



Themed Paper – Review

Arts activity and well-being for visually impaired military veterans: a narrative discussion of current knowledge

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ABSTRACT

Objectives: The objective of this study was to offer an overview of literature relating to the topic of arts activity within the context of military and veteran health and to consider the implications of current knowledge on future research with visually impaired veterans.

Study design: A search for literature addressing the topic of visual art activities with visually impaired veterans was undertaken. No research addressing this topic was identified. A review of literature on the related topics of mental health and well-being in military veterans, visual impairment and mental health and well-being, and art therapy for veteran populations was carried out to offer an overview of current knowledge.

Results: While there is growing evidence of the benefits of arts engagement among both general and military populations, the role of the visual arts in the everyday lives of broader veteran samples, and the impact of these activities on holistic well-being, remains underexplored. The current article highlights the need for art as activity to be differentiated from art as therapy and argues that the former might offer a tool to positively impact the holistic well-being of visually impaired veterans.

Conclusions: Future research relating to the use of visual art activities in the context of veteran health and well-being should endeavour to explore the potential impacts of engagement on holistic well-being. Research is needed to build on anecdotal evidence of the positive impact of arts engagement on visually impaired veterans by systematically exploring if, and how, holistic well-being in this population may be impacted by engagement with visual art activities.

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Introduction and rationale

The impetus of this narrative review resides in the ongoing programme of art activities run for members by Blind Veterans UK (BVUK).¹ Creative activities have long formed a core element of the care offered to BVUK members, delivered by a team of specialist rehabilitative staff with training in the arts. Run from workshops at BVUK's centres in Brighton and Llandudno, in North Wales (see Fig. 1, supplementary online material), art and craft activities are offered to any interested member, regardless of prior experience. Some may engage with these activities as part of their 'Introduction week' at centres, or recreationally during ongoing visits, and others

may partake in specific training weeks or theme weeks, which provide opportunities for extended creative engagement and skills development. Among those activities offered are photography, painting, mosaic, ceramics, woodwork and textiles. Since the onset of the COVID-19 pandemic and the launch of remote services, members have continued to enjoy creative activities remotely. This has included the offer of ongoing online/telephone 'Creative Hobby Circles' for social and creative discussions, and a programme of short-term creative activities such as a 'Painting for Beginners and Improvers' and a 'Christmas Craft' project. Through art and craft, BVUK aim to meet a variety of member-focused goals, and anecdotal feedback from members confirms their enjoyment, and the positive impact, of these activities. Similarly, the BVUK arts teams observe the progress made in the veterans towards individual goals, and the opportunities provided to socialise with others who share similar experiences, both relating to military life and sight loss. After this anecdotal feedback, a systematic exploration of how

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Fig. 1. Blind Veterans UK members engaged in group art activities.

art as activity, that is to say art activities utilised in a non-clinical setting, might impact on different aspects of member well-being.

To frame our ongoing discussion, it is important to first define the key terms ‘veteran’, ‘well-being’ and ‘art activity’. We use ‘veteran’ to encompass anyone who has served at least one day in the armed forces, either as full-time regular personnel or a reservist.² ‘Well-being’ refers to a holistic concept of health and happiness that is impacted by both physical abilities (e.g. one’s ability to attend and perform well at work) and subjective appraisal of one’s physical, cognitive and/or affective state.^{3,4} As Vogt et al. (2018) propose in their work with US veterans, well-being is multidimensional, influenced by both life functioning and satisfaction. This holistic approach considers multiple factors as contributing to a person’s health and well-being, just as health and well-being may impact on objective life outcomes. This approach is especially important when considering the creative art engagement of veterans with a VI at BVUK, for whom functioning in some areas of life may be impacted by sight loss (e.g. independent mobility) but an active and fulfilling life is promoted through activity, training and rehabilitation. Finally, ‘art activity’ refers to person-centred activity rather than patient-centred treatment (art as therapy). Underlying this definition is the assumption that arts engagement within non-clinical populations is valuable and offers positive outcomes to the individual. There has been growing recognition of the potential role of non-clinical art activity in supporting health and well-being in general populations.^{5,6} Engagement with art and craft activities such as textile-craft making and pottery, for example, has been found to provide individuals with opportunities to experience a sense of achievement and growth, to be creative and to feel uplifted, and to develop both physical and cognitive skills.^{7–10} It should be noted that evidence relating to the impact of arts engagement is often viewed sceptically; claims of positive bias, the challenge of assessing outcomes and variation in the use of terms such as ‘art therapy’, ‘community arts’ and ‘art’ itself, raise questions within the field.¹¹ However, such scepticism might also prove beneficial, highlighting the importance of clear distinctions between therapist- and non-therapist facilitated practice, definitions of key concepts, and clear communication regarding the samples, methods and measures used. The need for a systematic and transparent approach to explorations of well-being in relation to arts activities is apparent. With this in mind, this article offers a cautious but optimistic discussion of the potential role of visual art engagement in the promotion of positive well-being outcomes for veterans who have a VI.

Methods

To conduct this narrative discussion, a contextual overview of literature relating to the mental health and well-being needs of UK veterans and veterans with a VI was first collated. Next, information and evidence relating to the visual arts for visually impaired veterans was sought via online databases, focussing on the principal themes of the arts and well-being, mental health and visually impaired veterans. Key search terms included ‘military art therapy’, ‘(UK) veteran art therapy’, ‘arts activity veterans’, ‘arts (UK) veterans well-being’ and ‘visually impaired veterans art/s’. No research addressing the role or impact of visual arts in the lives of visually impaired UK veterans was identified. However, key literature relating to the use of the visual arts with military veterans in the United States, and with veterans with a diagnosed mental health condition, was reviewed. This offered opportunities to highlight limitations of current knowledge in the field of visual arts and veteran health, and the need to include visually impaired veterans in future research.

What do we know about the mental health and well-being needs of UK veterans?

There are around 2.4 million armed forces veterans in the UK.¹² Recent wars (Iraq and Afghanistan) have seen a greater number of casualties surviving battlefield injuries, with younger injured veterans likely to live longer than in previous conflicts due to enhanced body armour and medical evacuation.¹³ Many of these individuals experience severe injuries to areas not directly protected by body armour, and sensory loss is common among those who experience blast trauma.^{14–18} In addition to physical injury, a decrease in mortality has seen a rise in the number of returning service personnel with mental health support needs, with those who experience combat found to be at greatest risk of negative mental health outcomes.^{19–21} In general, research has indicated that veterans may be more likely to experience mental health difficulties than serving military personnel, including higher rates of self-harm and posttraumatic stress syndrome (PTSD).^{22,23} Similarly, research has suggested that veterans may be at greater risk of mental health difficulties compared with the general population.²⁴ Prevalence of common mental health disorders (72%) and alcohol misuse (43%) among mental health treatment-seeking veterans is high.²⁵ The Royal British Legion (2014) found that 6% of veterans reported depression,²⁶ a rate higher than the 3.3% prevalence reported among adults in the general population,²⁷ although only 3% of veterans reported anxiety, compared with the 5.9% reported for UK adults.²⁷ Furthermore, Murphy et al.²⁸ found that alcohol misuse was no greater among UK veterans compared with members of the general public attending an NHS general hospital, and the Ministry of Defence²⁹ identified no differences between the self-reported health of veterans and non-veterans. Factors such as early service leaving, non-routine discharge, unemployment and physical health problems have, however, been associated with mental health difficulties and suicide in veterans.^{30–33}

Veterans and VI

Sensory impairment may be an additional factor impacting on the mental health of veterans. Research demonstrates associations between sensory loss (hearing, visual and dual) and the experience of mental health difficulties and emotional distress in non-veteran samples.^{34–37} Both hearing loss and sight loss have been associated

with feelings of social isolation across the adult age range.^{38–41} These findings are reflected in research with British veterans, for whom hearing loss and tinnitus have been associated with poor sleep, difficulties with communication and social functioning, and feelings of loneliness.²⁶

A small pool of literature exists in relation to sight loss in veteran populations.⁴² A qualitative study by Stevelink et al.⁴³ found that sight loss in younger veterans may lead to a loss of confidence and independence, loss of jobs, and relationship difficulties. However, it is notable that the literature surrounding sight loss in veteran samples has, thus far, been limited, despite nearly half of all ex-service personnel in the UK being over the age of 75 and as such, at increased risk of sight loss.²⁹ Sight loss in older adults has been associated with lower psychological well-being, poorer quality of life, functional impairment in daily life and higher rates of depression and anxiety.^{36,44–47}

The above research indicates that an interaction between veteran status and factors such as sensory loss and age may impact mental health and well-being. However, military veteran status and/or the incidence of sight loss does not guarantee poor mental health and well-being outcomes. Factors such as social support and specific psychological programmes have been associated with positive well-being outcomes in those who experience sight loss.^{48–50} Although, research relating to low-vision rehabilitation indicates that these services may have a limited impact on mental health and well-being, with a tendency towards addressing practical challenges rather than psychological need.^{50–52} Literature indicates that programmes which go beyond visual-related functioning and adopt a more holistic view of health and well-being, may be most beneficial to those who experience sight loss.⁵⁰ Arts interventions may, therefore, offer a useful tool with which to address the health and well-being needs of the UK veteran population.

Visual arts in the lives of military veterans

The non-therapeutic use of visual art activities with veterans has received limited attention in the UK. A US-based study by Kracker et al.⁵³ explored satisfaction with different types of activity for older US veterans at a care facility, finding that art activities were rated poorly, while activities such as watching a movie and listening to music were viewed more favourably. However, this quantitative study provided no insight into the lived experiences of veterans engaging with these activities, nor considered their potential impact on different aspects of well-being. By contrast, Hasio⁵⁴ found that arts and crafts provided veterans attending a veterans' hospital in the United States with valuable opportunities for self-expression, knowledge and skill-development and a chance to help newcomers to learn new techniques. It remains that the role of visual art activities and their impact on holistic well-being for UK veterans remains largely overlooked. This is despite increasing evidence of the impact that the arts have on the health and well-being of communities and individuals, and the growing use of art therapy for veterans with mental health trauma over the past 15 years.^{55,56} A brief overview of literature relating to art therapy and its impacts on veterans within clinical contexts is provided below to frame our ongoing discussion of visual art activity in relation to veteran well-being.

Art as therapy for veterans with a clinically diagnosed mental health condition

In 2012, the National Endowment for the Arts established a partnership with the Department of Defense to offer creative arts therapies to active-duty US service personnel, with the goal of

addressing the needs of injured service members with traumatic brain injury and PTSD. More recently, a 2019 special issue of *The Arts in Psychotherapy* offered an overview of current research being carried out in this field. The issue highlighted the psychological stigma that military groups often experience, the negative impact of this on the uptake of mental health treatments, and the role that art therapies may play in providing a non-invasive but intensive treatment programme to serving and ex-service personnel.⁵⁷ Creative arts interventions with these groups have included music therapy,^{58,59} the performing arts,^{60,61} art appreciation⁶² and the visual arts.^{63,64} The therapeutic success of interventions spanning these artistic mediums is widely recognised and there has been progress towards offering creative arts therapies via clinical video telehealth for service members and veterans in the United States.^{65–67} Indeed, most research in this field has been carried out with US veterans and/or veterans with a diagnosis of PTSD.^{68–71} Although, there has been increasing recognition of the role that the arts may play in the lives of UK veterans and their families impacted by trauma, to provide low-cost interventions which encourage community, develop understanding, and create high-quality artistic output.⁷²

A range of artistic mediums and approaches have been used in visual art therapy with veterans; as Lobban⁷³ writes, 'Different contexts call for adaptive approaches with specific frameworks to meet particular needs. It is not a case of one size fits all' (p. 15). Ramirez et al.⁵⁶ list a plethora of activities which might be used, including drawing, photography, painting, quilting, crocheting and sculpting. Mask-making has also become popular in therapy contexts because it allows the individual to distance themselves from the psychological experience under exploration, giving opportunity for expression and externalisation, which may also help others to understand a patient's challenges and struggles.^{63,74} Through a combination of movement, touch, vision, memory and imagery, the creative process helps veterans to address the non-verbal core of traumatic memories.⁷⁵ Reflecting this, multiple beneficial mechanisms have been identified in the art therapy literature relating to veteran mental health: self-awareness; the ability to safely express a range of emotions and traumatic experiences through art; improved interpersonal communication, self-regulation and cognition; an improved ability to manage stressors (by finding and applying new problem-solving approaches during art making and daily life); progression from non-verbal to verbal processing; and artistic pleasure.^{63,69} The value of group environments in facilitating shared experience and conversations in the therapeutic art process has also been highlighted.^{69,76,77}

In the UK, specialist NHS veteran mental health services have been available since 2011, although art therapy is not routinely offered.^{78,79} UK-based charity *Combat Stress* deliver art therapy as one element of a six week residential Intensive PTSD Treatment Programme, which offers veterans access to a range of clinicians, and both individual and group therapeutic sessions.⁷⁹ A theme-based art therapy approach is used to enable veterans to make gradual progress towards the expression and processing of difficult material.⁷³ During sessions, art is made, followed by a reflection and discussion relating to the images created.⁷⁷ Figures reported by the All-Party Parliamentary Group on Arts suggest that 87% of veterans who completed the *Combat Stress* art therapy programme between 2012 and 2014 saw a reduction in PTSD symptoms and comorbid anxiety and depression, anger and alcohol use, which was maintained at their six-month follow-up.⁸⁰ It should be noted that no data regarding the number of participants in the programme was reported, and furthermore, it is difficult to establish the specific impact of art therapy when provided as just one facet of support by *Combat Stress*. This is indicative of the larger challenge of evidencing the efficacy of art therapy with adult clients due to

various limitations within the literature: a large number of studies lack comparison groups; some studies offer art therapy alongside other types of treatment methods, such as verbal therapy; and a range of indices are used to measure outcomes, making comparison difficult.⁸¹

Limitations of current knowledge in the field of visual arts and veteran health

The above discussion demonstrates that a range of visual arts have been used to meet therapeutic goals in both serving military personnel and veterans. Reflecting this, art therapy has been integrated as part of a standardised treatment protocol delivered to veterans to address the symptoms of PTSD, and other comorbid and interrelated mental health conditions. However, there are several limitations of the evidence base surrounding the therapeutic application of the arts within veteran populations. First, sample sizes have typically been small, often relying on case studies of programmes. This has provided opportunities for the gathering of valuable qualitative accounts, but a paucity of data relating to measurable mental health or well-being outcomes. For those that have used quantitative measures, there has been little consistency in the measure chosen. Instruments have varied from established therapeutic instruments such as the Core Outcome Measure (CORE-OM)⁶⁴ to a focus on one aspect of psychological well-being such as anxiety,⁸² or changes in clinical symptomology of psychological conditions.⁵⁸ Second, most data addressing the use of art therapy with current and ex-service personnel relates to US samples; this raises questions regarding the role of visual arts in both the everyday lives, and therapeutic experiences, of British veterans. Finally, existing research has tended to focus primarily on the experiences of those who have clinically diagnosed mental health conditions such as PTSD. Thus, while the therapeutic application of the arts for military veterans has been considered, the role of the arts in providing leisure and social engagement, and its place in non-clinical community settings for UK veterans across the adult age-range, has largely been overlooked. Art as activity may offer benefits to the wider UK veteran population relating to holistic well-being needs, the promotion of good mental health, and the maintenance of active social and leisure lives, but this has not been explored. This is surprising given the cognitive, social, emotional and physical well-being benefits which have been associated with engagement with art activities in general populations.^{5,8,10} Finally, there has been little consideration of the role of the visual arts in the lives of veterans who have a VI, and research has yet to systematically address the various aspects of well-being which may be impacted by art activities in this population. This is despite evidence from the fields of art therapy and fine art of visual art activities offering visually impaired people valuable opportunities for self-expression, a sense of joy and accomplishment, as well as opportunities for others to ‘see’ into the world of these individuals.^{83,84} As Nelson⁸⁵ writes, responding to a visual stimulus with minimal sight can ‘inspire remarkable associations that are visual, memorable, and useful’ (p. 28), while the tactile aspects of art making may be of particular importance to those with limited functional vision.⁸⁶

Where next?

Visual arts in therapy has been used with veteran populations and is well-documented as an important therapeutic tool for many members of this group. Similarly, research suggests that the visual arts may have a therapeutic role to play in the lives of individuals who have a VI, regardless of the barrier that a VI may appear to pose to visual art engagement. However, much of the research relating to

art therapy in veteran samples has been carried out with American veterans, and research exploring the use of the visual arts as a therapeutic intervention for civilians with a VI has been limited in scope, with a primary focus on the experiences of children with a VI. As such, British veterans in general, and visually impaired veterans in particular, are underrepresented in the literature surrounding art engagement for health and well-being. It is also apparent that while the use of art therapy is common in the literature surrounding veteran health, the non-therapeutic artistic experiences of British veterans, and the impact of engaging in art as activity on holistic well-being, has yet to be systematically explored. As such, current research fails to represent the wider veteran population which, as with the general population, spans those who have received a diagnosis of a mental health condition, those who are living with an undiagnosed condition, and those whose mental health is good and their satisfaction with life high. At present, there exists no knowledge regarding the functions and goals associated with engagement with art as activity for veterans with a VI, nor any tool with which potential well-being outcomes might be measured for this group. Exploration of the role of the visual arts in the lives of visually impaired UK veterans would bring an underrepresented population into the discourse surrounding arts in veteran health and well-being, and contribute to understandings of the life experiences of both the UK veteran population, and the wider visually impaired community.

Conclusions

This article has discussed literature relating to the use of art activities with military and veteran samples in relation to health and well-being. Discussion has highlighted a distinct gap in the literature: the role of visual art activities in the lives of blind British military veterans. Anecdotal evidence from the art and craft activities currently run by BVUK, research from the broader field of arts and health, and evidence gathered with veterans in clinical contexts, suggest that these activities may offer a valuable tool for creativity, self-exploration and enjoyment for visually impaired veterans, and indeed, the wider visually impaired and UK veteran communities. The role of visual art activities in achieving positive well-being outcomes for blind British veterans may offer a rich source for future investigation.

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Competing interests

The authors have no conflicts of interest to declare.

References

1. BVUK. Art & craft. 2020. Available from: <https://www.blindveterans.org.uk/how-we-can-help/support-we-provide/art-craft/>.
2. Ministry of Defense. *Veterans: key facts*. 2017.
3. Vogt D, Taverna E, Nillni Y, Tyrell F. *Manual for the Well-Being Inventory (WBI): a multidimensional tool for assessing key components of well-being*. Boston, MA: National Center for PTSD; 2018.
4. Diener E, Suh EM, Lucas RE, Smith HL. Subjective well-being: three decades of progress. *Psychol Bull* 1999;**125**(2):276.

5. Davies C, Knuiman M, Rosenberg M. The art of being mentally healthy: a study to quantify the relationship between recreational arts engagement and mental well-being in the general population. *BMC Publ Health* 2015;16(1):15.
6. Løkken B. Are playing instruments, singing or creating theatre good for health? Associations with self-related health and all-cause mortality in the HUNT3 Study (2006–08). *Eur J Publ Health* 2017;27(3):208–9.
7. Burt EL, Atkinson J. The relationship between quilting and wellbeing. *J Publ Health* 2012;34(1):54–9.
8. Pöllänen S. Elements of crafts that enhance well-being: textile craft makers' descriptions of their leisure activity. *J Leisure Res* 2015;47(1):58–78.
9. Lamont AR, N A. Knit one, play one: comparing the effects of amateur knitting and amateur music participation on happiness and wellbeing. *Appl Res Qual Life* 2019;1–20.
10. Genoe MR, Liechty T. Meanings of participation in a leisure arts pottery programme. *World Leis J* 2017;59(2):91–104.
11. Jaatinen P-M. *Rethinking visual art practice in relation to well-being: a conceptual analysis*. Jyväskylä University Printing House: Jyväskylä University; 2015.
12. Office for National Statistics. *Annual population survey*. 2017.
13. Fossey M, Hacker Hughes J. *Traumatic limb loss and the needs of the family*. London: Blesma; 2014.
14. Bulson R, Jun W. Visual symptomatology and referral patterns for Operation Iraqi Freedom and Operation Enduring Freedom veterans with traumatic brain injury. *J Rehabil Res Dev* 2012;49(7):1075.
15. Pogoda TK, Hendricks AM, Iverson KM, Stolzmann KL, Kregel MH, Baker E, et al. Multisensory impairment reported by veterans with and without mild traumatic brain injury history. *J Rehabil Res Dev* 2012;49(7).
16. Lew HL, Pogoda TK, Baker E, Stolzmann KL, Meterko M, Cifu DX, et al. Prevalence of dual sensory impairment and its association with traumatic brain injury and blast exposure in OEF/OIF veterans. *J Head Trauma Rehabil* 2011;26(6):489–96.
17. Oleksiak M, Smith BM, Andre JRS, Caughlan CM, Steiner M. Audiological issues and hearing loss among Veterans with mild traumatic brain injury. *J Rehabil Res Dev* 2012;49(7).
18. Swan A, Nelson J, Swiger B, Jaramillo C, Eapen B, Packer M, et al. Prevalence of hearing loss and tinnitus in Iraq and Afghanistan veterans: a chronic effects of neurotrauma consortium study. *Hear Res* 2017;349:4–12.
19. Godfrey KM, Mostoufi S, Rodgers C, Backhaus A, Floto E, Pittman J, et al. Associations of military sexual trauma, combat exposure, and number of deployments with physical and mental health indicators in Iraq and Afghanistan veterans. *Psychol Serv* 2015;12(4):366.
20. Stevelink S, Jones M, Hull L, Pernet D, MacCrimmon S, Goodwin L, et al. Mental health outcomes at the end of the British involvement in the Iraq and Afghanistan conflicts: a cohort study. *Br J Psychiatry* 2018;213(6):690–7.
21. Sundin J, Herrell RK, Hoge CW, Fear NT, Adler AB, Greenberg N, et al. Mental health outcomes in US and UK military personnel returning from Iraq. *Br J Psychiatry* 2014;204(3):200–7.
22. Jones N, Sharp ML, Phillips A, Stevelink SA. Suicidal ideation, suicidal attempts, and self-harm in the UK armed forces. *Suicide Life-Threatening Behav* 2019;49(6):1762–79.
23. Williamson AK, Riendeau RP, Stolzmann K, Silverman AF, Kim B, Miller CJ, et al. An exploratory analysis of self-reported protective factors against self-harm in an enrolled veteran general mental health population. *Mil Med* 2019;184(11–12):e738–44.
24. Bergman BP, Mackay DF, Smith DJ, Pell JP. Non-fatal self-harm in Scottish military veterans: a retrospective cohort study of 57,000 veterans and 173,000 matched non-veterans. *Soc Psychiatr Psychiatr Epidemiol* 2019;54(1):81–7.
25. Murphy D, Ashwick R, Palmer E, Busuttill W. Describing the profile of a population of UK veterans seeking support for mental health difficulties. *J Ment Health* 2019;28(6):654–61.
26. Royal British Legion. *A UK household. Survey of the Ex-service Community*; 2014. 2014.
27. NatCen. *Adult Psychiatric Morbidity Survey. Survey of mental health and well-being*. England; 2014. 2016.
28. Murphy D, Palmer E, Westwood G, Busuttill W, Greenberg N. Do alcohol misuse, service utilisation, and demographic characteristics differ between UK veterans and members of the general public attending an NHS general hospital? *J Clin Med* 2016;5(11):95.
29. Ministry of Defence. *Annual population survey: UK armed forces veterans residing in great Britain*. 2017. 2019.
30. Brignone E, Fargo JD, Blais RK, Carter ME, Samore MH, Gundlapalli AV. Non-routine discharge from military service: mental illness, substance use disorders, and suicidality. *Am J Prev Med* 2017;52(5):557–65.
31. Barr N, Kintzle S, Alday E, Castro C. How does discharge status impact suicide risk in military veterans? *Soc Work Ment Health* 2019;17(1):48–58.
32. Smith NB, Mota N, Tsai J, Monteith L, Harpaz-Rotem I, Southwick SM, et al. Nature and determinants of suicidal ideation among US veterans: results from the national health and resilience in veterans study. *J Affect Disord* 2016;197:66–73.
33. Wood DS, Wood BM, Watson A, Sheffield D, Hauter H. Veteran suicide risk factors: a national sample of nonveteran and veteran men who died by suicide. *Health Soc Work* 2020;45(1):23–30.
34. Chen J, Liang J, Ou J, Cai W. Mental health in adults with sudden sensorineural hearing loss: an assessment of depressive symptoms and its correlates. *J Psychosom Res* 2013;75(1):72–4.
35. Fellingner J, Holzinger D, Pollard R. Mental health of deaf people. *Lancet* 2012;379(9820):1037–44.
36. Kempen GI, Ballemans J, Ranchor AV, van Rens GH, Zijlstra GR. The impact of low vision on activities of daily living, symptoms of depression, feelings of anxiety and social support in community-living older adults seeking vision rehabilitation services. *Qual Life Res* 2012;21(8):1405–11.
37. Nyman SR, Gosney MA, Victor CR. Emotional well-being in people with sight loss: lessons from the grey literature. *Br J Vis Impair* 2010;28(3):175–203.
38. Ciorba A, Bianchini C, Pelucchi S, Pastore A. The impact of hearing loss on the quality of life of elderly adults. *Clin Interv Aging* 2012;7:159.
39. Heffernan E, Coulson NS, Henshaw H, Barry JG, Ferguson MA. Understanding the psychosocial experiences of adults with mild-moderate hearing loss: an application of Leventhal's self-regulatory model. *Int J Audiol* 2016;55(sup3):S3–12.
40. Brunes A, Hansen MB, Heir T. Loneliness among adults with visual impairment: prevalence, associated factors, and relationship to life satisfaction. *Health Qual Life Outcome* 2019;17(1):24.
41. Grow SJL, Towers A, Yeung P, Alpess F, Stephens C. The relationship between loneliness and perceived quality of life among older persons with visual impairments. *J Vis Impair Blind (JVIB)* 2015;109(6):487–99.
42. Stevelink SA, Fear N. Psychosocial impact of visual impairment and coping strategies in female ex-Service personnel. *BMJ Milit Health* 2016;162(2):129–33.
43. Stevelink SA, Malcolm EM, Fear NT. Visual impairment, coping strategies and impact on daily life: a qualitative study among working-age UK ex-service personnel. *BMC Publ Health* 2015;15(1):1–7.
44. Han J, Lee H, Jung J, Park E-C. Effects of self-reported hearing or vision impairment on depressive symptoms: a population-based longitudinal study. *Epidemiol Psychiatr Sci* 2019;28(3):343.
45. Pinquart M, Pfeiffer JP. Psychological well-being in visually impaired and unimpaired individuals: a meta-analysis. *Br J Vis Impair* 2011;29(1):27–45.
46. van der Aa HP, Comijs HC, Penninx BW, van Rens GH, van Nispen RM. Major depressive and anxiety disorders in visually impaired older adults. *Investig Ophthalmol Vis Sci* 2015;56(2):849–54.
47. Zheng Y, Wu X, Lin X, Lin H. The prevalence of depression and depressive symptoms among eye disease patients: a systematic review and meta-analysis. *Sci Rep* 2017;7:46453.
48. Guerette AR, Smedema SM. The relationship of perceived social support with well-being in adults with visual impairments. *J Vis Impair Blind (JVIB)* 2011;105(7):425–39.
49. Nyman SR, Dibb B, Victor CR, Gosney MA. Emotional well-being and adjustment to vision loss in later life: a meta-synthesis of qualitative studies. *Disabil Rehabil* 2012;34(12):971–81.
50. Rees G, Ponczek E, Hassell J, Keeffe JE, Lamoureux EL. Psychological outcomes following interventions for people with low vision: a systematic review. *Expet Rev Ophthalmol* 2010;5(3):385–403.
51. Siira HJ, Falck AA, Kyngäs HA. Low vision rehabilitation over the course of a year: the experiences and feelings of elderly people with visual impairments. *J Nurs Educ Pract* 2019;9(8).
52. Binns AM, Bunce C, Dickinson C, Harper R, Tudor-Edwards R, Woodhouse M, et al. How effective is low vision service provision? A systematic review. *Surv Ophthalmol* 2012;57(1):34–65.
53. Kracker J, Kearns K, Kier FJ, Christensen KA. Activity preferences and satisfaction among older adults in a veterans administration long-term care facility. *Clin Gerontol* 2011;34(2):103–16.
54. Hasio C. Veterans and an arts and crafts programme: a community of understanding and hope. *Int J Educ Through Art* 2010;6(1):75–84.
55. Clift S, Camic PM. *Oxford textbook of creative arts, health, and wellbeing: international perspectives on practice, policy, and research*. USA: Oxford University Press; 2016.
56. Ramirez J, Eryana E, Guillaum M. A review of art therapy among military service members and veterans with post-traumatic stress disorder. *J Milit Veter Health* 2016;24(2):40.
57. Edwards J. Creative arts therapies provide effective support in the aftermath of trauma. *Arts Psychother* 2019;62:1.
58. Story KM, Beck BD. Guided Imagery and Music with female military veterans: an intervention development study. *Arts Psychother* 2017;55:93–102.
59. Wellman R, Pinkerton J. The development of a music therapy protocol: a Music 4 Life® Case Report of a veteran with PTSD. *Music Med* 2015;7(3):24–39.
60. Wasmuth S, Pritchard K. Theater-based community engagement project for veterans recovering from substance use disorders. *Am J Occup Ther* 2016;70(4). 7004250020p1-p.11.
61. Wilbur S, Meyer HB, Baker MR, Smiarowski K, Suarez CA, Ames D, et al. Dance for Veterans: a complementary health program for veterans with serious mental illness. *Arts Health* 2015;7(2):96–108.
62. Ketch RA, Rubin RT, Baker MR, Sonnes AC, Ames D. Art appreciation for veterans with severe mental illness in a VA Psychosocial Rehabilitation and Recovery Center. *Arts Health* 2015;7(2):172–81.
63. Jones JP, Drass JM, Kaimal G. Art therapy for military service members with post-traumatic stress and traumatic brain injury: three case reports highlighting trajectories of treatment and recovery. *Arts Psychother* 2019;63:18–30.
64. Mims R. Military veteran use of visual journaling during recovery. *J Poetry Ther* 2015;28(2):99–111.

65. Levy CE, Spooner H, Lee JB, Sonke J, Myers K, Snow E. Telehealth-based creative arts therapy: transforming mental health and rehabilitation care for rural veterans. *Arts Psychother* 2018;**57**:20–6.
66. Lightstone AJ, Bailey SK, Voros P. Collaborative music therapy via remote video technology to reduce a veteran's symptoms of severe, chronic PTSD. *Arts Health* 2015;**7**(2):123–36.
67. Spooner H, Lee JB, Langston DG, Sonke J, Myers KJ, Levy CE. Using distance technology to deliver the creative arts therapies to veterans: case studies in art, dance/movement and music therapy. *Arts Psychother* 2019;**62**:12–8.
68. Campbell M, Decker KP, Kruk K, Deaver SP. Art therapy and cognitive processing therapy for combat-related PTSD: a randomized controlled trial. *Art Therapy* 2016;**33**(4):169–77.
69. Smith A. A literature review of the therapeutic mechanisms of art therapy for veterans with post-traumatic stress disorder. *Int J Art Ther* 2016;**21**(2):66–74.
70. Lobban J, Murphy D. Understanding the role art therapy can take in treating veterans with chronic post-traumatic stress disorder. *Arts Psychother* 2019;**62**: 37–44.
71. Strouse S, Hass-Cohen N, Bokoch R. Benefits of an open art studio to military suicide survivors. *Arts Psychother* 2021;**72**:101722.
72. O'Connor A. *Transforming trauma: moral injury and arts with military veterans, families and communities*. London: Winston Churchill Memorial Trust; 2018.
73. Lobban J. Factors that influence engagement in an inpatient art therapy group for veterans with post traumatic stress disorder. *Int J Art Ther* 2016;**21**(1): 15–22.
74. Walker MS, Kaimal G, Gonzaga AM, Myers-Coffman KA, DeGraba TJ. Active-duty military service members' visual representations of PTSD and TBI in masks. *Int J Qual Stud Health Well-Being* 2017;**12**(1):1267317.
75. Lobban J. The invisible wound: veterans' art therapy. *Int J Art Ther* 2014;**19**(1): 3–18.
76. Kopytin A, Lebedev A. Humor, self-attitude, emotions, and cognitions in group art therapy with war veterans. *Art Therapy* 2013;**30**(1):20–9.
77. Lobban J. *The development and practice of art therapy with military veterans. Art therapy with military veterans: trauma and the Image*. Abingdon: Routledge; 2017. p. 9–25.
78. Lobban J. *Art therapy for military veterans with PTSD: a transatlantic study*. Winston Churchill Memorial Trust; 2016.
79. Preston R. Assessing the potential use of art therapy in the United Kingdom Ministry of defence department of community mental health. *Int J Art Ther* 2019;**24**(4):151–7.
80. All-Party Parliamentary Group on Arts HaW. *PTSD intensive treatment programme: an adaptive model of art therapy*. 2017.
81. Regev D, Cohen-Yatziv L. Effectiveness of art therapy with adult clients in 2018—what progress has been made? *Front Psychol* 2018;**9**:1531.
82. Steinberg-Oren SL, Krasnova M, Krasnov IS, Baker MR, Ames D, Dance Let's. A holistic approach to treating veterans with posttraumatic stress disorder. *Fed Pract* 2016;**33**(7):44.
83. DiGiulio D. *The use of art therapy with the blind to impact a sense of capability*. Long Island University [undergraduate thesis; 2017].
84. Szubielska M. People with sight impairment in the world of visual arts: does it make any sense? *Disabil Soc* 2018;**33**(9):1533–8.
85. Nelson S. A professional artist and curator who is blind. In: Axel ES, Levent NS, editors. *Art beyond sight: a resource guide to art, creativity, and visual impairment*. New York: American Foundation for the Blind; 2003. p. 28–31.
86. Bingley A. Touching space in hurt and healing: exploring experiences of illness and recovery through tactile art. In: Paterson M, Dodge M, editors. *Touching space, placing touch*. Oxford: Ashgate; 2012. p. 71–88.



Original Research

Childhood immunization appointment reminders and recalls: strengths, weaknesses and opportunities to increase vaccine coverage



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ABSTRACT

Objectives: Childhood immunization coverage has been shown to be greatly impacted by parental forgetfulness regarding immunizations and appointments. Evidence supports the use of reminders and recalls to overcome this barrier, which remind parents about upcoming immunization appointments and inform them once their child is overdue for an immunization. In this study, we sought to identify reminder/recall strategies used throughout a large Canadian province and determine the perceived strengths, weaknesses and areas of improvement of existing strategies.

Study design and methods: An environmental scan was performed in 2018 in two phases: (1) interviews with public health leaders from the five zones of Alberta and (2) an online survey of public health centres across the province. Data analysis occurred in 2018 and 2019.

Results: Commonly reported strengths of reminders and recalls included their ability to increase appointment attendance and remind parents about immunizations, respectively. A major identified weakness was their time-consuming/resource-intensive nature. Many participants believed reminder/recalls could be improved by modernizing delivery methods. Educational information or strategies to overcome language barriers were rarely incorporated into reminder/recall systems.

Conclusions: There was support for incorporating text messaging and automation into reminder/recall systems while encouraging continued exploration of novel reminder/recall delivery methods. Tailoring reminder/recalls to the needs and preferences of target populations can maximize the effectiveness of these systems. This includes modernizing methods of delivery, addressing language barriers, providing educational information, and allotting some degree of flexibility to local level management of reminder/recalls.

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Introduction

Parental forgetfulness can have a substantial impact on whether a child becomes fully immunized with all recommended vaccines.^{1–4} Studies demonstrate that long breaks between scheduled vaccines and competing household demands are associated with parental forgetfulness, and subsequently, incomplete childhood immunization.^{1,5,6} One strategy to overcome the barrier

of parental forgetfulness, as suggested by researchers and immunization program administrators, is via immunization appointment reminders and recalls.^{1,2,4}

Reminders notify parents about upcoming or missed appointments, while recalls inform parents once their child is overdue for an immunization.⁷ This 'reminder/recall' strategy has been shown to increase appointment attendance^{8–10} and was strongly endorsed by the US Task Force on Community Preventive Services.¹¹ In a systematic review by Szilagyi et al.,¹² reminder/recall systems were deemed effective in 12 of 15 studies that analysed their impact on childhood immunization appointments. Other reviews demonstrated that reminder/recall systems are effective

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and economical across a variety of settings, populations, and immunization types.^{8,9} Reminder/recall messages may be sent via manual or automated telephone calls, postcards, letters, or text messages.¹³ They may consist of a multicomponent intervention, performed once or numerous times.^{8,12}

The purpose of this study was to identify the diversity of reminder/recall strategies used across the Canadian province of Alberta, a large geographic area with a mixture of large urban centres and remote rural regions. We sought to understand strengths and limitations of current reminder/recall strategies, their perceived effectiveness, and potential innovations to improve reminder/recall systems.

Methods

Reminder/recall policies and practices across Alberta were explored via an environmental scan.¹⁴ Alberta is a province in Canada with a single, province-wide healthcare delivery system operated by Alberta Health Services (AHS). For administration purposes, the province (population 4.1 million) is separated into five zones: North, Edmonton, Central, Calgary, and South. Within each zone, recommended childhood immunizations are publicly funded and administered by nurses in community-based public health centres (PHCs), starting at two months of age.¹⁵ This study took place in all five zones, including urban and rural settings.

Recruitment and data collection

In phase I of the study, public health directors and/or designates of each zone were contacted via email for a telephone or in-person interview. Participants were asked about zone-wide reminder/recall policies, perceived strengths and weaknesses of current strategies, suggested improvements and any plans to update reminder/recalls.

In phase II, we contacted (through intermediaries) the managers ($n = 43$) of all 136 PHCs that provide immunization services in Alberta. Managers were asked to complete an online survey with the choice of completing surveys for each PHC they oversaw, or designating a nurse from each PHC to do so. The survey addressed current reminder/recall practices, perceived strengths and weaknesses and suggested improvements.

Study data were collected and managed using REDCap¹⁶ electronic data capture tools hosted and supported by the Women and Children's Health Research Institute at the University of Alberta.

Data analysis

We used content analysis of phase I participants' interview responses to identify major thematic categories. We conducted descriptive analysis of phase II survey responses. Data analysis occurred in 2018 and 2019.

Results

Phase I interviews

In phase I, nine public health directors and/or designates representing the AHS zones were interviewed. Content analysis of participants' narrative responses revealed the following thematic categories: use of technology, automated versus manual delivery,

standardization or centralization of reminder/recall systems and language barriers.

Use of technology

Participants reported that reminders were most commonly sent by telephone calls. These were also frequently used for recalls, with some zones supplementing with postcards or letters. Participants from three zones indicated that while text message reminder/recalls are used in a few PHCs, this was not pervasive or consistently performed, particularly for recalls. However, most zones had plans to increase use of text message reminder/recalls in the near future, as technology being introduced across the province would be capable of sending automated texts.

Participants identified the adoption of newer technologies, such as text messaging, into reminder/recalls as being advantageous. Participants from two zones reported that a major advantage of texts is their ability to contact individuals that were previously difficult to reach; for instance, families with transient lifestyles and lower socio-economic status who relied on cellphones with text-only plans because of costly telephone minutes. Participants foresaw that text messaging would facilitate contact with more parents. In one zone, text message reminders were piloted at a PHC that served a largely transient population with high 'no-show' rates. When implemented with other reminder methods, they reported that texts were well-received/preferred by parents and 'no-show' rates noticeably decreased.

Some participants stated that while there is progress with updating reminder/recall technologies, methods need to continue to be modernized. One participant suggested exploring social media platforms, while another proposed an online system that also facilitates appointment booking. A third participant supported email-based reminder/recalls, as this would allow PHCs to provide more extensive educational information.

Automated versus manual delivery

Participants described an imminent shift in the way reminder/recalls were to be performed, including plans for a province-wide automated system. They identified pros and cons associated with the proposed changes. Some believed automation would decrease staff workload and resources needed to conduct reminder/recalls, which would be especially helpful for larger PHCs. Yet, participants believed it would result in a loss of personal contact associated with manual calls. One participant explained that with existing strategies, a nurse could discuss immunization barriers with parents and provide educational information while parents are on the phone. With automated delivery, participants believed this would not occur or would be more difficult. Two participants stated that smaller PHCs have more time to carry out reminder/recalls manually and would prefer this over automated processes.

Standardization/centralization

Participants reported strengths and limitations associated with standardizing reminder/recall processes and/or adopting a centralized system. Benefits outlined by participants included consistency and adherence to best practices across the province. Further, it would ensure that reminder/recall messages are in fact being sent to all parents. Identified weaknesses included the loss of flexibility that each zone or PHC currently possesses, which allows them to conduct reminder/recalls as they see fit. Standardization or centralization would hinder the ability to

individualize messages. This would most likely occur with changing reminder/recalls to provincial level management, which participants opposed. Most argued that each PHC, and even each zone, is most familiar with the population they serve; thus, nuances of local communities could be overlooked with provincial level management.

Language barriers

All participants agreed that difficulties associated with language barriers were increasingly prevalent, although this was unaddressed in existing reminder/recall policies. Some participants reported that telephone interpretation services were available; however, it was uncertain how frequently these were utilized. Two participants noted that they lacked the capacity to book appointments or send reminder/recalls in all necessary languages. One participant suggested that an online booking system could be developed to facilitate appointment booking in the client's language, track the preferred language for reminder/recalls, and allow for translation services to be arranged for the appointment.

Phase II online survey

Online surveys were completed for 88.2% (120/136) of PHCs in Alberta that deliver immunization programs. Of these, 41.7% (50) sent appointment booking reminders (messages/calls reminding parents to book an appointment), 87.5% (105) sent pre-appointment reminders (messages/calls reminding parents of an upcoming appointment), 56.7% (68) sent missed appointment reminders (messages/calls to parents following a missed appointment/'no-show'), 89.2% (107) sent recalls (messages/calls to parents for children with delayed immunizations and no booked appointment), and 2.5% (3) reported not using any of these strategies.

Timing

Most PHCs (80.0%; 96/120) sent pre-appointment reminders 1–2 days before the appointment. While there was often not a scheduled time they were sent (46.7%; 56/120), they were rarely sent outside of PHC hours (1.7%; 2/120). Missed appointment reminders were typically sent either immediately after the appointment was missed (35.0%; 42/120) or within 1–2 days (30.0%; 36/120). Missed appointment reminders and recalls were only reported as being sent during PHC hours.

Educational information

Few PHCs reported the inclusion of educational information in reminders/recalls. Only 5.0% of PHCs reported providing this in appointment booking reminders, 13.3% in pre-appointment reminders, 1.7% in missed appointment reminders, and 12.5% in recalls. Most often, this consisted of a link to the provincial immunization website (ImmunizeAlberta.ca; Table 1).

Table 1
Types of educational information and their inclusion in reminders and recalls (N = 120).^a

Type of information	Appointment booking reminders	Missed appointment reminders	Pre-appointment reminders	Recalls
Routine immunization schedule	0.8% (1)	0.0% (0)	0.0% (0)	6.7% (8)
Information about the vaccine(s)	0.8% (1)	0.0% (0)	0.8% (1)	8.3% (10)
Information about the disease(s)	0.8% (1)	0.0% (0)	0.8% (1)	6.7% (8)
Visit Immunize Alberta website	5.0% (6)	0.8% (1)	12.5% (15)	5.0% (6)
Benefits of immunization	0.0% (0)	0.0% (0)	0.0% (0)	0.8% (1)
Total (N = 120)	5.0% (6)	1.7% (2)	13.3% (16)	12.5% (15)

^a Note that participants were able to select as many responses as applicable.

Table 2
How language barriers are addressed in reminders and recalls.^a

Method	Reminders, % (n) N = 18 ^b	Recalls, % (n) N = 28 ^b
Telephone interpretation services	83.3% (15)	82.1% (23)
Printed material in the client's language	22.2% (4)	28.6% (8)
Bilingual staff/healthcare providers	22.2% (4)	28.6% (8)

^a Note that participants were able to select as many responses as applicable.
^b 18 public health centres reported addressing language barriers in reminders, while 28 reported addressing language barriers in recalls.

Language barriers

Respondents indicated 15.9% (18/113) of PHCs had a way to overcome language barriers in their reminder system, and 26.2% (28/107) of PHCs addressed language barriers in their recall system. Language barriers were predominantly addressed using telephone interpretation services for both reminders (83.3%) and recalls (82.1%; Table 2).

Perceived strengths, weaknesses and suggested improvements

Major strengths of reminder systems included their ability to increase appointment attendance (28.3%) and the personal

Table 3
Perceived strengths, weaknesses and suggested improvements of reminder systems.^a

Perceived strengths, weaknesses and suggested improvements	Total, % (n) N = 113 ^b
Perceived strengths	
Greater appointment attendance	28.3% (32)
Personal contact	26.5% (30)
Timely contact	9.7% (11)
Automated system beneficial	7.1% (8)
Consistent approach	6.2% (7)
Other	12.4% (14)
N/A	4.4% (5)
Perceived weaknesses	
Time-consuming/resource-intensive	27.4% (31)
Need newer or more contact methods	23.0% (26)
Difficult to get a hold of clients	19.5% (22)
No consistency/not consistently done	8.8% (10)
Language barriers	8.0% (9)
Cannot confirm if automated messages or voicemails were received	7.1% (8)
Other	21.2% (24)
N/A	1.8% (2)
Suggested improvements	
Text messaging	41.6% (47)
Automated system	25.7% (29)
Email messages	15.9% (18)
Clients should have choice in how reminders are delivered	8.8% (10)
Interactive features with automated messages (confirm/cancel/re-book appointment)	7.1% (8)
Address language barriers	6.2% (7)
Other	12.4% (14)
N/A	0.9% (1)

^a Note that participants' narrative responses may have encompassed multiple categories.
^b 113 public health centres reported using some kind of reminder system.

Table 4
Perceived strengths, weaknesses and suggested improvements of recall systems.^a

Perceived strengths, weaknesses and suggested improvements	Total, % (n) N = 107 ^b
Perceived strengths	
Reminds parents about immunizations	38.3% (41)
Personal contact/can answer questions or discuss refusal	26.2% (28)
Consistent approach	9.3% (10)
Other	6.5% (7)
N/A	4.7% (5)
Perceived weaknesses	
Time-consuming/resource-intensive	17.8% (19)
Need newer or more contact methods	16.8% (18)
Difficult to get a hold of clients	16.8% (18)
Not effective at increasing immunization levels	5.6% (6)
Clients are not receptive to messages	4.7% (5)
Other	30.8% (33)
N/A	1.9% (2)
Suggested improvements	
Need newer or more contact methods	24.3% (26)
Automated system	16.8% (18)
Interactive features for automated system or text messaging	3.7% (4)
More contact points or attempts at nurse's discretion	3.7% (4)
Other	21.5% (23)
N/A	10.3% (11)

^a Note that participants' narrative responses may have encompassed multiple categories.

^b 107 public health centres reported using a recall system.

contact facilitated by manual systems (26.5%; Table 3). Identified weaknesses included the time-consuming/resource-intensive nature of manually delivered reminders (27.4%), the necessity for more technologically advanced and diverse methods for reminder delivery (23.0%) and challenges with attempting to contact clients (19.5%; Table 3). Suggested strategies to improve reminders included delivering reminders via text messages (41.6%) or emails (15.9%), and shifting from manual to automated delivery (25.7%; Table 3).

Commonly identified strengths of recalls included their ability to remind parents about immunizations (38.3%), provision of personal contact which allows staff to answer questions or discuss refusals (26.2%) and the consistency with which they are performed (9.3%; Table 4). Similar to reported reminder weaknesses, participants believed recalls were time-consuming/resource-intensive (17.8%), required updated and more diverse delivery methods (16.8%) and posed difficulties associated with contacting clients (16.8%; Table 4).

Discussion

Four thematic categories were identified in phase I interviews: use of technology, automated versus manual delivery, standardization/centralization of systems and language barriers. In phase II, we determined the number of PHCs that perform reminder/recalls and identified what participants viewed as strengths, weaknesses and areas for improvement. Our findings confirm previous research and contribute new knowledge on strategies to optimize the effectiveness of reminders and recalls.

Use of technology

Participants in both phases believed it was important to explore more technologically advanced reminder/recall strategies, including text messages, social media and email. In a survey study conducted by Clark et al.¹⁷ in Michigan, they found that many parents were willing to receive reminder/recalls via email, cellphone calls and texts. These researchers suggested that increasing delivery methods could better tailor reminder/recall systems to the target population.¹⁷

Other researchers found that expanding reminder options and allowing clients to choose how they receive reminders would likely enhance their effectiveness,¹⁸ as clients were more likely to receive and respond to messages.¹⁹

Text messaging

Of phase II participants, 41.6% believed text message delivery could improve reminder systems. A phase I participant whose zone had piloted text messages stated that many parents preferred communication via texts. Two phase I participants stated that a significant number of parents, particularly those with transient lifestyles and lower socio-economic status, rely on cellphones with text-only plans; thus, the use of texts better allowed PHCs to reach these clients. Other studies similarly found that text message reminder/recalls were beneficial for low-income minorities.^{17,20–22} For these populations, cellphones were a more reliable form of communication than landlines or mail,²⁰ as cellphone contact information was often more stable than a home address or landline phone number.^{17,22} Low-income minorities were more likely to only use cellphones and communicate via text messaging, as compared to non-minority individuals of higher socio-economic status.²⁰ Studies have also shown that parents favoured receiving texts over mail- or telephone-based communication.^{20,23} Additional benefits of text message reminder/recalls include their ability to access a large proportion of the population,²⁴ facilitate communication more promptly and conveniently^{25,26} and provide parents with a record of information (e.g. clinic's hours, address and phone number) which could later be referred to.²²

Social media and smartphone apps

Some phase I participants suggested that reminder/recall methods needed updating to reflect current communication trends. One participant suggested exploring social media platforms, such as Facebook or Twitter. Abahussin and Albarrak²⁷ found that despite the considerable usage of social media and smartphones, few reminder strategies harnessed these technologies for immunization appointment reminders. They believed smartphone apps dedicated to immunizations could facilitate reminder delivery (e.g. via push notifications or calendar alerts), allow immunization tracking and provide educational information.²⁷ Such apps would require fewer resources when compared to traditional reminder/recall strategies, would not require up-to-date client contact information and could have multilingual capabilities.^{27,28}

Email

One phase I participant recommended delivering reminders/recalls via email, as staff could then include more educational information. Email reminders were supported by 15.9% of phase II participants. Researchers found that email reminders/recalls are convenient, reduce costs, facilitate prompt communication and provide written information to clients.²⁹ However, another study demonstrated that email reminders were frequently undelivered, which researchers attributed to errors when transcribing email addresses.³⁰ Additional issues raised by researchers include potential violations in privacy and confidentiality, and possible increases in workload if appointment rescheduling requires lengthy email exchanges.²⁹

Automated versus manual delivery

Phase I participants reported plans to implement automated reminder/recall systems throughout all zones. Phase I participants regarded this change positively, believing this would enhance the efficiency of reminder/recall systems, allowing staffing resources to be concentrated elsewhere, and would promote consistent

reminder/recall delivery. This was also supported by phase II respondents, where a frequently reported weakness of reminders (27.4%) and recalls (17.8%) was the time-consuming, resource-intensive nature of manual systems. Many participants suggested automated reminders (25.7%) and recalls (16.8%) would improve current systems. Pereira et al.¹³ supported use of automated reminder/recall systems, citing benefits such as decreased costs, reductions in staff workload and more consistent reminder/recall usage. Further, Perri-Moore et al.³¹ found that automated reminders can be individualized and are effective at promoting appointment attendance regardless of gender, age group or socio-economic status of the target population.

