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Letters to the Editor

The Post-Acute and Long-Term Care Crisis in the Aftermath of COVID-19: A Dutch Perspective



To the Editor:

We read with great interest the article by Laxton et al about solving the COVID-19 crisis in post-acute and long-term care.¹

In the Netherlands, the peak of the first wave of the pandemic seems to be behind us, and it is now becoming apparent how hard the nursing home population has been hit and how disruptive the pandemic is for Dutch nursing homes as well. Morbidity and mortality in nursing homes that suffered outbreaks of COVID-19 have been high despite the fact that Dutch nursing home care benefits from well-developed care infrastructure that is fully integrated in the national health sector.² Despite this, the nursing home sector was overshadowed by the huge national attention for COVID-19 in acute hospital care, resulting in evident shortages of personal protective equipment (PPE) and the inability to develop an adequate testing policy because of a too low national test capacity as well. As such, the nursing homes were, through no fault of their own, prone to become a prey of the virus. Furthermore, the influx of new nursing home residents has been severely reduced.³ Negative expressions in the media, the fear of contracting SARS-CoV-2 if admitted, and isolation from loved ones because of profound restrictions on family visits to curtail outbreaks have led to a situation in which many potential new residents prefer to stay at home despite their actual need for nursing home care. These developments are alarming on several levels, conceivably leading to an increased risk of adverse outcomes in very frail old patients who currently receive suboptimal care at home. We foresee that the virtual standstill nursing home care has reached will cause a subsequent wave of increased older adult abuse, falls, and increased morbidity and mortality in frail old community-dwelling people. There are also important financial implications. Most notably, in US nursing homes with more patients financed by Medicaid, COVID-19–related mortality was higher, likely because of fewer resources compared with other facilities.^{4,5} As such, new value-based financing models may help to ensure appropriate and affordable post-acute and long-term care in the long run. Nevertheless, in the Netherlands, having a robust public insurance system aimed at ensuring health equity from birth till long-term (nursing home) care, we are currently still on the brink of a new era in which ethical debates regarding the organization and financing of long-term care are necessary to guarantee sustainable nursing home care in the future.

We are now at serious risk of permanently disrupting our nursing home care. In the Netherlands, this development has occurred despite a prior embrace of value-based health care practices.⁶ We therefore wholeheartedly agree with Laxton et al that

although still in grip of this terrible crisis and anxious for a second wave, the time for change is now. Urgent policy is needed to curtail the extent of the nursing home crisis. Successful recovery will depend not only on whether nursing home care is delivered through a value-based approach, but also on effective precautions that prevent nursing home outbreaks. It is therefore reassuring that the first experiences allowing visitors back in the nursing homes have had a positive impact on well-being and have not led to new COVID-19 cases,⁷ but it remains to be seen how this situation evolves if a second wave were to occur.

Another important aspect that deserves reconsideration is the (architectural) design of the nursing home facilities. It is self-evident that private rooms, and thus the ability to isolate suspected patients, will help in limiting virus transmission. Moreover, by clustering smaller numbers of residents in living and/or dining rooms, or even in small-scale freestanding living facilities (such as the Green House Model or Green Care Farms), a possible outbreak may be contained more easily.^{8,9} A convenient by-product is that more individualized and intimate care can be delivered. Furthermore, interventions within existing infrastructures such as optimization of factors such as adequate ventilation, regulation of temperature, more space per resident, and separate office spaces have been long known to contribute to infection control and may be interventions that are easier to achieve short-term.¹⁰ However, because it is very unlikely that all nursing homes will be renovated or rebuilt in the near future, we also suggest that stronger structural attention be paid to the controlled implementation of good hygiene and infection protocols, with special attention to basic hand hygiene (washing), providing and using PPE, timely recognition of symptoms, and testing. The effectiveness of such interventions should be investigated in clinical studies to achieve evidence-based policies.

US nursing homes may benefit from informed policy decisions by careful comparisons between the United States and countries such as the Netherlands that are now in the recovery phase after the initial peak.

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Unanticipated Therapeutic Value of the Patient-Centered Outcomes Research Institute (PCORI) Stakeholder Engagement Project for Homebound Older Adults



A major goal of the Patient-Centered Outcomes Research Institute (PCORI) is to bring patients, caregivers, and other stakeholders into the research process and build a community that enhances patient-centered outcomes research (PCOR).¹ There are about 2 million older adults in the United States who are homebound; another 5.3 million are unable to leave their homes without help.² Disproportionately burdened by multimorbidity, functional impairment, and low social capital, these individuals are not engaged in PCOR. We recently completed a PCORI-sponsored project to engage homebound older adults and their caregivers as Stakeholder Advisors to create a patient-centered research agenda for the field. On completion of the project, we explored the potential benefits or harms from participating as a PCOR Stakeholder Advisor.

Methods

Eight homebound older adults or caregivers were recruited through 2 home-based medical care practices. We used Zoom

videoconferencing on modified tablets designed for older adults (Grandpads) to interact with Stakeholder Advisors in 8 monthly meetings. We provided education and training on research in general and PCOR and guided them in developing research questions. Over the course of the meetings, the Stakeholder Advisors developed a research agenda for the field of home-based medical care consisting of 14 research domains and 127 research questions. One month after the final meeting, participants completed a telephone survey to evaluate the impact of participation using a 5-point Likert-type scale (Table 1). This work was approved by the Institutional Review Boards of both institutions.

Results

During meetings, Advisors anecdotally attributed an unexpected sense of purpose, reduced loneliness, and a new feeling of connection to their participation and expressed a wish that the project and connection could continue after the study period. One participant reported feeling “joy to be part of something, know you aren’t alone.” Seven of 8 Stakeholder Advisors completed the evaluation survey (1 was hospitalized and unable to complete). All respondents reported being very satisfied with their experience and all reported being likely or extremely likely to recommend taking part in research to others (Table 1). All agreed or strongly agreed that it improved their mood; 5 of 7 reported that it built their confidence and made them feel less lonely. No participants reported feeling that the researchers were too nosy, participation was a burden, or feeling relieved that the project was over. All participants expressed a wish to be involved in future research, and 6 of 7 respondents planned to remain in contact with other stakeholders they “met” virtually during the study.

Discussion

During a project to develop a research agenda for the field of home-based medical care, we found that research participation conferred an unexpected therapeutic benefit to homebound patients and their caregivers. This effect has previously been documented as a by-product of qualitative research.^{3,4} To our knowledge, this is the first time therapeutic benefit has been documented in a stakeholder engagement project in the homebound. In this vulnerable population, participation in research was not burdensome; in fact, it gave participants a sense of purpose and belonging and reduced isolation.

Inclusion of persons with disabilities on advisory and review panels is federally mandated,⁵ and starting in 2019, the National Institutes of Health also mandated the inclusion of participants of all ages in research.⁶ Our project provides potential methods to facilitate this through videoconferencing using modified tablet technology. Homebound older adults are a particularly vulnerable segment of our aging population who are at high risk for social isolation and loneliness.^{7,8} Our work highlights additional benefits that their inclusion in research may bring by addressing and reducing unmet social needs and thus providing additional justification for their inclusion. Our success in engaging a hard-to-reach population and the benefits that we observed in this small sample warrant further study.

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