Knowledge-sharing process on "Isolation and loneliness of older people during the COVID-19 pandemic: formal/informal care"

Red line document

The goal of this red line document is to provide a short background and summary of the state of the art on the topics of isolation and loneliness during the pandemic. This document will be expanded as the knowledge-sharing process will proceed. The knowledge-sharing process proposed by JPI MYBL aims to complement, and provide a concrete perspective, to existing research on these issues by involving policy makers, stakeholders, and researchers. The aim of the knowledge-sharing process is to shed light on these issues, also examining best practices and policy measures that have been implemented throughout Europe to limit the direct and indirect negative consequences of the pandemic, that could last for several years. The goal is also to disseminate knowledge, research and practices; and therefore contribute to the JPI visibility.

Background

Self-evidently, it is important to study people's well-being and loneliness for human rights, dignity, and if decision makers or policy makers do nothing about it, it can have negative consequences on depression, physical health, unhealthy behaviours and in the end, wost a lot to social security. Loneliness is also economically costly for the individuals and the society. Research has estimated an annual cost of being lonely of about 1000 euros (Mihalopoulos et al. 2020). Individuals who feel lonely also tend to use healthcare services more than non-lonely people (Gerst-Emerson and Jayawardhana 2015), with negative consequences on public health expenditures. It has also been estimated that 1 euro invested in interventions to fight against loneliness can have an economic return between 1.2 and 44 euros (see the studies reviewed by Mihalopoulos et al. 2020).

Population ageing is a long-term trend which began several decades ago in Europe. Increased life expectancy is a clear triumph for humanity but, coupled with fertility reduction and postponement, it implies the ageing of populations (Grundy & Murphy 2017), which was already one of the big challenges before of the onset of the COVID-19 pandemic for most countries, especially in Europe (Rau et al. 2013). Among the challenges posed by population ageing and reduced family networks, risks of social isolation of older people and their care needs already were among the most pressing before the pandemic.

The COVID-19 pandemic, and the non-pharmaceutical measures implemented to fight the spread of the virus, have exacerbated pre-pandemic vulnerabilities. Social contacts and caregiving have been put under strain with potential negative long-term negative consequences on older people's physical and mental health. In addition, manifestations of ageism have increased, which further increases risks of isolation and negative wellbeing consequences for older people. Raised ageism during the COVID-19 pandemic have been documented in the literature. An example was the creation of the hashtag in Twitter #BoomerRemover that was used to refer to the pandemic and to depict older adults as vulnerable and helpless against COVID-19. High mortality rates amongst older adults were considered an 'inevitable' and 'normal' outcome of this pandemic

While mortality and covid-related health conditions have been largely examined since the onset of the pandemic, more research is needed on isolation and loneliness of older people during the pandemic, and see how policy makers can change care/ health policies and/ or adapt e.g. campaigns against raising ageism. Also, it will be important to draw suggestions for policy and practice based on the existing knowledge and experiences accumulated since the first lockdowns implemented in Europe at the beginning of 2020.

Short state of the art

Risk of death due to COVID-19 clearly increases with age (Guan et al., 2020), but within age groups, preexisting health conditions represent a key risk factor (Clark et al., 2020). Yet, older people have been portrayed as a homogeneously vulnerable group, which resulted in increased ageism and intergenerational tension (Ayalon, 2020). For instance, policy actors

and media have encouraged especially older people to limit their travel, movements, and physical interactions (Ayalon, 2020), putting them at a particular high risk of isolation.

Raised ageism during the COVID-19 pandemic have been documented in the literature (Fraser et al., 2020; Meisner, 2021). Ageism during the pandemic has taken different forms, including negative or hostile ageism (Cesari & Proietti, 2020), which has received the most attention, and also some forms of compassionate ageism (Vervaecke and Meisner, 2021). Increased ageism is worrying also because of its known influence on isolation and loneliness (WHO, 2021).

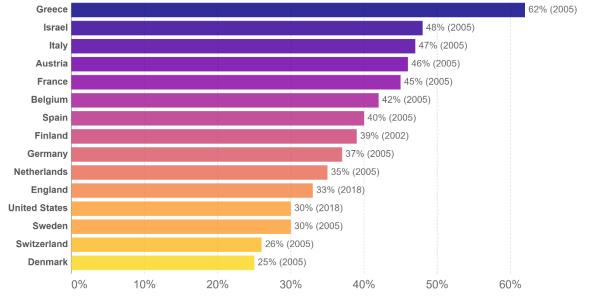
In the decade preceding the COVID-19 pandemic, scholars and public health officials have been increasingly concerned about risks of loneliness driven by shifts such as decreasing fertility, increases in living alone, and other factors, especially in the United States and Europe (Dahlberg et al., in press; Holt-Lunstad, 2017; Holt-Lunstad et al. 2015; National Academies of Sciences, Engineering, and Medicine, 2020).