The limited research performed on the timing of immunization reminders suggests that parents do not have a stated preference for time of day they are received.²⁰ However, it seems likely that sending messages to parents in the evenings, when they are most likely to be available, might be preferable. Having an automated system in place would allow for timing of messages to be scheduled based on the time of day they are most likely to be received.

Drawbacks to automated systems were also reported. Phase I participants believed automated reminder/recalls would eliminate the personal contact facilitated by manual calls. This was echoed by 2.8% of phase II participants regarding recalls. It was also noted that some clients have reported difficulty understanding automated reminders (1.8%) and that clients have received multiple automated calls regarding the same appointment (1.8%). These potential disadvantages should be considered, as automated systems become widespread.

Standardization/centralization

Phase I participants recognized that standardization/centralization of reminder/recalls was associated with strengths and limitations. Of those interviewed, only one zone had a centralized system that delivered automated reminders to the entire zone, via a central information technology centre.

Participants identified two major benefits associated with standardization/centralization: (1) consistency and adoption of best practices throughout the zone or province and (2) certainty that reminder/recalls were sent to all parents. When a standardized reminder/recall system was implemented in England across 32 primary care practices, an increase in immunization uptake was observed, and participants believed standardized systems were superior to previous systems.³² In a Colorado study that analysed the impact of a centralized reminder/recall system, researchers found most parents were open to receiving reminder/recalls from a central department rather than a local provider, and centrally delivered automated messages ensured more consistent delivery.³³

Identified limitations of standardization/centralization included the possible loss of flexibility that each zone or PHC would have with sending reminder/recalls; therefore, messages may no longer be individualized to the target population. Another major concern with standardization involved discrepancies in resources between sites, as rural PHCs often had fewer resources than urban sites. Maintaining flexibility with reminder/recall processes was supported by McLean et al.,³⁴ who asserted that reminders must be tailored to the needs of the client if they are to be effective. They argued that, particularly for at-risk individuals who are less likely to attend appointments, it is important that there is personal contact in order for staff to provide information and address any immunization barriers.³⁴

Language barriers

Language barriers were not typically addressed by existing reminder/recall systems, as only 15.9% of phase II participants reported addressing this in reminders and 26.2% for recalls. There is little research on the consideration of language barriers in reminder/recalls; however, researchers have found that after adjusting for socio-economic factors, contact with the healthcare system, and culture, those who spoke a language other than English at home were less likely to access preventive healthcare services, suggesting that lack of access to these services stemmed from communication barriers.³⁵ Researchers recommended improving communication with these groups to enhance their receptiveness to preventive services.³⁵ With increasing use of technology (e.g. texts, automated calls and online modalities), there is potential for adapting reminder/recalls into numerous languages.

Conclusion

As reminder/recall strategies continue to evolve, we believe it is important that immunization programs: (1) provide more than basic appointment information in reminders (e.g. educational information) and continue to allow opportunities for discussions with parents during the recall process; (2) adopt automated delivery for reminders, but continue sending recalls manually so that staff can have direct discussions with parents and assess barriers to immunization; (3) continue to explore how modern technologies (e.g. text messaging, email, social media, smartphone apps); can be integrated into reminder/recall systems and allow parents to choose their preferred method of communication; (4) provide as much flexibility as possible to local levels for reminder/recall system management, as this would best ensure that messages are tailored to the target population; and (5) consider how language barriers can be addressed, especially as newer delivery methods are developed.

In addition to immunization reminders, it is important to explore other strategies for increasing demand for vaccines and attendance at appointments. Interventions to address vaccine hesitancy and enhance the immunization experience, including pain management, are areas for ongoing improvement. The ongoing COVID-19 pandemic may also influence public acceptance of childhood vaccinations, and only time will tell whether it will enhance or decrease demand for vaccines. As COVID-19 vaccination programs unfold, with many vaccines requiring two doses, the use of immunization reminders will likely become increasingly important.

Author statements

Ethical approval

Ethics (University of Alberta Health Research Ethics Board PRO #00080817) and AHS zone-specific operational approvals were obtained for the study and informed consent was obtained from all participants.

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Competing interests

None declared.

CRediT authorship contribution statement

K.M. Jong: Formal analysis, Investigation, Data curation, Writing – original draft. **C.A. Sikora:** Conceptualization, Writing – review & editing. **S.E. MacDonald:** Conceptualization, Methodology, Resources, Writing – review & editing, Supervision, Project administration.

References

- Bell CA, Simmonds KA, MacDonald SE. Exploring the heterogeneity among partially vaccinated children in a population-based cohort. *Vaccine* 2015;**33**: 4572–8. <https://doi.org/10.1016/j.vaccine.2015.07.004>.
- Lemstra M, Rajakumar D, Thompson A, Moraros J. The effectiveness of telephone reminders and home visits to improve measles, mumps and rubella immunization coverage rates in children. *Paediatr Child Health* 2011;**16**:e1–5. <https://academic.oup.com/pch/article/16/1/e1/2639451>.
- Temoka E. *Becoming a vaccine champion: evidence-based interventions to address the challenges of vaccination*. South Dakota Medicine; 2013. p. 68–72. Special Edition. http://www.sdsma.org/docs/pdfs-new_site/journal/2013/.
- Thomas M, Kohli V, King D. Barriers to childhood immunization: findings from a needs assessment study. *Home Health Care Serv Q* 2004;**23**:19–39. https://doi.org/10.1300/J027v23n02_02.
- Hagan D, Phetlu DR. Determinants of parents' decisions on childhood immunisations at Kumasi Metropolis in Ghana. *Curationis* 2016;**39**:1–7. <https://doi.org/10.4102/curationis.v39i1.1554>.
- Hermann JS, Simmonds KA, Bell CA, Rafferty E, MacDonald SE. Vaccine coverage of children in care of the child welfare system. *Can J Public Health* 2018;**7**:1–8. <https://doi.org/10.17269/s41997-018-0135-5>.
- Centers for Disease Control and Prevention (CDC). Recommendations of the Advisory Committee on immunization practices, the American Academy of Pediatrics, and the American Academy of family physicians: use of reminder and recall by vaccination providers to increase vaccination rates. *MMWR Morb Mortal Wkly Rep* 1998;**47**:715. <https://www.cdc.gov/mmwr/preview/mmwrhtml/00054628.htm>.
- Briss PA, Rodewald LE, Hinman AR, et al. Reviews of evidence regarding interventions to improve vaccination coverage in children, adolescents, and adults. *Am J Prev Med* 2000;**18**:97–140. [https://doi.org/10.1016/S0749-3797\(99\)00118-X](https://doi.org/10.1016/S0749-3797(99)00118-X).
- Jacobson Vann JC, Szilagyi P. Patient reminder and recall systems to improve immunization rates. *Cochrane Libr* 2005;**3**:1–71. <https://doi.org/10.1002/14651858.CD003941.pub2>.
- Williams N, Woodward H, Majeed A, Saxena S. Primary care strategies to improve childhood immunisation uptake in developed countries: systematic review. *JRSM Short Rep* 2011;**2**:1–21. <https://doi.org/10.1258/shorts.2011.011112>.
- Task Force on Community Preventive Services. Vaccine-preventable diseases: improving vaccination coverage in children, adolescents, and adults. *MMWR Morb Mortal Wkly Rep* 1999;**48**:1–15. <https://www.cdc.gov/mmwr/preview/mmwrhtml/rr4808a1.htm>.
- Szilagyi PG, Bordley C, Vann JC, et al. Effect of patient reminder/recall interventions on immunization rates: a review. *JAMA* 2000;**284**:1820–7. <https://doi.org/10.1001/jama.284.14.1820>.
- Pereira JA, Quach S, Heidebrecht CL, et al. Barriers to the use of reminder/recall interventions for immunizations: a systematic review. *BMC Med Inf Decis Making* 2012;**12**:145–54. <https://doi.org/10.1186/1472-6947-12-145>.
- Graham P, Evitts T, Thomas-MacLean R. Environmental scans: how useful are they for primary care research? *Can Fam Physician* 2008;**54**:1022–3. <http://www.cfp.ca/content/cfp/54/7/1022.full.pdf>.
- Alberta Health. *Alberta immunization strategy 2007–2017*. Alberta Health Website; 2007. <https://open.alberta.ca/dataset/e771c4d4-c677-45a2-9bff-7424f71d0a35/resource/e761dd24-275a-44ec-a51d-75b8190305c8/download/immunization-strategy-07.pdf>.
- Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap) – a metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inf* 2009;**42**:377–81. <https://doi.org/10.1016/j.jbi.2008.08.010>.
- Clark SJ, Butchart A, Kennedy A, Dombkowski KJ. Parents' experiences with and preferences for immunization reminder/recall technologies. *Pediatrics* 2011;**128**:e1100–5. <https://doi.org/10.1542/peds.2011-0270>.
- Morris J, Wang W, Wang L, Peddecord KM, Sawyer MH. Comparison of reminder methods in selected adolescents with records in an immunization registry. *J Adolesc Health* 2015;**56**:S27–32. <https://doi.org/10.1016/j.jadohealth.2015.01.010>.
- Kempe A, O'Leary ST, Shoup JA, et al. Parental choice of recall method for HPV vaccination: a pragmatic trial. *Pediatrics* 2016;**137**:e20152857. <https://doi.org/10.1542/peds.2015-2857>.
- Hofstetter AM, Vargas CY, Kennedy A, Kitayama K, Stockwell MS. Parental and provider preferences and concerns regarding text message reminder/recall for early childhood vaccinations. *Prev Med* 2013;**57**:75–80. <https://doi.org/10.1016/j.ypmed.2013.04.007>.
- Ahlers-Schmidt CR, Chesser A, Hart T, Paschal A, Nguyen T, Wittler RR. Text messaging immunization reminders: feasibility of implementation with low-income parents. *Prev Med* 2010;**50**:306–7. <https://doi.org/10.1016/j.ypmed.2010.02.008>.
- Anderson MF. Evidence-based public health is the answer to increasing American childhood vaccination rates, not legislative fortitude. *Saint Louis Univ J Health Law Pol* 2016;**10**:293–321. <https://heinonline.org/HOL/LandingPage?handle=hein.journals/sljhlp10&div=21&id=&page=>.
- Kharbanda EO, Stockwell MS, Fox HW, Rickert VI. Text4Health: a qualitative evaluation of parental readiness for text message immunization reminders. *Am J Public Health* 2009;**99**:2176–8. <https://doi.org/10.2105/ajph.2009.161364>.
- Niederhauer V, Johnson M, Tavakoli AS. Vaccines4Kids: assessing the impact of text message reminders on immunization rates in infants. *Vaccine* 2015;**33**: 2984–9. <https://doi.org/10.1016/j.vaccine.2015.04.069>.
- Ahlers-Schmidt CR, Chesser AK, Paschal AM, et al. Parent opinions about use of text messaging for immunization reminders. *J Med Internet Res* 2012;**14**:1–9. <https://doi.org/10.2196/jmir.1976>.
- Rand CM, Vincelli P, Goldstein NP, Blumkin A, Szilagyi PG. Effects of phone and text message reminders on completion of the human papillomavirus vaccine series. *J Adolesc Health* 2017;**60**:113–9. <https://doi.org/10.1016/j.jadohealth.2016.09.011>.
- Abahussin AA, Albarrak AI. Vaccination adherence: review and proposed model. *J Infect Publ Health* 2016;**9**:781–9. <https://doi.org/10.1016/j.jiph.2016.09.006>.
- Peck JL, Stanton M, Reynolds GE. Smartphone preventive health care: parental use of an immunization reminder system. *J Pediatr Health Care* 2014;**28**:35–42. <https://doi.org/10.1016/j.pedhc.2012.09.005>.
- Atherton H, Sawmynaden P, Meyer B, Car J. Email for the coordination of healthcare appointments and attendance reminders. *Cochrane Database Syst Rev* 2012;**8**:1–23. <https://doi.org/10.1002/14651858.CD007981.pub2>.
- Dombkowski KJ, Cowan AE, Costello LE, Fisher AM, Clark SJ. Feasibility of automated appointment reminders using email. *Clin Pediatr* 2014;**53**:1004–7. <https://doi.org/10.1177/0009922814527505>.
- Perri-Moore S, Kapsandoy S, Doyon K, et al. Automated alerts and reminders targeting patients: a review of the literature. *Patient Educ Counsel* 2016;**99**: 953–9. <https://doi.org/10.1016/j.pec.2015.12.010>.
- Atchison C, Zvoc M, Balakrishnan R. The evaluation of a standardized call/recall system for childhood immunizations in Wandsworth, England. *J Community Health* 2013;**38**:581–7. <https://doi.org/10.1007/s10900-013-9654-4>.
- Saville AW, Beaty B, Dickinson LM, Lockhart S, Kempe A. Novel immunization reminder/recall approaches: rural and urban differences in parent perceptions. *Acad Pediatr* 2014;**14**:249–55. <https://doi.org/10.1016/j.acap.2014.02.003>.
- McLean SM, Booth A, Gee M, et al. Appointment reminder systems are effective but not optimal: results of a systematic review and evidence synthesis employing realist principles. *Patient Prefer Adherence* 2016;**10**. <https://doi.org/10.2147/PPA.S93046>. 479–479.
- Woloshin S, Schwartz LM, Katz SJ, Welch HG. Is language a barrier to the use of preventive services? *Journal of General Internal Medicine* 1997;**12**(8):472–7. <https://doi.org/10.1046/j.1525-1497.1997.00085.x>.



Original Research

Determinants of health-related quality of life among homeless individuals during the COVID-19 pandemic



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ABSTRACT

Objective: To clarify which variables are associated with the health-related quality of life (HRQoL) among homeless individuals during the COVID-19 pandemic.

Study design: Cross-sectional research.

Methods: Data were taken from the Hamburg survey of homeless individuals (n = 151). HRQoL was assessed using the EQ-5D tool. More precisely, the EQ-5D-5L questionnaire was used to quantify problems in five health dimensions (i.e. mobility, self-care, usual activities, pain/discomfort, anxiety/depression), and its visual analog scale (EQ-VAS) was used to record the according self-rated health status. Explanatory variables include sex, age, education, marital status, country of origin, health insurance, and chronic alcohol consumption.

Results: With regard to HRQoL, most frequently, problems were reported as pain/discomfort (47.3%), followed by anxiety/depression (32.4%), mobility (29.7%), usual activities (20.7%) and self-care (4.6%). The mean EQ-VAS score was 75.34 (SD 22.23; range 1–100), and the mean EQ-5D-5L index was 0.84 (SD 0.23; range 0.32–1). Regressions showed increasing problems in mobility and self-care with higher age, whereas EQ-VAS was positively associated with younger age. Furthermore, EQ-5D-5L index was positively associated with younger age and higher education. Summarized, among this cohort, a higher age is associated with a lower HRQoL.

Conclusion: Remarkably high EQ-VAS values and rather few problems in the five dimensions investigated here were reported among the homeless individuals during the COVID-19 pandemic particularly compared with the general population. Moreover, study findings particularly stress the link between higher age and lower HRQoL among homeless individuals. This knowledge is important to address homeless individuals at risk of poor HRQoL. Longitudinal studies are required to confirm the given findings.

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Introduction

In recent years, homelessness has increased substantially in most countries. In 2018, there were around 678,000 homeless individuals in Germany,¹ about 6600 of them in Hamburg (home city of the working group and city with the second largest general population in Germany).² The increase in homeless people

demonstrates the relevance of understanding and monitoring this population, as they are known to show higher rates of premature mortality than the general population, particularly driven by suicide, unintentional injuries and proneness to violence, and an increased prevalence of a range of infectious diseases, mental disorders, and substance misuse.^{3,4} Moreover, mortality is substantially increased in these homeless people; the standardized mortality ratios are typically 2–5 times higher than in the age-standardized general population.^{3,5,6}

Therefore, it is important to understand this traditionally 'unseen', but growing population to reduce morbidity and mortality among homeless individuals and to come up with suitable offers for

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improvement of their quality of life and possible reintegration in society.

Particular consideration should be given to homeless populations during the recent spread of the novel SARS-CoV-2 virus, which affects health and social systems globally.⁷ Homeless populations are questioned as possible ‘super spreaders’—they are more transient and geographically mobile than individuals in the general population and often lack safe housing and access to sanitary care with potentially less access to news and information reducing the awareness to socio-economic regulations, making tracking and prevention of transmission difficult to impossible.^{8,9} Moreover, homeless people might be at higher risks of severe courses of COVID-19 (as they show higher mortality ratios and prevalence of chronic and infectious diseases) and also lack places to isolate and recover from the illness. However, little is known about infection rates among homeless people in Germany. Lindner et al. examined one homeless shelter in Berlin.¹⁰ Out of 51 tested persons, no one was tested positive. A study from Aarhus, Denmark, tested 295 homeless individuals with no one being tested positive and only 11 persons carrying antibodies.¹¹ On the contrary, studies from other highly developed countries registered high prevalence of COVID-19 among homeless: 12% tested positive in Rhode island,¹² and 10.5% in King County, Washington.¹³ Due to these varying data, it is difficult to estimate the rate of infection among homeless individuals in the Hamburg region.

To assign the findings of this study to the respective cutbacks in the daily life, one must consider the current regulations in Germany at the time of data collection. First nationwide measures were taken in March 2020, e.g. at a time interval with shutdown of schools. Only 1 week later, travel and contact regulations were intensified. In the following weeks, these measures were even prolonged. First eases became active by the end of April 2020 under the condition to wear facial masks at public places where distance of 1.5 m to one another could not be kept safely.¹⁴

Until today, many studies have analyzed the health-related quality of life (HRQoL) among different populations. However, to the best of the author’s knowledge, little is known about the factors associated with the HRQoL among homeless individuals in general and particularly in times of the COVID-19 pandemic, even though it has been shown in several studies that HRQoL is inversely associated with mortality. This has been shown in middle-aged and older adults.^{15–17} Therefore, the aim of this study is to identify factors associated with HRQoL among homeless people in times of the COVID-19 pandemic exemplified on a representative sample from Hamburg, Germany. This knowledge is important to address homeless individuals at risk of poor HRQoL, as single factors known to be associated with a lower HRQoL can be targeted more effectively.

Methods

Sample collection

Cross-sectional data were taken from the Hamburg survey of homeless individuals. In this study, two interviewer visited homeless persons in specialized medical practices or lodging houses, shelters for the night and asked potential participants. Out of 154 persons who were asked, three refused to participate (response rate 98.1%). Consequently, $n = 151$ individuals were included in the Hamburg survey of homeless individuals. In this given study, a total analytical sample of $n = 111$ individuals were included due to missing values in the rest.

The survey was performed with homeless individuals in a separate room within the institution/shelter/practice between May 25th and June 03rd 2020. We started by questioning about basic

demographic information followed by a physical examination, a blood withdrawal, a nasopharyngeal swap, and a questionnaire-based interview. If the participants were able to read and understand the questions on their own, they were asked to fill out the questionnaire. However, most participants had difficulties with at least one of the requirements. Therefore, most questionnaires were filled out via face-to-face interviews.

Written informed consent was provided by all participants prior to the investigations. We received a positive ethics vote from the ethics committee of Hamburg Medical Association (application number: PV7333).

Dependent variables

In our study, the EQ-5D-5L measurement was used to assess HRQoL.¹⁸ It is a widely used, well-validated tool for assessing generic HRQoL consisting of five items (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression) with five different levels (no problems, slight problems, moderate problems, severe problems, extreme problems).¹⁹ An individual health status for each individual can be garnered by drawing the vector across each declared level of the five dimensions. For example, the state ‘11122’ indicates no problems in mobility, self-care, and usual activities but slight problems in pain/discomfort and anxiety/depression. Based on value sets derived from country-specific societal preferences one index (EQ-5D index) for each of the $5^5 = 3125$ EQ-5D health states can be calculated. Such a value set has been developed for Germany ranging from -0.661 (extreme problems in all five dimensions) to 1 (no problems in any dimension).²⁰ Also, allowing negative values, the German value set is possible to describe HRQoL conditions worse than death. To analyze the factors associated with HRQoL, the answers of the participants were dichotomized for regression analysis ($0 =$ no problem; $1 =$ problems including slight problems, moderate problems, severe problems, and extreme problems) in this study.

The questionnaire also contains a visual analog scale (EQ-VAS), which quantifies self-evaluated health based on the participants’ preferences and ranges from $0 =$ worst imaginable health to $100 =$ best imaginable health (EQ-VAS score).

Independent variables

The following sociodemographic variables were considered: age (years), sex (female; male), marital status (single; divorced; married; widowed), country of origin (grouped into Germany, neighboring European country, and other), and education (grouped into ‘primary’, ‘secondary’, and ‘tertiary’ according to the Comparative Analysis of Social Mobility in Industrial Nations [CASMIN] classification). The division of the country of origin is based on the fact that immigrants from neighboring countries would only have to cross one border to reach Germany and the assumption that people from directly neighboring countries might share more alike cultures. However, another possible variable is dichotomizing the country of origin into: Germany, other.

Furthermore, health-insurance coverage (grouped into existent/non-existent) and chronic alcohol consumption (carbohydrate-deficient transferrin [CDT] blood value $< 2.5\%$ defined as normal, $CDT > 2.5\%$ defined as elevated)²¹ were included.

Statistical analysis

First, basic characteristics of the analyzed sample were described. Thereafter, the factors probably associated with problems in EQ-5D dimensions were analyzed using multiple logistic regressions (no problems vs problems). Subsequently, multiple

Table 1
Sample characteristics stratified by problems.

Mean (SD)/n (%)	Mobility		Self-care		Activities		Pain		Anxiety	
	No problems (n = 78)	Problems (n = 33)	No problems (n = 102)	Problems (n = 5)	No problems (n = 88)	Problems (n = 23)	No problems (n = 58)	Problems (n = 53)	No problems (n = 75)	Problems (n = 36)
Sociodemographic data										
Sex:										
- Male	66 (74.2%)	23 (25.8%)	81 (95.3%)	4 (4.7%)	72 (80.9%)	17 (19.1%)	47 (52.8%)	42 (47.2%)	65 (73.0%)	24 (27.0%)
- Female	12 (54.5%)	10 (45.5%)	21 (95.5%)	1 (4.5%)	16 (72.7%)	6 (27.3%)	11 (50.0%)	11 (50.0%)	10 (45.5%)	12 (54.5%)
Age	43.0 (12.5)	47.4 (12.3)	43.3 (12.0)	55.6 (13.3)	44.0 (12.4)	45.5 (13.4)	43.3 (11.4)	45.4 (13.8)	44.7 (12.0)	43.5 (13.8)
Education ^a :										
- Primary	22 (62.9%)	13 (37.1%)	30 (90.9%)	3 (9.1%)	27 (77.1%)	8 (22.9%)	17 (48.6%)	18 (51.4%)	21 (60.0%)	14 (14%)
- Secondary	52 (74.3%)	18 (25.7%)	67 (97.1%)	2 (2.9%)	56 (80.0%)	14 (20.0%)	36 (51.4%)	34 (48.6%)	50 (71.4%)	20 (28.6%)
- Tertiary	4 (66.7%)	2 (33.3%)	5 (100.0%)	0 (0.0%)	5 (83.3%)	1 (16.7%)	5 (83.3%)	1 (16.7%)	4 (66.7%)	2 (33.3%)
Marital status										
- Married, living together with spouse	0 (0%)	0 (0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0%)	0 (0%)
- Married, living separately from spouse	5 (55.6%)	4 (44.4%)	7 (87.5%)	1 (12.5%)	8 (88.9%)	1 (11.1%)	6 (66.7%)	3 (33.3%)	7 (77.8%)	2 (22.2%)
- Single	53 (68.8%)	24 (31.2%)	75 (97.4%)	2 (2.6%)	57 (74.0%)	20 (26.0%)	37 (48.1%)	40 (51.9%)	50 (64.9%)	27 (35.1%)
- Widowed	5 (83.3%)	1 (16.8%)	5 (100.0%)	0 (0.0%)	6 (100.0%)	0 (0.0%)	4 (66.7%)	2 (33.3%)	5 (83.3%)	1 (16.7%)
- Divorced	15 (78.9%)	4 (21.1%)	15 (88.2%)	2 (11.8%)	17 (89.5%)	2 (10.5%)	11 (57.9%)	8 (42.1%)	13 (68.4%)	6 (31.6%)
Country of origin:										
- Germany	35 (62.5%)	21 (37.5%)	53 (96.4%)	2 (3.6%)	40 (71.4%)	16 (28.6%)	26 (46.4%)	30 (53.6%)	33 (58.9%)	23 (41.4%)
- Neighboring Country	22 (73.3%)	8 (26.7%)	27 (93.1%)	2 (6.9%)	27 (90.0%)	3 (10.0%)	20 (66.7%)	10 (33.3%)	27 (90.0%)	3 (10.0%)
- Other	21 (84.0%)	4 (16.0%)	22 (95.7%)	1 (4.3%)	21 (84.0%)	4 (16.0%)	12 (48.0%)	13 (52.0%)	15 (60.0%)	10 (40.0%)
Lifestyle factors										
Health insurance:										
- Yes	51 (67.1%)	25 (32.9%)	70 (95.9%)	3 (4.1%)	56 (73.7%)	20 (26.3%)	38 (50.0%)	38 (50.0%)	45 (59.2%)	31 (40.0%)
- No	27 (77.1%)	8 (22.9%)	32 (94.1%)	2 (5.9%)	32 (91.4%)	3 (8.6%)	20 (57.1%)	15 (42.9%)	30 (85.7%)	5 (14.3%)
Chronic alcohol consumption:										
- Yes	48 (70.6%)	20 (29.4%)	39 (95.1%)	2 (4.9%)	35 (81.4%)	8 (18.6%)	24 (55.8%)	19 (44.2%)	40 (58.8%)	28 (41.2%)
- No	30 (69.8%)	13 (30.2%)	63 (95.5%)	3 (4.5%)	56 (73.7%)	15 (22.1%)	34 (50.0%)	34 (50.0%)	35 (81.4%)	8 (16.6%)
Quality of life										
Mobility										
- No problems	–	–	74 (98.7%)	1 (1.3%)	66 (84.6%)	12 (15.4%)	50 (64.1%)	28 (35.9%)	45 (59.2%)	31 (40.8%)
- Problems	–	–	28 (87.5%)	4 (12.5%)	22 (66.7%)	11 (33.3%)	8 (24.2%)	25 (75.8%)	30 (85.7%)	12 (36.4%)
Self-care										
- No problems	74 (72.5%)	28 (27.5%)	–	–	82 (80.4%)	20 (19.6%)	55 (53.9%)	47 (46.1%)	70 (68.6%)	32 (31.4%)
- Problems	1 (20.0%)	4 (80.0%)	–	–	3 (60.0%)	2 (40.0%)	1 (20.0%)	4 (80.0%)	2 (40.0%)	3 (60.0%)
Usual activities										
- No problems	66 (75.0%)	22 (25.0%)	82 (96.5%)	3 (3.5%)	–	–	52 (59.1%)	36 (40.9%)	66 (75.0%)	22 (25.0%)
- Problems	12 (52.8%)	11 (47.8%)	20 (90.9%)	2 (9.1%)	–	–	6 (26.1%)	17 (73.9%)	9 (39.1%)	14 (60.9%)
Pain/discomfort										
- No problems	50 (86.2%)	8 (13.8%)	55 (98.2%)	1 (1.8%)	52 (89.7%)	6 (10.3%)	–	–	49 (84.5%)	9 (15.5%)
- Problems	28 (52.8%)	25 (47.2%)	47 (92.2%)	4 (7.8%)	36 (67.9%)	17 (32.1%)	–	–	26 (49%)	27 (50.9%)
Anxiety/depression										
- No problems	54 (72.0%)	21 (28.%)	70 (97.2%)	2 (2.8%)	66 (88.0%)	9 (12.0%)	49 (65.3%)	26 (34.7%)	–	–
- Problems	24 (66.7%)	12 (33.3%)	32 (91.4%)	3 (8.6%)	22 (61.1%)	14 (38.9%)	9 (25.0%)	27 (75.0%)	–	–

^a Education according to Comparative Analysis of Social Mobility in Industrial Nations classification.

Table 2
Determinants of problems in EQ-5D dimensions. Findings of multiple logistic regressions.

	Problems in dimension mobility	Problems in dimension self-care	Problems in dimension usual activities	Problems in dimension pain/discomfort	Problems in anxiety/depression
Sociodemographic data					
Age	1.04 (1.00–1.08)*	1.14 (1.01–1.30)*	1.03 (0.99–1.08)	1.03 (0.99–1.06)	1.01 (0.97–1.04)
Gender: male (ref: female)	2.79 (0.90–8.59)	0.84 (0.06–11.53)	1.54 (0.44–5.41)	1.19 (0.42–3.40)	2.60 (0.88–7.72)
Marital status: single (ref: other ^a)	1.98 (0.69–5.69)	0.44 (0.05–4.02)	5.71 (1.32–24.69)*	2.16 (0.84–5.56)	1.80 (0.59–5.47)
Country of origin:					
- Neighboring country (ref: Germany)	0.67 (0.18–2.55)	2.88 (0.16–53.39)	0.48 (0.09–2.39)	0.43 (0.12–1.45)	0.43 (0.09–1.97)
- Other	0.42 (0.11–1.65)	2.44 (0.13–46.07)	0.94 (0.23–3.88)	1.17 (0.39–3.52)	2.07 (0.63–6.86)
Education ^b :					
- Secondary (ref: primary)	0.49 (0.18–1.28)	0.14 (0.01–1.55)	0.94 (0.32–2.78)	0.80 (0.34–1.88)	0.63 (0.24–1.62)
- Tertiary	0.71 (0.09–5.62)	1 empty	0.40 (0.03–4.91)	0.12 (0.01–1.24)	0.36 (0.04–3.18)
Lifestyle factors					
Health insurance: yes (ref: no)	1.05 (0.32–3.38)	2.11 (0.20–21.86)	0.27 (0.06–1.26)	0.84 (0.31–2.29)	0.27 (0.07–0.99)*
Chronic alcohol consumption: yes (ref: no)	1.44 (0.49–4.29)	0.76 (0.05–11.86)	1.33 (0.41–4.31)	1.25 (0.47–3.31)	0.61 (0.21–1.78)
Constant	0.02 (0.01–0.40)**	0.0002 (0.00–0.52)*	0.01 (0.0005–0.41)*	0.20 (0.02–2.38)	0.16 (0.01–2.7)
Pseudo R ²	0.09	0.26	0.12	0.07	0.15
Observations	111	103	113	113	112

Odds ratios are reported; 95% CI in parentheses; ***P < 0.001, **P < 0.01, *P < 0.05.

^a Marital status: other (married, living separately from spouse; widowed; divorced).

^b Education according to Comparative Analysis of Social Mobility in Industrial Nations classification.

linear regressions were used to investigate the determinants of EQ VAS and EQ-5D index. The significance level was set at $P < 0.05$ in all statistical tests. Stata 16.0 (Stata Corp., College Station, Texas) was used to perform statistical analyses.

Results

In the total analytical sample ($n = 111$), average age was 44.3 years (SD 12.6 years, ranging from 19 to 86 years), and 20% of the individuals were female. While 50.4% of the individuals were born in Germany, 27% of the individuals were born in direct neighboring countries. In sum, 63% of the individuals had secondary education. Moreover, 69.3% of the individuals were single, whereas none was married and still living together. In total, 68.5% of the individuals reported to have health insurance. The CDT value, which is indicative of chronic alcohol consumption, was elevated above the threshold defined in 38.7% of the individuals.

Average EQ-VAS score was 75.34 (SD 22.23, ranging from 1 to 100), and the mean EQ-5D index was 0.84 (SD 0.23, ranging from 0.32 to 1) in times of the COVID-19 pandemic.

Sample characteristics for our total analytical sample (with mobility as outcome measure) are described in Table 1. Of the total sample, 66.7% of the individuals reported problems in at least one of the EQ-5D dimensions, with only 1.6% of the individuals reporting 'extreme' problems and the majority describing their problems as slightly or moderately. Most frequent were problems with pain/discomfort (47.3%), followed by anxiety/depression (32.4%), mobility (29.7%), usual activities (20.7%), and self-care (4.6%). Extreme problems were most frequent with pain/discomfort (4.5%) and anxiety/depression (1.8%) and not reported with self-care and usual activities (both 0%).

Regression analysis

Findings of multiple logistic regressions (with problems in the dimensions mobility, self-care, activities, pain/discomfort, and anxiety/depression as outcome measures) are described in Table 2. Regressions showed that the likelihood of mobility problems or self-care problems was positively associated with higher age (with problems in mobility as outcome measure, odds ratio (OR): 1.04 [95%-CI: 1.00–1.08]; with problems in self-care, OR: 1.14 [95% confidence interval {CI}: 1.01–1.30]). Moreover, the likelihood of problems with usual activities was positively associated with being single (odds ratio (OR): 5.71 (95% confidence interval {CI}: 1.32–24.69). The likelihood of problems with anxiety/depression was negatively associated with an existing health insurance (OR: 0.27 [95%-CI: 0.07–0.99]).

Findings of multiple linear regressions (with EQ-VAS and EQ5D Index as outcome measures) are described in Table 3. Regressions revealed that EQ-VAS was positively associated ($\beta = -0.30$, $P < 0.05$) with younger age. Furthermore, regressions showed that EQ-5D-5L index was positively associated with younger age ($\beta = -0.004$, $P < 0.05$) and higher education (i.e. tertiary education; $\beta = -0.14$, $P < 0.05$).

In Supplementary Tables 2 and 3, regressions with dichotomized country of origin can be found. Supplementary Table 1 shows bivariate test results along with descriptive statistics. Moreover, in Supplementary Tables 2 and 3, regressions were displayed (with 'months of being homeless' added to the main model).

Discussion

The aim of this study was to determine factors associated with HRQoL of homeless individuals during the COVID-19 pandemic.

Table 3
Determinants of EQ-VAS and EQ-5D-5L Index (GER). Findings of multiple linear regressions.

	EQ-VAS	EQ-5D-5L index (GER)
Sociodemographic data		
Age (years)	−0.30 (0.15)*	−0.004 (0.002)*
Gender: male (ref: female)	−5.17 (4.93)	−0.04 (0.05)
Marital status: single (ref: other ^a)	−3.45 (4.72)	−0.05 (0.05)
Country of origin:		
− Neighboring country (ref: Germany)	−1.47 (8.06)	−0.05 (0.07)
− Other	−5.83 (6.16)	−0.07 (0.08)
Education ^b :		
− Secondary (ref: primary)	−0.80 (4.27)	0.02 (0.05)
− Tertiary	1.45 (8.43)	0.14 (0.06)*
Lifestyle factors		
Health insurance: yes (ref: no)	9.57 (6.21)	0.08 (0.07)
Chronic alcohol consumption: yes (ref: no)	1.71 (5.47)	0.05 (0.04)
Constant	96.41 (10.78)***	1.07 (0.11)***
R ²	0.08	0.09
Observations	112	107

Beta-coefficients (unstandardized) are reported; robust standard errors in parentheses; *** $P < 0.001$, ** $P < 0.01$, * $P < 0.05$.

^a Marital status: other (married, living separately from spouse; widowed; divorced).

^b Education according to Comparative Analysis of Social Mobility in Industrial Nations classification.

Analyzing scarce data of homeless individuals, this study adds first knowledge to the factors associated with HRQoL in this cohort during the COVID-19 pandemic exemplarily for Hamburg, Germany. While the majority of sociodemographic and lifestyle factors were not associated with the outcome measures, higher age was associated with several outcome measures in this given study as it was reported also in previous research.^{5,22} The age association seems reasonable, as with higher age mobility, and the ability to take care of oneself most commonly becomes more difficult, and the incidence of age-related conditions such as cognitive or functional impairment increases.³ However, one might have expected this association to be even more pronounced. A possible explanation for the non-significant association between age and problems with usual activities, pain/discomfort, and anxiety/depression might be that with higher age, homeless individuals who experience health deteriorations simultaneously lower their own expectations regarding HRQoL (in terms of problems with pain, anxiety/depression, and usual activities). However, given the vulnerability (e.g. in terms of multimorbidity, chronic alcohol, and drug abuse) of homeless individuals, the non-significant association between problems in the dimension pain/discomfort and higher age is notable and requires further research, particularly longitudinal studies to tackle the issue of selection bias ('survival of the fittest'). However, the high response rate for this study forms the rationale for a relatively realistic and representative cohort at least for the Metropolitan region Hamburg, Germany.

Thus far, only a few studies exist identifying problems in the five dimensions among homeless individuals.^{5,22–24} For example, in a study from 2012, performed by Sun et al.⁵ examining HRQoL among homeless individuals in Stockholm (Sweden), the participants reported most problems in the dimension pain/discomfort. Other studies revealed comparable findings (in terms of chronic pain conditions,^{25,26} reporting most problems in dimension pain/discomfort^{5,22}). In sum, in terms of problems within the five dimensions of EQ-5D, our findings are in good accordance with previous research, and the special pandemic situation in 2020 seems not to shift the pre-existing problems of homeless individuals regarding their life quality fundamentally.

Moreover, the authors expected the HRQoL (particularly in terms of EQ-VAS and EQ-5D index) to be lower in women as they more often suffer from anxiety/depression disorders^{27,28} and more often face chronic pain conditions.²⁹ However, regressions did not show any association between sex and HRQoL here. This may be

caused by the fact that many women live in 'hidden homelessness',³⁰ and as a result, the study team was able to reach only a small share resulting in only 20% female participants. It may be the case that the women accessible are facing similar environmental influences as homeless men. Therefore, they may not differ in terms of HRQoL. However, future research is required to clarify this issue.

Compared with the general adult population in Germany,³¹ homeless individuals rated their HRQoL as quite high, particularly when considering their living conditions and the recent cutbacks in daily life owed to the pandemic spread of the SARS-CoV-2 virus. In Germany, the general population under regular conditions has a mean EQ-VAS of 71.59 (SD 21.36) and EQ-5D index of 0.88 (SD 0.18) in the year 2014 (March to April).³¹ More precisely, in the age category 45–54 years, the average EQ-5D Index was 0.87, SD 0.17 (men: 0.89, SD 0.15; women: 0.86, SD 0.19). Slightly higher (35–44 years) or comparable (55–64 years) average EQ-5D Indices have been reported in adjacent age groups.

Initially, we expected HRQoL of homeless individuals to be very low, as previous research has reported for other homeless cohorts^{23,32} and against the backdrop of the COVID-19 pandemic (e.g. fear of COVID-19 and its consequences). However, mean EQ-5D index in this study was also higher than that in previous research among homeless people: 0.84 in this study vs 0.65 in a study by Kozloff et al., which was performed between 2009 and 2011 in Toronto, Canada.²³ This discrepancy may be due to the fact that homeless people adapt to the circumstances of living without a permanent home. Another explanation may be that they optimistically rate—or, negatively interpreted, idealize—their HRQoL. Moreover, publication bias may explain that rather low HRQoL values and not identifying significant correlates of HRQoL are not published in peer-reviewed journals. It might be possible that the given results reflect the actual subjective perception.

Some strengths and limitations are worth noting. To best of our knowledge, there are only a few studies reporting on EQ-5D in homeless people, and this is the very first study reporting on HRQoL of homeless people during the SARS-CoV-2 pandemic. One strength of the present study is that the EQ-5D-5L questionnaire is a common and valid measure to assess the HRQoL. Most interviews were conducted by only two interviewers. However, even though most data were collected by interviews, some participants who were able to read and write also conducted the study by filling out the questionnaire themselves. This is to be regarded as a limitation in terms of consistency. Recruiting samples of homeless individuals

for surveys is difficult because reaching them is hard when being transient and a substantial proportion of eligible persons might be reluctant to participate due to distrust of official institutions or due to cognitive problems and illnesses. Nevertheless, despite the mentioned difficulties about reaching this special and vulnerable population, we were able to include 151 persons. In addition, the response rate of 98.1% was remarkably high.

However, due to the cross-sectional character of the study, the exposure and outcome are assessed contemporary, and it is therefore not possible to constitute a true cause and effect relationship. Due to possible participation bias and exclusion criteria, individuals in bad mental and physical conditions are likely to have been underrepresented at the time of recruitment. Furthermore, resting on the fact that we were only able to visit homeless shelters, some selection bias is likely to be present, excluding homeless people who avoid any institutional accommodations. Moreover, some covariates may be missing: future research including covariates such as income, hygienic practices and knowledge of COVID-19, and preexisting health status before COVID-19 is important among homeless individuals.

Conclusion

Remarkably high EQ-VAS values were reported among the homeless individuals during the COVID-19 pandemic in Hamburg, Germany. Moreover, study findings particularly stress the link between higher age and lower HRQoL. This knowledge is important to address homeless individuals at risk of poor HRQoL. Longitudinal studies are required to confirm the findings presented.

Author statements

Ethical approval

We received a positive ethics vote from the ethics committee of Hamburg Ethics committee (application number: PV7333).

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Competing interests

The authors declare that they have no conflict of interest.

Consent to participate

Written informed consent was provided by all participants prior to the investigations.

Consent for publication

Not applicable.

Availability of data and material (data transparency)

The data sets analyzed during the current study are not publicly available due to ethical restrictions involving patient data but are available from the corresponding author on reasonable request.

Code availability (software application or custom code)

Not applicable.

CRediT authorship contribution statement

V. van R uth: Conceptualization, Methodology, Formal analysis, Writing – original draft, Writing – review & editing, Funding acquisition. **H.-H. K nig:** Conceptualization, Writing – review & editing, Supervision. **F. Bertram:** Conceptualization, Writing – review & editing. **P. Schmiedel:** Writing – review & editing. **B. Ondruschka:** Writing – review & editing. **K. P uschel:** Conceptualization, Writing – review & editing. **F. Heinrich:** Conceptualization, Writing – review & editing, Funding acquisition. **A. Hajek:** Conceptualization, Methodology, Formal analysis, Writing – review & editing, Supervision.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.puhe.2021.02.026>.

References

1. Wohnungslosenhilfe Bf. *Wohnungslosigkeit: Kein Ende in Sicht*. 2018.
2. Entscheidung GfOu. *Befragung obdachloser, auf der Stra e lebender Menschen und wohnungsloser,  ffentlich-rechtlich untergebrachter Haushalte*. 2018. Hamburg.
3. Fazel S, Geddes JR, Kushel M. The health of homeless people in high-income countries: descriptive epidemiology, health consequences, and clinical and policy recommendations. *Lancet* 2014;**384**(9953):1529–40.
4. Nilsson SF, Nordentoft M, Fazel S, Laursen TM. Homelessness and police-recorded crime victimisation: a nationwide, register-based cohort study. *Lancet Publ Health* 2020;**5**(6):e333–41.
5. Sun S, Irestig R, Burstr m B, Beijer U, Burstr m K. Health-related quality of life (EQ-5D) among homeless persons compared to a general population sample in Stockholm County, 2006. *Scand J Publ Health* 2012;**40**(2):115–25.
6. Hwang SW, Aubry T, Palepu A, Farrell S, Nisenbaum R, Hubley AM, et al. The health and housing in transition study: a longitudinal study of the health of homeless and vulnerably housed adults in three Canadian cities. *Int J Publ Health* 2011;**56**(6):609–23.
7. Lewer D, Braithwaite I, Bullock M, Eyre MT, White PJ, Aldridge RW, et al. COVID-19 among people experiencing homelessness in England: a modelling study. *Lancet Respir Med* 2011;**8**(12):1181–91.
8. Tsai J, Wilson M. COVID-19: a potential public health problem for homeless populations. *Lancet Publ Health* 2020;**5**(4):e186–7.
9. Perri M, Dosani N, Hwang SW. COVID-19 and people experiencing homelessness: challenges and mitigation strategies. *CMAJ* 2020;**192**(26):E716–e9.
10. Lindner AK, Sarma N, Rust LM, Hellmund T, Krasovski-Nikiforovs S, Wintel M, et al. Monitoring for COVID-19 by universal testing in a homeless shelter in Germany: a prospective feasibility cohort study. *medRxiv* 2020. 10.04.20205401.
11. Storgaard SF, Eiset AH, Abdullahi F, Wejse C. First wave of COVID-19 did not reach the homeless population in Aarhus. *Dan Med J* 2020;**67**(12).
12. Karb R, Samuels E, Vanjani R, Trimbuc C, Napoli A. Homeless shelter characteristics and prevalence of SARS-CoV-2. *West J Emerg Med* 2020;**21**(5):1048–53.
13. Tobolowsky FA, Gonzales E, Self JL, Rao CY, Keating R, Marx GE, et al. COVID-19 outbreak among three affiliated homeless service sites - king county, Washington, 2020. *MMWR Morb Mortal Wkly Rep* 2020;**69**(17):523–6.
14. Matuschek C, Moll F, Fangerau H, Fischer JC, Z nker K, van Griensven M, et al. Face masks: benefits and risks during the COVID-19 crisis. *Eur J Med Res* 2020;**25**(1):32.
15. Hao W, Li J, Fu P, Zhao D, Jing Z, Wang Y, et al. Physical frailty and health-related quality of life among Chinese rural older adults: a moderated mediation analysis of physical disability and physical activity. *BMJ Open* 2021;**11**(1):e042496.
16. Phyto AZZ, Ryan J, Gonzalez-Chica DA, Woods RL, Reid CM, Nelson MR, et al. Health-related quality of life and all-cause mortality among older healthy individuals in Australia and the United States: a prospective cohort study. *Qual Life Res* 2021;**30**:1037–48.
17. Kroenke CH, Kubzansky LD, Adler N, Kawachi I. Prospective change in health-related quality of life and subsequent mortality among middle-aged and older women. *Am J Publ Health* 2008;**98**(11):2085–91.
18. EuroQol—a new facility for the measurement of health-related quality of life. *Health Pol* 1990;**16**(3):199–208.

19. Devlin NJ, Krabbe PF. The development of new research methods for the valuation of EQ-5D-5L. *Eur J Health Econ* 2013;**14**(Suppl 1):S1–3.
20. Ludwig K, Graf von der Schulenburg JM, Greiner W. German value set for the EQ-5D-5L. *Pharmacoeconomics* 2018;**36**(6):663–74.
21. Bortolotti F, Sorio D, Bertaso A, Tagliaro F. Analytical and diagnostic aspects of carbohydrate deficient transferrin (CDT): a critical review over years 2007–2017. *J Pharmaceut Biomed Anal* 2018;**147**:2–12.
22. Levorato S, Bocci G, Troiano G, Messina G, Nante N. Health status of homeless persons: a pilot study in the Padua municipal dorm. *Ann Ig* 2017;**29**(1):54–62.
23. Kozloff N, Pinto AD, Stergiopoulos V, Hwang SW, O'Campo P, Bayoumi AM. Convergent validity of the EQ-5D-3L in a randomized-controlled trial of the Housing First model. *BMC Health Serv Res* 2019;**19**(1):482.
24. Gentil L, Grenier G, Bamvita JM, Dorvil H, Fleury MJ. Profiles of quality of life in a homeless population. *Front Psychiatr* 2019;**10**:10.
25. Hwang SW, Wilkins E, Chambers C, Estrabillo E, Berends J, MacDonald A. Chronic pain among homeless persons: characteristics, treatment, and barriers to management. *BMC Fam Pract* 2011;**12**(1):73.
26. Fisher R, Ewing J, Garrett A, Harrison EK, Lwin KK, Wheeler DW. The nature and prevalence of chronic pain in homeless persons: an observational study. *F1000Res* 2013;**2**:164.
27. Roy T, Lloyd CE. Epidemiology of depression and diabetes: a systematic review. *J Affect Disord* 2012;**142**(Suppl):S8–21.
28. Baxter AJ, Scott KM, Vos T, Whiteford HA. Global prevalence of anxiety disorders: a systematic review and meta-regression. *Psychol Med* 2013;**43**(5):897–910.
29. Geneen LJ, Moore RA, Clarke C, Martin D, Colvin LA, Smith BH. Physical activity and exercise for chronic pain in adults: an overview of Cochrane Reviews. *Cochrane Database Syst Rev* 2017;**4**(4):Cd011279.
30. Watson J, Crawley J, Kane D. Social exclusion, health and hidden homelessness. *Publ Health* 2016;**139**:96–102.
31. Grochtdreis T, Dams J, K nig H-H, Konnopka A. Health-related quality of life measured with the EQ-5D-5L: estimation of normative index values based on a representative German population sample and value set. *Eur J Health Econ* 2019;**20**(6):933–44.
32. Wolf J, Burnam A, Koegel P, Sullivan G, Morton S. Changes in subjective quality of life among homeless adults who obtain housing: a prospective examination. *Soc Psychiatr Psychiatr Epidemiol* 2001;**36**(8):391–8.



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Short Communication

Influence of malaria endemicity and tuberculosis prevalence on COVID-19 mortality



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ABSTRACT

Objectives: Regarding severe acute respiratory syndrome coronavirus 2, it is known that a substantial percentage of the adult population does not become infected when exposed to this novel coronavirus. Several studies provide an initial indication of the possible role of pre-existing immunity, whether cross-immunity or not. The possible role of latent tuberculosis (TB) and malaria has been suggested to create innate cross heterogeneous immunity. In this study, we looked for the influence of these factors on coronavirus disease 2019 (COVID-19) mortality in malaria-endemic countries.

Study design: Eighty malaria-endemic countries were enrolled in this cross-sectional study. Data subjected to testing included TB prevalence, Bacillus Calmette-Guérin (BCG) vaccine coverage, malaria incidence, and COVID-19 mortality.

Methods: Hierarchical multiple regression type of analysis was used for data analyses. TB prevalence per 100,000 population standardized to BCG coverage rates was taken as a direct factor in the test. Malaria incidence per 1000 population was considered an intermediate factor. The outcome was COVID-19 mortality per million population.

Results: The results showed with robust statistical support that standardized TB prevalence was significantly associated with reduced COVID-19 mortality. Malaria had an additional effect in reducing COVID-19 mortality, with a highly significant association.

Conclusions: Malaria and standardized TB prevalence are statistically significant factors associated negatively with COVID-19 mortality.

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Introduction

In 2011, Netea et al.¹ proposed the term ‘trained immunity’ to describe the ability of innate immune cells to non-specifically adapt, protect, and remember primary stimulation.

