

Caring in the XXI century: the sustainability of long-term care in aging societies—mapping challenges and developing solutions within the Age-It Research Program

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Decision Editor: Giorgio Di Gessa, PhD (Social Sciences Section)

Abstract

Objectives: The process of population aging characterizing Italian society will lead to a greater demand for long-term care (LTC) services, while simultaneously reducing the availability of caregivers. Spoke 5 activities develop interdisciplinary solutions to meet the challenges and seize the opportunities that emerge from this transformation.

Methods: The article summarizes the outputs from Spoke 5 of the Age-It research program, highlighting their implications for practitioners and policymakers. The research activities contribute to: (a) mapping care needs and resources; (b) developing innovative digital tools to monitor caregivers' well-being and support them; (c) advancing integrative planning for age-friendly environments; (d) developing e-learning platforms addressing caregivers' needs; (e) identifying existing policy shortcomings.

Results: Spoke 5 developed an index of LTC risks that measures the balance between the demand and the potential supply of care at the municipal level; critical areas only partially overlap with traditional socioeconomic cleavages. The analysis of informal care distribution reveals that high socioeconomic status (SES) individuals outsource more demanding caregiving tasks, whereas low-SES families face high-intensity care demands. Innovative digital tools and e-learning platforms are presented. The analysis of policies supporting Italian informal caregivers indicates that they are characterized by a significant geographical and institutional fragmentation.

Discussion: The progression of macro sociodemographic trends has pushed Italy's existing “care equilibrium” to its limits; innovative solutions are needed. Adopting a multidimensional and multidisciplinary approach, focusing on the goal of supporting caregivers' well-being and training, and overcoming policy fragmentation are key to creating an LTC system that is socially and economically sustainable.

Keywords: Caregiver, Well-being, Remote monitoring, Wearable sensors, Training

A large number of high-income societies are experiencing a significant and rapid process of population aging. This results from both increasing longevity and decreasing fertility. The demographic shift resulting from these simultaneous processes—i.e., “aging from the bottom” and “aging from the top”—brings significant challenges and opportunities. An aging population, characterized by a growing number of older adults and a shrinking working-age population, will lead to a greater demand for long-term care (LTC) services, while simultaneously reducing the availability of both formal and informal

caregivers. Socioeconomic, cultural, and institutional adaptations to this new reality represent a challenge, but also an opportunity to transform industrialized economies by prioritizing value-driven, care-focused, and person-centered activities and occupations.

It is in this demographic and social landscape, which characterizes many societies, that the Italian case may serve as a paradigmatic example. Italy is not only at the forefront of this demographic transformation, with a life expectancy of 83 years and a total fertility rate of 1.2 in 2023, but also faces these

Received: March 11 2025; Accepted: August 7 2025

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challenges within a unique context. This context includes persistently low fertility levels, a macroeconomic environment characterized by substantial public debt and, consequently, increasing limitations to the expansion of government expenditure, and a welfare system defined by a “familism by default” approach (Saraceno & Keck, 2010). Many of these characteristics are not unique to Italy. For example, the strong reliance on informal family caregiving is also prevalent in other Southern and Eastern European countries and many Southeast Asian societies (Jiang et al., 2024). Thus, the Italian experience offers valuable insights for other countries undergoing similar demographic transitions.

Traditionally in Italy, and in a number of Southern and Eastern European countries, the demand of LTC for older individuals has been met through: (a) a limited provision of public care services offered by local governments and healthcare institutions; (b) the prioritization of policies providing financial support to non-self-sufficient older individuals (c) a limited range of services provided by volunteer and not-for-profit organizations; and (d) heavy reliance on informal care, primarily shouldered by (female) partners and adult children; and, among middle and high-class families, (e) the outsourcing of care and housekeeping services to low-paid care providers, often women of immigrant origin (Pavolini & Ranci, 2008).

However, this fragile equilibrium becomes increasingly problematic as the baby boomer cohorts¹ enter later life and ongoing macro-demographic and social trends continue to evolve (Alderotti et al., 2025, in this supplement). In addition to increasing longevity and decreasing fertility, factors such as the growing participation of Italian women in the paid labor market and greater geographical separation between family generations are further undermining the stability and adequacy of the existing LTC system. Despite financial support from national and regional governments to individuals with limited self-sufficiency having grown in both generosity and coverage (Fosti et al., 2024), the different scale of the challenge posed by the need to provide LTC to an aging population also redefines its nature.

The ongoing progression of macro sociodemographic trends has pushed Italy’s existing “care equilibrium” to its limits; new solutions are needed to address the rising demand for LTC and to harness the opportunities arising from this transformation. Achieving long-term, socioeconomic sustainability of the LTC system requires interventions and policies that integrate medical, institutional, and technological solutions. Within this framework, the development of a person-centered, affordable, and integrated LTC provision is needed to meet the challenge and seize the opportunities emerging from the aging of the Italian population.

Thus far, the focus of most previous research, interventions, and policies on LTC has been on care receivers. Much of the potential benefits associated with the adaptation to population aging, however, may arise from focusing on the well-being and skills of informal caregivers. Despite the substantial amount of support provided to their relatives, the well-being of family caregivers is still too often overlooked. Being a caregiver impacts individuals’ physical, emotional, and social health; it leads to cutting time on other activities such as paid work, resting and sleeping, and leisure activities (Bookwala, 2009; Carmichael & Ercolani, 2016; Pinquard & Sörensen 2003; Urwin et al., 2023). Increasing the *social, economic, and institutional sustainability of LTC systems* requires (re)focusing on supporting caregivers; investing in caregivers’ well-being and

skills also leads to an improvement in care recipients’ well-being (Kilmer et al. 2024).

