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ANALYSIS



Intensive care: balancing risk and benefit to facilitate informed decisions

More efforts are needed to engage with the wider healthcare community and the public about what intensive care can—and can't—achieve, say **Jamie Gross and colleagues**

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Changing population demographics and improved chronic disease management have led to a growing proportion of patients being admitted to intensive care units (ICUs) with co-existing chronic disease and frailty.¹² This has contributed to greater demand for intensive care services, which is steadily increasing at a rate of about <u>4% a year</u>.³ Limited bed capacity in ICUs results in cancelled urgent operations and in non-clinical transfers to other such units.⁴ Given that intensive care is an expensive resource with healthcare costs for survivors that commonly extend well beyond admission,⁵ this trend is unlikely to be sustainable. Crucially, for patients with chronic disease and established frailty, undergoing the burden of a prolonged stay in intensive care for an acute illness may not deliver sustainable benefit,⁵⁶ with the important caveat that the definition of "benefit" is a very individual thing.

Can anything be done to tackle the mismatch between supply and demand for intensive care? Perhaps part of this increasing demand is due to unrealistic expectations of what medicine—in particular intensive care—can achieve, along with an underappreciation of the burdens of both a critical care stay and future survivorship.⁷ One approach might be to increase public awareness about what admission to intensive care could mean for patients and their families, to facilitate informed decision making.

Pitfalls of intensive care

The onset of critical illness can be a highly stressful time for patients and their families. Most people do not express their wishes for the management of a future hypothetical life threatening crisis, so when a patient is incapacitated by acute illness relatives are often faced with the burden of trying to determine what that person would have wanted. Adding this to the confused framework around surrogate decision making increases anxiety for all. No prognostic scoring systems currently available can reliably predict meaningful individual patient outcomes, so, understandably, the default pathway is often to give that person the perceived best chance of "survival." This is further compounded by the historic view held by medics, patients, and relatives that survival is the over-riding goal that defines success or failure of medical intervention.

For most patients admitted to intensive care, the outcome might initially seem favourable. But the life sustaining treatments provided might come at a cost to patients and to family members. This is commonly overlooked or underappreciated at the time of considering whether admission is appropriate.

Organ support (particularly for those receiving mechanical ventilation) is commonly associated with discomfort, pain, delirium, and delusional perceptions as patients drift in and out of consciousness brought about by sedation and the effect of acute illness.⁸ Delusional perceptions contribute to frightening and distressing sensory experiences that may be re-experienced and may contribute to the development of post-traumatic stress disorder (PTSD).⁹ Any prolonged stay in intensive care may also result in physical weakness, which can persist long term¹⁰ and can coexist with lasting cognitive impairment and memory problems, anxiety, depression,¹¹ and PTSD.⁹ These may all contribute to a poorer quality of life, which may never return to that experienced before being admitted to the ICU.¹²⁻¹⁴ These major adverse effects can affect anyone, irrespective of age, frailty, and comorbidity. They may not be well recognised among non-intensive care healthcare professionals and are generally not understood by the public.

Families of patients in intensive care can experience fear and helplessness, especially when survival is uncertain. They may then begin to recognise possible long lasting physical limitations, psychological or cognitive impairment, and requirements for support after their relative leaves hospital. Anxiety, depression, and PTSD in family members may persist long after the patient is discharged from the ICU or has died.¹⁵ Should the patient survive beyond hospital discharge, families are often faced with the added strain of providing most of the support in the community.¹⁶

To admit or not to admit?

Deciding which patients are likely to benefit from admission to the ICU is a daily challenge for intensivists. Patients referred with signs of impending or established organ failure should undergo an ethically guided decision making process. This should assess whether the patient has a reversible acute condition or progression of chronic disease that is unlikely ever to improve; the patient's ability to recover medically and functionally based on their physiological and functional reserve; and, as far as can be determined, the patient's values and wishes. These form the basis of reasoning whether the benefits of treatments offered on the ICU outweigh the burdens, and, if not, investigating what alternative care is available. Such care might include antibiotics for sepsis on the ward or even mildly invasive cardiovascular support on the high dependency unit to give the patient a chance of survival, but with the understanding that further escalation of organ support (such as mechanical ventilation) in the event of further deterioration is a "step too far" for some, where harm is likely to outweigh benefit. In these situations, when active treatment to reverse any acute condition has failed, a focus towards palliative interventions might be more appropriate to ensure comfort and a dignified death.

Frailty, physiological reserve, and the capacity to recover

Frailty is an increasingly recognised multidimensional phenomenon (encompassing physical, psychological, cognitive, and social impairment) and relates to a state of increased vulnerability caused by illness or age related decline in the body's physical and psychological reserves.¹⁷¹⁸ Older people with frailty can live for many years if free from illness but are at risk of a dramatic decline in health and functional status from an apparently minor stressor, such as a fall or infection.¹⁷ Frailty affects 14% of people over the age of 60, and prevalence increases from 6.5% in those aged 60-69 to 65% in those aged 90 or over in England.¹⁹ The prevalence of frailty in ICUs exceeds 40% in patients over the age of 80^{20} and consistent evidence shows that frailty is associated with lower survival and higher hospital re-admission rates.^{21 22} Frail patients that leave the ICU are less likely to be discharged home and often have worse physical and psychosocial outcomes (compared with baseline and overall) than their non-frail counterparts, which translates to a poor quality of life for individuals and increased demand on health and social care resources.^{21 22} Trajectory of frailty may also be important; evidence indicates that a more rapid progression of frailty or decline in functional status is associated with worse outcomes above and beyond frailty itself.²³

