On Old Age and Its Multiplicity: Exploring Discourses and Materialities about Getting Older

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Abstract: Old age is at the core of complex constellations composed by media discourses, care and mundane activities, and affective and technological practices that involve a wide range of human and non-human actors. While during the last years concepts such as "active" and "successful" ageing have more and more emphasised the individual responsibility of older adults in managing their own health, in the context of the Covid-19 pandemic elderly have been increasingly framed as vulnerable subjects. This Crossing Boundaries will explore the different instances assumed by the "old age" as an emerging object by the enactment of discourses and materialities. In doing so, this Crossing Boundaries mobilizes different theoretical perspectives, such as STS, media studies and sociology of health. The authors will explore three main issues: 1) the public discourse about the health status of older people; 2) the collective management of Alzheimer's disease in and outside institutions; 3) the involvement of older adults in designing information and communication technologies.

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Introduction

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To what extent is old age a matter of concern in the contemporary world marked by the Covid-19 Pandemic? This Crossing Boundaries (CB) section of *Tecnoscienza* tries to address this question, gathering three contributions at the crossroads of STS, media studies and sociology of health. Recent research in the field of *age studies*[1] seeks to understand how the old age – and, along with it, the aged bodies and the health conditions of older adults, the self-care practices enacted by them and the expectations that surround this segment of population – is discursively and materially produced in different ways, depending on the time and the spatial context. Across the different historical periods and local settings, new meanings associated with old age can replace or intertwine previous ones, redefining what seems possible, desirable, appropriate, or inappropriate for later life stages. Following the contributions hosted within the Special Issue "Ageing and Technology", previously published for this journal in 2020 (vol 11, no. 2), old age can be interpreted as an object, i.e., "something people act toward and with" (Star 2010, 603) – at the centre of complex constellations of socio-material practices (Cozza et al. 2020). Such constellations are composed by media discourses, care practices and mundane activities, affective and technological practices that involve a wide range of actors (such as older adults, but also peers, relatives, neighbours, new and old media, private companies, innovative or old-fashioned infrastructures and technologies) contributing at configure old age as a matter of concern, that is, an object relevant in a certain temporal and spatial context that, at the same time, materialised in daily relations (see Latour 2004).

Drawing on these theoretical insights, the aim of this CB is to reflect about the different versions of the old age object that emerge from the enactment of some of the above cited discursive and material practices. Considering the so-called "pandemic times" – that have put the elderly and their health conditions at the core of public debate – it is urgent and politically pertinent to reflect (once again) on the practices and meanings associated with the later stages of life. In enacting such a reflection, the authors of this CB will consider the following different settings in which the old age object emerges and takes shape: the public discourse about the health status of older people (see Bosco and Cappellato, this issue); the collective management of Alzheimer's disease in and outside institutions (see Castellaccio, this issue); and the involvement of older adults in designing of information communication technologies (see Piras, this issue). By considering these different settings in which practices and meanings about later stages of life emerge, the three contributions hosted in this CB aim at facing the following questions: 1) What are the different forms that the object

"old age" takes in contemporary society? 2) How do the different forms of old age get in relation to each other? 3) To what extent has Covid-19 affected the stability among these different forms of old age?

The first question regards the *multiplicity* of old age. In this regard, according to Annemarie Mol (2003, 5):

> If practices are foregrounded there is no longer a single passive object in the middle, waiting to be seen from the point of view of seemingly endless series of perspectives. Instead, objects come into being – and disappear – with the practices in which they are manipulated.

Age studies have underlined how since the 80s the role of older people in the contemporary societies has been redefined by the reproduction of complex textures composed by media discourses (Asquith 2009; Shimoni 2018), institutional policies (Lassen and Moreira 2014), technological innovations and daily practices (Lassen 2015; Siira et al. 2020; Carlo and Bonifacio 2021) in which old age is enacted as a period of life compatible with an active role in different everyday domains such as work, health, social engagement and sexuality. This way of conceiving and practicing old age clashes with the pre-existing ones in which older people were represented as passive recipients of pensions (Cumming and Henry 1961), homogeneously characterised by frailty, dependency, loss of cognitive and physical functions (Seefeldt et al. 1977; Midwinter 1991; Ainsworth and Hardy 2007; Martin 2009). Despite the heterogeneous empirical contexts considered by the contributions of this CB, the authors share a common interest toward disentangling the tensions and interactions between the "passive" and the "active" versions of old age: if in the first case older adults are conceived as people needing support (Cozza and De Angeli 2015), in the second one they become directly responsible for their own health and wellbeing.

The second question mentioned above regards the relationships between different forms of old age that emerged over the last few years. As we will see in the next pages, the passive and active versions of old age exist in relation to each other, being characterised by a *mutual constitution relationship*. Paraphrasing Brent Slife (2004, 158):

> the representations and the practices concerning old age – even if they appear absolutely at odds – are not first self-contained entities and then interactive (...), they start out and forever remain in relationship.