Against this background, the present article aims to provide a description of the main lines of investigation, some preliminary results, and outcomes of Spoke 5 of the Age-It Program (for full details about the overall research program of Age-It, see Vignoli et al. (2025) in this supplement). Spoke 5 is articulated into six work packages (WP). By using and collecting microdata from general population surveys and registers, the first WP provides an updated picture of (long-term) care needs and resources associated with Italian population aging, their distribution across different geographical areas and social groups and strata. WPs 2 and 3 aim at developing prototypical solutions that—by integrating digital technologies, medical and institutional protocols—will support the monitoring of caregivers’ physical, psychological, and social well-being and the provision of tailored support measures. In particular, the reference population of the two WPs is, respectively, informal caregivers of older individuals affected by Alzheimer’s and dementia, and caregivers of older people discharged from the hospital after Heart failure (HF). The fourth WP focuses on the (built) environments where older people live, the role they have in reducing or aggravating the burden of disabilities, and on the development of instruments and protocols to improve the planning of age-friendly environments. WPs 5 and 6 aim at developing information, e-learning, and policy tools to support informal caregivers. The present article presents some of the preliminary results of WP1, aiming at mapping and providing measures of care needs and resources from the perspective of the aging Italian population; it also provides a description of a set of policy-relevant tools and outcomes from the other WPs, highlighting their implications for practitioners and policymakers.

The discussion is organized into four main sections. First, we report the preliminary results of the set of studies conducted by the Spoke 5 team, aiming to measure and map older adult care needs, resources, and potential gaps. Special attention is given to spatial inequalities in LTC needs and resources, as well as to differences between caregivers from different social strata. Second, we describe at the conceptual level two e-health solutions aiming to digitally monitor caregivers’ well-being. This includes two prototypes of medical monitoring systems designed for caregivers of older patients with dementia or HF. In the third section, we focus on the technological approaches aiming at improving the relationship between caregivers and care receivers and the built environment; in particular, we focus on the relevance of the concept and measurement of “walkability” and its utilization as a tool to increase older people’s autonomy. Fourth, we address the educational needs of caregivers by introducing, at the conceptual level, the structure and contents of an open learning platform. The platform will provide professional and informal caregivers with easy access to resources, skill-building tools, and information on available services. Finally, we review existing national LTC policies, offering recommendations to improve care provision at the national and regional levels.²

A portrait of emerging care needs and resources

Italy leads Europe in population aging, with the highest proportion of individuals over 65 and 75 years. However, increased longevity

has not (entirely) translated into more years of good health; Italians at 65 have an average of 9 years of healthy life expectancy, below the European average (Fosti et al., 2024). Simultaneously, declining fertility rates have further accelerated since the 2008 Great Recession, and the quota of childlessness reached 20% among Italian women born in the 1970s. Rising childlessness among the older population poses a significant challenge to Italy's long-term care system (Albertini & Mencarini, 2014).

Another important trend to consider is internal migrations and depopulation. Like many other countries, Italy has been characterized by an increasing urbanization of population, moving from more remote and poorer areas to large urban parts of the country (Bonifazi et al. 2021). In those remote areas, the simultaneous trends of young people migration, lack of immigrant inflows, and decreasing presence of public services—such as hospitals, transports, schools—have created a hyper-accelerated process of population aging, paralleled by a diminishing availability of care services. These communities, therefore, face a triple deficit in care: limited informal care from adult children, fewer private caregivers due to low immigration, and inadequate public formal care due to underfunded local administrations. Monitoring the risk level associated with the mismatch between emerging LTC needs and informal and formal caregiving potential is essential to allow public institutions to act based on empirical evidence; this is even more relevant in remote areas. Therefore, measuring and mapping Italian older population care needs, care resources, and the associated gaps is a key goal of the Age-It Program; more specifically, Spoke 5 aims at complementing existing knowledge on the topic by producing such “care maps” along two main dimensions: geographical and socioeconomic ones. To this aim, we have developed a multidimensional index of “LTC risk”. It is designed to capture the balance between the demand and the potential supply of care at the municipal level (Figure 1; Versascina et al., 2024). Demand is estimated based on the percentage of the population aged 80 and over. The potential supply of support is assessed by combining the Potential Support Ratio (i.e., the ratio of the population aged 80+ to the population aged 50–64; Myers & Nathanson, 1982) and territorial accessibility to public services, as measured by the “Inner Areas indicator” (ISTAT, 2022). The availability of informal support and access to services are indeed crucial factors in determining the actual level of dependency among older people in each specific area from a functional perspective. The LTC risk index and its future developments could represent an important tool to guide the future allocation of public resources addressing the needs of the older population.

Informal care available to the older population is very unequally distributed. In Italy, the 2007 value of the Gini index calculated on the amount of informal care provided to/received by individuals aged 50 and over was higher than 0.6; in the same year, the Gini for household incomes was slightly above 0.3 (Albertini & Prandini, 2021). Thus, to have a comprehensive picture of inequalities that matter in later life, it is important to analyze the association between socioeconomic status (SES) and informal care. Such an approach could also significantly complement the LTC risk index in terms of guiding the allocation of public resources not only between different geographical areas, but also targeting different social groups of the Italian population. A social stratification perspective considers resources like education, income, and wealth. Higher education provides relational and cognitive skills to navigate care systems

and correlates with longer life expectancy. Income and wealth capture different economic aspects: income reflects immediate purchasing power, while wealth represents long-term financial stability. Income is more readily usable for care services, whereas wealth, often tied to assets, can be harder to mobilize and, in means-tested welfare systems, it can limit access to public care benefits (Albertini & Pavolini, 2017).

