

2.2 Older people with care needs in Norway during the COVID-19 pandemic

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The pandemic in Norway led to restrictions on nursing home visits, a reduction in practical help for home-dwelling elderly people, and limits on social activities. These services, Anne Skevik Grødem notes, took a long time to return to normal, placing an additional burden on informal carers and leading to widespread concern about the welfare of older people with care needs.

On 12 March 2020, the Norwegian government implemented strict measures to limit the spread of COVID-19. The main approach was to limit mobility, which included closing schools and kindergartens, mandating working from home whenever possible, and closing most services that involved face-to-face contact. On 14 March, the government also closed the country's borders. The new situation was highly disruptive for individuals in need of care services, as well as for their formal and informal carers.

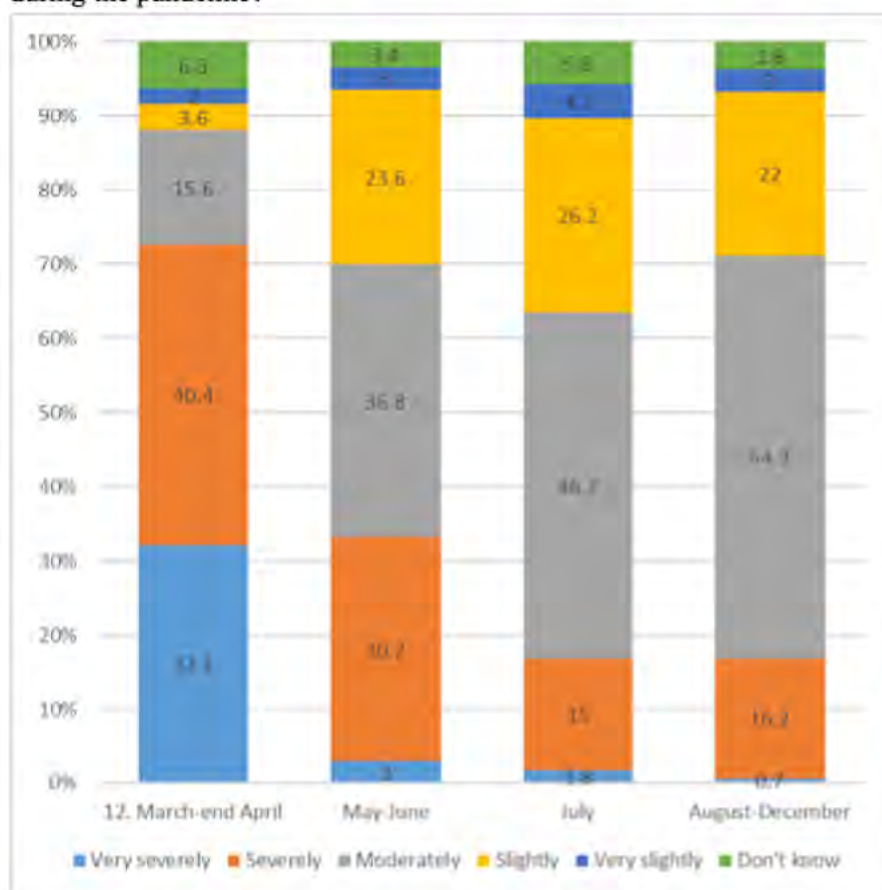
Before examining the various issues in detail, it is worth noting that a high proportion of elderly people in Norway live in their own homes and manage with very little help, and most of them found ways to cope during the restrictions (Røde Kors, 2021). Some emphasised that they had been through hard times before – a 92-year-old woman compared the situation to the Second World War, and expressed relief that at least blackout curtains were not required this time. Besides, being retired, they were used to spending a lot of time at home, and talking on the phone or communicating online provided an outlet for many. The pandemic took its toll on everybody, but data do not suggest that healthy, self-reliant elderly people were worse off than other age groups (NOU 2022:5).