Studies conducted over the past few decades have revealed certain adaptations connected with innate immune cells (i.e., monocyte/macrophages), and natural killer cells are responsible for the non-specific effects of a vaccination beyond its target.²

Latent tuberculosis (TB) infection was suggested to create a heterogeneous immune response to the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) viral infection in different patterns and severity based on different Bacillus Calmette-Guérin (BCG) statuses.^{3,4} Further studies have consolidated such a role for latent TB.^{5–7}

In Italy, it has been suggested that the Black population is less affected by coronavirus disease 2019 (COVID-19) owing to suggested previous exposure to malaria and the presence of anti-glycosylphosphatidylinositol antibodies, which have a possible protective effect against malaria reinfection and may give cross-protection against SARS-CoV-2 infection.^{8,9} Furthermore, an epidemiological paradox between COVID-19 and malaria endemicity was noticed during the initial phase of the pandemic.¹⁰

Adding to this evidence, further study showed that high endemicity of TB and malaria and universal BCG programs were suggested to have a cushioning effect on the proportion of the population affected by COVID-19.⁶

Both BCG implementation and latent TB prevalence, later on, did not fully explain variances in COVID-19 mortalities across different countries. In South Africa, for example, the COVID-19 mortality per million (M) population was 238 per M population at the time of the study, whereas the TB prevalence per 100,000 population was 520, which is very high. Moreover, these studies did not explain the low

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COVID-19 mortality rates in countries that have relatively low TB prevalence per 100,000 population, such as Togo, Benin, and Mali, where the estimated TB prevalence is 36, 56, and 53, whereas COVID-19 mortality per M population is 3, 3, and 6, respectively.

Our study's background hypothesis stands on the possible heterogeneous immunity generated by malaria in addition to possible heterogeneous immunity generated by TB. This study compared COVID-19 mortality in malaria-endemic countries against TB prevalence standardized by BCG coverage. Then, the mortality rate was tested again when the malaria incidence effect was added to the composite sample to look for statistical associations and significances.

This study addressed mortalities instead of morbidities because the real number of affected people was beyond counting, and many confounders affect testing because of the wide distribution of asymptomatic persons. Furthermore, this study considered standardized TB prevalence to BCG coverage instead of non-standardized TB prevalence values.

Results and findings

Eighty malaria-endemic countries were enrolled in this cross-sectional study. Data subjected to testing included TB prevalence, BCG coverage, malaria incidence, and COVID-19 mortalities as it were on August 31, 2020.

Hierarchical regression of a composite multiple linear model was used for data analyses.

According to hierarchical regression analysis, the direct factor reducing mortality rates concerning COVID-19 was the standardized TB/100,000 population by BCG vaccination coverage percentage in 2018 through dividing the factor of TB prevalence/100,000 population rates by the factor of BCG vaccination coverage in 2018. The indirect effect that reduced the mortality rates, named as an intermediate factor, was the malaria incidence for 2018 per 1000 population.

We investigated the validity of the assumptions of the studied model that adopted the results of the quantitative measurements. Table 1 shows the results of the multiple linear model fitness test resulting from the regression analysis of variance.

The effectiveness of the model's fitness was observed in quality when the intermediate factor was present.

The level of significance was greatly reduced compared with the case of the model's quality in the absence of the intermediate factor (Table 1).

Table 2 shows the results from estimating some descriptive statistics accompanying the analysis of the composite linear model. The level of the increase in the value of the multiple correlation coefficient is evidenced by the presence of the intermediate factor in the composite regression analysis.

Table 1
Fitness test results for the regression analysis of variance with and without effectiveness of an intermediate factor.

Model	SOV*	SS**	Df***	MSS****	F	P-value *****
Without intermediate factor	Regression	170266.9	2	85133.45	3.833	0.026, S
	Residuals	1710329.0	77	22212.07		
	Total	1880595.9	79	–		
With intermediate factor	Regression	322044.1	3	107348	5.235	0.002, HS
	Residuals	1558551.8	76	20507.26		
	Total	1880595.9	79	–		

*SOV, source of variation;
 **SS, sum of squares;
 ***Df, degree of freedom;
 ****MSS, mean sums of squares;
 *****HS, highly significant at P < 0.01;
 S, significant at P < 0.05.

Table 2
Results of some descriptive statistics accompanying the analysis of the composited linear model of studied functions.

Model	R, Multiple Correction	R square	Adjusted R square	Standard error of the estimate
1	0.301	0.091	0.067	149.0371
2	0.414	0.171	0.139	143.2036

TB = tuberculosis; BCG = Bacillus Calmette-Guérin.
 1: predictors: (constant), BCG vaccination coverage 2018 in percentage, TB prevalence per 100,000.
 2: predictors: (constant), BCG vaccination coverage 2018 in percentage, TB prevalence per 100,000, malaria incidence for 2018 per 1000.

Discussion

In this study, the prevalence of exposure to *Mycobacterium* spp. (standardized to BCG vaccine coverage) by populations was negatively associated with COVID-19 deaths per M population. This supports the previously mentioned studies.^{3–7}

TB prevalence standardization for BCG coverage was an important factor with regard to studying countries currently implementing BCG programs, as long as the coverage was reflecting the degree of benefits added to the factor (latent TB prevalence) that the coverage does. Likewise, the influence of time duration of cessation of the BCG vaccination program was a factor in determining COVID-19 mortality in countries that ceased implementing this vaccine, which we concluded in our previous study.¹¹

Malaria can induce an immunological response that is significantly associated with a reduction in COVID-19 mortality. This association needs confirmatory immunological and clinical control studies to establish causation. This finding can explain the variances in COVID-19 mortality among different countries much deeper than latent TB and BCG vaccination. Differences in BCG vaccination policies were of concern earlier than for latent TB, which later became a more prominent concern. Previous studies were conflicting and were criticized because of the possible confounding factors.

In this study, all countries were implementing national BCG programs, but countries with TB prevalence per 100,00 population normalized by BCG coverage rates showed a significant association with the reduction in COVID-19 mortality. The supportive evidence for TB prevalence and malaria incidence in this study was obtained using a robust statistical method—hierarchical multiple regression analysis.

Hierarchical multiple regression analysis is a subset of regression methods that we chose to prove our theory using collected evidence for a proposed role of variables entered in blocks.¹²

Table 3

Estimating parameters of the regression and composite regression models in the presence of the indirect effect of the intermediate factor.

Regression and composite regression models	B	Standard error	Standard Beta	t-value	P-value*
(Constant)	126.98	25.87	–	4.908	0.000,HS
(Constant)	–22.11	8.53	–0.282	–2.593	0.011,S
(Constant)	152.38	26.58	–	5.734	0.000,HS
Standardized of TB/100000 by BCG vaccination coverage percent (2018)	–18.00	8.34	–0.229	–2.16	0.034,S
Malaria incidence for 2018 per 1000	–0.331	0.122	–0.289	–2.717	0.008,HS

TB = tuberculosis; BCG = Bacillus Calmette-Guérin.

* HS: highly significant at $P < 0.01$; S: significant at $P < 0.05$.

TB prevalence was in the 1st block in this study, malaria incidence was in the 2nd block, and reduction of COVID-19 mortality was the effect.

This test allowed us to look at the R square change and F-statistic change between the two models, in addition to reporting the level of significance for each predictor variable that was entered into the model in predetermined iterations.

Table 2 shows that the R square was 0.091 and increased to 0.171 when the intermediate factor was added to the composite.

Furthermore, these results show that constant parameters constitute a significant proportion causing COVID-19 mortality measured (152.38). TB prevalence, when standardized to a BCG coverage rate, made a –22.11 change, and when malaria incidence was included in the regression model (constants), it made a –0.331 further change. Constants constituted a considerable number not included in the regression model (Table 3).

Based on the benefits of heterogeneous immunity, possibly, two important questions may need to be answered: Does a potent malaria vaccine need to be considered for malaria eradication? Does latent TB management in the future need to be more conservative?

Limitations

Possible confounding variables have not been evaluated, such as population density, ethnicity, life expectancy, comorbidities, lifestyle, the pandemic phase, data accuracy, and health services.

Conclusions

Although confounding variables have not been evaluated, the results of this study suggested that malaria incidence and TB prevalence are possible determining factors for COVID-19 mortality. Further research is needed for exploring such findings.

Author statements

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Ethical approval

Ethical permission is not necessary as this study analyzed publicly published data, and patients were not involved.

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Competing interests

There was no conflict of interest.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.puhe.2021.02.018>.

References

1. Netea MG, Quintin J, van der Meer JW. Trained immunity: a memory for innate host defense. *Cell Host Microbe* 2011;9(5):355–61.
2. Kleinnijenhuis J, et al. Long-lasting effects of BCG vaccination on both heterologous Th1/Th17 responses and innate trained immunity. *J. Innate Immun.* 2014;6:152–8.
3. Raham TF. TB prevalence correlation to covid- 19 mortality. *medRxiv* 2020. <https://doi.org/10.1101/2020.05.05.20092395>.
4. Al-Momen H, Raham TF, Daher AM. Tuberculosis versus COVID-19 mortality: a new evidence. *Internet Open Access Maced J Med Sci* 2020 Sep.25:179–83. Available from: <https://www.id-press.eu/mjms/article/view/5248> [cited 2021 Jan.17];8(T1).
5. Takahashi H. Role of latent tuberculosis infections in reduced COVID-19 mortality: evidence from an instrumental variable method analysis. *Med Hypotheses* 2020:144110214. <https://doi.org/10.1016/j.mehy.2020.110214.657-8501>. Japan.
6. Banerjee S, Saha A. Finding tentative causes for the reduced impact of covid-19 on the health systems of poorer and developing nations: an ecological study of the effect of demographic, climatological and health related factors on the global spread of covid-19. *medRxiv* 2020. <https://doi.org/10.1101/2020.05.25.20113092>. [Accessed 26 May 2020].
7. Singh S, Maurya RP, Singh RK. “Trained immunity” from *Mycobacterium* spp. exposure or BCG vaccination and COVID-19 outcomes. *PLoS Pathog* 2020;16(10):e1008969. <https://doi.org/10.1371/journal.ppat.1008969>.
8. Gomes LR, Martins YC, Ferreira-da-Cruz MF, Daniel-Ribeiro CT. Autoimmunity, phospholipid-reacting antibodies and malaria immunity. *Lupus* 2014 Oct;23(12):1295–8. <https://doi.org/10.1177/0961203314546021>.
9. Parodi A, Cozzani E. Coronavirus disease 2019 (COVID 19) and Malaria: have anti glycoprotein antibodies a role? *Med Hypotheses* 2020;143:110036. <https://doi.org/10.1016/j.mehy.2020.110036> [published online ahead of print, 2020 Jun 25].
10. Napoli PE, Nioi M. Global spread of coronavirus disease 2019 and malaria: an epidemiological paradox in the early stage of A pandemic. *J Clin Med* 2020;9(4):1138. <https://doi.org/10.3390/jcm9041138>. Published 2020 Apr 16.
11. Raham TF. Impact of duration of cessation of mass BCG vaccination programs on covid -19 mortality. *J Cardiovasc Dis Res* 2020;11(4):255–9.
12. Ross A, Willson VL. Hierarchical multiple regression analysis using at least two sets of variables (in two blocks). In: *Basic and advanced statistical tests*. Rotterdam: SensePublishers; 2017. p. 61. https://doi.org/10.1007/978-94-6351-086-8_10.



Original Research

Influences on emergency department attendance among frail older people with deteriorating health: a multicentre prospective cohort study

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ABSTRACT

Objectives: To examine the patterns and influences on repeated emergency department attendance among frail older people with deteriorating health.

Study design: Multicentre prospective cohort study (International Access Rights and Empowerment II study) with convergent mixed methods design.

Methods: Eligible patients were aged ≥ 65 years, with Clinical Frailty Score ≥ 5 , and ≥ 1 hospital admission or ≥ 2 acute attendances in the previous 6 months. Questionnaires were administered to participants over 6 months and we extracted clinical data from the medical records. We conducted modified Poisson multivariable regression analysis to identify factors associated with repeated emergency department attendance (≥ 2 over 6 months) and thematic analysis of qualitative interviews.

Results: A total of 90 participants were recruited. The mean age was 84 years, and 63% were women. Of 87 participants, 21 experienced repeated emergency department attendance. Severe and/or overwhelming pain (adjusted prevalence ratio 2.44, 95% confidence interval 1.17–5.11), greater number of comorbidities (1.32, 1.08–1.62), ≥ 10 community nursing contacts (2.93, 1.31–6.56), and a total of ≥ 2 weeks spent in hospital during the previous 6 months (2.91, 1.24–6.84) were associated with repeated attendance. From 45 interviews, we identified influences on emergency department attendance: 1. inaccessibility of community healthcare; 2. perceived barriers to community healthcare seeking; 3. perceived benefits of hospital admission; 4. barriers to recovery during previous hospital admission (unsuitable food, inactivity); and 5. poorly coordinated transitions between settings.

Conclusions: We identified missed opportunities to optimise older people's recovery during hospital admission, such as improved food and a timely and coordinated discharge, which may reduce reattendances. Proactive care in the community with systematic assessment of symptoms may be required, particularly for those with multimorbidity.

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Introduction

Frail older people with serious illness are an important and growing population globally.¹ Described as the 'disadvantaged dying', older people experience under-assessment of symptoms and lower access to specialist palliative care services.^{2,3} This is

recognised as an important public health issue.⁴ A challenge for the clinical management of frail older people is the unpredictability of their illness trajectory.⁵ This is characterised by acute episodes of deterioration and recovery, often accompanied by emergency attendances to the hospital.^{6,7}

Acute hospital admissions, typically facilitated via the emergency department (ED), rise sharply towards the end of life.⁸ This is at odds with the commonly held preference among older people to remain in their usual place of care.⁹ Frequent ED attendance has become a critical health policy issue in recent years, given the growing demand on EDs globally due to population ageing and rising multimorbidity.¹⁰ Approaches to prevent or minimise avoidable ED attendances, which can be burdensome for this group, are desirable.

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service use, equipment, medication and informal care).²¹ Clinical data such as diagnoses were extracted at baseline and comorbidity was calculated using Elixhauser's index.²² Details of ED attendance and hospital admissions were extracted from participants' medical records at baseline (ED attendance and hospital admissions in the 6 months before recruitment) and 24 weeks (ED attendance and hospital admissions during the study).

We descriptively analysed patterns of ED attendance. Our primary outcome was repeated ED attendance, defined as ≥ 2 ED attendances over the 6-month duration of the study. We used multivariable modified Poisson regression analysis with robust error variance²³ to examine factors associated with repeated ED attendance. All explanatory variables were collected at baseline, and were considered for inclusion in the model if there was evidence of an association from a recent systematic review (moderate/high strength evidence),¹¹ and from a previous study of frequent end-of-life attendances.¹² Factors identified in the thematic analysis of qualitative interviews were also considered. Explanatory variables included the following: 1. illness factors: comorbidity, physical (pain, breathlessness) and psychological symptoms (anxiety); 2. service factors: weeks spent in hospital in past 6 months, contact with a General Practitioner (GP) (yes, no) and community nursing contacts (0, 1–9 and ≥ 10) in the last 3 months; and 3. individual factors: age and gender. We imputed median number of contacts when the participant indicated a service was received but omitted number of times. Only complete cases were considered for other variables. We assessed collinearity and only included explanatory variables that were not significantly associated with each other. We used backward manual selection to determine the variables included in the final parsimonious regression model, removing variables when $P > 0.05$, except for age and gender, which were included to control for potential confounding.

Qualitative interviews and analysis

A maximum-variation purposive sampling approach was used to encompass a breadth of experiences and views from a group with diverse characteristics across age, living status, functional status and service utilisation (Table S2). Qualitative interviews were undertaken in the participant's care setting at 12-week intervals over the 6-month study duration (Fig. S1—topic guide summary).

We analysed transcripts using thematic analysis²⁴ in NVivo.12. Following familiarisation, data were inductively coded and initial codes grouped into themes with relationships between codes considered. Codes and themes were further reviewed and refined. Two transcripts were independently double-coded, and the coding frame was checked against the main framework and discussed. Memos were used throughout the process to record reflections.

We analysed quantitative and qualitative components in parallel. Integration during analysis occurred iteratively, with themes identified from the interviews informing variable selection and associations prompting further exploration in the qualitative data.²⁵ The final integrated findings were used to develop a model of influences on ED attendance (Fig. 1).²⁶

Results

We recruited 90 older people (45% of identified eligible patients) including eight nominated informal carers for those who lacked capacity to consent (Fig. S2): mean age 84 years (range 69–101), most were women (63%) (Table 1). In the 6 months before baseline, participants had a median of one ED visit (range 0–8) and two hospital admissions (range 0–5) with a mean length of stay of 24 days (median 17 days, range 0–100 days).

Patterns of ED attendance

A total of 87 complete cases were included in the ED modelling (96.7%). Over the 6 months, most attended the ED at least once (57.5%), with 24.1% attending two or more times (range 0–17 times) (Fig. 2).

Factors associated with repeated ED attendance

In an adjusted model, severe and/or overwhelming pain at baseline (prevalence ratio 2.44, 95% confidence interval 1.17–5.11), number of comorbidities (1.32, 1.08–1.62), ≥ 10 contacts with a community nurse (2.93, 1.31–6.56), and ≥ 2 weeks in hospital in the 6 months before baseline (2.91, 1.24–6.84) were independently associated with an increased risk of repeated ED attendance (Table 2).

Table 1
Baseline demographic and clinical characteristics of participants (N = 90).

Baseline characteristics		N = 90
Age	Mean (SD)	84 (7)
	Median (min, max)	84 (69,101)
Gender	Female	57 (63%)
Ethnicity	English/Welsh/Scottish/ Northern Irish	76 (84%)
	Irish/Other White	6 (7%)
	Asian	1 (1%)
	African/Caribbean	5 (6%)
	Other	1 (1%)
	Education—age at which left education	≤ 15 years
	16–19 years	22 (25%)
	Post-secondary school vocational qualification	2 (2%)
	University	9 (10%)
Living status	Lives alone	46 (51%)
Australia-Modified Karnofsky Performance Status ²⁷	Mean (SD)	49.8 (10.3)
	Median (min, max)	50 (20,80)
Clinical frailty score (5–9) ¹⁴	5—Mildly frail	26 (29%)
	6—Moderately frail	43 (48%)
	7—Severely frail	20 (22%)
	8—Very severely frail	1 (1%)
Activities of daily living (score of 0 = full dependency) ²⁰	Mean (SD)	13.1 (4.8)
	Median (min, max)	14 (1,20)
Diagnoses	Circulatory	79 (88%)
	Respiratory	36 (40%)
	Cancer	21 (23%)
	Dementia	9 (10%)
Other conditions	Cognitive impairment/delirium	18 (20%)
	Elixhauser comorbidity index ²²	Mean (SD)
	Median (min, max)	3 (0,8)
Baseline pain (IPOS) ²⁸	Not at all/slightly/moderately	64 (72%)
	Severely/Overwhelmingly	25 (28%)
Number of specialist teams involved in the care	Mean (SD)	2.0 (1.5)
	Median (min, max)	2 (0,6)
Emergency department visits in 6 months before baseline	0–1	49 (54%)
	≥ 2	41 (46%)
	Median (min, max)	1 (0,8)
Time spent in hospital in 6 months before baseline	<2 weeks	36 (40%)
	≥ 2 weeks	54 (60%)
	Median days (min, max)	17 (0,100)
General practitioner contacts in 3 months before baseline	0 contacts	37 (42%)
	≥ 1 contacts	52 (58%)
	Median (min, max)	1 (0,12)
Community nurses contacts in 3 months before baseline	0 contacts	46 (51%)
	1–9 contacts	28 (31%)
	≥ 10 contacts	15 (17%)
	Median (min, max)	0 (0,180)

SD = standard deviation; IPOS= Integrated Palliative care Outcome Scale; min = minimum value; max = maximum value. Missing data for ethnicity (n = 1); education (n = 2); activities of daily living (n = 3); specialist teams involved in patients' care (n = 1); pain (n = 1); community nurse contacts (n = 6); general practitioner visits (n = 4).

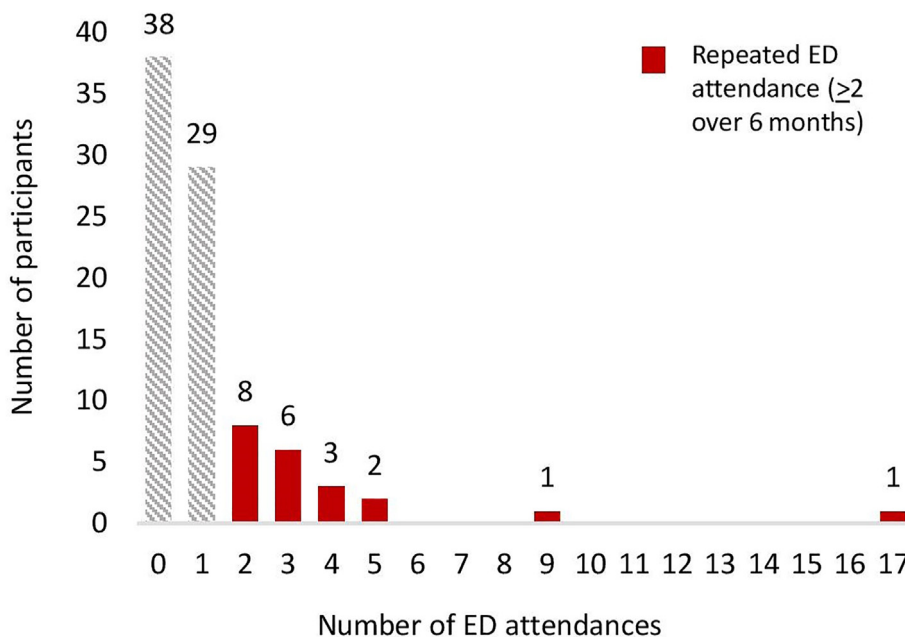


Fig. 2. Frequency of emergency department (ED) attendance over 6 months (n = 87).

Table 2 Multivariable analysis using modified Poisson regression to examine the association between individual, illness, and service factors and repeated ED attendance (≥ 2 over 6 months).

Variable		Unadjusted		Adjusted	
		Prevalence ratio (N = 87)	95% CI	Prevalence ratio (N = 87)	95% CI
Individual factors					
Age	(continuous)	0.99	0.93–1.05	1.01	0.95–1.07
Gender	Male (ref)	-	-	-	-
	Female	0.78	0.37–1.64	0.64	0.31–1.32
Illness factors					
Pain at baseline	Not at all/slightly/moderately (ref)	-	-	-	-
	Severely/overwhelmingly	1.53	0.72–3.23	2.44*	1.17–5.11
Elixhauser comorbidity index ²²	(continuous)	1.28*	1.08–1.53	1.32*	1.08–1.62
Service factors					
Contacts with district nurse in the 3 months before baseline	0 (ref)	-	-	-	-
	1–9 contacts	1.18	0.45–3.05	1.37	0.53–3.60
	≥ 10 contacts	2.57*	1.12–5.90	2.93*	1.31–6.56
Time in hospital in the 6 months before baseline	<2 weeks (ref)	-	-	-	-
	≥ 2 weeks	2.15	0.86–5.37	2.91*	1.24–6.84

CI = confidence interval; ref = reference.

*Represents significant associations at $P < 0.05$.

Influences on ED attendance identified from qualitative interviews

A total of 45 qualitative interviews were conducted with 18 older people (including one interview conducted with a family member on behalf of a participant with severe dementia) and seven carers (Tables S1 and S2) with up to three interviews each.

We identified the following five main themes that influenced ED attendance: 1. inaccessibility of community healthcare; 2. perceived barriers to healthcare seeking in the community; 3. perceived support and benefits of hospital admission; 4. barriers to recovery during previous hospital admission; and 5. poorly coordinated transitions (Table S3), which are described in detail in the following sections.

Inaccessibility of community healthcare

Limited availability of the GP. Although many found contact with their GP important, difficulty getting an appointment was a recurring theme. P17013: *It's like trying to make an appointment with the Pope* (82-year-old female). Many noted the benefits of seeing their own GP but found it increasingly difficult to see the same doctor.

Lack of proactive care. A lack of proactive care, particularly from the GP, was noted. C15011 *There's no-one coming to see him. There's nothing ... there's no backup* (Wife of 82-year-old male). Accessing care was especially problematic in the context of multiple co-existing conditions. For example, a participant, who had five

coexisting conditions, described her conversation with a receptionist about missing an appointment for eye surgery due to illness.

P15019: 'well I'm ever so sorry' she said, 'but I'll have to take you off the list'. I said 'so what does that mean then?' She said 'well you'll have to start all over again'. (79-year-old female).

Perceived barriers to healthcare seeking in the community

Perceived illness severity. Knowing when illness becomes serious enough to seek help was described as challenging, particularly for those living alone. This was exacerbated by participants' reporting receiving insufficient information from health professionals about their health status or treatment. Delays to healthcare seeking resulted in crises and subsequent emergency hospital care.

P17021: If you're with someone, they'd say 'well, look. Take an aspirin or something. Go to bed. If you're not well in the morning we'll see.' if you're on your own ... you think, 'well is this a time to press this [alarm button]?' (89-year-old female).

'Don't want to worry them'. Participants commonly expressed the notion that they were considered to be 'draining' resources from an overstretched health system. There was evidence of stoicism, not wanting to worry people or make a fuss, which was linked with delayed health seeking, leading to a crisis.

P17018: I didn't want to call the doctors because you know they're so busy, and then by the Wednesday I really started to feel really bad. (82-year-old female).

Perceived support and benefits of hospital admission

Reassurance of support. Knowing that there is someone who could be contacted in case of a crisis in the community settings was reassuring, and participants described this as providing them with 'peace of mind', improving confidence and conceptualised as a 'safety net'.

Hospital as a comfort and 'to get on the radar'. Despite the majority stating a preference to avoid further hospitalisation, benefits of hospital admission were described, including the comfort of knowing that help is there if needed. *P15005: The fact that when I did need them, need help, it was around just like that, it's there. I just pushed a button and the nurses came. (84-year-old male).* A hospital attendance resulting in access to more care was also described as a benefit. One carer described a recent hospital admission as being a 'worthwhile trip', which got them 'on the radar'.

Barriers to recovery during previous hospital admission

Participants described how aspects of hospital care paradoxically hindered recovery. Prominent themes were the poor quality of food and sleep in hospital, which were acknowledged as being important for recovery. Participants noted that the food was not suited to people who are feeling unwell, with poor quality food and large off-putting portion sizes. One participant contrasted their time in a rehabilitation unit with their hospital experience, the former having the "idea of making you better".

P17002: It was more homely I think. Um, the food was cooked on the premises, which I think ... food and sleep are the important things (80-year-old female).

Participants also commented on the lack of physical activity while in hospital, with missed opportunities to encourage getting

out of bed, leading to reduced function. This made the transition back to the usual care setting challenging and was linked to a return to hospital.

Poorly coordinated transitions

Unprepared discharge. Participants described being discharged before they felt well enough, and without sufficient preparation. In some cases, this resulted in readmission to hospital.

P17021: each time I came out of hospital that was pretty bad, um they just got me in here [home], dumped me over there and there wasn't anyone here and I thought 'if only there had been someone here to say 'look, just sit there; I'll make you a cup of tea; get warm', but there was no one. (89-year-old female).

For participants repeatedly transitioning between care settings, coordination was lacking. There was difficulty accessing services due to administrative errors, for example, lost appointment letters. One participant described themselves as having 'fallen through the net again'.

Discussion

Main findings

Repeated ED attendance, defined as two or more attendances over 6 months, was experienced by almost one in four frail older people with serious illness in this study. From the integration of quantitative and qualitative findings, we found important and modifiable areas that influence repeated ED attendance (Fig. 3). We found that those with severe pain and with multimorbidity were at higher risk of repeated attendance. We identified that lack of proactive care in the community was problematic as older people faced barriers to healthcare seeking from primary care, for example, challenges in perceiving illness severity. We found an association between recent extended time in hospital and repeated ED attendance, and when explored in the qualitative data, we identified barriers to recovery during hospital admission, such as food that is unsuitable for an older person who is acutely unwell, and limited physical activity.

Our finding that severe pain was associated with subsequent repeated attendance may signal the need for systematic assessment of symptoms within primary care. There has been a recent trend of declining primary care provision in the United Kingdom and elsewhere, which challenges this ideal.²⁹ We found that limited GP availability was linked to repeated subsequent ED attendance. Our findings suggest that a more proactive approach from primary care would support frail older people, who face barriers to early primary care seeking, such as concerns not to worry the doctor and seek the comfort and safety of hospital care.³⁰ Perceiving illness severity was challenging, which limited timely access to primary care. This points to the need for greater provision of information about treatment and discussion of their illness progression in the context of this uncertainty. The use of population-based risk stratification approaches, such as the e-frailty index, to identify increasing risk to unplanned hospital attendance, nursing home admission and mortality, offers a promising approach to this challenge.³¹

The association between community nursing contacts and higher likelihood of repeated ED attendance, while counterintuitive, is supported by findings from a mortality follow-back survey.¹² This finding may reflect that these individuals are less well and in need of more support. Alternatively, it may signal limited provision of proactive person-centred care with short and task-based nursing visits. A previous study of older people's care in the last 3 months of life found that those who had a key health professional involved in

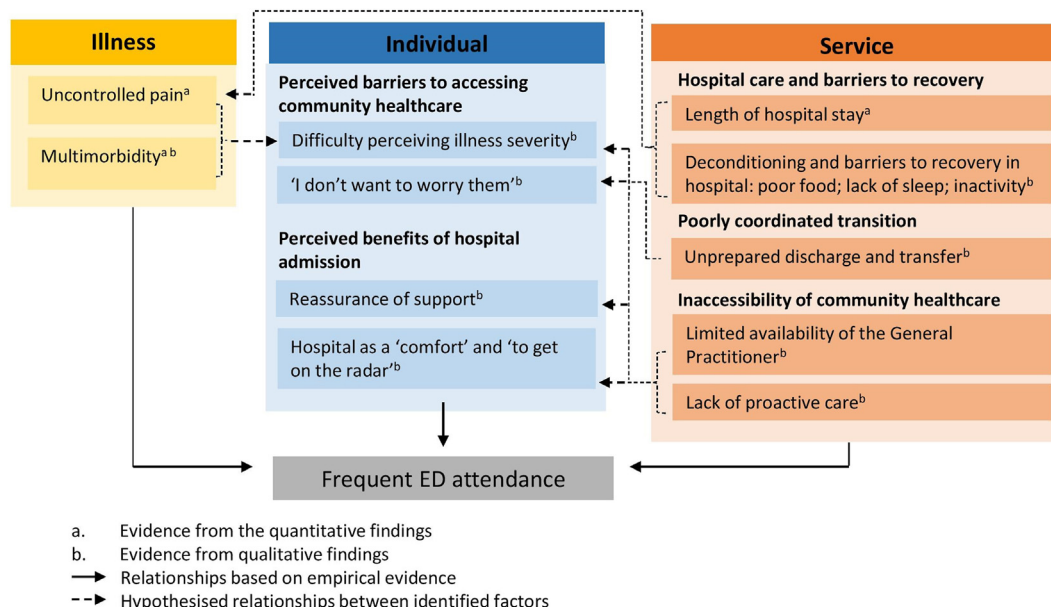


Fig. 3. Factors that increase the likelihood of repeated ED attendance.

their care had reduced frequent end-of-life ED attendance,¹² offering a promising area for future research. Recent national initiatives to recognise and support people living with frailty through integrated and multidisciplinary team working may help support this population³² but require robust evaluation.

Our finding that extended hospital stay is associated with subsequent repeated ED attendance is in keeping with evidence from other studies of hospital inpatients.^{33,34} ‘Trauma of hospitalisation’, characterised by disturbances of sleep, nutrition, mobility and mood, was found to be associated with higher ED attendances and readmissions.³³ This has also been termed ‘post-hospital syndrome’: a transient period of vulnerability following hospital stay.³⁵ For older people with frailty and serious illness, these minor stressors can have major health implications.⁶ Currently, models of hospital care focus predominantly on the treatment of single acute illnesses at the expense of holistic care and consideration of the person’s broader illness trajectory. Minor modifications to care in hospital including greater focus on optimising function and nutrition may have a considerable impact on frail older people’s return ED visits and hospital readmissions. Our findings suggest that involving or consulting with older people in the design of food provision in hospitals is important.

Strengths and limitations

This mixed methods study allowed for an in-depth investigation of an issue that has important policy implications but currently a sparse evidence base. A key strength is that we successfully recruited a group of patients often neglected in research studies because of serious illness, unstable presentation and the accompanying ethical and practical challenges. We recruited participants who predominantly had serious illnesses other than cancer, for whom there is limited evidence. Prospective cohort studies are the strongest of observational designs and yet prospective research on this topic is rare. Integrating quantitative and qualitative findings were key to enriching our understanding of repeated ED attendance and allowed older people to voice aspects of their care that were important to them.

This study sampled frail older people with recent acute healthcare utilisation, therefore findings may not be generalizable

to a similar group who are supported well at home. There were unmeasured confounders that were therefore not included in the modelling, for example, socioeconomic status and social isolation. There was overrepresentation of White British participants in the sample compared with the local population, restricting exploration of ethnicity as an explanatory variable.

Conclusion

We found there are missed opportunities during hospital admission to optimise function and recovery, which may reduce ED reattendance. This includes providing an environment in which sleep and physical activity are enabled, providing food that is suitable for acutely unwell older people, and a timely and coordinated discharge from hospital to ensure care can continue in the community as planned. Our findings suggest a proactive approach in the community, including systematic assessment of symptoms, is particularly important for frail older people with multimorbidity given unpredictable disease courses and uncertainty about when to seek help.

Author statements

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Ethical approval

The study received approval from Health Research Authority (Camberwell and St Giles Research Ethics Committee; reference 16/LO/2048, 21st February 2017).

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Competing interests

None declared.

Authors' contributions

Concept and planning of the study design and protocol writing: AEB, SNE, CJE and IJH. Data collection: AEB and SNE. Analysis and interpretation: AEB, LAH, SNE, CJE and IJH. Drafting and approval of manuscript: AEB, LAH, SNE, CJE and IJH.

Appendix A. Supplementary data

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References

- Bone AE, Gomes B, Etkind SN, Verne J, Murtagh FE, Evans CJ, et al. What is the impact of population ageing on the future provision of end-of-life care? Population-based projections of place of death. *Palliat Med* 2018;**32**:329–36.
- Burge FI, Lawson BJ, Johnston GM, Grunfeld E. A population-based study of age inequalities in access to palliative care among cancer patients. *Med Care* 2008;**46**:1203–11.
- Lloyd AKM, Carduff E, Cavers D, Kimbell B, Murray S. *Why do older people get less palliative care than younger people?* Marie Curie: University of Edinburgh; 2015.
- Higginson IJ, Koffman J. Public health and palliative care. *Clin Geriatr Med* 2005;**21**:45–55 [viii].
- Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. *BMJ* 2005;**330**:1007–11.
- Clegg A, Young J, Iliffe S, Rikkert MO, Rockwood K. Frailty in elderly people. *Lancet* 2013;**381**:752–62.
- Keeble E, Parker SG, Arora S, Neuburger J, Duncan R, Kingston A, et al. Frailty, hospital use and mortality in the older population: findings from the Newcastle 85+ study. *Age Ageing* 2019;**48**:797–802.
- Bardsley M, Georghiou T, Spence R, Billings J. Factors associated with variation in hospital use at the end of life in England. *BMJ Support Palliat Care* 2016;1–8.
- Stow D, Spiers G, Matthews FE, Hanratty B. What is the evidence that people with frailty have needs for palliative care at the end of life? A systematic review and narrative synthesis. *Palliat Med* 2019;**33**:399–414.
- National Audit Office. *Reducing emergency admissions: department of health & social care*. England: NHS; 2018.
- Bone AE, Evans CJ, Etkind SN, Sleeman KE, Gomes B, Aldridge M, et al. Factors associated with older people's emergency department attendance towards the end of life: a systematic review. *Eur J Publ Health* 2019;**29**:67–74.
- Bone AE, Evans CJ, Henson LA, Gao W, Higginson IJ. Patterns of emergency department attendance among older people in the last three months of life and factors associated with frequent attendance: a mortality follow-back survey. *Age Ageing* 2019. <https://doi.org/10.1093/ageing/afz043>.
- Ev Elm, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, Vandenbroucke JP. Strengthening the reporting of observational studies in epidemiology (STROBE) statement: guidelines for reporting observational studies. *BMJ* 2007;**335**:806–8.
- Rockwood K, Song X, MacKnight C, Bergman H, Hogan DB, McDowell I, et al. A global clinical measure of fitness and frailty in elderly people. *Can Med Assoc J* 2005;**173**:489–95.
- Pulok MH, Theou O, van der Valk AM, Rockwood K. The role of illness acuity on the association between frailty and mortality in emergency department patients referred to internal medicine. *Age Ageing* 2020;**49**:1071–9.
- Kelley AS, Covinsky KE, Gorges RJ, McKendrick K, Bollens-Lund E, Morrison RS, et al. Identifying older adults with serious illness: a critical step toward improving the value of health care. *Health Serv Res* 2016;**52**(1):113–31.
- Peduzzi P, Concato J, Kemper E, Holford TR, Feinstein AR. A simulation study of the number of events per variable in logistic regression analysis. *J Clin Epidemiol* 1996;**49**:1373–9.
- Murtagh FEM, Ramsenthaler C, Firth A, Groeneveld EI, Lovell N, Simon ST, et al. A brief, patient- and proxy-reported outcome measure in advanced illness: validity, reliability and responsiveness of the Integrated Palliative care Outcome Scale (IPOS). *Palliat Med* 2019;0269216319854264.
- EuroQol. *EQ5D*. 22/11/2018. 2018. <https://euroqol.org/eq-5d-instruments/>.
- Mahoney FI, Barthel DW. Functional evaluation: the Barthel Index: a simple index of independence useful in scoring improvement in the rehabilitation of the chronically ill. *Md State Med J* 1965;**14**:61–5.
- Goldberg RW, Seybolt DC AL. Reliable self-report of health service use by individuals with serious mental illness. *Psychiatr Serv* 2002;**53**:879–81.
- Elixhauser A, Steiner C, Harris DR, Coffey RM. Comorbidity measures for use with administrative data. *Med Care* 1998;**36**:8–27.
- Zou G. A modified Poisson regression approach to prospective studies with binary data. *Am J Epidemiol* 2004;**159**:702–6.
- Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;**3**:77–101.
- Moseholm E, Fetters MD. Conceptual models to guide integration during analysis in convergent mixed methods studies. *Methodological Innovations* 2017;**10**. 2059799117703118.
- Plano Clark VL, Anderson N, Wertz JA, Zhou Y, Schumacher K, Miaskowski C. Conceptualizing longitudinal mixed methods designs: a methodological review of health sciences research. *J Mix Methods Res* 2014;**9**:297–319.
- Abermethyl AP, Shelby-James T, Fazekas BS, Woods D, Currow DC. The Australia-modified Karnofsky Performance Status (AKPS) scale: a revised scale for contemporary palliative care clinical practice [ISRCTN81117481]. *BMC Palliat Care* 2005;**4**:7.
- Hearn J, Higginson IJ. Development and validation of a core outcome measure for palliative care: the palliative care outcome scale. *Quality in Health Care : QHC*. 1999;**8**:219–27.
- Hobbs FDR, Bankhead C, Mukhtar T, Stevens S, Perera-Salazar R, Holt T, et al. Clinical workload in UK primary care: a retrospective analysis of 100 million consultations in England, 2007–14. *Lancet* 2016;**387**:2323–30.
- Robinson J, Gott M, Gardiner C, Ingleton C. A qualitative study exploring the benefits of hospital admissions from the perspectives of patients with palliative care needs. *Palliat Med* 2015;**29**(8):703–10.
- Clegg A, Bates C, Young J, Ryan R, Nichols L, Ann Teale E, et al. Development and validation of an electronic frailty index using routine primary care electronic health record data. *Age Ageing* 2016;**45**:353–60.
- NHS. *The NHS long term Plan*. 2019.
- Rawal S, Kwan JL, Razak F, Detsky AS, Guo Y, Lapointe-Shaw L, et al. Association of the trauma of hospitalization with 30-day readmission or emergency department visit. *JAMA Internal Medicine* 2019;**179**:38–45.
- Covinsky KE, Palmer RM, Fortinsky RH, Counsell SR, Stewart AL, Kresevic D, et al. Loss of independence in activities of daily living in older adults hospitalized with medical illnesses: increased vulnerability with age. *J Am Geriatr Soc* 2003;**51**:451–8.
- Krumholz HM. Post-hospital syndrome — an acquired, transient condition of generalized risk. *N Engl J Med* 2013;**368**:100–2.



Original Research

Just a bad flu? Tackling the “infodemic” in Ireland through a comparative analysis of hospitalised cases of COVID-19 and influenza



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ABSTRACT

Objectives: COVID-19 infection has been compared to seasonal influenza as an argument against non-pharmacological population-based infection control measures known as “lockdowns”. Our study sought to compare disease severity measures for patients in Ireland hospitalised with COVID-19 against those hospitalised with seasonal influenza.

Study design: This is a retrospective population-based cohort study.

Methods: COVID-19 hospital episodes and seasonal influenza hospital episodes were identified using relevant International Classification of Disease (ICD-10) codes from the Irish national hospitalisation dataset. The occurrences of key metrics of disease severity, length of stay, intensive care admission, ventilatory support, haemodialysis and in-hospital mortality were measured and compared between the two groups using odds ratios with 95% confidence intervals (CIs), stratified by age.

Results: Hospitalised COVID-19 episodes had a mean length of stay more than twice as long as hospitalised influenza episodes (17.7 days vs 8.3 days). The likelihood of all measures of disease severity was greater in COVID-19 episodes, and the odds of in-hospital mortality were five-fold higher in this group compared with seasonal influenza episodes (OR 5.07, 95% CI 4.29–5.99, $P < 0.001$). Greater likelihood of increased disease severity was observed for COVID-19 episodes in most age groups.

Conclusions: COVID-19 is a more severe illness than seasonal influenza in hospitalised cohorts. It is imperative that public health professionals ensure that evidence-based advocacy is part of the response to COVID-19 to tackle a dangerous “infodemic” that can undermine public health control measures.

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Introduction

In late December 2019, a cluster of pneumonia cases of unknown aetiology were identified in Wuhan, China.¹ The cause of this outbreak was subsequently identified as a novel strain of coronavirus named Severe Acute Respiratory Syndrome Coronavirus 2 (SARS CoV-2).² Patients with SARS CoV-2 presented with acute respiratory illness, which progressed to pneumonia and acute respiratory failure in many cases. This presentation came to be known as Coronavirus Disease 2019 (COVID-19).²

COVID-19 has become a pandemic affecting millions of people worldwide with the first case in Ireland notified on February 29th

2020.^{3,4} Similar to other countries, subsequent rapid spread in the Irish population mandated the introduction of significant non-pharmacological interventions including severe societal restrictions, known as “lockdowns”, in mid-March 2020.^{5,6} Whilst effective in limiting cases,^{7,8} relaxation of restrictions during the summer in Ireland was followed by a further surge of cases from late autumn 2020,⁹ resulting in the reintroduction of a modified lockdown on October 21st 2020.¹⁰ These restrictions were released again in December 2020, with an expectation of re-introduction in early 2021 to deal with a resurgence of cases following the holiday period.

Given the substantial impact lockdowns have had on wider social, economic and educational spheres,^{11,12} counter-arguments against their use are emerging. A common counter-argument is that COVID-19 is essentially “a bad flu” and that similar lockdowns are not implemented during influenza seasons. This argument has featured in the debate on pandemic response in Ireland and has

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even been used by leading medical professionals to advocate against the use of population-based restrictions for COVID-19 control.¹³ The World Health Organization (WHO) has identified misinformation and the “infodemic” as a critical challenge in addressing COVID-19.¹⁴ It undermines political leadership for difficult decision-making, as well as public support for public health measures, including potentially driving vaccine hesitancy in the future.^{15,16} Critical reviews of scientific evidence are central to building carefully designed and delivered COVID-19-specific risk communication strategies, which are essential to control both the disease and the associated “infodemic”.¹⁷

Current evidence indicates that hospitalised cases of COVID-19 were more likely to be male, younger and have fewer comorbidities than hospitalised cases of seasonal influenza.¹⁸ Hospitalised COVID-19 patients tended to have a longer mean length of hospital stay (14 days; 95% Confidence Interval (CI) 12–16, $P < 0.001$) when compared to hospitalised influenza A (6.5 days; 95% CI 6–8, $P < 0.001$) and hospitalised influenza B cases (6.7 days; 95% CI 5.3–8, $P < 0.001$).¹⁹ Mortality amongst hospitalised COVID-19 patients (6.5%; 95% CI 4.5–9, $P < 0.001$) was found to be similar to that of influenza A patients (6%; 95% CI 5–6.5, $P < 0.001$) but higher than that of influenza B patients (3%; 95% CI 2–4, $P < 0.001$); however, significant variability in mortality rates of influenza A was observed depending on the subtype of the virus involved as well as the reporting country.¹⁹

The assertion that COVID-19 was “just a bad flu” can be tested empirically to challenge the “infodemic” and better inform key decision-makers and the public. WHO’s Pandemic Influenza Severity Assessment (PISA) document identifies three concepts in order to determine the severity of infection with pandemic influenza: transmissibility, disease seriousness and impact.²⁰ The objective of this study was to measure the disease seriousness and impact of COVID-19 from the perspective of the Irish healthcare sector through descriptive epidemiological analysis of COVID-19-related hospital episodes with a specific focus on mean length of hospital stay, resource use during hospital stay and in-hospital mortality and benchmarking these results against influenza-related hospital episodes.

Methods

Data source

The Hospital In-Patient Enquiry (HIPE) system, managed by the Health Service Executive (HSE) Healthcare Pricing Office, was the data source for this study and was accessed via the Health Atlas Ireland system maintained by the HSE National Health Intelligence Unit.²¹ This database is a well-established, quality assured, national hospital care information system that uses International Classification of Disease-10 Australian Modification (ICD10 AM), Australian Classification of Health Interventions (ACHI) and Australian Coding Standards (ACS) coding to capture demographic, clinical and care data at discharge on all episodes of emergency and elective care across publicly funded hospitals in Ireland. While private hospital activity in Ireland is not captured in the system, in terms of inpatient care, that sector is focused almost exclusively on provision of elective care so HIPE is likely to have high completeness for acute hospital episodes related to COVID-19 and influenza in Ireland.

Inclusion criteria

The COVID-19 data included in this study consisted of episodes of hospitalisation discharged up to August 10th 2020; these data effectively captured the “first wave” of COVID-19 in Ireland.²²

COVID-19-related discharge episodes were defined by the presence of any of the following (ICD-10) codes: U07.1, B34.2 or B97.2. Influenza-related discharge episodes were identified between January and December of both 2018 and 2019 with the following ICD-10 codes: J09, J10.0, J10.1, J10.8, J11.0, J11.1 or J11.8. For both clinical conditions, relevant codes were identified across any of the 30 diagnostic fields on the episode’s HIPE record. The timeframe of influenza-related discharge episodes included in this study was selected with reference to national epidemiological surveillance information to assure it was both current and representative of recent variation in influenza seasonal severity.^{23,24}

Statistical analysis

In order to identify the impact of both COVID-19 and influenza on acute hospital services, the following variables were examined: mean length of hospital stay (days), Intensive Care Unit (ICU) admission requirement (number; %), haemodialysis requirement (ACHI Codes 131000-131008) (number, %) and invasive and non-invasive ventilation requirement (ACHI Codes 1388200/1388201/1388202 or 9220900/9220901/9220902) (number, %). The number and proportion of in-hospital mortality in both cohorts were also measured. To take account of potential differences in age-profiles of cases, data were stratified according to the following age-groups: 0–19 years, 20–39 years, 40–64 years, 65–84 years and 85 years and older. This age stratification allowed an analysis of COVID-19 patients that aligned with age categories commonly used for health service planning in Ireland: child and adolescent (0–19 years), early adulthood (20–39 years), middle adulthood (40–64 years), late adulthood (65–84 years) and elderly (85 years and older). This grouping also enabled statistical disclosure control. Odds ratios (ORs), with 95% CIs and significance tests for each variable measured, were also calculated using standard procedures to compare the likelihood of adverse outcomes in COVID-19-related episodes relative to influenza episodes.²⁵ For statistical disclosure control purposes, where observed cases were less than 5, these are not reported and are displayed as “<5”.

Results

In total, 4,837 COVID-19 and 5,369 influenza discharge episodes were identified, and the disease severity and impact were described and compared by age group.

Mean length of stay

Fig. 1 displays the mean length of stay for hospitalised episodes of COVID-19 and influenza stratified by age-group. Across all age-groups, hospitalised episodes of COVID-19 had longer lengths of stay compared to influenza episodes. In adult cases, this difference was most pronounced in the 65–84 year age group. In total, hospitalised COVID-19 episodes had a mean length of stay more than twice as long as hospitalised influenza (17.7 days vs 8.3 days).

Hospital resource requirement

Table 1 provides the proportion of COVID-19 and influenza hospital episodes requiring ICU admission, invasive and non-invasive ventilation and haemodialysis stratified by age group and compares the odds of each adverse outcome.

In general, a higher proportion of COVID-19-related hospital episodes were admitted to ICU than influenza-related hospital episodes, except for those aged 85 and older where the proportion of ICU admission was greater for influenza-related hospital episodes. The likelihood of ICU admission was significantly higher for

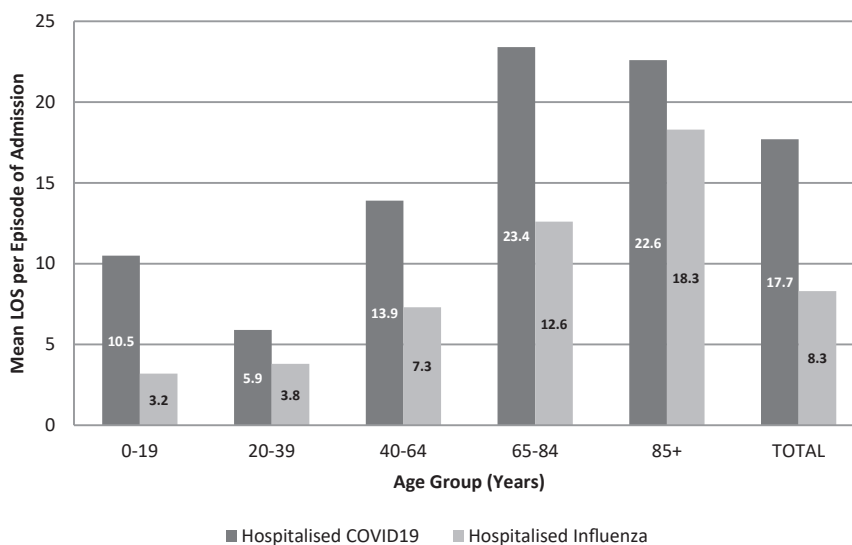


Fig. 1. Mean lengths of stay (LOS) in days per episode of admission for hospitalised COVID-19 and influenza patients, stratified by age group.

COVID-19-related hospital episodes than influenza-related episodes in age groups under 65 years and overall. Compared with influenza, COVID-19-related hospital episodes were almost two times more likely to be admitted to ICU (odds ratio [OR] 1.75, 95% CI 1.53–2.0, $P < 0.001$).

