

International comparison of long-term intergenerational informal caregiving in ordinary and COVID-19 pandemic-stress time

Dissertation for the attainment of the academic degree

Doctor philosophiae (Dr. phil.)

submitted by the Institute of Gerontology

Faculty of Education and Social Sciences

of the University of Vechta, Germany

as a joint PhD degree (Cotutelle) with the Faculty of Education

of the Free University of Bozen-Bolzano, Italy,

accepted by the Senate of the University of Vechta

From

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List of abbreviations

ACG: Adult Caregiver

AYC: Adolescent Young Caregivers

CSAM: Caregiver Stress Appraisal Model

CSM: Caregiver Stress Model

GrPs: Grandparents

ICSAM: Intergenerational Caregiving Stress and Appraisal Model

ICGs: Informal Caregivers

LTC: Long-Term Care

MACA: Multidimensional Assessment of Caring Activities

OCG: Older Caregiver

OP: Older People

OCRs: Other Care Recipients

PANOC: Positive and Negative Outcomes of Caring

PS: Propensity Score

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Abstract

Background: Population ageing and the consequent growing up of multiple chronic diseases are increasing long-term care (LTC) demand worldwide. In Europe and beyond, regardless of the welfare regime, the bulk of care for older people is carried out by informal caregivers (ICGs), often adults and older adults. Nevertheless, recently, many studies shed light on young people playing the role of caregivers (named Adolescent Young Carers-AYCs) of frail older family members, often grandparents (GrPs). Intergenerational caregiving negative outcomes (e.g. high level of stress and poor physical health and mental well-being) can occur, especially in countries with under developed LTC systems. The COVID-19 outbreak represented a real “stress-test” for the European LTC systems, bringing to light their limits and weaknesses. The virus containment measures exacerbated the living and health conditions of ICGs and non-self-sufficient older adults by restricting the possibility of accessing many social and health services. The overall aim of this work is to deeper the characteristics of intergenerational caregiving both in ordinary circumstances and in Pandemic time, with the ambition of providing a new conceptual framework for its interpretation.

Methods: Four studies were carried out between 2020 and 2022. Studies 1 and 2 report the results of a survey targeted to AYCs aged 15–17, carried out in the framework of the Me-We project “Psychosocial support for promoting mental health and well-being among young adolescent caregivers in Europe”, which received funding by the European Union’s Horizon 2020 research and innovation programme (H2020; 2018-2021) under grant agreement No. 754702. Study 1 compares a sub-sample of AYCs of GrPs to another sub-sample of AYCs of other care recipients (OCRs), e.g., parents, siblings, and friends. The analysis included a final sample of 817 AYCs. Linear or logistic regression models were built, and multivariate analyses were repeated. Study 2 considers two sub-samples of 87 AYCs living in Italy and 75 living in Slovenia. A multiple linear regression model was built for the quantitative data. Qualitative data were content analysed using an open coding process. Studies 3 and 4 report the results of an online survey reaching 2,468 European caregivers from 16 countries, carried out in Winter 2020/2021. Study 3 focused on two sub-samples of ICGs of older people with LTC needs living in Germany and Italy (149 and 173, respectively). A logistic regression analysis was performed by country to obtain an adjusted estimate of the risk of worsening caregivers’ health. Study 4 focused on 1,390 ICGs and compared the effects of the Pandemic on two sub-samples of 848 adult caregivers (ACGs) and 542 older caregivers (OCGs). The differences between the two groups were estimated using logistic regression and adjusted for all potential confounders. All analyses were repeated after propensity scores (PS).

Results: Study 1: AYCs of GrPs experienced more positive caregiving outcomes than AYCs of OCRs across the six countries included in the analysis. Being female or non-binary, and having a migration background, were associated with more negative outcomes. Study 2: 80% of respondents were females and one out of three AYCs reported health problems due to their caring responsibilities. Italian respondents faced communicative and practical problems, while Slovenians experienced mainly emotional discomfort. Study 3: the risk of worsening caregivers’ health increased by more than 40% for German caregivers compared to Italian ones, despite the former receiving more formal services than the second ones. Furthermore, the overall health risks and protecting factors differed by country. Study 4: ACGs experienced more worsening physical conditions, took care of older relatives with more severe health conditions and increased the hours of care more than OCGs. Regardless of age, females were more exposed to health risk and poor quality of life than males. Also new caregivers were mainly females and their physical health and quality of life were put at risk by caregiving.

Discussion: The four studies confirmed the overwhelming presence of women in formal intergenerational caregiving, underlining they are at greater health risk than males at any age and at any time. The COVID-19 outbreak has only exacerbated gender inequalities in the distribution of care tasks. The quick interruption of

care services and the overall stressful situation given by the global health crisis did not allow ICGs to make a proper and timely appraisal of their situation, causing an evident deterioration in their overall health conditions.

Conclusions: Results call for reforms of LTC systems across Europe boosting in-home care and providing more practical and psychological support targeted to ICGs of all ages. Moreover, further research on gender inequalities in intergenerational caregiving is recommended. The Intergenerational Caregiving Appraisal and Stress Model (ICASM), an original theoretical framework, is proposed as a possible lens to interpret the experience of today intergenerational caregiving, characterized by older care recipients with chronic diseases and multimorbidities and by women with multiple social roles.

1. Background

1.1. Population ageing and increase in Long-Term care demand

World and European populations are increasing in life expectancy and ageing. In 2019, in the OECD countries, more than one in six people was older than 65, and it is expected that population over 80 will reach over 1.2 billion in 2050 in many countries (OECD, 2020). In the same year, in Europe, 20.3% of the population was aged 65 years or over, and Germany and Italy represented the fourth and the first oldest countries across the EU Member States, with 21.8% and 23.2% over 65 aged people of the whole population respectively (Eurostat, 2021). Even at regional level, the highest shares of older adults were found in Chemnitz (28.9%) in Germany, followed by Liguria (28.5%) in Northern Italy (Eurostat, 2020).

As a consequence of the extended later life, even the number of older people with chronic disease and multimorbidities is increasing. In Europe, 70% of over 75-year-old people, representing almost 10% of the whole population, reports chronic and long-standing disease (European Union, 2019), while across the OECD countries, about 60% of elderly population suffer from multiple chronic conditions (OECD, 2020). In 2019, in Germany, the number of people in need of care totalled 4.1 million, while in Italy, 3.8 million people aged 65 and over had severe difficulties in basic functional activities (i.e., severe motor, sensory and cognitive limitations), and more than one in two older people had multimorbidity, reporting at least three chronic diseases (Li, 2019; ISTAT, 2020).

Because of the above, Europe's demand for Long-Term Care (LTC) (i.e., the delivery of a range of care services to meet the health needs of people limited in their ability to live independently) is dramatically increasing.

1.2. Formal and informal LTC services to dependent older people in Europe: a particular focus on Germany and Italy

In Europe, older people are often cared for by a “collage” of different social and health services delivered by different providers belonging to: i) the formal sectors i.e. by care professionals; ii) the semi-formal sector i.e. by no care professionals often working in domestic environment; iii) the informal networks i.e. no professional and no-trained family caregivers. This paragraph focuses on the offer of formal (§ 1.2.1) and semi-formal LTC services (§ 1.2.2).

1.2.1 Public and formal LTC services

Although similar ageing processes characterize Germany and Italy, the response to the growing need for care differs in these countries, in terms of funding and services provision, due to different LTC concepts. Germany has one of the most elaborated and all-embracing welfare regimes, characterized by universal public and accessible health care, including care allowance i.e. monetary transfer, (in kind) home care services and residential care (as detailed below) (Laenen et al., 2019). In 2019, in Germany, 80% of people in need of care were cared for at home and 20% in one of the 15,400 LTC facilities (e.g., nursing homes) (Frank and Babitsch, 2018). Older people with nursing care needs can choose between professional service (Pflegesachleistung) or monetary transfers. In the first case, they are taken care of at home by professional caregivers who have a contract with nursing insurance funds and nursing homes (Destatis, 2020) and provide a non-standardised number of hours of care by different degrees of care need. The provider is directly paid by the LTC Insurance (LTCl), unless the care received exceeds the appropriate level of benefits; then, the care recipient bears the

difference (Laenen et al., 2019; Geraedts et al., 2000). Alternatively, elder home care can be supported by cash benefits (Döbele and Becker, 2016; Shütte, 2009). The monetary care contribution is calculated according to individually determined care degrees (1–5), ranging from 40 EUR for care degree 1 to almost 2,000 EUR for care degree 5 (Theobald and Luppi, 2018).

In Italy, characterized by a Mediterranean welfare regime (Esping-Andersen, 1999), LTC is not conceived and organized as a comprehensive model. However, it juxtaposes multiple legislative interventions to integrate different national and regional legislations and social and health services (Rotolo et al., 2014). Italian LTC provides a medium/low level of support, with unregulated cash payments and service delivery (Theobald and Luppi, 2018). It stands on three pillars: residential care, home care and monetary transfers. Residential care (i.e., nursing homes and day care services) is managed mainly by private bodies or Non-Governmental Organisations acting as third parties of municipalities (Costa, 2013; Rotolo, 2014). Concerning home vs residential care, in Italy, in 2018, 90% of older people with at least three chronic diseases were cared for at home (compared to 80% in Germany) and 10% lived in one of the 7,372 nursing homes (about half of those available in Germany), whose number of beds differs region by region (ISTAT, 2019). The provision of beds in nursing homes differs region by region, but it remains far from addressing the older population's needs (Barbabella et al., 2017; Courbage et al., 2020).

The most common monetary transfer is the State Care Allowance (“Indennità di accompagnamento” in Italian) (Berloto and Notarnicola, 2019) introduced by Law number 18/1980, provided by the National Social Security Institute (Istituto Nazionale di Previdenza Sociale-INPS) and financed by tax revenues. It is a fixed monthly contribution (cash-for-care) of 522,10 EUR per month, provided to dependent people, regardless of the degree and type of care needed and economic situation of beneficiaries, without the obligation to declare the use made of it (Ibidem).

The main differences between Italian and German LTC are that in Italy, contrary to what happens in Germany, i) dependent older people cannot choose between professional home care and monetary transfer; ii) home care involves care professionals for a very low number of hours (16 h in one year per beneficiary)(Barbabella et al, 2017); iii) monetary transfer is not provided with graduated amounts according to the level of care need. For details, please read the third attached scientific paper based on Study 3.

1.2.2 Semi-formal LTC services: the migrant care workers

Despite the described differences, German and Italian LTC systems are similar in the extensive employment of Migrant Care Workers (MCWs) as a response to the absence of an appropriate and enough supply of residential and home care services. It is not possible to describe the LTC in Italy and Germany without considering MCWs, because they represent the main means to guarantee tailored and around-the-clock assistance and supervision to older people with LTC needs by helping family members hold on to the tradition of family care for ageing parents/relatives. MCWs are in the middle ground between formal and informal care because, even when they are hired with a regular work contract, they are often employed as housework assistants and not as caregivers (especially in Italy), and it may happen that fewer hours of work are declared than those really worked. Moreover, most of them are not trained in elderly care even though they perform professional tasks such as feeding, washing, bedsores care, pads change, etc

In Germany, about 200,000 MCWs from Central and Eastern Europe are employed, especially from Poland, Romania and Slovakia, providing home care for one or more older people, but the estimated number of unregistered care staff is high (Horn et al., 2019). Typically, they are recruited and engaged by brokering agencies that also organize the travel to Germany. Two (or more) commuting MCWs alternate shifts of 2–12 weeks and live 24/7 with the older care recipient (Steiner et al., 2019).

In Italy, almost one million declared domestic workers in 2020: 90% were female, and 70% had a migration background, mainly from Eastern Europe (INPS, 2021). It is estimated that 60% of Italy's domestic workers are undeclared (i.e., without a formal employment contract), which means that around 1.3 million people have no rights in the workplace. The undeclared employment of MCWs is facilitated by the lack of restrictions or justification for using the State Care Allowance that is often used by beneficiaries and their family members to pay the MCWs. Contrary to Germany, in Italy, MCWs are mainly recruited by older people's families via word-of-mouth and NGOs and employed mostly in live-in situations and by long-term work commitments, even if the frequent turnover of the workers is quite common, given the 24-h caring activities that they are required to carry out.

1.3. Informal Caregivers: the backbone of the LTC

Regardless of the level of development of the LTC systems and the welfare regime, informal caregivers (ICGs) play a pivotal role in the provision of assistance to older and/or disabled family members across Europe and beyond (European Commission and Social Protection Committee, 2021a). Therefore, it is crucial to know the definition of ICGs, who they are, and their needs.

1.3.1 Informal caregivers' profile in the intergenerational care setting

A recent definition provided by Tur-Sinai et al. (2020) states that informal caregivers can be identified as people who provide – usually – unpaid care, at least weekly, to someone with a chronic illness, disability or other long-lasting health, social or care need, outside a professional or formal framework and as part of an unpaid non-contractual voluntary work. This definition aligns with Eurocarers and considers both a societal and a scientific perspective used by grey as well as by scientific literature on the topic. A great part of ICGs are relatives, friends or neighbours who provides unpaid physical and/or emotional care to someone with a chronic or disabling condition and help with activities of daily living such as grocery, shopping, bathing, dressing and medical tasks (Eurocarers, 2021).

While country-specific estimations of the rate of informal caregiving are often lacking, it is estimated that in Europe, 80% of all LTC is provided by ICGs, whose numbers range from 10% to 25% of the total population (Zigante, 2018), with average rates varying significantly between countries, depending on how informal care is defined and measured (Tur-Sinai et al., 2021). Most caregivers are women who provide the bulk of caregiving as spouses, middle-aged daughters or daughters-in-law aged 45 to 75 (European Commission, 2018). A comparison based on three European Surveys—the European Health Interview Survey (EHIS), the European Quality of Life Survey (EQLS), and the Study on Health and Ageing in Europe (SHARE)—shows similar prevalence rates of informal caregiving (albeit different estimations due to partially different methodological aspects characterizing the three surveys) in Germany and Italy: respectively 17.70% (SHARE: 13.66/EHIS: 20.02/EQLS: 19.40) and 18.26% (SHARE: 23.80/EHIS: 20.32/EQLS: 10.66) of adults aged 50 and over (Tur-Sinai et al., 2020).

Great differences emerge concerning gender. In fact, in Italy and Germany, the share of women aged 45–64 providing informal care is 27% and 11%, respectively, compared to 18% and 8% of men in the same age range. As for the intensity of care, Italian women spend, on average, more than 17 hours per week providing care, compared to about 12 hours provided by men. while in Germany, men carry out about 11 hours of care per week, similarly to women who carry out 10 (European Commission and Social Protection Committee, 2021).

Recently, a bulk of literature highlighted the phenomenon of caregiving in childhood, youth and adolescence. Children and adolescents under 18, in fact, may also find themselves in the situation of caring

for an older, sick or disabled family member frequently on a regular basis. Such young people are named “young carers” (YC) (Aldridge and Becker, 1993; Becker 2000). The group of young caregivers (YCs), also includes youngsters in the middle adolescence phase i.e. aged 15-17: they are termed Adolescents Young Carers (AYCs) (Teipel, 2013). The involvement of minors in caring for an older family member is related to population ageing trends (Eurostat, 2020) and the increasing connected demand for LTC (European Commission and Social Protection Committee, 2021), especially in countries with low-developed LTC systems. AYCs provide care to one or more family member(s) or close friend(s) and often carry out significant or substantial caring activities (Becker, 1995; Becker, 2000; Aldridge and Becker, 2003), without receiving any training for their caring role (Joseph et al., 2020). There are few cross-country and large sample research studies on (A)YCs. The figures reported in available national studies suggest that the prevalence of (A)YCs is between 2% and 8% of all children, young people, and young adults in advanced industrialized capitalist societies (Leu and Becker, 2019). Nevertheless, these are rough estimates of the prevalence of (A)YCs in the whole young population because every national study adopted a different definition of caring and (A)YC, and a different methodology to identify and count them (e.g., the age range) (Leu and Becker, 2019). However, results collected at the national level seem to suggest that caring for a sick or disabled family member during adolescence and youth is quite a common phenomenon (Leu et al., 2018). Generally, AYCs of GrPs are under-represented in international social research (D’Amen et al., 2021).

1.3.2 Policy response and support services targeting informal caregivers in Germany and in Italy

The German law recognizes informal caregivers (social law XI §19), which defines them as people who provide non-professional home care to others in need of LTC due to a physical, mental or emotional illness or disability. Social protection services will only address the needs of caregivers if they provide at least 14 hours of weekly care to a care-dependent person (Eurocarers, 2021). Since January 1st 2013, to fulfil the minimum of 14 hours a week, the informal care provided to more than one beneficiary can be added up. The long-term care insurance (LTCI) of the person in need of care pays the contributions to social protection insurance (SPI) for the ICG, if the latter lives in European Economic Area or in Switzerland, cares for at least 60 days per year, s/he is not gainfully employed for more than 30 hours per week, and is not receiving a full old-age pension (European Commission, 2018). Moreover, since 2008, LTCI organisations have been obliged to offer free training courses in LTC for ICGs and counselling. This service is provided by case managers employed by LTCI funds at a long-term care support basis or through qualified experts (Eurocarers, 2021). Since 2011, the German Federal Ministry of Family Affairs, Senior Citizens, Women and Youth operates a counselling hotline (“Pflegetelefon”) for ICGs (Ibidem). The Act to Reorient the LTCI (“Pflege-Neuausrichtungsgesetz” – PNG) came into effect partly on the 30th of October 2012 and on the 1st of January 2013, respectively improved, among others, the benefits of respite care and short-term residential care for persons receiving care allowance. If the ICG gets sick or goes on holiday, the LTCI pays benefits for up to four weeks of respite or short-term residential care (European Commission, 2018). Since 2008, ICGs working as employees in companies employing more than 15 people can benefit from an unpaid leave from work of up to six months with continued social insurance coverage (Act on Caregiving Leave) (Frisina Doetter and Rothgang, 2017). The Care Leave Act of 2015 (‘Pflegezeitgesetz’) introduced a wage compensation for acute care leave of up to 10 days (typically 90% of net earnings), available through LTCI in the form of “Pflegeunterstützungsgeld” or “care support payments” (Davare, 2022). Furthermore, the Family Care Act, came into force in 2012, establishes that ICGs living with a family member in need of care can reduce their working hours to a minimum of 15 hours per week over a maximum duration of two years (Ibidem).

The condition of ICGs living in Italy is consistently different. In this country, there is not a national frame law recognising the ICGs. In August 2019, a bill entitled “Disposizioni per il riconoscimento ed il sostegno del

caregiver familiari” was submitted at the national Parliament. Instead, it was a unified proposal, combining all the proposals submitted in the previous year. The bill intends to systematise and recognise carers' activities more explicitly and formally than in the present legislation. Unfortunately, the COVID-19 outbreak and the political crisis overshadowed the discussion and approval of this law. Nevertheless, some Regional Authorities e.g., Emilia-Romagna, Lombardia, and Umbria, approved regional laws recognising the role of ICGs and/or promoting financial support measures e.g. Marche Region (Eurocarers, 2021).

The lack of a national law recognising the role of the ICGs and guaranteeing their rights means that there is not an integrated system of psycho-social supports explicitly addressed to the ICGs, such as training on LTC, counselling, psychological support and respite care. However, there are self-help groups and emotional support groups promoted by day-care centres and carers' associations at local level. These interventions, although valuable, do not guarantee help continuity and are not part of an integrated network of social, psychological and health services.

Concerning working caregivers, according to the Law 104/1992, care leave is granted only to public and private employees (the self-employed and those employed in domestic and household services are excluded), who have to care for severely disabled relatives. Working caregivers are entitled to two different types of care leaves: 3 working days of paid leave per month for short-term leave at the condition that the ICG is a close relative of the person with the disability even when not co-habiting; up to 2 years of paid leave for longer leave provisions to care for a seriously disabled child or relative. The leave is paid at 100% of earnings up to an annual ceiling (adapted over time according to inflation), in the case that ICG lives under the same roof as the person in need of care.

Law No 183/2010 introduced the principle of “sole carer”, which means that in a household, only one worker can attend to the needs of a severely disabled person (European Commission, 2016).

On 10 October 2022, the “Delegated Law Design on Older People (“Disegno di Legge recante deleghe al governo in materia di politiche in favore delle persone anziane”, hereafter DLD, also in implementation of mission 5, component 2, reform 2, of the “National Recovery and Resilience Plan on care for the dependent elderly” was approved by Parliament, which promotes integrated forms of support for ICGs and their involvement in social and health programming. The DLD introduces important novelties for ICGs of dependent older people. The first is their recognition as the direct recipients of health and psychological assessment for drafting an individualised care plan, policies aimed at social and welfare protection, certification of care skills, and work reintegration measures.

Concerning AYCs, there are different responses to them across the European countries, varying from a clear recognition, protection and support in policy and legislation (e.g. in UK) through non-specific legislation that somehow can be extended to them, such for example, laws for the protection of minors and children or the families (e.g. in Italy), to a total lack of recognition and support (e.g. in Slovenia) (Leu et al., 2022). However, irrespective of current measures in place in the different European countries, (A)YCs are often not recognised and fall through gaps in policy and legal safety nets (Ibidem).