LIMITS TO VISITS IN CARE INSTITUTIONS

The pandemic nevertheless raised a number of challenges for care services, which in Norway are the responsibility of municipalities. Since the

1980s, care institutions have been downscaled, and most care recipients live in their own home (Gautun & Grødem, 2015). By 2020, more than 80% of residents in care institutions had dementia. Care institutions continued to operate as normally as possible in March 2020, although many altered staff rotation schedules to minimize the number of staff coming in and out. The Directorate of Public Health issued guidelines on how to protect vulnerable residents in care homes, and how to act if a resident contracted the virus (NOU 2022:5, p. 410). Difficult issues arose over family visits, however: 72% of municipalities reported in a survey that visits to residents in care institutions were severely or very severely limited in March and April 2020 (Figure 1).

Figure 1. To what extent were visits to residents in nursing homes restricted during the pandemic?



Source: Deloitte 2021:42. Based on survey of municipalities, N varies between 109 and 105

Visiting restrictions and physical distancing had painful consequences for individuals with later-stage dementia. Residents would sometimes be distressed, or act out, because they could not understand why they could no longer meet, or touch, their loved ones.

MY CARE HOME IS MY CASTLE

To compensate for the downscaling of institutional care, municipalities across Norway have built designated “care homes” (omsorgsboliger) for residents with care needs. While typically designed to accommodate disability and facilitate care, they are legally the residents’ home, and hence their castle. It therefore caused a minor scandal when newspapers revealed that many municipalities closed care homes to visitors in March and April 2020. On 20 April 2020, the Directorate of Public Health stated that local authorities had no legal right to do this, and that care home residents were free to make their own decisions – even in a pandemic. This process highlighted an issue that care organizations and the families of care recipients had been pointing up for years, namely that municipalities fail to distinguish properly between the legal statuses of institutions and care homes.

