population (20-64)
- Data collected between end of September 2020 and end of February 2021
- Specific themes for caregivers included:
 - information about the care recipient
 - types of assistance provided
 - changes to caregiving during the COVID-19 pandemic
 - changes to organisational aspects of care
 - job related implications of caregiving during a pandemic

Do informal carers differ from non- carers?



Results

At baseline: 1081 respondents



Caregivers

n=80 adults reported
being an informal
caregiver



Women



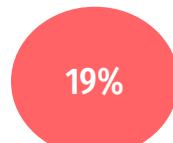
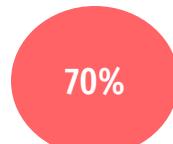
In paid work

Caregivers

- The vast majority care for only one individual, most commonly a parent or mother/father in-law (63.7%), partner (13.7%) or child (13.7%)
- Care recipients mostly suffer from dementia (11.2%) or a chronic condition (18.7%)
- Caregivers report having a professional training (43.7%), a high school diploma (16.2%) or a university degree (20%)
- Caregivers report having enough or more than enough to live

Caregivers vs. non-caregivers

Caregivers



Women

Older than 40 years

Retired or unemployed

Difficulties in making ends meet

Non-caregivers

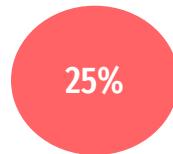


Caregivers vs. non-caregivers

Caregivers



20%



25%

Report health as 'fair'

Non-caregivers



11%



15%

Symptoms of anxiety

Caregivers vs. non-caregivers

Caregivers



Worried about becoming ill with Covid-19



Worried about passing along the virus

Non-caregivers

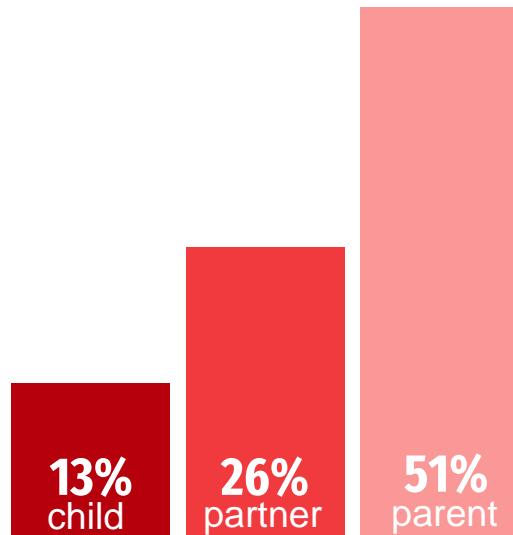


How has the COVID-19 pandemic influenced the lives of adult caregivers in Ticino?