1.4. Intergenerational caregiving outcomes on informal caregivers' health in ordinary and pandemic stress-time

Previous research on (older) adult ICGs has demonstrated that the negative aspects of informal intergenerational caregiving are associated with depression, anxiety, stress, morbidity, physical problems and low quality of life (especially when they take care of older relatives with dementia) (Hooker et al., 2002; Del-Pino-Casado et al., 2019). Caregiving responsibilities (e.g., moving, toileting, feeding, cleaning the care recipient and administering drugs) can represent a risk for ICGs' overall health (i.e., physical and mental well-

being) (Pinquart and Sörensen, 2011; Santini et al., 2016; Verbakel, 2018; Bom et al., 2019; Barbosa et al., 2020). This risk can vary with the caregivers' age; older caregivers may cope better with caregiving responsibilities than younger ones (Mohanty and Niyonsenga, 2019). Moreover, ICGs' overall health varies with the living condition; it may worsen when the caregiver cohabits with the care recipient (Litwin et al., 2014). Caregiving can also lead to difficulties in social inclusion and participation (Greenwood, 2019) and especially middle-aged ICGs, playing multiple roles within the household as parents of adolescent and/or young children, daughter and son and/or daughter/son-in-law, may be penalized in labour market participation, due to the difficulties in reconciling paid work and care duties (Censis-AIMA, 2016; Ikeda, 2017; Socci et al., 2021)

AYCs of GrPs perform instrumental activities of daily living and provide companionship and emotional support (Dellmann-Jenkins and Brittain, 2003; Orel and Dupuy, 2002). They can adopt the role of the primary or auxiliary carer, especially in multigenerational families (Orel and Dupuy, 2002).

AYCs (of GrPs) can experience both positive and negative caregiving outcomes. Positive outcomes include soft skills such as maturity (Fives et al., 2013), resilience in the face of difficulties (Svanberg et al., 2010), empathy (Stamatopoulos, 2018), and better self-efficacy (Frauhaus et al., 2006). Conversely, negative outcomes include frustration and stress, mental health problems (Carers Trust, 2016), and poor well-being (Cohen et al., 2012; Doran et al., 2003), in addition to the risk of experiencing inequalities in accessing health services (Hamilton, 2013), and of having fewer education and employment opportunities in the long-term (Kaiser and Shulze, 2015; Kettell, 2018; Kavanaugh et al., 2016). In addition, AYC often face numerous challenges at school, such as tardiness and/or absenteeism, and difficulties in completing or carrying out homework and meeting deadlines (Siskowsky, 2006).

AYCs of GrPs seem to experience more positive caring outcomes than AYC of other care recipients e.g., parents and siblings (Orel and Dupuy, 2002; Santini et al., 2020). This could be related to the auxiliary role in providing support to parents who are primary caregivers and/or due to feelings of affection towards grandparents and the desire to return the help received in childhood, which may mitigate the negative effects of caregiving (Santini et al., 2020).

The COVID-19 outbreak has worsened the health condition and quality of life of ICGs of older people. That entailed the cancellation and/or the postponement of many social and health care services targeted to older people, e.g., daycare centres and home care services, the adoption of contingency measures for nursing care homes (e.g., relatives' visit interruptions) and a range of restrictions affecting social life (better known as "stay at home measures"). The latter exacerbated situations of social isolation and worsening mental health, already evident among ICGs before the Pandemic, especially among those with limited technological skills, as they cannot benefit from the extensive opportunities to connect with others via the internet or social media (Sumner et al., 2020).

The Government Responses Stringency Index (GRSI) (Hale, 2020), collecting systematic information on policy measures that governments have taken to tackle COVID-19, has different scores across European countries. However, German and Italian government responses show similar scores, presenting a maximum difference of three points over the outbreak, except for the periods around 21 March 2020, when the government response stringency level was 68.06 in Germany and 91.67 in Italy; on 21 March 2021, when it was 75 and 84.26, and on 17 September 2021, when it was 56 and 68.98 in Germany and Italy, respectively. Moreover, German and Italian governments adopted "*extensive restrictions for isolation and hygiene in Long-Term Care facilities, by prohibiting all non-essential external visitors, and/or requiring all community-dwelling older people to stay at home and not leave home with minimal exceptions and receive no external visitors*" (Hale, 2020).

The interruption, postponement and cancellation of social, health and community services for older people with LTC needs and for ICGs made the latter feel alone (CIRCLE, 2020) and entailed the increase of

prevalence and intensity, or the change of caring activities carried out by informal caregivers (Lightfoot and Moone, 2020) with a dramatic impact on their physical health and mental well-being (Carers UK, 2020; Giebel et al., 2021; Gräler et al., 2020; Maccora et al., 2020; Lorenz-Dant, 2020; Phillips et al., 2020; Rothgang et al., 2020). In many countries, they experienced a great increase in their psychological and physical burden (Giebel, 2021) as well as stress and anxiety (Vahia et al., 2020). This is also the case for Italy and Germany (Kostiál, 2021), where lockdowns caused a shortfall in private and semi-formal care services, e.g. MCWs, especially during the peak of the infection, namely between March and June 2020. (Leiblfinger et al., 2020; Schmidt et al., 2020).

Recent studies (Gräler et al., 2020; Kent et al., 2020) have highlighted several stressors for ICGs, as a consequence of the COVID-19 outbreak, as emotional stress, health stress (due to the reduced access to healthcare services during the Pandemic) (Onwumere, 2021) and social isolation. In addition, many informal caregivers reported worse health conditions and quality of life as a consequence of the outbreak in different European countries (Lightfoot and Moon, 2020; Phillips et al., 2020; Carers UK, 2020), and evidence shows that this occurred more strongly than among non-caregivers (Rodrigues et al., 2021).

During the Pandemic, adults' difficulties in reconciling work and care responsibilities and the closure of schools confining children and adolescents at home, increased the involvement of young people in the assistance of older family members living in the same household (Lightfoot and Moon, 2020; Phillips et al., 2020). However, these restrictions prevented them from meeting their own mental health needs and managing homeschooling requirements (Blake-Holmes and McGowan, 2022). A recent longitudinal study on young Italian caregivers (aged 18-29) (Landi et al., 2022), showed that insufficient home space and greater time spent working and learning from home were significantly correlated with higher caregiving responsibilities during the COVID-19 outbreak. The same study highlighted that young adult caregivers reported higher caregiving responsibilities than non-carers and that caregiving responsibilities were longitudinally related to poorer mental health outcomes, operationalised as higher fear of the virus, anxiety, depression and lower well-being.

1.5. Caregiving stress models

Since COVID-19 represented an additional stressor for ICGs, the most accredited caregivers' stress models are briefly described in this paragraph.

Interest in ICGs of dependent older persons began in the last decade of the last century when several scholars sought to understand the impact of caregiving on people's physical health and mental well-being. As a result, stressors and stress-mitigating factors of caregiving have been the object of study as well as the processes that can lead ICGs of older people to the acceptance of their condition and role and, consequently, to the adoption of effective coping strategies.

One of the first scholars to develop a theoretical paradigm for interpreting the stress process of ICGs of an older person was Leonard Pearlin (Pearlin et al., 1990). The main feature of the conceptual components of his Caregiver's Stress Model (CSM) is to conceive the informal caregiver's stress as a *process*, not as a state or a condition. Consequently, Pearlin is interested not simply in the factors that trigger caregiver's stress, but in how these factors arise and how they stand in relation to each other.

The first element that Pearlin considers and includes in his conceptual framework is the caregiver's economic and social background, i.e., socioeconomic status, family composition, caregiving history, and relationship to the care recipient, access to and the use of resources (named as "network" by the Author). In his model, stressors are conditions, experiences and activities that threaten and fatigue informal caregivers. They can be primary (e.g. behavioural disturbances and level of dependency of the care recipient) and secondary (family conflict, work-life balance, economic problems and social life restrictions) stressors. Coping

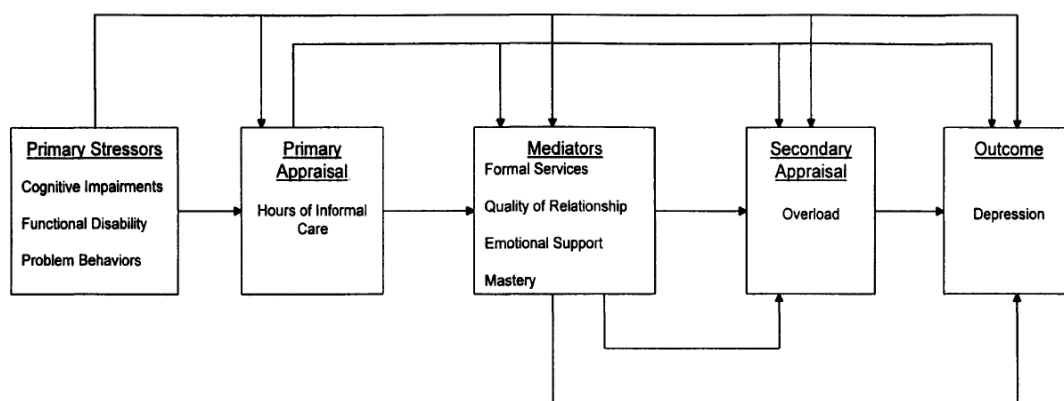
and social support can mediate the stressors power. The exposition to stressors damages ICGs' mental well-being (depression, anxiety, irascibility, cognitive disturbances) and physical health as well as their capabilities to continue carrying on caregiving activities (i.e. yielding of role). Thus, Pearlin argues that ICGs' depression depends mainly on caregiving stressors, e.g. actual tasks and the amount of care.

After and in opposition to Pearlin, Lawton (1989), argued that it is not so much the amount or nature of care activities performed by the caregiver that determines the impact of caregiving on the caregiver's well-being as the perception and meaning attached to them i.e. the "appraisal" of the life experience. This is the caregiver appraisal model (CAM).

Yates (1999) tries to integrate the CSM by Pearlin and the CAM by Lawton in a unique model: the caregiving stress appraisal model (CSAM), thinking that the two models had limitations. In fact, on the one hand, Pearlin does not consider the possible positive effects of caregiving and the nature of the relationship between care provider and care recipient, considering the characteristics of the care recipient exclusively as stressors. On the other hand, in Lawton's framework, the components of appraisal overlap with components of resources and coping strategies.

Yates' CSAM links caregiving stressors, caregiving appraisals and potential mediators to the caregiver's well-being. It includes the condition of the care recipient, namely cognition, functional disability and behavioral problems, as primary stressors. The primary appraisal consists of recognising the older people's care needs, measured through the number of hours of care. The secondary appraisal is the recognition of the overload i.e. the burden that translates into depression. Possible mediators between the first and the second appraisal are formal services, quality of the relationship to the care recipient, emotional support and mastery (Figure 1).

Figure 1 Yates' Caregiver's Stress Appraisal Model (CSAM) (Yate, 1999)



In the Discussion, the CSAM is questioned as a theoretical lens to interpret the experience of today's ICGs of dependent older people and, in light of the results that emerged from the studies described below, a new paradigm is proposed.

2. Study aims, research questions and relevance

2.1 Aims and research questions

Initially, the doctoral work aimed to deepen intergenerational caregiving activities' features in different European countries. Meanwhile, the COVID-19 outbreak hit the world. So I wanted to understand how and

to what extent the Pandemic was mining the overall health and well-being of ICGs of older people with a special focus on comparing Germany and Italy.

This dissertation considers the results of four studies: two involving AYC of GrPs in no pandemic time, and two involving adult and older adult ICGs of older people with long-term care needs in pandemic times. In detail:

Study 1-Positive and negative caregiving outcomes on Adolescent Young Caregivers of Grandparents, wants to provide a picture of the experience lived by AYC of grandparents (GrPs) in five European countries. The main research question is: Is there any difference in positive and negative caregiving outcomes between AYC of GrPs and AYC of other care recipients (OCRs)? (Santini et al., 2020).

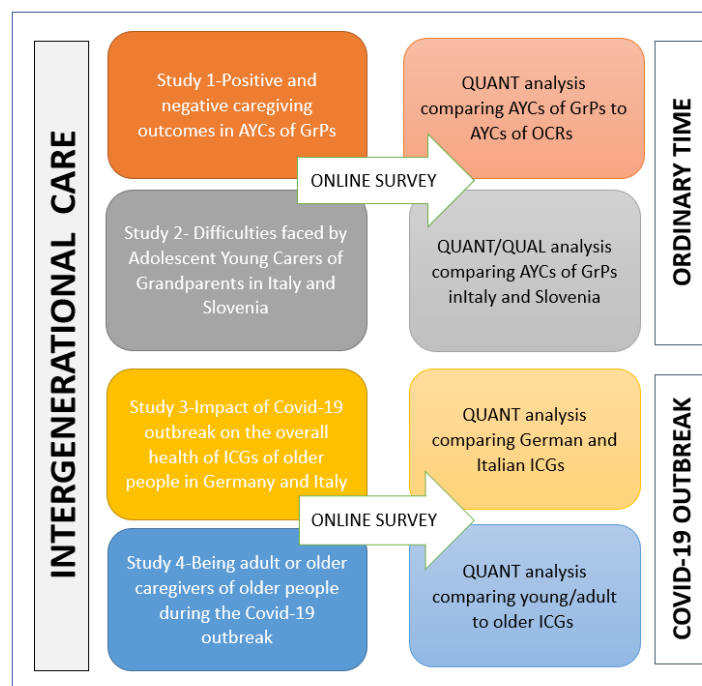
Study 2-Difficulties faced by Adolescent Young Carers of Grandparents in Italy and Slovenia compares the condition of AYC of GrPs in Italy and Slovenia, the two countries with the highest rates of AYC caring for grandparents compared to the other countries surveyed by the European Me-We study, funded by the European Union (Horizon 2020; 2018-2021). The analysis wants to answer the following research question: What are the difficulties and support needs of AYC of GrPs in Italy and in Slovenia? (Santini et al., 2022a)

Study 3- Impact of COVID-19 outbreak on the overall health of informal caregivers of older people seeks to understand the extent to which government-dictated restrictive measures and the discontinuation and/or decrease in many support services for older people with disabilities in Europe have affected the health of informal caregivers living in Germany and Italy. This study aimed to answer the following question: Which factors worsened or mitigated the impact of the COVID-19 outbreak on the overall health of informal caregivers of older people in need of care in Germany and in Italy? (Santini et al., 2022b)

Study 4- Being an adult or an older caregiver of older people during the COVID-19 outbreak seeks to understand whether the Pandemic had a different impact on ACGs compared to OCGs of older people with disabilities. The research in this case is extended to Europe and wants to answer the following research question: Did the outbreak's impact differ among young adult caregivers compared to older caregivers of older people across Europe? (Socci et al., submitted)

Figure 2 provides an overall picture of the four studies.

Figure 2 Dissertation structure (Author's own elaboration)



2.2 Relevance

Study 1-Positive and negative caregiving outcomes on Adolescent Young Caregivers of Grandparents is the first large-scale international study on AYC aged 15–17 years, an under-covered topic in social and health sciences, and the first cross-national study comparing AYC of GrPs with AYC providing care to other care recipients (OCRs). Hence, the findings can enrich the debate on this topic, orienting future policies and research.

Study 2-Difficulties faced by Adolescent Young Carers of Grandparents in Italy and Slovenia

One of the few mixed-method studies focused on and “giving voice” to AYC of GrPs and framing the outcomes in the LTC systems of the two study countries.

The relevance of *Study 3- Impact of COVID-19 outbreak on the overall health of informal caregivers of older people*, lies in comparing the impact of the outbreak on ICGs of older people with LTC needs in Germany and Italy; taking into consideration different LTC systems; involving large samples of informal caregivers.

Study 4- Being an adult or an older caregiver of older people during the COVID-19 outbreak relevance relies on the comparison of the effects of the second Pandemic (Winter of 2020-21), on ACGs vs OCGs of OP, when the consequence of the first and of the following pandemic waves have cumulated over time.

As such, combining the results of the four studies may advance the knowledge on how LTC and public health policies adopted in ordinary and in pandemic times by European Governments at macro social level, influenced the positive and negative outcomes of intergenerational caregiving on ICGs of different ages. Secondary, the studies may contribute to the debate on a new theoretical framework for interpreting intergenerational caregiving in post-pandemic times.

3. Methods

3.1 Participants' recruitment

3.1.1 Studies 1 and 2

The online survey, on which Studies 1 and 2 are based, was carried out between March and October 2018 and targeted adolescents aged 15–17. The data collection sheet was elaborated in English and translated into the study countries' languages. Since this was the first international and large sample survey on AYC in Europe aiming at mapping this phenomenon, the only criteria for being included were being aged between 15–17 years and being available to fill in the questionnaire. Within the samples of the study countries (Italy, the Netherlands, Slovenia, Sweden, Switzerland, the United Kingdom) AYC were identified using two anchoring questions (§ 4.3) and afterwards, a sub-sample of AYC of GrPs was compared to a sub-sample of AYC of OCRs, e.g., parents, siblings, friends. In Italy, Slovenia, and Switzerland, respondents were mainly recruited among high school students. In the Netherlands, participants were recruited through schools, care support centers, patient and carer organizations, and social media channels. In Sweden, the youngsters were reached in schools, social care, and civil society organizations. In the United Kingdom (UK), where there is a high level of awareness on the topic and wide availability of specialized non-governmental organizations for young carers, the recruitment took place mainly through young carers projects and a small number of schools.

3.1.2 Studies 3 and 4

Respondents of Studies 3 and 4 were mainly recruited by means of dissemination activities carried out through websites, social media channels (mainly on Twitter and Facebook groups or pages targeting informal caregivers and cared-for persons), local charities, webinars, and welfare or voluntary organizations at national, regional, or local levels. These procedures were repeated regularly between November 2020 and March 2021. The only inclusion criterion was providing regular care and/or support (i.e. not occasional or temporary) to one or more people with their daily activities, personal care, or other ways due to their physical or mental illness, disability or old age. Study 3 and 4 focussed on sub-samples of ICGs of OP with LTC needs.

3.2 Data Collection Procedures

3.2.1 Studies 1 and 2

The first survey (hereafter Me-We survey) was targeted to AYCs and collected data analysed by studies 1 and 2. The second survey (hereafter COVID-19) was targeted to ICGs of OP with LTC needs and provided data analysed in studies 3 and 4.

The Me-We survey was carried out using the 1ka online platform to guarantee participants' anonymity and privacy on different electronic devices, e.g., personal computers, laptops, tablets, and smartphones. In some cases, data collection in school settings required a *paper and pencil* data collection mode due to the large number of participants encountered in school classrooms and the limited availability of electronic devices. The original English version of the questionnaire was translated into the national languages independently by two researchers per national team and revised by a third national team member.

3.2.2 Studies 3 and 4

The COVID-19 survey was carried out between November 2020 and March 2021 and promoted by Eurocarers. It was available in 10 European languages (i.e., Czech, English, Estonian, Finnish, Finnish/Swedish, French, German, Italian, Portuguese, and Swedish): the original questionnaire English version was translated into the national languages independently by volunteer scholars cooperating with Eurocarers.

3.3 Data collection tools and outcome measures

3.3.1 Studies 1 and 2

The questionnaire used by Studies 1 and 2 comprised four sections: (1) demographic and caregiving information, (2) impact of caring on education and available support services, (3) open-ended questions for collecting suggestions on needs and valuable supports for AYCs and (4) feedback on questionnaire compilation. Study 1 analysed data collected through sections one and two, while Study 2 focussed on data collected through sections three and four.

The first section began with questions about age, gender, country of birth, nationality, living condition, migration background, family composition, and caregiving hours per day. Then, in order to evaluate the effects of caregiving activity on younger people, the following self-reported measures were applied: "Multidimensional Assessment of Caring Activities" (MACA-YC18) (Joseph et al., 2009), "Positive and Negative Outcomes of Caring" (PANOC-YC20) (Joseph et al., 2009), "KIDSCREEN-10" (Ravens-Sieberer et al., 2010), and "Health problems in connection with caring", which was an ad hoc developed single-item

measure. To identify AYC's among all the surveyed adolescents, a question about a family member or friend having a health related-condition was asked, followed by an additional anchoring question, i.e., "Do you provide care, support, or assistance to a family member or friend because of their health-related condition?". It was followed by questions defining caregiving hours per day and profiling the relationship to the care recipient/s (e.g., mother, father, grandmother, grandfather, boyfriend, classmate), their health-related condition and level of impairment. All respondents then replied to both the MACA-YC18 and PANOC-YC20, and to the item on health problems in connection with caring.

MACA-YC18 is an 18-item self-report questionnaire asking young people about the type and frequency of their caring activities (items are rated on a 3-point scale where "never" = 0, "some of the time" = 1, and "a lot of time" = 2). An overall score is calculated ranging from 0 to 36. PANOC-YC20 is a 20-item self-report measure that indexes of care provision's positive and negative outcomes, ranging from 0 to 20. Each item is rated on a 3-point scale: "never" = 0, "some of the time" = 1, and "a lot of the time" = 2. KIDSCREEN-10, a 10-item measure of the health-related quality of life standard, ranging from 10 to 50 was also applied. Each item is answered on a 5-point intensity or frequency response scale. AYC's were also asked to report if they suffered from physical (e.g., back pain, headache, muscle tension), psychological (e.g., anxiety, depression), or other health problems related to care activity provided by answering a multiple-choice question.

The second section of the questionnaire included dichotomous and multiple-choice questions about the impact of caregiving on education and the support available for AYC's and their families, both formal (e.g., statutory agency/supportive governmental programs, services, and state monetary benefits) and informal (e.g., help from other family members, friends, neighbors).