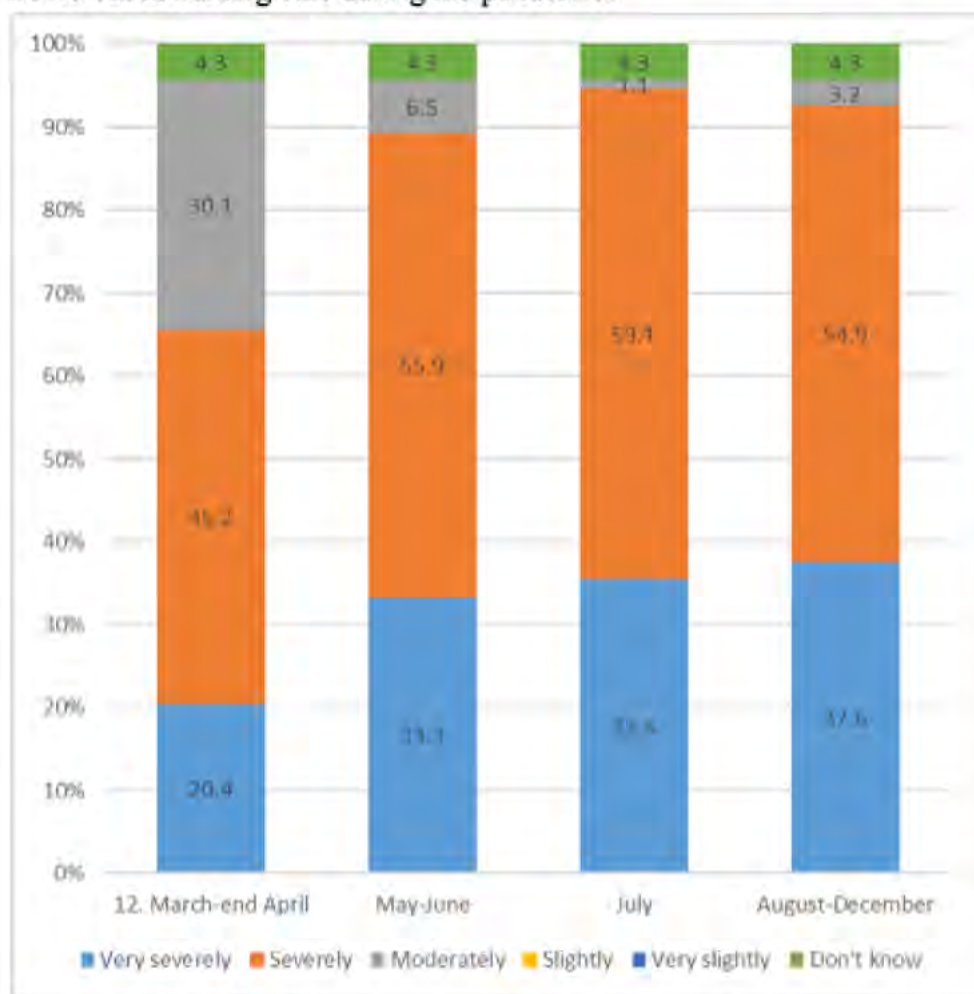
REDUCED PRACTICAL HELP AND SOCIAL ACTIVITY

Surveys indicate that municipalities largely maintained medical help to home-dwelling care recipients during all stages of the pandemic. They were more likely to reduce practical help, such as help with cleaning or laundry (Figure 2). An often-quoted reason for limiting services in the home was fear of contagion on the part of users or their families, who refused such help in order to limit the number of people coming in and out of the user’s home. In other cases, services were downscaled because local authorities redeployed personnel to handle other tasks related to the ongoing pandemic. The pandemic represented a major burden for local authorities, and practical help to the elderly – and other recipients of care services – was not always a top priority.

The services that suffered most during the pandemic were social activities for the elderly. Activity centres and day centres are important meeting places where elderly people can socialize, have a meal, and take part in various activities. Many municipalities closed these centres for much of 2020, and many also scaled down respite services for home-dwelling el-

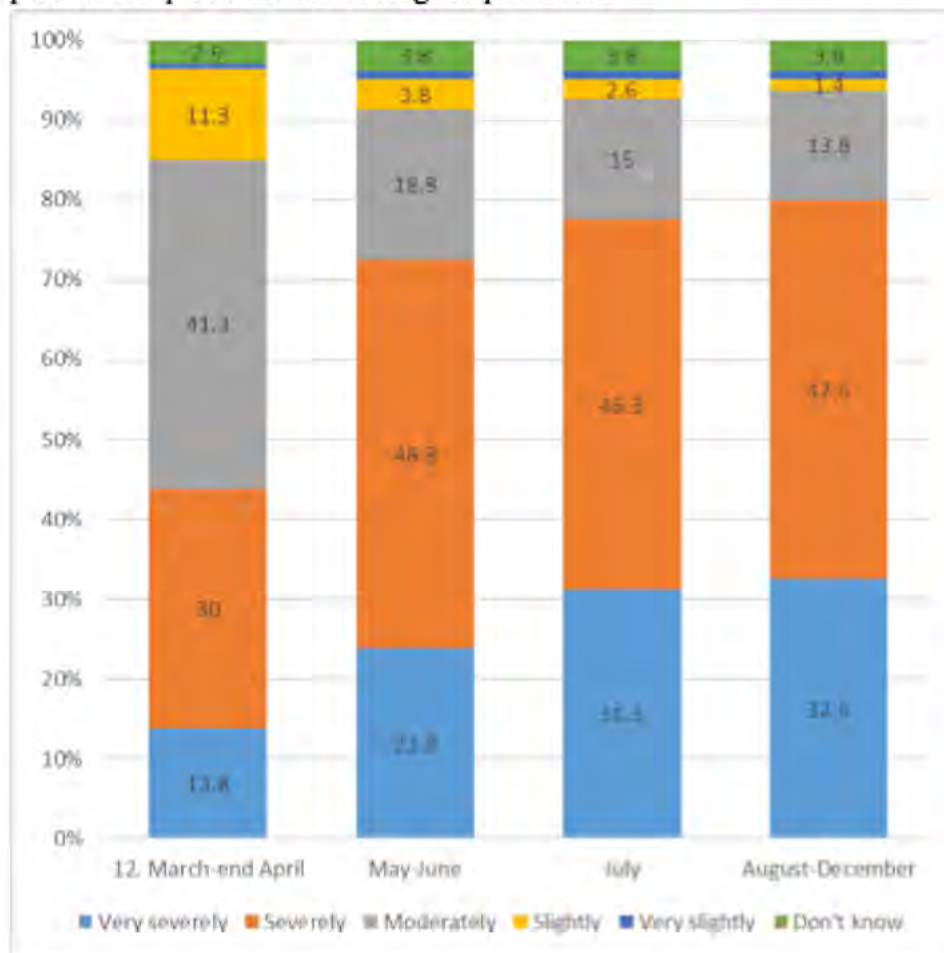
derly people with dementia, which severely increased the burden on informal carers. Under these circumstances, it is not surprising that 52% of the next of kin of elderly people with dementia reported additional burdens during the pandemic, and that 80% were concerned about the welfare of their relative with dementia (Nasjonalforeningen for folkehelsen, no date). As one informal carer put it, “She sits alone all day. Her joy of life and memory are declining rapidly”.