Data from the European Health Interview Survey (Eurostat, 2019) shows that in Italy, education and income are positively associated with providing lower-intensity weekly care (under 10 hr) to older, non-self-sufficient relatives. This relationship, however, weakens or disappears at higher caregiving intensities (Figure 2, see also Floridi et al., 2021). High SES individuals may have the financial means to outsource more demanding caregiving tasks, such as personal care, while focusing on less intensive duties like housework, shopping, and minor care tasks. These are often motivated by affection and personal choice (Bauer & Sousa-Poza, 2015; Bonsang, 2009). This aligns with previous findings from qualitative research and with the complementarity/mixed responsibilities thesis, which is often used to explain cross-country variations in intergenerational caregiving (Brandt et al., 2009; Da Roit, 2007). A deeper understanding of the association between individuals' SES and care provision represents a crucial step to addressing caregiver burdens and tailoring support policies in an effective way.

A few additional statistics on recent trends, based on our own elaboration of the data of the Family and Social Subjects survey, help us complete this short overview of care needs and resources in Italy. Between 2003 and 2016, among families in which at least one of the members was 75 years old or older, the use of paid assistance (i.e., paid caregivers and domestic workers) rose from 14.5% to 20.3%. At the same time, although the number of such families grew from nearly 4 million to almost 5.5 million, access to public care services remained unchanged at 10%. At the same time, there are signs of resilience in informal care within the Italian familistic system: between 2003 and 2016, there was only a slight decline in the proportion of these families who received informal help from non-cohabiting individuals, from 26.1% to 22.6%, whereas the proportion of adults providing help to non-cohabiting individuals steadily grew from 23% to 33%. These trends suggest that the needs of families with individuals aged 75 and over have grown over time, but these families have increasingly had to manage their care requirements using their own economic or time resources, while having limited access to public long-term care services.

Mapping the care needs and resources of the present-day Italian population is an essential step to designing tools and policy measures that can support Italian society and institutions in building a resilient, socially and economically sustainable LTC system. Adopting a multidomain approach—involving institutional, technological, and medical expertise—and focusing on the well-being of informal caregivers, Spoke 5 has developed a set of prototypical tools which are described in the following section.

Integrating technological, institutional, and individual resources to support informal caregivers' well-being

The previous paragraph highlighted the increasing care needs of the Italian aging population; from previous literature, we know that in that specific institutional and social context, these

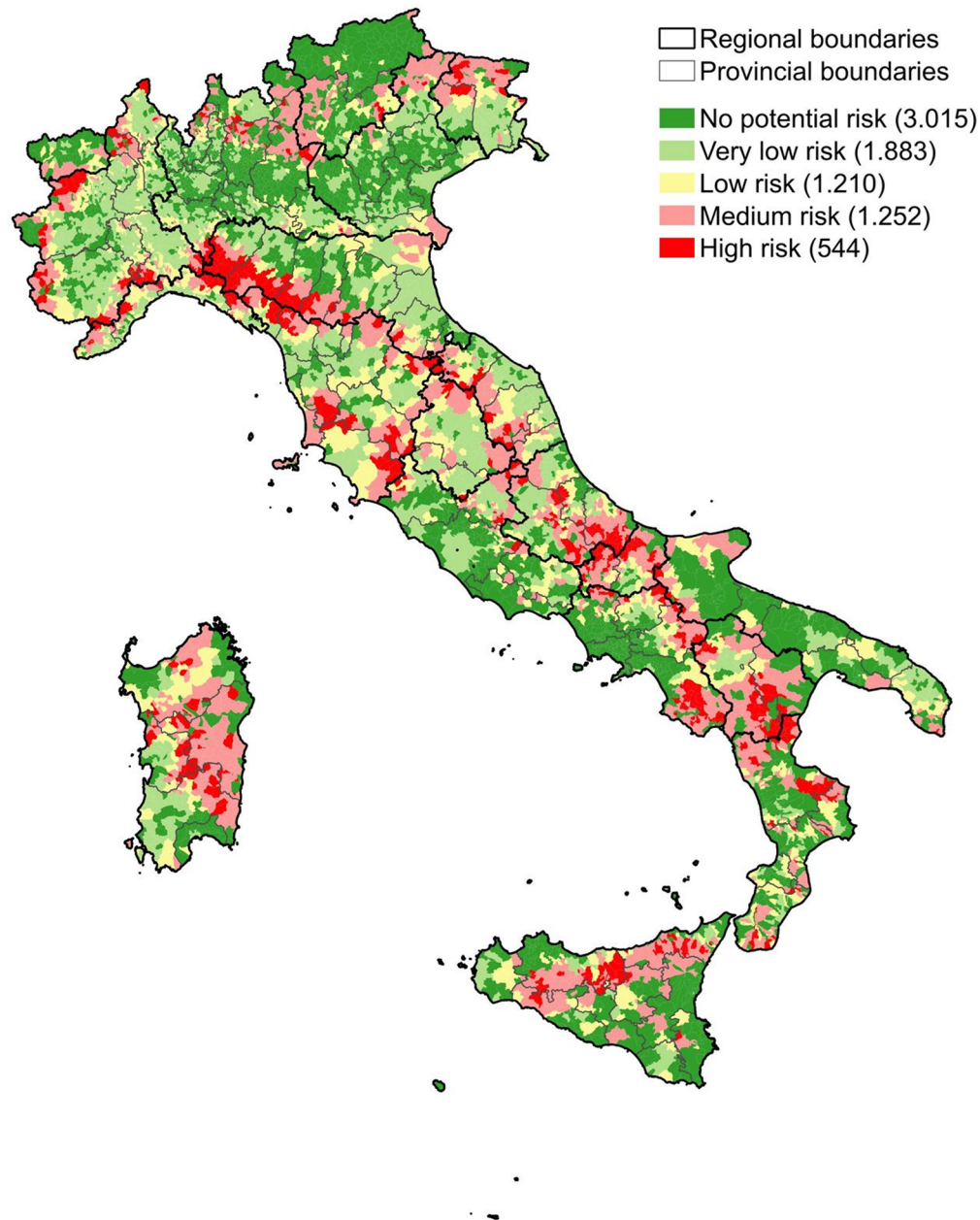


Figure 1. Long-term care risk index for Italian municipalities—Italy 2021. Reproduced by permission from the copyright owner Società Editrice il Mulino. Source: Verrascina et al. (2024).