The third and fourth sections of the questionnaire included open-ended questions aimed at collecting AYC's' emotions, difficulties, and suggestions for improving available support.

3.3.2 Studies 3 and 4

The questionnaire of Studies 3 and 4 included multiple choice questions and moved through six thematic areas: 1) caregivers and care recipients' socio-demographic information; 2) the impact of COVID-19 on the caregivers' health status and on the caring situation; 3) the availability and use of social and health services both for caregivers and for care recipients; 4) caregivers' employment and economic status; 5) the use of technology during the outbreak; 6) caregivers' suggestions on how to improve social and health care services for better supporting them during the outbreak and beyond.

Study 3 outcome variable is the response to the question, "Considering your current situation, compared to before the Pandemic, how has the Pandemic impacted your overall health status?". Respondents had three options for answering: "my overall health status... 1) improved; 2) did not change; 3) worsened". We dichotomized this variable into "My overall health status improved/did not change" vs. "My overall health status worsened".

Here other variables used for the analysis are just listed: details on how some of them were created/calculated are available in Study 3 enclosed at the end of this document. "Caregiving (post-pre difference in hours of care)"; "Service provision (Continuity)"; "Formal social and health service provision (Discontinuity)"; "Service provision (Continuity)"; "Formal support effectiveness (at least 1 very/extremely)"; "Informal support effectiveness (at least 1 very/extremely)"; "Living condition".

The analysis of Study 4 focused on the responses of the surveyed informal caregivers of older people to the following question: "Considering your current situation compared to before the Pandemic, how has the COVID-19 outbreak impacted the following aspects of your life?" (RQ1). After an initial overall evaluation of all the above items (i-vi), we focused on the main aspects of the caregiver's well-being: health status (distinguishing between physical and psychological) and quality of life. Respondents were asked to indicate

if the corresponding situation has improved, has not changed, or has worsened. Three answer options were available: e.g. “my physical condition/mental health-psychological state of mind/quality of life” “improved”, “did not change”, “or worsened”. All the answers to these questions were recoded, assuming 1 if the situation has worsened and 0 in all other cases.

For identifying “new informal caregivers” due to the Pandemic, respondents were asked the following anchoring question: “Have you started providing care to someone as a result of the COVID-19 outbreak?” (RQ2) (answer categories Yes/No).

3.4 Data Analysis

3.4.1 Study 1-Positive and negative caregiving outcomes on Adolescent Young Caregivers of Grandparents (Santini et al., 2020)

Preliminary analyses included test of differences between the two groups (i.e., AYC of GrPs, and AYC of OCRs) using t-test for continuous variables (i.e., scores on the MACA-YC18, PANOC-YC20 Negative, PANOC-YC20 Positive, KIDSCREEN-10) and chi-square tests for the dichotomous variable (i.e., self-reported health problems in connection to the caring role). Among all outcomes, only those statistically significant in the previous analysis were kept for the multivariate analysis. In addition, linear or logistic regression models (depending on the type of dependent variable) were built to estimate the association between caring for GrPs and health and well-being outcomes in AYC, taking into account potential confounders (age, gender, hours a day spent providing care, country of birth, formal services). Finally, multivariate analyses were repeated, including a fixed effect regression model on the country variable. A 2-tailed p-value <0.05 was considered significant. In order to avoid heteroskedasticity issues and to accept the constant variance assumption, robust standard errors were applied using White’s procedure. Moreover, to detect collinearity of the regressors with the constant, variance inflation factors (VIFs) were calculated, confirming that no collinearity issue could be raised. Data were analyzed using STATA version 15.1 (StataCorp, College Station, TX, USA).

3.4.2 Study 2-Difficulties faced by Adolescent Young Carers of Grandparents in Italy and Slovenia (Santini et al., 2022a)

This study compares the situation of AYC of GrPs in Italy and Slovenia that emerged from an online survey carried out in six European countries within the mentioned EU-funded project “Me-We” (Hanson et al., 2022). Italy and Slovenia represented the two countries with higher numbers of AYC of GrPs among the study respondents, whose percentages within the national samples were 36.3% and 28.3%, respectively, in comparison with 10.1% in the Swedish, 9.4% in the English, 9.4% in the Dutch, and 6.5% in the Swiss samples. In this study, a mixed-methods (MM) design (Creswell and Clark, 2017) was adopted by coupling qualitative (QUAL) with quantitative (QUANT) findings such that the QUAL data could provide country-contextual data for enriching the interpretation of the QUANT data in each respective country. Furthermore, this study employs a triangulation design, more specifically validating the QUANT data model, as open-ended questions were embedded within a larger quantitative survey. QUANT and QUAL data were analysed separately and then integrated while contrasting and comparing each phase's results. The QUANT data quantified the impact of caring on AYC’s lives, e.g., AYC’s health condition, well-being, and school performance. The QUAL findings provided the country’s context with regard to care and information on the condition of AYC of GrPs living in the two countries, thus expanding and supporting the quantitative analysis.

Concerning QUANT measures, continuous variables were reported as mean and standard deviation (SD); comparison of variables between groups was performed by unpaired Student's t-test or one-way analysis of variance (ANOVA), as appropriate. Categorical variables were expressed as the absolute number and percentage, and statistical significance was assessed by Pearson's Chi-square test. The statistical significance for this study was set at $p < 0.05$. Statistical analyses were conducted using the Stata 15.1 Software Package for Windows (StataCorp., College Station, TX, USA).

The QUAL responses were content analysed by applying an open coding process (Strauss and Corbin, 1998), a method through which concepts and their dimensions are identified and discovered directly from the qualitative data. Following this process, categories referring to the same phenomenon were grouped into sub-categories and these were subsequently grouped into higher-order categories, with the support of MAXQDA 2020 software to provide a clear description of the findings with a focus on a comparison between the Italian and Slovenian AYC respondents.

The trustworthiness of the qualitative elements of the study (i.e., credibility, dependability, transferability) was reached by ensuring methodological rigor and internal process assessment as recommended by literature on social sciences research methodology (Lincoln and Guba, 1985; Golafshani, 2003; Shenton, 2004).

3.4.3 Study 3- Impact of COVID-19 outbreak on the overall health of informal caregivers of older people (Santini et al., 2022b).

ICGs and care recipients' characteristics, divided by country, were compared using the chi-square test for categorical variables and the Student's t-test for continuous variables. Data are reported as means (\pm SD) for continuous variables and as absolute frequencies for categorical variables. Thus, we compared subjects according to the outcome variable "overall health status" (improved/did not change vs. worsened) and to the variable "country" (Germany vs. Italy).

In order to obtain an adjusted estimate of the risk of worsening in overall health status, a logistic regression analysis was performed by country. Initially, we considered only crude models, but then we adjusted for age and gender, and finally, we built a fully adjusted model with only significant variables. A p -value < 0.05 was considered statistically significant. Statistical analysis was carried out using SPSS for Win V24.0 (SPSS Inc., Chicago, IL, USA).

3.4.4 Study 4- Being a young adult or an older caregiver of older people during the COVID-19 outbreak (Socci & Santini, 2023 – submitted)

Normal distribution for continuous variables was assessed using the Shapiro-Wilk test and reported as either mean and standard deviation or median and interquartile range on the basis of their distribution. Comparison of variables between groups was performed according to their distribution by either unpaired Student t-test or Mann-Whitney U test. Categorical variables were expressed as absolute frequency and percentage and analysed by Chi-square test. Given the different levels of data, the statistical model had to consider the existence of a clustered structure (Hox, 1998) since each country has a specific background and people living in the same area tend to experience similarities. Therefore, differences between the two age groups were estimated using multilevel logistic regression, adjusted for all potential confounders in order to allow the decomposition of total variability into a primary level (subject-related variability) and a secondary level (country variability) (Austin et al., 2001).

All analyses were repeated after propensity scores (PS) matching to adjust for the bias inherent to the different respondent characteristics at baseline. A sub-analysis was conducted only for the group of "new

carers". Since this is a small number of subjects, PS-matching was not applied. A 2-tailed P value <.05 was considered significant. Data were analysed using STATA version 15.1 (StataCorp, College Station, TX) (Socci et al., submitted).

3.5 Ethic issues

The data presented in the four studies were processed in full compliance with both national laws on data protection and the General Data Protection and Regulation (European Union, 2016/679; Regulation, G.D.P.R., 2016) to guarantee the respondents' anonymity and privacy. All respondents were recruited on a voluntary basis following the Declaration of Helsinki (World Medical Association, 1964; 2013). Respondents gave informed consent to participate in the study by filling in the questionnaire.

In the case of Studies 1 and 2, ethics approval was obtained from relevant ethical review boards in all six partner countries prior to the start of the data collection. Moreover, an information letter and the first page of the online questionnaire clarified that AYC's participation was voluntary and that they could withdraw at any time without any explanation. Informed consent was also secured from parents/legal guardians, following applicable national legislation and institutional guidance. No data was collected that could lead to any specific individual being identified to protect the youngsters' anonymity fully.

In the case of Studies 3 and 4, electronic consent was requested from respondents before filling in the questionnaire, confirming that participants (1) had read the background information to the study; (2) voluntarily agreed to participate; (3) were at least 18 years old.

4. Results

4.1 Study 1- Positive and negative caregiving outcomes on Adolescent Young Caregivers of Grandparents (Santini et al., 2020)

Out of 817 AYC's, 138 (16.9%) were caring for a GrP (Table 1). The AYC's surveyed were mainly female (72.4% vs 24.7% male, while 2.9% identified themselves as transgender/non-binary) and a similar ratio can be seen among both AYC's of GrPs (76.1% female, 21% male, and 2.9% transgender/non-binary) and of OCRs (71.5% female, 25.5% male, and 3% transgender/non-binary). Within the whole sample, 7.2% of AYC's aged 15 and 46.4% of those aged 16–17, respectively were providing care to a GrP, while 13.8% of respondents aged 15, 43.8% of those aged 16, and 42.4% of those aged 17 were caring for OCRs.

92.3% of the AYC's of OCRs, and 93.5% of the AYC's of GrPs were born in their country of residence. 39% of AYC's of OCRs could count on formal and public care services to support them/their families (e.g., state care allowance and home care services), compared to 26.5% of AYC's of GrPs ($p = 0.005$).

AYC's of OCRs reported caring for four hours a day, about one hour more than AYC's of GrPs, (2.9 h a day on average).

The highest share of AYC's of GrPs, i.e., 36.3%, was from Italy, while 28.3% was from Slovenia.

Table 1 Sample characteristics according to the care recipients: AYC of OCRs and AYC of GrPs, n (%)

	AYCs			p
	Total	OCRs	GrPs	
	817 (100%)	679 (83.1 %)	138 (16.9%)	
Gender				0.536
Male	202(24.7%)	173(25.5%)	29(21.0%)	
Female	591(72.4%)	486(71.5%)	105(76.1%)	
Transgender/non-binary	24(2.9%)	20(3.0%)	4(2.9%)	
Age				0.104
15	104(12.7%)	94(13.8%)	10(7.2%)	
16	361(44.2%)	297(43.8%)	64(46.4%)	
17	352(43.1%)	288(42.4%)	64(46.4%)	
Country of birth %				0.631
National	752(92.5%)	623(92.3%)	129(93.5%)	
Abroad	61(7.5%)	52(7.7%)	9(6.5%)	
Formal support services received by AYC's family				0.005
No	394(49.1%)	310(46.6%)	84(61.8%)	
Yes	296(36.9%)	260(39.0%)	36(26.5%)	
I do not know	112(14.0%)	96(14.4%)	16(11.8%)	
Informal support received by AYC's				0.093
No	570(71.2%)	482(72.4%)	88(65.2%)	
Yes	231(28.8%)	184(27.6%)	47(34.8%)	
Hours a day spent providing care, mean±sd	3.9±5.0	4.0±5.2	2.9±3.6	0.014
Country of residence				<0.001
CH	40(4.9%)	31(4.6%)	9(6.5%)	
IT	116(14.2%)	66(9.7%)	50(36.3%)	
NL	79(9.7%)	66(9.7%)	13(9.4%)	
SE	280(34.3%)	266(39.2%)	14(10.1%)	
SL	135(16.5%)	96(14.1%)	39(28.3%)	
UK	167(20.4%)	154(22.7%)	13(9.4%)	

Note: data are n (%) where not specified

AYCs of OCRs and AYC of GPs did not differ in the amount of caring activities (MACA-YC18) or in health-related quality of life (KIDSCREEN). In the PANOC-YC20, AYC of OCRs reported significantly higher negative outcomes and significantly lower positive outcomes (PANOC-YC20) than AYC of GrPs: linear and logistic regression show that caring for GrPs was associated with lower negative and higher positive outcomes, while it was unrelated to health problems. Detailed data are reported in Table 2 of the published scientific paper based on Study 1 enclosed at the end of this document.

Table 2 shows the linear and logistic regression results between the exposition variable (in column) and the two outcome variables PANOC-YC20 and Health problems related to caring responsibilities (in the rows). In this table and in the following, MACA-YC18 and KIDSCREEN-10 are not included due to the lack of statistical significance at multivariate or already at descriptive levels.

Caring for GrPs was associated with lower negative and higher positive outcomes, unrelated to caregiving-related health problems. The age of AYC is not associated with caregiving outcomes or health status. Being female or transgender/non-binary AYC is positively associated with experiencing both more negative outcomes of caring and health problems due to caregiving compared to male AYC. The greater the number of hours of assistance per day, the more likely that AYC report negative outcomes and a one-unit

increase in hours of assistance per day was associated with a 6% increase in the odds of reporting health problems due to caregiving. Moreover, having a migrant background was associated with greater negative care outcomes, but was not associated with positive ones or health problems.

Table 2 Exposure factors to positive and negative caregiving outcomes and health problems among AYC of OCRs and AYC of GrPs (n=817)

Exposure factors	PANOC-YC20 Negative Outcomes		PANOC-YC20 Positive Outcomes		Health problems in connection to care role	
	β	P	β	p	OR	p
Caring for GrPs (ref. No)	-1.09	0.010	1.20	0.008	0.94	0.765
Age (ref.15)						
16	-0.76	0.159	0.49	0.330	0.76	0.245
17	-0.75	0.157	0.68	0.179	0.77	0.278
Gender (ref. Male)						
Female	0.90	0.021	0.41	0.275	1.53	0.016
Transgender/non-binary	3.50	0.006	-1.76	0.127	4.71	0.002
Hours a day spent providing care	0.22	<0.001	0.01	0.721	1.07	<0.001
Country of birth (ref. National)						
Abroad	2.49	<0.001	0.36	0.560	1.30	0.382
Formal services (ref.No)						
Yes	1.86	<0.001	-0.38	0.292	1.79	<0.001
Don't know	1.38	0.007	-0.58	0.256	0.84	0.457
Constant	3.71	<0.001	11.89	<0.001	0.43	0.003
R ²	0.139		0.025		0.059	

Notes: data are coefficients (β), odds ratios (OR) and level of statistical significance (p). Robust standard errors were applied. Mean Variance Inflation Factors (VIFs) for the models was 1.34 (range: 1.02-2.58).

Noteworthy, when the country variable is included in the regression model, gender, the amount of daily care hours and migration background continue to be related to both negative outcomes and health problems. The data variation after the inclusion of the country variable in the regression model is reported in Table 4 of Santini et al., 2020.

4.2 Study 2- Difficulties faced by Adolescent Young Carers of Grandparents in Italy and Slovenia (Santini et al., 2022a)

4.2.1 QUANT analysis

Study 2 sample is comprised of 162 AYC caring for GrPs, 87 from Italy and 75 from Slovenia, respectively (Table 3). Female participants represented 79% of the whole sample, with a statistically significant difference between the two study countries. In fact, female respondents constituted more than 93% of the sample in Slovenia compared to 66.7% in Italy. In Italy, the AYC were mainly aged seventeen years (48.3%), while in

Slovenia, they were sixteen years (53.3%). In both Italy and Slovenia, AYC's were born in the same country where they resided. 64.0% of Slovenian respondents lived with grandparent(s) compared to 19.5% of Italians.

Italian and Slovenian AYC's provided 2.7 and 2.3 hours of care per day to their GrPs, respectively. The most common diseases among the GrPs of the surveyed AYC's, were physical disability (more than 62% in both countries), cognitive impairment (35.6% in Italy and 25.3% in Slovenia), and mental illness (20.7% in Italy and 24% in Slovenia), without any statistical significance.

Table 3 Respondents' characteristics by country and GrPs' disease/s

	AYCs			P
	Total	Italy	Slovenia	
Gender, n(%)	162 (100%)	87 (53.7%)	75 (46.3%)	<0.001
Male	30 (18.5%)	27 (31.0%)	3 (4.0%)	
Female	128 (79.0%)	58 (66.7%)	70 (93.3%)	
Transgender/non-binary	4 (2.5%)	2 (2.3%)	2 (2.7%)	
Age, n(%)				0.006
15	10 (6.2%)	10 (11.5%)	0 (0.0%)	
16	75 (46.3%)	35 (40.2%)	40 (53.3%)	
17	77 (47.5%)	42 (48.3%)	35 (46.7%)	
Country of birth, n(%)				0.020
National	156 (96.3%)	81 (93.1%)	75 (100.0%)	
Abroad	6 (3.7%)	6 (6.9%)	0 (0.0%)	
Living with the grandparent(s), n(%)	65 (40.1%)	17 (19.5%)	48 (64.0%)	0.000
Hours a day spent providing care, n(%)	2.5 ± 2.6	2.7 ± 2.6	2.3 ± 2.6	0.421
GrPs' disease(s)*				
Physical disability, n(%)	102(63.0%)	54(62.1%)	48(64.0%)	0.800
Cognitive impairment, n(%)	50(30.9%)	31(35.6%)	19(25.3%)	0.157
Mental illness, n(%)	36(22.2%)	18(20.7%)	18(24.0%)	0.613
Other, n(%)	38(23.5%)	14(16.1%)	24(32.0%)	0.017
Addiction (e.g., drugs, alcohol), n(%)	12(7.4%)	7(8.1%)	5(6.7%)	0.738

*More than one choice possible

Approximately one-third of Slovenian and Italian AYC's reported health problems because of their caregiving activities (Table 4). Italian and Slovenian AYC's of GrPs reported a medium caring activity (MACA) score ranging from 10 to 13. Interestingly, positive caregiving outcomes (PANOC-Pos) prevailed on negatives ones in both the sample groups and Slovenian AYC's experienced more positive caregiving outcomes than Italian AYC's (p=0.048). The KIDSCREEN-10 score indicates that both Italian and Slovenian AYC's felt quite happy, physically healthy and satisfied with life. Nevertheless, Slovenian respondents reported a worse health-related quality of life compared to Italian peers with a statistically significant difference even if with a score near the upper limits of the significance threshold (p=0.004).

More than 73% of Slovenian and nearly half of Italian respondents reported not receiving formal support. However, among AYC's of GrPs receiving formal support, those living in Slovenia did not receive as much formal support as AYC's in Italy (the difference is statistically significant, p=0.003). Only approximately one-third of the two sample groups received informal help e.g., from other family members and neighbours.

Table 4 Caregiving outcomes and support services received by AYC's of GrPs

	AYCs of GrPs			p
	Total N=162	Italy N=87	Slovenia N=75	
Health problems, n(%)	55 (33.9%)	28 (32.2%)	23 (36.0%)	0.609
MACA score, mean±sd	11.9 ± 4.9	10.8 ± 4.2	13.4 ± 5.2	0.001
PANOC-Pos, mean±sd	14.5 ± 4.1	13.9 ± 4.2	15.4 ± 3.7	0.048
PANOC-Neg, mean±sd	2.8 ± 3.4	2.6 ± 3.2	3.2 ± 3.5	0.376
KIDSCREEN, mean±sd	33.2 ± 6.8	34.7 ± 6.7	31.4 ± 6.5	0.004
Formal support services received by AYC's' family, n(%)				0.003
No	98 (60.5%)	43 (49.4%)	55 (73.3%)	
Yes	33 (20.4%)	20 (23.0%)	13 (17.3%)	

I do not know	31 (19.1%)	24 (27.6%)	9 (9.4%)	
Informal help, n(%)	49 (32.2%)	28 (33.3%)	21 (30.9%)	0.748

p values chi square and t-test as appropriate

Slovenian AYCs receiving formal help reported more health problems, provided more hours of care, had more negative caregiving outcomes (PANOC-Neg), and received informal support significantly more often than AYCs who do not receive formal support. AYCs' health condition by received formal support, are fully reported in Table 3 of Santini et al., 2022.