Figure 2a. To what extent has the municipality succeeded in maintaining home-based nursing care during the pandemic?



Source: Deloitte 2021:38. Based on survey to the municipalities, N=93.

Figure 2b. To what extent has the municipality succeeded in maintaining practical help in the home during the pandemic?



Source: Deloitte 2021:39. Based on survey to the municipalities, N=80

A LONG PANDEMIC FOR THE ELDERLY

In Norway, the most severe restrictions were lifted in late April 2020. Between April 2020 and February 2022, COVID restrictions were less stringent and mainly limited to the geographical areas where infection rates were high. Analyses of pandemic management, however, show that municipalities were often unsure how to act, and tended to follow national recommendations “to the letter” in order “to be sure they were doing enough” (NOU 2022:5). Hence, as late as in June 2021, humanitarian organizations were still hearing from distraught family members who were not allowed to visit their institutionalized loved one more than once

a week (Nasjonalforeningen for folkehelsen, 2021). Also, months after the reopening in April 2020, only 37% of municipalities said the senior centres were operating as normal.

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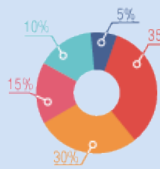
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Loneliness and social exclusion among older Europeans before and during the COVID-19

edited by

Bruno Arpino



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Preface

This e-book is the main output of a knowledge sharing process organized by the Joint Programming Initiative “More Years Better Lives – The Potential and Challenges of Demographic Change” (JPI-MYBL).

Launched in 2009, JPI-MYBL brought together several EU and non-EU countries to create a common research framework aiming to better coordinate, harmonize, and synchronize the research programmes of the participating countries on the topic of demographic change. The ultimate goal of JPI-MYBL is to better understand the complex effects of demographic change¹ and to produce evidence on the relationship between demographic change, equality, and wellbeing. It adopts a transnational and interdisciplinary approach to find innovative solutions that make “societal ageing” a resource and not a burden. It also involves different actors including researchers, policymakers and stakeholders.

In 2022, JPI-MYBL launched a knowledge-sharing process on isolation and loneliness among older people during the COVID-19 pandemic. The process consisted of four connected online workshops, scheduled in a specific time window (about six months), and attended by three groups of actors: stakeholders, researchers, and policy representatives who were invited to respond to a common “red line document” posted on the JPI-MYBL website.² A synthesis of this document is included in the Introduction of this e-book. Participants in the four knowledge-sharing workshops were later invited to prepare a short article based on their presentations. Their contributions are presented in this e-book, along with additional articles on the topics of isolation and loneliness among older people.

¹ Further information about JPI-MYBL, its projects and activities are available on the website:

jp-demographic.eu .

² jp-demographic.eu/Knowledge_Covid_Red-line_comments_clean.pdf

Introduction

BRUNO ARPINO, GIUSEPPE GABRIELLI & HEIDRUN MOLLENKOPF

The demographic changes of the past and coming years will profoundly modify the population structure in Europe. These transformations are associated with changes in the distribution of resources and opportunities across Europe and beyond – changes that require adjustments in all areas of life, both at individual level and across society as a whole. Among these changes, population ageing is a long-term trend which began several decades ago in Europe. Increased life expectancy is a triumph for humanity but, coupled with fertility reduction and postponement, it causes population ageing (Grundy & Murphy 2017).

