






COMMENTARY

COVID-19: Opportunities for interdisciplinary research to improve care for older people in Sweden

REBECCA BAXTER^{1*}, WOSSENSEGED BIRHANE JEMBERIE^{2,3*}, XIA LI⁴,
MAHWISH NASEER^{5,6}, MASCHA PAUELSEN⁷, JACQUES SHEBEHE⁸,
EMILIA W.E. VIKLUND⁹, XIN XIA¹⁰, LINN ELENA ZULKA¹¹
& ANDREEA BADACHE^{12,13}

¹Department of Nursing, Umeå University, Sweden, ²Department of Social Work, Umeå University, Sweden, ³Centre for Demographic and Ageing Research (CEDAR), Umeå University, Sweden, ⁴Department of Medical Epidemiology and Biostatistics, Karolinska Institutet, Sweden, ⁵School of Education, Health and Social Studies, Dalarna University, Sweden, ⁶Ageing Research Centre, Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, Sweden, ⁷Department of Health Sciences, Luleå University of Technology, Sweden, ⁸Clinical Epidemiology and Biostatistics, School of Medical Sciences, Örebro University, Sweden, ⁹Department of Health Sciences, Faculty of Education and Welfare Studies, Åbo Akademi University, Finland, ¹⁰Department of Neurobiology, Care Sciences and Society, Karolinska Institute, Sweden, ¹¹Department of Psychology, Centre for Ageing and Health (AgeCap), University of Gothenburg, Sweden, ¹²Department of Disability Sciences, School of Health Sciences, Örebro University, Sweden, ¹³Swedish Institute of Disability Research, Örebro University, Sweden

Abstract

The emergence of COVID-19 has changed the world as we know it, arguably none more so than for older people. In Sweden, the majority of COVID-19-related fatalities have been among people aged ≥ 70 years, many of whom were receiving health and social care services. The pandemic has illuminated aspects within the care continuum requiring evaluative research, such as decision-making processes, the structure and organisation of care, and interventions within the complex public-health system. This short communication highlights several key areas for future interdisciplinary and multi-sectorial collaboration to improve health and social care services in Sweden. It also underlines that a valid, reliable and experiential evidence base is the sine qua non for evaluative research and effective public-health systems.

Keywords: COVID-19, Sweden, aged, ageing, older people, public health, patient and public engagement (PPE), evidence-based policy

Introduction

This short communication aims to highlight opportunities for interdisciplinary research and multi-sectorial collaboration, with a view towards strengthening health and social care services for older people living in Sweden in the wake of the coronavirus disease 2019 (COVID-19) pandemic. In this discussion, we emphasise the need for

research to evaluate decision-making processes and interventions across various sectors, the structure and organisation of the health-care system and the impact of COVID-19 on the lived experience of older people in Sweden. The authors are doctoral affiliates of the Swedish National Graduate School for Competitive Science on Ageing and Health (SWEAH). SWEAH's mission is to support

*These authors contributed equally to this work.

Correspondence: Rebecca Baxter, Department of Nursing, Umeå University, 901 87 Umeå, Sweden. Email: rebecca.baxter@umu.se

Date received 6 August 2020; reviewed 25 September 2020; accepted 5 October 2020

© Author(s) 2020

Article reuse guidelines: sagepub.com/journals-permissions

DOI: 10.1177/1403494820969544

journals.sagepub.com/home/sjp



interdisciplinary research to improve the quality of life, well-being and health outcomes for the ageing population.

As of 29 June 2020, the Swedish National Board of Health and Welfare (Socialstyrelsen) reported that people aged ≥ 70 years accounted for 90% ($n=4674$) of all COVID-19-related deaths ($n=5194$) [1]. Of those aged ≥ 70 years who died, 26.9% were receiving social services and 51.5% were residents in long-term care (LTC) facilities [1]. In mid-March 2020, the Public Health Agency of Sweden (Folkhälsomyndigheten) recommended self-isolation and physical/social distancing for people aged ≥ 70 years [2], and in late March 2020, the Swedish government passed legislation restricting non-essential visitors to LTC facilities and special accommodation for older people [3]. However, many older people rely on outside help from informal caregivers, and around 71% of people aged ≥ 65 years living in ordinary housing use municipal home-care services [4], making 'perfect' adherence to distancing regulations almost impossible. For example, it has been estimated that over a 2-week period, a person using home-care services meets an average of 15 health and social care workers, each of whom have contact with more than 10 clients [4]. This is concerning, as numerous care transitions and contact with different service providers have been associated with an increased risk of infection for older people [5], illustrating the complexity of integrating safety regulations and care requirements across multiple sectors.