needs are mainly met via family support (Saraceno, 2018). Therefore, monitoring the well-being of informal caregivers to better support them and preserve their well-being, represents a necessary step in the process of building a resilient and socially sustainable LTC system. Caregivers play an increasingly vital role in geriatrics for three main reasons: (a) the rising prevalence of chronic diseases among older people has heightened frailty and disability, making caregiver involvement critical in routine care, (b) family caregivers are often familiar with patients' end-of-life preferences, reinforcing their regulatory importance in advanced care planning, and (c) caregivers act as social and digital mediators, bridging the gap for elderly patients who struggle with navigating private and public care options. At the same time, caregivers' well-being is key to healthcare system sustainability, as caregiver burnout often

leads to unnecessary hospitalizations or institutionalization of older family members, as well as contributing to worsening caregivers' own health status.

To address these challenges, exploring e-health solutions to support caregivers' well-being represents a potentially game-changing approach. Within the Age-It program, we developed two web applications that aim at collecting data on caregivers for two distinct care receivers' health conditions. The goal is to validate technological models that assist patients and actively engage caregivers. Specifically, our focus is on informal caregivers of older adults with HF and caregivers of dementia patients. These two groups were selected due to the high prevalence of these conditions among the older population; their significant impact on disability and dependency; and the resulting stress on caregivers. Both conditions often involve

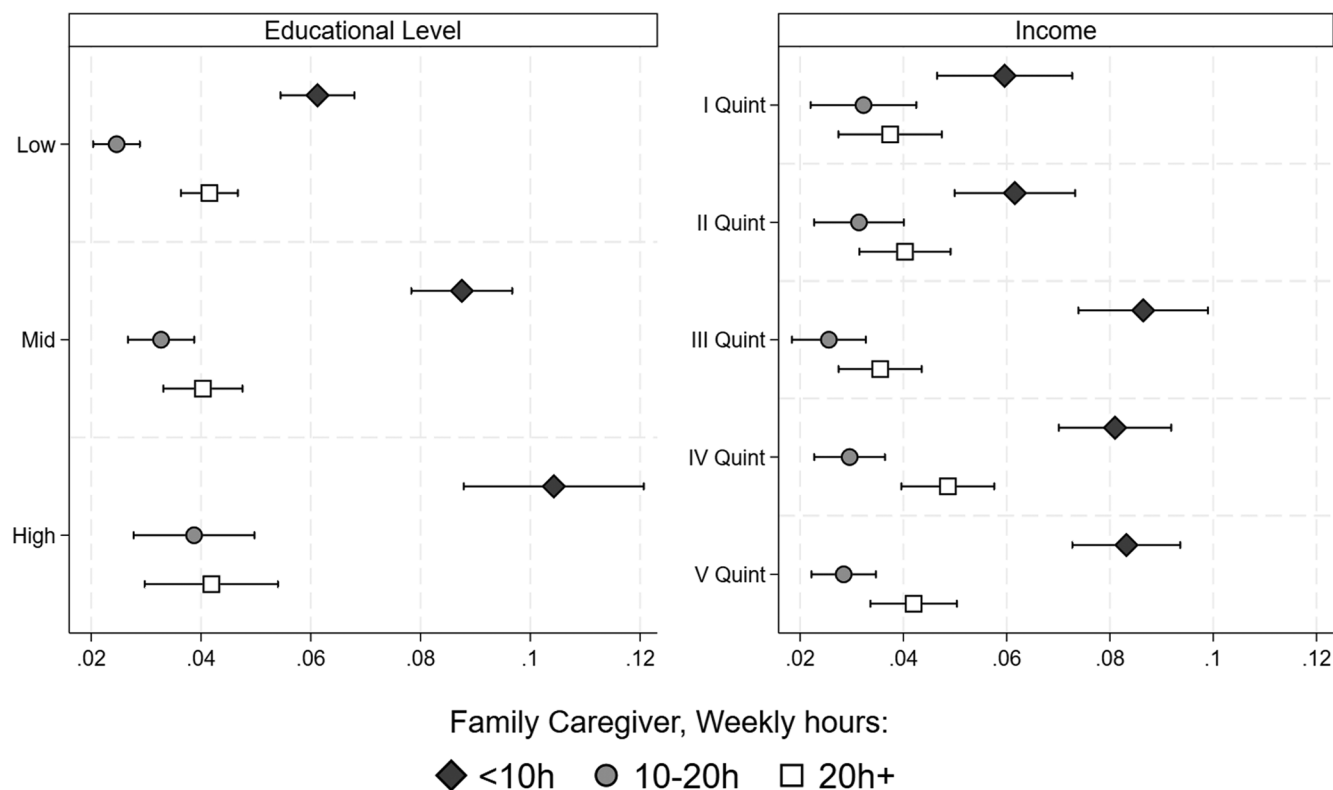


Figure 2. Predicted probabilities based on a multivariate logistic model of providing care with different intensities to a family member, by educational level and income. Italian female population aged 50 years or more. Source: Own elaborations, Eurostat (2019). 95% CI. Results from a multinomial logistic regression model, separately by gender, on a sample of 22286 individuals (11961 women) 50+ years old, without cohabiting parents and/or children with disabilities. The dependent variable includes the following categories: (A) no care provided, or care provided to a non-family member; (B) care provided to a family member for less than 10 hr per week; (C) care provided to a family member for between 10 and 20 hr per week; (D) care provided to a family member for 20 or more hours per week. The variable was constructed based on the following question: “Do you take care of or assist, at least once a week, one or more people with problems due to aging, chronic illness, or infirmity?”. Controlling variables included in the model are the respondent’s age, macro-region of residence, employment status, household composition, born in Italy or not.

unrecognized comorbidities, but key differences shaped their inclusion. Dementia emphasizes caregiving challenges, particularly in identifying issues like depression, social isolation, and somatic symptoms. Differently, HF highlights the need for therapy optimization, requiring active caregiver involvement to enhance the patient’s quality of life.