A similar pattern was observed when the requirement for ventilation and haemodialysis in COVID-19 episodes was compared to that for influenza. In general, the likelihood of invasive or non-invasive ventilation was greater among COVID-19 hospital episodes compared with influenza hospital episodes across all age groups (OR 2.31, 95% CI 2.01–2.66, $P < 0.001$), and statistically increased odds of ventilation were observed for COVID-19 hospital episodes in the 20–84 year age groups. The likelihood of haemodialysis was also greater among COVID-19 hospital episodes compared with influenza hospital episodes across all age groups (OR 2.97, 95% CI 2.24–3.95, $P < 0.001$), and statistically increased odds of haemodialysis were observed for COVID-19 hospital episodes aged older than 40 years.

In-hospital mortality

Table 1 also provides the proportion of COVID-19 and influenza hospital episodes where in-hospital mortality was recorded, stratified by age-group. Overall, across all age groups, 15.3% of COVID-19-related hospital episodes experienced in-hospital mortality compared with 3.4% of influenza-related hospital episodes indicating a five-fold increased likelihood of in-hospital mortality for hospital episodes related to COVID-19 (OR 5.07, 95% CI 4.29–5.99, $P < 0.001$). While an increased likelihood of in-hospital mortality was observed for COVID-19-related hospital episodes in each age group, the difference was significant in age groups older than 40 years, with ORs increasing from 2.27 (95% CI 1.43–3.61, <0.001) in the 40–64 year group to 4.99 (95% CI 3.54–7.03, <0.001) in the 85 years and older group.

Discussion

This study was undertaken to help tackle the “infodemic” threatening the public health response to the COVID-19 pandemic in Ireland. Using Irish national inpatient data, it identified that COVID-19-related episodes had a greater likelihood of more intense

resource requirement and adverse outcomes than influenza episodes. These differences were significant for the overall population and remained significant in most age-groups following stratification.

Comparison with other studies

Our findings are similar to other comparisons of COVID-19 and influenza patients. In Pormohammad et al.’s systematic review, COVID-19 patients had longer mean lengths of hospitalisation compared to influenza A and B patients (14 days vs 6.5 and 6.7 days respectively),¹⁹ which is similar to the findings of this study (17.7 vs 8.3 days for COVID-19 and influenza respectively). Pormohammad et al. reported similar rates of mortality in COVID-19 and influenza A patients (6.5% vs 6%) but higher rates of mortality in COVID-19 versus influenza B patients (6.5% vs 3%).¹⁹ This study did not distinguish between influenza strains as this was not recorded in the ICD coding in the data source, but a much higher rate of in-hospital mortality in COVID-19 compared with influenza patients (15.3% vs 3.4%) was found. Influenza patients admitted to hospitals in Ireland in 2018 and 2019 were examined and data were included from influenza seasons where influenza B was the predominant circulating strain (2017/2018 season) and where influenza A was the predominant circulating strain (2018/2019) in Ireland,^{23,24} resulting in outcomes where both influenza strains are captured. We report higher mortality rates to those reported by Pormohammad et al., which reflects our focus on hospitalised cases, and we provide greater detail on age patterning of mortality for COVID-19 hospitalisations relative to seasonal influenza.¹⁹

COVID-19 patients aged 65–84 years in this study did not have significantly higher odds of ICU admission compared to similarly aged influenza patients. However, COVID-19 patients aged 85 years and older were significantly less likely to be admitted to ICU compared to influenza patients in the same age group. This was an unexpected finding, but should be interpreted with caution given the small numbers and the lack of full adjustment for comorbidities and other factors related to clinical decisions regarding ICU admission. While the finding raises potential questions about clinical prioritisation for scarce ICU resources, compared to influenza patients, COVID-19 patients in this age group had similar odds of receiving ventilator support. This included non-invasive

Table 1 Comparison of age-stratified descriptive epidemiology and unadjusted odds ratios for ICU admission, invasive and non-invasive ventilation, haemodialysis and in-hospital mortality in episodes of COVID-19 and influenza hospitalisations.

Age Group (Years)	Disease	ICU Admission			Ventilation			Haemodialysis			In-Hospital Mortality		
		n (%)	OR ^a (95% CI)	P-value ^b	n (%)	OR ^a (95% CI)	P-value ^b	n (%)	OR ^a (95% CI)	P-value ^b	n (%)	OR ^a (95% CI)	P-value ^b
0–19	Influenza	56 (4.0)	1.0		60 (4.3)	1.0		<5	1.0		<5	1.0	
	COVID-19	9 (10.2)	2.73 (1.30–5.72)	P = 0.008	5 (5.7)		ns	<5	8.03 (0.72–89.41)	ns	<5	8.03 (0.72–89.41)	ns
20–39	Influenza	33 (4.5)	1.0		14 (1.9)	1.0		7 (0.9)	1.0		<5	1.0	
	COVID-19	44 (7.5)	1.70 (1.06–2.70)	P = 0.03	35 (6.0)	3.21 (1.71–6.03)	<0.001	7 (1.2)	1.24 (0.43–3.55)	ns	9 (1.5)	2.80 (0.86–9.15)	ns
40–64	Influenza	100 (9.0)	1.0		80 (7.1)	1.0		33 (2.9)	1.0		24 (2.2)	1.0	
	COVID-19	298 (18.0)	2.22 (1.74–2.82)	<0.001	297 (17.9)	2.82 (2.17–3.65)	<0.001	82 (4.9)	1.70 (1.13–2.57)	P = 0.011	79 (4.8)	2.27 (1.43–3.61)	<0.001
65–84	Influenza	173 (10.2)	1.0		147 (8.7)	1.0		26 (1.5)	1.0		108 (6.4)	1.0	
	COVID-19	210 (11.2)	1.11 (0.90–1.37)	ns	252 (13.5)	1.64 (1.32–2.03)	<0.001	72 (3.8)	2.56 (1.63–4.04)	<0.001	417 (22.3)	4.21 (3.36–5.26)	<0.001
85+	Influenza	24 (5.4)	1.0		24 (5.4)	1.0		<5	1.0		47 (10.6)	1.0	
	COVID-19	14 (2.2)	0.40 (0.20–0.77)	P = 0.007	38 (6.0)	1.12 (0.66–1.89)	ns	13 (2.1)	19.33 (1.15–326.03)	P = 0.039	235 (37.2)	4.99 (3.54–7.03)	<0.001
All	Influenza	385 (7.2)	1.0		325 (6.0)	1.0		67 (1.2)	1.0		185 (3.4)	1.0	
	COVID-19	575 (11.9)	1.75 (1.53–2.00)	<0.001	627 (13.0)	2.31 (2.01–2.66)	<0.001	175 (3.6)	2.97 (2.24–3.95)	<0.001	741 (15.3)	5.07 (4.29–5.99)	<0.001

ns: Not Significant; ICU: Intensive Care Unit; OR: Odds Ratio; COVID-19: Coronavirus Disease 2019; CI: confidence interval.

^a ORs were calculated with 95% confidence intervals and P values based on Chi-squared tests of proportions.

^b Significance level set at a p-value ≤0.05. Characteristics meeting this significance threshold are shaded in grey.

ventilation support delivered outside the ICU setting, which may have been a more clinically appropriate care given these patients' individual needs. Furthermore, COVID-19 patients in this age group were more likely to receive haemodialysis care than influenza patients.

Auvinen et al. reported higher proportions of ICU admission (29% vs 6%), invasive ventilation (29% vs 3%) and in hospital mortality (4% vs 0%) in COVID-19 patients compared to influenza patients.²⁶ While we also reported higher rates of these adverse outcomes for COVID-19 hospitalisations, as discussed above, our age-specific findings on ICU admission are different, possibly reflecting differences in local resource availability and clinical practices. Cobb et al. examined COVID-19 and influenza patients admitted to ICUs.²⁷ Logistic regression modelling reported no difference in the odds of renal replacement therapy and mechanical ventilation in COVID-19 patients compared to influenza patients, but did report an almost two-fold increase in odds of in hospital mortality for COVID-19 patients compared to influenza patients following adjustment for age, gender and a number of comorbidities. These findings are similar to those reported in this study in terms of increased likelihood of adverse outcome for COVID-19 hospitalised patients; however, we reported unadjusted ORs and used stratification to confirm the age-patterning of risk. Neither Auvinen et al. nor Cobb et al. stratified their outcomes analysis by age group.^{26,27} This comparison shows that our study supports many of the findings in medical literature comparing COVID-19 patients and influenza patients, specifically longer lengths of hospitalisation and higher rates of mortality, ICU admission and ventilation in COVID-19 patients. It also provides a valuable insight into the impact of COVID-19 on Irish hospitals during the “first wave” of the pandemic.

Strengths and weaknesses

This study is the first to provide a comparison of COVID-19 and influenza episodes of hospitalisation in the Irish population. A robust and definitive national dataset was used to identify large numbers of episodes of hospitalisation in both the COVID-19 (n = 4,837) and influenza cohorts (n = 5,369).²¹ This dataset is quality assured and has been used by other groups to produce epidemiological studies.²⁸

While we have not adjusted for all potential prognostic factor differences between the two groups compared, our view is that our approach of age-stratification is epidemiological and clinically useful since it provides an opportunity to examine the effect of age-group on the relative likelihood of adverse outcome within each age stratum. Most other prognostic factors, such as comorbidity, are likely to be age-related and similar between the two groups. This is supported by Pormohammad et al.'s finding of a similar occurrence of comorbidities such as cardiovascular/cerebrovascular disease, chronic respiratory disease and diabetes amongst COVID-19 and influenza cohorts.¹⁹

Identification of influenza episodes focused on 2018 and 2019, and the question of representativeness and comparability may arise. The majority of COVID-19 episodes included in this study were notified from March 2020 onwards and while data on influenza hospitalisations in the same period was available, we chose not to use this since the influenza season in Ireland was ending when COVID-19 arose and we have since observed significant changes in influenza activity to patterns expected owing to the wider impact of non-pharmacological measures.²⁹ The 2017/2018 influenza season in Ireland was severe due to a mismatch between the vaccine used and the circulating strain that season.²³ The 2018/2019 season in Ireland was a moderate season where the circulating strain matched the vaccine used that

season.²⁴ Using aggregated data from both years allowed us to incorporate outcomes from both a severe and moderate season and allowed us to estimate a “typical” influenza season.

A limitation of HIPE data on both influenza and COVID-19 hospitalisations was that in order to maintain patient anonymity, geo-location of individual episodes was limited to their county of residence, which is used in Ireland to assign an area-based deprivation index so as to examine the effect of socio-economic status on health.²¹ Additionally, ethnicity of episodes of hospitalisation was not recorded in the HIPE database.²¹ As a result, analysis of episode distribution according to deprivation indices or patient ethnicity was not possible.

Data on hospitalised episodes of influenza sourced from HIPE were not stratified according to the serotype of influenza identified because the ICD-10 coding does not distinguish this detail. Mortality rates varied when COVID-19 was compared to influenza A and influenza B.¹⁹ However, as our study’s cohort of hospitalised influenza episodes included a season where influenza A was the dominant circulating strain and a season where influenza B was the dominant circulating strain, although influenza mortality rates were not stratified by serotype, they are likely to be representative of both strains. Finally, seasonal influenza vaccine may have attenuated resource use and outcomes of hospitalised episodes. However, the uptake of seasonal influenza vaccines by individuals in high risk groups in Ireland has consistently failed to reach the target of 75% as set by WHO.³⁰ HPSC reported influenza vaccine uptake for those aged 65 years and older in the 2017/2018 season to be 57.6% and in the 2018/2019 season to be 65.9% both far below the target.³¹ Influenza vaccine uptake amongst attendees at a respiratory outpatient clinic in Ireland was as low as 54%.³² Uptake of influenza vaccine in patients aged over 65 actually fell in Ireland between the 2004/2005 season and the 2014/2015 season.³³ Therefore, whilst influenza vaccination may have played a role in limiting the numbers of influenza hospitalisations and the clinical severity of these cases, it is unlikely to explain the increased disease severity and poorer outcomes observed in this study in COVID-19 patients compared with influenza patients, especially in patients aged less than 65 years.

Summary and conclusion

Our study adds to existing evidence confirming that COVID-19 is overall more severe than influenza amongst hospitalised patients. It corroborates this evidence in the Irish population using a robust national dataset and develops it by providing an epidemiologically and clinically relevant examination of the comparison of the two diseases by age group. It supports important public health efforts, such as targeting protective measures for higher-risk groups. Crucially, it provides evidence to counter arguments that COVID-19 is “just a bad flu”. In the era of misinformation and “infodemics”, public health professionals must not only combat the disease but must also ensure that they are positively engaged in evidence-based public health advocacy with accurate and relevant information to underpin discussion on measures to limit the impact of COVID-19.

Author statements

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Ethical approval

Ethical review was not required for this study. The data used in the study are controlled by the Health Service Executive (HSE) in Ireland. The study authors are registered medical professionals. Legal duties, organisational policies and good practices were observed in data handling and the data processing for the study was conducted for medical purposes by the authors to inform the statutory function of the HSE in Ireland to improve, promote and protect the health and welfare of the public (Section 7, Health Act 2004), thus consistent with General Data Protection Regulations and their application in Ireland.³⁴ HIPE data are anonymised for users and usual practices regarding statistical disclosure control were applied.

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Competing interests

None declared.

References

1. World Health Organization (WHO). *Timeline: WHO's COVID-19 response*. 2020. <https://www.who.int/emergencies/diseases/novel-coronavirus-2019/interactive-timeline>. [Accessed 14 December 2020].
2. Zheng J. SARS-CoV-2: an emerging coronavirus that causes a global threat. *Int J Biol Sci* 2020;16(10):1678–85. <https://doi.org/10.7150/ijbs.45053>. Published 2020 Mar 15.
3. World Health Organization (WHO). *Coronavirus disease (COVID-19) pandemic; Numbers at a glance*. 2020. <https://covid19.who.int/>. [Accessed 12 November 2020].
4. RTE. *First case of Covid-19 diagnosed in east of Ireland*. 2020. <https://www.rte.ie/news/coronavirus/2020/0229/1119357-coronavirus-ireland/>. [Accessed 12 November 2020].
5. European Centre for Disease Prevention and Control (ECDC). *Risk assessment on COVID-19, 4 December 2020*. 2020. <https://www.ecdc.europa.eu/en/current-risk-assessment-novel-coronavirus-situation>. [Accessed 14 December 2020].
6. RTE. *Timeline: six months of Covid-19*. 2020. <https://www.rte.ie/news/newslens/2020/0701/1150824-coronavirus/>. [Accessed 20 July 2020].
7. Flaxman S, Mishra S, Gandy A, Unwin H, Mellan T, Coupland H, et al. Estimating the effects of non-pharmaceutical interventions on COVID-19 in Europe. *Nature* 2020;584:257–61. <https://doi.org/10.1038/s41586-020-2405-7>.
8. Davies NG, Kucharski AJ, Eggo RM, Gimma A, Edmunds WJ, Jombart T, et al. Effects of non-pharmaceutical interventions on COVID-19 cases, deaths, and demand for hospital services in the UK: a modelling study. *Lancet Public Heal* 2020;5(7):e375–85. [https://doi.org/10.1016/S2468-2667\(20\)30133-X](https://doi.org/10.1016/S2468-2667(20)30133-X).
9. Health Protection Surveillance Centre. *Epidemiology of COVID-19 in Ireland*. 2020. [https://www.hpsc.ie/a-z/respiratory/coronavirus/novelcoronavirus/casesinireland/epidemiologyofcovid-19inireland/september2020/COVID-19_Daily_epidemiology_report_\(NPHET\)_20200928_-_Website.pdf](https://www.hpsc.ie/a-z/respiratory/coronavirus/novelcoronavirus/casesinireland/epidemiologyofcovid-19inireland/september2020/COVID-19_Daily_epidemiology_report_(NPHET)_20200928_-_Website.pdf). [Accessed 1 November 2020].
10. Government of Ireland. *Ireland placed on level 5 of the plan for living with COVID-19*. 2020. <https://www.gov.ie/en/press-release/66269-ireland-placed-on-level-5-of-the-plan-for-living-with-covid/>. [Accessed 29 October 2020].
11. Government of Ireland. *Report on social implications of COVID-19 in Ireland; preliminary assessment*. 2020. <https://assets.gov.ie/74373/5cc1bbf59b447d3b841fa43cecf79d.pdf>. [Accessed 9 December 2020].
12. Economic and Social Research Institute. *The environmental and economic impacts of the COVID-19 crisis on the Irish economy*. 2020. https://www.esri.ie/system/files/publications/RS106_2.pdf. [Accessed 9 December 2020].
13. The Irish Times. *Draconian' restrictions around Covid-19 condemned by HSE doctor*. 2020. <https://www.irishtimes.com/news/health/draconian-restrictions-around-covid-19-condemned-by-hse-doctor-1.4352701>. [Accessed 16 November 2020].
14. World Health Organization (WHO). *Managing the COVID-19 infodemic: promoting healthy behaviours and mitigating the harm from misinformation and disinformation*. 2020. <https://www.who.int/news/item/23-09-2020-managing>

- the-covid-19-infodemic-promoting-healthy-behaviours-and-mitigating-the-harm-from-misinformation-and-disinformation. [Accessed 16 November 2020].
15. The Lancet. The truth is out there, somewhere. *Lancet* 2020;**396**(10247):291. [https://doi.org/10.1016/S0140-6736\(20\)31678-0](https://doi.org/10.1016/S0140-6736(20)31678-0).
 16. The Lancet Infectious Diseases. The COVID-19 infodemic. *Lancet Infect Dis* 2020;**20**(8):875. [https://doi.org/10.1016/S1473-3099\(20\)30565-X](https://doi.org/10.1016/S1473-3099(20)30565-X).
 17. Eysenbach G. How to fight an infodemic: the four pillars of infodemic management. *J Med Internet Res* 2020;**22**(6):e21820. <https://doi.org/10.2196/21820>.
 18. Burn E, You SC, Sena AG, Kostka K, Abedtash H, Abrahao MTF, et al. An international characterisation of patients hospitalised with COVID-19 and a comparison with those previously hospitalised with influenza. *medRxiv* 2020. <https://doi.org/10.1101/2020.04.22.20074336>. 2020.04.22.20074336.
 19. Pormohammad A, Ghorbani S, Khatami A, Razizadeh MH, Alborzi E, Zarei M, et al. Comparison of influenza type A and B with COVID-19: a global systematic review and meta-analysis on clinical, laboratory and radiographic findings. *Rev Med Virol* 2020:e2179. <https://doi.org/10.1002/rmv.2179>.
 20. World Health Organization (WHO). *Pandemic Influenza Severity Assessment (PISA): a WHO guide to assess the severity of influenza epidemics and pandemics*. 2017. <https://apps.who.int/iris/bitstream/handle/10665/259392/WHO-WHE-IHM-GIP-2017.2-eng.pdf?sequence=1>. [Accessed 9 November 2020].
 21. Healthcare Pricing Office. *Hospital in patient Enquiry instruction manual*. 2016. http://www.hpo.ie/hipe/hipe_instruction_manual/HIPE_Instruction_Manual_1.1.2016.pdf. [Accessed 9 November 2020].
 22. Health Protection Surveillance Centre. *Epidemiology of COVID-19 in Ireland*. 2020. [https://www.hpsc.ie/a-z/respiratory/coronavirus/novelcoronavirus/casesinireland/epidemiologyofcovid-19inireland/july2020/COVID-19_Daily_epidemiology_report_\(NPHET\)_31072020%20-%20Website.pdf](https://www.hpsc.ie/a-z/respiratory/coronavirus/novelcoronavirus/casesinireland/epidemiologyofcovid-19inireland/july2020/COVID-19_Daily_epidemiology_report_(NPHET)_31072020%20-%20Website.pdf). [Accessed 9 December 2020].
 23. Health Protection Surveillance Centre. *Annual Epidemiological Report; Influenza and other seasonal respiratory viruses in Ireland, 2017/2018*. 2020. https://www.hpsc.ie/a-z/respiratory/influenza/seasonalinfluenza/surveillance/influenzasurveillancereports/seasonsummaries/Influenza%202017-2018%20Annual%20Summary_Final.pdf. [Accessed 16 November 2020].
 24. Health Protection Surveillance Centre. *Annual Epidemiological Report; Influenza and other seasonal respiratory viruses in Ireland, 2018/2019*. 2020. https://www.hpsc.ie/a-z/respiratory/influenza/seasonalinfluenza/surveillance/influenzasurveillancereports/seasonsummaries/Influenza%202018-2019%20Season_Summary.pdf. [Accessed 16 November 2020].
 25. Lewis G, Sheringham J, Lopez Bernal J, Crayford T. *Mastering public health*. 2nd ed. Florida: CRC Press; 2017. p. 650.
 26. Auvinen R, Nohynek H, Syrjänen R, Ollgren J, Kerttula T, Mantyla J, et al. Comparison of the clinical characteristics and outcomes of hospitalized adult COVID-19 and influenza patients - a prospective observational study. *Infect Dis* 2020:1–11. <https://doi.org/10.1080/23744235.2020.1840623> (Lond).
 27. Cobb NL, Sathe NA, Duan KI, Seitz KP, Thau MR, Sung CC, et al. Comparison of clinical features and outcomes in critically ill patients hospitalized with COVID-19 versus influenza. *Ann Am Thorac Soc* 2020. <https://doi.org/10.1513/AnnalsATS.202007-805OC>. doi:10.1513/AnnalsATS.202007-805OC.
 28. Moloney ED, Smith D, Bennett K, O'Riordan D, Silke B. Do consultants differ? Inferences drawn from hospital in-patient enquiry (HIPE) discharge coding at an Irish teaching hospital. *Postgrad Med J* 2005;**81**(955):327–32. <https://doi.org/10.1136/pgmj.2004.026245>.
 29. Health Service Executive. *Influenza surveillance in Ireland- weekly report; week 49 2020 (30th November-6th December 2020)*. 2020. https://www.hpsc.ie/a-z/respiratory/influenza/seasonalinfluenza/surveillance/influenzasurveillancereports/20202021season/Influenza_Surveillance_Report_Week%2049%202020_Finalv1.0_10122020.pdf. [Accessed 11 December 2020].
 30. World Health Organization (WHO). Fifty-sixth World Health Assembly: Prevention and control of influenza pandemics and annual epidemics. Available at: https://www.who.int/immunization/sage/1_WHA56_19_Prevention_and_control_of_influenza_pandemics.pdf. [Accessed on 27 January 2021].
 31. Health Protection Surveillance Centre. Seasonal influenza vaccine uptake (provisional) in older people in Ireland, September 2019–May 2020. Available at: https://www.hpsc.ie/a-z/respiratory/influenza/seasonalinfluenza/influenzaandadults65yearsandolder/Seasonal%20Flu%20Vacc%20Uptake_65%20report_Sep%202019%20May%202020%20provisional%20for%20website.pdf. [Accessed 27 January 2021].
 32. Rossiter A, O'Morain NR, Varghese C, Lane S. Seasonal influenza vaccine uptake in a respiratory outpatients clinic. *Ir Med J* 2017 Feb 10;**110**(2):517. PMID: 28657262.
 33. Chaintarli K, Barrassa A, Cotter S, Mereckiene J, O'Donnell J, Domegan L. Decrease in the uptake of seasonal influenza vaccine in persons aged 65 Years and older in Ireland since the 2009 influenza A (H1N1) Pdm09 pandemic. *Ir Med J* 2017 Oct 10;**110**(9):630. PMID: 29372945.
 34. Irish Statute Book. *Health Act 2004*. 2020. <http://www.irishstatutebook.ie/eli/2004/act/42/section/7/enacted/en/html#sec7>. [Accessed 15 December 2020].



Review Paper

Knowledge, attitudes, and practices of the general population about Coronavirus disease 2019 (COVID-19): a systematic review and meta-analysis with policy recommendations

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ABSTRACT

Objectives: This study aimed to investigate and synthesize the current evidence on knowledge, attitudes, and practices (KAPs) of the general population regarding COVID-19.

Study design: This is a systematic review and meta-analysis.

Methods: We conducted a systematic search on PubMed/LitCovid, Scopus, and Web of Sciences databases for papers in the English language only, up to 1 January 2021. We used the Joanna Briggs Institute checklist developed for cross-sectional studies to appraise the quality of the included studies. All stages of the review conducted by two independent reviewers and potential discrepancies were solved with a consultation with a third reviewer. We reported the result as number and percentage. A meta-analysis conducted using a random effect model with a 95% confidence interval.

Results: Forty-eight studies encompassing 76,848 participants were included in this review. 56.53% of the participants were female. The mean age of the participants was 33.7 years. 85.42% of the included studies were scored as good quality, 12.50% as fair quality, and the remaining (2.08%) as low quality. About 87.5% examined all three components of the KAPs model. The knowledge component was reported as good and poor in 89.5% and 10.5% of the included studies, respectively. Of the studies that examined the attitude component, 100% reported a positive attitude. For the practice component, 93.2% reported satisfactory practice, and 6.8% poor practice. The result of the meta-analysis showed that the overall score of KAPs components about COVID-19 were 78.9, 79.8, and 74.1, respectively.

Conclusions: This systematic review and meta-analysis showed that the overall KAP components in the included studies were at an acceptable level. In general, knowledge was at a good level, the attitude was positive and practice was at a satisfactory level. Using an integrated international system can help better evaluate these components and compare them between countries.

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Introduction

Coronavirus disease 2019 (COVID-19) was reported on 31st December 2019 from Wuhan, China, and announced by the World Health Organization (WHO) as a pandemic on 11th March 2020.^{1,2} To date (27 January 2021), it was estimated that about 100 million people were infected with COVID-19 worldwide, of which about two million have died.³

COVID-19 is characterized by several flu-like symptoms including fever, respiratory problems (dry cough, shortness of

breath or difficulty breathing, sore throat), chills, headache, and loss of taste. In addition, this disease is much more severe with men, higher age groups, and patients with other pre-existing conditions, such as cardiovascular disease, chronic respiratory disease, diabetes, and hypertension.^{4,5} Based on existing evidence, about 81% of COVID-19 cases are mild, 14% are severe, and 5% are critical. The median time from symptoms onset to clinical recovery is approximately two weeks for mild cases and three to six weeks for severe or critical cases.⁶ The incubation period for this disease was reported as 2–14 days based on WHO reports. The mortality rate for this disease is different among countries and was reported between 2% and 5%.^{7,8} The most important ways to prevent this disease are to use a mask and maintain social distance.^{9–11} So far, there have been several cases of infection in the general public, especially doctors and medical staff, some of which have led to death.^{12–14}

Considering the extent and progress of COVID-19 disease and its major effects on economic, social, political, and cultural dimensions of all countries,^{15,16} people with COVID-19 must be motivated, informed, and engaged in all aspects of the disease. From the onset of the disease until now, various studies conducted worldwide have investigated this disease and some of these studies have examined the knowledge, attitudes, and practices (KAPs) of people with COVID-19. Having enough knowledge about a disease can always affect people's attitudes and practices, and on the other hand, negative attitudes and practices can increase the risk of disease and death. Therefore, understanding the general population's KAPs and knowing potential risk factors can help to achieve the outcomes of planned behavior.^{17,18}

Given the importance of the issue, conducting a review of studies that have examined the KAPs of individuals and summarizing the results can provide solid evidence for decision-makers in all countries to better manage the disease. Thus, this study aimed at conducting a systematic review to synthesize current evidence on KAPs of the general population with COVID-19 worldwide.

Materials and methods

Protocol and registration

We conducted a systematic review of the existing evidence related to KAPs of COVID-19 patients worldwide following Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) statements ([Appendix Supplementary file 1](#)).¹⁹ We also registered a protocol for this systematic review in the International Prospective Register of Systematic Reviews.²⁰

Eligibility criteria

We included all studies which met the following inclusion criteria: 1) cross-sectional survey; 2) investigate at least one component of the KAPs model regarding COVID-19 disease worldwide; 3) published or in-press original paper; 4) in English; 5) with a sample representative general population. No restrictions were applied to the setting, time, or quality of the study.

Information sources, search and study selection

We search the PubMed/LitCovid, Scopus, and Web of Sciences for papers in the English language only, up to 1 January 2021. We conducted a search in Google Scholar for retrieving studies that were not cited in the abovementioned databases. In addition, the reference lists of the final included articles were hand-searched. The keywords used in the search were attitude, knowledge, practice, awareness, perception, action, COVID-19, coronavirus disease,

SARS-CoV-2, and severe acute respiratory syndrome coronavirus 2. The full search strategy for the PubMed database is provided in [Supplementary file 2](#). When the search was complete, all records were transferred to the Endnote software (V. X8; Clarivate Analytics, Philadelphia, PA) and duplicates were removed. Then, studies based on the title, abstract, and full text were screened by two researchers independently by considering the prespecified eligibility criteria. Disagreements were solved through consultation with a third researcher.

Data collection process and data item

Two researchers independently engaged in the data collection process and extracted data including author, year, journal name, location, study design, data collection tools, sample size, focusing group, mean age or range, gender percent, and result related to KAPs model components. Potential disagreements were solved through consultation with a third researcher.

Quality appraisal

Included studies were critically appraised by two researchers independently. We used the Joanna Briggs Institute checklist developed for cross-sectional studies to appraise the quality of the included studies.²¹ This checklist contains eight simple and clear questions that cover topics such as inclusion criteria for sample; details about study subjects and setting; validity and reliability; criteria for measurement of the condition; confounding variables; and statistical analysis.²² The answer to each questions is yes, no, unclear, and not applicable. Potential discrepancies were resolved by consultation with a third researcher.

Synthesis of results

Descriptive analyses were carried out in most sections and the pooled data reported as a number or percentage for similar data items. We used Microsoft Excel software to design the charts. We categorized the result of each component based on the study by Bdair et al.²³ They categorized each component in two categories as follows: knowledge: (good ≥ 50) or (poor < 50), attitude: (positive ≥ 50) or (negative < 50), and practice: (satisfactory ≥ 50) or (unsatisfactory < 50). The Q-value was applied to discover between-study heterogeneity, and the I^2 statistic was calculated to assess statistical heterogeneity.²⁴ Based on Cochrane criteria if the heterogeneity was ≥ 50 , we used the random effect model.²⁵ Although there was heterogeneity between the studies above, this was negligible due to differences in settings as well as the use of different questionnaires. However, we used subgroup analysis based on regions to reduce this heterogeneity.²⁶ In addition, a meta-analysis using a random effect model with a 95% confidence interval (CI) was conducted via CMA software (Version 2) based on the percent reported for each component of the KAPs model of the included studies. Publication bias was assessed using Begg's and Egger's tests and visual inspection of the funnel plot.

Additional analysis

We contacted ten experts in the related field including health promotion, public health, health policy, epidemiology, and behavioral science via email and asked for their opinions on how to increase the levels of these components in the community. Comments were translated verbatim and then analyzed using content analysis. The results of this section are presented as policy recommendations.

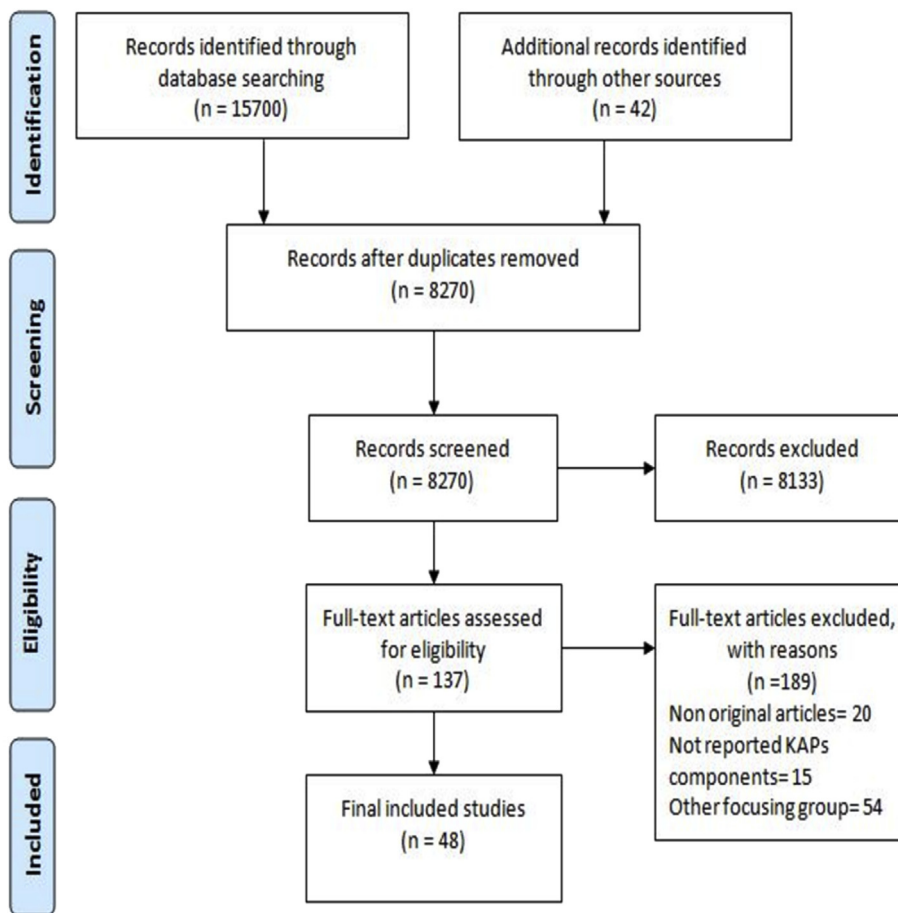


Fig. 1. PRISMA flow diagram.

Results

Study selection

A total of 15,742 records were retrieved from our database search. After removing duplicate, 8270 records were screened by title, abstract, and full text based on eligibility criteria, of which forty-eight studies were included in the final review.^{23,27–73} The PRISMA flow diagram for the complete study selection process is presented in Fig. 1.

Study characteristics

Forty-two studies encompassing 76,848 participants were included. In addition, 56.53% of the participants were female. The mean age of the participants was 33.7 years. Most studies were from Asia, Africa, and America, (Fig. 2A). The most important method of data collection was online questionnaires (Fig. 2B). Most studies examined all three components of the KAPs model, but some studies examined two components or one component. More details about the characteristics of included studies are presented in Table 1.

Quality appraisal

The overall mean quality score of the included studies was 5.70. Of the included studies, 41 studies (85.42%) were scored as good quality (score ≥ 6), 6 (12.50%) as fair quality (score 3–5), and

remaining (2.08%) as low quality (score <3) (Fig. 3). The lowest and highest quality scores in the studies were two and six, respectively. None of the studies scored on questions 5 and 6, which were related to identification and deal with confounding variables in the studies (for more details about items see Appendix Supplementary file 3).

Synthesis of results

Among the included studies, 87.5% examined all three components of the KAPs model simultaneously. The most studied component in the studies was the knowledge component with about 100%, followed by attitude and practice with 95.8% and 91.6%, respectively (Table 2, Fig. 4).

Of the studies that examined the knowledge component, 89.5% reported good knowledge, and 10.5% poor knowledge. As well as, of the studies that examined the attitude component, 100% reported a positive attitude. For the practice component, 93.2% reported satisfactory practice, and 6.8% unsatisfactory practice (Table 2, Fig. 5).

Meta-analysis

Based on the meta-analysis, the pooled overall score of KAPs components were 78.9 (95% CI: 96.1, 86.2, $P = 0.001$), 79.8 (95% CI: 80.8, 88.4, $P = 0.001$), and 74.1 (95% CI: 56.0, 86.5, $P = 0.011$), respectively. The results of subgroup analysis based on different continents of Africa, America, and Asia were 74.1, 74, and 83.8% for knowledge, 78.7, 63.2, and 85% for attitude, and 59.6, 78.5, and 81.5

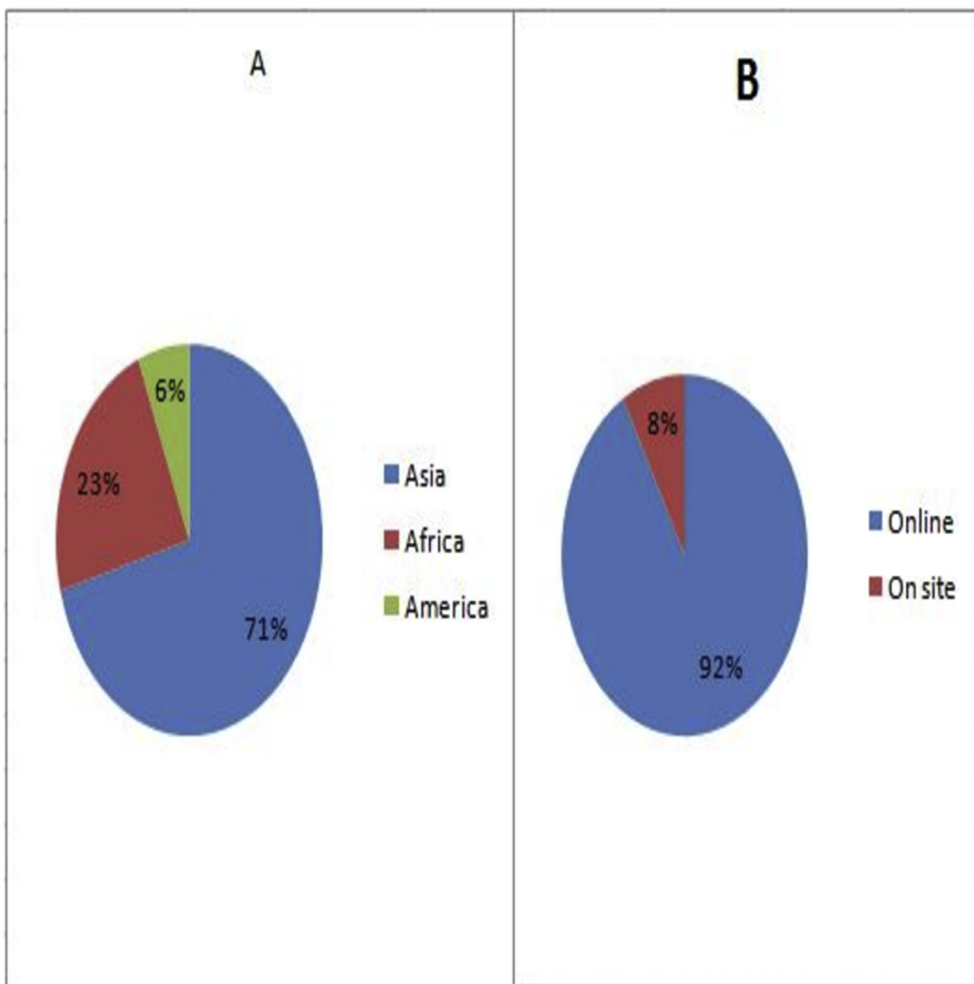


Fig. 2. The percentage of the included studies based on location (A) and data collection methods (B).

for practice components, respectively. The Asia continent had the highest percentage in all three components. The America continent had the lowest percentage in terms of knowledge and attitude, and the Africa continent had the lowest percentage in terms of practice (Table 3). Visual inspection of the funnel plot and results of Begg's (0.068) and Egger's test (0.082) did not showed significant evidence of publication bias (Appendix Supplementary file 4).

Policy recommendations

In accordance with experts, the policy recommendations for promoting the KAP components were as follow: holding training courses through virtual mass media; increase the commitment of government officials and policymakers to help conduct training courses; providing appropriate and evidence-based training content to enhance the components of the KAP; designing an integrated international system for measuring cup levels and comparing it between countries.

Discussion

COVID-19 has had serious, long-term, and sometimes irreparable effects on all aspects of the daily lives of individuals and society.^{74,75} Getting informed from the knowledge, attitude, and practice of different general population can play a vital role in shaping the prevention behavior against COVID-19,^{76,77} so the

study of these components in different communities and between different groups seems necessary.

Strength and weakness

One of the most important strengths of this study was that all stages of the study were conducted with two researchers and in all stages, in cases of disagreement, the third person and consensus were used. In addition, registering the protocol of this study and reviewing and modifying it in the PROSPERO platform is the strength of this study. A large number of the included studies did not report the validity and reliability of the questionnaires. The main reason for this is the rush to publish articles related to coronavirus disease. The included studies were from both high- and low-income countries and therefore generalization of results to all countries should be done with caution. On the other hand, owing to the high speed of publication of articles in this field, some other studies may be published at the time of writing the article and the review process, which has been missed. Of course, owing to the high speed of publishing articles, this limitation is inevitable.

Summary of study findings

We found that about 90% of the samples had good knowledge of COVID-19 (overall score: 78.9%). In addition, 100% of the samples were reported positive attitudes regarding COVID-19 (overall score:

Table 1
Summary characteristics of the included studies.

Reference (Author, Year)	Journal	Location	Study Design	Data Collection tool	Sample Size	Male (%)	Mean Age or range
Adesegun et al., 2020 ²⁷	American Journal of Tropical Medicine and Hygiene	Nigeria	Cross-sectional	Online questionnaire/ Google Form	1015	45.9	26.6
Alahdal et al., 2020 ²⁸	Journal of Infection and Public Health	Saudi Arabia	Cross-sectional	Online questionnaire/ Google Form	1767	25	18-60+
Al-Hanawi et al., 2020 ²⁹	Frontiers in Public Health	Saudi Arabia	Cross-sectional	Online questionnaire/ SurveyMonkey	3388	41.9	18-60+
Alhazmi et al., 2020 ³⁰	Journal of Public Health Research	Saudi Arabia	Cross-sectional	Online questionnaire/ Google Form	1513	45	18-60+
Alobuia et al., 2020 ³¹	Journal of Public Health	USA	Cross-sectional	Telephone survey	1216	48	18-60+
Amalakanti et al., 2020 ³²	Indian Journal of Medical Microbiology	India	Cross-sectional	Online questionnaire/ Google Form	1837	56.5	16-50+
Ashiq et al., 2020 ³³	Bangladesh Journal of Medical Science	Pakistan	Cross-sectional	Online questionnaire/ Google Form	316	46.5	16-40+
Azlan et al., 2020 ³⁴	PLOS ONE	Malaysia	Cross-sectional	Online questionnaire/ Survey Monkey	4850	42.1	34
Baig et al., 2020 ³⁵	PLOS ONE	Saudi Arabia	Cross-sectional	Online questionnaire/ Google Form	2117	52.5	18-61+
Bates et al., 2020 ³⁶	Journal of Communication in Healthcare	Colombia	Cross-sectional	Online questionnaire	482	28.1	18-50+
Bdair et al., 2020 ²³	Asia Pacific Journal of Public Health	Saudi Arabia	Cross-sectional	Questionnaire	575	57.4	NR
Clements, 2020 ³⁷	JIMIR public health and surveillance	USA	Cross-sectional	Online questionnaire/ MTurk platform	1034	58.2	37.11
Domiaty et al., 2020 ³⁸	Frontiers in Medicine	Lebanon	Cross-sectional	Online questionnaire/ Google form	410	42	–18-65+
Elayeh et al., 2020 ³⁹	PLOS ONE	Jordan	Cross-sectional	Online questionnaire/ Google Form	2104	24.6	18-55+
Fallahi et al., 2020 ⁴⁰	Journal of Military Medicine	Iran	Cross-sectional	Online questionnaire	836	27.5	–25-55+
Ferdous et al., 2020 ⁴¹	PLOS ONE	Bangladesh	Cross-sectional	Online questionnaire/ Google form	2017	59.8	12–64
Gao et al., 2020 ⁴²	BMC Public Health	China	Cross-sectional	Online questionnaire survey/Wenjuanxing platform	2136	21.9	33.1 ± 8.8
Ghazi et al., 2020 ⁴³	Public Health Education and Training	Iraq	Cross-sectional	Online questionnaire/ Google Form	272	58.1	36.35 ± 7.87
Haftom et al., 2020 ⁴⁴	Infection and Drug Resistance	Northern Ethiopia	Cross-sectional	In site/Self-administered questionnaire	331	69.5	18–69
Hager et al., 2020 ⁴⁵	PLOS ONE	Egypt, Nigeria	Cross-sectional	Online survey/Google Form	1437	52.5	18–59+
Hezima et al., 2020 ⁴⁶	Eastern Mediterranean Health Journal	Sudan	Cross-sectional	Online survey/Google Form	812	54.2	18+
Honarvar et al., 2020 ⁴⁷	International Journal of Public Health	Iran	Cross-sectional	In site/interview	1331	47.3	36 ± 13.9
Hossain et al., 2020 ⁴⁸	PLOS ONE	Bangladesh	Cross-sectional	Online/email.public groups on Facebook	2157	54.1	33.48 ± 14.65
Jadoo et al., 2020 ⁴⁹	Journal of Ideas in Health	Iraq	Cross-sectional	Online questionnaire/ Google Form/	877	41.7	all
Kakemam et al., 2020 ⁵⁰	Frontiers in Public health	Iran	Cross-sectional	Online questionnaire/ Porsline	1480	42.8	31.29
Kasemy et al., 2020 ⁵¹	Journal of Epidemiology and Global Health	Egypt	Cross-sectional	Online questionnaire/ Google Form	3712	47.8	23.31 ± 13.28
Lau et al., 2020 ⁵²	Journal of global health	Philippines	Cross-sectional	Online questionnaire/ SurveyCTO platform	2224	7.3	41.3
Mousa et al., 2020 ⁵³	Sudan Journal of Medical Sciences	Sudan	Cross-sectional	Online questionnaire/ WhatsApp, Telegram groups, Facebook, and Twitter	2336	39.3	17-51+
Ngwewondo et al., 2020 ⁵⁴	PLOS neglected tropical diseases	Cameroon	Cross-sectional	Online questionnaire/ WhatsApp, email, websites accounts	1006	46.9	33 ± 11.2
Nicholas et al., 2020 ⁵⁵	The Pan African Medical Journal	Cameroon	Cross-sectional	In site/questionnaire	545	56	18-50+
Pascawati et al., 2020 ⁵⁶	International Journal of Public Health Science	Indonesia	Cross-sectional	Online survey/ WhatsApp	155	49.7	11-60+
Paul et al., 2020 ⁵⁷	PLoS ONE	Bangladesh	Cross-sectional	Online survey/ Facebook and email	1589	60.5	18-45+
Roy et al., 2020 ⁶¹		India	Cross-sectional		662	48.6	29.9

(continued on next page)

Table 1 (continued)

Reference (Author, Year)	Journal	Location	Study Design	Data Collection tool	Sample Size	Male (%)	Mean Age or range
Rahman et al., 2020 ⁵⁸	Asian Journal of Psychiatry Bangladesh Medical Research Council Bulletin	Bangladesh	Cross-sectional	Online questionnaire/ Google Forms	1549	58	18–60+
Rajeh, 2020 ⁵⁹	The Open Dentistry Journal	Saudi Arabia	Cross-sectional	Online survey/ Facebook, WhatsApp, and Twitter	521	31.7	36.24
Reuben et al., 2020 ⁶⁰	Journal of Community Health	Nigeria.	Cross-sectional	Online survey/emails, WhatsApp and other social media	589	59.6	18–59
Sari et al., 2020 ⁶²	Journal of Community Health	Indonesia	Cross-sectional	Online questionnaire/ Google Forms/ WhatsApp	201	46.3	35.5
Sayedahmed et al., 2020 ⁶³	Scientific African	Sudan	Cross-sectional	Online questionnaire/ via Google	1718	38	12–50+
Sengeh et al., 2020 ⁶⁴	BMJ Open	Sierra Leone	Cross-sectional	In site/questionnaire	1253	52	18–60+
Susilkumar et al., 2020 ⁶⁵	International Journal Of Research In Pharmaceutical Sciences	India	Cross-sectional	Online questionnaire/ Google Forms	1015	49.3	20–60+
Tariq et al., 2020 ⁶⁷	Disaster Medicine and Public Health	Pakistan	Cross-sectional	Online survey/social media and authors own network	2121	13.7	21.8 ± 4.13
Tandon et al., 2020 ⁶⁶	Journal of Family Medicine and Primary Care	India	Cross-sectional	Online questionnaire/ online via mail and social media platforms	323	45.6	33.8
Van Nhu et al., 2020 ⁶⁸	Journal of Community Health	Vietnamese	Cross-sectional	Online survey questionnaire	1999	21.7	18–59
Xu et al., 2020 ⁶⁹	Journal Of Medical Internet Research	China	Cross-sectional	Online survey/ WhatsApp, Twitter	8158	37	18–60+
Yang et al., 2020 ⁷⁰	Journal of Advanced Nursing	China	Cross-sectional	Online questionnaire/ WeChat, Sina Weibo, QQ	919	21.7	18+
Yousaf et al., 2020 ⁷¹	Social Work in Public Health	India	Cross-sectional	Online questionnaire/ WhatsApp, Facebook, and Instagram	516	32.6	16–45+
Yue et al., 2020 ⁷²	Journal of Community Health	China	Cross-sectional	Online questionnaire/ WeChat, QQ	517	46.23	15–60
Zhong et al., 2020 ⁷³	International Journal of Biological Sciences	China	Cross-sectional	Online questionnaire	6910	34.3	16–50≤

*NR: not reported.

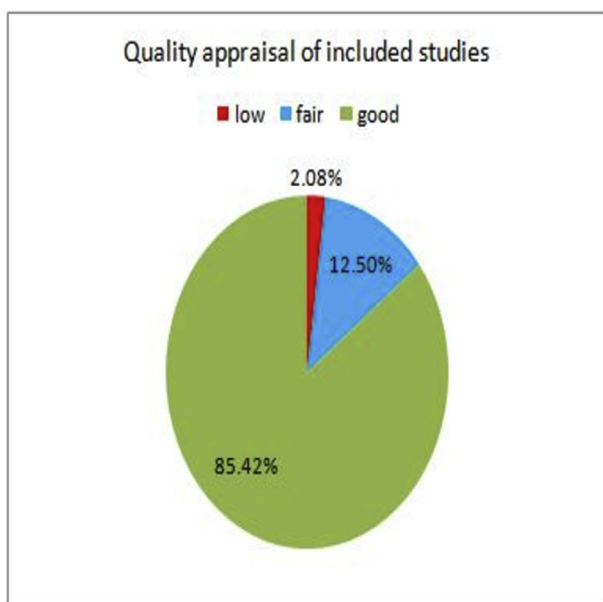


Fig. 3. The percentage of included studies based on quality score.

79.8%) and slightly more than 93% of samples performed satisfactory practices (overall score: 74.1%). The level of knowledge, attitudes, and practices is slightly high in the Asia continent. About 90% of the studies used an online questionnaire to collect data, and the most used platforms included Google form, SurveyMonkey, and Qualtrics. The most important social media through which the questionnaires were distributed were Facebook, WhatsApp, and Telegram. The most important sources for learning and staying up to date about COVID-19 mentioned in the studies were television, social media, the internet, radio, and friend and relatives.

Our result showed a high percentage of knowledge, attitudes, and practices in Asian countries. The probable reason for these higher percentages could be related to the factors such as the initial spread of the virus from this continent and the emergency acts that were taken earlier than other continents in this continent.^{78,79} However, owing to the lack of studies in developed countries and the change of some factors related to knowledge, attitude, and practice over the past year, the generalizability of these results is low.

The finding of our systematic review demonstrated good knowledge about COVID-19. In most studies, more than 80% of the participants had a good knowledge of issues such as causes, symptoms, ways of transmission, and ways of prevention. In addition, most participants had a high level of

Table 2
Results related to coronavirus-related KAPs components of the included studies.