Additional barriers to maintaining standards of care include resource shortages resulting from cuts to health and social care funding [6], unstable working conditions [7,8] and casual employment contracts [8,9]. Surveillance and preparedness are central to enacting appropriate responses to manage the spread of infections [10,11]. Yet, basic education and training regarding hygiene routines and infection control measures were already lacking prior to COVID-19 [7,9,12]. Data collected between the 9th and 22nd of May 2020 regarding Swedish LTC workers' compliance with processes related to basic hygiene routines and dress codes found only 59% adherence compared to 51% in 2019 [13]. Service providers reported lacking basic personal protective equipment, and many employees continued to work due to being short-staffed and feeling insecure about their employment [14,15]. Interdisciplinary and multi-sectorial collaboration is required to create better working conditions for staff and improve safety for people receiving homecare services or living in LTC. This should encompass provision of education and training for health and social care employees,

implementation of user-informed feedback loops to ensure responsive practices to emerging data, development of evidence-based clinical strategies for infection prevention and control and operationalisation of longitudinal surveillance involving multiple data sources.

Much of the responsibility for these pandemic-mitigating measures was placed on individuals to restrict contact with their families and communities, which is worrying, given that about 36% of adults aged ≥ 65 years in Sweden live alone [16,17] and experience loneliness and social isolation [18]. To maintain social connections and alleviate feelings of loneliness, many people around the world have turned to digital tools, which has actualised the importance of digital competence. Opportunities have arisen for new and existing digital technology to monitor medication adherence, enhance psychosocial well-being and facilitate connections between older people and their families, communities and healthcare services [19–22]. Research suggests that older people are positive towards digital technology, especially if it is perceived as beneficial and user-friendly [23]. However, such digital interventions might worsen health inequities given that 31% of Swedes aged >75 years did not use the Internet in 2019 [24], and poor accessibility and mistrust in information technology systems can affect adherence to digital services [25]. It is therefore important to evaluate the experience and evidence base for digital services carefully before implementing them into routine post-pandemic practice. For example, increased use of digital telehealth services may be necessary in the short term, but in the long term, this may risk opportunities for some older people to communicate and build relationships with care providers [26,27]. Inviting older people to share their experiences and preferences regarding the use of digital tools could contribute towards better implementation of effective and innovative interventions in health and social care services.

Experts in the field of ageing science have criticised the absence of targeted measures and adequate staffing to support frail older people living in ordinary homes and LTC facilities [28]. The Swedish Pensioners' Association also recently criticised the Public Health Agency of Sweden and the Swedish Civil Contingencies Agency for not including the opinion of people ≥ 80 years in their survey measuring the effect of the pandemic on care and services for older people [29], leading the agencies to acknowledge their error [30]. Research to evaluate decision-making processes, interventions and outcomes should therefore strive to encompass the perspective of multiple stakeholders. Researchers, healthcare

professionals and policymakers now have the *opportunity* and *responsibility* to partner with older people to set priorities for the development of streamlined and integrative public-health systems.

Opportunities for interdisciplinary research

Identification and evaluation of indicators for follow-up is necessary during and after emergency situations to improve future decision-making processes and public-health system preparedness, responsiveness and resilience. As SWEAH-affiliated doctoral researchers with diverse academic and professional backgrounds, we point to five key areas that require interdisciplinary and multi-sectorial research and collaboration to strengthen current and future health and social care services for older people:

- Enabling shared decision making and streamlined information sharing between branches of health and social care services to provide safe and integrated care;
- Improving working conditions for health and social care professionals via provision of adequate resources, job security and training for future healthcare crises through simulation and embedded education;
- Implementing user-informed feedback loops to ensure that policies and interventions are appropriate and responsive to the needs of health and social care systems and the people who use them;
- Cultivating opportunities for alternative forms of connection and communication for older people, including evidence-based digital technology;
- Creating opportunities for partnership with older people to set priorities and co-design research and policy that directly affects their lived experience and everyday lives.

Conclusion

We acknowledge that this communiqué is far from comprehensive. However, it is our hope that the lives of older people in Sweden can be improved through interdisciplinary and multi-sectorial collaboration among health and social care systems. Shared governance must encompass the lived experience of both healthcare providers and older people to improve outcomes across the care continuum. Emerging from this pandemic, we must be vigilant that the measures taken during this time do not become standard practice without support from a valid, reliable and *experiential* evidence base.

