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Ageing Population

Lessons From the "Very Old Intensive Care Patients" (VIP) Project, H. Flaatten, B. Guidet, D. deLange

In Search of a Crystal Ball: Predicting Long-term Outcomes in Critically Ill Older Adults, S. Jain, L. Ferrante

Nutritional Management of the Critically Ill Older Adult, O. Tatucu-Babet, K. Lambell, E. Ridley

Unmasking the Triumphs, Tragedies, and Opportunities of the COVID-19 Pandemic, *J. Patel, D. Heyland*

What Intensivists Can Learn From Geriatric Medicine, A. Reid, P. Young

Ageing and Critical Illness: What Does Quality Care Look Like? C. Subbe, C. Thorpe, R. Pugh

Lessons from COVID-19: ICU Preparedness, Ethical Issues and Digital Congresses, *JL Vincent*

Predicament Prevention for Pandemics. A. Michalsen

Challenges in the Management of Severe SARS-CoV2 Infection in Elderly Patients, O. Perez-Nieto, E. Zamarron-Lopez, M. Guerrero-Gutierrez et al.

Vitamin D in Critical Illness – Fifty Shades of VIOLET, K. Amrein, P. Zajic, M. Hoffman et al.

Angiotensin II in Post Cardiopulmonary Bypass Vasoplegia - The Experience So Far, N. Cutler, J. Signorelli, P. Wieruszewski et al.

Promising Techniques in Sepsis After Cardiac Surgery, G. Paternoster, Á. Nagy

Microtools to Identify and Resuscitate Microcirculatory Dysfunction in Critically Ill Patients, M. Hilty, C. Ince

The Future of Critical Care: The Human Capital, S. Ho, A. Wong, A. Butnar, M. Malbrain







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Unmasking the Triumphs, Tragedies, and Opportunities of the COVID-19 Pandemic

The COVID-19 pandemic has resulted in many changes to society and the

practice of critical care medicine. Perhaps now is the time to address defi-

ciencies in communication and decision-making that impact quality of care

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The COVID-19 pandemic has created a juxtaposition of triumph and tragedy. In triumph, the pandemic has metaphorically brought humans together like nothing else we have observed in recent times. The international community has been mobilised to provide the best patient care while simultaneously protecting health care workers by identifying solutions to local problems like workforce and resource shortages. Research priorities have shifted to rapidly test novel therapies, to identify a vaccine, and to establish 'best practices' for managing patients with COVID-19. With temporary obscurity of the electronic health record, doctors and other healthcare providers are talking with one another. The chatter is ripe with novel clinical observations and teeming with pearls and stories of how individuals and healthcare systems are innovating during a crisis. Thanks to social media, many communities, industries, and organisations have banded together to procure personal protective equipment (PPE) for front-line healthcare workers.

provided to older patients with serious illness.

In tragedy, over 25 million people have been infected and the death toll continues to climb, reaching nearly 850,000 worldwide, and unfortunately, older individuals bear the burden of severe disease, hospitalisations, and mortality (Johns Hopkins University 2020). Outcomes data demonstrate afflicted hospitalised individuals 80 years of age or higher survive less than 15%, and survivors often require more than three weeks of mechanical ventilation and prolonged hospital stay (Cummings et al. 2020). Pre-COVID-19, longitudinal post-critical illness follow-up studies suggest only 25% of older patients return to pre-critical illness level of functioning while 25% endure a significant reduction in their quality of life and functional status and the remainder will die (Heyland et al. 2016a). Not yet available, but longitudinal outcomes data from survivors of COVID-19 related critical illness are likely to be grim owing to the prolonged nature of illness. Death, while tragic, may overshadow the real tragedy, which is dying (or surviving) in a personally unacceptable manner. Here, we cast a light on problems with communication as it relates to decision-making for older individuals suffering from critical illness (no communication, insufficient communication, and ineffective communication) and how the COVID-19 pandemic has further impaired the decision-making process by

serving as a barrier to timely and effective communication. We offer pragmatic tools to enhance the decision-making process to ensure the older patient with COVID-19 disease transitions through the healthcare system in a personally acceptable manner.