4.2.2 QUAL analysis

The QUAL analysis shows that the surveyed Italian AYCs mostly required material support, including general and physical help, financial support and information and training, as depicted in the following quotations:

"I really need someone to help me assist the sick person"

"Financial support from the state since the merits and above all the great sacrifice of a boy who puts the lives of others first than his must be recognized"

"I would like to receive advice on how to better organize my day's activities"

"In the role of caregiver I would need a doctor with me to know how to help my grandma with the disease"

Conversely, Slovenian AYCs mostly needed emotional and moral support, especially from peers:

"I need moral support to feel more useful"

"My support could be, my good friends who I can confide in when it gets hard for me"

Both Italian and Slovenian AYCs experienced material difficulties, those faced in helping the care recipient with moving and handling and in managing therapy, including specific complications in managing care recipient's therapy:

"The main difficulty I face is changing the Stoma bag" (Slovenian respondent)

"Insecurities about the right medicines to make my grandfather take" (Italian respondent)

They also experienced difficulties in helping the care recipient with moving and handling, related to the relationship between AYCs and GrPs, highlighting the physical burden as a consequence of the age/weight gap and of the difficulty of moving a disabled and "uncooperative" grandparent safely:

"Her body weight is heavy for me and the smell of certain leakages is disgusting" (Italian respondent)

"The main problem is that I have problems lifting a person, that's why I also have back problems" (Slovenian respondent)

Financial constrains and difficulties in helping parent's life-work balance are specific to the Italian respondents. These often referred to practical challenges and logistical aspects, as shown in the following quotations:

"I think the Government should help more informal caregivers because you can often feel that you're not able to assist someone else due to financial constraints e.g. treatments, facilities, visits, medicines, etc ...)"

"Sometimes I also go to work with mom to help her and so it's difficult to combine study, care and work"

Slovenian respondents reported difficulties in the management of school life, as expressed by the sub-category "School problems": *"When I want to study someone always bothers me and that's when I lose my concentration"*

Italian AYCs would be content to receive some understanding from teachers: *"A little company and a form of empathy from the teachers would help me"*

They also referred communication difficulties, including difficulties in "conversing and talking" together with the care recipient/s and in "understanding" the care recipient's requests and problems:

*“Repeating things over and over to make them understand”
 “Understanding their problems and understanding how to help them not to think about it”
 “I find it difficult to understand my grandma: she has speech and hearing difficulties”*

Communication barriers made them feel uncomfortable and sad, and fear of not managing to take care:

*“I simply feel deeply sad to see my paternal grandparents in the state they are, suffering from dementia”
 “I’m worried that I can’t take good care of them”*

Slovenian respondents mainly underlined the difficulties in managing grandparents’ behavioural characteristics:

“Grandmother is sometimes grumpy if all things aren’t as she says, she complains a lot if I don’t have time to, and my brother could help because he’s on his computer most of the time, (she) is mad at me, insults me; she doesn’t think of the help from my younger brother” (Slovenian respondent).

4.3 Study 3- Impact of COVID-19 outbreak on the overall health of informal caregivers of older people (Santini et al., 2022b)

The overall sample was made of 319 ICGs of older people with LTC needs, 146 from Germany and 173 from Italy (Table 5). In both countries, respondents were mostly females (about 89% in Germany and 78% in Italy), and the mean age was about 55 years. Italian caregivers had a (statistically significant) higher educational level compared to German ones.

Considering the relationship with the care recipients, despite some country differences, though non-statistically significant, about 71% of the overall sample took care of grandparents and parents (including in-laws), and more than 18% looked after spouses and about 40% of respondents in both the study countries lived with the care recipient.

The majority of care recipients were aged over 80 and female, both in Germany (58%) and—with a higher percentage—in Italy (72%) (Table 5). In Germany, 79% suffered from physical disability, and in Italy more than 67%. In Germany 68.4% and in Italy 61.3% of older care recipients also reported psychological or mental issues, such as depression or anxiety. In both countries, about 7 older care recipients out of 10 had cognitive impairment (i.e., dementia and memory loss problems), and about 3 out of 10 had neurological disabilities (other than dementia or memory problems). Finally, more than 75% of care recipients in Germany and 63% in Italy suffered from chronic illness (e.g., diabetes and cancer) and 68.7% and 48.8% in Germany and Italy, respectively, from other long-term health conditions.

Table 5 Informal caregivers and older care recipients’ description and living arrangement

	Total (N=319)	Germany (N=146)	Italy (N=173)	p
Informal caregivers				
Gender				0.031
Male	51(16.04%)	15(10.27%)	36(20.93%)	
Female	264(83.02%)	130(89.04%)	134(77.91%)	
Prefer not to say	3(0.94%)	1(0.68%)	2(1.16%)	
Mean age	55.4±11.8	55.6±11.4	55.2±12.2	0.766
Educational level				0.000
Primary education	9(2.82%)	6(4.11%)	3(1.73%)	
Lower secondary education	51(15.99%)	39(26.71%)	12(6.94%)	
Upper secondary education	114(35.74%)	38(26.03%)	76(43.93%)	
Tertiary education	145(45.45%)	63(43.15%)	82(47.4%)	
Caring for				0.117
Grandparent/parent/parent in law	226 (70.8)	97 (66.4)	129 (74.6)	0.112

Spouse/Partner	59 (18.5)	36 (24.7)	23 (13.3)	0.009
Other (e.g. friends, neighbour, ex-spouses/partners)	23 (7.2)	9 (6.2)	14 (8.1)	0.507
Uncle/Aunt	7 (2.2)	3 (2.1)	4 (2.3)	0.876
Brother/Sister or Brother/Sister in law	4 (1.3)	1 (0.7)	3 (1.7)	0.401
Living arrangement in relation to the care recipient				0.015
In the same household	128(40.25%)	57(39.04%)	71(41.28%)	
In different household but in the same building	47(14.78%)	22(15.07%)	25(14.53%)	
Within walking distance	43(13.52%)	14(9.59%)	29(16.86%)	
Not within walking but less than 30 minutes one-way travel	69(21.7%)	30(20.55%)	39(22.67%)	
Between 30 minutes and one hour travelling	18(5.66%)	13(8.9%)	5(2.91%)	
Between one and three hours travelling	7(2.2%)	4(2.74%)	3(1.74%)	
Between three and five hours travelling	6(1.89%)	6(4.11%)	0(0%)	
Mean hours of care provided per week before the COVID-19 outbreak	36.9±50.9	32.4±37.5	40.7±59.8	0.154
Mean hours of care provided per week during the COVID-19 outbreak	45.6±50.0	44.1±44.8	46.8±54.2	0.636
Older care recipients				
Gender				0.029
Male	105(33.1%)	59(40.7%)	46(26.7%)	
Female	208(65.6%)	84(57.9%)	124(72.1%)	
Prefer not to say	4(1.3%)	2(1.4%)	2(1.2%)	
Mean age	81.2±8.1	81.6±8.3	80.9±7.9	0.499
Physical disabilities (caused, e.g. by frailty, accident, injury, illness)	220(73.1%)	111(79.3%)	109(67.7%)	0.024
Psychological/mental health issues (e.g. depression, anxiety, etc.)	191(64.5%)	93(68.4%)	98(61.3%)	0.201
Cognitive impairments (e.g. Alzheimer's, dementia, etc.)	212(70.9%)	104(74.8%)	108(67.5%)	0.165
Neurological disability or learning difficulty (not dementia and memory problems)	98(33.6%)	45(33.1%)	53(34%)	0.873
Other chronic illnesses (e.g. diabetes, heart disease, cancer, etc.)	204(68.7%)	102(75.6%)	102(63%)	0.020
Other long-term health conditions	169(57.7%)	90(68.7%)	79(48.8%)	0.001

German ICGs received double or even triple formal support compared to Italian ones with a statistically significant difference, especially social care, face-to-face help groups; practical help (e.g. preparing meals, laundry, housework, etc.); meal delivery, medications and drugs delivery, transportation and respite care. Full statistics are reported in Table 2 of Santini et al., 2022b.

The logistic regression analysis results concerning predictors of ICGs' change in health status during the Pandemic are reported in Table 6. In Germany, receiving informal support mitigated the risk of overall health worsening (OR=0.45), while psychological/mental health issues of the older care recipients (e.g. depression, anxiety, etc.) increased the risk (OR: 3.01). In addition, living within one hour of travelling to the older care recipient emerged as a possible protective factor for the overall health worsening (OR: 0.39 in the adjusted model), albeit with no statistical significance.

In Italy, discontinuity (i.e. interruption/postponement/cancellation) in formal social and health care services provision was a predictor of worsening of the overall health for ICGs, being associated with an increase of this risk by more than two and a half times on average (OR=2.54). In this country, such a lack of formal support was not counter-balanced by the informal support network, unlike in Germany. Moreover, in Italy, living within walking distance from the care recipient seems to prevent ICGs' health deterioration (OR: 0.40 in the adjusted model).

Table 6 Predictors of informal caregivers' overall health status worsening by country

Predictors	Worsened overall health status OR (95%CI)					
	Crude Model	Germany Age and gender adjusted Model	Fully adjusted Model*	Crude Model	Italy Age and gender adjusted Model	Fully adjusted Model**
Caregivers						
Age	1.03 (1.00 – 1.06)	1.03 (1.00 – 1.06)	1.03 (0.99 – 1.06)	1.00 (0.97 – 1.02)	1.00 (0.97 – 1.03)	1.00 (0.97 – 1.03)
Gender (Female)	1.11 (0.39 – 3.18)	1.23 (0.42 – 3.60)	1.15 (0.37 – 3.60)	1.55 (0.73 – 3.26)	1.54 (0.72 – 3.32)	1.48 (0.68 – 3.24)
Educational level	0.531	0.599		0.832	0.780	
Primary education	-	-		-	-	
Lower secondary education	0.89 (0.14 – 5.50)	1.15 (0.18 – 7.32)		0.50 (0.03 – 7.10)	0.38 (0.02 – 5.95)	
Upper secondary education	0.86 (0.14 – 5.29)	1.29 (0.20 – 8.43)		0.45 (0.04 – 5.17)	0.30 (0.02 – 3.99)	
Tertiary education	0.53 (0.09 – 3.13)	0.75 (0.12 – 4.65)		0.38 (0.03 – 4.37)	0.28 (0.02 – 3.72)	
Caregiving (Difference post – pre in hours of care)	1.02 (0.99 – 1.04)	1.02 (1.00 – 1.04)		1.01 (1.00 – 1.02)	1.01 (0.99 – 1.02)	
Service provision (Continuity)	0.71 (0.35 – 1.45)	0.81 (0.39 – 1.69)		1.14 (0.58 – 2.26)	1.15 (0.57 – 2.33)	
Formal social and health service provision (Discontinuity)	1.43 (0.62 – 3.32)	1.66 (0.70 – 3.94)		2.68 (1.06 – 6.76)	2.54 (0.99 – 6.48)	2.54 (1.00 – 6.48)
Formal support effectiveness (at least 1 very/extremely)	0.65 (0.31 – 1.39)	0.63 (0.29 – 1.37)		1.26 (0.68 – 2.34)	1.31 (0.69 – 2.46)	
Informal support effectiveness (at least 1 very/extremely)	0.42 (0.21 – 0.84)	0.45 (0.22 – 0.91)	0.45 (0.23 – 0.99)	0.78 (0.42 – 1.44)	0.82 (0.43 – 1.54)	
Living condition reference: <i>co-habiting</i>	0.083 -	0.075 -		0.230 -	0.263 -	
Walking distance	0.63 (0.20 – 2.01)	0.69 (0.21 – 2.26)		0.40 (0.17 – 0.98)	0.40 (0.16 – 0.99)	
Within 1 hour travel	0.41 (0.19 – 0.88)	0.39 (0.18 – 0.85)		0.68 (0.33 – 1.40)	0.76 (0.36 – 1.61)	
More than 1 hour travel	0.31 (0.08 – 1.21)	0.32 (0.08 – 1.26)		-	-	
Caregiver Infection (“I have personally been infected”)	2.10 (0.54 – 8.16)	1.81 (0.46 – 7.20)		2.43 (0.92 – 6.39)	2.64 (0.94 – 7.45)	
Older care recipients						
Psychological/mental health issues (e.g. depression, anxiety, etc.)	3.37 (1.59 – 7.16)	3.14 (1.45 – 6.77)	3.01 (1.38 – 6.56)	2.10 (1.09 – 4.05)	1.99 (1.01 – 3.91)	
Neurological disability or learning difficulty (not dementia and memory problems)	1.89 (0.89 – 4.03)	1.85 (0.85 – 4.02)		2.14 (1.09 – 4.23)	1.86 (0.93 – 3.73)	

*Significant ORs in bold.

* Cox & Snell R-square is 0.110

** Cox & Snell R-square is 0.031

4.4 Study 4- Being a young adult or an older caregiver of older people during the COVID-19 outbreak (Socci & Santini, 2023 – submitted)

The final study sample embeds 1,390 subjects (Table 7). For both age groups, the majority of caregivers are female: 85.5% in the group aged 18-64 and 71% in the group aged 65 and over. Mean age is 52.3±8.6 for ACGs and 73.0±5.4 for OCGs. Recipients' mean age is 81.7±7.8 for ACGs and 79.2±7.8 for older ones.

Most ICGs care for one or more person(s) with 4+ comorbidities, especially in the case of ACGs (72.4%), compared to OCGs (59.6%). Three out of four OCGs live together with the care recipient (75.6%), compared to about one-third (35.8%) of the ACGs. The latter were more keen to care for two or more people (30.7%) than older ones (8.3%).

Due to COVID-19-containing measures, ACGs experienced a higher increase in the number of hours of caregiving compared to older caregivers (50.6% vs 32.3%) and similarly in practical help (49.2% vs. 38%). Moreover, public or private support services were used less often by adult caregivers (41.4% vs. 56.3%), who more frequently declared difficulties in accessing such services (36.9% vs 23.4%), and more often reported hiring a migrant care worker (MCW) (16.6% vs 9.4%). Few respondents had started using new health technology for supporting caring activities in response to the shortfall and/or closure of services and there is not a statistically significant difference between adult and older caregivers, after PS matching (20.6% and 16.5%, respectively).

After PS matching, all the differences mentioned above remained statistically significant, and the increase in providing personal care and hygiene also emerged (38.9% for ACGs vs 30.2% for OCGs, p=0.037). Concerning the outcomes, the physical condition worsened, especially for ACGs rather than older ones (52.4% vs. 46.1%, p=0.023). Nevertheless, after PS matching, the worsening in physical condition was not significantly different between adult and older caregivers.

Table 7 Sample characteristics by age group of the caregiver before (FULL) and after the propensity score matching (PSM)

	FULL SAMPLE				PROPENSITY SCORE MATCHING			
	Total	18-64	65+	p	Total	18-64	65+	p
	N=1,390	N=848	N=542		N=776	N=388	N=388	
Covariates								
Female gender, n(%)	1,110(79.9%)	725(85.5%)	385(71.0%)	<0.001	628(80.9%)	314(80.9%)	314(80.9%)	1.000
Caregiver's Age, mean±sd	60.4±12.6	52.3±8.6	73.0±5.4	<0.001	62.6±12.4	52.5±8.7	72.6±5.3	<0.001
Recipient's Age, mean±sd	80.7±7.9	81.7±7.8	79.2±7.8	<0.001	80.8±8.1	81.5±8.1	80.2±8.0	0.028
Living together with the recipient, n(%)	714(51.4%)	304(35.8%)	410(75.6%)	<0.001	520(67.0%)	260(67.0%)	260(67.0%)	1.000
Caring for two or more people, n(%)	305(21.9%)	260(30.7%)	45(8.3%)	<0.001	86(11.1%)	43(11.1%)	43(11.1%)	1.000
Caregiver has personally been infected, n(%)	150(10.8%)	114(13.4%)	36(6.6%)	<0.001	76(9.8%)	49(12.6%)	27(7.0%)	0.003
Increasing amount of caring hours, n(%)	604(43.5%)	429(50.6%)	175(32.3%)	<0.001	328(42.9%)	200(51.6%)	125(32.2%)	<0.001

Increasing Personal care and hygiene, n(%)	463(33.3%)	302(35.6%)	161(29.7%)	0.073	268(34.5%)	151(38.9%)	117(30.2%)	0.037
Increasing Practical help in person , n(%)	623(44.8%)	417(49.2%)	206(38.0%)	<0.001	328(42.3%)	180(46.4%)	148(38.1%)	0.011
Public or private health support, n(%)	656(47.2%)	351(41.4%)	305(56.3%)	<0.001	393(50.6%)	173(44.6%)	220(56.7%)	<0.001
Difficulties in accessing support services, n(%)	440(31.7%)	313(36.9%)	127(23.4%)	<0.001	208(26.8%)	119(30.7%)	89(22.9%)	0.015
Caring for a person with 4+ comorbidities, n(%)	937(67.4%)	614(72.4%)	323(59.6%)	<0.001	540(69.6%)	270(69.6%)	270(69.6%)	1.000
Hiring MCW, n(%)	192(13.8%)	141(16.6%)	51(9.4%)	<0.001	94(12.1%)	62(16.0%)	32(8.2%)	<0.001
Have you ever used new health technology (e.g. telemedicine)?, n(%)				0.014				0.292
YES, since BEFORE the COVID-19 outbreak	257(18.5%)	174(20.5%)	83(15.3%)		144(15.6%)	80(20.6%)	64(16.5%)	
YES, I started AFTER the COVID-19 outbreak	73(5.3%)	50(5.9%)	23(4.2%)		36(4.6%)	16(4.1%)	20(5.2%)	
NO, NEVER USED (%)	1,060(76.3%)	624(73.6%)	436(80.4%)		596(76.8%)	292(75.3%)	304(78.4%)	
Outcomes								
My physical condition, n(%)	694(49.9%)	444(52.4%)	250(46.1%)	0.023	390(50.3%)	207(53.4%)	183(47.2%)	0.085
My mental health/psychological state of mind, n(%)	916(65.9%)	567(66.9%)	349(64.4%)	0.343	514(66.2%)	253(65.2%)	261(67.3%)	0.544
My quality of life, n(%)	1,084(78.0%)	638(75.2%)	446(82.3%)	0.002	606(78.1%)	290(74.7%)	316(81.4%)	0.024
Country, n(%)				<0.001				<0.001
Germany	143(10.3%)	116(13.7%)	27(5.0%)		95(12.2%)	70(18.0%)	25(6.4%)	
Czechia	108(7.8%)	92(10.8%)	16(3.0%)		61(7.9%)	46(11.9%)	15(3.9%)	
Estonia	56(4.0%)	50(5.9%)	6(1.1%)		30(3.9%)	24(6.2%)	6(1.5%)	
Finland	160(11.5%)	46(5.4%)	114(21.0%)		105(13.5%)	28(7.2%)	77(19.8%)	
Italy	166(11.9%)	131(15.4%)	35(6.5%)		66(8.5%)	41(10.6%)	25(6.4%)	
Portugal	216(15.5%)	198(23.3%)	18(3.3%)		144(18.6%)	127(32.7%)	17(4.4%)	
Sweden	463(33.3%)	162(19.1%)	301(55.5%)		240(30.9%)	40(10.3%)	200(51.5%)	
Other	78(5.6%)	53(6.3%)	25(4.6%)		35(4.5%)	12(3.1%)	23(5.9%)	

Table 8 shows the determinants of the worsening in the three outcome variables i.e. physical health, mental well-being and quality of life, before and after the PS matching. Here below, only the results emerging from the PS matching are reported.

After the PS matching, being female (OR=1.49; 95%CI=1.00-2.23), living together with the recipients (OR=1.73; OR=1.20-2.48) and having difficulties in accessing support services (OR=2.90; 95%CI=2.01-4.19) are statistically associated to a worsening in physical health.

Moreover, being female (OR=1.67; 95%CI=1.12-2.48), living together with the recipients (OR=1.48; OR=1.02-2.14), difficulties in accessing support services (OR=2.84; 95%CI=1.87-4.31) and caring for a recipient with four or more comorbidities (OR=1.44; 95%CI=1.01-2.07), were statistically significant in association with a worsening in mental health.

Furthermore, as regards quality of life, being female (OR=1.81; 95%CI=1.16-2.82); caring for two or more people (OR=0.48; 95%CI=0.28-0.83); having increased personal care and hygiene (OR=1.66; 95%CI=1.05-2.63) and difficulties in accessing support services (OR=1.92; 95%CI=1.20-3.08), remained significantly associated with a worsening in quality of life.