Reference (Author, Year)	Overall level of KAP components		
	Knowledge ^a Level (%)	Attitudes ^b Level (%)	Practices ^c Level (%)
Adesegun et al., 2020 ²⁷	Good (78)	Positive (66)	Satisfactory (60.4)
Alahdal et al., 2020 ²⁸	Good (58)	Positive (95)	Satisfactory (81)
Al-Hanawi et al., 2020 ²⁹	Good (81.6)	Positive (77.5)	Satisfactory (52.3)
Alhazmi et al., 2020 ³⁰	Good (81.3)	Positive (86.6)	Satisfactory (81.9)
Alobuia et al., 2020 ³¹	Good (59)	Positive (63)	Satisfactory (67)
Amalakanti et al., 2020 ³²	Good (94.4)	Positive (70)	Satisfactory (77)
Ashiq et al., 2020 ³³	Good (95.8)	Positive (87.6)	Satisfactory (94.3)
Azlan et al., 2020 ³⁴	Good (80.5)	Positive (83.1)	Satisfactory (73.4)
Baig et al., 2020 ³⁵	Good (68.1)	Positive (93.1)	Satisfactory (97.7)
Bates et al., 2020 ³⁶	Good (79.3)	Positive (63.5)	Satisfactory (91.7)
Bdair et al., 2020 ²³	Poor (51.1)	Positive (51.8)	Satisfactory (76.2)
Clements, 2020 ³⁷	Good (80.8)	NR	Satisfactory (69.5)
Domiaty et al., 2020 ³⁸	Good (75)	Positive (78.4)	NR
Elayeh et al., 2020 ³⁹	Good (60.9)	Positive (50.7)	Satisfactory (66.7)
Fallahi et al., 2020 ⁴⁰	Good (74.2)	Positive (80.2)	Satisfactory (67.5)
Ferdous et al., 2020 ⁴¹	Poor (48.3)	Positive (62.3)	Satisfactory (55.1)
Gao et al., 2020 ⁴²	Good (91.2)	Positive (98)	Satisfactory (96.8)
Ghazi et al., 2020 ⁴³	Good (95.2)	NR	Satisfactory (NR)
Haftom et al., 2020 ⁴⁴	Poor (42.9)	Positive (NA)	Satisfactory (NA)
Hager et al., 2020 ⁴⁵	Good (61.6)	Positive (68.9)	Satisfactory (62.1)
Hezima et al., 2020 ⁴⁶	Good (78.2)	Positive (89.2)	Satisfactory (53.1)
Honarvar et al., 2020 ⁴⁷	Good (63)	Positive (54)	Satisfactory (78)
Hossain et al., 2020 ⁴⁸	Good (86)	Positive (NR)	Satisfactory (NR)
Jadoo et al., 2020 ⁴⁹	Good (77.8)	Positive (70.1)	Satisfactory (85.5)
Kakemam et al., 2020 ⁵⁰	Good (87.5)	Positive (67.6)	Satisfactory (75.2)
Kasemy et al., 2020 ⁵¹	Good (64.1)	Positive (75.9)	Satisfactory (50.1)
Lau et al., 2020 ⁵²	Good (85.3)	Positive (67)	Satisfactory (82.2)
Mousa et al., 2020 ⁵³	Good (84.7)	Positive (80.2)	Satisfactory (72.2)
Ngwewondo et al., 2020 ⁵⁴	Good (84.1)	Positive (69)	Satisfactory (60.8)
Nicholas et al., 2020 ⁵⁵	Good (53.7)	Positive (73.5)	Satisfactory (60.9)
Pascawati et al., 2020 ⁵⁶	Good (97.4)	Positive (68.3)	Satisfactory (82.5)
Paul et al., 2020 ⁵⁷	Poor (67)	Positive (52.4)	Unsatisfactory (44.8)
Roy et al., 2020 ⁶¹	Good (NR)	Positive (86.7)	NR
Rahman et al., 2020 ⁵⁸	Good (57.6)	Positive (80.5)	Satisfactory (76.1)
Rajeh, 2020 ⁵⁹	Good (99)	Positive (99.6)	Satisfactory (73.3)
Reuben et al., 2020 ⁶⁰	Good (99.5)	Positive (79.5)	Satisfactory (81.1)
Sari et al., 2020 ⁶²	Good (98)	Positive (96)	Satisfactory (NA)
Sayedahmed et al., 2020 ⁶³	Good (68.3)	Positive (89.9)	Unsatisfactory (48.5)
Sengeh et al., 2020 ⁶⁴	Good (51.5)	Positive (83)	Unsatisfactory (41.1)
Susilkumar et al., 2020 ⁶⁵	Good (81)	Positive (91.1)	Satisfactory (87.7)
Tariq et al., 2020 ⁶⁷	Poor (49.2)	Positive (NR)	Satisfactory (NR)
Tandon et al., 2020 ⁶⁶	Good (99)	Positive (97)	NR
Van Nhu et al., 2020 ⁶⁸	Good (92.2)	Positive (68.6)	Satisfactory (75.8)
Xu et al., 2020 ⁶⁹	Good (93.7)	Positive (99.2)	NR
Yang et al., 2020 ⁷⁰	Good (85.2)	Positive (92.9)	Satisfactory (84.4)
Yousaf et al., 2020 ⁷¹	Good (88.9)	Positive (73.3)	Satisfactory (93)
Yue et al., 2020 ⁷²	Good (57)	Positive (93.3)	Satisfactory (68)
Zhong et al., 2020 ⁷³	Good (90)	Positive (94.1)	Satisfactory (97.2)

*NA: not report.

^a Knowledge: (good ≥ 50), (poor < 50).

^b Attitude: (positive ≥ 50), (negative < 50).

^c Practice: (satisfactory ≥ 50), (unsatisfactory < 50).

knowledge about symptoms such as high fever and dry cough, breathing difficulty and a small number had sufficient knowledge about other symptoms such as chills, headache, muscle pain, sore throat, and loss of taste or smell.^{28,33,34,41,49,50,57,63} More than 90% of the participants considered air droplets as a way to spread. This good level of knowledge can be due to widespread information through various means such as public media (television and radio), social media, and government announcements. In addition, preparing several guidelines and reports by WHO, CDC, and local government in times of outbreak and easy access to them have increased the level of information and knowledge of individuals regarding COVID-19.^{28,29,37,45,50,53,60,69} On the other hand, factors such as low literacy level, older age, and the presence of the rural population in the samples were

among the factors that have reduced the level of knowledge in the studies.^{31,35,64}

In this review, participants showed a positive attitude regarding COVID-19. Almost all participants believed in the importance of handwashing, disinfecting surfaces, using masks to prevent the spread of infection, resting at home in the event of symptoms, and maintaining social distance and limited contact. Of course, in some cases, there was a negative belief that it could be due to differences in instructions and guidelines by different institutions, such as what was about wearing a face mask at the beginning of the pandemic, and then it was recommended that the whole population should use a mask.^{23,34,38,41,80,81} Such cases show the importance of integrated guidelines and the focus of decision-making in times of crisis.^{39,82–85} Although having a responsible organization can help make better and faster

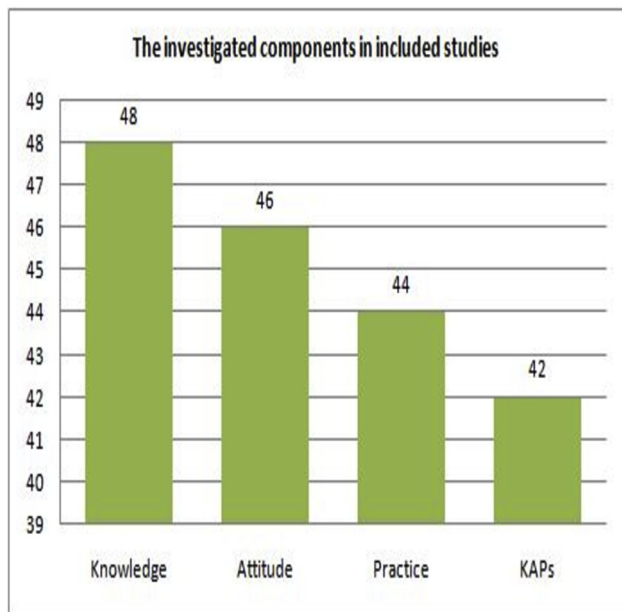


Fig. 4. The number of investigated components in the included studies.

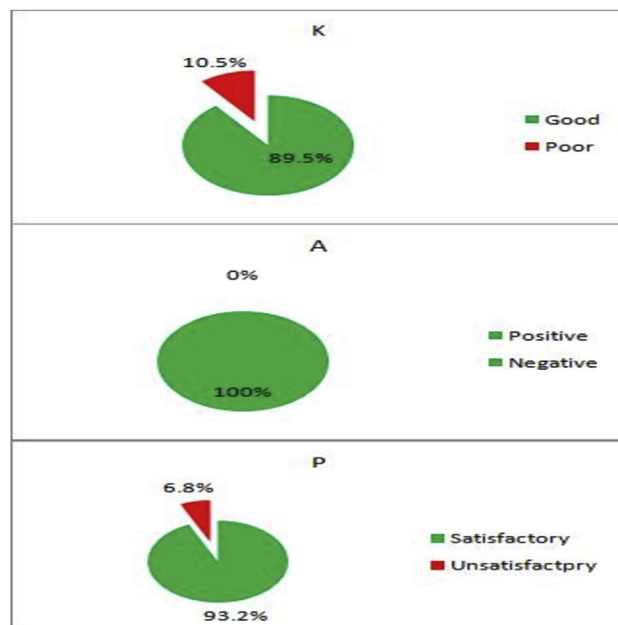


Fig. 5. The percentage of studies based on the knowledge (K), attitudes (A), and practices (P).

decisions, in such cases, political pressure is exerted by governments that such organizations should put the health of the people at the top and not refuse to make the right decisions due to political pressures.^{11,31,86–88}

In general, the level of practice of the participants in the studies was satisfactory. However, despite the good knowledge and positive attitude of the participants, the level of practice was still sometimes lower than expected. Numerous reasons for unsatisfactory practices have been cited in studies. Lack of availability (for example, masks and disinfectants), imposing financial costs on participants, ambiguity in instructions, not getting used to new conditions such as staying home and wearing a mask, exhaustion from existing conditions, and anxiety and stress of disease were among the causes mentioned in the studies.^{41,56,73,89–91} In this regard, some countries have imposed strict laws and penalties on people who do not follow the guidelines to improve their performance, but in many countries under study, such laws do not exist and have not been applied.^{38,50,61,92,93} Another factor that affects the performance of individuals was the presence of decision-makers in public and social media. Seeing a person without a mask at the height of a pandemic hurt a person's good practices.

Table 3
Meta-analysis of the pooled overall score of KAP components.

Component	Location	Number of studies	Score (%)	95% CI	Z-value	P-value
Knowledge	Africa	11	74.1	63.5, 82.5	4.13	0.001
	America	3	74.0	52.6, 88.0	2.17	0.001
	Asia	33	83.8	79.5, 87.4	11.1	0.001
	Overall	47	78.9	96.1, 86.2	5.02	0.001
Attitude	Africa	10	78.7	68.7, 86.1	4.93	0.001
	America	2	63.2	35.1, 84.6	0.91	0.359
	Asia	31	85.0	80.8, 88.4	11.4	0.001
	Overall	43	79.8	96.1, 87.5	4.70	0.001
Practice	Africa	10	59.6	48.5, 69.9	1.69	0.090
	America	3	78.5	61.5, 89.3	3.06	0.002
	Asia	26	81.5	76.9, 85.4	10.3	0.001
	Overall	39	74.1	56.0, 86.5	2.55	0.011

CI, confidence interval; KAP, knowledge, attitudes, and practices.

Given the diversity of settings and questionnaires, the authors of this article recommend that there be a need to design an integrated online system to assess the knowledge, attitudes, and practices of the population about health-related crises. Designing such an integrated system can help better compare countries because integrated items are used for comparison. On the other hand, designing such a system and disseminating its results can accelerate integrated decision-making and improve crisis management. On the other hand, the existence of such an integrated system can lead to an increase in solidarity, which was emphasized by the World Health Organization during the corona pandemic.^{94,95}

Conclusion

This systematic review showed that the KAP components in the participants are at an acceptable level. In general, knowledge was at a good level, the attitude was positive and practice was at a satisfactory level. Providing accurate and up-to-date information in times of crisis and disseminating them through responsible institutions and the mass media and holding online training

courses can help increase people's knowledge, attitudes, and practices.

Author statements

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Ethical approval

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Competing interest

The authors have declared that no competing interests exist.

Author contributions

MA-Z contributed to conception and design. MM, SS, and SH contributed to screen the records, data extraction, and quality appraisal. MA-Z and HA contributed to data analysis. MA-Z contributed to draft manuscript. SH and HA contributed to critical review. All authors approved the final version of the manuscript for publication.

Data availability statement

All relevant data are with the article and the attached supplementary information.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.puhe.2021.03.005>.

References

- Cao Z, Li T, Liang L, Wang H, Wei F, Meng S, et al. Clinical characteristics of coronavirus disease 2019 patients in Beijing, China. *PLoS One* 2020;**15**: e0234764.
- Arab-Zozani M, Hassanipour S. Features and limitations of LitCovid hub for quick access to literature about COVID-19. *Balkan Med J* 2020;**37**:231.
- <https://www.worldometers.info/coronavirus/#countries>.
- Arab-Zozani M, Hassanipour S, Ghoddoosi-Nejad D. Favipiravir for treating patients with novel coronavirus (COVID-19): protocol for a systematic review and meta-analysis of randomised clinical trials. *BMJ Open* 2020;**10**: e039730.
- Struyf T, Deeks JJ, Dinnes J, Takwoingi Y, Davenport C, Leeflang MM, et al. Signs and symptoms to determine if a patient presenting in primary care or hospital outpatient settings has COVID-19 disease. *Cochrane Database Syst Rev* 2020;**7**.
- Gaythorpe K, Imai N, Cuomo-Dannenburg G, Baguelin M, Bhatia S, Boonyasiri A, et al. *Report 8: symptom progression of COVID-19*. 2020.
- Organization WH. *Novel Coronavirus (2019-nCoV) situation report-7*. 2020. URL <https://www.who.int/docs/default-source/coronaviruse/situation-reports/20200127-sitrep-7-2019-ncov.pdf>. 2020.
- Wang C, Horby PW, Hayden FG, Gao GF. A novel coronavirus outbreak of global health concern. *Lancet* 2020;**395**:470–3.
- Feng S, Shen C, Xia N, Song W, Fan M, Cowling BJ. Rational use of face masks in the COVID-19 pandemic. *Lancet Respir Med* 2020;**8**:434–6.
- Siedner MJ, Harling G, Reynolds Z, Gilbert RF, Venkataramani A, Tsai AC. *Social distancing to slow the US COVID-19 epidemic: an interrupted time-series analysis*. MedRxiv; 2020.
- Arab-Zozani M, Ghoddoosi-Nejad D. Covid-19 in Iran: the good, the bad and the ugly strategies for preparedness—A report from the field. *Disaster Med Public Health Prep* 2020;1–6.
- Dewey C, Hingle S, Goelz E, Linzer M. Supporting clinicians during the COVID-19 pandemic. *Am Coll Physicians* 2020;752–3.
- Zhan M, Qin Y, Xue X, Zhu S. Death from Covid-19 of 23 health care workers in China. *N Engl J Med* 2020;**382**:2267–8.
- Ing E, Xu Q, Salimi A, Torun N. Physician deaths from corona virus (COVID-19) disease. *Occup Med* 2020;**70**:370–4.
- Yoosefi Lebni J, Abbas J, Moradi F, Salahshoor MR, Chaboksavar F, Irandoost SF, et al. How the COVID-19 pandemic effected economic, social, political, and cultural factors: a lesson from Iran. *Int J Soc Psychiatr* 2020;**1**:1–3. 0020764020939984.
- Yezli S, Khan A. COVID-19 social distancing in the Kingdom of Saudi Arabia: bold measures in the face of political, economic, social and religious challenges. *Trav Med Infect Dis* 2020;101692.
- Wu ZMcGoogan J. Characteristics of and important lessons from the coronavirus disease 2019 (COVID-19) outbreak in China: summary of a report of 72314 cases from the Chinese Center for Disease Control and Prevention. *J Am Med Assoc* 2020;**323**:1239–42.
- McEachan R, Taylor N, Harrison R, Lawton R, Gardner P, Conner M. Meta-analysis of the reasoned action approach (RAA) to understanding health behaviors. *Ann Behav Med* 2016;**50**:592–612. a publication of the Society of Behavioral Medicine.
- Moher D, Liberati A, Tetzlaff J, Altman DG, Group P. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Med* 2009;**6**:e1000097.
- Booth A, Clarke M, Dooley G, Ghera D, Moher D, Petticrew M, et al. The nuts and bolts of PROSPERO: an international prospective register of systematic reviews. *Syst Rev* 2012;**1**:1–9.
- Porritt K, Gomersall J, Lockwood C. JBI's systematic reviews: study selection and critical appraisal. *AJN Am J Nur* 2014;**114**:47–52.
- Arab-Zozani M, Pezeshki MZ, Khodayari-Zarnaq R, Janati A. Inappropriate rate of admission and hospitalization in the Iranian hospitals: a systematic review and meta-analysis. *Value Health Reg Issues* 2020;**21**:105–12.
- Bdair IA, Alshloul MN, Maribay GL. Public awareness toward coronavirus disease-2019. *Asia Pac J Publ Health* 2020;**35**:354–6.
- Hassanipour S, Faradonbeh SB, Momeni K, Heidarifard Z, Khosousi M-J, Khosousi L, et al. A systematic review and meta-analysis of pregnancy and COVID-19: signs and symptoms, laboratory tests, and perinatal outcomes. *Int J Reprod Biomed* 2020;**18**:1005.
- Arab-Zozani M, Mostafazadeh N, Arab-Zozani Z, Ghoddoosi-Nejad D, Hassanipour S, Soares JJ. The prevalence of elder abuse and neglect in Iran: a systematic review and meta-analysis. *J Elder Abuse Negl* 2018;**30**:408–23.
- Ferdousi R, Arab-Zozani M, Tahamtan I, Rezaei-Hachesu P, Dehghani M. Attitudes of nurses towards clinical information systems: a systematic review and meta-analysis. *Int Nurs Rev* 2020;**13**:1446–52.
- Adesegun OA, Binuyo T, Adeyemi O, Ehioghuae O, Rabor DF, Amusan O, et al. The COVID-19 crisis in Sub-Saharan Africa: knowledge, attitudes, and practices of the Nigerian public. *Am J Trop Med Hyg* 2020;**103**:1997–2004.
- Alahdal H, Basingab F, Alotaibi R. An analytical study on the awareness, attitude and practice during the COVID-19 pandemic in Riyadh, Saudi Arabia. *J Infect Public Health* 2020;**13**:1446–52.
- Al-Hanawi MK, Angawi K, Alshareef N, Qattan AMN, Helmy HZ, Abudawood Y, et al. Knowledge, attitude and practice toward COVID-19 among the public in the Kingdom of Saudi Arabia: a cross-sectional study. *Front Public Health* 2020;**8**.
- Alhazmi A, Ali MMH, Mohieldin A, Aziz F, Osman OB, Ahmed WA. Knowledge, attitudes and practices among people in Saudi Arabia regarding COVID-19: a cross-sectional study. *J Public Health Res* 2020;**9**.
- Alobuia WM, Dalva-Baird NP, Forrester JD, Bendavid E, Bhattacharya J, Kebebew E. Racial disparities in knowledge, attitudes and practices related to COVID-19 in the USA. *J Public Health (Oxf)*. 2020;**42**(3):470–8.
- Amalakanti S, Raman Arepalli KV, Koppolu RK. Gender and occupation predict coronavirus disease 2019 knowledge, attitude and practices of a cohort of a South Indian state population. *Indian J Med Microbiol* 2020;**38**: 144–56.
- Ashiq K, Ashiq S, Bajwa MA, Tanveer S, Qayyum M. Knowledge, attitude and practices among the inhabitants of Lahore, Pakistan towards the COVID-19 pandemic: an immediate online based cross-sectional survey while people are under the lockdown. *Bangladesh J Med Sci* 2020;**19**:S69–76.
- Azlan AA, Hamzah MR, Sern TJ, Ayub SH, Mohamad E. Public knowledge, attitudes and practices towards COVID-19: a cross-sectional study in Malaysia. *PLoS One* 2020;**15**:e0233668.
- Baig M, Jameel T, Alzahrani SH, Mirza AA, Gazzaz ZJ, Ahmad T, et al. Predictors of misconceptions, knowledge, attitudes, and practices of COVID-19 pandemic among a sample of Saudi population. *PLoS One* 2020;**15**:e0243526.
- Bates BR, Moncayo AL, Costales JA, Herrera-Céspedes CA, Grijalva MJ. Knowledge, attitudes, and practices towards COVID-19 among Ecuadorians during

- the outbreak: an online cross-sectional survey. *J Community Health* 2020;**45**:1158–67.
37. Clements JM. Knowledge and behaviors toward COVID-19 among US residents during the early days of the pandemic: cross-sectional online questionnaire. *JMIR Public Health Surveill* 2020;**6**:e19161.
 38. Domiati S, Itani M, Itani G. Knowledge, attitude, and practice of the Lebanese community toward COVID-19. *Front Med (Lausanne)* 2020;**7**.
 39. Elayah E, Aleidi SM, Ya'acoub R, Haddadin RN. Before and after case reporting: a comparison of the knowledge, attitude and practices of the Jordanian population towards COVID-19. *PLoS One* 2020;**15**:e0240780.
 40. Fallahi A, Mahdavi N, Ghorbani A, Mehrdadian P, Mehri A, Joveini H, et al. Public knowledge, attitude and practice regarding home quarantine to prevent COVID-19 in Sabzevar city, Iran. *J Mil Med* 2020;**22**:580–8.
 41. Ferdous MZ, Islam MS, Sikder MT, Mosaddek ASM, Zegarra-Valdivia JA, Gozal D. Knowledge, attitude, and practice regarding COVID-19 outbreak in Bangladesh: an online-based cross-sectional study. *PLoS One* 2020;**15**:e0239254.
 42. Gao H, Hu R, Yin L, Yuan X, Tang H, Luo L, et al. Knowledge, attitudes and practices of the Chinese public with respect to coronavirus disease (COVID-19): an online cross-sectional survey. *BMC Public Health* 2020;**20**:1–8.
 43. Ghazi HF, Taher TMJ, Abdalqader MA, Raheema RH, Baobaid MF, Hasan TN. Knowledge, attitude, and practice regarding coronavirus disease-19: population-based study in Iraq. *Open Access Maced J Med Sci* 2020;**8**:137–41.
 44. Haftom M, Petrucka P, Gemechu K, Mamo H, Tsegay T, Amare E, et al. Knowledge, attitudes, and practices towards COVID-19 pandemic among quarantined adults in Tigray region, Ethiopia. *Infect Drug Resist* 2020;**13**:3727.
 45. Hager E, Odetokun IA, Bolarinwa O, Zainab A, Okechukwu O, Al-Mustapha AI. Knowledge, attitude, and perceptions towards the 2019 coronavirus pandemic: a bi-national survey in Africa. *PLoS One* 2020;**15**:e0236918.
 46. Hezima A, Aljafari A, Aljafari A, Mohammad A, Adel I. Knowledge, attitudes, and practices of Sudanese residents towards COVID-19. *East Mediterr Health J* 2020;**26**:646–51.
 47. Honarvar B, Lankarani KB, Kharmandar A, Shaygani F, Zahedroozgar M, Rahmani Haghighi MR, et al. Knowledge, attitudes, risk perceptions, and practices of adults toward COVID-19: a population and field-based study from Iran. *Int J Publ Health* 2020;**65**:731–9.
 48. Hossain MA, Jahid MIK, Hossain KMA, Walton LM, Uddin Z, Haque MO, et al. Knowledge, attitudes, and fear of COVID-19 during the rapid rise period in Bangladesh. *PLoS One* 2020;**15**:e0239646.
 49. Jadoo SAA, Alhuseiny AH, Yaseen SM, Al-Samarrai MAM, Al-Delaimy AK, Abed MW, et al. Knowledge, attitude, and practice toward COVID-19 among Iraqi people: a web-based cross-sectional study. *J Ideas Health* 2020;**3**:258–65.
 50. Kakemam E, Ghoddoosi-Nejad D, Chegini Z, Salehiniya H, Hassanipour S, Ameri H, et al. Knowledge, attitudes, and practices among the general population around COVID-19 during the peak of the outbreak in Iran: a national cross-sectional survey. *Front Public Health* 2020;**8**:868.
 51. Kasemy ZA, Bahbah WA, Zewain SK, Haggag MG, Alkalash SH, Zahran E, et al. Knowledge, attitude and practice toward COVID-19 among Egyptians. *J Epidemiol Glob Health* 2020;**10**:378.
 52. Lau LL, Hung N, Go DJ, Ferma J, Choi M, Dodd W, et al. Knowledge, attitudes and practices of COVID-19 among income-poor households in the Philippines: a cross-sectional study. *J Glob Health* 2020;**10**:011007.
 53. Mousa KNA, Saad MMY, Abdelghafor MTB. Knowledge, attitudes, and practices surrounding COVID-19 among Sudan citizens during the pandemic: an online cross-sectional study. *Sudan J Med Sci* 2020;**15**:32–45.
 54. Ngwewondo A, Nkengazong L, Ambe LA, Ebogo JT, Mba FM, Goni HO, et al. Knowledge, attitudes, practices of/towards COVID 19 preventive measures and symptoms: a cross-sectional study during the exponential rise of the outbreak in Cameroon. *PLoS Neglected Trop Dis* 2020;**14**:e0008700.
 55. Nicholas T, Mandaah FV, Esemu SN, Vanessa ABT, Gilchrist KTD, Vanessa LF, et al. COVID-19 knowledge, attitudes and practices in a conflict affected area of the South West Region of Cameroon. *Pan Afr Med J* 2020;**35**:1–8.
 56. Pascawati NA, Satoto TBT. Public knowledge, attitudes and practices towards COVID-19. *Int J Publ Health Sci* 2020;**9**:292–302.
 57. Paul A, Sikdar D, Hossain MM, Amin MR, Deeba F, Mahanta J, et al. Knowledge, attitudes, and practices toward the novel coronavirus among Bangladeshis: implications for mitigation measures. *PLoS One* 2020;**15**:e0238492.
 58. Rahman SMM, Akter A, Mostari KF, Ferdousi S, Ummon IJ, Naafi SM, et al. Assessment of knowledge, attitudes and practices towards prevention of coronavirus disease (COVID-19) among Bangladeshi population. *Bangladesh Med Res Counc Bull* 2020;**46**:73–82.
 59. Rajeh M. COVID-19 and infection control in dental clinics; assessment of public knowledge, attitudes and practices in several regions of Saudi Arabia. *Open Dent J* 2020;**14**:489–97.
 60. Reuben RC, Danladi MMA, Saleh DA, Ejembi PE. Knowledge, attitudes and practices towards COVID-19: an epidemiological survey in North-Central Nigeria. *J Community Health* 2020;1–14.
 61. Roy D, Tripathy S, Kar SK, Sharma N, Verma SK, Kaushal V. Study of knowledge, attitude, anxiety & perceived mental healthcare need in Indian population during COVID-19 pandemic. *Asian J Psychiatr* 2020;**51**:102083.
 62. Sari C, Simsek EC, Ozdogan O. The outcomes of the postulated interaction between SARS-CoV-2 and the renin-angiotensin system on the clinician's attitudes toward hypertension treatment. *J Hum Hypertens* 2020;1–9.
 63. Sayedahmed AMS, Abdalla AAA, Khalid MHM. Knowledge, attitude and practice regarding COVID-19 among Sudanese population during the early days of the pandemic: online cross-sectional survey. *Sci Afr* 2020;**10**:e00652.
 64. Sengeh P, Jalloh MB, Webber N, Ngobeh I, Samba T, Thomas H, et al. Community knowledge, perceptions and practices around COVID-19 in Sierra Leone: a nationwide, cross-sectional survey. *BMJ Open* 2020;**10**:e040328.
 65. Susilkumar V, Vengadassalopathy S. Knowledge, attitudes, practices and psychological response towards COVID-19 pandemic among general public in India. *Int J Res Pharm Sci* 2020;**11**:892–900.
 66. Tandon T, Dubey AK, Dubey S, Manocha S, Arora E, Hasan MN. Knowledge, attitude, and perception of Indian population toward coronavirus disease (COVID-19). *J Fam Med Prim Care* 2020;**9**:4265.
 67. Tariq S, Tariq S, Baig M, Saeed M. Knowledge, awareness and practices regarding novel coronavirus among a sample of Pakistani population, a cross-sectional study. *Disaster Med Public Health Prep* 2020;1–20.
 68. Van Nhu H, Tuyet-Hanh TT, Van NTA, Linh TNQ, Tien TQ. Knowledge, attitudes, and practices of the Vietnamese as key factors in controlling COVID-19. *J Community Health* 2020;**45**:1263–9.
 69. Xue Q, Xie X, Liu Q, Zhou Y, Zhu K, Wu H, et al. Knowledge, attitudes, and practices towards COVID-19 among primary school students in Hubei Province, China. *Child Youth Serv Rev* 2020;**120**:105735.
 70. Yang K, Liu H, Ma L, Wang S, Tian Y, Zhang F, et al. Knowledge, attitude and practice of residents in the prevention and control of COVID-19: an online questionnaire survey. *J Adv Nurs* 2020;**77**:1839–55.
 71. Yousaf MA, Noreen M, Saleem T, Yousaf I. A cross-sectional survey of knowledge, attitude, and practices (KAP) toward pandemic COVID-19 among the general population of Jammu and Kashmir, India. *Soc Work Publ Health* 2020;**35**:569–78.
 72. Yue S, Zhang J, Cao M, Chen B. Knowledge, attitudes and practices of COVID-19 among urban and rural residents in China: a cross-sectional study. *J Community Health* 2020;**46**:286–91.
 73. Zhong B-L, Luo W, Li H-M, Zhang Q-Q, Liu X-G, Li W-T, et al. Knowledge, attitudes, and practices towards COVID-19 among Chinese residents during the rapid rise period of the COVID-19 outbreak: a quick online cross-sectional survey. *Int J Biol Sci* 2020;**16**:1745.
 74. Tull MT, Edmonds KA, Scamaldo K, Richmond JR, Rose JP, Gratz KL. Psychological outcomes associated with stay-at-home orders and the perceived impact of COVID-19 on daily life. *Psychiatr Res* 2020;113098.
 75. Haleem A, Javaid M, Vaishya R. Effects of COVID 19 pandemic in daily life. *Curr Med Res Pract* 2020;**10**:78–9.
 76. Lee M, Kang BA, You M. Knowledge, attitudes, and practices (KAP) toward COVID-19: a cross-sectional study in South Korea. *BMC Publ Health* 2021;**21**:1–10.
 77. Namikawa K, Kikuchi H, Kato S, Takizawa Y, Konta A, Iida T, et al. Knowledge, attitudes, and practices of Japanese travelers towards malaria prevention during overseas travel. *Trav Med Infect Dis* 2008;**6**:137–41.
 78. Chan EYY, Huang Z, Lo ESK, Hung KKC, Wong ELY, Wong SYS. Sociodemographic predictors of health risk perception, attitude and behavior practices associated with health-emergency disaster risk management for biological hazards: the case of COVID-19 pandemic in Hong Kong, SAR China. *Int J Environ Res Publ Health* 2020;**17**:3869.
 79. Arab-Zozani M, Ghoddoosi-Nejad D. COVID-19 in Iran: the good, the bad, and the ugly strategies for preparedness—A report from the field. *Disaster Med Public Health Prep* 2020;1–3.
 80. Olum R, Chekwech G, Wekha G, D.A. N, Bongomin F. Coronavirus disease-2019: knowledge, attitude, and practices of health care workers at Makerere University Teaching Hospitals, Uganda. *Front Public Health* 2020;**8**.
 81. Riccò M, Ferraro P, Gualerzi G, Ranzieri S, Bragazzi NL, Balzarini F, et al. Point-of-Care diagnostic of SARS-CoV-2: knowledge, attitudes, and perceptions (KAP) of medical workforce in Italy. *Acta Biomed : Atenei Parmensis*. 2020;**91**:57–67.
 82. Hong KH, Lee SW, Kim TS, Huh HJ, Lee J, Kim SY, et al. Guidelines for laboratory diagnosis of coronavirus disease 2019 (COVID-19) in Korea. *Ann Lab Med* 2020;**40**:351–60.
 83. Jin Y-H, Cai L, Cheng Z-S, Cheng H, Deng T, Fan Y-P, et al. A rapid advice guideline for the diagnosis and treatment of 2019 novel coronavirus (2019-nCoV) infected pneumonia (standard version). *Mil Med Res* 2020;**7**:4.
 84. Almofada SK, Alherbisch RJ, Almuhray NA, Almeshary BN, Alrabiah B, Al Saffan A, et al. Knowledge, attitudes, and practices toward COVID-19 in a Saudi Arabian population: a cross-sectional study. *Cureus* 2020;**12**:e8905.
 85. Usman IM, Ssempijja F, Ssebuufu R, Lemuel AM, Archibong VB, Ayikobua ET, et al. Community drivers affecting adherence to WHO guidelines against COVID-19 amongst rural Ugandan market vendors. *Front Public Health* 2020;**8**:340.
 86. Flinders M. Democracy and the politics of coronavirus: trust, blame and understanding. *Parliam Aff* 2020. gsaa013.
 87. Davies S. The politics of staying behind the frontline of coronavirus. *Wellcome Open Res* 2020;**5**:131.

88. Lewin KM. Contingent reflections on coronavirus and priorities for educational planning and development. *Prospects* 2020;**49**:17–24.
89. Mitchell BG, Russo PL, Kiernan M, Curryer C. Nurses' and midwives' cleaning knowledge, attitudes and practices: an Australian study. *Infect Dis Health* 2020;**25**:55–62.
90. Paul E, Alzaydani Asiri IA, Al-Hakami A, Chandramoorthy HC, Alshehri S, Beynon CM, et al. Healthcare workers' perspectives on healthcare-associated infections and infection control practices: a video-reflexive ethnography study in the Asir region of Saudi Arabia. *Antimicrob Resist Infect Contr* 2020;**9**: 1–2.
91. Xu H, Gan Y, Zheng D, Wu B, Zhu X, Xu C, et al. Relationship between COVID-19 infection and risk perception, knowledge, attitude, and four nonpharmaceutical interventions during the late period of the COVID-19 epidemic in China: online cross-sectional survey of 8158 adults. *J Med Internet Res* 2020;**22**:e21372.
92. Parmet WE, Sinha MS. Covid-19—the law and limits of quarantine. *N Engl J Med* 2020;**382**:e28.
93. Griffith R. Using public health law to contain the spread of COVID-19. *Br J Nurs* 2020;**29**:326–7.
94. Arab-Zozani M, Hassanipour S. Sharing solidarity experiences to overcome COVID-19. *Ann Glob Health* 2020:86.
95. Arora G, Kroumpouzou G, Kassir M, Jafferany M, Lotti T, Sadoughifar R, et al. Solidarity and transparency against the COVID-19 pandemic. *Dermatol Ther* 2020. dth13359.



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Online singing groups for people with dementia: scoping review

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ABSTRACT

Objectives: In the face of the SARS-CoV-2 pandemic, people with dementia and their carers are contending with serious challenges to their health and wellbeing, due to risk of severe illness, limiting of social contact and disruption to usual activities. Many forms of support for people with dementia and their carers, including singing groups, have moved online using videoconferencing. Previous research has demonstrated the benefits of group singing, which include cognitive stimulation, meaningful activity and peer support. However, although we know which aspects of the singing group experience participants find helpful, we do not know how this experience translates into an online videoconferencing format, and this is a very new field with little existing research. This article reviews the literature pertinent to online singing interventions and uses the findings to develop some suggestions for running an online singing group.

Study design: Scoping review.

Methods: Systematic literature searches were conducted in EMBASE, Medline, CINAHL, PsycINFO and Web of Science. Owing to the paucity of existing research, searches were also conducted in Google Scholar. The scope of the review covered five related areas: online music making and music therapy, telemedicine and telecare, everyday technology for people with dementia, digital arts and dementia, and use of technology for social interaction and leisure. Our analysis aimed to integrate the results to inform the implementation of online singing groups for people with dementia.

Results: Scoping of evidence from discrete fields of enquiry and different disciplinary traditions can inform the delivery of online singing in dementia. This literature also yields useful insights into the role of the carer and how best to support participants to use technology. Barriers and facilitators to online singing were found to relate both to the technology and to the individual participant.

Conclusion: Lockdown restrictions have led to much innovation, and this is likely to lead to changes in practice even after normal life resumes. The suggestions in this article will be helpful primarily for practitioners moving into online work and researchers investigating this novel area. They may also be useful to commissioners and policymakers because they reflect current knowledge about best practice.

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Background

For people with dementia, the restrictions imposed by pandemic-related lockdowns and the cessation of usual activities mean that routines are disrupted, support networks are compromised, and meaningful activities outside the home are suspended.^{1,3} It is likely that loneliness and confusion resulting from the abrupt loss of many forms of support are compounded by lack of the cognitive stimulation which slows mental decline in dementia.⁴ In short, the pandemic could have a profoundly negative impact on the lives of people with dementia and on their family carers.

Fortunately, in many cases, family visits, activities and support groups for people with dementia and their carers have moved online. Practitioners have responded to the crisis in dementia care with creativity and innovation by harnessing digital technology. Videoconferencing platforms offer relatively cheap and accessible means for groups to meet face to face but virtually. Activity videos uploaded to YouTube or streamed via Facebook Live are perhaps even easier to access, with the advantage that they can be revisited at any time. Consequently, many people with dementia and their carers have turned to technology to maintain their activities and social connections. The experiences of people with dementia, their carers, and musicians over the past months have shown that singing groups can take place online in a way which, although far from ideal, nevertheless offers a meaningful and worthwhile

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experience to those who participate. Therefore, this article focuses on replicating the community singing experience online.

Interest in the possible benefits of musicking for people with dementia and their carers has increased in recent years, and research evidence is growing. The most recent Cochrane systematic review found moderate evidence that music therapy improved depressive and behavioural symptoms in people with dementia.⁵ However, all the studies included in the Cochrane review were conducted in residential care settings. There has been less focus on musical interventions for people with dementia living in the community, who represent a majority of those with the condition.⁶ Singing groups are an example of a popular community-based intervention which may have benefits for both people with dementia and their family carers. Previous research has indicated some of the potential benefits of singing for people with dementia and their carers: improvement of some cognitive functions and reduced depression;⁷ providing meaningful and enjoyable activity;⁸ improving memory, social inclusiveness and mood;⁹ and sustaining or strengthening relationship within caring dyads.^{10,11} This evidence is promising but inconclusive, given that studies in this area are still scarce, and those that are conducted tend to have small samples and effect sizes. Furthermore, online singing is a new, unexplored field, and we do not currently know how these possible benefits carry over to this format.

Looking to the future, remotely delivered singing sessions offer potential advantages, especially for those who are unable to attend in person because of transport, mobility or timing issues. Even after singing groups can resume in their usual format, there may still be an appetite for online groups. If we can suggest ways that the key features of group singing can be replicated in online sessions, this information will provide a basis for future development and evaluation of this approach. Although there is very little existing research about online singing for people with dementia, a large quantity of relevant research in other areas can offer insight and evidence about some pertinent issues.

Aims

The aim of this scoping review is to analyse existing literature to inform the development and implementation of online singing for people with dementia. To accomplish this, we examine both the literature which is directly relevant to the implementation of online singing in dementia and the wider literature that pertains to this topic. Because the purpose of this review is to inform the process of implementing telesinging, the analysis of literature focuses on issues relating to implementation, such as accessibility and feasibility, rather than on the outcomes and effects of the interventions. However, outcomes are mentioned where they are relevant.

Methods

A scoping review was conducted to map the relevant and related literature.¹² Systematic searches identified any existing literature about videoconferenced singing for people with dementia. Subsequent, broader searches were conducted to explore relevant bodies of literature that could be applied to online singing in dementia.

Systematic searches

Systematic literature searches were conducted in EMBASE, Medline, CINAHL, PsycINFO and Web of Science in August 2020. Combinations of the following search terms were used: music, music therapy, singing, telecare, telemedicine, dementia, video calling, videoconferencing, technology, internet, online. These terms were identified a priori by the authors, based on their

knowledge of music therapy, dementia and technology research. **Table 1** sets out the search strategy as it was implemented (the structure was adapted as appropriate for each database).

Owing to the expected paucity of published research on this topic, any article was included if it discussed remotely delivered music or singing for people with dementia using videoconferencing technology, regardless of whether it was an empirical study or not. Conference proceedings were also considered for inclusion. Given the newness of the technology used, articles published before 2010 were excluded.

Searches for related literature

To find literature which was most relevant, influential and recent, and pertinent to telesinging, additional searches were made using Google Scholar. The articles returned in the searches tended to fall into one of five areas at the intersections of research into digital music making, technology as a medium for psychosocial interventions in dementia, and the use by people with dementia of new technology for health, leisure or to maintain independence. The relevance of each area is outlined below:

- **Digital arts and dementia.** This topic helps us to understand how people with dementia engage with and respond to arts-based activities delivered through a digital medium.
- **Everyday technology and dementia.** Research in this area can demonstrate how technology and accompanying instructions can be adapted to be accessible and dementia-inclusive.
- **Remotely delivered music or music therapy, including music teaching.** This area gives insight into how digital music making can be optimised, overcoming technical challenges and troubleshooting.
- **Technology for social interaction and leisure.** Studies involving use of technology by people with dementia for social/leisure reasons (as opposed to household tasks) can show us what kinds of software and hardware are accessible and helpful.
- **Telemedicine/telecare and dementia.** Studies in this field can give insight into whether a healthcare service usually delivered in person can be successfully adapted into a remote format.

The articles retrieved in these searches were read and briefly summarised. Because the main purpose of this review was to inform the implementation of telesinging, the focus of this enquiry was not the effects of the interventions described in the studies, but rather issues surrounding the accessibility and feasibility of their implementation, as well as the motivations behind their initiation. However, the impacts of the intervention were noted where relevant.

Results

Findings from systematic search

Fig. 1 shows how articles indexed by the main databases were assessed for inclusion in the review. Most of the articles excluded after reviewing full texts related to the use of technology by people with dementia, often including musical components. However, none of these articles described musical interventions delivered remotely using videoconferencing technology. **Table 2** lists the articles which were excluded and the reasons for their exclusion; some of these articles are discussed later in this article under “Literature related to telesinging”. The single article included from the systematic search is a journal article in Japanese from 2014 which describes music therapy conducted via Skype with people with dementia.¹³ Although the article itself could not be obtained,

Table 1
Search strategy for databases.

Line number	Search terms
1	TOPIC: (DEMENTIA)
2	TITLE: (dement* OR alzheimer*)
3	TITLE: ("nursing home*" OR "care home*" OR "residential care")
4	#1 OR #2 OR #3
5	TOPIC: (TECHNOLOGY)
6	TOPIC: (INTERNET)
7	TITLE: (web* OR internet* OR email* OR tablet* OR android* OR smartphone* OR facebook* OR skype* OR zoom* OR whatsapp* OR instagram* OR twitter* OR wechat* OR software* OR app OR "social network*" OR "social media*" OR "video call*" OR "video conferenc" OR "everyday technolog*")
8	#5 OR #6 OR #7
9	TOPIC: (MUSIC)
10	TOPIC: (MUSIC THERAPY)
11	TITLE: (music* OR sing OR sings OR singing OR singer* OR song* OR choir* OR choral* OR playlist* OR listen* or concert*)
12	#9 OR #10 OR #11
13	#4 AND #8 AND #12

the final report from the same project was downloaded from the study’s website, and run through online translation software. The resulting translation was sufficiently clear to be able to surmise the study’s methods and findings.

In this study, three participants who were diagnosed with dementia received individual music therapy via a video-calling platform (Skype).¹³ The therapist used CDs of personalised music which were created for each participant in the study, but additional description of session format is not provided. The effects of the therapy were assessed using the BEHAVE-AD scale for measuring behavioural and psychological symptoms of dementia (BPSD) and a technology which monitored the number of times the participant smiled during the session. The study found that BPSD decreased in two participants and was unchanged in one, while the number of smiles increased in two cases, and decreased in one. Questionnaires

completed by participants and their family members indicated they had noticed positive effects, including improved mood.

Although the study is very small and no firm conclusions can be drawn from the results, it does provide some proof of principle that music-based interventions for people with dementia can be conducted using videoconferencing. However, it does not describe how the participants responded to using Skype, nor how they interacted with a remote music therapist. To explore how teleinsing interventions can be implemented and optimised, it is necessary to draw on other, more tangentially related literature.

Literature related to telesinging

The broader searches of related literature from all sources enabled us to investigate the contribution of a range of disciplines to the topic of telesinging in dementia. Here we outline the evidence drawn from each field of enquiry and show how it may be applied to our area of interest.

Digital arts and dementia

A frequent theme in the literature about digital arts was the design of activities and technology to facilitate participation of people with dementia. This work points to the importance of balancing accessibility with population-appropriate technology. Ford et al.¹⁴ implemented a programme in a residential care setting using publicly available software applications (apps), selected for their simplicity and to exclude any that might be experienced as infantilizing. Peeters et al.¹⁵ emphasised the importance of an 'easy interface that is low tech' in their development of a personalised music and picture player.

Digital arts interventions are rarely designed for people with dementia to use independently, but are typically a shared activity between care partners, or in a group. While frequent interaction with the app is an indicator of engagement, Luyten et al.¹⁶ found that their touchscreen art installation 'VENSTER' stimulated more interactions among the group than it did between individuals and the installation. Successful engagement with digital arts interventions may be associated with enthusiastic involvement of the carer; Golden et al.¹⁷ observed that carers needed a lot of prompting to use an arts app, and reflected that the project may have added to their sense of 'burden'. This implies that the perspectives of both the carer and person with dementia need to be considered in developing digital tools.

Everyday technology and dementia

The literature around the use of everyday technology by people with dementia examines barriers to engagement, while challenging some commonly held views. A qualitative study by Nygard et al.¹⁸ found that the most important factors driving technology use were the embodiment of the physical movements required to operate it and a perceived need for the particular technology. They reported that people with dementia could learn to use new, complex technology, provided they were highly motivated to do so.¹⁹ There was consensus among authors that tailoring technology to the specific needs of a person with dementia and training in its use—individualisation, was vital.^{19–21} Furthermore, Bartels et al.²² indicated that people with dementia were able accurately to assess their own capabilities with regard to technology use.

Remote music therapy and music teaching—individual versus group experience

Although music teaching and music therapy are dissimilar in their aims, they encounter similar challenges when transferring to an online format. Research in music education indicates there may be subtle shifts in session dynamics when interaction is online; one

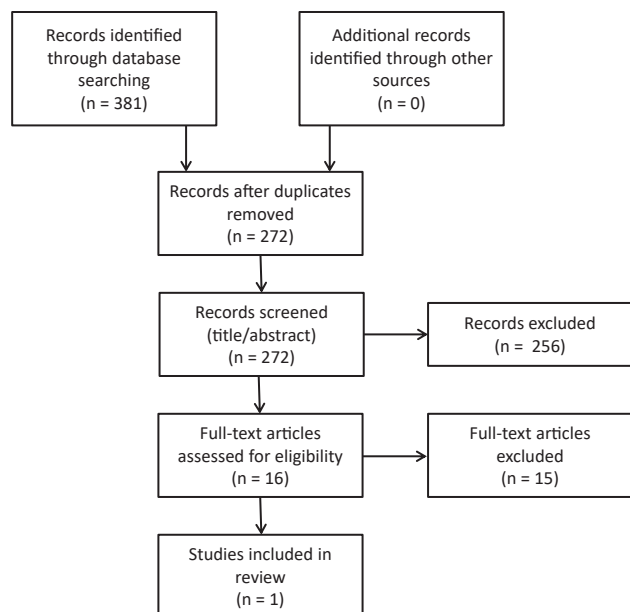


Fig. 1. PRISMA diagram for systematic literature search.

Table 2
Papers screened for inclusion at full text level and reasons for their exclusion.

Authors	Year	Title	Journal/Conference	Reason for excluding
Ford et al. ¹	2019	Evaluating the Impact of Music & Memory's Personalised Music and Tablet Engagement Program in Wisconsin Assisted Living Communities: Pilot Study	JMIR Aging	Study is about the use of personalised music and entertainment/leisure apps but does not include videoconferencing.
Gilson et al. ²	2019	Using Computer Tablets to Improve Moods for Older Adults With Dementia and Interactions With Their Caregivers: Pilot Intervention Study	JMIR Formative Research	Article discusses an individualised tablet engagement programme but is not about music or videoconferencing.
Golden et al. ³	2017	The Challenges of Developing a Participatory Arts Intervention for Caregivers of Persons With Dementia	Cureus	Article reports the results of an intervention based on pre-recorded videos of arts activities.
Han et al. ⁴	2020	Cognitive Intervention With Musical Stimuli Using Digital Devices on Mild Cognitive Impairment: A Pilot Study	Healthcare	Study is about a technology- and music-based approach to Cognitive Stimulation Therapy, but does not use videoconferencing.
Imtiaz et al. ⁵	2018	A Mobile Multimedia Reminiscence Therapy Application to Reduce Behavioral and Psychological Symptoms in Persons With Alzheimer's	Journal of Healthcare Engineering	Article describes the creation of a multisensory music/pictorial app to reduce behavioural symptoms, but does not involve videoconferencing.
Le Navenec & Parr Vijinski ⁶	2015	A Case Study of the Responses of a Person With Semantic Dementia to the Use of Music With Active Video	Neurodegenerative Diseases	Article describes using video clips played to the person with dementia during music sessions, not videoconferencing.
McCabe et al. ⁷	2019	Designing a Better Visit: Touch Screen Apps for People Living With Dementia and Their Visitors	Neurodegenerative Diseases	Study is about use of touchscreen tablets by dyads, but does not involve videoconferencing.
Nezerwa et al. ⁸	2014	Alive Inside: Developing Mobile Apps for the Cognitively Impaired	IEEE Long Island Systems, Applications and Technology Conference	Article describes the creation of a musical app, but videoconferencing is not involved.
Peeters et al. ⁹	2016	Designing a Personal Music Assistant That Enhances the Social, Cognitive, and Affective Experiences of People With Dementia	Computers in Human Behavior	Study deals with use of a personal music- based technology for people with dementia, but no videoconferencing.
Samuelsson & Ekstrom ¹⁰	2019	Digital Communication Support in Interaction Involving People With Dementia	Logopedics, Phoniatrics, Vocology	Study deals with the use of technology to stimulate and prolong conversation between caring dyads. Videoconferencing is not involved.
Tak et al. ¹¹	2015	Computer Activities for Persons With Dementia	The Gerontologist	Article discusses use of computers by people with dementia to carry out everyday leisure activities.
Tsolaki et al. ¹²	2015	New Technologies and Dementia	Neurobiology of Aging	Article is an overview of different technology-related projects but videoconferencing is not mentioned.
Tsolaki et al. ¹³	2015	Our Experience With Informative and Communication Technologies (ICT) in Dementia	Hellenic Journal of Nuclear Medicine	Article is an overview of various technology based interventions. Videoconferencing is not mentioned. (Similar work to the other Tsolaki et al. paper.)
Varshney et al. ¹⁴	2019	Dementia: A Cognitive Disability and Role of Non-Pharmacological Intervention Alzhatv in Cognitive Remediation	American Journal of Geriatric Psychiatry	Article is about watching pre-recorded family/entertainment/orientation videos.
Yamagata et al. ¹⁵	2013	Mobile App Development and Usability Research to Help Dementia and Alzheimer Patients	Ninth Annual Conference on Long Island Systems, Applications and Technology	Study deals with development of apps for people with dementia for social/leisure activities, but not videoconferencing. Same project as Nezerwa et al. (2014)

study found that online lessons were more dominated by verbal activity with less demonstration by teachers and students.²³

Three music therapy articles provide some insight into video-conference sessions. Baker and Krout²⁴ conducted a proof-of-concept study which compared face-to-face music therapy sessions with Skype© sessions for an adolescent with Asperger's syndrome. They found that the client liked using the technology and was more ready to engage and offer suggestions over Skype than in person. The therapist found that not being able to play guitar together and poor sound quality were limitations, but one-to-one, songwriting-based music therapy seems well-suited to videoconference delivery because it does not rely on synchronous playing.