This doesn't mean that frail elderly people should never be admitted to ICUs; many survive without any long term burden, particularly if their illness and stay in the ICU are short lived.²⁴ But careful consideration is needed, as their physiological reserve and ability to recover from more prolonged critical illness are diminished, which has major implications not just for survival but also for rehabilitation.^{21 22} Although medical teams have the final decision on admissions to ICUs, patients' views are very important, as they (and their families) will have to live with any potential consequences, which may be acceptable to some people but not to others. Unfortunately, patients are rarely consulted about their wishes for intensive care—only 12.7% in a French study cohort²⁵—despite evidence showing a decreased willingness of elderly patients with severe chronic disease to undergo highly burdensome therapy or to risk severe disability in order to avoid death.²⁶

Yet critical illness often occurs when patients lack capacity to have meaningful discussions about their wishes for care, so efforts should be focused on engaging with elderly, frail, and multimorbid patients at an earlier stage. This may include guiding them to more easily accessible information about the potential hazards of intensive care and encouraging them to discuss their wishes with their relatives or primary healthcare professional. The outcome of such discussions may vary substantially between individuals, which is likely influenced by family and social circumstances, religion, values, cultures, and beliefs, and these are important considerations.

The last phase of life

Since publication of the UK government's end of life care strategy in 2008,²⁷ much effort has been made to improve the quality of such care, with a focus on ensuring that patients receive the right care in the right place and at the right time. In Scotland, the Realistic Medicine programme²⁸ challenges doctors to look for ways to minimise burden and harm from overinvestigation and overtreatment and to ensure that patients are at the focal point of decision making. In parallel, national pilots have aimed to improve the training of healthcare professionals in holding such conversations (such as the serious illness conversations guide²⁹), the process of acute care where recovery is uncertain (such as the AMBER bundle³⁰), and the documentation of patient's wishes across healthcare settings (such as **ReSPECT³¹** and Coordinate My Care³²) so that they are known before the onset of acute illness and are easily accessed by any treating clinician. The Speak Up³³ and Choosing Wisely³⁴ campaigns, originating from Canada and the United States, respectively, have been designed to increase public engagement and support people to explore options and openly communicate and register their wishes about future care. These approaches, which fit under the umbrella of advance care planning, have been shown to not only improve patient and family satisfaction in the last phase of life³⁵ but to also reduce healthcare costs by preventing unwarranted hospital and ICU admissions and reducing length of stays in the ICU.³⁶

Information relating to intensive care could be introduced for some patients in advance care planning discussions, which may also include those relating to cardiopulmonary resuscitation, as "successful" resuscitation efforts almost always result in admission to an ICU. With this come fresh challenges, particularly as few healthcare professionals involved in advance care planning have a background in intensive care. Conversely, intensive care clinicians may not be familiar with the process of advance care planning; their first involvement in patient care is usually at the time of crisis. Thus, future cross specialty training should be explored, giving healthcare professionals the right information to disseminate to patients and helping to empower patients to openly explore and communicate future treatment preferences.

In addition to training, more research is needed to accurately identify which patients are least likely to benefit from intensive care, preferably at an earlier stage in the community setting; this was identified as a key topic in a recent research priority setting exercise.³⁷ Identifying patient pathways and interactions with health and social care services in the months that lead up

to a hospital or ICU admission would determine opportunities where active engagement could be explored. Perhaps the greatest challenge relates to how and when information is best shared with the public about the benefits and burdens of hospital care (including intensive care) and how health services should be restructured to support patients and their families to make informed choices and decisions about their wishes for future care, which is reviewed on a regular basis. This is one of the key areas for policy change set out in the Institute for Public Policy Research's *End of Life Care in England* briefing paper,³⁸ the goals of which align with improving quality of care while reducing the cost of care towards the end of life.

Key messages

Intensive care can be associated with substantial physical and psychosocial burdens for patients and may have adverse psychological consequences for families

Potential harms of intensive care are commonly overlooked in times of crisis when timely decisions need to be made about escalation of care

Frail, elderly patients have poorer outcomes after a stay in an intensive care unit (ICU) and are rarely consulted about their wishes for life sustaining treatments

The decision to admit a patient to the ICU should include assessment of whether the likely benefits outweigh the risks

Where possible, patients and their families should be involved in the decision making process

Earlier information about intensive care practices and outcomes may help patients make informed choices about their future care

Contributors and sources: JG is a consultant intensivist with a research interest in determining which patients benefit most from intensive care and improving patient autonomy surrounding decisions relating to ICU admission. BW is a patient/family representative who has had personal experiences of ICU as a relative. He was chairman of the Patients and Relatives Committee of the Intensive Care Society (ICS) and is an independent member of several trial steering committees. He also served on the NICE guidelines group that published the guideline on rehabilitation after critical illness in adults. PF is a consultant geriatrician and is end of life lead for the British Geriatrics Society. SJB is a consultant in intensive care medicine and professor of critical care and is former president of the ICS, with research interests in understanding and optimising long term outcomes after critical illness. He is chief investigator of several clinical studies, both locally and nationally, and led development of the NICE guideline on rehabilitation after critical illness. This article arose from discussions on treatment escalation plans, managing uncertain recovery, improving end of life care, promoting advance care planning and managing frailty. We all felt that the burdens of ICU care were rarely discussed even when advance care planning was being done and therefore patients and relatives were not being given the information required to make the right choices for them before an emergency arose.

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