Table 8 Determinants of most relevant outcomes before (FULL) and after the propensity score matching (PSM)

	My physical condition		My mental health/psychological state of mind		My quality of life	
	FULL	PSM	FULL	PSM	FULL	PSM
	OR(95%CI)	OR(95%CI)	OR(95%CI)	OR(95%CI)	OR(95%CI)	OR(95%CI)
Fixed Effects						
65+, ref.18-64	1.23(0.91-1.67)	1.16(0.80-1.68)	1.20(0.88-1.63)	1.17(0.79-1.72)	1.61(1.12-2.29)	1.50(0.97-2.33)
Female, ref. Male	1.47(1.09-1.98)	1.49(1.01-2.23)	1.70(1.26-2.29)	1.67(1.12-2.48)	1.50(1.07-2.11)	1.81(1.16-2.82)
Recipient's Age	1.00(0.99-1.02)	1.01(0.99-1.03)	1.00(0.98-1.01)	1.01(0.99-1.03)	0.99(0.98-1.01)	0.99(0.97-1.02)
Living together with the recipient	1.49(1.14-1.95)	1.73(1.20-2.48)	1.20(0.91-1.58)	1.48(1.02-2.14)	1.30(0.95-1.77)	1.38(0.90-2.11)
Caring for two or more people	1.17(0.87-1.58)	0.92(0.55-1.52)	1.17(0.86-1.61)	1.03(0.61-1.76)	0.85(0.61-1.19)	0.48(0.28-0.83)
Caregiver has personally been infected	1.87(1.27-2.74)	1.67(0.97-2.89)	1.15(0.77-1.71)	1.13(0.64-1.98)	1.06(0.68-1.65)	0.67(0.37-1.23)
Increasing amount of caring hours	1.46(1.11-1.91)	1.45(0.99-2.09)	1.01(0.76-1.34)	1.05(0.71-1.56)	1.38(0.99-1.90)	1.30(0.83-2.05)
Increasing personal care and hygiene	1.40(1.07-1.83)	1.38(0.96-1.99)	1.61(1.20-2.16)	1.40(0.95-2.08)	1.56(1.11-2.19)	1.66(1.05-2.63)
Increasing Practical help in person	1.22(0.94-1.59)	1.14(0.80-1.63)	1.29(0.98-1.69)	1.23(0.84-1.79)	1.22(0.89-1.66)	1.43(0.92-2.21)
Public or private health support	1.09(0.86-1.38)	1.09(0.79-1.50)	1.27(0.99-1.63)	1.29(0.93-1.80)	1.18(0.88-1.56)	1.35(0.91-1.98)
Difficulties in accessing support services	2.25(1.74-2.90)	2.90(2.01-4.19)	2.26(1.70-2.99)	2.84(1.87-4.31)	1.82(1.32-2.50)	1.92(1.20-3.08)
Caregiving for a person with 4+ comorbidities	1.63(1.26-2.10)	1.38(0.96-1.97)	1.57(1.21-2.03)	1.44(1.00-2.07)	1.05(0.78-1.42)	1.06(0.69-1.62)
Hiring MCW	1.11(0.78-1.58)	1.16(0.70-1.94)	0.96(0.67-1.39)	1.09(0.65-1.84)	1.23(0.81-1.88)	1.22(0.68-2.20)
Constant	0.14(0.04-0.53)	0.10(0.02-0.63)	0.46(0.12-1.83)	0.22(0.03-1.44)	1.58(0.34-7.36)	1.16(0.14-9.53)

Random Effects

Country

Variance	0.11(0.03-0.43)	0.11(0.02-0.59)	0.16(0.04-0.58)	0.17(0.03-0.82)	0.15(0.04-0.53)	0.21(0.05-0.81)
ICC	0.03(0.01-0.12)	0.03(0.01-0.15)	0.05(0.01-0.15)	0.05(0.01-0.20)	0.04(0.01-0.14)	0.06(0.02-0.20)

The “new caregivers” represent 13.2% of the overall sample. The overall demographic description of “new caregivers” and the outcomes analysis are reported in Table 3 of Socci & Santini, 2023. Here I just underline that “new caregivers” were most adults and females. New ACGs experienced a decrease in their physical condition more frequently than new OCGs, lived with the care recipient less frequently than OCGs and cared for two or more people with 4+ comorbidities. With regard to the determinants of the most relevant outcomes for “new carers”, it emerged that being female and caregiving for a recipient with 4+ comorbidities are statistically associated with worsening in physical condition. Difficulties in accessing support services is associated only with a worsening in mental health, while the association with worsening in quality of life is not statistically significant. The overall analysis is reported in Table 4 of the scientific paper based on Study 4 enclosed at the end of this document.

5. Discussion

The four described studies are aimed at increasing the knowledge about intergenerational caring and its impact on informal caregivers’ overall health, especially when public support services are interrupted and reduced, like during the COVID-19 outbreak.

5.1 Study 1-Positive and negative caregiving outcomes on Adolescent Young Caregivers of Grandparents (Santini et al., 2020)

This study showed that caring for a GrP can decrease the negative outcomes, e.g. frustration and sense of inadequacy (Orelet et al., 2004; Fruhauf and Orel, 2008), mental health problems (Carers Trust, 2016), and poor well-being (Cohen et al., 2012; Doran et al., 2003) compared to caring for OCRs. Moreover, it can influence the development of positive outcomes related to care (e.g., new relational skills, resilience, maturity, and empathy) (Orel and Dupuy, 2002; Svanberg et al., 2010; Fives et al., 2013; Stamatopoulos, 2018).

The onset of negative feelings was higher among AYC’s carrying out greater amounts of caregiving, thereby suggesting that, despite caring for a GrP can bring positive emotions, caring for an excessive number of hours, can nevertheless be potentially detrimental to AYC’s overall health and well-being.

Noteworthy, the study showed that female AYC’s experienced more negative feelings and health problems than males (Ferrant et al., 2014) and that transgender/non-binary AYC’s lived emotional distress in association with their caring role more than cisgender and heterosexual AYC’s (Boehmer et al., 2018).

Moreover, AYC respondents with a migrant background were observed to be more likely than other AYC’s to experience negative feelings in connection with caregiving, supporting previous literature on YC’s (Thomas et al., 2003). This is likely due to societal and cultural barriers to formal services (Pelle, 2012), and limited access to them (James, 2019).

Notably, when we considered the country variable, the statistical significance between AYC’s of OCRs, and AYC’s of GrPs, for the outcome variables disappeared, and the association of the outcome variables with migrant background and use of formal services was mitigated. This result suggests that the perception of

positive and negative outcomes of caregiving could also be driven by cultural patterns (Evans et al., 2017), representations of and meanings given to illness and long-term health conditions (Quinn et al., 2017), intergenerational family ties cohesion (Blanton, 2013; Fruhauf et al., 2006), perceived social support (Del-Pino Casado et al., 2019), self-recognition of the role of carer, and trust in social and health services (James, 2019). All factors, the above, that have been not considered by the study and then were not measured, representing a limitation of the study, as deepened in the next paragraph.

5.2 Study 2-Difficulties faced by Adolescent Young Carers of Grandparents in Italy and Slovenia (Santini et al., 2022a)

This study confirms that in Italy and Slovenia, two countries with a low level of awareness around informal caregiving and not-well-developed LTC systems (Leu and Becker, 2019), adolescents are often involved in caregiving tasks as part of a multigenerational caring family, playing the role of auxiliary caregivers, especially when they live in multigenerational households (Hamill, 2012; Schumacher et al., 2018). Youngsters and adolescents can be indispensable resources for their parents, who endeavour to reconcile paid work with the care of children and parents at the same time, in welfare regimes full of flaws. This is the case for Italy and Slovenia. Both have familialistic welfare regimes where formal care for older people ageing in the community is poorly developed and families supporting ageing in place have to provide a vast amount of informal care, mostly intergenerational (Schumacher, 2018; James, 2019; Hlebec, 2016). Moreover, in Slovenia, adult children have the lawful obligation to financially contribute to potential formal care of their older and dependent parents (Hlebec and Hrast, 2018) and involving grandchildren in caring activities may represent an attempt to save economic resources that would otherwise be allocated to the purchase of private health care.

In line with Study 1, caregiving for a GrP can entail more positive than negative outcomes for AYC's but this does not prevent the AYC's from facing difficulties. The sources of support requested by AYC's also reflect the LTC system where they live and grow up. In fact, Italian AYC's asked for monetary transfers probably because they are aware that this is the most common formal support that they can receive (Courbage et al., 2020; Barbabella, 2017). Similarly, given the lack of formal support, Slovenian AYC's requested emotional support from friends.

5.3 Study 3- Impact of COVID-19 outbreak on the overall health of informal caregivers of older people (Santini et al., 2022b)

This study confirms the increase in the intensity of care for both German and Italian ICGs (CIRCLE, 2020) and the worsening of their overall health as a consequence of the Pandemic (Phillips et al., 2020).

Predictive ICGs' health worsening and mitigating factors differ in the two countries. The interruption/cancellation/postponement of formal social and health care services increased the risk of health worsening only in Italy, where the discontinuity of service provision, more severe than in Germany, was not counteracted and balanced by informal care support provided by other family members. Conversely, German ICGs could count on sufficient (despite reduced) formal social and health care services and on relatively substantial informal care support.

The lack of informal support in Italy can be explained by the severe "stay at home" measures (accompanied by a massive media campaign) that were instituted in the country for protecting older relatives from the infection and that weakened family, friend and neighbourhood relationships, or at least prevented them from translating into effective help.

It is worth noting that although German ICGs received more support during the Pandemic, the risk of health worsening increased by 42% for German caregivers compared to the Italian ones and the psychological/mental health issues increased threefold compared to the risk of caregivers' physical health deterioration within the German sample. This can depend on the higher number of care recipients with long-term health conditions found in Germany (68.7%) compared to Italy (48.8%) and on the worsened mental and physical health condition of the German care recipients compared to Italian ones.

The higher risk of health worsening in the German sample may also depend on the ICGs' expectations concerning formal support in the two countries. The German LTC system stands on the provision of a large set of formal home-based in-kind services in normal times, which were probably not provided at the same standards during the Pandemic. Thus, the German ICGs, who are used to being widely supported by formal health and social care services, had to provide 8.7 hours of care per week more than before the outbreak. Consequently, they had a stronger self-perception of the impact of the shortfall in services on their well-being than Italian caregivers. However, they received more formal services than the Italian caregivers during the outbreak. The latter, conversely, very seldom receive extensive in-kind home services (even before the healthcare crisis). Therefore, the vast majority did not expect to receive a wide spectrum of homecare services during the lockdown and thus did not perceive that their health condition was worsened, despite feeling overwhelmed. The study also confirms the lower resilience of Italian formal and informal care supports in response to the reduction of care services during the Pandemic compared to Germany (Tur-Sinai et al., 2021).

5.4 Study 4- Being a young adult caregiver or an older adult caregiver of older people with LTC needs during the COVID-19 outbreak (Socci & Santini, 2023 – submitted)

This study highlights that being female represented the main risk for the European ICGs' physical health, mental well-being and quality of life during the second wave of the Pandemic. In fact, female caregivers in the sample, experienced a decrease in the quality of life more than males because they provided more frequently assistance and personal care to more than two persons compared to male counterparts (Beach et al., 2021; Li et al., 2021; Todorovic et al., 2020; Zucca et al., 2021; Zwar et al., 2022). Other health risk factors were co-habiting with the care recipient/s and difficulties accessing support services.

The comparison of ICGs by age highlights that being an ACG as opposed to an OCG did not determine a statistically significant worsening in the overall personal health status and quality of life. Despite the absence of statistical significance, data show that the adult cohort experienced a worsening in physical condition to a greater extent than the older cohort. This might be due to an increase in caregiving hours due to the interruption of care services during the lockdown. Moreover, ACGs took care of relatives with more severe health conditions (e.g. having 4+ comorbidities) compared to OCGs, entailing more physically strenuous caregiving activities, such as moving and handling and personal care and hygiene, that likely contributed to a deterioration in the physical health of adult caregivers. Also, considering that ACGs mostly did not co-reside with the care recipient/s, thereby causing them to travel to the care recipient's home, that might also have had a negative impact on their physical condition (e.g. fatigue and physical exhaustion). Furthermore, ACGs were more eager than OCGs to take on a caring role during the Pandemic and to increase their hours of care, especially personal care and hygiene. The study underlines that "new caregivers" were most middle-aged females, bearing an extremely high care burden, i.e. providing assistance to two or more older people with 4+ comorbidities, which demanded regular physical effort, e.g. for mobilization and personal hygiene, to the detriment of physical health.

Noteworthy, ACGs faced difficulties in accessing public and private services to a greater extent than OCGs. A possible explanation can be found in the multiple roles and responsibilities they faced in combining working activities with family commitments, likely having young/ adolescent children and older parents with long-term care needs. Thus, given the sudden onset of the COVID-19 outbreak, they were most likely unable to organize appropriate, quality assistance quickly enough (Giebel et al., 2021; Kostyál et al., 2021).

6 Limitations and strengths

6.1 Study 1 and 2

The convenience sampling strategy used in Studies 1 and 2 did not allow for the generalization of results to all European AYC. Moreover, although data on caring burden were partly collected by a question on the number of caring hours per day, the questionnaire did not include a question asking for the number of respondents' care recipients. Furthermore, the high number of missing values in the outcome variables considerably reduced the number of AYC to include in the analysis. This could have several explanations. For example, some youngsters could have found the questionnaire excessively lengthy, and so they might have decided to skip some questions.

Finally, the study did not consider cultural patterns, representations of ageing and illness nor family cohesion that might influence the AYC's answers.

Despite these limitations, these studies achieved an important goal, i.e., the comparability of findings on a large sample of AYC, and from a European, cross-country perspective. This is indeed, the first large-scale international study on AYC aged 15–17 years, and, to the best of our knowledge, the first cross-national study comparing AYC of GrP with AYC providing care to OCR. Hence, the findings can enrich the debate on this topic and orient future policies and research. First, since the perception of negative caregiving outcomes could be influenced by the strength of the intergenerational relationship between grandchild and GrP, such a relationship and the cohesion of the intergenerational ties within the household environment merit attention in future research, foreseeing specific questions on this aspect. Moreover, more research on AYC from a gender identity perspective would help identify the frailties of female and transgender/non-binary AYC and mitigate negative repercussions on AYC's mental health and well-being.

6.2 Study 3 and 4

The first limitation of Studies 3 and 4 concerns the rather small sample size, which, in the case of Study 1, is also different in the two countries, being more numerous in Italy than in Germany.

The second limitation is represented by the convenience, not randomized, sampling strategy of participants recruited for this study, which does not allow the generalization of results to all informal caregivers in the two countries and across Europe.

Another limitation is constituted by the channels chosen for the data collection, which reached only digitally literate and more highly educated people, thus excluding a priori many caregivers who are not familiar with online tools. This mirrors what is highlighted by the literature, i.e., that among older adults, the more educated have higher levels of digital skills. In fact, since complexity is an important barrier to technology adoption, people with a higher level of education seem to be more keen to overcome this type of problem (Rogers, 2005; Zhao et al., 2007).

Despite these limitations, the studies allowed us to reach a large sample of European ICGs of OP in a time when the Governments restriction did not permit to keep in physical contact with people, especially older ones. Moreover, the two analyses gave a picture of the overall condition of ICGs during the second pandemic wave, somehow showing several long-term cumulated adverse effects.

7 Conclusions and recommendations

The four studies embedded in this dissertation confirm that informal intergenerational caregiving is the backbone of LTC systems in Europe and show that female ICGs of all ages bear the greatest burden. Females are expected to provide care to family members since adolescence, especially if they live in multigenerational households. Thus, women and girls across Europe, especially in countries with underdeveloped LTC systems, are at higher risk of physical and mental health problems than the male counterpart.

The difficulties and strains that female ICGs of older people with LTC face at the individual level reflect the flaws of LTC systems at the macro level, as shown by the studies results, shaping the following policy and research recommendations.

7.1 Policy and interventions suggestions

The pre-requisite for any policy at support of ICGs is their recognition both from the legislative point of view, through a national law and coordinated, comprehensive supporting policies, and from a social security perspective, with the recognition of the time spent in informal care counting as pension credits or of care experience and skills earning qualifications for a possible later inclusion in the labour market (e.g., in the elder care sector).

A paradigm shift in the programming of policies and interventions for ICGs is needed, which should be age and gender-driven. Age-driven policies should indeed be shaped by the intergenerational solidarity concept and combine the needs and interests of older and younger-adult population cohorts in compliance with the European Union policy line on active ageing and intergenerational solidarity (European Commission, 2012). The policy could be translated into practice by means of intergenerational programs such that the generations can have more opportunities for meeting, collaborating, and exchanging experiences (Santini et al., 2018).

Gender-driven policies should be aimed at overcoming gender care inequalities by helping ICGs, especially females, conciliate caring duties and paid jobs and/or education. In this respect, such measures should address the ICGs' needs emerging from the multiple roles women play within the household, i.e. as parents of minor/adult disabled children and, at the same time, as children or spouses of older people with LTC needs. To this purpose, public administrations and private companies that have piloted various forms of agile work during the Pandemic e.g. smart and/or teleworking, should systematize and make them part of the daily work routine and add other measures such as time off and parental leave to elder care leave, especially in countries where they were absent or scarce before the Pandemic.

The four studies' results show that the physical and mental health of both adult and older ICGs of older people was worsened by co-habiting with the care recipient/s and by the interruption on home care services, during the Pandemic. This calls for new policies designed to find a balance between the ageing-in-place concept and the protection of ICGs' health, especially when they provide care to frail older people with 4+ comorbidities, by increasing the number of hours of home care provided by the public health system and the number of accessible and affordable residential facilities.

7.2 Intervention and services suggestions

Since, as underlined above, the first step towards the support of ICGs is their identification, training courses for front-line practitioners are needed to acquire a family-focused approach and increase their knowledge on intergenerational caregiving across the life course (Fast et al., 2021). Trained practitioners may actively reach out to, and subsequently identify, at an early stage, all family members, including AYC, involved in the regular help, support, and/or care of a frail older relative. This is the crucial first step towards the access to tailored information and education.

In an ideal world, social and health services should support families experiencing non-self-sufficiency before children and adolescents are forced to participate in caring activities and ICGs experience health conditions as a consequence of care. Since, realistically, it is not so, especially in countries with a low level of awareness around informal caregiving and AYC, intergenerational educational interventions could help ICGs of OP, especially AYC, develop proper and not-stereotyped representations of ageing, decide to assume or not the role of caregiver and ask proper support. ICGs should also benefit from responsive education and learning opportunities related to geriatric care and age-related issues, e.g., how to communicate with older people (especially if with dementia), how to move an “un-cooperative” disabled person, and what to do in case of an emergency.

Moreover, public preventive and monitoring health services should be planned especially targeted to older and/or female ICGs, for promoting physical health (such as scheduled screening and home visits) and mental well-being (such as periodic psychological interviews for countering depression and anxiety), in order to prevent they become the second and hidden victim of multimorbidity.

Finally, Study 4 underlined that only a small proportion of ICGs started using new health technology for the assistance during the outbreak. This result calls for the provision of new health technology and ICTs to deliver remote care services both to older care recipients (e.g. telemedicine, at-distance cognitive and physical tele-rehabilitation) and ICGs (e.g. emotional support and training), and of e-health training targeted towards ICGs. At-distance support services would reach ICGs at home while providing assistance or supervising the care recipient/s.

7.3 Research suggestions

Further research on intergenerational caregiving outcomes is recommended for shaping measures and policies which preserve the intergenerational emotional bonds, whilst protecting ICGs, especially AYC, from inappropriate responsibilities, undermining their mental health and well-being.

Since the perception of negative caregiving outcomes could be influenced by the strength of the intergenerational relationship, such a relationship and the cohesion of the intergenerational ties within the household environment merit attention in future research.

Moreover, more research on AYC from a gender identity perspective, on black, asian, and minority ethnic AYC, and on family caregiving in second-generation migrant families are needed to identify the frailties of female, transgender/non-binary and migrant AYC, and mitigate negative repercussions on mental health and well-being. Furthermore, given the possible influence of cultural factors on caregiving outcomes, country-specific research and further cross-national studies on AYC are recommended. Further and longitudinal research, especially on AYC of GrPs is recommended to understand if and to what extent AYC continue to be caregivers in their life course, namely if being a young caregiver is a predictor of being an adult caregiver.

The findings also suggest the need for follow-up studies on ICGs of older people, to understand how the return to normality was for them and which lesson they learned during the Pandemic. Qualitative and/or mixed-methods studies are recommended to deepen the nuances of intergenerational caregiving useful for designing evidence-based policies and measures to support ICGs both in ordinary and emergency circumstances.

7.4 A new conceptual framework for intergenerational caregiving

The complexity of the care needs of today's older population is characterised by multimorbidity of older population and by public health challenges posed by the increased demand of LTC. The Pandemic exacerbated such critical factors. Nevertheless, this time is also rich in opportunities provided by scientific and technological progress, first and foremost the opportunities brought by new technologies e.g. telemedicine, at-distance support, tele-rehabilitation.

All this requires new theoretical frameworks in order to correctly interpret the experience of today's ICGs involved in intergenerational caregiving. In the Yates' model, for example, the primary caregiving stressors are represented by the care recipients' cognitive impairment, functional disability and behavioural problems. First, limiting primary stressors to merely these factors seems reductive as it does not capture the many forms of physical, emotional and psychological stress caused by caring for a dependent older person when formal and informal supports are insufficient or even non-existent. Second, Yates considers formal support as a mediator between the first and the second appraisal, but he does not consider its absence as a stressor, as highlighted by the results of the studies embedded in this work.

Thus, in light of the results presented here, I suggest a new intergenerational caregiving appraisal and stress model (ICASM), that tries to consider most of the stressors and opportunities of our age (Figure 3). Therefore, the ICASM includes, among the primary stressors: ICGs' multiple roles, work-life imbalance, multimorbidity of care recipient, lack of formal support, intergenerational conflicts, lack of training, co-habiting with the care recipient, the amount of care (that in the case of AYC of GrPs cannot be buffered by the positive intergenerational relationship with the care recipient if it is too high), the intensity of care (e.g. personal hygiene).

Moreover, in the CSAM (Yate, 1999), it is assumed that ICGs can assess and evaluate their own condition. However, this concept may not apply in the case of AYC and of ICGs caring during the Pandemic. In fact, adolescents generally have a lower self-awareness of stressors and a lower level of metacognition or introspection compared to adults (Rith-Najarian et al., 2014; Weil et al., 2013), which may limit their capability of evaluating the care recipient and their own needs, as shown by Study 2. Moreover, concerning ICGs, regardless of their age, they could not have had the psychological and emotional resources for correctly evaluating their caring condition while they were immersed in a global health crisis, trapped at home with the care recipient and with many limitations to their personal freedom, as underlined by Studies 3 and 4.