A first kind of relationship among the different versions of old age concerns the development of contrasting dichotomies. As argued by various media studies scholars (see Holstein and Minkler 2003; Markson and Taylor 2000; Kessler et al. 2004), the two recurrent versions of old age object – the *old old* (i.e., the elderly with bad health conditions), and the *young old* (i.e., the active and independent older adult) – coexist only in constant conflict with each other. In the media sphere these two versions of old age

are used for reenforcing the idea that the old age can be experienced in two main ways and that – coherently with the neo-liberal ideology that turn bad/poor health in a matter of individual responsibility – the choice among them is up to the individual. Within this CB Bosco and Cappellato, by referring to the Covid-19 pandemic, investigate the juxtaposition between the active ageing/successful ageing rhetoric, the "vulnerability narrative" and the "burden" one. In contrast, Castellaccio and Piras explore collaborative dynamics among the different shape that the object old age can take. In the first contribution, the wide use of digital technologies during the Covid-19 pandemic assured both the assistance to people with Alzheimer's disease and their active involvement in social interactions, useful to treat the symptoms associated with the disease progression. In the second one, in the design processes aimed at developing new gerontechnologies, paternalistic representations of elderly's needs and rhetoric about the importance of their active participation in the enactment of new technologies can coexist. If the rhetoric of older people as active experts is useful for accessing to competitive calls announced by major national and international funding institutions, the image of elderly as passive recipient of care persists both in the projects and their implementation, preserving the interests of research and industrial partners involved in these projects (e.g., developing, evaluating, testing products and services that must have certain characteristics, despite the users' preferences).

The last question addressed by this CB regards the relevance of the Covid-19 pandemic in reshaping and reconfiguring the old age object. As recently observed (Miele and Nunes 2021) the Covid-19 pandemic strengthened mainstream rhetoric that objectified older individuals and favoured the enactment of practices (e.g., selective social isolation and marginalisation) that treat them as fragile recipients of care. Under this perspective, this CB explore in depth the changes and tensions produced by Covid-19 pandemic around old age, defining in detail the public discourses emerged during this global outbreak. In particular, authors focus on the ways through which the discourses emerged during pandemic challenge or reinforce some pre-existent trends in the public sphere, such as the emphasis on their individual responsibility of older adults (see Bosco and Cappellato, this issue) or on the importance given to social relations for their health (see Castellaccio and Piras, this issue).

Overall, this CB provide an understanding of old age object as a collective matter of concern marked by a multiplicity shaped by discourses and materialities enacted by complex networks of actors (Miele and Fornasini 2021). In doing so, this CB open a lively dialogue among different disciplines, as a fruitful way to approach the object old age from different angles and to reach a fully understandings of the ongoing changes that have affected it in the recent times.

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Aging Discourses during the Covid-19 Pandemic

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Through public discourse, concerned groups of people can establish – though not always intentionally or by consensus – what problems should be considered urgent and what issues need to be addressed. During the Covid-19 pandemic, the narratives enacted by different actors (such as policymakers and politicians, academics, "traditional" and digital media) have played a central role in defining how the public views and acknowledges the condition and needs of the older population. This paper explores how public discourses – in their performative dimension – can reveal the collective (partial) capacity to respond to the many issues affecting older adults that emerged during the pandemic emergency.

The Precarious Status of Older Adults

During the first global Covid-19 lockdown, some US economists estimated the cost of reopening at an average of $14.5 million per lost life. For older people, the figure dropped to $9 million, while other estimates valued the lives of people over seventy at only $3.7 million (Feltri 2020). Economic estimates aside, the idea of assigning a lower value to people as they age is not new. Indeed, early theories of aging focused primarily on the deficits associated with it (Bugental and Hehman 2007). Assuming that physical and cognitive decline is inevitable, some scholars described aging as a process of progressive withdrawal or disengagement associated with loss of roles (Cumming and Henry 1961), dependency and frailty (Priestley 2003), and, in some cases, a general deterioration in personal characteristics and emotional state (Makita et al. 2021). This deterioration is often associated with ageism, which the American physician and gerontologist Robert Butler described as early as the 1960s as:

a deep-seated uneasiness on the part of the young and middle-aged – a personal revulsion to and distaste for growing old, disease and disability; and fear of powerlessness, "uselessness," and death. (Butler 1969, 243)

Over the years, scholars have deepened, broadened, and clarified our understanding of aging processes by adding new concepts and articulations of social and physical characteristics and representations of old age. In addition to explicitly negative attitudes and stereotypes (Cesari and Proietti 2020), hidden and implicit mechanisms have also been identified. One is the so-called compassionate or benevolent ageism, which leads to paternalistic actions and forms of social support that implicitly assign the older population with attributes such as incompetence, frailty, dependency, passivity, and victimhood (Ayalon et al. 2020; Vervaecke and Meisner 2021).

Giving voice to older adults shows that their views of what constitutes wellbeing given the objective or inevitable changes brought by ageing are more varied and positive than younger people tend to believe (Jolanki and Spännäri 2019). Moreover, as reflected in the concept of "gerotranscendence" (Tornstam 1997), aging may be associated with greater emotional stability, life satisfaction, and a more conscious acceptance of human nature despite possible functional limitations under certain conditions. Drawing on physiological, psychological and sociological studies, Rowe and Khan (1997) have introduced the concept of successful aging, suggesting that people can often maintain their cognitive function, good health, and engagement in the community as they age. Over the years, an increasing number of public initiatives have made this prospect more concrete. Since 2002, the World Health Organization (see WHO 2002) has promoted a comprehensive, positive concept of active aging through actions that support older people's health, participation, security and quality of life. In 2012, the European Parliament proclaimed the "Year of Active Aging" and promoted a communication campaign under the slogan "Good health adds life to years" with images of healthy, active older people engaged in working, taking care of children, and even such extreme physical exercise as bungee jumping (see Gibbons 2016). However, both the successful aging paradigm and the active aging paradigm have come under criticism. This is largely due because they have been translated into economically oriented policies that focus on extending working lives without considering the other aspects, such as doing things that make us feel good in stimulating, inclusive, and relational environments (Foster and Walker 2015). Moreover, these perspectives that emphasize individual responsibility risk blaming those who cannot adapt to a rigid model of aging that makes no allowance for the undeniable fact that not all older people are the same (Stephens 2017).