Lightstone et al.²⁵ present a case study in which a veteran with complex PTSD attended music therapy via videoconferencing. Use of an established Canadian telehealth network meant that the internet connection was fast, secure and stable. Remote therapy in this case seemed as effective as in-person therapy. There is no mention in the article of any issues relating to latency or sound

quality, probably because latency will have a less pronounced effect on individual sessions than on work with several people in different locations. Using a custom-built virtual reality (VR) environment, Tamplin et al.²⁶ explored the possibility of group singing over the internet for people with quadriplegia. Low latency audio was achieved via a software platform called JackTrip. Participants reported that the latency between audio and video of about 1 s did not affect their singing experience, and that VR reduced their inhibitions about singing in front of other, but may have made it harder to read social cues. VR also facilitated the experience of "going somewhere" for singing sessions. Although the JackTrip technology enabled real time group singing, the level of technical involvement and set-up needed may present barriers for participants joining a singing group from their own home.

Technology for social interaction and cognitive stimulation

The group singing experience may be characterised as a social and leisure activity as much as a therapeutic intervention designed to support wellbeing and improve quality of life. The literature in

this area largely concerns the use of tablet devices, as these are considered portable, accessible and user-friendly.²⁷ It includes several instances of digital devices being used to support conversation and interaction between people with dementia and their carers.^{28–30} Samuelsson and Ekstrom (2019) found that using a tablet with photos, music and videos produced conversations between nurses and people with dementia that were less one-sided and covered a wider range of topics. Ferm et al.²⁹ showed that the device itself can become a stimulus to conversation, prompting discussion of developments in technology and experiences of using the device.

Several articles emphasise the importance of functional and reliable technology in facilitating further engagement. In a study of videoconferencing technology to connect with older people in remote parts of Finland, researchers found that robust technology and previous experience of use enabled successful participation, whereas lack of experience, technical problems and negative self-perception as a user of technology were seen as barriers.³¹ Ferm et al.²⁹ support this finding, stressing the importance of ensuring that initial experiences with technology are positive.

Telemedicine and telecare

There are many studies in telemedicine, so priority was given to more recent papers concerning at-home videoconferencing. Because telemedicine is driven by the potential to make economic savings in health care, there is a risk of bias in the literature which we could not control for in this review. That said, a number of studies have shown that dementia diagnostic testing conducted remotely via videoconferencing is not inferior to in-person testing, in terms of reliability.^{32–35} Participants were often very willing to use telemedicine because they lived in an underserved community.³⁶ People with dementia and their families readily accepted telemedicine, confounding researchers' expectations.³⁷ However, 30% of patients said that they felt more anxious in a video appointment than they would have done face to face. Moo et al.³⁸ compared people who accepted videoconferenced telemedicine to those who declined, and found that the main reason for declining was lack of a computer. Satisfaction with telemedicine was very high and the study showed it could be as successful as in-person visits. In some cases, participants chose telemedicine even when face-to-face care was available, implying good acceptability. The present pandemic is likely to generate even higher rates of telemedicine. Because lack of technology is the biggest barrier to taking part in telemedicine, the need for strategies to avoid excluding a proportion of people with dementia is once again emphasised.

Barriers and facilitators

Given the recency of online singing, it is not surprising that the interrogation of related literature proved more fruitful than the direct systematic searches. This also means that dementia-specific considerations in online singing have not emerged from our analysis. Still, the evidence gathered provides information about barriers and facilitators which can inform the development of online singing and which indicates how to optimise the musical experience of participants with dementia. Moreover, what works for this population will work for other groups. These barriers and facilitators are summarised, first, in relation to the individual participant and their psychological state, and second, in relation to the technology itself.

Psychological

Encountering obstacles when using technology can make participants less motivated to engage with it in the future, so care should be taken to minimise such problems and provide adequate

support. Getting online and using technology is itself a shared experience for the group and may become a topic of conversation, so it could help to reassure participants if facilitators are open about their own experiences and challenges. In addition to providing clear and simple instructions, previous studies indicate that support from another person to use unfamiliar technology may promote successful participation.

The experience of people with dementia in the online session may be more dependent on their interaction with their carer than it would be in a face-to-face session. The carer will also have more insight into how the person with dementia is responding to and engaging with the session. It follows that it may be helpful for the facilitator to provide some tips or instructions about how carers can maximise the person's enjoyment of the session, and in turn the facilitator can learn from the carer's feedback about how their person responds.

Because peer support and sharing knowledge between carers is an important part of the singing group experience for attendees,^{8–10} facilitators of online activities may wish to consider how they can support carers to build or maintain similar relationships in the online format (e.g. breakout rooms, text-based chat).

It is inevitable that not everyone will be able to access the required technology to join an online session, so facilitators should think carefully about what alternative formats they can offer to avoid excluding these participants.

Technological

Technology should be appropriate to the intended population and tailored to their needs and existing knowledge. The accessibility of the user interface is important; ease of use and functionality characterise successful applications of technology. It should not be assumed that people with dementia and their carers are novice technology users.

We know that group music-making is highly reliant on inter-participant synchronicity which makes its adaption to an online format a challenge. However, the existing music therapy literature suggests that online, videoconferenced sessions are a viable possibility. Playing and singing in unison is not possible with commonly available platforms due to audio latency. Available solutions are relatively complex and costly for groups. Group facilitators therefore need to work within latency restrictions and adapt the singing session to preserve a sense of togetherness and group feeling using the technology which is available. There remains a need for software applications to be developed to overcome the problem of audio latency, or for existing apps to be better distributed to this consumer group.

Conclusion

The public health crisis of SARS-CoV-2 has compelled practitioners to innovate to keep their singing groups musically together while remaining socially distant. Our scoping review highlights a number of logistical issues that can promote or inhibit the use of online singing by people with dementia and their carers. Overall, we found evidence of growing acceptability of digital interventions, largely from the telemedicine literature. There is evidence of their efficacy from remotely delivered music therapy, and evidence of the feasibility of digital apps to support social, leisure and practical needs. It is likely therefore that online singing could be taken up by millions of people with dementia worldwide as a relatively inexpensive aid to wellbeing and social inclusion, and in fact increased online provision could improve accessibility for those who live outside the large urban areas where most singing groups tend to take place. A key to scaling up this activity would be improved

software to overcome audio latency, while also tackling digital exclusion among older age groups. The pace of innovation in this field is rapid and literature lags behind. This scoping review provides a benchmark for further research and innovation. It should be useful to technology developers, researchers, service providers and practitioners.

Author statements

Ethical approval

Not required as this study involved reviewing existing literature.

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Competing interests

None declared.

References

- Jordan RE, Adab P, Cheng KK. Covid-19: risk factors for severe disease and death [Internet] *BMJ* 2020;**368**(March):1–2. <https://doi.org/10.1136/bmj.m1198>. Available from:..
- Brooke J, Jackson D. Older people and COVID-19: isolation, risk and ageism. *J Clin Nurs* 2020;**29**(13–14):2044–6.
- Greenberg NE, Wallick A, Brown LM. Impact of COVID-19 pandemic restrictions on community-dwelling caregivers and persons with dementia. *Psychol Trauma Theory, Res Pract Policy*. 2020:19–21.
- Woods B, Aguirre E, Spector AE, Orrell M. Cognitive stimulation to improve cognitive functioning in people with dementia. *Cochrane Database Syst Rev* 2012;**2**.
- van Der Steen JT, Smaling HJA, Van Der Wouden JC, Bruinsma MS, Scholten RJP, Vink AC. Music-based therapeutic interventions for people with dementia (Review). *Cochrane Database Syst Rev* 2018;**(7)**:1–86.
- Prince M, Knapp M, Guerchet M, McCrone P, Prina M, Comas-Herrera A, et al. Dementia UK: second edition overview. *Alzheimer's Soc* 2014;1–136.
- Sarkamo T, Laitinen S, Numminen A, Kurki M, Johnson JK, Rantanen P. Clinical and demographic factors associated with the cognitive and emotional efficacy of regular musical activities in dementia [Internet] *J Alzheimers Dis* 2016;**49**(3):767–81. Available from: <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=medl&NEWS=N&AN=26519435>.
- Camic PM, Williams CM, Meeten F. Does a "Singing Together Group" improve the quality of life of people with a dementia and their carers? A pilot evaluation study [Internet] *Dementia* 2011;**12**(2):157–76. Available from: <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=medl&NEWS=N&AN=24336767>.
- Osman SE, Tischler V, Schneider J. Singing for the Brain: a qualitative study exploring the health and well-being benefits of singing for people with dementia and their carers [Internet] *Dementia* 2014 Nov;**15**(6):1326–39. Available from: <http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=119144932&site=ehost-live>.
- Unadkat S, Camic PM, Vella-Burrows T. Understanding the experience of group singing for couples where one partner has a diagnosis of dementia [Internet] *00(00) Gerontol* 2017 Jun:1–11. Available from: <http://gerontologist.oxfordjournals.org/lookup/doi/10.1093/geront/gnv698>. 57, 3, 469–478.
- Tamplin J, Clark IN, Lee YEC, Baker FA. Remini-sing: a feasibility study of therapeutic group singing to support relationship quality and wellbeing for community-dwelling people living with dementia and their family caregivers. *Front Med* 2018;**5**(AUG):1–10.
- Noble H, Smith J. Reviewing the literature: choosing a review design. *Evid Base Nurs* 2018;**21**(2):39–41.
- Hori M, Iizuka M, Nakamura M, Aiba I, Saito Y, Kubota M, et al. At-home music therapy intervention using video phone (Skype) for elderly people with dementia [Internet] *Gan To Kagaku Ryoho* 2014;**41**(Suppl 1):33–5. Available from: <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=medl&NEWS=N&AN=25595076>.
- Ford JH, Dodds D, Hyland J, Potteiger M. Evaluating the impact of music & memory's personalized music and tablet engagement program in Wisconsin assisted living communities: pilot study. *J Med Internet Res* 2019;**21**(3):1–13.
- Peeters MMM, Harbers M, Neerincx MA. Designing a personal music assistant that enhances the social, cognitive, and affective experiences of people with dementia. *Comput Hum Behav* 2016 Oct;**63**:727–37.
- Luyten T, Braun S, Jamin G, van Hooren S, de Witte L. How nursing home residents with dementia respond to the interactive art installation 'VENSTER': a pilot study [Internet] *Disabil Rehabil Assist Technol* 2018;**13**(1):87–94. <https://doi.org/10.1080/17483107.2017.1290701>. Available from:..
- Golden A, Gammonley D, Hanna Powell G, Wan TT. The challenges of developing a participatory arts intervention for caregivers of persons with dementia. *Cureus* 2017;**9**(4).
- Nygård L. The meaning of everyday technology as experienced by people with dementia who live alone. *Dementia* 2008;**7**(4):481–502.
- Astell AJ, Malone B, Williams G, Hwang F, Ellis MP. Leveraging everyday technology for people living with dementia: a case study. *J Assist Technol* 2014;**8**(4):164–76.
- Tak SH, Zhang H, Patel H, Hong SH. Computer activities for persons with dementia [Internet] *Gerontol* 2015;**55**(Suppl 1):S40–9. Available from: <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=medl&NEWS=N&AN=26055780>.
- Wallcock S, Nygård L, Kottorp A, Malinowsky C. The use of everyday information communication technologies in the lives of older adults living with and without dementia in Sweden [Internet] *0(0) Assist Technol* 2019:1–8. <https://doi.org/10.1080/10400435.2019.1644685>. Available from:..
- Bartels SL, Assander S, Patomella AH, Jamnadas-Khoda J, Malinowsky C. Do you observe what I perceive? The relationship between two perspectives on the ability of people with cognitive impairments to use everyday technology [Internet] *0(0) Aging Ment Health* 2019;**24**(8):1–11. <https://doi.org/10.1080/13607863.2019.1609902>. Available from:..
- Dye K. Student and instructor behaviors in online music lessons: an exploratory study. *Int J Music Educ* 2014;**34**(2):161–70.
- Baker F, Krout R. Songwriting via Skype: an online music therapy intervention to enhance social skills in an adolescent diagnosed with Asperger's syndrome. *Br J Music Ther* 2009;**23**(2):3–14. Available from: <http://bjm.sagepub.com/lookup/doi/10.1177/135945750902300202>.
- Lightstone AJ, Bailey SK, Voros P. Collaborative music therapy via remote video technology to reduce a veteran's symptoms of severe, chronic PTSD. *Arts Health* 2015;**7**(2):123–36.
- Tamplin J, Loveridge B, Clarke K, Li Y, Berlowitz D J. Development and feasibility testing of an online virtual reality platform for delivering therapeutic group singing interventions for people living with spinal cord injury [Internet] *J Telemed Telecare* 2019;**26**(6):365–75. <https://doi.org/10.1177/1357633X19828463>. Available from:..
- Yamagata C, Kowtko M, Coppola JF, Joyce S. Mobile app development and usability research to help dementia and alzheimer patients. In: *2013 ninth annual conference on long Island Systems, Applications and Technology (LISAT 2013)*; 2013.
- Gilson A, Dodds D, Kaur A, Potteiger M, Ford JH. Using computer tablets to improve moods for older adults with dementia and interactions with their caregivers: pilot intervention study. *J Med Internet Res* 2019;**21**(9):1–13.
- Ferm U, Ekström A, Larsson E, Samuelsson C. Tablet computer-supported conversation between people with dementia and their carers: technology as interactional focus [Internet] *Univers Access Inf Soc* 2020:0123456789. <https://doi.org/10.1007/s10209-020-00745-4>. Available from:..
- Samuelsson C, Ekström A. Digital communication support in interaction involving people with dementia [Internet] *Logop Phoniater Vocology* 2019;**44**(1):41–50. <https://doi.org/10.1080/14015439.2019.1554856>. Available from:..
- Airola E, Rasi P, Outila M. Older people as users and non-users of a video conferencing service for promoting social connectedness and well-being—a case study from Finnish Lapland [Internet] *Educ Gerontol* 2020;**46**(5):258–69. <https://doi.org/10.1080/03601277.2020.1743008>. Available from:..
- Grosch MC, Weiner MF, Hynan LS, Shore J, Cullum CM. Video teleconference-based neurocognitive screening in geropsychiatry [Internet] *Psychiatr Res* 2015;**225**(3):734–5. <https://doi.org/10.1016/j.psychres.2014.12.040>. Available from:..
- Lindauer A, Seelye A, Lyons B, Dodge HH, Mattek N, Mincks K, et al. Dementia care comes home: patient and caregiver assessment via telemedicine. *Gerontol* 2017;**57**(5):85–93.
- Vahia IV, Ng B, Camacho A, Cardenas V, Cherner M, Depp CA, et al. Telepsychiatry for neurocognitive testing in older rural latino adults [Internet] *Am J Geriatr Psychiatr* 2015;**23**(7):666–70. <https://doi.org/10.1016/j.jagp.2014.08.006>. Available from:..
- Martin-Khan M, Flicker L, Wootton R, Loh PK, Edwards H, Varghese P, et al. The diagnostic accuracy of telegeriatrics for the diagnosis of dementia via video conferencing [Internet] *J Am Med Dir Assoc* 2012;**13**(5):487.e19–24. <https://doi.org/10.1016/j.jamda.2012.03.004>. Available from:..
- Tso JV, Farinpour R, Chui HC, Liu CY. A multidisciplinary model of dementia care in an underserved retirement community, made possible by telemedicine. *Front Neurol* 2016;**7**(DEC):1–6.
- Azad N, Amos S, Milne K, Power B. Telemedicine in a rural memory disorder clinic-remote management of patients with dementia. *Can Geriatr J* 2012;**15**(4):96–100.
- Moo LR, Gately ME, Jafri Z, Shirik SD. Home-based video telemedicine for dementia management [Internet] *Clin Gerontol* 2020;**43**(2):193–203. <https://doi.org/10.1080/07317115.2019.1655510>. Available from:..



Short Communication

Parental perceptions of COVID-19–like illness in their children

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ABSTRACT

Objectives: The objective of the study is to explore parents' perceptions of COVID-19–like symptoms in their child and attitudes towards isolating from others in the household when unwell.

Study design: The study used qualitative, semistructured interviews.

Methods: The study involved thirty semistructured telephone interviews with parents of children between 4 and 18 years. Thirty semistructured telephone interviews with parents of children between 4 and 18 years.

Results: We found four themes relating to symptom attribution ('normalising symptoms', 'err on the side of caution', 'experience of temperature', 'symptoms not normal for us'). In general, parents were more likely to attribute symptoms to COVID-19 if a temperature was present or the symptoms were perceived as 'unusual' for their family. Four themes relating to self-isolation ('difficult to prevent contact with children', 'isolation would be no different to lockdown life', 'ability to get food and supplies', 'limited space'). Parents believed they would find isolation within the household difficult or impossible if they had dependent children, had limited space or could not shop for groceries.

Conclusions: The findings highlight complexities in symptom perception, attribution and household isolation. We suggest that they can be overcome by (a) providing better guidance on what symptoms require action, (b) providing guidance as to how to prevent infection within the household and (c) by supporting families with grocery shopping through a potential second or third wave.

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Children can spread certain illnesses readily at school and, in order to prevent outbreaks, are encouraged to stay at home when ill or until they are no longer infectious.¹ How thoroughly children and parents adhere to the rules around sickness absence is unclear. In England, schools were closed nationally from 23rd March 2020, to prevent the spread of COVID-19² and reopened to all children in September. There have been concerns that some parents may continue to send children to school when experiencing the symptoms of COVID-19, which include fever and cough.³

Sending a child to school while symptomatic, rather than keeping them at home and arranging a test for COVID-19 as recommended by national guidance, may depend partly on how parents interpret their child's symptoms⁴ and partly on whether the parent is willing and able to keep the child off school. This in turn may require the parent to take time off work and affect the child's education. However, little is known about factors that are at play in this decision-making process.

In this article, we use data from interviews that explored parents' perceptions of COVID-19–like symptoms in their child and attitudes towards isolating from others in the household when unwell.

Two interviewers conducted semistructured telephone interviews lasting approximately 75 min between 15th and 21st April 2020 ($n = 30$, female = 20). All participants were aged 18 years or older and were the primary caregiver to a child who, from March 23rd, 2020 was not attending preschool or school in England because of COVID-19. At the time of data collection, the recognised symptoms of COVID-19 were a new, continuous cough and fever. Loss of sense of smell or taste was added on May 18th, 2020.⁵ At the time of interviewing, guidance stated that individuals who suspected they had symptoms should isolate as best they could from others in the household.⁶

A broad discussion guide was used, covering psychological well-being, educational activity while at home and adherence to social distancing guidance. Results for these aspects of the interviews will be reported elsewhere. In this manuscript, we focus on responses relating to symptom perception, attribution, and how parents thought they would react to the presence of symptoms among their

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Table 1
Supporting quotes for identified themes.

Topic	
Theme	Quote (Participant number; Age; Gender; Ethnicity; Highest education level; Education level of oldest child living at home, Number of children)
<i>Symptom attribution</i>	
Normalising symptoms	<p>'I've not done night shift work before, there's times where I've felt a bit odd, and I've thought ... 'Are these symptoms?' 'Am I showing symptoms of corona?' But then you think, 'Actually, no I'm just tired,' and, 'Actually, I've got a bit of a sore throat, because—' (P27; 25–49; Male; White; Higher education or equivalent; Secondary, 3)</p> <p>'My five-year-old did have cough, but then he gets cough around that time anyway ... cough is one of those things, you know if you get dust in the house, if it gets dusty or hay fever or whatever' (P22; 25–49; Female; BAME; A-Levels or equivalent; Primary, 5)</p> <p>'A cough ... it only lasted a day ... she didn't have any other symptoms [and] she has suffered with a cough since she was young' (P2; 25–49; Female; White; A-level or equivalent; Preschool, 2)</p> <p>'It was ... 24, 48 h of this horrible tickly cough that wouldn't go away but it wasn't continual and there was no other symptoms. Neither of the kids picked it up. So, I can only assume it was something more likely linked to hay fever or a cold' (P26; 25–49; Female; White; Higher education or equivalent; Primary, 2)</p>
Err on the side of caution	<p>'You can carry [COVID-19], but you don't have it yourself ... I just wouldn't wanna be responsible for anyone's illness' (P13; 25–49; Female; BAME; GCSEs or equivalent; Primary, 1)</p> <p>'If we thought we had any symptoms we'd be protecting ourselves' (P24; 25–49; Female; White; Higher education or equivalent; Primary, 1)</p> <p>'As soon as they get a cold or a cough, you're thinking, 'Is this the coronavirus?' And I know that's a bit paranoid, but ...' (P15; 25–49; Male; White; Higher education or equivalent; Secondary, 4)</p> <p>'definitely have to stay in if they were showing symptoms' (P4; 25–49; Female; BAME; Higher education; Secondary, 2)</p> <p>'I'll just keep her in to be safe ... and err on the side of caution for once.' (P5; 25–49; Female; White; A-level or equivalent; Secondary, 2)</p>
Experience of temperature	<p>'I was definitely self-isolating ... because I didn't want to pass it to my nana and because I know that that's the best thing to do, with any virus. Even regardless of coronavirus' (P11; 25–49; Female; BAME; Higher education or equivalent; Secondary, 1)</p> <p>'Before I was a oh-just-suck-it-up, he'll-be-fine, kind of mum. Unless there was a temperature' (P11; 25–49; Female; BAME; Higher education or equivalent; Secondary, 1)</p> <p>'Well if she didn't have a temperature, she had a cough ... or a bit of a cold, then I'd send her in, yeah' (P1; 25–49; Female; BAME; Higher education or equivalent; Secondary, 1)</p> <p>'Of course, we're concerned, because obviously I had temperature' (P14; 25–49; Male; BAME; Higher education or equivalent; Secondary, 4)</p> <p>'He got a temperature for about 24 h. I had a temperature, a sore throat and a headache for about two days. Possibly, we could have had mild symptoms. But I don't know, without being tested we won't know' (P23; 25–49; Female; White; British; Higher education or equivalent; Primary, 2)</p>
Symptoms not normal for us	<p>'We know each other, we'll know if something gets to that stage, we would go and get tested' (P10; 25–49; Male; White; Higher education or equivalent; Secondary, 2)</p> <p>'Everyone was so tired. I mean so tired, they couldn't watch telly, they couldn't do anything ... that was what was weird' (P8; 25–49; Female; White; Higher education or equivalent; Secondary, 4)</p> <p>'For [them] to lose [their] appetite is a key indicator if something is wrong [sic]' (P11; 25–49; Female; BAME; Higher education or equivalent; Secondary, 1)</p>
<i>Ability to isolate</i>	
Difficult to prevent contact with children	<p>'I don't know how that would work' (P4; 25–49; Female; BAME; Higher education; Secondary, 2)</p> <p>'That would break my heart, if I couldn't go near him. I genuinely don't know how I'd do that' (P12; 25–49; Female; White; A-Level or equivalent; Primary, 1)</p> <p>'Kids don't know boundaries ... it would be impossible for me and my husband not to get it I think' (P7; 25–49; Female; White; A-Level or equivalent; Preschool, 1)</p> <p>'Unless [we] were ... wearing gloves and a mask 24/7 to look after him [they could avoid catching COVID-19] ... But even then, I think ... we'd get it, because it's just too difficult with a three-year-old' (P7; 25–49; Female; White; A-Level or equivalent; Preschool, 1)</p> <p>'If it was me or [my partner], I don't think it would be much of a problem. We could just shut ourselves away, but if the kids got it, that would be different, and I think we'd almost certainly catch it from them' (P8; 25–49; Female; White; Higher education or equivalent; Secondary, 4)</p> <p>'I think we just accept the fact that we wouldn't be able to do that ... if one goes down, probably all of us would go down' (P9; 18–24; Female; White; GCSEs or equivalent; Primary, 2)</p> <p>'I have been panicking, which is why I've been staying in and extra precautions, because I feel if I was to get ill, I don't know how he'd cope looking after me and the kids' (P30; 25–49; Female; White; GCSEs or equivalent; Secondary, 3)</p> <p>'It would be basically impossible to. Especially my one-year-old and two-year-old. The one-year-old, the two-year-old, the four-year-old, they're constantly wanting to be with me ... And he's breastfeeding as well' (P22; 25–49; Female; BAME; A-Levels or equivalent; Primary, 5)</p> <p>'My little girl, she wouldn't understand it at all. It's no good having the conversation with her 'cause she just won't understand it' (P10; 25–49; Male; White; Higher education or equivalent; Secondary, 2)</p> <p>'They wouldn't understand 'no, you can't go and see mummy' or 'no you can't go and talk to daddy'. I think that would be quite hard' (P9; 18–24; Female; White; GCSEs or equivalent; Primary, 2)</p> <p>'That's a real worry for me because if I was ill, it's just me and the children, that is a real worry' (P29; 50–65; Female; White; Higher education or equivalent; Secondary, 2)</p> <p>'Being ill on my own with the kids ... was a bit of a pest. So, it was Mr YouTube had to look after them' (P23; 25–49; Female; White; British; Higher education or equivalent; Primary, 2)</p> <p>'It would be hard for anyone to look after a kid or kids on their own whilst they're also trying to look after [others in the household]' (P7; 25–49; Female; White; A-Level or equivalent; Preschool, 1)</p>
Isolation would be no different to lockdown life	<p>'Well apart from going to the park or ... shopping, very similar ... So yeah, I'd adapt to it. Plus I'd adapt to it even more because it's your life' (P28; 50–65; Male; White; A-Levels or equivalent; Secondary, 1)</p> <p>'We're not going anywhere; it's going to be very difficult for them to catch anything. We're just at home' (P18; 25–49; Female; White; Higher education or equivalent; Primary, 6)</p> <p>'They're that much self-isolated anyway' (P6; 25–49; Female; BAME; Higher education; Secondary, 2)</p> <p>'It would be easy, we've done it for six weeks. Another 14 days wouldn't do anything, would it?' (P30; 25–49; Female; White; GCSEs or equivalent; Secondary, 3)</p>

Table 1 (continued)

Topic	Quote (Participant number; Age; Gender; Ethnicity; Highest education level; Education level of oldest child living at home, Number of children)
Ability to get food and supplies	<p>'There's big network in my town, so if anyone is having to self-isolate, you can contact the [local] Coronavirus Project' (P19; 25–49; Female; Separated; White British; A-Levels or equivalent; Secondary, 5)</p> <p>'because occasionally we can get Tesco's slots' (P9; 18–24; Female; White; GCSEs or equivalent; Primary, 2)</p> <p>'The only thing I found really difficult [about self-isolation] was, I hated having to ask someone else to go and buy me food' (P23; 25–49; Female; White; British; Higher education or equivalent; Primary, 2)</p> <p>'I think then we'd struggle because apart from anything, you can't get online deliveries and that at the moment' (P12; 25–49; Female; White; A-Level or equivalent; Primary, 1)</p> <p>'I had to get a friend to do all my shopping for me. But thankfully I'd stocked up quite a lot of food, anyway, so it was all right. No, I didn't panic buy, I always have loads of food in anyway' (P23; 25–49; Female; White; British; Higher education or equivalent; Primary, 2)</p>
Limited space	<p>'We live in a three-bedroom bungalow ... it would be virtually impossible. Especially if more than one person had it, which it's likely to happen, in a house of six people' (P8; 25–49; Female; White; Higher education or equivalent; Secondary, 4)</p> <p>'It would be a challenge if [self-isolation] had happened. It's a relatively small house, it's got three bedrooms' (P21; 50–65; Male; White; Higher education or equivalent; Secondary, 3)</p>

BAME, Black, Asian and Minority Ethnic; GCSE, General Certificate of Secondary Education.

children. In our interview schedule, we asked parents whether their child had had 'coronavirus or coronavirus symptoms, either a high temperature or new continuous cough?'. We also asked a set of questions about whether the parent or child would find it difficult to self-isolate and how they would cope with self-isolation.

Results were analysed using an inductive approach to thematic analysis.⁷ We found four themes relating to symptom attribution and four themes relating to self-isolation. These are described in Table 1 with supporting quotes.

In terms of symptom attribution, parents appeared to go through a process of finding the most likely reason for the experience of symptoms, discounting COVID-19 if a more likely explanation was apparent ('normalising symptoms'). Symptoms were often normalised in day-to-day terms that reduced the perceived risk and thus the intention to isolate. Particularly if symptoms were transitory or mild, this reduced worry and increased the likelihood of attribution to a non-COVID explanation. Conversely some participants expressed a view that 'any symptoms' should be treated as if they were COVID-19 related ('err on the side of caution'). Given the context of the pandemic, they would isolate if they or a household member experienced either a cough or fever, to be on the safe side.

Some parents indicated that they would be more likely to attribute high temperature than a cough to COVID-19 ('experience of temperature'). While a cough could be put down to a sore throat or common cold, parents appeared more cautious about a temperature.

There was a sense among some participants that unexpected or unusual symptoms would be a particular cause for concern ('symptoms not normal for us'). Annual or seasonal experience of symptoms (e.g. hay fever) reduced parental concerns about whether symptoms were due to COVID-19 or not, as well as the experience of symptoms 'normal' to their household. Conversely, symptoms that were 'weird' or unusual for the person were 'a key indicator if something is wrong.'

Parents had varied beliefs about their ability to isolate from others in the home and particularly the difficulty of isolating from children ('difficult to prevent contact with children'). Across interviews, parents expressed that this was related to their child's age and their understanding of the virus, i.e. younger children do not understand boundaries or reasons why they cannot be close to their parents. A common, fatalistic sentiment was that if one member of their household presented symptoms of COVID-19, then the whole household would catch it. Single parents relied on novel sources of care when they themselves became ill – for example, increased dependence on online resources, such as gaming and YouTube

videos. When having to isolate due to symptoms, one parent stated they sent their child to their grandparent's house so that they could get sufficient rest to recover.

At the time of data collection, people could only leave home for very limited reasons (for example, shopping as infrequently as possible and a daily walk or exercise). Some parents noted that it would be easy to isolate the entire household as it would be no different to how they were already living during lockdown ('isolation would be no different to lockdown life').

Access to additional help or available resources was identified as impacting parents' ability to isolate. It would appear that ability to self-isolate was facilitated by connectedness to other members of the community and access to local shops ('ability to get food and supplies'); lack of this may make parents believe that they are not able to isolate. Some parents identified that the size of the home would be an additional challenge during self-isolation ('limited space').

Although rules and context have changed because the data were collected early in the pandemic, the findings highlight several key areas worthy of further exploration and quantification. We believe that there are two main implications.

First, parents' perceptions of whether a given symptom is a possible indicator of COVID-19 do not match the official guidance. Symptoms are often not attributed to COVID-19 unless a temperature is present. Data from a national UK study suggest that among those younger than 18 years, 48% of those who tested positive for COVID-19 reported having a temperature in the first 7 days of the illness.⁸ Because parents who identified 'not normal' symptoms or a temperature in themselves or their child were more inclined to attribute them to COVID-19, communications may benefit from highlighting that the presence of even one of the identified symptoms – i.e. a cough alone – necessitates self-isolation or request of a test, even if that symptom is mild.⁶

Second, isolation is seen as difficult by many parents. Given the guidance at the time of interviewing, parents ideally should have isolated from their children to the best of their ability. Many parents identified that this would be difficult or 'impossible'. Our findings also suggest that larger families and those living in smaller homes may find it particularly difficult to isolate. Indeed, research suggests that households with dependent children are less likely to adhere to self-isolation than those without children.⁹ Those who perceived household isolation to be easier were those who said it would be no different to their life in lockdown and would isolate even if they were not sure their or their child's symptoms were due to COVID-19. Parents who reported that they could rely on someone for help with food shopping were more likely to think they could isolate. This is in line with previous research.¹⁰ We suggest that

aiding families with grocery shopping may be a practical route to facilitating adherence to isolation. Although it might be impractical for supermarkets to do this, grassroots organisations played a key role in the first wave and could mobilise again in the second wave.

Author statements

Ethical approval

All participants received information sheets. Informed consent was provided electronically, before the interviews. The research was approved by the Psychiatry, Nursing and Midwifery Research Ethics Subcommittee at King's College London (ref MRSP-19/20-18349).

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Competing interests

G.J.R. and L.E.S. are participants in meetings of UK Scientific Advisory Group for Emergencies and its subgroups.

Author contributions

L.W. designed the interview schedule. A.H. and L.W. conducted interviews. A.H. wrote the first draft of the article with input from L.W., L.E.S., and G.J.R.

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The sponsor and funder of the study had no role in study design, analysis, interpretation, or writing of the report. The corresponding author had full access to all the data in the study and had final responsibility for the decision to submit for publication.

References

1. HM Government. *Health protection in schools and other childcare facilities*. London: HM Government; 2020 [updated 27 March 2019; cited 2020 1st October].
2. Adams R, Stewart H. *UK schools to be closed indefinitely and exams cancelled*. The Guardian; 2020 [cited 2020 1st October]. Available from: <https://www.theguardian.com/world/2020/mar/18/coronavirus-uk-schools-to-be-closed-indefinitely-and-exams-cancelled>.
3. Otte im Kampe E, Lehfeld A-S, Buda S, Buchholz U, Haas W. Surveillance of COVID-19 school outbreaks, Germany, March to August 2020. *Euro Surveill* 2020;**25**(38):2001645.
4. Smith LE, Weinman J, Yiend J, Rubin J. Psychosocial factors affecting parental report of symptoms in children: a systematic review. *Psychosom Med* 2020;**82**(2):187–96.
5. Roberts M. *Coronavirus symptoms: UK adds loss of smell and taste to list*. BBC News; 2020.
6. NHS UK. *When to self-isolate and what to do*. 2020 [cited 2020 1st October]. Available from: <https://www.nhs.uk/conditions/coronavirus-covid-19/self-isolation-and-treatment/when-to-self-isolate-and-what-to-do/#:~:text=When%20to%20get%20a%20test,of%20smell%20or%20taste>.
7. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;**3**(2):77–101.
8. Covid Symptom Study. *Surprising research findings on the early symptoms of COVID-19*. 2020 [cited 2020 1st October]. Available from: <https://covid.joinzoe.com/post/early-covid-signs>.
9. Smith LE, Potts HWW, Amlot R, Fear NT, Michie S, Rubin J. Adherence to the test, trace and isolate system: results from a time series of 21 nationally representative surveys in the UK (the COVID-19 Rapid Survey of Adherence to Interventions and Responses [CORSAIR] study). *medRxiv* 2020. <https://doi.org/10.1101/2020.09.15.20191957>.
10. Smith LE, Amlot R, Lambert H, Oliver I, Robin C, Yardley L, et al. Factors associated with adherence to self-isolation and lockdown measures in the UK: a cross-sectional survey. *Public Health* 2020;**187**:41–52.



Short Communication

Role of non–face-to-face social contacts in moderating the association between living alone and mental health among community-dwelling older adults: a cross-sectional study



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ABSTRACT

Objective: We examined the association between living alone and mental health and the moderating effects of face-to-face and non–face-to-face social contacts, among community-dwelling older adults.

Study design: Cross-sectional study.

Methods: This cross-sectional study recruited Japanese adults older than 60 years, who attended health check-ups held in a suburban town hall in July and August of 2018 and 2019. As mental health outcomes, depression was assessed using the Geriatric Depression Scale 15-items, loneliness was assessed using the University of California, Los Angeles Loneliness Scale 3-items, and happiness was self-rated on a 10-point scale. Face-to-face social contacts were evaluated by participants' frequency of meetings with relatives or friends, whereas non–face-to-face contacts were measured by the frequency of interactions via letter, telephone or e-mail. Multivariable linear regression analysis was conducted to examine the association between living alone with each mental health outcome and the effect modifications of having face-to-face and non–face-to-face social contacts.

Results: Data from 300 older adults were analysed. The participants' mean age was 73.0 years, 51.3% were female, and 16.0% lived alone. Living alone was significantly associated with poorer mental health. Regarding loneliness and low happiness, having face-to-face and non–face-to-face contacts more than once a week alleviated the adverse association of living alone (loneliness: face-to-face contacts, $P = 0.020$; non–face-to-face contacts, $P = 0.028$; happiness: face-to-face contacts, $P = 0.020$; non–face-to-face contacts, $P = 0.001$).

Conclusions: Our findings suggest that non–face-to-face, as well as face-to-face social contacts have a moderating effect on the adverse association of living alone with loneliness and happiness.

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Introduction

Owing to fast population ageing, the number of older adults living alone is rapidly increasing in Japan. Living alone during old age is associated with adverse health outcomes,¹ particularly an increased risk of poor mental health.² This is because of the heightened risk of social isolation and decreased social support for

older adults living by themselves. Therefore, living alone poses serious public health challenges for them.

Rich social relationships mitigate the adverse effects of living alone. Several studies suggest that maintaining social networks and support, even when living alone, reduce the risk of developing functional disabilities, difficulties in conducting instrumental activities of daily living and poor mental health.³ Literature indicates that social ties are a fundamental component of human well-being and play an important role in maintaining overall health.⁴ However, few studies deal with older adults' social relationships in terms of separately examining face-to-face and non–face-to-face social contacts. Thus, the effects of non–face-to-face social contacts, such as using the telephone, e-mail, or video chatting, on older adults'

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health outcomes are not well understood. With the spread of the coronavirus disease 2019 (COVID-19) globally,⁵ attention has shifted to non–face-to-face communications in various social conditions wherein face-to-face interactions outside one’s family have become restricted due to social restrictions on activities such as going out or meeting with others. Hence, it is necessary to examine the effects of non–face-to-face social interactions among older adults living alone.

Therefore, this study aimed to examine the association between living alone and mental health, and the moderating effect of face-to-face and non–face-to-face social contacts, among community-dwelling older adults.

Methods

Study population

This cross-sectional study recruited 320 Japanese older adults from Togo town, a suburban area in Japan, from a community-based health check-up survey held in the public town hall. It was conducted in July and August of 2018 and 2019. We excluded participants who lacked gender information (*n* = 1), were aged younger than 60 years (*n* = 13) and had self-reported dementia (*n* = 3) and depression (*n* = 3). Finally, we analysed data from 300 older adults.

Measures

Depression, loneliness and happiness were the mental health outcomes assessed using self-reported questionnaires. Depression was measured using 15 items of the Japanese version of the Geriatric Depression Scale (GDS-15).⁶ Loneliness was measured using 3-items of the Japanese version of the University of California, Los Angeles Loneliness Scale.⁷ Happiness was evaluated using the single item, ‘Do you think you are happy?’ with ratings scoring from one (not happy) to ten (very happy). All these outcomes were treated as continuous variables.

Regarding living arrangements, participants were dichotomised as either ‘living alone’ or ‘living with others’.

Face-to-face and non–face-to-face social contacts were assessed by the frequency of participants meeting with relatives or friends in person, or by the frequency of letter, phone or e-mail contacts with

others. These were measured by six categories based on a previous study:⁸ never = 0, every few months = 0.8, once to three times a month = 1.5, once a week = 4.3, two or three times a week = 10.8 and over four times a week to every day = 21.5. In terms of face-to-face and non–face-to-face contacts, all converted responses were added up and categorised into either ‘less than once a week’ (<4.3) or ‘more than once a week’ (≥4.3). In addition, we categorized them into four groups according to the combination of non–face-to-face and face-to-face social contacts more than once a week (none, only non–face-to-face contacts, only face-to-face contacts, and both non–face-to-face and face-to-face contacts).

Statistical analysis

To examine the association between living arrangements and mental health outcomes, a multivariable linear regression analysis was conducted and was adjusted for age, gender, education, household income, present illnesses, instrumental activities of daily living, drinking, smoking, and daily walking time. As explanatory variables, living arrangements, face-to-face contacts, non–face-to-face contacts, and their interaction terms were included in the analytical model (codes: living arrangements, living with others = 0 and living alone = 1; social contacts, less than once a week = 0 and more than once a week = 1). In addition, we conducted the analysis using the same analytical model, with living arrangements, the combination of non–face-to-face and face-to-face social contacts, and their interaction terms as explanatory variables.

To mitigate any potential bias due to missing information, we used the multiple imputation approach under the missing at random assumption and generated 20 imputed data sets by using the multiple imputation by chained equations procedure and pooled the results using the standard Rubin’s rule. All statistical analyses were performed using R software (version 3.6.3 for Windows).

Results

The participants’ mean age was 73.0 years (standard deviation = 5.8), and 154 (51.3%) were women. Of the participants, 48 (16.0%) lived alone, who, when compared with those living with

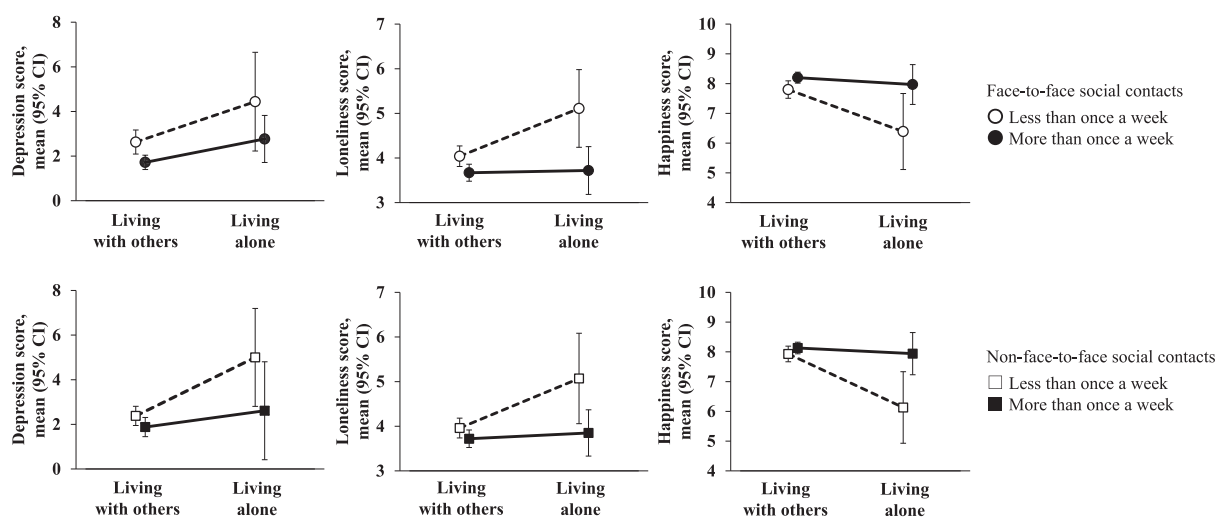


Fig. 1. The mean scores and 95% confidence intervals (CIs) of each mental health outcome by living arrangements, stratified by the frequency of social contacts. The upper graph shows the results of the stratification by the frequency of face-to-face social contacts, with the lower graph showing the frequency of non–face-to-face social contacts. Contacts occurring more and less than once a week are shown in black and white, respectively.

others, were more likely to be older; female; a non-drinker; and having a low educational background, low household income, a present illness, a low daily walking time, a high frequency of non-face-to-face social contacts, high depression, high loneliness and low happiness scores (see [Supplementary Table 1](#)).

[Fig. 1](#) shows the mean scores for each mental health outcome by living arrangements, stratified by the frequency of face-to-face and non-face-to-face social contacts. In addition, the results of the multivariable analysis are shown in [Supplementary Table 2](#). Regarding depression, the mean scores of those living alone tended to be higher than those living with others; however, no statistical interactions between living alone and social contacts with depression were found (face-to-face contacts, $P = 0.547$; non-face-to-face contacts, $P = 0.080$). Regarding loneliness, the mean scores of those living alone also tended to be higher than those living with others, with there being significantly negative interactions found between living alone and face-to-face social contacts for loneliness ($P = 0.020$) and non-face-to-face contacts ($P = 0.028$). Regarding happiness, the mean scores of those living alone tended to be lower than those living with others; significant positive interactions were found between living alone and face-to-face social contacts ($P = 0.020$) and non-face-to-face contacts ($P = 0.001$).

In addition, the combination of non-face-to-face and face-to-face social contacts significantly alleviated high loneliness ($P = 0.009$) and low happiness ($P = 0.002$) in those living alone; however, non-face-to-face or face-to-face contacts alone were not significant ([Supplementary Table 3](#)).

Discussion

This study examined the moderating effects of face-to-face and non-face-to-face social contacts on the association between living alone and mental health outcomes in older adults. Living alone was found to be associated with poorer mental health; however, in terms of loneliness and low happiness, face-to-face or non-face-to-face social contacts, occurring at least once a week, buffered these adverse associations. Moreover, the combined effects of both types of contacts were more significant. Our findings suggest that both face-to-face and non-face-to-face social contacts have moderating effects on poor mental health due to living alone; we highlight the value of social connections for mental health. Particularly, even though social contacts through face-to-face communication are limited due to the current social conditions resulting from the COVID-19 pandemic, non-face-to-face communication via telephone or e-mail remain important for maintaining the mental health of older adults living alone.

Various research, both in the social sciences and biomedicine, has found that social relationships are fundamentally crucial for human's mental health, revealing that depression is influenced by a lack of social interactions and support.⁹ For the mental health of older adults, the protective effects of non-physical contact have also been reported.¹⁰ Moreover, the characteristics of face-to-face and non-face-to-face contacts contributing to the overall maintenance of mental health are somewhat independent; for example, non-face-to-face contacts primarily help in obtaining emotional social support.¹⁰ Particularly, for older adults living alone, non-face-to-face social contacts are critical as they often experience difficulties in connecting with others outside their family under their specific social conditions that often limit their ability to go out or meet with others. However, because our survey was conducted in the period before the COVID-19 outbreak, whether there are similar benefits in situations wherein social conditions have severely limited peoples' ability to engage in face-to-face contacts should be explored.

Our study has several limitations. First, its cross-sectional nature means that there was potential for reverse causality. Therefore,

future studies using longitudinal data are required. Second, social contacts were evaluated using a self-administered questionnaire; non-face-to-face social contacts were evaluated based on the presence or absence of social exchanges by letter, telephone, or e-mail. Thus, we could not evaluate non-face-to-face contacts through other means (e.g., video chatting or using social networking services). Therefore, further investigations that evaluate the use of various non-face-to-face communication methods are still needed. Third, our study participants were recruited from those who visited the health check-ups held in their suburban town hall. These participants were, therefore, healthier and younger than typical community-dwelling older adults living in this area, thus reducing the generalisability of our results.

In conclusion, this cross-sectional study outlines the association between living alone with poor mental health outcomes among community-dwelling older adults. Furthermore, social contacts effectively alleviated loneliness and low happiness resulting from living alone, suggesting that non-face-to-face, as well as face-to-face contacts, have a moderating effect in this regard. To protect the mental health of older adults living alone, maintaining their social ties through various means is important.

Author statements

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Ethical approval

All participants in our study provided written informed consent before participation. The study protocol was approved by the ethics committee of Nagoya University (No. 18-502) and conducted based on the guidelines of the Declaration of Helsinki.

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Competing interests

None declared.

Author contributions

T.N. conceptualised and designed the study, collected the data, analysed the data, and drafted and revised the manuscript. I.N. contributed to data collection and reviewed and critically revised the manuscript. T.I.-H. contributed to data collection and reviewed and critically revised the manuscript. H.S., project administrator, contributed to data collection and reviewed and critically revised the manuscript. All authors have read and approved the final manuscript.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.puhe.2021.02.016>.

References

- Steinbach U. Social networks, institutionalization, and mortality among elderly people in the United States. *J Gerontol* 1992;**47**:S183–90.
- Honjo K, Tani Y, Saito M, Sasaki Y, Kondo K, Kawachi I, et al. Living alone or with others and depressive symptoms, and effect modification by residential social cohesion among older adults in Japan: the JAGES longitudinal study. *J Epidemiol* 2018;**28**(7):315–22.
- Sakurai R, Kawai H, Suzuki H, Kim H, Watanabe Y, Hirano H, et al. Poor social network, not living alone, is associated with incidence of adverse health outcomes in older adults. *J Am Med Dir Assoc* 2019;**20**:1438–43.
- Seeman TE. Social ties and health: the benefits of social integration. *Ann Epidemiol* 1996;**6**:442–51.
- World Health Organization. *Coronavirus disease (COVID-19) pandemic*. 2020. <https://www.who.int/emergencies/diseases/novel-coronavirus-2019>. [Accessed 9 November 2020].
- Wada T, Ishine M, Sakagami T, Okumiya K, Fujisawa M, Murakami S, et al. Depression in Japanese community-dwelling elderly—prevalence and association with ADL and QOL. *Arch Gerontol Geriatr* 2004;**39**:15–23.
- Saito T, Cable N, Aida J, Shirai K, Saito M, Kondo K. Validation study on a Japanese version of the three-item UCLA Loneliness Scale among community-dwelling older adults. *Geriatr Gerontol Int* 2019;**19**:1068–9.
- Saito M, Kondo K, Ojima T, Hirai H, the JAGES Group. Criteria for social isolation based on associations with health indicators among older people. A 10-year follow-up of the Aichi Gerontological Evaluation Study. *Nihon Koshu Eisei Zasshi* 2015;**62**:95–105.
- Umberson D, Crosnoe R, Reczek C. Social relationships and health behavior across life course. *Annu Rev Sociol* 2010;**36**:139–57.
- Roh HW, Lee Y, Lee KS, Chang KJ, Kim J, Lee SJ, et al. Frequency of contact with non-cohabitating adult children and risk of depression in elderly: a community-based three-year longitudinal study in Korea. *Arch Gerontol Geriatr* 2015;**60**:183–9.



Short Communication

Small-scale spatial analysis shows the specular distribution of excess mortality between the first and second wave of the COVID-19 pandemic in Italy



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ABSTRACT

Objectives: The objective of the study is to compare excess mortality (EM) patterns and spatial correlation between the first and second wave of the pandemic in Lombardy, the Italian region that paid an extremely high COVID-19-related mortality toll in March and April 2020.

Study design: We conducted a longitudinal study using municipality-level mortality data.

Methods: We investigated the patterns and spatial correlation of EM of men aged ≥ 75 years during the first two pandemic waves (March–April 2020 vs November 2020) of COVID-19, using the mortality data released by the Italian National Institute of Statistics. EM was estimated at the municipality level to accurately detect the critical areas within the region.