Caring for critically ill patients with COVID-19 disease has called for clustering care, preserving personal protective equipment, limiting interactions with patients, and prohibiting visitors into an ICU. The intended consequences of these measures are to protect healthcare workers and limit the spread of SARS-CoV-2 virus. The unintended consequences are unknown. However, communication between the healthcare team and families may be sub-optimal. Due to the prohibition of visitors, families are updated via telephone and unable to witness their loved one physically and emotionally suffering. Consequently, decision-making is marred and incomplete, without consideration of the subjective bedside experience gained by families, and decisions made with incomplete information opens a pathway for medical errors to occur, including the receipt of unwanted treatments.

Reviewing the consequences of inadequate communication from the pre-COVID era may provide insight into the magnitude of the problem. For example, older hospitalised patients were interviewed to identify their values and preferences for CPR and

compared those preferences to CPR orders in the medical chart (Heyland et al. 2016b). The chart indicated the patient prescribed CPR when, in fact, the patient did not identify it as a preference on average 35% of the time and this error rate ranged in 14-82% of hospitals surveyed. These data suggest older patients had the potential to receive a life-sustaining therapy (CPR) that was unwanted. In another study, families of 600 incapacitated patients aged 80 or older were interviewed throughout the patients' ICU stay. Families were interviewed to elucidate patients' underlying values and preferences. Preserving comfort and 'to suffer as little as possible' were the most common responses (Heyland et al. 2015). In fact, 24% of families expressed that the preferred medical treatment plan be 'comfort measures only.' Yet, all the older patients had been admitted to an ICU for aggressive treatments that increased their pain and promoted discomfort. Just over 50% of families acknowledged that a doctor had talked to them about treatment options. Approximately half of these older patients died in the hospital, on average, after two weeks of intensive care. Families were most dissatisfied with communication and decision-making and the amount of 'control' they had over what happened to their loved one.

Arguably, these results suggest the health care system's decision-making superseded patients' and critical care services served to prolong the dying experience, which seems inconsistent with a 'quality finish' from the patient's point of view. Finally, by analysing audio recordings of approximately 250 patient-clinician interactions in the ICU setting, Scheunemann and colleagues provided us with greater insights into how values and preferences are elicited from family members of critically ill patients (Scheunemann et al. 2019). Overall, 63% of family conferences contained no information exchange or deliberation about patient values or preferences and clinicians made treatment recommendations informed

by patient values and preferences in less than 10% of the conferences. These results suggest ICU family conferences to establish treatment plans often lack important elements of shared decision-making and 'patient-centred care.'

Overall, these data suggest poor-quality communication negatively impacts decisionmaking, which can lead to overutilisation of ICU services for older individuals who did not want them in the first place, or

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who, once in an ICU, had their dying experience unnecessarily prolonged, and thus, the ICU experience merely served to enhance discomfort and suffering. Not only do unwanted treatments harm patients and add stress on families, but during the COVID-19 pandemic, they (unnecessarily) expose health care providers to a greater risk of SARS-CoV-2 virus transmission. For some older patients, protracted critical illness represents a far worse state than death and data suggest many older individuals would rather choose conservation and dignity-preserving treatment pathways in lieu of aggressive supportive care system technology when faced with serious illness (Rubin et al. 2016). For older persons with SARS-CoV-2 infection requiring critical care services, the disease state has left them in isolation, tethered to machines, at-risk of never speaking again nor hearing a familiar voice or seeing a

recognisable face, which for many may be an unacceptable way to live or die. When the COVID-19 pandemic settles, it will be unclear how many older critically ill patients with SARS-CoV-2 infection will have received a life-sustaining therapy when their values and preferences would have suggested otherwise, merely due to inadequate or ineffective communication.