As a result, it seems likely that the value – and not just the economic value – of older people has always had an ambiguous status in different cultures and countries. This has led to narratives that have helped to normalise some representations to the detriment of others. At the same time, older people's

situation in recent decades has been marked by a further intensification of ambivalent dynamics that facilitate the coexistence of contradictory narratives.

According to Becca Levy (2017), the ambiguity is due to processes that, on the one hand, increase the visibility of older adults and their rights, but on the other, make supporting them an extremely demanding burden. Better living conditions have significantly extended the average lifespan. The growing presence of older people in Western societies has been accompanied by an increase in policies and services for them. In addition, increasing efforts to battle diverse discriminations led to the assumption that "age discrimination" against older adults could also be successfully fought. In Levy's view, however, the potential for destigmatising change has been thwarted by several opposing forces: 1) the rapid growth of the anti-aging industry has emphasised the negative aspects of aging in order to boost the silver economy; 2) smaller families and younger adults' geographical mobility have decreased intergenerational contact, leading to loneliness and social exclusion among seniors; 3) due to the lack of specific education aimed at increasing the recognition of the older population's worth, legislations and policies have proven insufficient to change stigmatising beliefs and behaviours; 4) and lastly, the heterogeneity of this segment of the population has slowed the formation of organised groups capable of coordinated action springing from a shared sense of identity (Levy 2017). Technology itself, as well as medical developments, have taken on an ambivalent role, as the extension of life expectancy and the increasing longevity of fragile people increase the cost for the community of their health and social care (Ayalon and Tesch-Römer 2018).

Aging Discourses in the Covid Era

The higher number of deaths among the older population during the Covid-19 pandemic reinforced the assumption that there is a correlation between age and vulnerability, with far-reaching negative consequences (CDC 2021; Alicandro et al. 2022). Assuming that "only certain populations are at risk for infection" creates "an environment in which younger generations may have felt invulnerable to the virus and that health recommendations did not apply to them" (Guest and Peckham 2022, 11). The perception that government measures to contain the virus were necessary to protect older adults intensified intergenerational conflicts (Anderson and Gettings 2022). This fostered resentment and anger toward those blamed for the restrictions that also affected younger people. Lastly, the arbitrary categorisation of older adults based on chronological age boundaries leads to a false homogenisation of the many individual differences and personal diversities seen in later life. The combined effect of these dynamics exacerbated the ambivalent status of older people, for instance by reinforcing ageist stereotypes while reducing attention to the context in which many older people lived (and died) during the long months of the

pandemic (Heymann 2021; Seifert 2021). There were widespread and documented human rights violations against old people in places intended for their protection, such as social and health care facilities and nursing homes (Amnesty International Italia 2020).

During the Covid-19 pandemic, there was a surge of ageist discourses focusing on the need to isolate and distance people over a certain age (Anderson and Gettings 2022). These narratives are linked to an emphasis on the ableism perspective (van der Horst and Vickerstaff 2021), which ascribes value only to a "particular kind of self and body […] that is projected as the perfect, species-typical, and therefore essentially and fully human" (Campbell 2001, 44). Such a view emphasises the otherness of those who do not meet standards, marginalising or nullifying their presence (Chouinard 1997), and promoting the internalisation of self-stigmatisation processes by people with functional limitations (Ayalon and Tesch-Römer 2018). Both European and North American media have "naturalised" a uniform narrative of older people as vulnerable, not self-sufficient and frail, thus reinforcing the intersections between ageism and ableism (Swift and Chasteen 2021; Vervaecke and Meisner 2021). Moreover, ageist practices in hospitals and nursing homes, such as adverse selection in the allocation of scarce resources (i.e., assigning higher priority for access to intensive care to younger people), have long been shrouded from attention (Emanuel et al. 2020).

As a result, the emphasis on individual responsibility for aging that was central to narratives in the pre Covid-19 pandemic period (Miele and Nunes 2022) took on new nuances suggesting mechanisms of blame and paternalism during the global outbreak. Online contents referring to Covid-19 as the "Boomer Remover" which first appeared on Reddit in the US and spread across social media such as Twitter, TikTok, and Instagram, suggested that older people should be sacrificed for younger generations (Meisner 2020; Ehni and Wahl 2020). This is a further instance of inter-generational conflict (Ayalon and Tesch-Römer 2018), with expressions of hostility that legitimised a "process of demographic cleansing of society of over sixty people (Godawa 2021, 92).

Statements by politicians in several countries denoted an explicit negative ageism (Cesari and Proietti 2020), which intentionally justifies prejudiced beliefs by spreading the message that older people are expendable (Barrett et al. 2020). The words of the lieutenant governor of Texas (who called for the self-sacrifice of those over seventy for the economic benefit of America's future generations) or those of the Italian governor of the Liguria region[2] are just a few examples of the widespread anti-aging narrative during the pandemic. Even in the case of benevolent ageism, well-intentioned efforts became harmful by homogenising older adults with phrases such as "our old people" and reinforcing stereotypes related to a supposedly non-self-sufficiency through a paternalistic ethos assuming that older adults need and want help because of their age, even when they do not (Vervaecke and Meisner 2021, 161). Similarly, the "vulnerability narrative"

– which views older people as a homogeneous and undifferentiated group of fragile and vulnerable people who needed to be protected – ties in with the "burden narrative", which focuses on the hardships that young people have had to deal with to protect the older population (Kornadt et al. 2021). Both narratives have been reinforced by the widespread "silver tsunami narrative," which depicts the growing number of old people in Western societies as a problem in terms of sustainability and inflationary healthcare, social, and financial costs (Kingsley 2015).

Conclusions: How Social is Health?