Providing informal care to older individuals after HF: the role of technology

Heart failure is a significant global healthcare challenge. Despite advancements in disease-modifying treatments, the incidence and prevalence of HF continue to rise, particularly among the elderly population (McDonagh et al., 2021). Over the past decades, substantial progress has been made in managing HF patients. However, hospitalizations and mortality rates remain high, and the incidence of HF has escalated into a pressing public health concern, especially among older adults (Tsao et al. 2023).

The clinical complexity of HF patients, combined with a shortage of dedicated outpatient clinics, has led healthcare systems to increasingly depend on family caregivers’ support. This is particularly critical in cases involving high levels of comorbidities, frailty, and disability. Such reliance often imposes a significant burden on caregivers, who are frequently at heightened risk of suffering physical and psychological negative consequences in relation to caregiving. Studies have documented disruptions in caregivers’ autonomic balance, alterations in the sleep-wake

cycle (García-Lorenzo et al., 2023; Su et al., 2023), and the development of pre-frailty and frailty (Kiljunen et al., 2024).

Preliminary research suggests that targeted interventions tailored to HF patients and their caregivers are essential. Such approaches alleviate caregiver burden and enhance the self-management capabilities of patients with HF (García-Lorenzo et al., 2023). For instance, instrumental monitoring of parameters associated with stress, depression, and multidimensional frailty patterns could yield valuable insights into both physical and psychological disease trajectories in caregivers of HF patients. Furthermore, remote monitoring technologies could facilitate the continuous observation and management of the caregiver/care-receiver dyad, enabling timely and synchronized intervention strategies when necessary.

Our overall goal is to improve the well-being of both patients and caregivers by preventing clinical deterioration and recurrent hospitalizations in patients with HF. To this end, we have developed an experimental protocol, which is currently in the recruitment phase. So far, 150 dyads have been enrolled, consisting of patients with Heart Failure with preserved Ejection Fraction (HFpEF) who experienced an episode of acute HF within the past six months, along with their caregivers.

This initial experimental protocol aims to assess the feasibility of an e-health-based approach for managing HF patients and their caregivers. In this model, dyads are remotely monitored 10 days per month to enable early detection of HF

worsening and caregiver stress, allowing for timely intervention, maintenance of clinical stability, and prevention of hospitalizations.

The monitoring platform and devices have been specifically designed to meet pathophysiological needs and align with clinical guideline recommendations. The platform, called Comprehensive and Adaptive Remote Evaluation System (CARES), provides an integrated remote continuous monitoring system for both HF patients and their caregivers. It analyzes data collected from a purpose-built, multiparametric wearable monitoring device (EasyQ, AEBiosystem srl, Italy), which is capable of directly and continuously monitoring ECG, thoracic impedance, body temperature, patient position, and inclination. From these signals, several additional parameters can be derived, including lung water content.

A device-agnostic e-health platform equipped with an advanced decision support system will be used to identify abnormalities detected by multiparametric wearable devices. These insights will inform the development of a risk index for hospital readmissions following HF episodes. Throughout the 12-month observation period, the study will monitor various parameters, including physical and cardiovascular health, multidimensional frailty (encompassing behavioral, functional, and psychosocial dimensions), and caregiver-patient relationship dynamics. The program will also assess the dyad's satisfaction with e-health-based management strategies, ensuring comprehensive support for both patients and caregivers.

Providing informal care to older individuals with dementia: the role of technology

Dementia represents a significant public health challenge, with the number of individuals affected doubling every 20 years due to population aging. Currently, approximately 47 million people worldwide are living with dementia, the majority of whom receive care from family members. Dementia family caregivers experience considerably higher levels of stress compared to non-dementia caregivers, with increased rates of anxiety, severe depressive symptoms, and physical health issues (Pinquart & Sörensen, 2003; Sallim et al., 2015). They are also at elevated risk for cardiovascular diseases, particularly hypertension, driven by chronic inflammation and sympathetic overactivation (Roepeke et al., 2012; Richardson et al., 2013).

Existing evidence indicates that monitoring can benefit caregivers by enabling a shift from reactive to proactive care (Wrede et al., 2021). Recent studies also indicate that digital tools designed to monitor caregivers' well-being and resilience can facilitate timely support, potentially preventing or delaying acute hospital and nursing home admissions (Bartels et al., 2022). User-friendly tools to monitor the well-being of informal caregivers are available; most address other conditions or combined interventions (Wrede et al., 2021). However, it remains unclear which is the optimal monitoring implementation to reduce caregivers' burden and enhance their well-being.

As part of the Age-It program, a web application has been developed that can comprehensively monitor the physical, psychological, relational, and social well-being of family caregivers of people with dementia. The app includes a questionnaire section about several life spheres of caregivers and care receivers. The data collected through the survey will be integrated with information gathered from wearable sensors worn by the caregivers. The main advantages of the app include (a) its integration with wearable sensors; (b) its availability online and

free of charge—eliminating the need for downloads—and (c) its long-term economic sustainability as an online tool, given the significantly reduced maintenance costs. In addition, the application enables monitoring of caregivers' well-being over time. In the early phases of the project, both the web app, as well as different types of sensors, and the data gathering processes, have been discussed and co-developed with stakeholders and potential users—the co-design process took place mainly via a series of focus groups. After piloting the study to fine-tune the entire protocol, the study was officially launched, and thus far, it has enrolled more than 80 active dementia patients' caregivers, and we foresee expanding the sample to more than 100 individuals. In addition to answering the survey via a web app, participants wear sensors monitoring their sleep, physical activity, and cardiac data for 24 hr for seven consecutive days. The observation is repeated at least three times with a six-month interval between consecutive observations.