Care recipients and types of care provided

Relation with care recipients

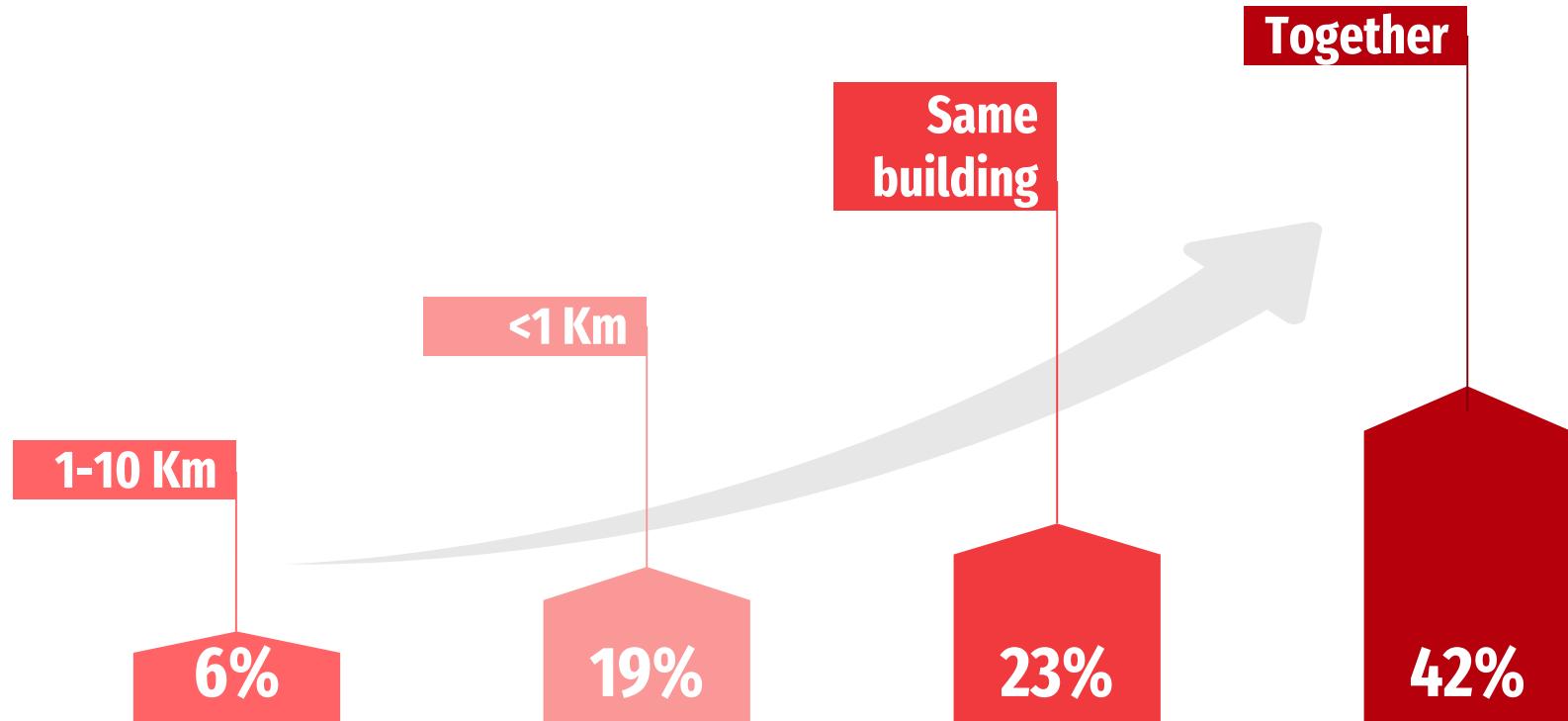


Type of care provided:

- Assistance with household chores
- Social support
- Assistance with transportation
- Assistance with activities of daily living (ADLs)
- Medical related tasks

Care provided

Distance to the recipient



Concerns

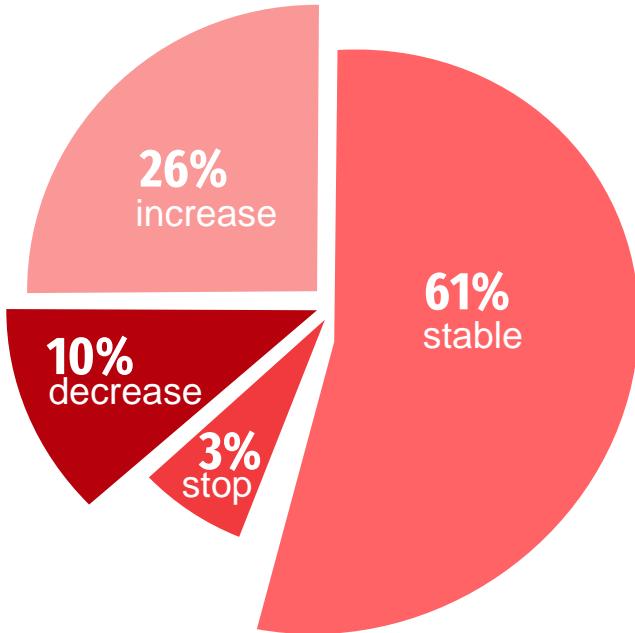


"I am worried about what will happen to the people I care for if I have to self-isolate or become ill"



"I am confident that I have a contingency plan in place in case of emergency"
→ help from another family member (58%) or home services (19%)

Changes to hours of care during lockdown (mid-March to mid-May)



Reasons for an increase:

- An increase in care requirements
- Decreased availability of others
- Desire to limit the presence of others in the household