A large multidisciplinary body of research has explored the characteristics and heterogeneity of aging processes, as well as the worrying prevalence of ageist language (Nussbaum et al. 2005) and the unsatisfactory responses to older people's needs in various health and social service settings. Numerous scholars have also emphasised that age itself is not necessarily predictive of Covid-19's clinical outcomes (Ehni and Wahl 2020; Meisner 2020). The etiologic correlation of Covid-19 and advanced age is much weaker when patients' comorbidities are taken into account. The location of outbreaks in terms of settings (e.g., in nursing homes) and geographical areas (especially northern Italy compared with the rest of the country) are also relevant factors for the spread of this disease (Poli 2020, 274). In addition, numerous studies have addressed the "double jeopardy" posed by the combination of ageism with gender- or ethnicity-based stigma (see Bugental and Hehman 2007 for a review about this issue). These studies have critically scrutinised key misconceptions about aging with a wealth of evidence refuting taken-for-granted assumptions. Some scholars argue that aging does not necessarily involve loss and decline, or that under certain conditions we have more control over the aging process than we are led to believe. Moreover, researchers note that many age-related losses may be reversible, as recent studies of brain neuroplasticity confirm. However, if we concentrate our gaze on the years leading up to the pandemic, we can see what Levy (2017) calls the persistent "age stereotype paradox" with a marked increase in prejudice toward older people. Two key discourses on aging continue to emphasise the rising costs to welfare systems' sustainability of extending life spans and reject the collective methods of activation and prevention that call for individual responsibility. This has led to a one-sided, unsatisfactory, and wholly unsubstantiated reading of aging.

Very few of the findings briefly reviewed here have been echoed in public discourses promoted by mainstream media and institutions. Here, it is worth noting that the unsatisfactory status of public debate is not specifically related to discourses on aging. Rather, it reflects the criteria of newsworthiness that emphasise content according to the attention it can receive, without delving into complex social phenomena. Although the pandemic has brought older adults back to the centre of discourses (Miele and Nunes 2022), the latter

have reaffirmed the oversimplification and normalisation of representations and content in new and traditional media (Makita et al. 2021) and in the positions of many institutional and political representatives around the world.

Lastly, aging seems to be the litmus test for what Nancy Fraser in her discussion of the crisis of care (2017) attributes to the social contradictions of contemporary capitalism. On the one hand, as Jolanki and Spännäri (2019) note, the fact that the lack of resources and cuts in social services have meant that welfare systems now seek to cover only what are regarded as basic needs does not allow us to address people's more complex requirements. We thus forget that "human life is much more than meeting the needs defined as basic needs in care contracts" (Jolanki and Spännäri 2019). On the other hand, even if the discourses about our inevitable decline were true, the question arises whether we really want to live in a society that excludes the frail and vulnerable (Dirindin 2018). Moreover, "the 'othering' of 'the elderly'" (Verbruggen et al. 2020, 230) – the claim that older adults are a separate, homogeneous social group – seems unfounded. Older people's condition tells us something about our future and our finitude, which causes us so much anxiety and denial.

Echoing John Rawls' (1971) thoughts on the veil of ignorance, whereby no one knows today what state they may be in tomorrow, "othering" and the idea of inevitable decline can be rejected without resorting to compassionate ageism. Frailty and its implications are not something that concerns only older adults. It concerns society as a whole, and policy makers must decide how to deal with it. The way we care for older people not only affects the people involved, but is one of the most important features of the (more or less) democratic society in which we live.

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Pandemic and Alzheimer's Disease. Have Care Practices for Elderly Patients Been Reconfigured?

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Alzheimer's disease is a condition increasingly common among older people and relevant for understanding broader phenomena (that may also involve other sectors of older populations), such as the reconfiguration of family networks around an especially debilitating disease, the strengths, and the weaknesses of services for non-autonomous elderly and the unmet needs of their caregivers. Considering the impact Alzheimer may have on people, this disease can be considered not only medical, but also "social" for several reasons (Frisone 2002; Pin Le Corre et al. 2009; Ngatcha-Ribert 2012). While there is no doubt that, on a physical-pathological-relational level, it predominantly affects older individuals, this disease also has significant implications for the people who care for them, with roughly 3 million people caring for the sick directly or indirectly. For caregivers and professionals, the social and personal cost is significant since their care work implies immense mental and physical fatigue with episodes of stress, burnout and social withdrawal (Cheng 2017; Moretti and Radin 2019). The onset of Alzheimer's disease acts as a true *biographical disruption* since, almost always, the disease and its management imply a drastic modification of one's life (Bury 1982; Altable and de la Serna 2020). In addition, this disease produces organizational and political-economic consequences on health care systems. As Alzheimer's cases grow, the demand for external and in-home care services increases, with regional networks of public services needing to be strengthened and reorganized. The burden associated with care also represents a point of economic strain, with growing cases calling for further instrumental examinations for diagnostics and monitoring. Beyond material needs, the intense social stigma of Alzheimer's disease persists. According to the World Alzheimer's Report 2019, 35 percent of people have hidden a family member's diagnosis of dementia from at least one person (Alzheimer's Disease International 2019).

The growing biographical, organizational, political, and economic re-percussions of Alzheimer's disease for patients, caregivers, and society have been further aggravated by Covid-19 (Cohen et al. 2020). In this respect, it is essential to investigate how care practices for older people with Alzheimer's have changed during the Covid-19 pandemic. Covid-19 has exacerbated the disease, and the psycho-physical and social conditions of caregivers (Cohen et al. 2020), and consequently, caregivers and professionals have reconfigured their care practices, often with the help of digital technologies. This contribution to the CS does not claim to be exhaustive, considering that the Covid-19 pandemic still cannot be said to have ended. Hence, this contribution mainly focuses on patients and caregivers, both inherently inseparable, through a theoretical lens developed at the cross-road between Sociology of Health and Science and Technology Studies.