By remotely monitoring all critical aspects of caregiving, the platform aims to improve caregivers' health outcomes and their ability to provide quality care. This platform will also be integrated with an online information and educational platform and chatbots (see the following section) to enhance caregivers' knowledge and skills and simultaneously reduce stress, ultimately benefiting both the dementia patient and the caregiver. We expect these platforms to be particularly valuable for caregivers among disadvantaged groups, such as those living in remote geographical areas or belonging to the lower-educated and less affluent social strata. These groups have limited access to healthcare services, as well as information and training on caring for dementia patients; remote monitoring, along with targeted training and information, can effectively help overcome these barriers (Oostra et al., 2023; Palumbo, 2016).

Assessing and designing caregiver-friendly built environments

An approach integrating technological solutions into supporting caregiving activities can be implemented not only when monitoring and supporting the caregivers, but also when shaping the built environment in which older care receivers live. The reliance on community, kin, and friendship networks in providing support and social integration to older individuals makes it more urgent than ever to pay adequate attention to the physical spaces in which people age, indeed. The availability and accessibility of infrastructures and services that are necessary for the activities of daily living—such as supermarkets, pharmacies, postal offices, and general practitioners' studios—play a significant role in the degree to which minor physical limitations connected with later life are “transformed” into limitations in daily living activities, impacting the level of autonomy of older individuals. Access to essential services is often a prerequisite for implementing an “ageing-in-place” approach. It is in this context that the operationalization and utilization of the concepts of accessibility and walkability become fundamental policy tools, especially when these instruments are adapted to the perspective of the older population and informal caregivers.

Accessibility refers to the ability to reach essential services, people, or activities and is measured through two main approaches: the spatial approach, which focuses on the physical distance between key locations, and the individual approach, which considers mobility constraints and personal

time-space limitations (Handy & Niemeier, 1997). Various quantitative methods assess accessibility, including infrastructure-based models (road and transport networks), activity-based models (opportunities accessible based on travel times), and utility-based models (rational transport choices). Walkability, i.e., the ease of walking within an area, is an important application—and measurement tool—of the larger concept of accessibility (Bollenbach et al., 2023). As a matter of fact, if we assess accessibility while adopting the perspective of not self-sufficient older individuals and their caregivers, we can easily see how the possibility of moving in the environment on foot is essential also in terms of their social inclusion in their living communities. Aging in place too often translates into the older individuals' "segregation" into their own apartments with scarce meaningful relations with individuals other than their formal and informal caregivers.

The concept of walkability integrates accessibility with built environment factors, such as urban density, land-use diversity, and infrastructure connectivity. Walkability has a direct impact on health and quality of life, especially in more remote areas such as Italy's remote areas, where built environment conditions significantly affect service accessibility for older adults and their caregivers.

However, many walkability measures overlook key variables like sidewalk quality, safety, and environmental perception. Furthermore, measures of walkability must consider not only spatial and infrastructural parameters, but also individual perceptions and the interaction between transportation, urban planning, and social needs. Geographic data systems (GIS) – which allow for a detailed spatial analysis, integrating demographic profiles, infrastructure conditions, and accessibility metrics—are an essential tool in the measurement of walkability. By combining GIS with wearable sensors, real-time physiological responses to environmental factors can be monitored, offering valuable insights into the perceived safety and comfort of pedestrian routes. This data can enhance simulations and predictive models for service allocation and urban planning (Crooks et al., 2019).

In the framework of the Age-It program, a research study was conducted in the municipality of Premeno (Piedmont, Italy) to evaluate accessibility to healthcare services in remote areas using GIS, agent-based simulations, and aerial data collection. With a population of around 700 inhabitants, Premeno was selected for its demographic and geographical characteristics. Collaboration with local authorities, the utilization of GIS data, and adopting an approach informed by walkability measures have resulted in innovative planning and relocation of the municipal offices and medical services, increasing the accessibility of these services to older, frail individuals and their caregivers (Garrone et al., 2024).

The relevance of knowledge and skill training in caring for older family members

Previous research has consistently documented the individual and social detrimental effects of unmet caregivers' needs on both their own well-being and that of the care recipients. The integrated digital tools described above will allow us to help decision-makers build more age-friendly environments and closely monitor Italian family caregivers' social, physical, and mental health. Beyond simply monitoring their well-being, the Age-It program also aims to provide support to informal

caregivers via information and training. As a matter of fact, comprehensive and accessible training, information dissemination, psychoeducation, skill-building programs, and interventions that promote self-care, physical activity, and psychological support are critical instruments to reduce caregivers' burden and improve support for older people (Schulz et al., 2020). Psychoeducational interventions (information about services and resources, and strategies to manage stress, behavioral symptoms, and care-related challenges) have proven essential in fostering resilience and enhancing the caregiver's ability to adapt to their role, ultimately ensuring high-quality care and the well-being of both caregivers and care recipients (Gallagher-Thompson and Coon, 2007). Formal caregivers and professional care workers also benefit from educational programs emphasizing collaboration with family caregivers and care recipients (Lamore et al., 2017).