Results: The areas that were mostly hit during the first wave of COVID-19 were generally spared by the second wave: EM of men aged ≥ 75 years in the municipality of Bergamo plummeted from +472% in March and April to –13% in November, and in Cremona the variation was from +344% to –19%. Conversely, in November 2020 EM was higher in some areas that had been protected in the first wave of the pandemic. Spatial correlation widely corroborates these findings, as large sections of the hot spots of EM detected in the first wave of the pandemic changed into cold spots in the second wave, and vice versa.

Conclusions: Our results reveal the specular distribution of EM between the first and second wave of the pandemic, which may entail the consequences of social distancing measures and individual behaviors, local management strategies, ‘harvesting’ of the frailer population and, possibly, acquired immune protection. In conclusion, our findings support the need for continuous monitoring and analysis of mortality data using detailed spatial resolution.

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Excess mortality (EM) during the first wave of the COVID-19 pandemic showed inhomogeneous distribution patterns in several countries.^{1–5} Odone and colleagues² analyzed EM due to COVID-19 during the first wave of the pandemic in Italy (March and April 2020). Odone² found an EM higher than 600% in hardest hit areas, whereas notified COVID-19 deaths accounted for only 43.5% of estimated EM. In a similar study conducted in Germany, Stang and colleagues³ found a significant amount of EM from March to May 2020, albeit lower than in Italy and other Western countries. Additional spatial analysis performed by Morfeld and colleagues⁴ showed that during the same period some federal states of

Germany and regions of Italy did not increase their standardized mortality rates. Supported by this evidence, Morfeld⁴ argued that by looking at countries alone some relevant information on the pandemic’s course and toll in smaller spatial units can be missed. Accordingly, analyses on mortality should be conducted with appropriate spatial resolution, and on a regular basis. In line with this conceptual framework, we would like to add further suggestions for discussion, starting from our previous findings on local patterns of EM in three regions of northern Italy severely hit by COVID-19 in the first half of 2020 (Lombardy, Veneto, and Emilia-Romagna).⁵

To corroborate Odone’s, Stang’s and Morfeld’s stances, we compared EM between the first and second wave of the pandemic, using the data updated to November 30, 2020 recently released by the Italian National Institute of Statistics (ISTAT). We specifically

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investigated the EM patterns of the two pandemic waves in the municipalities of Lombardy, the region that paid the highest COVID-19-related mortality toll in March and April 2020 in Italy. Methodological and statistical aspects are those of our previous works.^{5,6} For the sake of brevity, we present here only the EM of men aged ≥ 75 years, but additional analyses can be found at this link: <https://github.com/COVID-19-related-excess-mortality/Excess-Mortality>.

As shown in Fig. 1A, the uneven local pattern of EM was very clear in Lombardy in March and April 2020. While the central area of the region suffered the highest EM rates, as far as +4700% in the small municipalities surrounding Bergamo, in the northwestern area many municipalities showed lower mortality rates compared

with those of the five previous years. The main reason for these intraregional differences is likely the distance from the pandemic's epicenter, as well as the absence of intense mobility flows directly linking northwestern and central Lombardy. Thus, it seems reasonable to affirm that northwestern Lombardy benefitted from the strict lockdown measures nationally enforced on March 9.⁷

After the easing of the containment measures on May 4, 2020, a national lockdown was never put back in place in Italy, therefore no areas within the country had since then been preemptively protected as it happened in many regions during the first wave of the pandemic, not even when the second wave took off in late October. By that time, the virus had widely spread within the country, especially due to the rise in mobility flows during the summer

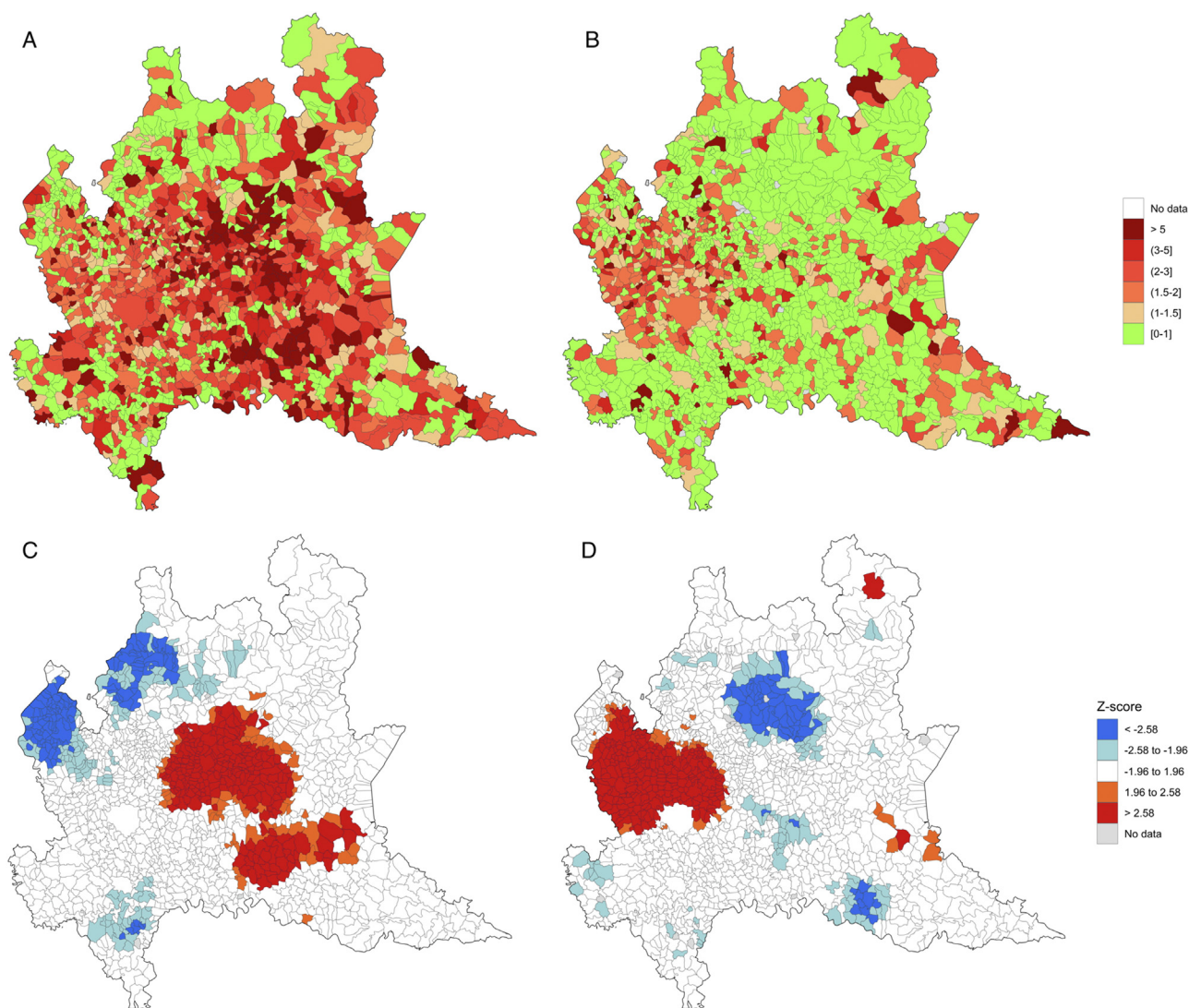


Fig. 1. Relative mortality in males aged ≥ 75 years in Lombardy region during the first wave (Fig. 1A, from March 1 to April 30, 2020) and the second wave (Fig. 1B, from November 1 to 30, 2020) of the COVID-19 pandemic. Municipalities are depicted with different colors according to the magnitude of their excess mortality. Green refers to municipalities with a relative mortality ≤ 1 , that is when observed deaths are lower than or equal to the expected deaths. When relative mortality is > 1 , increasing saturation of red is used, to reflect increasing values of relative mortality. No data municipalities are those for which no data was released by ISTAT or that had no deaths for the examined age-gender subgroups in any year between 2015 and 2020. Local autocorrelation expressed by the standardized Getis-Ord Gi statistic for relative mortality in males aged ≥ 75 years in Lombardy region during the first wave is reported in Fig. 1C (from March 1 to April 30, 2020) and Fig. 1D (from November 1 to 30, 2020) of the COVID-19 pandemic. High positive values of the z-scores (in red) denote spatially correlated municipalities with high values of excess mortality. High negative values of the z-scores (in blue) denote spatially correlated municipalities with low values of excess mortality. No data municipalities are those for which no data was released by ISTAT or that had no deaths for the examined age-gender subgroups in any year between 2015 and 2020. (For interpretation of the references to color in this figure legend, the reader is referred to the Web version of this article.)

period because of national and international tourism. Strict lockdowns were enacted only locally, and only when monitoring indicators pointed out a sustained circulation of the virus. In November 2020, the areas of Lombardy most affected by EM in March and April 2020 appeared to be spared (Fig. 1B) and the distribution of red ($EM > 1$) and green areas ($EM = 0-1$) seemed to mirror that of the first tragic wave.

Specifically, based on our analyses, EM of males aged ≥ 75 years in the municipality of Bergamo plummeted from +472% in March and April to -13% in November, while in Cremona the variation was from +344% to -19%, and in Lodi from +206% to +29%. Conversely, several towns of northwestern Lombardy that were less affected by the pandemic in March–April saw a remarkable rise of deaths in the same age group in November: in Como EM increased from +80% to +265%, and in Varese from +86% to +208%. Municipalities in the conurbation of Milano that in the first wave were less protected than northwestern Lombardy because of their closeness to the hotspots, showed similar EM figures in the two waves. In Milano EM was +129% in March–April and +93% in November, in Sesto San Giovanni +117% and +123%, and Cinisello Balsamo +115% and +108%. A notable exception to these patterns is the city of Brescia (one of the most hit in the first wave) in which the EM of males aged ≥ 75 years, although substantially reduced, remained as high as +104% in November, compared with +228% in March–April.

Spatial correlation widely corroborates these findings. During the first wave of the pandemic (Fig. 1C) a large hot spot of EM was identified in the central area around Bergamo, whereas large cold spots of reduced mortality were found in the north and northwest areas of Lombardy. In November, the spatial patterns of EM were specular, with a large hot spot of EM in the northwest of the region and cold spots in the areas where the pandemic first hit (Fig. 1D).

Looking at the small-scale level (municipalities), our results are similar to those reported by Morfeld, suggesting that the switch between the 'hot' and 'cold' EM areas may entail the presence of stricter social distancing measures and individual behaviors, effective local management strategies, and, possibly, acquired immune protection. Preliminary evidence coming from epidemiological studies on seroprevalence and incidence of COVID-19^{8,9} suggests that some sort of individual and community protection was developed by people living in those small area pockets of greater incidence in March and April 2020. Furthermore, it is plausible that in the areas most severely hit during the first wave, the people most susceptible to the virus paid the ultimate price in terms of mortality displacement (i.e. 'harvesting'¹⁰), causing a subsequent decrease in EM because of a decline in the number of highly vulnerable individuals. Moreover, people may have adopted adequate personal behaviors because a tragic event as the pandemic determines a huge emotional toll on their spirit and memory. For this reason, the high death rate in some areas in March and April could have led the people living there to act more cautiously and appropriately to slow down the spread of the virus, even before the official restrictions' enforcement in the region.

Our analysis presents some limitations. We used linear regression to derive a mortality trend from the previous five years, which in the less populated territorial units may be leveraged by anomalous mortality figures in the first or in the last year of the time interval used for prediction. Using EM estimate at the municipality level might also have favored the identification of larger hot or cold areas in the spatial analysis, particularly in the case of Lombardy where there is a multitude of very small municipalities. However, by using linear regression, we intended to capture a trend in

mortality where it exists, and in these cases its prediction is more accurate than the extrapolation of the average mortality observed in the previous five years. In addition, we reduced potential confounding by estimating EM within subgroups defined by age class and gender.

In conclusion, our findings support the need for continuous monitoring and analysis of mortality data using detailed spatial resolution. The shape and scale of EM hotspots in Lombardy are likely to be influenced by the arbitrary and unequal size of its administrative divisions, but small-scale granularity has the advantage of providing useful insights on the viral spread at the local level and to effectively capture the full effect of the COVID-19 pandemic, enabling the adoption of subsequent containment and mitigation measures.

Author statements

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Competing interests

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this article.

References

- Blangiardo M, Cameletti M, Pirani M, Corsetti G, Battaglini M, Baio G. Estimating weekly excess mortality at sub-national level in Italy during the COVID-19 pandemic. *PLoS One* 2020;**15**(10):e0240286. <https://doi.org/10.1371/journal.pone.0240286>.
- Odone A, Delmonte Dm, Gaetti G, Signorelli C. Doubled mortality rate during the COVID-19 pandemic in Italy: quantifying what is not captured by surveillance. *Publ Health* 2021;**190**:108–15. <https://doi.org/10.1016/j.puhe.2020.11.016>.
- Stang A, Standl F, Kowall B, Brune B, Böttcher J, Brinkmann M, et al. Excess mortality due to COVID-19 in Germany. *J Infect* 2020;**81**(5):797–801. <https://doi.org/10.1016/j.jinf.2020.09.012>. S0163-4453(20)30596-X.
- Morfeld P, Timmermann B, Groß JV, DeMatteis S, Campagna M, Lewis P, et al. COVID-19: spatial resolution of excess mortality in Germany and Italy. *J Infect* 2020;**25**. <https://doi.org/10.1016/j.jinf.2020.10.020>. S0163-4453(20)30678-2.
- Gibertoni D, Adja KYC, Golinelli D, Reno C, Regazzi L, Lenzi J, Sanmarchi F, et al. Patterns of COVID-19 related excess mortality in the municipalities of Northern Italy during the first wave of the pandemic. *Health Place* 2021;**67**:102508. <https://doi.org/10.1016/j.healthplace.2021.102508>.
- Gibertoni D, Sanmarchi F, Adja KYC, Golinelli D, Reno C, Regazzi L, Lenzi J. Small-scale spatial distribution of COVID-19-related excess mortality. *Methods (Duluth)* 2021;**8**:101257. <https://doi.org/10.1016/j.mex.2021.101257>.
- Presidenza del Consiglio dei Ministri. Ulteriori disposizioni attuative del decreto-legge 23 febbraio 2020, n. 6, recante misure urgenti in materia di contenimento e gestione dell'emergenza epidemiologica da COVID-19. (20A01522). *Gazz Uff Della REPUB Ital* 2020;**59**:3–6.
- Perico L, Tomasoni S, Peracchi T, Perna A, Pezzotta A, Remuzzi G, et al. COVID-19 and lombardy: TESTing the impact of the first wave of the pandemic. *EBio Med* 2020;**61**:103069. <https://doi.org/10.1016/j.ebiom.2020.103069>.
- Percivalle E, Cambiè G, Cassaniti I, Nepita EV, Maserati R, Ferrari A, et al. Prevalence of SARS-CoV-2 specific neutralising antibodies in blood donors from the Lodi red zone in lombardy, Italy, as at 06 April 2020. *Euro Surveill* 2020;**25**(24):2001031. <https://doi.org/10.2807/1560-7917.ES.2020.25.24.2001031>.
- Cheng J, Xu Z, Bambrick H, Su H, Tong S, Hu W. Heatwave and elderly mortality: an evaluation of death burden and health costs considering short-term mortality displacement. *Environ Int* 2018;**115**:334–42. <https://doi.org/10.1016/j.envint.2018.03.041>.



Original Research

The price of precision: trade-offs between usability and validity in the World Health Organization Health Economic Assessment Tool for walking and cycling

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ABSTRACT

Objectives: The widely used World Health Organization (WHO) Health Economic Assessment Tool (HEAT) for walking and cycling quantifies health impacts in terms of premature deaths avoided or caused as a result of changes in active transport. This article attempts to assess the effect of incorporating 'life-years' as an impact measure to increase the precision of the model and assess the effect on the tool's usability.

Study design: This article is a methods paper, using simulation to estimate the effect of a methodological change to the HEAT 4.2 physical activity module.

Methods: We use the widely used WHO HEAT for walking and cycling as a case study. HEAT currently quantifies health impacts in terms of premature deaths avoided or caused as a result of changes in active transport. We assess the effect of incorporating "duration of life gained" as an impact measure to increase the precision of the model without substantially affecting usability or increasing data requirements.

Results: Compared with the existing tool (HEAT version 4.2), which values premature deaths avoided, estimates derived by valuing life-years gained are more sensitive to the age of the population affected by an intervention, with results for older and younger age groups being markedly different between the two methods. This is likely to improve the precision of the tool, especially where it is applied to interventions that affect age groups differentially. The life-years method requires additional background data (obtained and used in this analysis) and minimal additional user inputs; however, this may also make the tool harder to explain to users.

Conclusions: Methodological improvements in the precision of widely used tools, such as the HEAT, may also inadvertently reduce their practical usability. It is therefore important to consider the overall impact on the tool's value to stakeholders and explore ways of mitigating potential reductions in usability.

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Introduction

There has been an increasing awareness of the need to incorporate Health in All Policies (HiAP) to ensure that non-health government agencies work in partnership to incorporate considerations of health and well-being when

developing policy.¹ One simple way in which HiAP is often facilitated is through quantitative Health Impact Assessments (HIA), simple statistical models of the world, which aim to quantify the costs and benefits of interventions.^{2,3} To make HIA easier and cheaper to implement, online tools have been developed, which allow stakeholders to undertake their own HIA.^{4,5}

The WHO-Europe's Health Economic Assessment Tool (HEAT 4.2) is an example of a widely used HIA tool designed specifically for a HiAP purpose,¹ allowing decision-makers in the transport sector to incorporate the health implications of walking and cycling

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into economic appraisals.⁶ The tool has been used directly by public sector decision-makers in different locations, including Kuopio (Finland), Parnu (Estonia), Brighton & Hove (UK), Modena (Italy), and Viana do Castelo (Portugal), and by academics in a number of published studies over the past two decades.^{7,8} One of the reasons why the HEAT has been so popular is that it is simple and easy to use, as one of the core principles of the HEAT is to be “as user-friendly as possible”.⁶

The HEAT 4.2 has four modules: physical activity, air pollution, crash risk, and carbon emissions.⁶ The physical activity module generally accounts for most of the estimated intervention effect.^{4,9} Within the physical activity module, the estimated net mortality risk change is valued using the Value of a Statistical Life (VSL), an estimate of the societal willingness to pay for a reduction of one statistical fatality.¹⁰ The measure is commonly used in transport planning.^{11,12}

Previous studies have compared the results derived by the HEAT with other HIA tools, such as the Integrated Transport and Health Impact Modelling Tool and Dynamic Modelling for Health Impact Assessment.^{13,14} Other studies have assessed the effect of the method used to aggregate benefits within HEAT.¹⁵ However, these comparisons have focused on the effect of the shape of the dose–response relationship between physical activity and health outcomes¹³ and the choice of a static vs dynamic modeling methodology.¹⁴ To the best of our knowledge, there are no published studies of the effect of the health valuation method, the valuation of lives saved vs life-years gained, on the results of Health Impact Assessment tools for walking and cycling or physical activity. This paper attempts to fill that gap in the literature.

The VSly represents society's willingness to pay for reductions in fatality risk, which result in an additional statistical life-year. When using the VSly reductions in fatality risks, younger populations, with greater expected life-years remaining, are valued more highly than reductions in fatality risks for older populations. When the population affected by a policy is representative of society, valuing premature deaths averted using the VSL and life-years saved using the VSly are likely, conceptually, to yield similar results. However, when the population is not representative, in terms of age, the two approaches are likely to yield very different results. Attempting to value policies in response to the COVID-19 pandemic made this particularly apparent: multiplying the number of premature deaths averted by the VSL resulted in much higher values than multiplying expected life-years saved by the VSly since COVID-19 related mortality rates rise super-linearly with age.^{16,17} In this article, we argue that the same holds for the HEAT: multiplying premature deaths averted from walking and cycling interventions by VSL is likely to yield different results than multiplying life-years saved by the VSly if the distribution of age in the intervention group does not match the age distribution implicit in the selected HEAT age group.

We begin by using a simple algorithm to derive estimates of VSly from the VSL values used by the HEAT. We then compare the results, for the physical activity module of the HEAT, for six hypothetical scenarios using both the VSL and VSly methods. We focus on how a relatively simple HIA tool, the HEAT, could be adapted to better reflect the age distribution within the active travel population. We also discuss the potential implications of these adaptations on the tool's usability, a core principle of the HEAT,⁶ and suggest means by which the tool could remain easy to use.

All data and code (in R software environment) is provided in an open access online repository (<https://anonymous.4open.science/r/b1ac653f-7e70-43ab-870c-f3ccc4d63914/>).

Methods

Data and measures

This study relies on data used in the HEAT 4.2 and previously described in a study by Kahlmeier et al.,⁶ that is, WHO country names, country ISO3 codes, VSL estimates based on the OECD Recommendations on Mortality Risk Valuation in Environment, Health and Transport Policies,¹² and dose–response relationships between walking and cycling and mortality from a study by Kelly et al.¹⁸ This study also makes use of two additional data sets: population estimates and life tables for 2017 from a study by Dicker et al.¹⁹ Table A1 in the supplementary material shows a full list of the variables used in the analysis.

Study design

This paper is a methods paper, using simulation to estimate the effect of a methodological change to the HEAT 4.2 physical activity module.

Analysis

First, we estimate, for each of the 51 WHO European Region countries included in the HEAT tool, the VSly (in 2015 Euros). We then go on to compare the societal value of premature deaths averted for six scenarios when using the VSly method, the current HEAT method for the full adult range (VSL-1), stratified by younger vs older adults (VSL-2), and the use of VSL using individual age mortality risks (VSL-55).

Estimating the value of a statistical life-year

The VSL estimate used in the HEAT model is based on a meta-analysis of stated preference studies,¹² in which individuals were asked how much they were willing to pay for a small reduction in mortality risk. The estimates vary considerably between countries, ranging from approximately EUR 143,000 in Tajikistan to almost EUR 7m (2015 values) in Luxembourg. The mean age of participants within the studies in HEAT countries was 50 years. By making the assumptions that (1) the VSL at the age of elicitation is the value derived from future life-years until death and (2) all years are valued equally, it is possible to estimate the VSly using the equation below. The equation inverts the equations used to calculate the VSL in Annex 1.A1 of the OECD report published in 2012.¹²

$$VSly = \frac{VSL_{50}}{\sum_{i=50}^{109} \prod_{a=50}^i Pr(S)_a \times \frac{1}{(1+r)^{a-50}}} \quad (1)$$

The VSly is equal to the VSL at age 50 years divided by the discounted expected life-years remaining between age 50 and 109 years, the maximum age in our data. The discounted expected life-years remaining is calculated for each age a , using the probability of survival, $Pr(S)$, to the next birthday, as well as the annual discount rate, r . The VSly for a country is greater where VSL is greater, annual survival probabilities from 50 to 109 years are lower, or if the discount rate is greater.

The $Pr(S)$ estimates were derived from the Global Burden of Disease Estimates¹⁹ and validated against the UN World Population Prospects life tables.²⁰ The discount rate, r , was set to zero within this analysis for simplicity because different nations use different discount rates in decision-making. The discounted life-years remaining at each age were validated against the yll package in R.²¹

Estimating monetary benefit using the VSLY

The VSLY method estimates the value of premature deaths averted by (1) estimating the relative risk associated with an intervention, given increases in walking and cycling using a linear dose–response function from;¹⁸ (2) estimating discounted life-years saved, given the relative risk, population age distribution, and baseline mortality rates by age; and (3) multiplying the estimated discounted life-years saved by the VSLY estimate.

The equation is shown below:

$$MB = dLYS \times VSLY \tag{2}$$

Discounted life-years saved (dLYS) can be estimated by multiplying the absolute difference in the relative risk of death (ADRR), estimated using a relative risk function from a study by Kelly et al. (2014), by the age-specific mortality rates MR_i to estimate the effect of an intervention on mortality for the population in each age group pop_i. These changes are then multiplied by discounted expected life-years remaining dLYR_i (itself estimated from Global Burden of Disease life tables) for each age group to give overall discounted life-years saved.

As the absolute difference in relative risk is independent of age, it can be factorized, giving Equation 3 (below) in the case of an intervention affecting 20- to 74-year-olds.

$$dLYS = \Delta RR \times \sum_{i=20}^{74} MR_i \times dLYR_i \times pop_i \tag{3}$$

Inputting this back into our original equation gives:

$$MB = VSLY \times \Delta RR \times \sum_{i=20}^{74} MR_i \times dLYR_i \times pop_i \tag{4}$$

where i has 55 values representing each age from 20 to 74 years. Note that both VSLY and ADRR are constants while mortality rate, discounted life-years remaining, and population vary with age.

This equation is not substantially more complex than the existing HEAT method (in Equation 5 below), in which monetary benefit is the VSL multiplied by the absolute difference in relative risk associated with an intervention, age group mortality risk, and the number affected.

$$MB = VSL \times \Delta RR \times MR_{20-74} \times pop_{20-74} \tag{5}$$

Comparing four methods for six hypothetical scenarios

To compare the proposed VSLY model with the current HEAT models, we estimate the annual, per capita monetary benefit using four different methods: (1) VSL-1 refers to the current HEAT model with a single mortality rate for the entire population aged 20–74 years, (2) VSL-2 uses the current HEAT model with two mortality rates based on weighted population means (walking: 20–44 and 45–74; cycling: 20–44 and 45–64), (3) VSL-55 uses the existing HEAT model methodology (valuing premature deaths averted using the VSL) but with separate mortality risk estimates for each age from 20 to 74 years, and finally, (4) the VSLY model described previously, using individual ages as in (3) but valuing life-years saved using the VSLY estimates derived earlier. In all cases, the discount rate was set to zero for ease of comparison. We use the four methods to estimate the value of six hypothetical scenarios, three for walking and three for cycling, as shown in Table 1 alongside results for France.

Results

There is considerable heterogeneity in the VSLY estimates of WHO-Europe countries, ranging from EUR 5828 in Kyrgyzstan to

EUR 216,838 in Luxembourg, with higher values in western Europe than in eastern Europe. A full table of the VSLY estimates derived are provided in the supplementary material in Table A2 and are broadly aligned with previous estimates of societal willingness to pay for a statistical life-year.²²

In the first simple scenario, an extra 10-min walking per week for every person aged 20–74 years, the VSLY method results in approximately 25% lower estimated benefits than VSL-1 or VSL-2 (current method with one or two age groups). The effect is not because of more precise mortality rate estimates; the VSL method applied to a population categorized in 1-year age bands (VSL55) results in the same estimates to the VSL model with one and two groups (VSL-1 and VSL-2). Rather, the different estimates for the VSLY are due to assigning our estimates of life-years remaining to each prevented premature death. A full set of results are available in the supplementary material: Table A3 for the three walking scenarios (Scenarios 1, 2, and 3) and Table A4 for the three cycling scenarios (Scenarios 2, 4, and 6).

Fig. 1 displays the results from Scenario 1 graphically for all 51 countries. The current ‘best’ HEAT method, the VSL with two age groups (VSL-2), is shown on the x-axis as the reference method, and all other methods are depicted in a color-coded scatter plot with a 45-degree line used to depict equity. As these assessments cover the entire HEAT age range (20–74 years), the VSL-1 and VSL-55 estimates are identical to the VSL-2 estimates and therefore lie (jittered) on the 45-degree line. The monetary benefits estimated by the VSLY (blue) are around one-third lower than those estimated by the current VSL-2 model (black line). This is because those with the greatest mortality rates (older people) also have the lowest discounted life-years remaining, thereby reducing the effect that older people have on the mean.

Fig. 1 shows the estimates generated by increased activity in the population aged 20–74 years. However, this masks differences in estimates for the two current HEAT age groups (20–44 and 45–74 years). Fig. 2 depicts the estimates generated by stratifying the analysis to the population aged 20–44 years (left) and 45–74 years (right). In both cases, the VSL55 (green) estimates are equal to the VSL-2 estimates. The VSL-1 (red) method results in higher values when restricting the analysis to younger people and lower values for older people. The VSLY (blue) estimates tend to be greater than that of the VSL-2 in younger people and lower in older people because younger populations have more expected life-years remaining.

Because there are clear differences in the values generated by different methods, and these differences vary between older and younger populations, we also looked at how the valuation methods differ over the life course in an exemplar country. Fig. 3 below shows a comparison of annual monetary benefits per capita (2017 Euro) associated with 10 min/week of additional walking, for each individual age from 20 to 74 years for the Latvian population using the four different models: VSL-1 (red), VSL-2 (black), VSL-55 (green), and VSLY (blue).

The VSL-1 method generates the same results regardless of age, the VSL-2 method generates different results for the population aged 20–44 years to those aged 45–74 years, and the VSLY (blue) and VSL-55 (green) results are similar until around age 55 years, with monetary benefit increasing as age, and therefore, mortality rates increase. However, the VSLY model does not increase as quickly with age because life-years remaining are falling with age also—this is particularly stark from age 60 years onwards.

Finally, it is interesting to observe the differences in results between countries when using the VSLY methods. Fig. 4 shows the estimated per capita annual monetary benefit of an additional 10 min of walking per week per person aged 20–74 years for the HEAT countries on a choropleth map. There are large differences in

Table 1
 Monetary benefit estimates for France for each of the six scenarios using the VSL method with two age groups and the VS LY method with individual ages (assumes scenario population is representative of the general population within that age range).

Scenario	VSL method result (two groups) in 2017 EUR	VS LY method result in 2017 EUR
Population aged between 20 and 74 do an additional 10 min of walking per week.	86.56	63.75
Population aged between 20 and 64 do an additional 10 min of cycling per week.	77.85	72.5
Population aged between 20 and 44 do an additional 10 min of walking per week.	15.11	21.73
Population aged between 20 and 44 do an additional 10 min of cycling per week.	22.27	32.03
Population aged between 45 and 74 do an additional 10 min of walking per week.	147.27	99.45
Population aged between 45 and 64 do an additional 10 min of cycling per week.	143.42	120.26

VSL, value of statistical life; VS LY, value of statistical life-year.

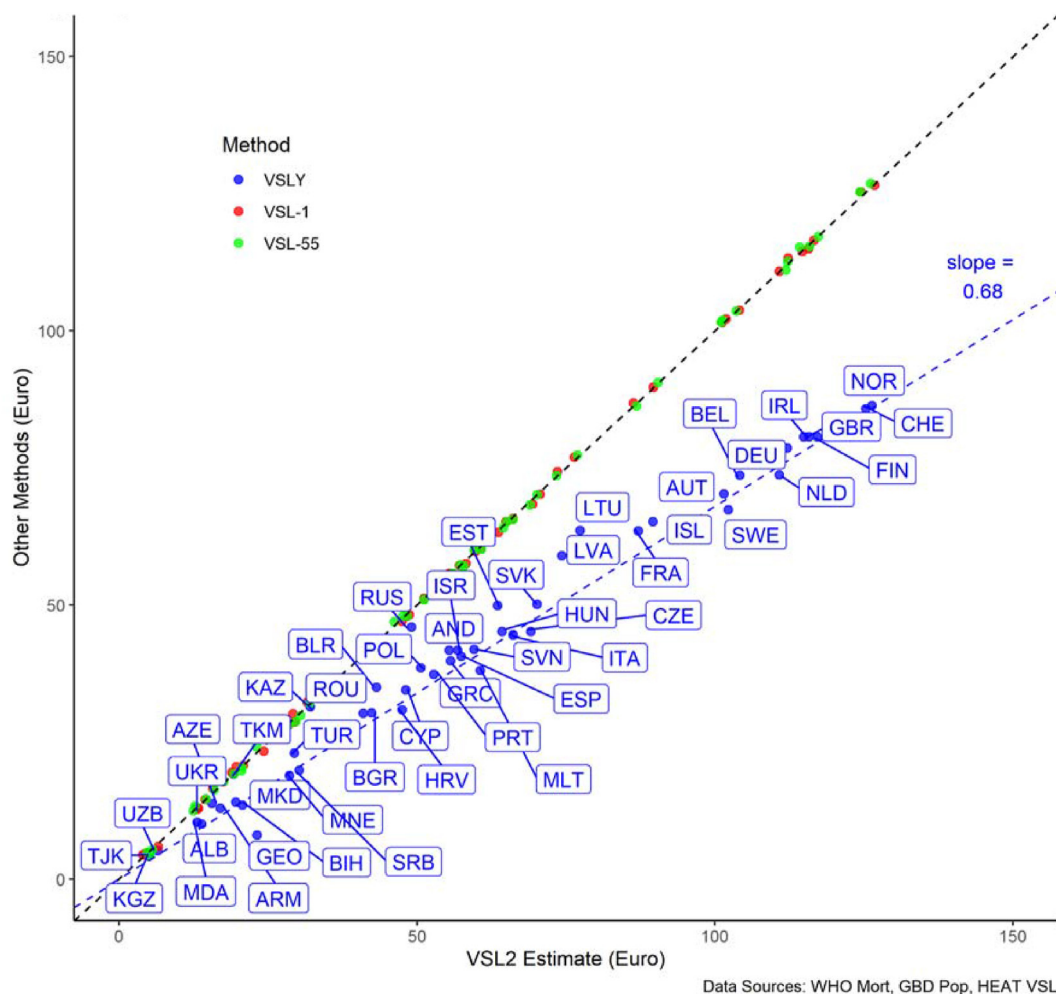


Fig. 1. Estimated annual monetary benefit per capita (in 2017 Euro) in scenario 1, comparing alternative methods to VSL-2. VSL, value of statistical life; VS LY, value of statistical life-year; VSL-1, VSL for full adult age range; VSL-2, VSL stratified by younger vs older adults; VSL-55, VSL using individual age mortality risks.

estimated monetary benefit per capita between HEAT countries, with estimated monetary benefit ranging from EUR 4.52 in Tajikistan to EUR 117.13 in Luxembourg.

Discussion

This study is the first to compare the effect of the valuation method used to value averted premature deaths in a Health Impact Assessment tool for physical activity. It uses the WHO HEAT 4.2 for walking and cycling as a case study to compare the estimates of the value of active transport using two different methods: the Value of Statistical Life and the Value of Statistical

Life-Year. We show that the VS LY approach generates lower estimates and is more sensitive to differences in the age of the affected population than the VSL with two age groups (VSL-2). However, this comes with a trade-off: although the use of the VS LY may be more accurate, there are additional data requirements of the user. As the minimal data entry requirements of HEAT 4.2 have shown to be a main barrier to wider use of the HEAT, this potential additional user burden warrants serious consideration.

Our findings align with those of previous studies, for example, the work of Robinson et al.,¹⁶ which found that estimates using the VS LY method result in lower valuations of interventions to reduce

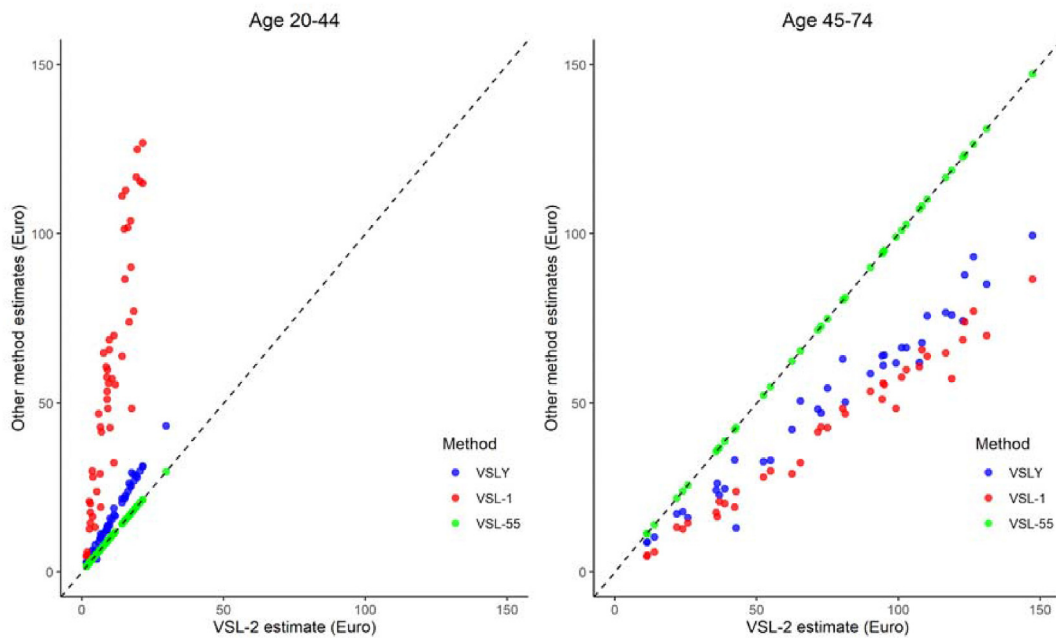


Fig. 2. Estimated annual monetary benefit (in 2017 Euro) per capita from 10-min additional weekly walking using country-specific population age distributions from 20 to 44 years (left) and 45–74 years (right), VSLY vs current HEAT models. VSL, value of statistical life; VSLY, value of statistical life-year; VSL-1, VSL for full adult age range; VSL-2, VSL stratified by younger vs older adults; VSL-55, VSL using individual age mortality risks.

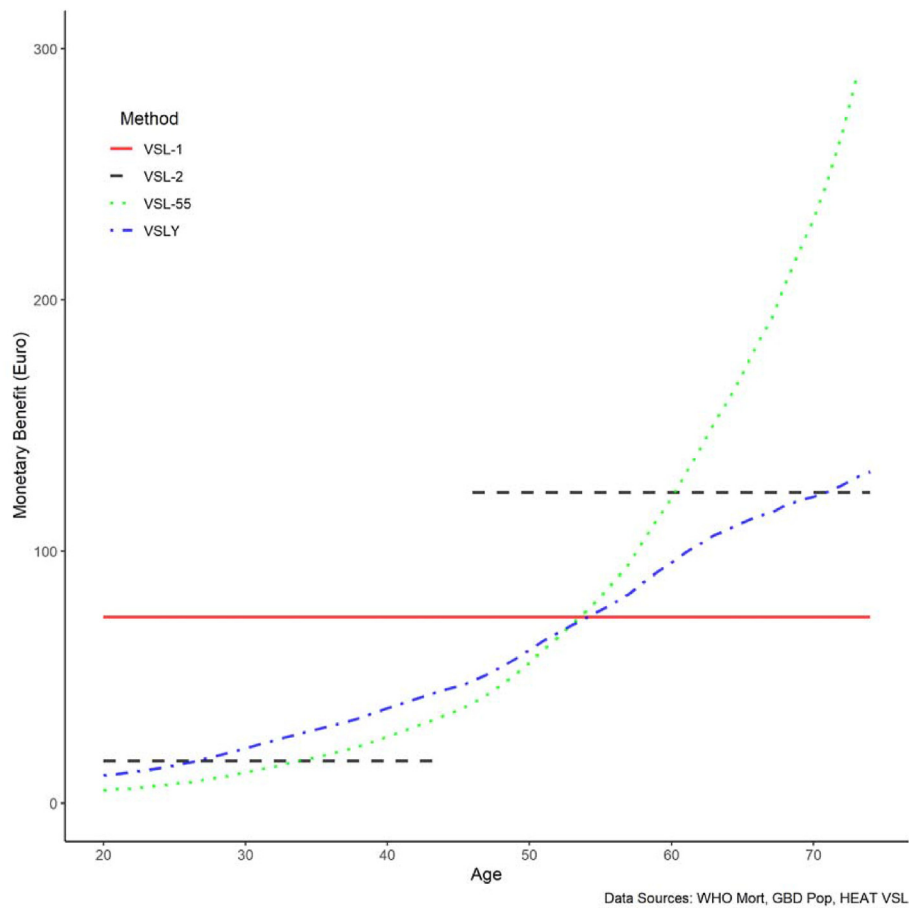


Fig. 3. Annual monetary benefit per capita (in 2017 Euro) from 10-min additional weekly walking for each age of Latvian population, using each method. VSL, value of statistical life; VSLY, value of statistical life-year; VSL-1, VSL for full adult age range; VSL-2, VSL stratified by younger vs older adults; VSL-55, VSL using individual age mortality risks.

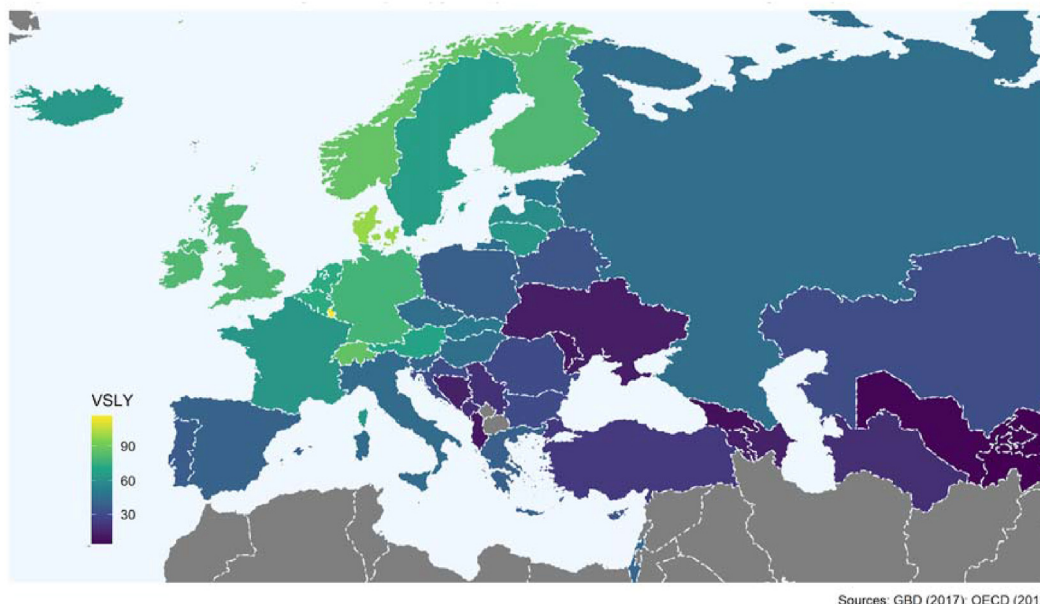


Fig. 4. Map of estimated per capita annual monetary benefit (2017 Euro) of an additional 10 min of weekly walking per person aged 20–74 years for 51 HEAT countries. HEAT, Health Economic Assessment Tool; VSLY, value of statistical life-year.

COVID-19 deaths, primarily from older populations. However, this is the first study that has explicitly analyzed the significance of these methodological decisions for an HIA tool. It is also the first to critique the valuation methods in the physical activity module of the WHO HEAT for walking and cycling. We offer a simple enhancement to the current HEAT physical activity module, which remains within the framework used by transport planners but incorporates the duration of life.

Differences in the estimates using VSL and VSLY methods provoke normative questions about the valuation of premature mortality. The VSL values mortality risk equally irrespective of age, thereby valuing a year of expected life more highly for older persons. On the other hand, the VSLY assigns a constant value to a life-year, but, as a result, values mortality risk reduction in younger persons more highly.¹⁷ Transport economics typically uses the former, health economics the latter (and includes quality of life). As an HIA tool used widely in transport planning, the HEAT straddles two fields. The appropriate method may depend on the decision problem itself. Giving the tool user the ability to choose which method they would like to use would be a useful future feature in the tool.

There are several limitations of this study. The biggest perceived challenge to implementing the VSLY in the HEAT is the difficulty users in many countries would face in inputting the age distribution of those affected by an intervention. There is therefore a trade-off between precision and usability in this HIA tool. Potential solutions include (1) using the distribution of age in the general population as a default for the active travel population with the option to manually overwrite or (2) the creation of a bespoke age distribution from user-defined parameters, for example, minimum, maximum, and median age. Although neither of these solutions are perfect, they may provide a compromise between usability and accuracy.

A further challenge exists specifically for the HEAT tool in explaining the VSLY method to stakeholders and users. Transport planners are familiar with the concept of the VSL, but gaining buy-in for the use of the VSLY requires an explanation of how discounted life expectancy is calculated. This is another example of where the adaptation of a widely used tool, already being used by

stakeholders to support or inform policy, must be carefully considered even if it is methodologically valid. Over the duration of the HEAT's existence the core team have attempted to achieve balance between complexity and precision on the one hand and usability on the other.²³ However, recent developments in data availability, statistical programming, and web-based user interfaces have made it easier to allow stakeholder engagement in complex models.²⁴ Therefore, the improvements in the conceptual validity provided by the VSLY method should justify implementation within the global version of HEAT currently under development.

An additional issue for accurate valuation of increased population walking and cycling is that the VSL estimates used (in both the VSL and VSLY methods) are derived from a stated preference study with a median age of 50 years. As VSL has been shown to peak around age 50 years,¹¹ calculating the VSLY from this figure may result in overestimates. Further research is needed to develop stated preference values that account for the many different factors influencing respondents of different ages.

Conclusion

Our findings suggest that incorporation of duration of life gained into the HEAT is theoretically possible, yields very different results where intervention populations are not representative of overall populations, and is more aligned with guidance from the field of health economics. However, where changes to improve the precision of widely used tools such as the HEAT may also reduce their practical usability, it is important to consider the overall impact on the tool's value to decision-makers and other stakeholders. Thus, it will be important to consider the usability of the modified model in practice in future work.

Author statements

Ethical approval

No ethical approval was required for this simulation study, and all data used are available in the public domain.

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Competing interests

None.

Authors' contributions

R.S. contributed to conceptualization, data curation, formal analysis, investigation, methodology, project administration, software, visualization, and writing, reviewing, and editing the article. C.T. and H.S. contributed to supervision and reviewing and editing the article. T.G. contributed to project administration, methodology, and reviewing and editing the article. S.K. contributed to project administration and reviewing and editing the article. E.G. contributed to supervision and reviewing and editing the article. All authors have fulfilled criteria for authorship.

Data availability

Data & Code: <https://anonymous.4open.science/r/b1ac653f-7e70-43ab-870c-f3ccc4d63914/>

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.puhe.2021.03.016>.

References

- Kahlmeier S, Racioppi F, Cavill N, Rutter H, Oja P. "Health in all policies" in practice: guidance and tools to quantifying the health effects of cycling and walking. *J Phys Act Health* 2010;7:S120–5.
- Organization WH, others. *Health impact assessment: main concepts and suggested approach-göteborg consensus paper*. 2000.
- Lock K. Health impact assessment. *BMJ* 2000;320:1395–8.
- Mueller N, Rojas-Rueda D, Cole-Hunter T, De Nazelle A, Dons E, Gerike R, et al. Health impact assessment of active transportation: a systematic review. *Prev Med* 2015;76:103–14.
- Waheed F, Ferguson GM, Ollson CA, MacLellan JL, McCallum LC, Cole DC. Health impact assessment of transportation projects, plans and policies: a scoping review. *Environ Impact Assess Rev* 2018;71:17–25.
- Kahlmeier S, Götschi T, Cavill N, Castro Fernandez A, Brand C, Rojas Rueda D, et al. *Health economic assessment tool (HEAT) for walking and for cycling. Methods and user guide on physical activity, air pollution, injuries and carbon impact assessments*. 2017.
- Using the health economic assessment tools (HEAT) for walking and cycling: lessons learnt*. World Health Organization; 2017.
- Brown V, Diomedes BZ, Moodie M, Veerman JL, Carter R. A systematic review of economic analyses of active transport interventions that include physical activity benefits. *Transport Pol* 2016;45:190–208.
- De Nazelle A, Nieuwenhuijsen MJ, Antó JM, Brauer M, Briggs D, Braun-Fahrlander C, et al. Improving health through policies that promote active travel: a review of evidence to support integrated health impact assessment. *Environ Int* 2011;37:766–77.
- Viscusi WK, Aldy JE. The value of a statistical life: a critical review of market estimates throughout the world. *J Risk Uncertain* 2003;27:5–76.
- Aldy JE, Viscusi WK. Adjusting the value of a statistical life for age and cohort effects. *Rev Econ Stat* 2008;90:573–81.
- Mortality risk valuation in environment, health and transport policies*. OECD; 2012.
- Woodcock J, Givoni M, Morgan AS. Health impact modelling of active travel visions for England and Wales using an integrated transport and health impact modelling tool (ITHIM). *PLoS One* 2013;8:e51462.
- Mansfield TJ, MacDonald Gibson J. Health impacts of increased physical activity from changes in transportation infrastructure: quantitative estimates for three communities. *BioMed Res Int* 2015;2015.
- Götschi T, Loh TH. Advancing project-scale health impact modeling for active transportation: a user survey and health impact calculation of 14 US trails. *J Transport Health* 2017;4:334–47.
- Robinson LA, Sullivan R, Shogren JF. Do the benefits of COVID-19 policies exceed the costs? Exploring uncertainties in the age–VSL relationship. *Risk Anal* 2020. <https://doi.org/10.1111/risa.13561>.
- Viscusi WK. *Pricing the global health risks of the COVID-19 pandemic. Forthcoming journal of risk and uncertainty*. Vanderbilt Law Research Paper; 2020.
- Kelly P, Kahlmeier S, Götschi T, Orsini N, Richards J, Roberts N, et al. Systematic review and meta-analysis of reduction in all-cause mortality from walking and cycling and shape of dose response relationship. *Int J Behav Nutr Phys Act* 2014;11:132.
- Dicker D, Nguyen G, Abate D, Abate KH, Abay SM, Abbafati C, et al. Global, regional, and national age-sex-specific mortality and life expectancy, 1950–2017: a systematic analysis for the global burden of disease study 2017. *Lancet* 2018;392:1684–735.
- UN. *World population prospects 2019: highlights (st/esa/ser. A/423)*. 2019.
- Soetewey A. *Yll: compute expected years of life lost (YLL) and average YLL*. 2018.
- Nilsson A. *The monetary value of a human life-examining the differences between sectors*. 2014.
- Götschi T, Kahlmeier S, Castro A, Brand C, Cavill N, Kelly P, et al. Integrated impact assessment of active travel: expanding the scope of the health economic assessment tool (HEAT) for walking and cycling. *Int J Environ Res Publ Health* 2020;17:7361.
- Smith R, Schneider P. Making health economic models shiny: a tutorial. *Welcome Open Res* 2020;5:69.



Short Communication

Timeliness and completeness of laboratory-based surveillance of COVID-19 cases in England

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ABSTRACT

Objectives: The aim of the study was to evaluate completeness and timeliness of the rapidly developed surveillance of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) infection in England using patient-level data.

Study design: This is an observational study wherein public health surveillance systems are evaluated.

Methods: Data were collected in the Public Health England's Second-Generation Surveillance System through routine laboratory reporting processes, as well as via enhanced testing in collaboration with commercial partners. Three periods were chosen to present developments in disease surveillance around the first pandemic wave in England. Completeness of valid entries for key demographic and epidemiological fields was summarised. Timeliness was assessed using recorded date intervals: from sample collection to the laboratory reporting a positive result, the positive result being received by the national surveillance system and the data being available for epidemiological analysis.