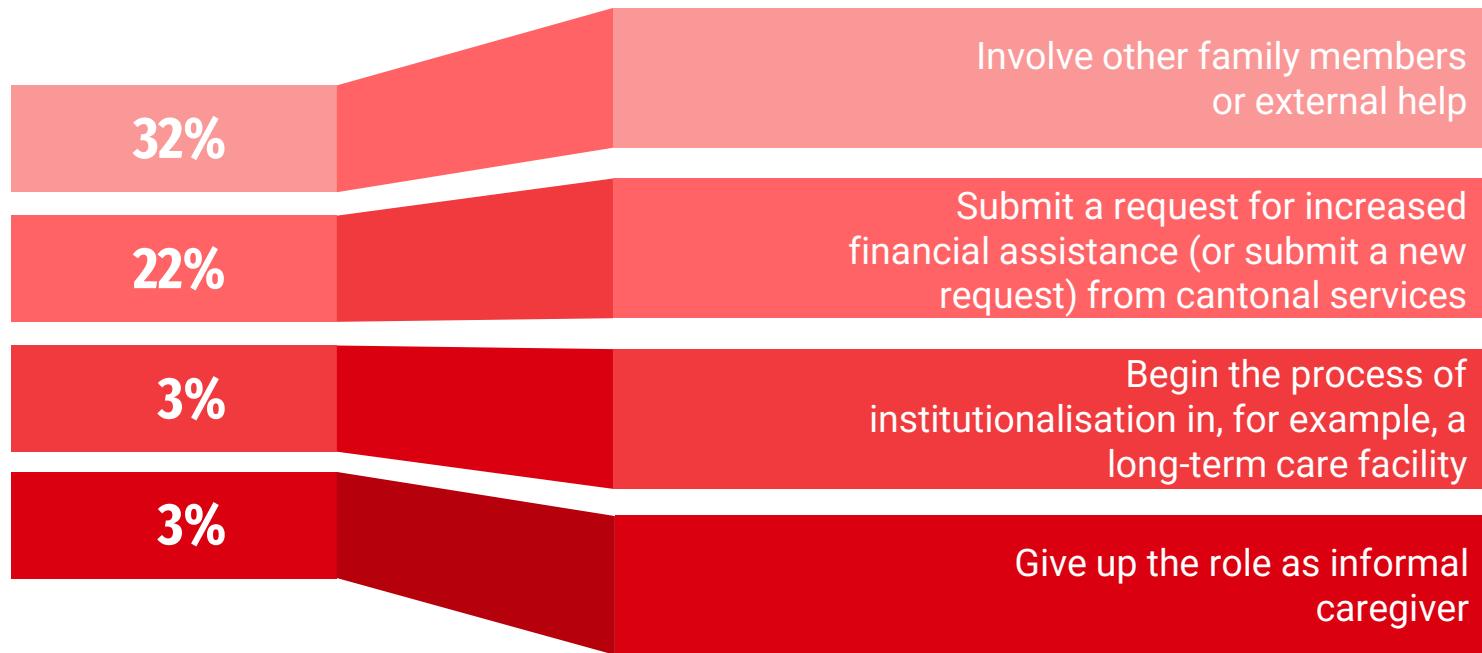
Reasons for a decrease:

- A decrease in care requirements
- Another family caregiver started to help

Work

- 68% of caregivers reported being in paid work
- The majority work between 80-100%
- Only 2 of these reported changes to their conditions of employment due to their caregiver role

Future



Discussions

Q1

We found statistically significant differences in terms of socio-demographics, reported health and worries related to the Covid-19 pandemic

Q2

- Carers are worried about what will happen to the people they care for if they have to self-isolate or become ill; the burden tends to remain within the family, even in case of an emergency
- Almost half of the carers reported changes in the hours of care provided
- Limited impact on work commitment
- Future plans focus on the involvement of other family caregivers or the request of financial support