Fortunately, triumph and tragedy converge on opportunity. In continuing to triumph, when the COVID-19 pandemic dust finally settles, perhaps the exercise in masking and physical distancing will stoke and sustain a collective yearning for human connection, where we seize opportunities to build bridges, instead of silos, to enrich our lives through meaningful interactions with our families, colleagues, and communities. In remediating the tragedies, the pandemic presents us with opportunities to innovate. Not isolating SARS-CoV-2 infected individuals increases the risk to healthcare workers and the burden on healthcare systems, and thus the tragedy of dying alone may be inevitable. Many centres have installed bedside videoconferencing technology for loved ones to hold virtual bedside vigils, and where available, compassionate use of PPE for families to visit dying patients. As the pandemic rages, addressing inadequate communication and incongruent decision-making may be the most important opportunity to tackle, to ensure healthcare systems do not breach the boundary of patients' values and preferences. The core of patient-centred care asks: how do we ensure right treatments are applied to the right patient at the right time to derive the right benefit?

To address inadequate communication surrounding decision-making, some experts call for more 'end of life' conversations or the traditional form of advance care planning (Rubenfeld 2020; Shajahan 2020). Unfortunately, these approaches are likely not helpful during the COVID-19 pandemic. Planning for death under conditions of certainty (like advanced cancer) is not

the same as planning for unexpected and serious illness (like SARS-CoV-2 pneumonia), where prognosis may be uncertain (Heyland 2020).

The basic tenets of clinical decisionmaking include providing information on the prognosis and possible treatments, learning about patients' personal values and preferences, and using language of shared-decision making. We do not believe "in the moment" clinical decision-making is as simple as asking patients their values and preferences. We have previously shown eliciting values in an open-ended, unconstrained manner, like what often happens in the real world, whereby the patient does not explicitly see the conflict between competing values, may not be helpful in determining the best plan of care for seriously ill patients (Heyland et al. 2017). Lay people's expressed values often conflict with each other and bear little relationship to their preferences for medical care (Heyland et al. 2017). A statement like, "My mom is a fighter" could imply she should be given every chance at curative treatment without acknowledgement of risks and alternatives. What is not transparent in such a statement is the collateral damage of this value-driven choice: survivors of prolonged critical illness experience significant reductions in their physical, psychological, and cognitive functions which impair quality of life. Some patients even consider survival from critical illness a health state 'worse than death' (Rubin et al. 2016). The early experiences with SARS-CoV-2 infected patients requiring critical care services demonstrate their mortality rate exceeds 50%, and survivors often require weeks of mechanical ventilation (Livingston and Bucher 2020; Wu and McGoogan 2020). We do not know the long-term health outcomes of survivors of critical care with SARS-CoV-2 pneumonia but early experiences suggest survivors will be similar to other survivors of prolonged critical illness and will experience significant reductions in their quality of life (Servick 2020). For

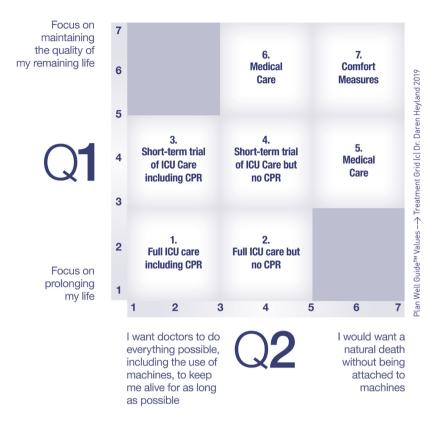


Figure 1: Values-Preferences Grid
The cell that is at the intersection to the answers to the values question may be indicative of the medical treatment plan that might be right for the patient.

many older patients or those living with chronic or life-limiting illnesses and barely maintaining their independence, further reductions in quality of life may not be an acceptable form of living.