Results: In each period, demographic variables were more than 95% complete and enhanced ethnicity more than 85%, allowing a rich understanding of the general characteristics of COVID-19 cases in England. The proportion of cases completing all reporting stages of the national system within 3 days of when the specimen was taken increased from 69.1% in period 1 to 76.6% in period 3. In period 3, the median number of days to complete all reporting stages decreased to 2, from 3 in previous periods. Analysis of each reporting stage offers suggestive evidence that timeliness of the system has improved as reporting has become established over time.

Conclusions: Timely processing of data for epidemiological use was consistent and rapid once received by the national system. Delays in timeliness were most likely to occur in the first stage of the reporting process, before laboratory input to the surveillance platform. Existing national surveillance mechanisms enhanced during the response have succeeded in providing rapid collection and reporting of case data to facilitate epidemiological monitoring and analysis and guide public health policy and strategy.

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Surveillance of the novel coronavirus disease, COVID-19, was escalated in England in early 2020, with initial cases reported in January 2020.¹ Rapid detection of new incident cases was a key priority, and initial processes were built into existing laboratory reporting systems including the Second-Generation Surveillance System (SGSS) and Respiratory DataMart.² Urgent need to improve case ascertainment, as well as to alleviate testing capacity challenges, resulted in the UK government's deployment of a strategy to scale up testing for COVID-19 in April 2020.³ This policy referred to

testing 'pillars', with three pillars that contributed to detection of cases with current infection: pillar 1, aiming to strengthen established testing pathways, such as National Health Service (NHS) and Public Health England (PHE) laboratories; pillar 2, initiating testing capacity through commercial partners, and pillar 4, swab testing for surveillance studies. This expansion of testing aimed to provide more rapid results to improve data collection to better understand the epidemiological characteristics of infection and to support key workers' ability to return to work with reduced risk. Based on key priorities of data completeness and timeliness, we evaluated the rapidly developed and expanded laboratory surveillance system for severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) around the first pandemic wave in England (see Fig. 1).

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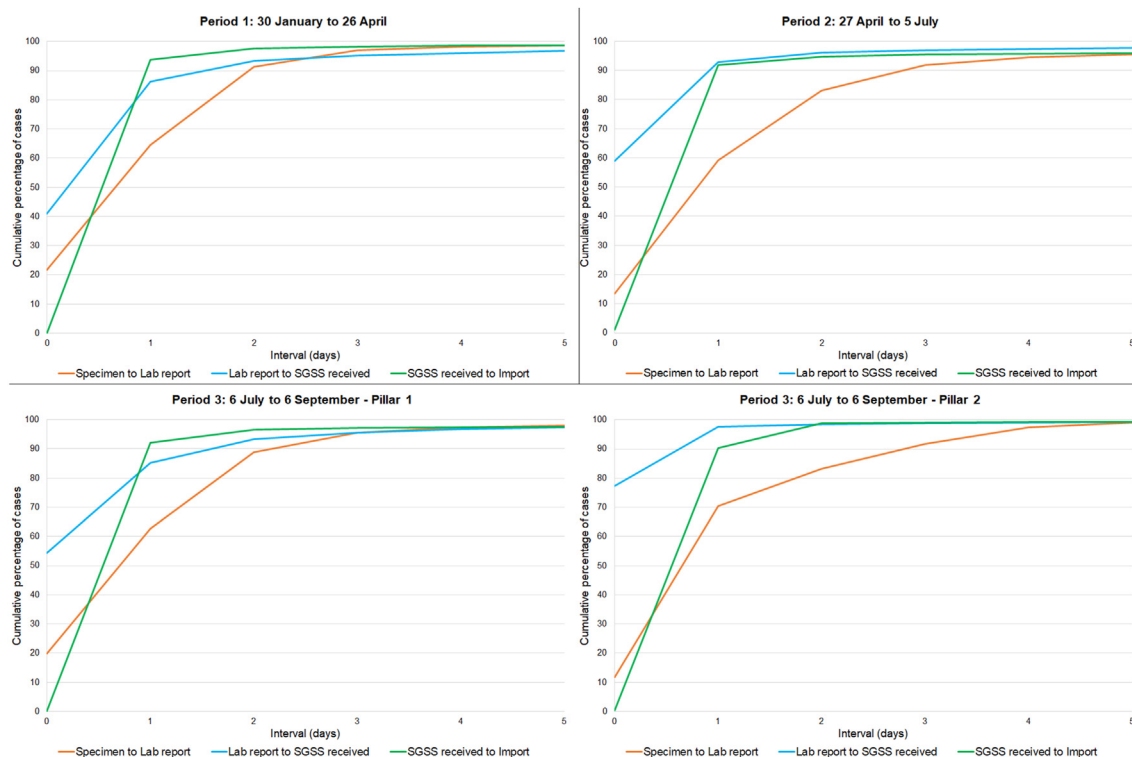


Fig. 1. Time interval between reporting stages, by period. SGSS, Second-Generation Surveillance System.

Data on laboratory-confirmed cases of SARS-CoV-2 infection are legally required to be submitted to PHE by the operators of diagnostic laboratories; submitted laboratory data are managed within the SGSS. Three periods were chosen to present developments in the surveillance system's timeliness and completeness. Cases were assigned to a period by laboratory report date, which has 100% completeness and validity. The periods were January 30–April 26 (the set-up period; ends with the week with the highest number of cases reported), April 27–July 5 (the peak, including some of the highest testing demand and rapid escalation of new systems; ends at the low point of reported cases after the peak) and July 6–September 6 (beginning of the post-first-wave period, as defined in national surveillance reporting).⁴

Some criteria of this analysis were assessed based on the reporting pillar. It is important to note that pillar testing stratification mainly defines the reporting pathways and may not always represent homogenous populations. Pillar 1 includes testing of patients in hospitals (through routine diagnostic investigations or due to COVID-19 symptoms), as well as testing of healthcare and social care workers. Pillar 2 testing broadly represents community testing in the wider population, including mildly symptomatic cases and testing from mobile units. Both pillar 1 and pillar 2 contain some outbreak investigations and care home testing, wherein reporting is based on whether the testing is carried out by a PHE/NHS (pillar 1) or commercially contracted (pillar 2) laboratory. Pillar 4 swab tests can be reported into either pillar 1 or pillar 2 depending on the diagnostic laboratory contracted for the study, and pillar 4 results are not consistently distinguishable within the surveillance system. While pillar 1 is built upon existing laboratory reporting pathways with established data flows, pillar 2 and 4 required new processes to be created for both data collection and submission. This can lead to differences in both timeliness and completeness of reported data fields by the reporting pillar.

Key demographic and epidemiological fields were reviewed for completeness, and the percentage of records containing valid entries was summarised for each period. These fields included surname, forename, sex, date of birth, NHS number, residential postcode and ethnicity as well as epidemiological measures such as the date of symptom onset, hospital-acquired infection, travel exposure and symptom status indicators.

All data apart from the residential postcode and ethnicity fields are unmodified from the SGSS. Data recorded explicitly as 'Unknown' or as a default value (i.e., 01/01/1900) were classified as missing. Data on ethnicity were obtained from the NHS Digital Hospital Episode Statistics (HES) and Secondary Uses Service (SUS) databases.^{5,6} Ethnicity assignment follows the same process as HES-Office for National Statistics mortality linkage, whereby personal identifiers (NHS number, sex, age and postcode) from HES and SUS are linked to people testing positive for COVID-19 in an iterative manner as per eight predefined matching criteria.⁷ Where there are differing ethnicities for the same personally identifiable information, priority is given based on (a) a valid ethnicity (i.e., not including 'Unknown' or 'Prefer not to say'), (b) the most recent date and (c) higher ranked data sets. The data sets are ranked, starting with the highest, as follows: SUS live feed, HES Admitted Patient Care, Outpatient HES and HES Accident and Emergency. Where this linkage did not result in a valid ethnicity for cases reported through pillar 2, the self-reported pillar 2 ethnicity was used. Postcodes that were indicated as being populated with laboratory or GP default information were considered missing for the purpose of assigning patient residential information.

Timeliness was assessed using four key date fields to construct three intervals: (a) from specimen date to laboratory report date, which is the time between the sample being collected and the laboratory reporting positive results to its systems; (b) from laboratory report date to SGSS receipt date, indicating the time taken

from the positive result being available to the result being received by the national surveillance system; and (c) from SGSS receipt date to import date, the time between receipt in the SGSS and the data being imported so that it can be used by epidemiologists, statisticians and modellers. Some of these intervals occur on the same day; for instance, intervals 2 and 3 could occur on the same day. The timeliness analysis included only case records from April 14 for pillar 1 and from May 26 for pillar 2 owing to limitations on available date fields before then, and the end of the analysis period was September 6, 2020.

There were 303,082 cases that met the inclusion criteria for this analysis: 125,779 cases in period 1, 120,403 in period 2 and 56,900 in period 3. Completeness of these data is described in Table 1. Demographic variables, including name, sex, postcode and date of birth, were more than 95% complete in each period, and ethnicity was more than 85% complete owing to the enhancement process. This is a detailed demographic data set allowing a rich understanding of the general characteristics of COVID-19 cases in England, as demonstrated in its use informing the evidence base and in the wider public health literature across various mediums. Examples include daily dissemination of data to local and national public health to inform policy decision-making (including local public health restrictions),^{8,9} modelling to provide forecasting and tracking of the pandemic in real time,^{10–12} routine surveillance reporting of official statistics^{4,13} and peer-reviewed research.^{14,15}

The least complete demographic field was the NHS number, an identifier linked to a patient's electronic health record. This field is routinely enhanced in the SGSS through matching to the Demographic Batch Service.¹⁶ Low completeness is likely due to matching requiring a high level of precision that is not always available for self-reported information (such as through pillar 2). Completeness for this field decreased across the study period from 92.9% to 80.8%. While part of this decrease reflects an increasing proportion of national COVID-19 cases being reported through the pillar 2 reporting pathway, pillar 1 completeness also decreased from approximately 94% in periods 1 and 2 to 80.9% in period 3.

Key epidemiological surveillance variables reported by laboratories were mainly incomplete. Availability of the date of symptom onset decreased from 2.2% to 0.2% from period 1 to 3, as the proportion of cases detected through pillar 2 increased, with almost entirely incomplete data for this field, after its inclusion in pillar 2 data collection in May. The asymptomatic indicator has shown the greatest completeness improvement, increasing from 1.4% to 88.5% across the analysis periods. This is almost entirely due to improvements in completeness for pillar 2 testing, in which this became a mandatory variable in late June 2020. Other indicators, such as travel exposure and hospital-acquired infection status, were generally unavailable through pillar 1 and not collected through pillar 2.

Analysing the three key date intervals in the system reporting process shows that most timeliness variance between the three periods occurs in the first 3 days from when the specimen is collected. (Fig. 1) The interval between the specimen date and laboratory report date—which incorporates the time taken for specimens to arrive, be tested and be processed within laboratories—was the longest interval in each period. This interval was completed within 3 days for 90% of cases in each period. The timeliness of the second reporting stage, from laboratory report to SGSS receipt date, improved significantly over time, completing within 1 day from 41% to 74.5% of reports between periods 1 and 3. The final reporting stage, from SGSS receipt to import date, occurred within 1 day for 90% of cases in all periods, demonstrating that processing for epidemiological use was consistent and rapid once data were received by the national system.

The two primary COVID-19 case reporting pathways (i.e., pillars) show distinct patterns in reporting by interval. The first interval, from the specimen date to the laboratory report date, is typically shorter for those within the pillar 1 system, with 95% processed within 3 days, whereas it takes up to 4 days to see that level of completeness for pillar 2. Conversely, reporting from the laboratory to the SGSS is quicker through pillar 2, with more than three-quarters of cases received by the SGSS on the same day as the laboratory report (77.3%, compared with 54.4% of cases from pillar 1 laboratories).

Combining the three reporting stages describes the overall timeliness of case data being reported through the surveillance system from the date a patient is tested. The largest improvements in timely reporting occurred between days 1 and 3. The proportion of cases completing all reporting stages within 2 days increased from 27.2% in period 1 to 53% in period 3 and within 3 days increased from 69.1% to 76.6% over the same time. The proportion completing within 4 days was relatively stable in each period (from 84.4% to 86.8%). In period 3, the median number of days to complete all reporting stages decreased to 2, from 3 in previous periods.

Analysis of each reporting stage of the new surveillance system offers suggestive evidence that the timeliness of the system has improved as COVID-19 reporting has become established over time. Delays in timeliness are most likely to occur in the first stage of the reporting process, before laboratory input to the surveillance platform. Efforts to consistently improve system-wide timeliness, in each reporting pillar, should be directed to strengthening this first reporting stage.

Data-driven insights to inform decision-making for the pandemic response rely on timely and complete data on laboratory-confirmed cases. The SGSS is the principal data source used by stakeholders for these purposes, but relies on data being reported by diagnostic laboratories with sufficient information to rapidly inform the epidemiology. The limited collection and reporting of key information by laboratories, such as the date of symptom onset, hospitalisation and travel exposure, prevents the identification of detailed risk factors for transmission and severity of infection. Increase in lack of patient NHS number submitted by diagnostic laboratories imposes a burden on secondary mechanisms such as deterministic and probabilistic data linkages and poses a hurdle to facilitating broader health informatics linkages going forward.

The COVID-19 pandemic has changed the landscape of public health surveillance in England. Existing surveillance mechanisms that have been enhanced during the response, such as the SGSS, have succeeded in providing rapid collection and reporting of case data to facilitate epidemiological monitoring and analysis and guide the public health policy and strategy. Larger-scale health service or diagnostic laboratory reporting improvements, as well as an emphasis on high-quality data collection, may be required to address the remaining limitations. The surveillance and health information structures that have been developed, and will continue to be refined, will allow public health services to better characterise the pandemic to the benefit of healthcare professionals and the public, with potential learning and application for the surveillance of other infectious diseases in the future.

Author statements

Ethical approval

Ethical approval was not required. The authors were already able to access the anonymised data set and it is not possible to identify individuals from the information provided.

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Competing interests

All co-authors are employed by Public Health England, who run the surveillance system described. The authors have no competing interests to declare.

Data statement

The data analysed during this study are not publicly available owing to a need to protect the individual's anonymity. These data are confidential, but fully anonymised data may be available from the corresponding author on reasonable request. Aggregated and anonymised output from the data set described is publicly available at <https://coronavirus.data.gov.uk/details/cases>.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.puhe.2021.03.012>.

References

- Holden B, Quinney A, Padfield S, Morton W, Coles S, Manley P, et al. COVID-19: public health management of the first two confirmed cases identified in the UK. *Epidemiol Infect* 2020. <https://doi.org/10.1017/S0950268820001922>. 28 August.
- Public Health England. *Sources of COVID-19 surveillance systems*. 2020. 2 October 2020. Available at: <https://www.gov.uk/government/publications/national-covid-19-surveillance-reports/sources-of-covid-19-systems>.
- Department of Health & Social Care. *Coronavirus (COVID-19): scaling up testing programmes*. 2020. 4 April 2020. Available at: <https://www.gov.uk/government/publications/coronavirus-covid-19-scaling-up-testing-programmes>. [Accessed 15 December 2020].
- Public Health England. *National flu and COVID-19 surveillance weekly reports 2020*. 2020. 8 October 2020. Available at: <https://www.gov.uk/government/statistics/national-flu-and-covid-19-surveillance-reports>. [Accessed 15 December 2020].
- NHS Digital. *Hospital Episode statistics (HES)*. 2020. 19 November 2020. Available at: <https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/hospital-episode-statistics>. [Accessed 15 December 2020].
- NHS Digital. *Secondary uses service (SUS)*. 2020. 14 December 2020. Available at: <https://digital.nhs.uk/services/secondary-uses-service-sus>. [Accessed 15 December 2020].
- Health and Social Care Information Centre. *A guide to linked mortality data from hospital Episode statistics and the office for national statistics*. 2015. June 2015. Available at: https://digital.nhs.uk/binaries/content/assets/legacy/pdf/r/q/hes-ons_linked_mortality_data_guide.pdf. [Accessed 15 December 2020].
- Department of Health & Social Care. *COVID-19 contain framework: a guide for local decision-makers*. 2020. 29 December 2020. Available at: <https://www.gov.uk/government/publications/containing-and-managing-local-coronavirus-covid-19-outbreaks/covid-19-contain-framework-a-guide-for-local-decision-makers#data>. [Accessed 9 March 2021].
- Department of Health & Social Care. *Coronavirus (COVID-19): full list of local restriction tiers by area*. 2020. 26 November 2020. Available at: <https://www.gov.uk/guidance/full-list-of-local-restriction-tiers-by-area>. [Accessed 9 March 2021].
- Davies N, Barnard R, Jarvis C, Russell T, Semple M, Jit M, et al. Association of tiered restrictions and a second lockdown with COVID-19 deaths and hospital admissions in England: a modelling study. *Lancet Infect Dis* 2020. [https://doi.org/10.1016/S1473-3099\(20\)30984-1](https://doi.org/10.1016/S1473-3099(20)30984-1). 24 December.
- MRC Biostatistics Unit COVID-19 Working Group. *Nowcasting and forecasting of the COVID-19 pandemic*. 2021. 12 February 2021. Available at: <https://www.mrc-bsu.cam.ac.uk/tackling-covid-19/nowcasting-and-forecasting-of-covid-19/>. [Accessed 8 March 2021].
- Scientific Advisory Group for Emergencies. *Scientific evidence supporting the government response to coronavirus (COVID-19): evidence considered by the Scientific Advisory Group for Emergencies (SAGE)*. 2020. 26 June 2020. Available at: <https://www.gov.uk/government/collections/scientific-evidence-supporting-the-government-response-to-coronavirus-covid-19#modelling-inputs>. [Accessed 8 March 2021].
- Public Health England. *Statistics at PHE*. 2021. Available at: <https://www.gov.uk/government/statistics/national-flu-and-covid-19-surveillance-reports>. [Accessed 8 March 2021].
- Mensah A, Sinnathamby M, Zaidi A, Coughlan L, Simmons R, Ismail S, et al. SARS-CoV-2 infections in children following the full re-opening of schools and the impact of national lockdown: prospective, national observational cohort surveillance, July–December 2020. *England. Journal of Infection* 2021. <https://doi.org/10.1016/j.jinf.2021.02.022>. 25 February.
- Harman K, Allen H, Kall M, Dabrera G. Interpretation of COVID-19 case fatality risk measures in England. *J Epidemiol Commu Health* 2021. <https://doi.org/10.1136/jech-2020-216140>. 29 January.
- NHS Digital. *Access data on the personal demographics service - demographics Batch service (DBS)*. 2020. 7 December 2020. Available at: <https://digital.nhs.uk/services/demographics/access-data-on-the-personal-demographics-service>. [Accessed 15 December 2020].



Review Paper

Vaccine hesitancy in the era of COVID-19

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ABSTRACT

Objectives: In 2019, a new coronavirus has been identified and many efforts have been directed toward the development of effective vaccines. However, the willingness for vaccination is deeply influenced by several factors. So the aim of our review was to analyze the theme of vaccine hesitancy during COVID-19 pandemic, with a particular focus on vaccine hesitancy toward COVID-19 vaccine.

Study design: Narrative review.

Methods: In November 2020, we performed a search for original peer-reviewed articles in the electronic database PubMed (MEDLINE). The key search terms were “Vaccine hesitancy AND COVID-19”. We searched for studies published during COVID-19 pandemic and reporting information about the phenomenon of vaccine hesitancy.

Results: Fifteen studies were included in the review. The percentage of COVID-19 vaccine acceptance was not so high (up to 86.1% students or 77.6% general population); for influenza vaccine, the maximum percentage was 69%. Several factors influenced the acceptance or refusal (ethnicity, working status, religiosity, politics, gender, age, education, income, etc.).

The most given reasons to refuse vaccine were as follows: being against vaccines in general, concerns about safety/thinking that a vaccine produced in a rush is too dangerous, considering the vaccine useless because of the harmless nature of COVID-19, general lack of trust, doubts about the efficiency of the vaccine, belief to be already immunized, doubt about the provenience of vaccine.

Conclusions: The high vaccine hesitancy, also during COVID-19 pandemic, represents an important problem, and further efforts should be done to support people and give them correct information about vaccines.

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Introduction

The World Health Organization (WHO) defined the vaccine hesitancy as a behavior, influenced by a number of factors including issues of confidence (do not trust vaccine or provider), complacency (do not perceive a need for a vaccine, do not value the vaccine), and convenience (access). Vaccine-hesitant individuals are a heterogeneous group who hold varying degrees of indecision about specific vaccines or vaccination in general. Vaccine-hesitant individuals may accept all vaccines but remain concerned about vaccines, some may refuse or delay some vaccines but accept others; some individuals may refuse all vaccines.¹

In December 2019, a cluster of patients presented with pneumonia caused by an unknown pathogen that was linked to the seafood wholesale market in Wuhan, China. Subsequently, a new coronavirus was identified by sequencing the whole genome of patient samples.² It was named severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) by the Coronavirus Study Group of the International Committee on Taxonomy of Viruses,³ and the disease caused by the virus was named coronavirus disease 2019 (COVID-19) by the WHO.

After infecting and causing the death of thousands of persons in China, the virus has spread, reaching Italy and other European countries and the USA, with the number of confirmed new cases currently increasing every day.⁴ The WHO declared it a pandemic due to the widespread infectivity and high contagion rate.

Many efforts have been directed toward the development of vaccines against COVID-19 to avert the pandemic and most of the developing vaccine candidates have been using the S-protein of SARS-CoV-2.⁵

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Currently, three vaccines are authorized and recommended to prevent COVID-19. Large-scale (phase 3) clinical trials are also in progress or being planned for other COVID-19 vaccines in the United States.^{6,7}

The presence of available vaccines is the key element to minimize new infections, so it is crucial to vaccinate people, and especially healthcare workers.⁸

However, the willingness for vaccination is deeply influenced especially by the mistrust of health authorities, as demonstrated in other studies focused on vaccine trials of HPV and HIV, in Europe and United States.^{9,10}

The worldwide COVID-19 crisis may have a more or less important impact on public trust in public health authorities, science, and medicine, from a country to another, as per the burden of its health and socioeconomic consequences and intensity of controversies.¹¹

In addition to a segment of population that refuses vaccines, the novelty of the disease and concerns over safety and efficacy of the vaccine have generated a sizable proportion of US people indicating reluctance to getting vaccinated against COVID-19.¹²

But this phenomenon is also spread elsewhere: in May 2020, about 25% of people in 5 surveys in France (representative samples of 1000 adults) stated that they would refuse a future vaccine against it if it would have been available, mainly due to safety concerns around a vaccine developed in an emergency situation.¹³

The aim of our study was, therefore, through a narrative review, to deepen and analyze the theme of vaccine hesitancy during COVID-19 pandemic, with a particular focus on vaccine hesitancy toward the COVID-19 vaccine.

Methods

Search strategy

In November 2020 (the search was performed on November 3rd), we performed a search for original peer-reviewed articles in the electronic database PubMed (MEDLINE). The key search terms were “Vaccine hesitancy AND COVID-19”. We searched for studies published during COVID-19 pandemic (up to November 2020) and reporting information about the phenomenon of vaccine hesitancy.

Inclusion criteria

We considered eligible for the review all the articles (original articles, but also letters to the editor if containing original data) that reported data on i) type of investigated vaccine (COVID-19 vaccine but also other vaccines if investigated), ii) a deep and complete analysis of the attitude toward the vaccine and the main reasons or factor influencing this attitude. We considered eligible for the review all descriptive studies, written in English, French, Spanish, Italian.

Study selection and data extraction

Studies were selected in a 2-stage process. Titles and abstracts from electronic searches were scrutinized by 2 reviewers independently (A.N. and G.T.) and full manuscripts and their citations list were analyzed to retrieve missing articles and to select the eligible manuscripts as per the inclusion criteria. The level of agreement between the reviewers was high. Then, each article was further reviewed to identify the manuscripts suitable for our review.

Results

The literature search yielded 49 publications. The titles, abstracts, and full texts of these manuscripts were screened, resulting in 15 studies considered potentially eligible to be included in the review (4 articles were letters without original data, 1 was a review, 29 were not in line with the aim of the study).^{8,13–26}

The studies, published in 2020, have been conducted in the period March–September 2020; they involved a minimum of 316 (Pogue et al.) and a maximum of 5024 (Salali et al.) participants. Studies have been conducted in several countries: USA, UK, Turkey, France, Malta, Italy, Hong Kong, Israel, Canada, Japan, Spain, Switzerland involving a variegated typology of participants (most of them were focused on general population adult or not, others specifically on some categories, e.g., students, parents, healthcare workers). Two vaccines have been analyzed: COVID-19 vaccine has been investigated by most of authors (except for Goldman et al. who focused only on influenza); influenza vaccine has been investigated also by Grech et al. and by Wang et al. The principal results of our review are shown in [Table 1](#).

Percentage of vaccine acceptance

The percentage of vaccine acceptance was not so high: only in an Italian study (Barello et al.) 86.1% participants (who were students) chose to be vaccinated against COVID-19. If considering general population, this percentage lessened to a maximum 77.6% (Detoc et al.) people who declared who will probably or certainly accept COVID-19 vaccine. Although all the studies have been conducted in different periods, the percentages did not differ so much.

For influenza vaccine alone, the situation is similar: the maximum percentage of acceptance was reported in the study of Grech et al. (69%), but the only study focused exclusively on influenza vaccine (Goldman et al.) showed that only 54.3% of parents were favorable to vaccinate their children and 58.3% intended to vaccinate themselves.

Influencing factors and reasons given by participants who refused the vaccination

Factors that influenced the choice to accept the vaccines (or not) could be resumed as follows:

- **Ethnicity:** black/African had a lower acceptance
- **Working status:** unemployed people had a lower acceptance
- **Personal belief:** participants with personal belief against vaccines had lower acceptance; those who received vaccinations (especially influenza) in the past had a higher acceptance
- **Religiosity:** religiosity was negatively correlated with COVID-19 vaccination
- **Politics (!):** Respondents who declared Democratic political partisanship were significantly more likely to choose to receive vaccination (Kreps et al.). Those who felt close to radical parties or those who did not vote/did not feel close to any party were significantly more likely to refuse the vaccine (Ward et al.). Those who voted for far left or far right candidate in the last elections were more likely to refuse vaccination (COCONEL Group). Pogue et al. observed that political ideology had no relationship with the attitude toward vaccination.
- **Gender:** Women had a lower acceptance.
- **Education (!):** participants with low education had a lower acceptance (except for the study conducted in Turkey by Salali et al.)
- **Age (!):** low age was associated to a lower willingness to receive vaccination. Except for the study of Palamenghi et al. who

Table 1
Main characteristics of the studies included in the review (n/r = not reported or not explicitly reported).

Author, year	Setting	Period of study	Method	Inclusion criteria	Participants	Investigated vaccine	Sociodemographic characteristics	Attitude toward vaccination
Olagoke, 2020	USA	22 March 2020	Survey	- >18 years old - Living in USA	501	COVID-19	- Mean age 32.44 (SD 11.94) years - Females 55.29% - White 53.71% - Employed 53.71% - Median age 43 years (range 30–58) - Females 51% - White 73%	- Black/African, unemployed, and with personal belief against vaccines had lower COVID-19 vaccination intention - Religiosity was negatively correlated with COVID-19 vaccination
Kreps, 2020	USA	9 July 2020	Questionnaire	- US adults	1971	2 Hypothetical COVID-19 vaccines ^a		- 56% participants declared to choose the presented vaccine - A greater vaccine efficacy, a longer protection duration and a lower incidence of side effects were associated to a higher probability of choosing a vaccine - Respondents were less likely to choose vaccines developed outside of the United States, particularly from China - Respondents who declared Democratic political partisanship were significantly more likely to choose to receive vaccination - Women, black, low education, and low age were associated to a lower willingness to receive vaccination - 31% (Turkey) and 14% (UK) were unsure to be vaccinated - 3% in both countries refused to be vaccinated - Acceptance was higher among those who believed the natural origin of pandemics, among those who had higher anxiety related to COVID-19 - Men were more likely to accept vaccines - Have a graduate degree and children decreased the odds of vaccine acceptance in Turkey, but not in UK
Salali, 2020	UK and Turkey	May 2020	Survey	- >18 years old - Living in UK or Turkey	- 1088 in UK - 3936 in Turkey	COVID-19	n/r	- Women, young people (<35 years old) and those with a lower income were more likely to refuse vaccines - No difference was observed between those who were diagnosed with COVID-19 and those who were not - Those who were highly concerned about being infected were less likely to refuse the vaccine - Those who felt close to radical parties or those who did not vote/did not feel close to any party were significantly more likely to refuse the vaccine - Most given reasons to refuse vaccine were: being against vaccines in general (27.6%), thinking that a vaccine produced in a rush is too dangerous (64.4%), considering the vaccine useless because of the harmless nature of COVID-19 (9.6%). Other respondents refused vaccine because of a general lack of trust, doubts about the efficiency of the vaccine or belief to be already immunized
Ward, 2020	France	April 2020	Cross-sectional online survey	n/r	5018	COVID-19	- <35 years old (N = 1290) - 35–64 years old (N = 2494) - >64 years old (N = 1234) - Females (N=2629) - Males (N = 2389)	- Respondents routinely vaccinated were more likely to receive COVID-19 vaccine - Respondents who had a greater perceived impact of COVID-19 in America were more likely to receive COVID-19 vaccine - Income and political ideology had no relationship with the attitude toward vaccination - 68.57% of respondents indicated they were amenable to receive the vaccine - 15.89% neither agreed or disagreed - The main reasons to refuse vaccine were: concerns about safety (45.45%) and lack of trust in the source (13.54%) and other reasons (15.45% – above all more testing before accepting vaccine)
Pogue, 2020	USA	n/r	Survey	n/r	316	COVID-19	- <18 years old 2.16% - 18–25 years old 12.45% - 26–35 years old 18.21% - 36–45 years old 31.48% - 46–55 years old 3.4% - >55 years old 32.41% - Females 49.38% - White 63.27%	
	Italy		Survey		1004	COVID-19	- 18–38 years old 34.4%	

(continued on next page)

Table 1 (continued)

Author, year	Setting	Period of study	Method	Inclusion criteria	Participants	Investigated vaccine	Sociodemographic characteristics	Attitude toward vaccination
Graffigna, 2020		Early days of the so-called phase 2		- Italian citizens	adult		- 39–52 years old 33.6% - >52 years old 32.1% - Females 50.9%	- 58.6% of respondents indicated they agreed to receive the vaccine - 15.4% disagreed - 26.2% were uncertain about receiving the vaccine - Respondents with a general positive attitude toward vaccine were more likely to receive COVID-19 vaccine - There was a positive relationship between health engagement and willingness to vaccinate
Detoc, 2020	France	26 March 2020–20 April 2020	Survey	n/r	3259	COVID-19	- <30 years old 20.6% - 30–49 years old 46.11% - 50–64 years old 24.6% - 65–80 years old 8.3% - >80 years old 0.4% - Females 67.4% - 24.1% had chronic medical conditions	- Vaccine hesitancy 35.3% - 77.6% will certainly or probably be vaccinated against COVID-19 - 83.1% men and 74.2% women were COVID-19 vaccine acceptors ($P < 0.05$) - 81.5% healthcare workers and 73.7 non-healthcare workers were COVID-19 vaccine acceptors ($P < 0.05$) - Older age, male gender, fear about COVID-19, be healthcare workers and individual perceived risk were associated with COVID-19 vaccine acceptance
Fisher, 2020	USA	16–20 April 2020	Survey	- Adults	991	COVID-19	- 18–29 years old 20.4% - 30–44 years old 25% - 45–59 years old 24.6% - >60 years old 30% - Females 51.5% - White 63.3%	- 57.6% participants intended to be vaccinated - 31.6% were not sure - 10.8% did not intend to be vaccinated - Females, young, black/hispanic, those with a lower education and income, those who did not receive influenza vaccine were less likely to have intention to accept vaccination - The main reasons to refuse vaccine were: concerns about the vaccine, need additional information, anti-vaccine attitude, low trust in vaccine development
Palamenghi, 2020	Italy	Phase 1 (early days after initial spread of SARS-COV-2) and Phase 2 (early days after the Italian reopening after lockdown)	Survey	- Italian citizens	968 (phase 1) 1004 (phase 2)	COVID-19	n/r	- 59% of participants intended to be vaccinated (Phase 2) - Decrease in trust toward scientific research, and vaccines' efficacy - Middle age group had a reduced willingness to be vaccinated compared with 18–34 years old people and over 60 years old people.
Dror, 2020	Israel	March 2020	Survey	- Healthcare personnel or general population	1941	COVID-19	n/r	- No difference in vaccine acceptance among healthcare personnel or not - Males, those who perceived themselves at higher risk of infection, people currently vaccinated against influenza had a higher acceptance - The rate of acceptance of COVID-19 vaccine was lower than the acceptance of Influenza vaccine among healthcare workers
Barello, 2020	Italy	n/r	Cross-sectional study	- Students	934	COVID-19	- Mean age 23.6 (SD 4.9) years old - Females 79.6%	- 86.1% chose to be vaccinated - 13.9% refused to be vaccinated - No significant differences were observed for socio-demographic characteristics or for type of study (healthcare students or not)
COCONEL Group, 2020	France	27–29 March 2020	Online survey	- French population over 18 years old	1012	COVID-19	n/r	- 26% refused to be vaccinated - Refusals were higher among low-income people, young women and older than 75 years old - Those who voted for far left or far right candidate in the last elections were more likely to refuse vaccination
Grech, 2020	Malta	11–16 September 2020	Questionnaire	- Healthcare workers	1002	COVID-19 and influenza	n/r	Influenza: - Significant increase in willingness to be vaccinated (from 49% to 69%) COVID-19 - Almost 50% expressed their willingness to be vaccinated

Wang, 2020	Hong Kong	26 February – 31 March 2020	Survey	- Nurses (not retired 806 or working in administrative or academic positions)	COVID-19 and Influenza	- 18–29 years old 22.7% - 30–39 years old 36% - 40–49 years old 24.2% - >50 years old 17.1% - Females 80.8% - 25.8% had chronic medical conditions	- Almost 25% were undecided and almost 25% did not want to be vaccinated - Men were more likely to accept vaccine Influenza: - Similar acceptance rate between 2019 and 2020 (47.5% and 44.7% respectively) COVID-19 - 40% nurses had intention to accept COVID-19 vaccination - Males, those with chronic diseases, or those who accepted the seasonal influenza vaccine in 2019 were more likely to have intention to accept COVID-19 vaccination - The main reasons to refuse vaccine were: suspicion on efficacy, effectiveness, safety (76.43%); believing vaccination is not necessary (18.05%) - 54.3% intended to vaccinate their children (+15.9% compared to the past 12 months) - 58.3% intended to receive a vaccine for themselves - 1025 had no intention to vaccinate their children - Parents who received vaccination or vaccinated their children in the past or those who were worried about COVID-19 had a higher probability to vaccinate their children
Goldman, 2020	USA, Canada, Israel, Japan, Spain, Switzerland	27 March 2020–30 June 2020	Survey	- Parents caregivers of patients older than 1 year and younger than 19 years old	Influenza	- 274 (26.7%) +102 (24.4%) fathers ^b - 723 (70.5%)+299 (71.5%) mothers ^b - Mean age 40.7	

^a Because the study was conducted before the development of a vaccine

^b Calculated respectively on who do not want plan to vaccinate (1025) and who plan to vaccinate (418)

observed that middle age group had a reduced willingness to be vaccinated compared with 18–34-year-old people and people aged more than 60 years. Also the COCONEL group observed a higher hesitancy among older than 75 years.

- **Income (!)**: participants with lower income had lower acceptance. Pogue et al. observed that income had no relationship with the attitude toward vaccination.
- **COVID-19 infection**: no difference observed between those who have been infected and those who have not.
- **Concern about COVID-19**: those who were highly concerned about being infected were less likely to refuse the vaccine.
- **Working in healthcare settings (!)**: healthcare workers had a higher acceptance. Except for the study of Dror et al. who observed no difference in vaccine acceptance among healthcare personnel and not-healthcare personnel. Also Barello et al. observed no significant differences among healthcare students or not.

(!) = this symbol is used to highlight factors with conflicting results.

The most given reasons to refuse vaccine were being against vaccines in general, concerns about safety/thinking that a vaccine produced in a rush is too dangerous, considering the vaccine useless because of the harmless nature of COVID-19, general lack of trust, doubts about the efficiency of the vaccine, belief to be already immunized, doubt about the provenience of vaccine.

Discussion

Our review highlighted an overall high vaccine hesitancy toward the COVID-19 vaccine, but also toward influenza vaccine. These results are not surprising: studies around the world on vaccine hesitancy, in general, showed prevalence ranging from 8% to 15%.^{27–29} However, it should be specified that the speed of the pandemic and the considered time span (up to November 2020) could make our results not totally representative of the real situation.

One of the most interesting aspects of the review is the point-to-point analysis of factors that influenced the acceptance or refusal. This represents, however, an instantaneous photography of the actual situation: in fact, as Williams et al. reported, although the reasons why parents chose to delay or refuse vaccines for their children have been thoroughly examined, the reasons for vaccine delay or refusal may change over time.³⁰

In our review black or African people had a lower acceptance rate. This datum is in line with another study that showed that among African Americans, there was a higher degree of skepticism and concern about the flu vaccine.³¹

Our review highlighted that unemployed people and those with a lower income had a lower acceptance rate; however, Pogue et al. observed that income had no relationship with the attitude toward vaccination. In addition, participants with low education had a lower acceptance rate (except for the study conducted in Turkey by Salali et al.). These data are partially in line with what reported by Danis et al.: their study revealed how economic hardship represented a determinant of vaccine hesitancy, while no association was found between economic hardship and vaccine refusal. On the other hand, the lower education of both mother and father was a valid predictor of refusal of all vaccines, while hesitancy seemed to not be affected by parental education.³²

In another survey although caregivers from households in the 3rd or 4th quintiles were more likely to fully immunize their children than those in the other quintiles, this was not statistically significant.³³

Our findings showed that a higher level of education seemed to be a protective factor against refusing vaccines. However, there was

no consensus about this association in other studies, some being in contrast,^{34,35} in accordance³⁶ or showing no significant association.³⁷ Parents with a higher-education background may use selected sources of information, relying on a critical-thinking attitude and making more active choices.³⁸

In our review, we observed that religiosity was negatively correlated with COVID-19 vaccination. This particular aspect has already been described by other authors which observed that some people avoided vaccination based on religious grounds including religious explanations (“God did not take any medicine”) or associating vaccines with Satanism.³⁹

One of the most interesting aspects of our review is the influence of political ideology on vaccine acceptance or refusal: people who declared Democratic political partisanship were significantly more likely to choose to receive vaccination; those who felt close to radical parties or those who did not vote/did not feel close to any party were significantly more likely to refuse the vaccine; those who voted for far left or far right candidate in the last elections in France were more likely to refuse vaccination. This kind of analysis has already been conducted by Kennedy et al. with a focus on populist party: they observed that the support for populist parties could be used as a proxy for vaccine hesitancy, at least in the Western European context, with an increase in support being a signal for public health actors to be vigilant.⁴⁰

In our review, we observed that women had a lower acceptance rate. This datum is in line with other studies that found high rates of women expressing concerns about the safety of vaccines and expressing a lack of trust in the quality and impartiality of information provided by healthcare professionals.⁴¹

In our review, we observed three apparently independent phenomena: 1) low age was associated to a lower willingness to receive vaccination; 2) those who were highly concerned about being infected were less likely to refuse the vaccine; 3) no difference observed between those who have been infected and those who have not. It is important to remember that risk perception is an important factor influencing risk behaviors and people with lower risk perception tend to take risk behaviors or reduce preventive behaviors.⁴² Young people (such as college students as reported by Ding et al.) are usually healthy, and often have mild symptoms after being infected with COVID-19, which can have a significant impact on the spread of COVID-19.⁴³ So it is conceivable that they could tend to refuse vaccination because of the scarce perception of the risk so, as suggested by Ding et al., it is necessary to improve the risk perception of college students through health education in various ways, and attention should be paid to some college students with low risk perception.⁴³

Vaccine acceptance from healthcare workers had conflicting results: in general, healthcare workers had a higher acceptance, but in the study of Dror et al. no difference was observed in vaccine acceptance among healthcare personnel and not-healthcare personnel; also Barello et al. observed no significant differences among healthcare students or not. The problem of vaccine hesitancy among healthcare workers has been extensively studied by the European Centre for Disease Control reporting that healthcare workers had concerns relating to the risks of vaccination and expressed a lack of trust in health authorities. Even some healthcare workers were also against vaccination in general.⁴⁴

The most given reasons to refuse vaccine were as follows: being against vaccines in general, concerns about safety/thinking that a vaccine produced in a rush is too dangerous, considering the vaccine useless because of the harmless nature of COVID-19, general lack of trust, doubts about the efficiency of the vaccine, belief to be already immunized, doubt about the provenience of vaccine.

These evidences are quite in line with what reported in other studies. For example, Pugliese-Garcia et al. reported in their survey

the respondents' fear of being injected incorrectly or contracting infections, of the fear of pain.³⁹ Perceptions of vaccine effectiveness were often grounded in misconceptions about how, for whom and for how long vaccines work. Respondents believed that vaccines worked against illnesses, particularly for childhood illness, rather than being disease-specific.³⁹ Alabbad et al., instead, reported that the most common reason for vaccine refusal was believing that it had no positive effect and that it was unnecessary.²⁸

Krishnamoorthy et al. interviewed parents and health workers, who reported that the major reason for the hesitancy was the rumors spread regarding the safety of the vaccine through social media. They have mentioned that the message was circulated with friends, relatives, and other community domains without confirming the authenticity of the information. However, repeated awareness sessions through various mass media channels have helped to overcome these barriers.⁴⁵

In some studies, even, some participants preferred informal, traditional, and religious approaches to prevention and cure. Participants described cases of young men using beer, spirits and local alcohol, Tujiljili, Junta, and Kachasu, while others used other informal and traditional alternatives such as traditional brews, herbs, and tattoos.³⁹

Conclusions

Vaccine hesitancy still remains high, also during COVID-19 pandemic, and the reasons for vaccine refusals are several. This phenomenon represents an important problem, because increasing hesitancy leads to falls in coverage and often precedes an infectious disease outbreak.⁴⁰

Healthcare professionals (especially general practitioners and pediatricians) should be involved to support people and help informed deciding about vaccinations.^{46,47} However, although researchers have begun to develop and evaluate interventions for vaccine-hesitant people (especially parents), the current data do not support one method for intervention as superiorly effective over others; therefore, continued development and evaluation of interventions is needed.³⁰

Author statements

Ethical approval

Ethical approval is not necessary because it is a review of the literature.

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Competing interests

None declared.

References

1. Group, T.S.V.H.W. *What influences vaccine acceptance: a model of determinants of vaccine hesitancy*. 2013.
2. Zhou MY, et al. From SARS to COVID-19: what we have learned about children infected with COVID-19. *Int J Infect Dis* 2020;**96**:710–4.
3. Gorbalenya AE, B SC, Baric RS, de Groot RJ, Drosten C, Gulyaeva AA. *Severe acute respiratory syndrome-related coronavirus: the species and its viruses – a statement of the Coronavirus Study Group*. 2020.
4. Pascarella G, et al. COVID-19 diagnosis and management: a comprehensive review. *J Intern Med* 2020;**288**(2):192–206.

5. Dhama K, et al. COVID-19, an emerging coronavirus infection: advances and prospects in designing and developing vaccines, immunotherapeutics, and therapeutics. *Hum Vaccines Immunother* 2020;**16**(6):1232–8.
6. CDC. *Different COVID-19 vaccines*. Updated Jan. 15, 2021. 28/01/2021; Available from, <https://www.cdc.gov/coronavirus/2019-ncov/vaccines/different-vaccines.html>.
7. Agency, E.M. *Treatments and vaccines for COVID-19: authorised medicines*. 2021. 19/2/2021; Available from, <https://www.ema.europa.eu/en/human-regulatory/overview/public-health-threats/coronavirus-disease-covid-19/treatments-vaccines/treatments-vaccines-covid-19-authorised-medicines>.
8. Grech V, Gauci C, Agius S. Vaccine hesitancy among Maltese healthcare workers toward influenza and novel COVID-19 vaccination. *Early Hum Dev* 2020: 105213.
9. Strauss RP, et al. Willingness to volunteer in future preventive HIV vaccine trials: issues and perspectives from three U.S. communities. *J Acquir Immune Defic Syndr* 2001;**26**(1):63–71.
10. Karafillakis E, et al. HPV vaccination in a context of public mistrust and uncertainty: a systematic literature review of determinants of HPV vaccine hesitancy in Europe. *Hum Vaccines Immunother* 2019;**15**(7–8):1615–27.
11. Verger P, Dube E. Restoring confidence in vaccines in the COVID-19 era. *Expert Rev Vaccines* 2020:1–3.
12. Chou WS, Budenz A. Considering emotion in COVID-19 vaccine communication: addressing vaccine hesitancy and fostering vaccine confidence. *Health Commun* 2020:1–5.
13. Group C. A future vaccination campaign against COVID-19 at risk of vaccine hesitancy and politicisation. *Lancet Infect Dis* 2020;**20**(7):769–70.
14. Olagoke AA, Olagoke OO, Hughes AM. Intention to vaccinate against the novel 2019 coronavirus disease: the role of health locus of Control and religiosity. *J Relig Health* 2020 Oct;**30**:1–16.
15. Kreps S, et al. Factors associated with US adults' likelihood of accepting COVID-19 vaccination. *JAMA Netw Open* 2020;**3**(10):e2025594.
16. Salali GD, Uysal MS. COVID-19 vaccine hesitancy is associated with beliefs on the origin of the novel coronavirus in the UK and Turkey. *Psychol Med* 2020:1–3.
17. Ward JK, et al. The French public's attitudes to a future COVID-19 vaccine: the politicization of a public health issue. *Soc Sci Med* 2020;**265**:113414.
18. Pogue K, et al. Influences on attitudes regarding potential COVID-19 vaccination in the United States. *Vaccines* 2020;**8**(4).
19. Graffigna G, et al. Relationship between citizens' health engagement and intention to take the COVID-19 vaccine in Italy: a mediation analysis. *Vaccines* 2020;**8**(4).
20. Detoc M, et al. Intention to participate in a COVID-19 vaccine clinical trial and to get vaccinated against COVID-19 in France during the pandemic. *Vaccine* 2020;**38**(45):7002–6.
21. Wang K, et al. Intention of nurses to accept coronavirus disease 2019 vaccination and change of intention to accept seasonal influenza vaccination during the coronavirus disease 2019 pandemic: a cross-sectional survey. *Vaccine* 2020;**38**(45):7049–56.
22. Fisher KA, et al. Attitudes toward a potential SARS-CoV-2 vaccine: a survey of U.S. Adults. *Ann Intern Med* 2020 Dec;**173**(12):964–73.
23. Palamenghi L, et al. Mistrust in biomedical research and vaccine hesitancy: the forefront challenge in the battle against COVID-19 in Italy. *Eur J Epidemiol* 2020;**35**(8):785–8.
24. Dror AA, et al. Vaccine hesitancy: the next challenge in the fight against COVID-19. *Eur J Epidemiol* 2020;**35**(8):775–9.
25. Goldman RD, et al. Willingness to vaccinate children against influenza after the coronavirus disease 2019 pandemic. *J Pediatr* 2020 Jan;**228**:87–93.
26. Barello S, et al. 'Vaccine hesitancy' among university students in Italy during the COVID-19 pandemic. *Eur J Epidemiol* 2020;**35**(8):781–3.
27. Giambi C, et al. Parental vaccine hesitancy in Italy - results from a national survey. *Vaccine* 2018;**36**(6):779–87.
28. Alabbad AA, et al. Prevalence of influenza vaccine hesitancy at a tertiary care hospital in Riyadh, Saudi Arabia. *J Infect Public Health* 2018;**11**(4):491–9.
29. Cunningham RM, et al. Prevalence of vaccine hesitancy among expectant mothers in Houston, Texas. *Acad Pediatr* 2018;**18**(2):154–60.
30. Williams SE. What are the factors that contribute to parental vaccine-hesitancy and what can we do about it? *Hum Vaccines Immunother* 2014;**10**(9):2584–96.
31. Quinn SC, et al. Exploring racial influences on flu vaccine attitudes and behavior: results of a national survey of White and African American adults. *Vaccine* 2017;**35**(8):1167–74.
32. Danis K, et al. Socioeconomic factors play a more important role in childhood vaccination coverage than parental perceptions: a cross-sectional study in Greece. *Vaccine* 2010;**28**(7):1861–9.
33. Akwataghibe Ngozi N, O EA, Broerse Jacqueline EW, Popoola Oluwafemi A, Agbo Adanna I, Dieleman Marjolein A. Exploring factors influencing immunization utilization in Nigeria—a mixed methods study. *Front Public Health* 2019;**7**:392.
34. Anello P, et al. Socioeconomic factors influencing childhood vaccination in two northern Italian regions. *Vaccine* 2017;**35**(36):4673–80.
35. Hak E, et al. Negative attitude of highly educated parents and health care workers towards future vaccinations in the Dutch childhood vaccination program. *Vaccine* 2005;**23**(24):3103–7.
36. Bocquier A, et al. Socioeconomic differences in childhood vaccination in developed countries: a systematic review of quantitative studies. *Expert Rev Vaccines* 2017;**16**(11):1107–18.
37. Arat A, et al. Social inequities in vaccination coverage among infants and pre-school children in Europe and Australia - a systematic review. *BMC Publ Health* 2019;**19**(1):290.
38. Feiring B, et al. Do parental education and income matter? A nationwide register-based study on HPV vaccine uptake in the school-based immunisation programme in Norway. *BMJ Open* 2015;**5**(5):e006422.
39. Pugliese-Garcia M, et al. Factors influencing vaccine acceptance and hesitancy in three informal settlements in Lusaka, Zambia. *Vaccine* 2018;**36**(37): 5617–24.
40. Kennedy J. Populist politics and vaccine hesitancy in Western Europe: an analysis of national-level data. *Eur J Publ Health* 2019;**29**(3):512–6.
41. Rosso A, et al. Factors affecting the vaccination choices of pregnant women for their children: a systematic review of the literature. *Hum Vaccines Immunother* 2020;**16**(8):1969–80.
42. Adefuye AS, et al. HIV sexual risk behaviors and perception of risk among college students: implications for planning interventions. *BMC Publ Health* 2009;**9**:281.
43. Ding Y, et al. Risk perception of coronavirus disease 2019 (COVID-19) and its related factors among college students in China during quarantine. *PloS One* 2020;**15**(8):e0237626.
44. ECDC. *Vaccine hesitancy among healthcare workers and their patients in Europe*. 2015.
45. Krishnamoorthy Y, et al. Factors related to vaccine hesitancy during the implementation of Measles-Rubella campaign 2017 in rural Puducherry-A mixed-method study. *J Fam Med Prim Care* 2019;**8**(12):3962–70.
46. Danchin MH, et al. Vaccine decision-making begins in pregnancy: correlation between vaccine concerns, intentions and maternal vaccination with subsequent childhood vaccine uptake. *Vaccine* 2018;**36**(44):6473–9.
47. Bechini A, et al. Impact assessment of an education course on vaccinations in a population of pregnant women: a pilot study. *J Prev Med Hyg* 2019;**60**(1): E5–11.