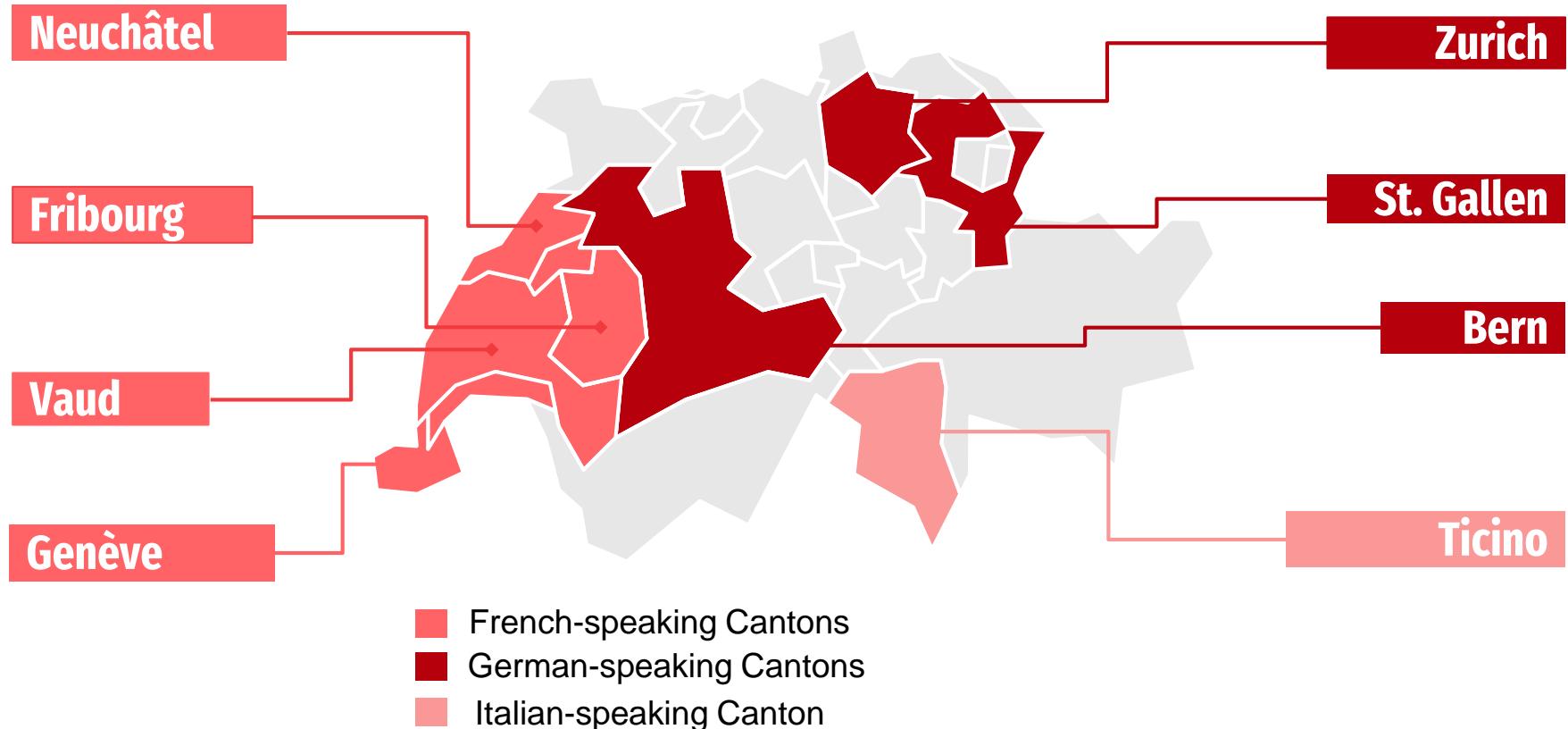
Discussions

- During this public health crisis, intervention/program planning should target the specific characteristics and needs of family caregivers, and adapt the current offer to the pandemic restrictions (i.e. use of telemedicine/phone support)
- As systems of social and long-term care increasingly consider family carers an important figure (and rely on their support), understanding the implications of this role is fundamental for their ongoing involvement
- Limitations: small study, but the first one exploring the impact of the COVID-19 pandemic on caregivers

Future steps

- We collected data among our sample of people aged 65+ (n=47)
- We are now collecting data using a revised version of the questionnaire at the national level – this will be the first study exploring the impact of the COVID-19 pandemic on caregivers in 8 Swiss Cantons

Caregiving in Corona Immunitas (national level)



THANK YOU FOR YOUR ATTENTION

sara.levati@supsi.ch



Prof Luca Crivelli (PI)
Prof Emiliano Albanese (PI)
Dr Rebecca Amati (PM)

Prof Laurie Corna
Dr Maddalena Fiordelli
Prof Spartaco Greppi
Dr Sara Levati
Prof Cesarina Prandi