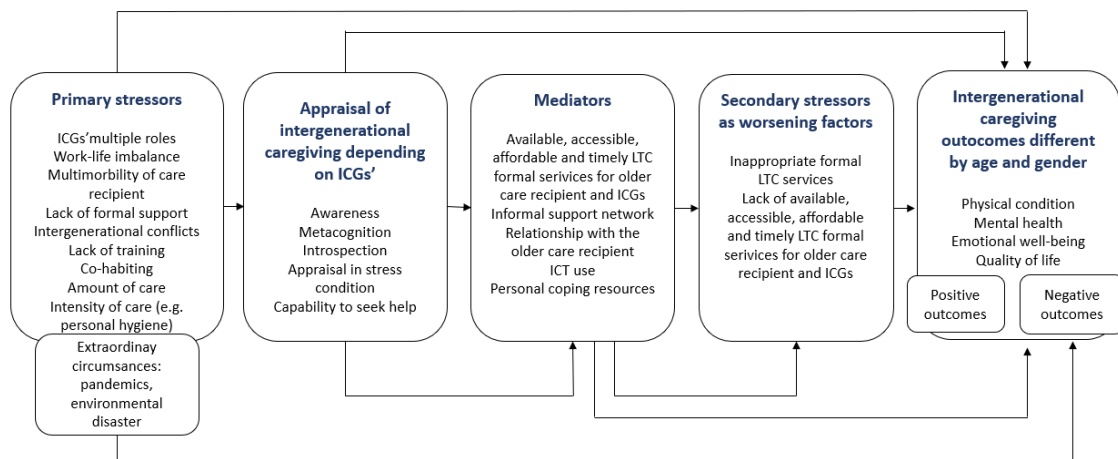
In light of the four studies' results, mediators of stress should include available, accessible, affordable and timely LTC formal services for older care recipients as well as for ICGs, informal support networks, the quality of the relationship with the older care recipient, the use of ICTs addressing ICGs and older people's health needs (e.g. telemedicine and at-distance health parameters monitoring, at-distance emotional support), and ICGs' personal coping resources.

Furthermore, in his model, Yates does not consider time as a factor to take into consideration. Conversely, the latter should be considered because the slow response by the healthcare systems to the ICGs' needs, or the missing provision of timely, available, accessible and affordable support represents an additional source of stress, impacting ICGs' mental well-being mainly. Especially during the Pandemic, in the time gap between the loss of any support and the re-organisation of the care, the health problems nestle and proliferate in

ICGs' minds and bodies. In such a context, the ICGs could just ascertain the overload and the negative outcome on their overall health and quality of life. In fact, the quick interruption of care services did not allow the ICGs to make a proper and timely appraisal of the increased number of caring hours or the overload. Thus, the time of response of the LTC systems to OP and ICGs' health and social needs is an important variable to monitor because it reflects the level of effectiveness and the overall scaffold of the standing health and social services, regardless of an extraordinary global event such as the COVID-19 outbreak. Furthermore, the lack of mediators, described and meant above, represents a source for secondary stressors, i.e. further factors worsening ICGs' overall health.

Finally, as highlighted by the four studies, the intergenerational caregiving outcomes should be meant as different by ICGs age (meant as the stage where they are in the life course and their psychological, physical and emotional development) and by gender. The ICASM also embeds these dimensions for interpreting the stress lived by ICGs of different ages and gender.

Figure 3 Intergenerational caregiving appraisal and stress model (ICASM) (Author's own elaboration)



8 References

- Aldridge, J. Where are we now? Twenty-five years of research, policy and practice on young carers. *Crit. Soc. Policy* **2018**, *38*, 155–165.
- Aldridge, J.; Becker, S. *Children Caring for Parents with Mental Illness: Perspectives of Young Carers, Parents and Professionals*; Policy Press: Bristol, UK, 2003.
- Aldridge, J.; Becker, S. *Children Who Care: Inside the World of Young Carers*; Loughborough University: Loughborough, UK, 1993.
- Austin, P.C.; Goel, V.; van Walraven, C. An introduction to multilevel regression models. *Can J Public Health*. **2001**, *92*, 150–154.
- Barbabella, F.; Poli, A.; Chiatti, C.; Pelliccia, L.; Pesaresi, F. La bussola di NNA: Lo stato dell'arte basato sui dati. In *L'assistenza Agli Anziani Non Autosufficienti in Italia. 6 Rapporto 2017/2018. Il Tempo Delle Risposte [Assistance to Non Self-Sufficient Elderly People in Italy. 6th Report 2017/2018. Time for Answers]*; NNA Network Non Autosufficienza; Maggioli: Santarcangelo di Romagna, Italy, 2017; pp. 33–38. Available online: https://www.luoghicura.it/wp-content/uploads/2017/12/NNA_2017_6%C2%B0_Rapporto.pdf
- Barbosa, F.; Voss, G.; Delerue Matos, A. Health impact of providing informal care in Portugal. *BMC Geriatr.* **2020**, *20*, 440.
- Beach, S.R.; Schulz, R.; Donovan, H.; Rosland, A.M. Family caregiving during the COVID-19 Pandemic. *Gerontologist* **2021**, *61*, 5, 650–660. <https://doi.org/10.1093/geront/gnab049>.
- Becker, S. Defining young carers indifferent national contexts. In *Young Carers in Europe. An Exploratory Cross-National Study in Britain, France, Sweden and Germany*; Becker, S., Ed.; Department of Social Sciences Loughborough University: Loughborough, UK, 1995; Available online: <http://www.ycrg.org.uk/youngCarersDownload/Young%20Carers%20in%20Europe1.pdf> (accessed on 12 December 2022).
- Becker, S. Young carers. In *The Blackwell Encyclopedia of Social Work*; Davies, M., Ed.; Blackwell: Oxford, UK, 2000; p. 378.
- Berloto, S.; Notarnicola, E. La prospettiva dei policy-makers: Quali temi e innovazioni stanno promuovendo le regioni? In *Il Futuro del Settore LTC: Prospettive dai Servizi, dai Gestori e Dalle Policy Regionali 2 Rapporto Osservatorio Long Term Care [The Future of the LTC: Perspectives from Services, Providers and Regional Policies. 2nd Report LTC Observatory]*; Notarnicola, E., Fosti, G., Eds.; Egea: Milano, Italy, 2019; pp. 75–106. Available online: https://cergas.unibocconi.eu/sites/default/files/files/fosti_notarnicola.pdf?CVID=mRDrVdE&MOD=AJPERES
- Blake-Holmes, K.; McGowan, A. 'It's Making His Bad Days into My Bad Days': The Impact of Coronavirus Social Distancing Measures on Young Carers and Young Adult Carers in the United Kingdom. *Child Fam. Soc. Work*. **2022**, *27*, 22–29.
- Blanton, P.W. Family caregiving to frail elders: Experiences of young adult grandchildren as auxiliary caregivers. *J. Intergener. Relatsh.* **2013**, *11*, 18–31.
- Boehmer, U.; Clark, M.A.; Heeren, T.C.; Showalter, E.A.; Fredman, L. Differences in caregiving outcomes and experiences by sexual orientation and gender identity. *LGBT Health* **2018**, *5*, 112–120.

Bom, J.; Bakx, P.; Schut, F.; van Doorslaer, E. The Impact of Informal Caregiving for Older Adults on the Health of Various Types of Caregivers: A Systematic Review. *Gerontologist* **2019**, *59*, e629–e642.

Carers Trust. *Invisible and in Distress: Prioritising the Mental Health of England's Young Carers*; Report; Carers Trust: London, UK, 2016; Available online: https://carers.org/sites/default/files/invisibleandindistress_report.pdf (accessed on 15 May 2021).

Carers UK. *Caring behind Closed Doors: Forgotten Families in the Coronavirus Outbreak*; Carers UK: London, UK, 2020; Available online: https://www.carersuk.org/images/News_and_campaigns/Behind_Closed_Doors_2020/Caring_behind_closed_doors_April20_pages_web_fnal.pdf (accessed on 3 November 2021).

Censis-AIMA. *L'impatto Economico e Sociale Della Malattia di Alzheimer: Rifare il Punto Dopo 16 Anni* [The Economic and Social Impact of Alzheimer's Disease: Take Stock after 16 Years]; Censis: Rome, Italy, 2016.

CIRCLE. *Caring and COVID-19. Loneliness and Use of Services*; CIRCLE: Sheffield, UK, 2020; Available online: http://circle.group.shef.ac.uk/wp-content/uploads/2020/08/CARING-and-COVID-19-Loneliness-and-use-of-services_04.08.20.pdf

Cohen, C.; Greene, J.; Toyinbo, P.; Siskowsky, R.N. Impact of family caregiving by youth on their psychological well-being: A latent trait analysis. *J. Behav. Health Serv. Res.* **2012**, *39*, 245–256.

Costa, G. Private Assistants in the Italian Care System: Facts and Policies. *Obs. Soc. Br.* **2013**, *14*, 99–117.

Courbage, C.; Montoliu-Montes, G.; Wagner, J. The effect of Long-Term Care public benefits and insurance on informal care from outside the household: Empirical evidence from Italy and Spain. *Eur. J. Health Econ.* **2020**, *21*, 1131–1147.

Creswell, J.W.; Clark, V.L.P. *Designing and Conducting Mixed Methods Research*; Sage Publications: Thousand Oaks, CA, USA, 2017.

Davare, R.; Kreis, F.; Scheitlin, A. Population ageing and challenges for long-term care policies. European centre for social welfare policies and research. *Policy Brief* **2022**, *4*, 6-8.

D'Amen, B.; Socci, M.; Santini, S. Intergenerational caring: A systematic literature review on young and young adult caregivers of older people. *BMC Geriatr.* **2021**, *21*, 1–17.

Dellmann-Jenkins, M.; Brittain, L. Young adults' attitudes toward filial responsibility and actual assistance to elderly family members. *J. Appl. Gerontol.* **2003**, *22*, 214–229.

Del-Pino-Casado, R.; Rodriguez Cardosa, M.; Lopez-Martinez, C.; Orgeta, V. The association between subjective caregiver burden and depressive symptoms in carers of older relatives: A systematic review and meta-analysis. *PLoS ONE* **2019**, *14*, e0217648.

Destatis. *Pflegestatistik 2019 [Care Statistics 2019]*; Statistisches Bundesamt: Wiesbaden, Germany, 2020.

Döbele, M.; Becker, U. *Pflegeversicherung, in Ambulante Pflege von A bis Z*; Springer: Heidelberg/Berlin, Germany, 2016; pp. 265–269.

Doran, T.; Drever, T.; Whitehead, M. Health of young and elderly carers: An analysis of UK census data. *BMJ* **2003**, *327*, 1388.

Esping-Andersen, G. *Social Foundation of Postindustrial Economies*; Oxford University Press: New York, NY, USA, 1999; p. 218.

Eurocarers. Country profiles, 2021; Available online: <https://eurocarers.org/country-profiles/germany/> (accessed on 30 December 2022).

Eurocarers/IRCCS-INRCA. Impact of the Covid-19 Outbreak on Informal Carers across Europe. Final Report; Eurocarers/IRCCS-INRCA: Brussels, Belgium; Ancona, Italy, 2021; Available online: <https://eurocarers.org/wp-content/uploads/2021/05/EUC-Covid-study-report-2021.pdf> (accessed on 1 December 2021).

European Commission and Social Protection Committee. Long-Term Care Report. Trends, Challenges and Opportunities in an Ageing Society; Publications Office of the European Union: Luxembourg, 2021a. Available online: <https://ec.europa.eu/social/main.jsp?catId=738&langId=en&pubId=8396>

European Commission. Informal Care in Europe. Exploring Formalisation, Availability and Quality; European Commission: Brussels, Belgium, 2018.

European Commission. ESPN Thematic Report on work-life balance measures for persons of working age with dependent relatives. Italy. European Commission: Brussels, Belgium, 2016.

European Commission. ESPN. Thematic report on challenges in long-term care. Germany. European Commission: Brussels, Belgium 2018.

European Union. Ageing Europe. Looking at the lives of older people in the EU, 2019. Available online <https://ec.europa.eu/eurostat/documents/3217494/10166544/KS-02-19%E2%80%91EN-N.pdf/c701972f-6b4e-b432-57d2-91898ca94893> (accessed on 20 January 2021).

European Union. Regulation, G.D.P. Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation). *Off. J. Eur. Union* **2016**, 59, 294.

Eurostat. Elderly population across EU regions, 2020. Available online <https://ec.europa.eu/eurostat/web/products-eurostat-news/-/DDN-20200402-1#:~:text=In%202019%2C%2020.3%25%20of%20the,share%20from%20a%20decade%20earlier> (accessed on 23 January 2023).

Eurostat. Population Structure and Ageing, 2021. Available online: https://ec.europa.eu/eurostat/statistics-explained/index.php?title=Population_structure_and_ageing#The_share_of_elderly_people_continues_to_increase (accessed on 13 December 2021).

Evans, B.C.; Coon, D.W.; Belyea, M.J.; Ume, E. Collective care: Multiple caregivers and multiple care recipients in Mexican American families. *J. Transcult. Nur.* **2017**, 28, 398–407.

Fast, J.; Keating, N.; Eales, J.; Kim, C.; Lee, Y. Trajectories of family care over the lifecourse: Evidence from Canada. *Ageing Soc.* **2021**, 41, 5, 1145–1162. Doi:10.1017/S0144686X19001806.

Ferrant, G.; Pesando, M.C.; Nowacka, K. *Unpaid Care Work: The Missing Link in the Analysis of Gender Gaps in Labour Outcomes*; OECD Development Centre: Paris, France, 2014; Available online: https://www.oecd.org/dev/development-gender/Unpaid_care_work.pdf (accessed on 8 January 2023)

Fives, A.; Kennan, D.; Canavan, J.; Brady, B. Why we still need the term 'young carer': Findings from an exploratory study of young carers in Ireland. *Crit. Soc. Work* **2013**, *14*, 49–61.

Frank, J.; Babitsch, B. Kompression oder Expansion der Morbidität in der ambulanten Versorgung? [Compression or expansion of morbidity in outpatient care?]. *Z. Gerontol. Geriatr.* **2018**, *51*, 557–566.

Frisina Doetter, L.; Rothgang, H. The German LTC policy landscape, SOCIUM, Research Center on Inequality and Social Policy University of Bremen, **2017**.

Fruhauf, C.A.; Jarrott, S.E.; Allen, K.R. Grandchildren's perceptions of caring for grandparents. *J. Fam. Issues* **2006**, *27*, 887–911.

Fruhauf, C.A.; Orel, N.A. Developmental Issues of Grandchildren Who Provide Care to Grandparents. *The International Journal of Aging and Human Development* **2008**, *67*, 3, 209–230. Doi:10.2190/AG.67.3.b

Geraedts, M.; Heller, G.V.; Harrington, C.A. Germany's Long-Term-Care Insurance: Putting a Social Insurance Model into Practice. *Milbank Q.* **2000**, *78*, 375–401. Available online: <http://www.jstor.org/stable/3350599> (accessed on 9 October 2021).

Giebel, C.; Cannon, J.; Hanna, K.; Butchard, S.; Eley, R.; Gaughan, A.; Komuravelli, A.; Shenton, J.; Callaghan, S.; Tetlow, H.; et al. Impact of COVID-19 related social support service closures on people with dementia and unpaid carers: A qualitative study. *Aging Ment. Health* **2021**, *25*, 1281–1288.

Golafshani, N. Understanding Reliability and Validity in Qualitative Research. *Qual. Rep.* **2003**, *8*, 597–607.

Gräler, L.; Bremmerset, L.; van Excel, J.; Bakx, P.; van Bochove, M. Informal care in times of public health crisis: Objective burden, subjective burden and quality of life of caregivers in the Netherlands during the COVID-19 pandemic. In Proceedings of the Presented at the VID Conference 'Demographic Aspects of the COVID-19 Pandemic and Its Consequences', Vienna, Austria, 30 November–1 December 2020. Available online:

https://www.oeaw.ac.at/fleadmin/subsites/Institute/VID/PDF/Conferences/2020/COVID19/Posters/1.5_graeller.pdf (accessed on 30 October 2021).

Hale, T.; Webster, S.; Petherick, A.; Phillips, T.; Kira, B. Oxford COVID-19 Government Response Tracker; Blavatnik School of Government: Oxford, UK, 2020. Available online: <https://www.bsg.ox.ac.uk/research/research-projects/coronavirus-government-response-tracker> (accessed on 23 July 2021).

Hamill, S.B. Caring for grandparent with Alzheimer's disease: Help from "forgotten" generation. *J. Fam. Issues.* **2012**, *33*, 1195–1217.

Hamilton, M.G.; Adamson, E. Bounded agency in young carers' lifecourse-stage domains and transitions. *J. Youth Stud.* **2013**, *16*, 101–117.

Hanson, E.; Barbabella, F.; Magnusson, L.; Brolin, R.; Svensson, M.; Yghemonos, S.; Hlebec, V.; Bolko, I.; Boccaletti, L.; Casu, G.; et al. Research and Innovation for and with Adolescent Young Carers to Influence Policy and Practice—The European Union Funded “ME-WE” Project. *Int. J. Environ. Res. Public Health* **2022**, *19*, 9932.

Hlebec, V.; Hrast, M.F. Characteristics and Determinants of Intergenerational Financial Transfers Within Families Using Mixed Care for Elderly People. *Drus. Istraz.* **2018**, *27*, 27–46.

Hooker, K.; Bowman, S.R.; Coehlo, D.P.; Lim, S.R.; Kaye, J.; Guariglia, R.; Li, F. Behavioral change in persons with dementia: Relationships with mental and physical health of caregivers. *J. Gerontol. B Psychol. Sci. Soc. Sci.* **2002**, *57*, 453–460.

Horn, V.; Schweppe, C.; Böcker, A.G.M.; Bruquetas Callejo, M.M. Live-in migrant care worker arrangements in Germany and the Netherlands. Motivations and justifications in family decision-making. *Int. J. Ageing Later Life* **2019**, *13*, 1–31.

Hox, J.J. Multilevel modeling: When and why. In *Classification, data analysis and data highways*; Balderjahn, I., Mathar, R., Schader, M., Eds.; Springer: New York, NY, USA, 1998; pp. 147–154.

Ikeda, S. Supporting working carers’ job continuation in Japan: Prolonged care at home in the most aged society. *Int. J. Care Caring* **2017**, *1*, 63–82.

INPS-Istituto Nazionale per la Previdenza Sociale [Italian National Institute for Social Protection]. *Osservatorio sui Lavori Domestici [Italy’s Domestic Workers Observatory]*; INPS Publishing: Rome, Italy, 2021. Available online: <https://www.inps.it/news/osservatorio-sui-lavoratori-domestici-pubblicati-i-dati-2020>

ISTAT-Istituto Nazionale di Statistica-Italian [National Institute of Statistics]. *Censimento Permanente Della Popolazione e Abitazioni [Permanent Census of the Population and Housing]*; ISTAT: Rome, Italy, 2020. Available online: <http://www.quotidianosanita.it/allegati/allegato3125672.pdf> (accessed on 23 July 2021).

ISTAT-Istituto Nazionale di Statistica-Italian [National Institute of Statistics]. *Le Condizioni di Salute Della Popolazione Anziana in Italia. Anno 2019 [Health Condition of Older Population in Italy. Year 2019]*; ISTAT: Rome, Italy, 2019. Available online: <https://www.istat.it/it/files/2021/07/Report-anziani-2019.pdf>

James, E. Caring Alone. Why Black, Asia and Minority Ethnic Continue to Struggle to Access Support. Report. 2019. Available online: https://www.batod.org.uk/wp-content/uploads/2019/05/caring_alone_report.pdf (accessed on 15 January 2023).

Joseph, S.; Becker, S.; Becker, F.; Regel, S. Assessment of caring and its effects in young people: Development of the Multidimensional Assessment of Caring Activities Checklist (MACA-YC18) and the Positive and Negative Outcomes of Caring Questionnaire (PANOC-YC20) for young carers. *Child Care Health Dev.* **2009**, *35*, 510–520.

Joseph, S.; Sempik, J.; Leu, A.; Becker, S. Young carers research, practice and policy: An overview and critical perspective on possible future directions. *Adolesc. Res. Rev.* **2020**, *5*, 77–89.

Kaiser, S.; Schulze, G.C. Between inclusion and participation: Young carers who are absent from school. *JCEP* **2015**, *14*, 314–328.

Kavanaugh, M.S.; Stamatopoulos, V.; Cohen, D.; Zhang, L. Unacknowledged caregivers: A scoping review of research on caregiving youth in the United States. *Adolesc. Res. Rev.* **2016**, *1*, 29–49.

Kent, E.E.; Ornstein, K.A.; Dionne-Odom, J.N. The family caregiving crisis meets an actual pandemic. *J. Pain Symptom. Manag.* **2020**, *60*, e66–e69.

Kettell, L. Young adult carers in higher education: The motivations, barriers and challenges involved—A UK study. *JFHE* **2018**, *44*, 100–112.

Kostyál, L.Á.; Széman, Z.; Almási, V.E.; Fabbietti, P.; Quattrini, S.; Socci, M.; Lamura, G.; Gagliardi, C. Impact of the COVID-19 Pandemic on Family Carers of Older People Living with Dementia in Italy and Hungary. *Sustainability* **2021**, *13*, 7107.