Social isolation and feelings of loneliness among older people are among the challenges posed by population ageing and shrinking family networks. Isolation and loneliness have negative consequences on individuals that may result in poor physical health, unhealthy behaviours, poor wellbeing and, ultimately, depression.

Loneliness also has an economic cost for individuals and society; it reduces interpersonal interactions, and thus social capital, and adversely affects physical and mental health (Burlina & Andrés 2021). Research has estimated that the annual cost of loneliness is about 1,000 euros per capita (Mihalopoulos et al. 2020). Individuals who feel lonely also tend to use healthcare services more than others (Gerst-Emerson and Jayawardhana 2015), with negative consequences on public health expenditures.

Loneliness and social isolation among older adults were already important research and policy topics before the onset of the COVID-19 pandemic (Tesch-Roemer & Huxhold 2019; Victor et al. 2000). However, the spread of COVID-19 and the physical distancing measures to limit transmission of the virus exacerbated pre-pandemic vulnerabilities linked to isolation and loneliness in ageing societies. While mortality and COVID-related health conditions have been extensively examined since the very beginning of the pandemic, JPI-MYBL felt that more comprehensive research was needed on isolation and loneliness among older adults over this period. This motivated the knowledge-sharing process briefly introduced in the Preface, with the key goal of understanding what suggestions

for policy and practice can be drawn, based on existing research and the expert knowledge and experience accumulated since the first lockdowns in Europe in early 2020.

ISOLATION, LONELINESS, AND THE COVID-19 PANDEMIC

In the decades preceding the COVID-19 pandemic, scholars and public health officials became increasingly concerned about the growing risks of loneliness driven by societal shifts such as fertility decline, the increase in one-person households and other factors, especially in the United States and Europe. A broad array of studies investigated the determinants and consequences of loneliness and social isolation (e.g., Dahlberg et al., 2022; de Jong et al. 2016; Fokkema et al. 2012; Morgan et al. 2021).

After the outbreak of the pandemic, physical distancing was imposed or encouraged at national, regional, and local levels, to mitigate the spread of COVID-19. People were asked to avoid public social spaces and minimize physical contact with others. Measures also included stay-at-home orders, and full physical isolation of high-risk individuals, such as older adults with pre-existing conditions (Plümper & Neumayer, 2020). While these mitigation measures were effective in slowing the spread of COVID-19 and reducing mortality, they may have increased isolation among older adults, possibly exacerbating the “loneliness pandemic” and the risks factors for loneliness (Dahlberg, 2021).

Studies have suggested that older adults were more resilient to loneliness than younger adults during COVID-19 (e.g., Beam & Kim, 2020; Bu et al., 2020; Luchetti et al., 2020). Thus, increased physical isolation due to the anti-COVID restrictions does not seem, on the whole, to have exacerbated feelings of loneliness among older adults. This finding may reflect a combination of factors, including lowered expectations for social interaction during the pandemic (Dahlberg, 2021) or increased contact at a distance (Arpino et al. 2021 a,b).

Although possibly more resilient than younger adults, it is unclear whether, and to what extent, older adults across Europe experienced increases in loneliness during COVID-19. Existing evidence offers 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. (2022) show that individuals who lack certain close family ties (e.g., unpartnered people) have been at higher risk of reporting increased feelings of lone-

liness since the onset of the pandemic. This suggests that older people who lacked emotional and practical support might have been particularly exposed to its direct and indirect consequences. Van Tilburg (2022) shows that loneliness, and particularly emotional loneliness, increased between 2019 and 2020, although having a partner before the pandemic provided some protection.