As data show (see map below), feelings of loneliness greatly vary across countries. In Europe, older people in Mediterranean countries tend to report more frequently feelings of loneliness than older people in Nordic countries.

Self-reported loneliness among older adults

Our World in Data

Share of survey respondents who report feeling lonely at least some of the time. For all countries estimates correspond to population ages 65+, except in the following cases: US (ages 72+); UK (ages 65-74); and Finland (ages 75+).



Source: Our World in Data based on Sundström et al. (2009), Savikko et al (2005), ONS (2019) and CIGNA (2018) CC BY Note: Estimates correspond to people who report feeling lonely "some of the time", "most of the time", or "almost all the time". This is in contrast to those that report feeling lonely "rarely", "almost none of the time", or "never".

After the arrival of the COVID-19 pandemic, "physical distancing" was emphasized at national, regional, and local levels to mitigate the spread of the disease. These mitigation recommendations included avoidance of public social spaces, minimizing physical contact with others, stay-at-home orders, and full physical isolation of high-risk individuals, such as older adults with pre-conditions (Plümper & Neumayer, 2020). While these mitigation efforts were likely useful to "slow the spread" of COVID-19 and reduce mortality, they may have increased isolation among older adults, possibly exacerbating the "loneliness pandemicthe risks factors for loneliness (Dahlberg, 2021).

Despite potential overlap between "the loneliness pandemic" and the COVID-19 pandemic and the elevated risk for older adults, preliminary studies suggest that older adults' were more resilient than younger adults to loneliness during COVID-19 (e.g., Beam & Kim, 2020; Bu et al., 2020; Groarke et al., 2020; Luchetti et al., 2020; McQuaid et al., 2021; Palgi et al., 2020; Varga et al., 2021). Thus, increased physical isolation due to the anti-covid restrictions does not seem to have reverberated, on the whole, on more feelings of loneliness. This finding may reflect a combination of factors, including lowered expectations for social interaction during COVID-19 (Dahlberg, 2021) or increased contacts at a distance (Arpino et al. 2021c).

Although older adults may have showed a higher resilience during the pandemic compared to younger adults, it is unclear, however, whether and to what extent older adults across Europe experienced increases in loneliness during COVID-19. The existing evidence offered mixed results (see the review by Dahlberg, 2021). In addition, although some studies showed unchanged feelings of loneliness among older adults, overall, relevant heterogeneities may exist. Along this line, Arpino et al. (2021a) show that individuals who lack certain close family ties (e.g., unpartnered people) have been at higher risk of reporting increased feelings of loneliness since the onset of the pandemic. This suggests that older people who lacked emotional and practical support might have been particularly at risk of suffering the direct and indirect consequences of the pandemic. Given that informal caregiving is mostly provided by close family members (Agree & Glaser 2009; Verbeek-Oudijk et al. 2014; Wolff et al., 2016), childless and unpartnered individuals might have been the groups at the highest risk of experiencing unmet care needs during the pandemic. Instead, research has shown that family caregiving has continued during the pandemic (Rodrigues et al. 2021), also to replace reduced availability of formal care services or fear of contagion by care professionals (Vislapuu et al. 2021). Studies have also reported higher anxiety and depression among family caregivers during the pandemic (Beach et al. 2021). The conclusions of these examples of research can lead to adaptation of public policies or the creation of public services targeting subgroups of childless and unpartnered individuals, or a pandemic hotline for interacting with lonely people, etc.

The increased need of care and the higher burden put on family caregivers' shoulders calls for new policy and practice solutions. Older people residing in nursing homes have been at a particularly high risk of isolation, loneliness and reduced care received. The COVID-19 has pointed out an urgent need for higher standards of care in nursing homes in Europe (Miralles et al. 2021), and the development of community-based alternatives and services to support the persons with care needs and the families with care responsibilities which could be inspired by the principles outlined in a UN (2020) policy brief launched in the early phases of the pandemic. The development of good quality affordable available and accessible community-based services is paramount to the meaningful inclusion in the community, these services should be developed in collaboration with all the stakeholders, from users to practitioners, including persons with care needs and their families. In parallel, broader-scope interventions to reduce isolation and loneliness among the general population can and need to be implemented e.g. by improving transport and through laws and policies to address ageism, inequality and the digital divide (WHO 2021b).