Laenen, T.; Rossetti, F.; van Oorschot, W. Why deservingness theory needs qualitative research: Comparing focus group discussions on social welfare in three welfare regimes. *Int. J. Comp. Sociol.* **2019**, *60*, 190–216.

Landi, G.; Pakenham, K.I.; Cattivelli, R.; Grandi, S.; Tossani, E. Caregiving Responsibilities and Mental Health Outcomes in Young Adult Carers during the COVID-19 Pandemic: A Longitudinal Study. *Int. J. Environ. Res. Public Health* **2022**, *19*, 15149. <https://doi.org/10.3390/ijerph192215149>

Lawton M.P., Kleban M.H., Moss M., Rovine M., Glicksman A. Measuring caregiving appraisal. *J. Gerontol.* **1989**, *44*, 61–71. doi: 10.1093/geronj/44.3.P61.

Leiblfinger, M.; Prieler, V.; Schwiter, K.; Steiner, J.; Benazha, A.; Lutz, H. Impact of the COVID-19 Pandemic on Live-in Care Workers in Germany, Austria, and Switzerland. International Long-Term Care Policy Network: London, UK, 2020. Available online: <https://ltccovid.org/2020/05/14/impact-of-the-covid-19-pandemic-on-live-in-care-workers-in-germany-austria-and-switzerland/> (accessed on 6 January 2023).

Leu, A.; Jung, C.; Frech, M.; Sempik, J.; Moser, U.; Verner, M.; Becker, S. Study protocol: Young carers and young adult carers in Switzerland. *BMC Health Serv. Res.* **2018**, *18*, 1–6.

Leu, A.; Becker, S. Young carers. In *Oxford Bibliographies in Childhood Studies*; Montgomery, H., Ed.; Oxford University Press: New York, NY, USA, 2019. Available online: <https://www.oxfordbibliographies.com/view/document/obo-9780199791231/obo-9780199791231-0120.xml> (accessed on 22 January 2023).

Leu, A.; Guggiari, E.; Phelps, D.; Magnusson, L.; Nap, H.H., Hoefman, R.; Lewis, F.; Santini, S.; Socci, M.; Boccaletti, L.; Hlebec, V.; Rakar, T.; Hudobivnik, T.; Hanson, E. Cross-national Analysis of Legislation, Policy and Service Frameworks for Adolescent Young Carers in Europe. *Journal of Youth Studies* **2022**, *25*, 9, 1215–1235. Doi: 10.1080/13676261.2021.1948514

Li, J. Study and Comparison of Elderly Care System in Germany and China. Ph.D. Thesis, University of Bremen, Bremen, Germany, 2019. Available online: http://www.share-project.org/uploads/tx_sharepublications/Study_and_Comparison_of_Elderly_Care_System_in_Germany_and_China.pdf (accessed on 13 December 2021).

Li, Q.; Zhang, H.; Zhang, M.; Li, T., Ma, W.; An, C.; Chen, Y.; Liu, S.; Kuang, W.; Yu, X.; Wang, H. Prevalence and risk factors of anxiety, depression, and sleep problems among caregivers of people living with neurocognitive disorders during the COVID-19 Pandemic. *Front Psychiatry* **2021**, *11*, 1516. <https://doi.org/10.3389/fpsy.2020.590343>.

Lightfoot, E.; Moone, R.P. Caregiving in Times of Uncertainty: Helping Adult Children of Aging Parents Find Support during the COVID-19 Outbreak. *J. Geront. Soc. Work* **2020**, *63*, 542–552.

Lincoln, Y.S.; Guba, E.G. *Naturalistic Inquiry*; Sage: Beverly Hills, CA, USA, 1985.

Litwin, H.; Stoeckel, K.J.; Roll, A. Relationship Status and Depressive Symptoms among Older Co-Resident Caregivers. *Aging Ment. Health* **2014**, *18*, 225–231.

Lorenz-Dant, K. Germany and the COVID-19 Long-Term Care Situation. LTC Covid; International Long Term Care Policy Network, Care Policy and Evaluation Centre-London School of Economics: London, UK, 2020. Available online: https://ltccovid.org/wp-content/uploads/2020/05/Germany_LTC_COVID-19-26-May-2020.pdf (accessed on 30 October 2021).

Maccora, J.; Ee, N.; Hosking, D.; McCallum, J. Who Cares? Older Australians Do; National Seniors: Canberra, Australia, 2020. Available online: <https://nationalseniors.com.au/uploads/NSA-ResearchReport-Whocares.pdf> (accessed on 23 October 2021).

Mohanty, I.; Niyonsenga, T. A longitudinal analysis of mental and general health status of informal carers in Australia. *BMC Public Health* **2019**, *1*, 1436.

OECD. *Who Cares? Attracting and retaining Care Workers for the Elderly. OECD Health Policy Studies*; OECD Publishing: Paris, France, 2020.

Onwumere, J. Informal carers in severe mental health conditions: Issues raised by the United Kingdom SARS-CoV-2 (COVID-19) Pandemic. *Int. J. Soc. Psychiatry* **2021**, *67*, 107–109.

Orel, N.A.; Dupuy, P. Grandchildren as auxiliary caregivers for grandparents with cognitive and/or physical limitations: Coping strategies and ramifications. *Child. Study J.* **2002**, *32*, 193–213.

Pearlin, L.I.; Mullan, J.T.; Semple, S.J., Skaff, M.M. Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist* **1990**, *30*, 5, 583–94.

Pelle, J. Young carers from black and minority ethnic community. In *Child and Adolescent Mental Health: Theory and Practice*; Hooper, C., Thompson, M., Laver-Bradbury, C., Gale, C., Eds.; Taylor&Francis: Boca Raton, FL, USA, 2012; pp. 351–356.

Phillips, D.; Paul, G.; Fahy, M.; Dowling-Hetherington, L.; Kroll, T.; Moloney, B.; Duffy, C.; Fealy, G.; Lafferty, A. The invisible workforce during the COVID-19 pandemic: Family carers at the frontline. *HRB Open Res* **2020**, *3*, 24.

Pinquart, M.; Sörensen, S. Spouses, Adult Children, and Children-in-Law as Caregivers of Older Adults: A Meta-Analytic Comparison. *Psychol. Aging* **2011**, *26*, 1–14.

Quinn, C.; Jones, I.R.; Clare, L. Illness representations in caregivers of people with dementia. *Aging Ment. Health* **2017**, *21*, 553–561.

Ravens-Sieberer, U.; Erhart, M.; Rajmil, L.; Herdman, M.; Auquier, P.; Bruil, J.; Power, M.; Duer, W.; Abel, T.; Czemy, L.; et al. Reliability, construct and criterion validity of the KIDSCREEN-10 score: A short measure for children and adolescents' well-being and health-related quality of life. *Qual. Life Res.* **2010**, *19*, 1487–1500.

Rith-Najarian, L.R.; McLaughlin, K.A.; Sheridan, M.A.; Nock, M.K. The biopsychosocial model of stress in adolescence: Self-awareness of performance versus stress reactivity. *Stress* **2014**, *17*, 193–203. doi: 10.3109/10253890.2014.891102.

- Rodrigues, R.; Simmons, C.; Schmidt, A.E.; Steober, N. Care in times of COVID-19: The impact of the pandemic on informal caregiving in Austria. *Eur. J. Ageing* **2021**, *18*, 195–205.
- Rogers, E. *Diffusion of Innovations*, 5th ed.; Free Press: New York, NY, USA, 2005.
- Rothgang, H.; Wolf-Ostermann, K.; Domhoff, D.; Franziska, H.; Heß, M.; Kalwitzki, T.; Ratz, K.; Schmidt, A.; Seibert, K.; Stolle, C.; et al. How Covid-19 Has Affected Informal Caregivers and Their Lives in Germany; Socium: Bremen, Germany, 2020. Available online: https://www.socium.uni-bremen.de/uploads/Schnellbericht_Befragung_pfleger_Angehoriger_-_print.pdf (accessed on 4 January 2022).
- Rotolo, A. Modelli istituzionali e percorsi degli utenti. In *Il Welfare e la Long-Term Care in Europa [Welfare System and Long-Term Care in Europe]*; Fosti, G., Notarnicola, E., Eds.; Egea: Milan, Italy, 2014; pp. 93–114.
- Santini, S.; Andersson, G.; Lamura, G. Impact of incontinence on the quality of life of caregivers of older persons with incontinence: A qualitative study in four European countries. *Arch Gerontol. Geriatr.* **2016**, *63*, 92–101.
- Santini, S.; Socci, M.; D’Amen, B.; Di Rosa, M.; Casu, G.; Hlebec, V.; Lewis, F.; Leu, A.; Hoefman, R.; Brodin, R.; et al. Positive and Negative Impacts of Caring among Adolescents Caring for Grandparents. Results from an Online Survey in Six European Countries and Implications for Future Research, Policy and Practice. *IJERPH* **2020**, *17*, 6593.
- Santini, S.; Tombolesi, V.; Baschiera, B.; Lamura, G. Intergenerational programs involving adolescents, institutionalized elderly, and older volunteers: Results from a pilot research-action in Italy. *Biomed. Res. Int.* **2018**, *2018*, 1–14.
- Schmidt, A.E.; Leichsenring, K.; Stafinger, H.; Litwin, C.; Bauer, A. The Impact of COVID19 on Users and Providers of Long-Term Care Services in Austria. Country Report in LTC; International Long-Term Care Policy Network, Care Policy and Evaluation Centre-London School of Economics: London, UK, 2020.
- Schumacher, A.; Willems, H. Caring for the elderly. Effects on family and adolescents. In *Cultures of Care*; Boll, T., Ferring, D., Valsiner, J., Eds.; Information Age Publishing Inc.: Charlotte, NC, USA, 2018; Chapter 5; pp. 99–122.
- Schütte, W. Das Leistungskonzept der Pflegeversicherung im Reformprozess—Angehörigenpflege, Pflegegeld und, Neues Verwaltungsrecht. *Sozialgerichtsbarkeit* **2009**, *4*, 185–192.
- Shenton, A.K. Strategies for Ensuring Trustworthiness in Qualitative Research Projects. *Educ. Inf.* **2004**, *22*, 63–75.
- Siskowsky, C. Young Caregivers: Effect of Family Health Situations on School Performance. *J. Sch. Nurs.* **2006**, *22*, 163–169.
- Socci, M.; Principi, A.; Di Rosa, M.; Carney, P.; Chiatti, C.; Lattanzio, F. on behalf of the UP-TECH Research Group. Impact of working situation on mental and physical health for informal caregivers of older people with Alzheimer’s disease in Italy. Results from the UP-TECH longitudinal study. *Aging Ment. Health* **2021**, *25*, 22–31.
- Stamatopoulos, V. The young carer penalty: Exploring the costs of caregiving among a sample of Canadian youth. *Child Youth Serv.* **2018**, *39*, 180–205.

Steiner, J.; Prieler, V.; Leibfingler, M.; Benazha, A. Völlig legal!? Rechtliche Rahmung und Legalitätsnarrative in der 24h-Betreuung in Deutschland, Österreich und der Schweiz. *Österreichische Zeitschrift für Soziologie* **2019**, *44*, 1-19.

Strauss, A.L.; Corbin, J.M. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*; Sage Publications: Thousand Oaks, CA, USA, 1998.

Sumner, A.; Hoy, C.; Ortiz-Juarez, E. *Estimates of the Impact of COVID-19 on Global Poverty*; UNU-WIDER: Helsinki, Finland, 2020.

Svanberg, E.; Stott, J.; Spector, A. 'Just helping': Children living with a parent with young onset dementia. *Aging Ment. Health* **2010**, *14*, 740–751.

Teipel, K. *Understanding Adolescence Seeing Through a Developmental Lens*; University of Minnesota, Konopka Institute, State Adolescent Health Resource Center: Minneapolis, MN, USA, 2013.

Theobald, H.; Luppi, M. Elderly care in changing societies: Concurrences in divergent care regimes—A comparison of Germany, Sweden and Italy. *Curr. Sociol.* **2018**, *66*, 629–642.

Thomas, N.; Stainton, T.; Jackson, S.; Cheung, W.Y.; Doubtfire, S.; Webb, A. 'Your friends don't understand': Invisibility and unmet need in the lives of 'young carers'. *Child. Fam. Soc. Work* **2003**, *8*, 35–46.

Todorovic, N.; Vracevic, M.; Rajovic, N.; Pavlovic, V.; Madzarevic, P.; Cumic, J.; Mostic, T.; Milic, N.; Rajovic, T.; Sapic, R.; Milcanovic, P.; Velickovic, I.; Culafic, S.; Stanisavljevic, D.; Milic, N. Quality of life of informal caregivers behind the scene of the COVID-19 epidemic. *Serbia. Medicina* **2020**, *56*, *12*, 647. Doi: [10.3390/medicina56120647](https://doi.org/10.3390/medicina56120647)

Tur-Sinai, A.; Bentur, N.; Fabbietti, P.; Lamura, G. Impact of the Outbreak of the COVID-19 Pandemic on Formal and Informal Care of Community-Dwelling Older Adults: Cross-National Clustering of Empirical Evidence from 23 Countries. *Sustainability* **2021**, *13*, 7277.

Tur-Sinai, A.; Teti, A.; Rommel, A.; Hlebec, V.; Lamura, G. How Many Older Informal Caregivers Are There in Europe? Comparison of Estimates of Their Prevalence from Three European Surveys. *IJERPH* **2020**, *17*, *24*, 9531. Doi: [10.3390/ijerph17249531](https://doi.org/10.3390/ijerph17249531)

Vahia, I.V.; Blazer, D.G.; Smith, G.S.; Karp, J.F.; Steffens, D.C.; Forester, B.P.; Reynolds, C.F. COVID-19, mental health and aging: A need for new knowledge to bridge science and service. *Am. J. Geriatr. Psychiatry* **2020**, *28*, 695–697.

Verbakel, E. How to Understand Informal Caregiving Patterns in Europe? The Role of Formal Long-Term Care Provisions and Family Care Norms. *Scand. J. Public Health* **2018**, *46*, 436–447.

Weil L.G., Fleming S.M., Dumontheil I., Kilford E.J., Weil R.S., Rees G., Dolan R.J., Blakemore S.J. The development of metacognitive ability in adolescence. *Conscious. Cogn.* **2013**, *22*, 264–271. Doi: [10.1016/j.concog.2013.01.004](https://doi.org/10.1016/j.concog.2013.01.004).

World Medical Association. World medical association declaration of Helsinki: Ethical principles for medical research involving human subjects. *JAMA* **2013**, *310*, 2191–2194.

Yates M.E., Tennstedt S., Chang B.H. Contributors to and mediators of psychological well-being for informal caregivers. *J. Gerontol. B Psychol. Sci. Soc. Sci.* **1999**, 54, 12–22. Doi: 10.1093/geronb/54B.1.P12

Zhao, H.; Kim, S.; Suh, T.; Du, J. Social institutional explanations of global internet diffusion: A cross-country analysis. *J. Glob. Inf. Manag.* **2007**, 15, 28–55.

Zigante, V. Informal Care in Europe - Exploring Formalisation, Availability and Quality; Publications Office of the European Union: Brussels, Belgium, 2018.

Zucca, M.; Isella, V.; Di Lorenzo, R.; Marra, C.; Cagnin, A.; Cupidi, C.; Bonanni, L.; Laganà, V.; Rubino, E.; Vanacore, N.; Agosta, F.; Caffarra, P.; Sambati, R.; Quaranta, D.; Guglielmi, V.; Appollonio, I.M.; Logroscino, G.; Filippi, M.; Tedeschi, G.; Ferrarese, C.; Rainero, I.; Bruni, A.C. and the SINDem COVID-19 Study Group. Being the family caregiver of a patient with dementia during the coronavirus disease 2019 lockdown. *Front Aging Neurosci.* **2021**, 13, 132, 653533. [Doi: 10.3389/fnagi.2021.653533](https://doi.org/10.3389/fnagi.2021.653533)

Zwar, L., König, H.H., Hajek, A. Gender Differences in Mental Health, Quality of Life, and Caregiver Burden among Informal Caregivers during the Second Wave of the COVID-19 Pandemic in Germany: A Representative, Population-Based Study. *Gerontology* **2022**. Doi: [10.1159/000523846](https://doi.org/10.1159/000523846).

Declaration of contribution according to CRediT (Contributor Roles Taxonomy)

Publication 1: (Santini et al. 2020)

Santini, S.; Socci, M.; D’Amen, B.; Di Rosa, M.; Casu, G.; Hlebec, V.; Lewis, F.; Leu, A.; Hoefman, R.; Brolin, R.; Magnusson, L.; Hanson, E. Positive and Negative Impacts of Caring among Adolescents Caring for Grandparents. Results from an Online Survey in Six European Countries and Implications for Future Research, Policy and Practice. *Int. J. Environ. Res. Public Health* **2020**, *17*, 6593. <https://doi.org/10.3390/ijerph17186593>

Impact Factor: 4.614

Contribution in details: Conceptualization; Methodology and data curation (with Mirko Di Rosa); Validation (with Feylyn Lewis and Elizabeth Hanson); Investigation; Writing—Original Draft Preparation; Supervision.

Publication 2: (Santini et al., 2022a)

Santini, S.; D’Amen, B.; Socci, M.; Di Rosa, M.; Hanson, E.; Hlebec, V. Difficulties and Needs of Adolescent Young Caregivers of Grandparents in Italy and Slovenia: A Concurrent Mixed-Methods Study. *Int. J. Environ. Res. Public Health* **2022**, *19*, 2837. <https://doi.org/10.3390/ijerph19052837>

Impact Factor: 4.614

Contribution in details: Conceptualization; Methodology and data curation (with Mirko Di Rosa and Barbara D’Amen); Validation (with Elizabeth Hanson); Investigation; Writing—Original Draft Preparation; Supervision.

Publication 3: (Santini et al., 2022b)

Santini, S.; Socci, M.; Fabbietti, P.; Lamura, G.; Teti, A. Factors Worsening and Mitigating the Consequences of the COVID-19 Outbreak on the Overall Health of Informal Caregivers of Older People with Long-Term Care Needs Living in Germany and in Italy. *Int J Environ Res Public Health* **2022**, *19*(3):1694. <https://doi.org/10.3390/ijerph19031694>

Impact Factor: 4.614

Contribution in details: Conceptualization; Methodology and data curation (with Paolo Fabbietti and Andrea Teti); Investigation (with Marco Socci); Writing—Original Draft Preparation; Supervision.

Publication 4: (Socci & Santini, 2023 – submitted)

Socci, M[§]; Di Rosa, M., Quattrini, S.; Lamura, G., Hanson, E., Magnusson, L.; Yghemonos, S.; Cavrini, G.; Teti, A.; Santini, S. [§] Being an adult or an older caregiver of older people during the Pandemic: empirical evidence from a cross-national survey in Europe. *PLOS ONE* **2023**- submitted.

[§] MS and SS have contributed equally and share first authorship

Impact factor: 3.752

Contribution in details: Conceptualization; Methodology and data curation (with Mirko Di Rosa and Giulia Cavrini); Investigation (with Marco Socci); Writing—Original Draft Preparation; Supervision.