Given that informal caregiving is mostly provided by close family members (Agree & Glaser 2009; Verbeek-Oudijk et al. 2014), childless and unpartnered individuals were, in principle, those at highest risk of experiencing unmet care needs during the pandemic. In fact, research has shown that family caregiving continued during the pandemic (Di Gessa et al. 2022; Rodrigues et al. 2021), in some cases replacing formal care services to avoid possible 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 increased need of care and the heavier burden placed on family caregivers call for new policy and practice solutions. Older people in residential care are at a particularly high risk of isolation, loneliness and reduced care. COVID-19 has pointed up an urgent need for higher standards of care in nursing homes in Europe (Miralles et al. 2021), and for the development of community-based alternatives and services to support persons with care needs and families with care responsibilities. These alternatives and services 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 being paramount for meaningful inclusion in the community, these services should be developed in collaboration with all 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 public transport and through laws and policies to address ageism, inequality and the digital divide (WHO 2021b).

THE EXPERIENCE OF THE KNOWLEDGE SHARING PROCESS

The aim of the JPI-MYBL knowledge-sharing process on “Isolation and loneliness of older people during the COVID-19 pandemic: formal/informal care” was to complement existing research and to provide a concrete perspective on the issues concerned. Policy representatives, stakeholders,

and researchers were involved in the entire process (see Preface), with the aim of shedding light on the topic and disseminating knowledge, practices and policy measures implemented throughout Europe to limit the direct and indirect negative consequences of the pandemic, whose impact may be felt for years to come.

The process consisted of four online workshops. Their synthetic reports are available on the JPI-MYBL website, and brief summaries of each are provided here.

WORKSHOP 1 - STAKEHOLDERS

In the first workshop, stakeholders presented their views on needs and presented key studies concerning the main topic to an audience of other stakeholders, researchers and policy makers. The stakeholders emphasized that older people themselves must be included in the discussions. It was highlighted that good practices and tools for influencing policy on a local level already exist, but that their impact is difficult to measure.

WORKSHOP 2 - RESEARCHERS

In the second workshop, researchers presented some scientific outcomes to an audience of stakeholders, other researchers and policy makers. The presentations highlighted the importance of family, friends, and other social contacts in preventing loneliness. The stakeholders signalled again that the perspective of older persons themselves should be embedded in research. It also became clear that some research topics, methodologies, and research groups had been overlooked in previous research. For example, cross-country comparisons or differentiation between urban and rural conditions were rare (see, however, Atzendorf & Gruber 2021 for an exception). These differences might provide important pointers to understand what kind of welfare state or policy, or what practices might reduce the impact of the pandemic, and perhaps loneliness in general.

WORKSHOP 3 - POLICY MAKERS

In the third workshop, policy makers reacted to the solicitations received in the previous workshops by providing their points of view and suggesting possible actions. It emerged that loneliness policies differ across countries. Overall, it was concluded that the COVID-19 pandemic highlighted the issues related to loneliness and isolation and showed the

strengths and limitations of policies and interventions. When it comes to “curing” loneliness (among older adults), there is still a long way to go. For the future, it is important to investigate why some older adults are lonely and some are not, and to use that knowledge to prevent loneliness among individuals of all ages.

WORKSHOP 4 - SYNTHESIS

After the third workshop, the JPI-MYBL sent out a questionnaire to participants to collect their views on the process and the lessons learned. The process ended with a meeting during which the participants made a synthesis of all the input and agreed on recommendations for the future. The questionnaire results highlighted the gap between research and policy. All the different perspectives were highly appreciated, and it was agreed that the workshops were interesting because the participants were very open about their findings and their opinions and were able to learn from each other.

In conclusion, the knowledge-sharing process pointed up the particular need to:

- include older persons’ perspectives in the discussions at all levels
- close “blank spots” (i.e., unexplored areas) in research, and
- find more effective ways to translate knowledge into political interventions.

The experience gained with the knowledge-sharing process, the results, and the prospective issues that emerged from the joint discussions showed convincingly that JPI-MYBL can move closer to its goal and should continue to pursue the approach used. To increase the Programme’s impact in the future, the commitment of participating countries should be widened, and cooperation among the different actors strengthened, with further improvements in the distilling, translating, and dissemination of knowledge.

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