Acknowledgements

The doctoral learning process has been supported by the Swedish National Graduate School for Competitive Science on Ageing and Health (SWEAH). SWEAH is funded by the Swedish Research Council (DNR: 2013-08755; PI: Susanne Iwarsson) and aims to develop creative cooperation among Swedish higher education institutions and cross-disciplinary collaboration among ageing and health researchers. For more information on SWEAH's affiliates, activities and partnerships see <https://www.sweah.lu.se/en/>. We thank SWEAH affiliate Dr Arianna Poli for her valuable feedback on this manuscript. We also thank the health and social care professionals who have been working on the frontline in the fight against COVID-19.

Declaration of conflicting interests


The authors declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Funding

The authors received no financial support for the research, authorship and/or publication of this article.

ORCID iDs

Rebecca Baxter  <https://orcid.org/0000-0001-6595-6298>

Wossenseged Birhane Jemberie  <https://orcid.org/0000-0002-4378-6803>

Mascha Pauelsen  <https://orcid.org/0000-0002-2510-7571>

Jacques Shebehe  <https://orcid.org/0000-0002-0044-0781>

Emilia W.E. Viklund  <https://orcid.org/0000-0002-5852-1381>

References

- [1] The National Board of Health and Welfare. Statistik över antal avlidna i covid-19 [Statistics on COVID-19 related deaths], <https://www.socialstyrelsen.se/statistik-och-data/statistik/statistik-om-covid-19/statistik-over-antal-avlidna-i-covid-19/> (2020, accessed 24 June 2020).
- [2] The Public Health Agency of Sweden. Personer över 70 år begränsa sociala kontakter tills vidare [Individuals older than 70 years should restrict their social social contacts until further notice], <https://www.folkhalsomyndigheten.se/nyheter-och-press/nyhetsarkiv/2020/mars/personer-over-70-ar-begransa-sociala-kontakter-tills-vidare/> (2020, accessed 3 July 2020).
- [3] Ministry of Health and Social Affairs. Nationellt besöksförbud på äldreboenden [National ban on visits to long-term care facilities for older people], <https://www.regeringen.se/pressmeddelanden/2020/03/nationellt-besoksforbud-pa-aldreboenden/> (2020, accessed 2 July 2020).