The Pandemic and Critical Issues for Alzheimer's Patients

During the Covid-19 pandemic in Italy, two lockdowns were particularly relevant regarding restrictions and potential social and economic consequences: the first from March to May 2020 and the second from October 2020 to March 2021, coinciding with the return of winter the following year. These measures were decided on a national scale to reduce the spread of Sars-COV-2, involving social distancing and isolation. The Covid-19 pandemic had enormous social consequences, affecting every sphere and daily activity of the individual (Favretto et al. 2021).

In the context of chronic diseases such as Alzheimer's and other forms of dementia, two scenarios were presented during the pandemic to manage the condition: those who were residing in dedicated facilities[3] and those who instead were at home.

Sick people staying at home in the pre-pandemic period, could take advantage of an array of home care professionals (e.g., geriatrician doctors, nurses, social workers, physiotherapists, and educators) who went to patients and caregiver's homes, and other local support services offered in the area (daycare centers, Alzheimer's Cafes, volunteer work, and Association events).

However, these types of homecare resources were discontinued with the advent of Covid-19. In nursing homes and domestic environments, care practices had to quickly reconfigure to cope with the disintegration of care networks and the rapid worsening of caregivers' social and psychological health resulting from Covid-19 containment measures. Not only did lockdown measures create significant challenges to the practical management of Alzheimer's patients (Caratozzolo et al. 2020), but also to the mental health and well-being of caregivers and professionals who reported cases of chronic stress and burnout (Arcuri et al. 2020; Cravello et al. 2021). Regarding people with Alzheimer's disease, it has been argued that social connection is the best form of treatment for disease progression and, in particular, for preserving the so-called residual abilities (i.e., the cognitive

and physical capabilities not yet affected by the disease): maintaining active relationships, especially with family members, and giving to older persons a role and identity (Kovacs et al. 2021; Cravello et al. 2021). During the pre-Covid-19 pandemic period, those who did not live in residential facilities could access many services: daycare centers; parish-related events; Alzheimer's Cafes; voluntary support groups; city-sponsored events in the area; events and spaces provided by associations; but also, family and friend support; home visits by care aides, educators, nurses, physiotherapists, and geriatricians. Alzheimer's patients, since March 2020, have been largely isolated to reduce virus spread and risk of exposure, resulting in social isolation. This situation has contributed to the sudden progression of the disease as most care and treatment activities have been suspended (Numbers and Brodaty 2020). In general, patients with this type of dementia saw a worsening and deterioration of psychological and physical conditions (El Haj et al. 2020; Lara et al. 2020).

Compounding these stressors, Alzheimer's patients carry a high risk of contracting Covid-19 given the cognitive impairments inherent in the definition of the disease that causes difficulties in following health prevention procedures (such as respecting the physical distancing rules). At the same time, caregivers have also experienced an exacerbation of their condition, coping with several complex issues, such as disrupting the daily routines and increasing caregiving load.

Digitizing Alzheimer's Care: According to a Process of Co-constitution with Digital Technologies

In the context of the Covid-19 pandemic, care practices performed by caregivers in their own home, as well as within healthcare facilities for people with Alzheimer's, have been transformed by the increasing use of information and communication technologies (ICTs). For many families, the digital has entered homes and daily lives in ascendant ways. Using ICTs for daily support has been feasible and, in some cases, useful for contact with the outside world (e.g., using a cell phone or tablet for calls). Since the early 2000s, video calls have been practiced for diagnostic consultations regarding Alzheimer's disease (Loh et al. 2007), putting an early form of telemedicine into practice (Dai et al. 2020). Following the Covid-19 pandemic, telemedicine was readily applied to ensure appropriate support for patients and caregivers: facilitating a virtual network of immediate communication on day-to-day activities between individuals and the care system, thereby activating a "humanized communication" in which the position of the individual was central.

However, technology cannot be reduced to a mere technical tool. As technology is increasingly used in everyday life by older people (including those with medical conditions), the popular image of aging changes: from smartphones, and fitness devices, to electric bicycles and tablets; older adults are seen as capable figures, exercising agency through the use of

technologies (Peine et al. 2017; Peine and Neven 2021). In this regard, the concept of "gerontechnology" has been proposed to define specific technologies for older users, emphasizing how aging inevitably influences (and is influenced by) the design of technology (Kwon 2017). As highlighted in the field of Science and Technology Studies, technologies require to be analyzed within situated settings of interactions, where human subjects and technological objects can cooperate or conflict (Sismondo 2010). Peine and Neven (2021) described such process through the "co-constitution of aging and technology model" (CAT) from the observation that the forms and practices of aging are not given apart from gerontechnologies, but rather aging is constitutive of the technology itself. The CAT model predicts a close and evolving relationship between aging and technology, with both influencing and contaminating each other. Four essential areas cyclically interact with each other: 1) the lives of older people, 2) the imagery of aging, 3) technological artifacts, and 4) their design processes. This process continuously reshapes everyday practices, technologies and the collective imaginary of aging.

The CAT approach may be relevant for understanding the implementation of digital technologies that occurred during the pandemic by Alzheimer's patients, caregivers, and professionals (nurses, healthcare workers, physiotherapists, psychologists, and educators) involved in their daily care. The daily lives of these three actors (patients, caregivers, and care professionals) have changed as a result of being mediated and co-constituted by technologies. From this perspective, aging is seen and understood as a phase of life capable of using ICT. The Covid-19 pandemic has accelerated a process already underway and offered the opportunity for reconfiguring the view of aging concerning the use of digital technologies. As a result, the world for older adults has also changed (despite the fact that the pandemic has cast them into an even more at-risk category). Both technologies and older people shaped each other in many ways: on the one hand, technologies adapted to respond to health emergency needs by using different devices and tools, for example tablets that allowed video calls to maintain a connection with the outside world. On the other hand, older people adapted to technologies to find solutions to meet their needs, requiring them to enhance their expertise, for example for having calls with doctors, professionals, and relatives, but also to perform cognitive exercises.