Evidence suggests that while psychosocial interventions for caregivers are effective, their implementation is often fragmented and inconsistent across regions and healthcare systems. Furthermore, the heterogeneity of existing programs—varying in theoretical frameworks, content delivery, and access—poses challenges to caregivers. Care needs evolve throughout the disease trajectory, from knowledge acquisition during early diagnosis to skill-building in managing symptoms during moderate stages, and support for decisions related to institutionalization or end-of-life care in advanced stages (Gallagher-Thompson et al., 2020).

The Age-It program aims to develop and test an e-learning platform for caregivers, integrated with the monitoring tools described above, addressing the most significant training needs identified through focus groups and interviews. The target users include informal caregivers, formal caregivers, and migrant care workers. In a series of focus groups conducted within the program, informal caregivers of dementia patients reported the need to understand dementia, manage behavioral symptoms, and access reliable information. They emphasized the need for user-friendly digital tools with practical content, such as symptom management and legal considerations. Migrant Family Care Assistants (MFCAs) reported harsh working conditions and the need for training in dementia care techniques, stress management, and language skills.

Focus groups and interviews identified the need for an e-learning platform that should be accessible across multiple devices, prioritizing ease of navigation to ensure accessibility for those less familiar with digital platforms. Key features include practical caregiving advice (emergency responses, daily care routines, behavioral management) in the form of concise video tutorials (e.g., using real-life scenarios) to accommodate caregivers' time constraints. The platform should also integrate reliable external resources (e.g., national dementia organizations, agencies, local caregiving services) and bibliographic references to support evidence-based practices; it should prioritize minimalist design (clear icons), progress tracking (e.g., progress bars, feedback messages), and mobile optimization (touch screen friendly interactions, large clickable areas). According to focus group participants, personalization options like bookmarking and adjustable font sizes, alongside interactive elements like quizzes, are essential to enhance engagement. Clear, jargon-free language, a consistent visual design, and a calm aesthetic will support caregivers in managing stress and navigating content effectively. Integrated external resources will provide quick access to supplementary support.

The educational platform that is being developed within the Age-It program will be populated with training modules targeted at the needs of caregivers. Among the various topics covered in the platform, there is information on dementia and prevention (disease characteristics, risk factors, and early interventions); daily care practices; verbal and non-verbal strategies to improve interactions (e.g., between MFCA and care-recipients); information on non-pharmacological therapies (cognitive stimulation and creative therapies); information on ICT tools for home safety and well-being; ethical and legal aspects; dementia services available in Italy; emergency management. Prototypes incorporating Large Language Model (LLM) and Natural Language Processing (NLP) tools are also being tested with end users; the team is in the early phases of piloting a chatbot (“AICareBot”) specifically trained—i.e., fed with official documents, guidelines, informative and educative resources created or vetted by the Spoke 5 team—to provide support and answers to older people’s informal caregivers. The chatbot will guide access to learning content and give, in time, tailored feedback on the needs and challenges the caregivers are facing. These efforts aim to support caregivers while fostering sustainable aging communities and enhancing care quality.

Policies to support informal caregivers in Italy: recent developments in the background of international developments

If a large part of the Spoke 5 activities are focused on assessing LTC needs and resources, and to create tools that support older people’s caregivers, on the other hand it is clear that meeting the challenge of building a resilient, socially and economically sustainable LTC system necessitates as a first and necessary step a significant development in the way in which public institutions deal with the increasing LTC needs of an ageing population. With this in mind, a significant part of the Spoke 5 activities are devoted to: (a) analyzing, from a comparative perspective, the policy landscape characterizing the Italian LTC system; (b) identifying the main gaps and bottlenecks; (c) highlighting and disseminating emerging context-specific best practices.

Recognizing the challenges faced by informal caregivers, EU countries have implemented various policy mixes to offer support to informal caregivers. However, significant cross-national and regional disparities remain in the type, scope, and comprehensiveness of these policies. While some countries offer more comprehensive care leave policies, financial benefits, and respite care services, others provide limited support, leaving caregivers at risk of burnout or other negative psychological and socioeconomic consequences (European Commission, 2021).

In Italy, the government has only recently begun to address these challenges through reforms, including the restructuring of financial support funds. However, many services remain underdeveloped, placing a significant burden on caregivers. For instance, a care allowance is paid to care receivers but not to informal caregivers, and policies addressing caregivers’ needs in terms of counseling and emotional support services are missing at the national level. Not surprisingly, Italy’s public policies address only 6 of the 17 indicators used by a recent cross-national analysis of EU Member States’ alignment with the EU’s approach to informal care (Eurocarers, 2024). The shortcomings of this policy landscape are particularly problematic for women: they represent the largest part of (unsupported) Italian family caregivers and, in most cases, during their life courses have already borne the cost of providing care to

young children, with limited support from public institutions (Naldini & Saraceno 2022; Saraceno 2018). The following two paragraphs review the main characteristics and most recent changes in caregiver support policies in Italy, at the regional and national levels.

Limited and unequal: the bottom-up push for regional policies to support Italy’s informal caregivers

Over the past decade, policies addressing informal care for older people with long-term care needs have gained prominence in debates on reforming Italy’s long-term care sector. This shift has largely been driven by the bottom-up pressure coming from organizations representing older people and caregivers calling for stronger support measures to compensate for the limited availability of formal care services.

As a result, regional governments—responsible for implementing such measures—have taken the lead, and since 2014, ten regions out of twenty have enacted laws recognizing informal caregivers. This legislative output varies considerably across regions: while some of this legislation provides substantial practical support, other regional laws simply recognize caregivers’ roles in daily care (Calvi et al., 2025). Moreover, the definition of “caregiver” adopted by regional laws varies considerably—from more restrictive formulations (based on kinship relationships) to more inclusive ones (based on affective bonds) – also affecting eligibility for (and access to) support services.