List of publications

Articles in scientific peer-reviewed journals

1. **Santini, S.**; Andersson, G.; Lamura G. Impact of incontinence on the quality of life of caregivers of older persons with incontinence (OPI): a qualitative study in four European Countries. *Archives of Gerontology and Geriatrics* **2016**, 63, 92–101. Doi:10.1016/j.archger.2015.10.013
2. **Santini, S.**; Tombolesi, V. Solidarietà intergenerazionale e invecchiamento attivo: l'esperienza del progetto "Ri-Generiamoci" in Invecchiamento e rapporti intergenerazionali tra solidarietà e conflitto, Giovanni Lamura e Marco Socci (Eds., *Prisma Economia Società Lavoro* **2015**, 3, 91-108.
3. Gagliardi, C.; **Santini, S.** La longevità attiva in ambito rurale: la sperimentazione nelle Marche, in Giovanni Lamura e Marco Socci (Eds.) in Invecchiamento e rapporti intergenerazionali tra solidarietà e conflitto, *Prisma Economia Società Lavoro* **2015**, 3, 2015, 121-135.
4. **Santini, S.**; Socci, M.; Principi A. Progetti per la vita dopo la pensione: tipologie di Anziani attivi in Italia, *Giornale di Gerontologia* **2015**, LXIII, 4, 2, 34.
5. Principi, A.; **Santini, S.**; Socci, M.; Smeaton, D.; Cahill, K.E.; Vegeris, S.; Barnes, H. Retirement plans and active ageing: perspectives in three countries. *Ageing and Society* **2016**, 1-27 Doi:10.1017/S0144686X16000866.
6. Tesauro, T.; **Santini, S.** L'attivazione psico-relazionale di anziani in residenza attraverso pratiche di auto-narrazione e programmi intergenerazionali in due regioni italiane: i casi Memory e Ri-generiamoci, *Autonomie Locali Servizi Sociali* **2016**, 2.
7. Baschiera, B.; **Santini, S.**; Socci, M. Intergenerational entrepreneurship education: older entrepreneurs reducing youngsters' social and work disengagement. *Problems of Education in the 21st Century* **2018**,76,1, 7-20.
8. Principi, A.; Smeaton, D.; Cahill, K.; **Santini, S.**; Barnes, H.; Socci, M. What Happens to Retirement Plans, and Does This Affect Retirement Satisfaction? *The International Journal of Aging and Human Development* **2018**, 90, 2,152-175. doi:[10.1177/0091415018796627](https://doi.org/10.1177/0091415018796627)
9. **Santini, S.**; Tombolesi; V., Baschiera, B.; Lamura, G. Intergenerational Programs Involving Adolescents, Institutionalized Elderly, and Older Volunteers: Results from a Pilot Research-Action in Italy, *BioMed Research International* **2018**,1-14 doi: 10.1155/2018/4360305.
10. Carsughi, A.; **Santini, S.**; Lamura, G. Impact of the lack of integrated care for older people with urinary incontinence and their family caregivers: results from a qualitative study in a central italian region. *Annali Istituto Superiore di Sanità* **2019**, 55,1, 26-33. Doi: 10.445/ANN_19_01_06

11. Gagliardi, C.; **Santini, S.**; Piccinini, F.; Fabbietti, P.; Di Rosa M. A pilot programme evaluation of social farming horticultural and occupational activities for older people in Italy. *Health and Social Care in the Community* **2019**, *27*, 207-214.
12. **Santini, S.**; Piccinini, F.; Gagliardi, C. Can a green care informal learning program foster active aging in older adults? Results from a qualitative pilot study in Central Italy. *Journal of Applied Gerontology* **2019**, *39*(11), 1240–1249. Doi: <https://doi.org/10.1177/0733464819883769>
13. **Santini, S.**; Fabbietti, P.; Lamura, G. The impact of the absorbent products distribution system on family caregivers of older people with incontinence in Italy: perception of the support received. *BMC Geriatrics* **2019**, *19*, 239. doi: [10.1186/s12877-019-1254-4](https://doi.org/10.1186/s12877-019-1254-4)
14. **Santini, S.**; Baschiera, B.; Socci, M. Older adult entrepreneurs as mentors of young people neither in employment nor education and training (NEETs). Evidences from multi-country intergenerational learning program, *Educational Gerontology* **2020**, *46*,3, 97-116. Doi: [10.1080/03601277.2020.1714142](https://doi.org/10.1080/03601277.2020.1714142)
15. Baschiera, B.; Socci, M.; **Santini, S.** When Intergenerational interdependency gives rise to new spaces of inclusivity in Special Education. The Be the Change Project (Boosting Entrepreneurship Through Intergenerational Exchange). *Formazione&Insegnamento* **2020**, XVIII-1.
16. Stara, V.; **Santini, S.**; Kropf, J.; D’Amen, B. Exploring the effectiveness of digital health coaching programs among older employees in transition to retirement: a systematic literature review. *Journal of Medical Internet Research* **2020**, *22*(9):e17809. Doi: [10.2196/17809](https://doi.org/10.2196/17809).
17. **Santini, S.**; Galassi, F.; Kropf, J.; Stara, V. A Digital Coach Promoting Healthy Aging among Older Adults in Transition to Retirement: Results from a Qualitative Study in Italy. *Sustainability* **2020**, *12*,18,7400.
18. **Santini, S.**; Socci, M.; D’Amen, B.; Di Rosa, M.; Casu, G.; Hlebec, V.; Lewis, F.; Leu, A; Hoefman, R.; Brolin, R.; Magnusson, L.; Hanson, E. Positive and Negative Impacts of Caring among Adolescents Caring for Grandparents. Results from an Online Survey in Six European Countries and Implications for Future Research, Policy and Practice. *Int. J. Environ. Res. Public Health* **2020**, *17*, 6593. doi.org/10.3390/ijerph17186593
19. Nap, H.H.; Hoefman, R.; de Jong, N.; Lovink, L.; Glimmerveen, L.; Lewis, F.; **Santini, S.**; D’Amen, B.; Socci, M.; Boccaletti, L.; Casu, G.; Manattini, A.; Brolin, R.; Sirk, K.; Hlebec, V.; Rakar, T.; Hudobivnik, T.; Leu, A.; Berger, F.; Magnusson, L.; Hanson, E. The awareness, visibility and support for young carers across Europe: a Delphi study. *BMC Health Serv Res* **2020**, *20*, 921. <https://doi.org/10.1186/s12913-020-05780-8>
20. D’Amen, B.; Socci, M.; **Santini, S.** Intergenerational caring: a systematic literature review on young and young adult caregivers of older people. *BMC Geriatr* **2021**, *21*, 105. <https://doi.org/10.1186/s12877-020-01976-z>
21. Socci, M.; **Santini, S.**; Dury, S.; Perek-Białas, J.; D’Amen, B.; Principi, A. "Physical Activity during the Retirement Transition of Men and Women: A Qualitative Longitudinal Study", *BioMed Research International* **2021**, Article ID 2720885, 16 pages, 2021. <https://doi.org/10.1155/2021/2720885>
22. **Santini, S.**, Stara, V., Galassi, F., Merizzi, A., Schneider, C., Schwammer, S., Stolte E, Kropf J. User Requirements Analysis of an Embodied Conversational Agent for Coaching Older Adults to Choose Active and Healthy Ageing Behaviors during the Transition to Retirement: A Cross-National User Centered Design Study. *International Journal of Environmental Research and Public Health* **2021**, *18*,18, 9681. Doi: <https://doi.org/10.3390/ijerph18189681>
23. Leu, A.; Guggiari, E.; Phelps, D.; Magnusson, L.; Nap, H.H.; Hoefman, R.; Lewis, F.; **Santini, S.**; Socci, M.; Boccaletti, L.; Hlebec, V.; Rakar, T.; Hudobivnik, T.; Hanson, E. Cross-national Analysis of Legislation, Policy and Service Frameworks for Adolescent Young Carers in Europe, *Journal of Youth Studies* **2021**. Doi: [10.1080/13676261.2021.1948514](https://doi.org/10.1080/13676261.2021.1948514)

24. D'Amen, B.; Socci, M.; Di Rosa, M.; Casu, G.; Boccaletti, L.; Hanson, E.; **Santini, S.** Italian Adolescent Young Caregivers of Grandparents: Difficulties Experienced and Support Needed in Intergenerational Caregiving—Qualitative Findings from a European Union Funded Project. *Int J Environ Res Public Health* **2021**, *23*,19(1):103. Doi: 10.3390/ijerph19010103.
25. **Santini, S.**; Socci, M.; Fabbietti, P.; Lamura, G.; Teti, A. Factors Worsening and Mitigating the Consequences of the COVID-19 Outbreak on the Overall Health of Informal Caregivers of Older People with Long-Term Care Needs Living in Germany and in Italy. *Int J Environ Res Public Health* **2022**, *19*,3,1694. Doi: 10.3390/ijerph19031694. PMID: 35162718; PMCID: PMC8835160.
26. **Santini, S.**; D'Amen, B.; Socci, M.; Di Rosa, M.; Hanson, E.; Hlebec, V. Difficulties and Needs of Adolescent Young Caregivers of Grandparents in Italy and Slovenia: A Concurrent Mixed-Methods Study. *Int. J. Environ. Res. Public Health* **2022**, *19*, 2837. <https://doi.org/10.3390/ijerph19052837>
27. **Santini, S.**; Finco, M.; Galassi, F. Education and Employment of Refugees and Migrants in the Formal Elderly Healthcare Sector: Results from an Online Survey in Italy. *Sustainability* **2022**, *14*, 3540. <https://doi.org/10.3390/su14063540>
28. Merizzi, A.; Biasi, R.; Zamudio, J.F.Á.; Spagnuolo Lobb, M.; Di Rosa, M.; **Santini, S.** A Single-Case Design Investigation for Measuring the Efficacy of Gestalt Therapy to Treat Depression in Older Adults with Dementia in Italy and in Mexico: A Research Protocol. *Int. J. Environ. Res. Public Health* **2022**, *19*, 3260. <https://doi.org/10.3390/ijerph19063260>
29. Galassi, F.; Merizzi, A.; D'Amen, B.; Santini, S. Creativity and art therapies to promote healthy aging: A scoping review. *Frontiers in Psychology* **2022**,*13*. Doi: 10.3389/fpsyg.2022.906191. ISSN=1664-1078
30. **Santini, S.**; Rampioni, M.; Stara, V.; Di Rosa, M.; Paciaroni, L.; Paolini, S.; Fioretti, S.; Valenza, S.; Riccardi, G.R.; Pelliccioni, G. Cognitive Digital Intervention for Older Patients with Parkinson's Disease during COVID-19: A Mixed-Method Pilot Study. *Int. J. Environ. Res. Public Health* **2022**, *19*,14844. <https://doi.org/10.3390/ijerph192214844>
31. **Santini, S.**; Fabbietti, P.; Galassi, F.; Merizzi, A.; Kropf, J.; Hungerländer, N.; Stara, V. The Impact of Digital Coaching Intervention for Improving Healthy Ageing Dimensions among Older Adults during Their Transition from Work to Retirement. *Int. J. Environ. Res. Public Health* **2023**, *20*, 4034. <https://doi.org/10.3390/ijerph20054034>
32. Hanson, E.; Lewis, F.; Barbabella, F.; Hoefman, R.; Casu, G.; Boccaletti, L.; Leu, A.; Hlebec, V.; Bolko, I.; **Santini, S.**; Svensson, M.; Becker, S.; Magnusson, L. (2023) Ethical Considerations When Conducting Pan-European Research with and for Adolescent Young Carers, Ethics and Social Welfare, DOI: 10.1080/17496535.2023.2205654
33. Barbabella, F.; Magnusson, L.; Boccaletti, L.; Casu, G.; Hlebec, V.; Bolko, I.; Lewis, F.; Hoefman, R.; Brolin, R.; **Santini, S.**; Socci, M.; D'Amen, B.; de Jong, Y.; Bouwman, T.; de Jong, N.; Leu, A.; Phelps, D.; Guggiari, E.; Wirth, A.; Morgan, V.; Becker, S.; Hanson, E. Recruitment of Adolescent Young Carers to a Psychosocial Support Intervention Study in Six European Countries: Lessons Learned from the ME-WE Project. *Int J Environ Res Public Health*. **2023** Mar 14;*20*(6):5074. doi: 10.3390/ijerph20065074.

Book chapters

1. Chiatti, C.; Melchiorre, M.G.; Di Rosa, M.; Principi, A.; **Santini S.**; Döhner H., Lamura G. Family networks and supports in older age in Phellas, C. (Ed.) *Aging in European Societies*, Springer, New York, NY, USA, 2013.

2. Barbabella, F.; Poli, A.; **Santini, S.**; Lamura, G. The role of informal caregivers in long-term care for older people: needs and supports, in Boll T., Ferring D. & Valsiner J. (Eds.), *Cultures of Care in Ageing*. IAP, Information Age Publishing Inc., Charlotte, NC, 2018.
3. Di Rosa, M.; Barbabella, F.; Poli, A.; **Santini, S.**; Lamura G. Migrant care workers in Italian households: recent trends and future perspectives, in Christensen K. & Pilling D. (Eds.) *The Routledge Handbook of Social Care Work Around the World*, Routledge, New York, NY, USA, 2018.
4. **Santini, S.**; Carsughi, A.; Lamura G. Quali servizi integrati a sostegno dei caregiver familiari di anziani non autosufficienti per la gestione dell'incontinenza urinaria? Criticità e suggerimenti da uno studio condotto nelle Marche, in Porcu S. e Giarelli G. (Eds.), *Long-term care e non-autosufficienza: questioni teoriche, metodologiche e politico-organizzative*, Franco Angeli, Milano, Italy, 2019.

Curriculum Vitae et Studiorum

PERSONAL DATA

Name and surname: Sara Santini

Date and place of birth: 12.01.1975, Ancona (Italy)

Nationality: Italian

WORK EXPERIENCE

From 1st July 2015 up today

IRCCS INRCA-National Institute of Health and Science on Aging (Italy)

Public elder care provider and research institute

Permanent position as senior researcher and project manager

Quantitative and qualitative research on:

informal caregivers of older frail people

intergenerational relationships and solidarity

the use of digital technology for boosting active and healthy ageing

Between September 2016 and December 2018 she coordinated the international consortium of the "Be The Change"- "Boosting entrepreneurship through intergenerational exchange" project, funded by Erasmus+ Programme-KA2.

Between 2018 and 2021 she was the INRCA principal investigator of two projects:

1.Me-We- "Psychosocial Support for Promoting Mental Health and Well-being among Adolescent Young Carers in Europe" (2018-2021) funded by the European Commission (Horizon2020 Programme);

2. AgeWell-A digital coach for promoting healthy aging of older adults in transition from work to retirement (2019-2022), funded by AAL funding programme.

She is currently the research manager/PI of the following European research projects:

-HERO (2020-2022), funded by Erasmus+ Programme-KA2

-SOUND (2022-2024)-Training Social and healthcare professional in music-based therapeutic intervention to support older people with Dementia, funded by Erasmus+ programme-KA2 (Coordinator).

-AGE-IT Ageing Well in an Ageing Society, funded by the National Recovery and Resilience Plan (involved in Spoke 6-WP5: Training of formal and informal caregivers)

-Vitality Smart solutions and educational programs for anti-fragility and inclusivity SAFINA (involved in Spoke 7-WP1 and WP2).

From 2019 to 2021

Polytechnic University of the Marche Region- UNIVPM

Faculty of Medicine-Nursing Sciences

Contract professor at the course of Sociology

Teacher of Sociology of Health

From 2000 – 2015

IRCCS INRCA-National Institute of Health and Science on Aging (Italy)

Public elder care provider and research institute

Researcher

She was responsible for the qualitative data analysis of the following national and European research projects on aging, reconciliation of care and work and caregivers quality of life: *“Il ruolo della donna nell’assistenza familiare all’anziano”* (2000-2001), *ESAW - Invecchiare bene: studio europeo sul benessere in età adulta* *Ageing Well: European Study of Adult Well-Being* (2001-2004), *“Risk factors in postmenopausal woman caregiver”* (2000-2002), *Equal DIPO- Migrant women caring for older people in the Marche Region, (2002-2005)*, *“Carers@Work: the reconciliation of work and care for an older family member”* (2008-2010), *Quality of life in caregivers of dependent people affected by incontinence in Europe”* (2010-2011).

From 2012 to 2014, she is the person in charge of data collection, analysis and international dissemination in the *“AIDA” project- Advancing Integration for a Dignified Ageing*: author of the deliverable *“Album of European Good practices of integration”* (2012-2014), and she dealt with data collection and updating of 78 ICTs based initiative for the *“Carict-Publ”* project, for which she has collected information from web and previous scientific publications, kept contacts with services’ coordinators and delivered case-studies that will be published on an online repository. She has also coordinated two subcontractor bodies for the creation of the web platform.

In 2012 she was in charge of data collection and analysis for the local project *“Rigeneriamoci”*, aiming at fostering the intergenerational relationships between teenagers of a secondary school and a group of elderly of a care centre in Ancona.

From September 2014 to March 2017 she’s dealing with qualitative data collection and analysis (face to face semi-structured interviews) in one international longitudinal study on the transition from work to retirement (Extending Working Life) and a second local project about Active Ageing in rural areas.

March-September 2004	Municipality of Ancona Social Services Researcher Data collection and analysis for the Social Services Report-2004
2001-2002	Centre for Voluntary Services, Ancona Education for voluntary activities improvement Teacher <i>Teaching to teen-agers groups</i> EBAM Ancona Via Calatafimi 1, Antares Research Centre of Bologna Research area Researcher Recruitment, survey and data analysis
EDUCATION AND TRAINING	
2019-2023	University of Vechta (Germany)/Università di Bolzano (Italy) PhD student in Gerontology International comparison of long-term intergenerational informal caregiving in ordinary and in Covid-19 pandemic-stress time
May 2012-May 2013	University of the Marche Region (UNIVPM)- Faculty of Economics Master in Management of Network Healthcare organisations (Management delle organizzazioni sanitarie di rete)
September- October 2011	IRCCS INRCA Methodological training Epidemiology applied to gerontology
May 2011	GRUNTVIG/COMENIUS SEMINAR “LEARNING IN LATER LIFE-GENERATIONAL COOPERATION” Active citizenship, European citizenship and dimension, gender training, inclusive approach, intercultural education, pedagogy and didactics.
15th July 2001	Conservatory “L. D’Annunzio”, Pescara (Italy) Conservatory Bachelor Degree in Violin Violin “Maestro”

1995– 2000

“Alma Mater Studiorum” University of Bologna (Italy)

Master’s Degree in Political Science. Specialization: Political and social science (21st July, 2000)

“Donne immigrate su percorsi di emancipazione: il caso delle Peruviane ad Ancona” [Migrant women on emancipatory paths: the case of Peruvian women in Ancona]

108/110

May 2000

Degree in social operator in the prevention of prostitution and trafficking in migrant women in Italy

Help relationship management prevention measures and socio-sanitary aspects.

Caritas Ancona Osimo and Provincial Council

98/100

1989- 1994

Liceo Classico Statale C. Rinaldini, Ancona

Humanistic High School

General Certificate of Education

60/60

Editorial activity

Reviewers for several international journals e.g. IJERPH, Sustainability, BMJ, Plos One.

Invited presentations

Invited as speaker at:

-3^o International Young Carers Conference, Adolescent Young Carers of grandparents: results from the “Me-We” online survey, 4th May 2021.

-International weeks, University of Vechta, The impact of Covid-19 outbreak on family carers of older, frail and disabled people in Italy and in Germany: preliminary findings from an online survey,

31 May-11 June 2021.

-Human rights for all ages: promoting a life course perspective and intergenerational cooperation to combat ageism, 18 November, 2021, Slovenia, Brdo Congress Centre.

Speech slot: 14.00-15.10 Intergenerational cooperation as a way to combat ageism

Grants

-“Be The Change”-“Boosting entrepreneurship through intergenerational exchange” project, 266.000,00€, funded by Erasmus+ Programme-KA2, Agenzia Nazionale Erasmus Plus Indire.

-Me-We (partner), <https://me-we.eu/the-project/>, about total 6 million €, funded by Horizon 2020 Program.

- Age Well (partner), <http://www.aal-europe.eu/projects/agewell/>, 250.000,00€, funded by AAL Program.

-HERO (partner), <https://hero-erasmus.csl.gr/it/casa-2/>, 221.564,00€, funded by Erasmus+ Programme-KA2, Erasmus Plus National Agency-Cyprus

-SOUND (coordinator), <https://soundeuproject.eu/>, 249.992,00€, funded by Erasmus+ Programme-KA2, Agenzia Nazionale Erasmus Plus Indire.

-NEXUS (partner), <https://nexusproject.eu>, 250.000,00€, funded by Erasmus+ Programme-KA2, Ireland National Agency.

PERSONAL SKILLS

Mother tongue: Italian

Other language(s):

	Understanding		Speaking		Writing
	Listening	Reading	Spoken interaction	Spoken production	
English	C1	C2	C1	C2	C1
Spanish	B1	B2	B1	B1	B1

JOB-RELATED SKILLS

Curious and creative in finding problems solutions, with good emotional intelligence and strong interpersonal and management skills. She is not discouraged in the face of difficulties and always finds the solution thanks to the dialogue in the work team. Good conflict management and good diplomatic skills.

-Member of the National Association of Numerous Families (as mother of five children)

-Eurocarers Board member <https://eurocarers.org/staff-category/executive/>

-Board member and founder of the Cultural Association A.C.M.O. <https://www.centromusicaleorlandini.it/>, promoting music learning for people of all ages, local and international projects and cultural events boosting community life and solidarity

DIGITAL SKILLS

Microsoft Office Chrome, Mozilla Firefox, Max-Qda Plus (Qualitative Data Analysis), SPSS.

According to law 679/2016 of the Regulation of the European Parliament of 27th April 2016, I hereby express my consent to process and use my data provided in this CV.

Sara Santini



Acknowledgements

I would like to express my special gratitude to those people without whose assistance the preparation of this doctoral thesis would never have come about.

My greatest thanks go first to Prof. Dr. Andrea Teti, my first supervisor, and Prof. Dr. Giulia Cavrini, my second supervisor, for giving the always friendly and appreciative support, and the friendly, helpful and trusting guidance at every stage of the “cotutelle” doctorate. I would like to express my sincere gratitude for the confidence in my abilities and the confident consent to supervise my work, which made the doctorate possible in the first place. My immense gratitude goes to Prof. Dr. Andrea Teti and to the Senate of the University of Vechta for giving me the opportunity to fulfil my dream of obtaining a doctorate, overcoming all stereotypes of age, gender and social background. Not everyone would have given this chance to a over 40-woman, mother of five children.

I would also like to thank all my colleagues, first and foremost Marco Socci, Paolo Fabbietti, Mirko Di Rosa, Barbara D’Amen and Giovanni Lamura, for their constructive and profitable cooperation during the preparation of the joint publications.

I wholeheartedly thank Professor Elizabeth Hanson for always supporting me, in research as well as in personal life, and teaching me how to combine scientific rigor with empathy and ethics.

A special thought goes to the informal caregivers I interviewed in more than 20 years scientific career, for sharing with me their feelings and difficulties, but also for teaching me that caring may make us better human beings.

Finally, my personal thanks go to my husband Francesco who has always supported and encouraged me, taking care of our children when I was busy collecting and processing data, writing articles and this thesis, and travelling to Brixen for the cotutelle. I thank my children Pietro, Matteo, Jacopo, Giovanni and Maria, because every day they give me the motivation to improve myself and to try to improve the society we live in, also through my humble scientific contribution.