Technologies stimulated interaction between people with Alzheimer's disease and actors that were required to stay in isolation due to virus containment measures. Smartphones and other digital devices allowed people and patients hosted in healthcare facilities to maintain contact with their relatives and exercise different forms of socialization. Technologies also enable the performance of playful-educational activities for patients. Telemedicine created space for linkages between older people, home patients, and health professionals to create therapeutic alliances. ICT, then, made the provision of online training possible, as well as psychological and legal support services for caregivers. In addition, digital technologies have

changed the everyday life for older adults, and have in-turn been reshaped by them (users). The organizational logic of healthcare facilities and the needs of family members certainly shaped the ways and purposes for which technologies were used. For example, the limited availability of technological infrastructure within nursing homes led to long-distance calls being conducted for limited periods so that all patients and family members had access to this mode of communication.

Finally, the emerging images of Alzheimer's patients have also been reconfigured. The diffusion of ICTs in the everyday life of people with Alzheimer's disease often represented as "living dead" in western societies (Peel 2014), has enhanced the idea that these actors can be in connection with the rest of the world through digital technologies and, at the same time, can become competent and active users of these objects. As technologies are used, new values, practices, and subjectivities are also continuously negotiated (Peine and Neven 2021).

Conclusions

The changes that have emerged during the Covid-19 pandemic concerning the care practices of Alzheimer's patients mainly concern:
   1. The increased circulation of digital and ICT, often understood as e-health technologies, that is digital health services, platform, and tool supporting the management of health, illness and wellbeing (Lambousis et al. 2002);
   2. An acceleration of co-constitution in the relationship between technology and aging (which had already begun before the pandemic).

Despite the growing implementation of digital technologies, the specific experiences of Alzheimer's patients and their caregivers are still exceptionally precarious and still unfortunately invisible. The precarious reality of caregiving is attributed mainly to the personal and social commitment that disease management requires being overlooked. The caregiver is often not socially recognized or valued, thus constituting a form of unpaid "invisible work" (Star and Strauss 1999), and the pandemic has exacerbated an already fragile situation.

In this framework, the concept of co-constitution between aging and technologies leads to rethinking the relationship between representations of aging, caregiving practices, and digital technologies. In the specific case of Alzheimer's care in the context of the Covid-19 pandemic, this contribution highlighted how digital technologies have changed the lives of patients and their caregivers, setting up a network of relationships that allow for the continuous negotiation by concerned actors of the perception of aging, technology design, elderly life, and digital technologies.

The turning point, also for future studies, lies in considering aging (and related pathologies) appears as a "collective process" that internally involves

media discourses, care and daily living activities, clinical and medical routines, and marketing strategies forming complex constellations (Cozza et al. 2020). According to this view, aging is not only about older adults, but also about other actors (relatives, caregivers, social media, companies, infrastructure, etc.) who, in the process of co-constitution, define what aging is and how the challenges that arise, such as Alzheimer's disease, can be addressed.

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In Need of Seniors in Need: Paternalism, Tensions and Paradoxes in Users' Participation in Gerontechnology Design

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The inclusion of seniors in the design of gerontechnologies is part of a broader discourse that has been developing since the 1970s. Such inclusion affects several domains and promotes the involvement of citizens in the co-production of public services (Osborne et al. 2016), workers in production processes (Bannon et al. 2018) and marginal subjects in rural communities (Chambers 1981), to name a few of the areas of intervention. Despite significant differences, these experiences are united by identifying participation as the key to pursuing the dual goals of encouraging bottom-up democratic processes and proposing technical solutions that are more efficient by increasing the chances of adoption. Although these two objectives are always present, the instrumental view that regards participation as a "good thing" because it enables the creation of better technologies, processes or projects often prevails (Mackay et al. 2000).

The debate is rich, and it questions the very meaning of involvement, which is often presented as a level in scale, given Arnstein's (1969) pioneering work. In such scales, more marginal forms (i.e., consultation) are distinguished to gradually proceed towards more inclusive forms (i.e., involvement, participation) until a role of full and equal collaboration (i.e., co-production) is attributed to prospective users (Stark et al. 2021). In this contribution, similar to much of the relevant literature, I shall use the terms "involvement" and "participation" interchangeably regarding the diverse set of approaches involving different forms of relationships between designers and users[4].

The recent Covid-19 pandemic has made the issue of users' participation in technology design even more relevant, given the growing attention in this period on remote monitoring addressed to older and/or clinically fragile people, with the aim of reducing their access to healthcare facilities and preventing the circulation of virus among these sectors of population. Moreover, the involvement of the elderly in the design of gerontechnologies constitutes a privileged vantage point for analysing some of the diverse social representations of aging. Indeed, in this field, political-institutional drives, epistemic-methodological considerations and pragmatic needs are mixed together and operationalised in policy documents and research practices. Involvement in design processes, when observed from these different perspectives, offers the possibility of highlighting paradoxes and tensions between visions of the elderly, who are at various times considered active subjects, passive receivers of care, subjects in need and individuals needed to realise technologies.