Research questions

The general research questions that will be addressed are the following:

- What has been the impact of the pandemic and the non-pharmaceutical measures implemented to fight the spread of the virus on isolation and loneliness among older people, especially those needing care?
- Did increased ageism contribute to more isolation and loneliness among older people?
- How formal and informal caregiving has been re-organized during the COVID-19 pandemic (be it in care homes, in hospitals, but also for the great majority of older people living at home)?
- To what extent changes in caregiving contributed to worsening or improving of older people's wellbeing during the pandemic (with a focus on the role of families, crucial during this pandemic)?
- Was the impact on isolation and loneliness stronger for individuals with poorer socio-economic resources and those who lack close family ties? If yes, to which amount? And how can public policies address this challenge?
- Was the impact of the COVID-19 on isolation, loneliness, ageism and care different across European countries?
- What policies and practices have been implemented throughout Europe to reduce social isolation, loneliness and ageism, and to guarantee adequate care provided to older people?

- Was there a positive impact/ outcome of the pandemic and the non-pharmaceutical measures implemented to fight the spread of the virus on isolation and loneliness (e.g. more digital contacts)?
- What can policies and practices do to reduce social isolation, loneliness and ageism, and to guarantee adequate care provided to older people?
- How can lessons learnt from the impact of the pandemic on loneliness be used to "build back better"? Is there a way to reinvent care?
 - Extensive research on long term care already exists, the workshop will be the occasion to discuss the outcomes and reflect on the organization of care, be it short or long term
- How much would it cost to do nothing?

Cross-cutting issues to be mainstreamed (taken into consideration) in the process and papers:

- Inequality (including gender but not restricted to it). E.g.:
 - o access to infrastructure (be it in urban or rural areas)
 - access to internet and digital transformation: who is benefiting from it, what are the outcomes?
 - access to housing
 - quality of local environment (availability of parks, quality of streets, etc.)
- Intergenerational perspective: intergenerational interactions or relations, also in terms of solidarity
- Positive aspects
 - For instance, the fact that the pandemic and its restrictions raised awareness on the triage issue and exposed inherent ageism in the system
 - Another example: the digitalisation and development of ICTs and the connectivity it can bring in this period of physical distancing. Or the fact that the perception of older employees in the workplace improved with regards to their digital competencies?
 - Highlight where there have been successes or improvements (one could argue delivery services have improved).

Preliminary dissemination plan

The present red line document represents a call for contributions, reports and working papers that will be produced along this knowledge and sharing process according to the following deadlines:

- November 2021 identification of the main policy makers, stakeholders, and researchers (GA members could suggest researchers and key stakeholders including policy makers; SAB and SOAB to be asked as well to contribute with suggestions)
- December 2021 Dissemination plan (to be designed from the beginning and consolidated during the exchanges with stakeholders)
- December 15, 2021 deadline for presenting provisional written contributions by invited stakeholders
- December 2021 online 1 day-workshop on "<u>key studies and needs</u>", speakers: researchers involved and stakeholders; participants: researchers, stakeholders, and policy makers, chair: Nathalie Noupadja (JPI-SOAB). Objective: Fostering interaction and lively exchange
- February 2022 deadline for having the final report of the February workshop
- *February*-March: submit a workshop proposal for the EWRC (European Week of Regions and Cities)
- *February/ begin March 2022* deadline for presenting written contributions by invited researchers
- February 2022 online 1 day-workshop on "<u>empirical evidences across Europe</u>", speakers: researchers involved and other invited researchers, stakeholders and/or policy makers highly involved ; participants: other researchers, stakeholders and policy makers, chair: Johan Fritzell (JPI-SAB)
- April 1, 2022 deadline for having the final report of the March 22 workshop
- *April 15, 2022* deadline for presenting provisional written contributions by invited policy makers
- April 25, 2022 online 1 day-workshop on "<u>sustainability, organization and policy</u> <u>responses</u>", speakers: policy makers, participants: stakeholders and researchers, chair: Peter Allebeck (JPI-MYBL)

- May 25, 2022 deadline for having the final report of the Apr.25 workshop
- Mid-June, 2022 Final ½ day face-to-face event on "synthesis of previous events and needed for the future", speakers: Nathalie Noupadja, Johan Fritzell, and Peter Allebeck, chair: Bruno Arpino
- June, 16-17 2022 Rome, Italian inter-ministerial conference on aging
- October 2022: high level event on results (at the EWCR or European week of healthy aging)

It is expected that three main dissemination strategies will be pursued during the knowledge and sharing process:

- At least three online reports or documents that collect the views of the different actors (stakeholders, policy makers and researchers) that will attend the three scheduled online workshops on the considered topics.
- 2. A large media coverage will be dedicated to publicizing (through media/ social media, internet and newspaper) the final synthetic report, to be be launched during a final event, which will briefly report what was discussed and observed during the three online workshops, highlighting in particular: needs, empirical evidences and political responses and activities.
 - a. Organise the dissemination: make sure to ask the tweeter account of all participants in the project : list and disseminate this information
- One international publication (special issue or co-edited book) will collect the presented scientific contributions on the considered topics with an introduction carried out by one (or more) stakeholder representative and a concluding section covering policy implications.

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