The national context: current reforms and their limitations

At the national level, progress has been slower. The 2018 Budget Law was the first to define who a “family caregiver” is and established a “National Fund for the Support of the Family Caregiver’s Role,” which was allocated to regions for implementation. More recently, the Legislative Decree 29/2024 built on this, introducing measures such as caregiver participation in care planning, assessments of their support needs, access to respite services, training, labor market reintegration, and advocacy promotion. However, critical issues remain. The decree does not clarify whether non-cohabiting caregivers or non-kin with affective relationships qualify for support, potentially excluding them. Moreover, benefits and support are not necessarily linked to the actual care provided.

Future legislation should, therefore, aim at adopting a broader, more inclusive definition of caregiver, removing cohabitation requirements, and recognizing affective relationships beyond family ties. It should also ensure flexibility in addressing changing care needs and allow formal recognition of professional caregivers as secondary caregivers, aligning with the European Work-Life Balance Directive. The most recent developments seem to show that, while more resources are being made available to support caregivers, these are likely to benefit only a limited group of caregivers, i.e., those cohabiting with their care recipients (Calvi et al. 2025).

Conclusions

How can care of older adults be managed in the context of a familistic welfare regime, increasing longevity, and decreasing fertility? How can we build a resilient, socially and economically sustainable LTC systems that meet the challenges and seize the opportunities created by the process of population aging?

We suggest that adopting a multidomain and multidisciplinary approach, and focusing on the policies and instruments supporting older people caregivers, represent an important first step in the direction of building a sustainable system. Spoke 5 activities aim at advancing the knowledge and improving the tools available to Italian public institutions and society to build a future-proof LTC system.

Providing long-term care to an increasing number of older people is often represented as one of the main and most difficult challenges arising from population aging. In Southern Europe (and East Asia) people and institutions have mainly relied on informal support from the family network to meet the needs of dependent older people. Analyzing the sustainability of long-term care in these contexts represents a sort of acid test for all high-income countries experiencing the phenomenon of rapid population aging. We suggest that focusing our research and policy interventions on caregivers will allow us to identify not only the challenges but also the opportunities offered by the adaptation of social care and welfare systems to the new demographic landscape characterizing many high-income societies. The conundrum of meeting the challenge of providing care to an increasing quota of (aging) population, while facing increasing constraints to the growth of public expenditures and to the availability of working-age individuals, can be solved by adopting an approach that focuses on integrated technical, medical and institutional solutions aiming at improving the skills, productivity and well-being of both informal and formal caregivers. To this aim, the article presents some of the instruments and tools that are being developed within the Age-It program.

First, we put forward an analytical framework that can inform policymakers on the significant geographical heterogeneities in the LTC needs and resources, as well as on the distribution of the burden of informal care along the dimension of social stratification. We have developed an index of LTC risks that represents an important tool for policy design and targeting. It is shown that critical areas are not solely concentrated in the Southern Italian regions, but rather that they are to be found all along the peninsula in the remote areas of the Apennines, southern Tuscany, Sardinia, and Sicily. When considering the association between informal care and an individual's SES, it emerges that more educated and affluent people are more likely to provide care, but this is generally of low intensity, while no between-class differences emerge when intensive care is considered. This suggests that in Italy, high SES individuals have the financial means to outsource more demanding caregiving tasks while focusing on less intensive duties. In contrast, low-educated and low-income families are more likely to face high-intensity care demands with limited possibility of outsourcing care work and access to public services.

Second, the Spoke 5 team has developed different interventions, e-learning platforms, and educational tools that, by integrating technological, medical, and institutional solutions, aim at monitoring and supporting the well-being of caregivers. We expect that these instruments will be key to designing and implementing policies aimed at preventing informal caregivers' health and well-being deterioration, and providing essential information and training to caregivers.

Finally, a political atlas represents an essential instrument to improve policy knowledge transfers between different institutional levels and actors—from national policymakers to local stakeholders and not-for-profit organizations. The LTC policy landscape in Italy, as in many other European countries, is still

very fragmented, especially when it comes to supporting informal caregivers. Stimulating knowledge transfers and the dissemination of effective and inclusive policies is an essential step in the direction of meeting the challenges and seizing the opportunities connected with population aging.

Author notes

1. In the Italian context, we can identify this cohort as those individuals born after the Second World War and up to the 1964 peak in fertility.
2. It is worth noting that the order in which the results and WP are presented—i.e., first the sections on how to support informal caregivers, followed by an analysis of public policies addressing the needs of older individuals and their informal caregivers—does refer to any implicit assumption about how the responsibility of providing care to frail older people should be distributed between public institutions, families and friends, market actors, and volunteering associations. Previous studies and our own analysis, in fact, highlight that in the Italian context these responsibilities are often overwhelmingly left onto the shoulders of the care receiver's families, and particularly on those of their wives and daughters (Naldini & Saraceno, 2022).

Funding

This publication was produced with the co-funding European Union—Next Generation EU, in the context of The National Recovery and Resilience Plan, Investment Partenariato Esteso PE8 “Conseguenze e sfide dell'invecchiamento,” Project Age-It (Ageing Well in an Ageing Society).

Conflict of interest

None declared.

Data availability

All the public-use microdata used in the article are freely downloadable from the Italian National Institute of Statistics website: <https://www.istat.it/>.

Supplement sponsorship

This article appears as part of the supplement titled “Ageing Well in an Ageing Society: Italy at the Forefront of Population Aging,” sponsored by the National Recovery and Resilience Plan, Next Generation EU, Project Age-It: “Ageing Well in an Ageing Society” (Decree of the Italian Ministry of University and Research no. 1557–11 October 2022, Project Code: PE0000015, CUP B13D22001320006). The views and opinions expressed are only those of the authors and do not necessarily reflect those of the European Union or the European Commission. Neither the European Union nor the European Commission can be held responsible for them.

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