This paper focuses on three representations of the elderly that emerge from their implicit conceptualisation in relation to their contribution to design activities. To present them, I shall build on Robert Cooper

distinction between distal and proximal thinking (1992), the former referring to a structured view of the social in terms of codified interactions and functions and the latter to the continuous network of actions that shapes a set of heterogenous materials. The first representation, the elderly as active expert, presents a distal, high-level and formalised institutional perspective. The other representations, the elderly as diminished user and legitimizer of the design process, emerge from confronting the mundane and pragmatic demands of design practices with users.

Distal Representations of Involvement in Design: The Elderly as Active Experts

From early pioneering experiences, participation has been increasingly codified in institutional processes that often explicitly call for the inclusion of stakeholders in the design, implementation and evaluation processes, with research often becoming a requirement in competitive calls for major national and international funding institutions (Compagna and Kohlbacher 2015), in addition to having a legitimising function (infra, the "legitimising elder").

From a distal perspective, collaboration between designers and the elderly appears to be an opportunity for a positive-sum game, where the adoption of participatory methodologies would enable forms of mutual learning between users and designers, thus contributing to the enrichment of the latter's skills (Björgvinsson et al. 2010; Kushniruk and Nøhr 2016) or transforming their role into that of "facilitators" who would enable users to make the relevant decisions in the process (Sanders and Stapper 2008). This perspective is based on the dual assumption that older people are "experts by experience" (Beimbor et al. 2016) who are capable (if properly guided) of providing guidance to planners while simultaneously taking for granted their interest in active involvement.

From this view, participation in design processes can be considered a specific instance of a general trend. With some level of simplification, the elderly person involved in the development of assistive technology can be likened to a chronic patient who wishes to take charge of their condition by acquiring increasing skills in self-management and making their knowledge gained through personal experience available to peers.

These assumptions, while intercepting and embodying a general "spirit of the times" in the specific realm of the implementation of health and wellness technologies, align with the rhetoric of putting patients "at the centre" or "in the driver's seat" of their own care, which coincides with the notion of gerontechnologies as assistive tools that promote independent living and reduce their need to access to social and health services. Participation is thus welded to a representation of active aging in which individuals are eager to manage their own care and compensate for deficiencies related to the decline of the welfare state (Katz 2000). The elderly people participating in designing technologies of which they may become users are

thus an emblem of "successful aging" that is characterised by an ability to remain productive, active, capable of self-determination and vigorous that comes from staying healthy and managing the risks associated with the passage of age and is presented as a model to be imitated in the neoliberal representation (Latimer 2018; Miele and Nunes 2022). This representation of participants in the design stages transfers to future users of technologies who are discursively configured as individuals interested in self-management of their own health, which aligns with a representation of the expert patient capable of requiring fewer interventions from health services and saving time and costs to the system as a whole (Greenhalgh 2009).

This distal perspective is widely shared in institutional representations and comes in the form of stimulating the adoption of participatory methodologies to the point of prescribing their use (Compagna and Kohlbacher 2015) due to the belief that this constitutes a beneficial situation for all people involved. Elderly patients would exercise their desire to stay active and put their experiences to use, designers would enrich their knowledge and skills, and society would benefit from the implementation of tools that are more closely aligned with the real needs of the target population, with spill-over effects on their condition.

Participation in Collaborative Design Practices: The Elderly as "Diminished" Users

The idea that the elderly population needs digital technologies specifically made for them accompanies the history of the internet and mobile technologies. Underlying this focus is the consideration that the elderly, even the young elderly (55-64 years), as non-natively digital, should be provided with simplified tools that are ergonomically adapted to their limited skills and abilities. The example of a cell phone equipped with large buttons and icons constitutes the best-known manifestation of this trend (Joyce et al. 2007).

This view of the elderly as "diminished users" becomes even more pronounced in the field of assistive technology design, wherein a generic age-related inadequacy is compounded by specific needs related to health conditions, and the elderly are often "implicated but not present in the development" (Frennert and Östlund 2014). Such representations are also reflected in participatory methodologies designed to engage the elderly, which rest on the dual belief that they are characterised by generic age-related deficits and passive receivers of technologies. As noted by Peine et al. (2014), forms of engaging older people in technology design often implicitly assume that this population is unable to actively collaborate in rethinking their living contexts by incorporating new technologies. Instead, the techniques adopted assume the existence of a predetermined set of static needs and demands that the technology should satisfy, and these must be identified by researchers through various techniques. In line with this perspective, critical analyses of gerontechnology implementation

processes have observed how the involvement of seniors is limited to certain stages and not the entire arc, from design to implementation, typically preferring assessment or having seniors' needs represented by their caregivers (Lazar et al. 2016). While from a distal perspective, seniors are considered active subjects, engagement practices are permeated by a "paternalistic stance" (Peine et al. 2014) that infantilises seniors by emphasising their deficits.

Widening our gaze to the debate on approaches to user involvement, the case of gerontechnology development takes some of the tensions highlighted by critical perspectives on participatory approaches to the extreme. Participatory design, for example, considers the encounter between designers and users as the moment at which use is imagined before it happens or "use-before-use" in Redström's (2008) definition. This perspective, which is considered unrealistic by its critics, is countered by several methodological proposals to enable users to take ownership of flexibly made technologies to adapt to unexpected uses. Concepts such as "continuing design-in-use", "continuous design and redesign", "unfinished design" and "meta design" have been proposed to imagine forms of "designing for design after design" (see Ehn 2008). While influential in theoretical debate, such critical perspectives rarely find application in participatory design practices and are virtually absent in the field of gerontechnology development. As a result, the representation of the elderly as a subject characterised by deficits qualifies them as incapable of active participation in processes of appropriation and redesign by relegating them to the role of passive users of tools made to satisfy a stable set of needs.