- [4] The National Board of Health and Welfare. Vård och omsorg om äldre. Lägesrapport 2019 [Health and social care of older people. Progress report 2019], <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2019-3-18.pdf> (2019, accessed 3 July 2020).
- [5] Lindahl JF, Hoffman T, Esmacilzadeh M, et al. High seroprevalence of SARS-CoV-2 in elderly care employees in Sweden. *Infect Ecol Epidemiol* 2020;10:1789036.
- [6] Plesner Å. Budget ur balans – en granskning av äldreomsorgens ekonomi och arbetsmiljö [Budget out of balance – a review of the economy and working environment of elderly care], <https://arenaide.se/wp-content/uploads/sites/2/2020/03/budget-ur-balans-2020-03-25-compressed.pdf> (2020, accessed 9 September 2020).
- [7] The Swedish Work Environment Authority. Projekt rapport Äldreomsorgen 2017–2019: Riskfylld arbetsmiljö – utmaningar för framtidens äldreomsorg [Project report Elderly care 2017–2019: Risky work environment – challenges for future elderly care], <https://www.av.se/globalassets/filer/publikationer/rapporter/2018-007023-projekt-rapport-aldreomsorgen-2017-2019.pdf> (2020, accessed 9 September 2020).
- [8] Lundgren D. *Leadership, psychosocial work environment, and satisfaction with elder care among care recipients: analysing their associations and the structural differences between nursing homes and home care*. PhD thesis, Jönköping University, School of Health and Welfare, Jönköping, 2018.
- [9] The Swedish Association of Local Authorities and Regions. Fakta om äldreomsorgen i ljuset av coronapandemi [Facts about social care in light of coronavirus pandemic], https://skr.se/download/18.c6705bc172ca813b9c99/1593093396355/Fakta_om_aldreomsorgen_i_ljuset_av_coronapandemin.pdf (2020, accessed 3 July 2020).
- [10] Haenen APJ, Verhoef LP, Beckers A, et al. Surveillance of infections in long-term care facilities (LTCFs): the impact of participation during multiple years on health care-associated infection incidence. *Epidemiol Infect* 2019;147:e266.
- [11] Team EPHE, Danis K, Fonteneau L, et al. High impact of COVID-19 in long-term care facilities, suggestion for monitoring in the EU/EEA, May 2020. *Euro Surveill* 2020;25:2000956.
- [12] The Local Sweden. Coronavirus: Sweden admits failure to protect elderly in care homes. *The Local Sweden*, 10 May 2020.
- [13] The Swedish Association of Local Authorities and Regions. Mätning av följsamhet till hygienrutiner och klädregler: Kommunens resultat [Measures of compliance with hygiene routines and dress code: results for municipalities], <https://skr.se/halsasjukvard/patientsakerhet/matningavskadorivarden/matningbasalahygienrutiner/resultatmatningbkh.2277.htm> (2020, accessed 3 July 2020).
- [14] Department of Infection Control and Hospital Hygiene in Region Stockholm. Kartläggning av covid-19 på SÄBO i Stockholms län [Survey of COVID-19 in elderly care homes in Reion Stockholm], <https://www.sll.se/globalassets/bilagor-till-nyheter/2020/05/kartlaggning-av-covid-19-pa-sabo-i-stockholms-lan.pdf> (2020, accessed 24 June 2020).
- [15] Sveriges Television. JO utreder Arbetsmiljöverkets rekommendationer om skyddsutrustning [Parliamentary Ombudsman investigates the Swedish Work Environment Authority's recommendations on personal protective equipment], <https://www.svt.se/nyheter/inrikes/jo-utreder-arbetsmiljoverkets-rekommendationer-om-skyddsutrustning> (2020, accessed 3 July 2020).
- [16] Shaw BA, Fors S, Fritzell J, et al. Who lives alone during old age? Trends in the social and functional disadvantages of Sweden's solitary living older adults. *Res Aging* 2018;40:815–38.
- [17] Padyab M, Reher D, Requena M, et al. Going it alone in later life: a comparative analysis of elderly women in Sweden and Spain. *J Fam Issues* 2019;40:1038–64.
- [18] Taube E, Kristensson J, Midlöv P, et al. Loneliness among older people: results from the Swedish National Study on Aging and Care – Blekinge. *Open Geriatr Med J* 2013;6:1–10.
- [19] Toh X, Tan H, Liang H, et al. Elderly medication adherence monitoring with the Internet of Things. In: *2016 IEEE International Conference on Pervasive Computing and Communication Workshops (PerCom Workshops)*, Sydney, Australia, 14–18 March 2016. Piscataway, NJ: IEEE, pp.1–6.
- [20] Linn AJ, Vervloet M, Van Dijk L, et al. Effects of eHealth interventions on medication adherence: a systematic review of the literature. *J Med Internet Res* 2011;13:e103.
- [21] Forsman AK, Nordmyr J, Matosevic T, et al. Promoting mental wellbeing among older people: technology-based interventions. *Health Promot Int* 2018;33:1042–54.
- [22] Yang Y, Li W, Zhang Q, et al. Mental health services for older adults in China during the COVID-19 outbreak. *Lancet Psychiatry* 2020;7:e19.
- [23] Chen K and Chan AHS. A review of technology acceptance by older adults. *Gerontechnology* 2011;10:1–12.
- [24] The Swedish Internet Foundation. Svenskarna och internet 2019 [The Swedes and the Internet 2019], <https://internetstiftelsen.se/kunskap/rapporter-och-guider/svenskarna-och-internet-2019/> (2019, accessed 11 September 2020).
- [25] Nymberg VM, Bolmsjö BB, Wolff M, et al. 'Having to learn this so late in our lives. . .' Swedish elderly patients' beliefs, experiences and expectations of e-health in primary health care. *Scand J Prim Health Care* 2019;37:41–52.
- [26] Agha Z, Roter DL and Schapira RM. An evaluation of patient-physician communication style during telemedicine consultations. *J Med Internet Res* 2009;11:e36.
- [27] Cimperman M, Brenčić MM, Trkman P, et al. Older adults' perceptions of home telehealth services. *Telemed J E Health* 2013;19:786–90.
- [28] Skoog I, Ekdahl AW, Cederholm T, et al. Testa äldrevårdens personal – varje dag: Debatt [Test the old-age care staff – every day: debate article]. *Aftonbladet*, 2020.
- [29] The Public Health Agency of Sweden. För personal inom äldreomsorg [For elderly care staff], <https://www.folkhalsomyndigheten.se/smittskydd-beredskap/utbrott/aktuella-utbrott/covid-19/information-till-varden/personal-inom-aldreomsorg/> (2020, accessed 9 September 2020).
- [30] Arleij J. MSB: 'Vi tar åt oss av kritiken' [We understand the criticism]. *Senioren*. Stockholm: SPF Seniorerna, 2020.