Next, many healthcare providers may unfortunately treat patients as informed consumers and, after describing the various treatment options, ask them "What do you want us to do?" Such a strategy violates the principles of shared medical decision-making where most people want to share in decisional responsibility with their healthcare providers. Moreover, most people are ill-informed about the risks, benefits and possible outcomes of lifesustaining treatments and should not be treated as informed consumers.

We suggest a new approach to planning for serious illness called Advanced Serious Illness Preparations and Planning (ASIPP), which aims to prepare patients (or their surrogates) for 'in the moment' clinical decision-making (Heyland 2020). Ideally, before a crisis, ASIPP calls for asking patients their values in a way that highlights the trade-off with competing values. Questions like, "Are you the kind of person that wants medical treatments to focus on prolonging your life or enhancing the quality of your remaining days?" and "Are you the kind of person who prefers a natural death or are you willing to accept the use of machines, such as breathing machines, to prolong your life, for as long as possible?" allows doctors to link stated values to medical treatments that could be proposed to treat serious illness in a reliable and transparent way, thus reducing medical errors (Figure 1) (Heyland 2020). Complementary decision aids, such as the Plan Well Guide, are useful in helping

patients clarify their authentic values and informing patients about the risks, benefits and possible outcomes of these different treatment options and have been shown to improve the quality of serious illness decisions (Heyland et al. 2020).

Once informed, asking patients, "Are you willing to put up with the risks and possible outcomes of critical care treatments?" will help doctors then propose the 'acceptable' treatment plan for the seriously ill patient using the language of shared decision-making. In a recent randomised clinical trial, this approach improved decision-making quality, patient and physician satisfaction, and reduced time physicians spent on their interactions with patients compared to usual care (Heyland et al. 2020). If there is not time to 'prepare' the patient in advance of clinical decision-making, as often is the case, the Plan Well Guide provides a worksheet, which enables clinicians to optimally elicit values and transparently link them to acceptable treatment preferences (Plan Well Guide 2020). A similar decision-aid tool aimed at family members of critically ill patients, called "My ICU Guide," has been developed and undergoing clinical evaluation (Van Scoy et al. 2017).

In the midst of the COVID-19 pandemic, addressing deficits in serious illness communication and decision-making may seem like a far-fetched idea. We argue, if our aim is to reduce the demand on precious and finite critical care services, there is no better time than now to address these deficits. Importantly, the crucial conversation may ensure patients get the care that is right for them, which may preserve autonomy, enhance justice and fairness of allocation, and reduce the potential to minimise exposing health care professionals to the SARS-CoV-2 virus. The alternative, and foregone conclusion, is the "rationing conversation," where only patients who have the best chances of surviving are going to get ICU care. We worry the rationing conversation is threatening to lay individuals. They fear beneficial treatments may be withheld from them or their loved ones and that their lives are unworthy of saving. We believe a focus on efforts to restore 'patient-centredness' to health care decision-making ("What are your authentic values and informed treatment preferences?") would be welcomed and embraced, as opposed to the rationing conversation. Perhaps, by prioritising 'patient-centred' care and optimal communication and decision-making practices, we could reduce unwanted ICU admissions, preserve resources, and delay, minimise, or even omit the 'rationing' conversation to ensure the right patient receives the right treatment at the right time to derive the right benefit.

Conflicts of interest

Neither author has any conflicts of interest to report. ■

Key Points

- The COVID-19 pandemic has created a juxtaposition of triumph and tragedy.
- Poor-quality communication negatively impacts decision-making, which can lead to overutilisation of ICU services for older individuals.
- Limiting the spread of disease is the intended consequence of quarantine, strict hospital isolation, and prohibiting hospital visitors during the COVID-19 pandemic. However, the fault lines from fractured communication during the pre-COVID era may deepen during the COVID-19 pandemic and lead to the unintended consequences of impoverished decision-making and improper and perhaps unwanted resource
- Now is the time to put new processes and procedures in place to improve communication and decisionmaking with seriously ill older patients regarding the use of life-sustaining treatments.

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