However, as Peine et al. (2014) observed, the perspective of the elderly person as a "diminished" user cannot be rejected outright, as it allows for the condition to be adequately represented and contributes to the realisation of technologies that offer substantial help for elderly people with severe and well-defined problems. This perspective highlights the tensions between an inclusive view of participation and the existence of difficulties to be overcome in the mundane practices of participatory processes with users with age-related limitations.

Institutionalised Participation: The Legitimising Elder

Since the pioneering experiences of half a century ago, participatory methods have become a prerequisite in various fields, including gerontechnology (Peine and Neven 2019). The institutionalisation of participation as crucial strategy in technology implementation (Compagna and Kohlbacher 2015) finds its concretisation in the policy documents of research-funding institutions. While this constitutes undoubted success for the promoters of participatory methods, it also transforms participation into a required act and a design goal to be achieved with others. In this context, participation in design, regardless of its actual contribution, operates as a legitimation mechanism in which elders involved in design vouch for the appropriateness

of the technical solution in terms of both ease of use and usefulness. In this perspective, elderlies' participation is not perceived as the inclusion of an active expert in the design process (see above) nor it is shaped by the representation of elderlies as diminished users. Rather, participation is requested to fulfil the task of "user involvement" required by funding institutions or expected at societal level.

In the context of competitively funded research, the emergence of paternalism, which is partly inscribed and partly an emerging effect of funding policies, deserves attention. Paternalism is often implicit in funding calls for projects that describe the elderly as subjects "in need" to be supported through dedicated technologies. However, the characteristics of such technologies are often detailed in the call itself and are part of a research and innovation agenda dictated by the research community and the officials of funding institutions. Moreover, the needs of the elderly must be met through the implementation of tools that go "beyond the state of the art". Rather than being at the centre of the process, older people's involvement is confined to moments predetermined by researchers at the funding proposal writing stage and framed in a rigid and barely modifiable timeframe. The combination of this dual mechanism is that any "need" expressed by the elderly must meet the dual requirement of being answered in the technology described in the announcement and particularly in a version of it that requires knowledge advancement (Piras 2021). In this context, it is not surprising that participation is often restricted to the evaluation stages and less present in the actual design stages (Frennert and Östlund 2014), even to the point of indirect forms of involvement, purely for the purpose of legitimising the process (Östlund et al. 2015).

The widespread rhetoric about the centrality of users in design and patients in care processes is supported by implicit assumptions about the desire for participation, which are rarely empirically found. Several papers have shown that involving older people requires significant effort that researchers could not put forth without the support of intermediary organisations (i.e., senior centres, non-profit organisations) (Merkel and Kucharski 2019), whose role in the processes of selection, recruitment and the ability to modify project goals is insufficiently investigated (Piras 2021).

Complexity in recruitment is sometimes related to the representation of the elderly as a condition characterised by a high availability of free time. However, elderly people who are in good condition are often busy with personal or family commitments. Paradoxically, it is these elders who most frequently participate in activities carried out by intermediate organisations. Thus, they become overrepresented in the selection aspect of the design-involvement processes. Conversely, marginal or low-educated individuals become marginalised or uninvolved in favour of older people with more resources, with the design exacerbating social inequalities instead of reducing them (Künemund and Hahmann 2016). A limiting case of selection bias is that offered by the SARS-CoV-2 pandemic, in which traditional

in-person collaborative working methods were made impossible. Only a handful of papers testified to engagement processes via digital systems (Cerna et al. 2022; Muñoz et al. 2022), with selection bias favouring elders with sufficient digital literacy and appropriate communication tools who may not be representative of the technology's target population.

Pandemic-related restrictions pose an additional conceptual and practical challenge in imagining methodologies that can combine the pragmatic needs for communication via technology-mediated engagement without excluding segments of the population.

Conclusions

The participatory design processes of gerontechnologies offer a privileged vantage point for analysing aging representations and the tensions and paradoxes among them. The tensions and paradoxes are the product of the gap between idealised forms of participation, which originate from the history and evolution of participatory approaches in technology development and its institutionalisation, as well as the complexity of its implementation.

While the involvement of elderly users is unanimously considered a goal to be pursued, the concrete conditions under which involvement takes place influence not only its forms but also the implicit configurations of users. While the progressive institutionalisation of participation may have consolidated the awareness of the ability of older people to be active partners in every stage of the design process, it risks turning their involvement into "yet another task" and leading to opportunistic approaches.

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Notes

[1] As also done by Peine and Neven (2021), the term Age Studies is used as a label that include a broad strand of studies that have reflected on contemporary representations and practices associated with ageing, using a broad variety of disciplinary backgrounds, including the humanities and the social sciences.

[2] "Yesterday in Liguria, 22 out of 25 deaths were very old patients. Most of them were pensioners who are no longer indispensable to the productive efforts of our country, but who must be protected", see https://tg24.sky.it/politica/2020/11/01/coronavirus-toti-anziani (Accessed May 1, 2022)

[3] It is a socio-sanitary residential facility dedicated to elderly people who are not self-sufficient, who need full-time medical, nursing and rehabilitation assistance and for whom keeping them in their own environment/home is not possible. In Italy it is called RSA (Residenza Sanitaria Assistenziale) which means "health care residence". In the Emilia-Romagna region, it is called CRA (Casa Residenza Anziani) which stands for "home for the elderly".

[4] User-Centered Design refers to those processes in which users contribute to the understanding of the context and needs to be met by designers. Participatory Design refers to active involvement in design, typically through workshops. In co-design, there is a symmetrical relationship between designers and users, who are seen as equal collaborators. Other labels have also been proposed over time and, as mentioned above, are often used interchangeably to refer (generically) to all those design processes that utilise users' involvement in some way.