
Enhancing patient/family engagement in the ICU



The call for meaningful patient and family engagement in healthcare and research is gaining impetus. It emanates from increased expectations of patients and families to participate in shared decision-making, greater emphasis on patient and family-centred care as a healthcare objective, and the democratisation of medical knowledge through information technology which provides patients and families with access to ever increasing communication about health matters, says an article in press in the *American Journal of Respiratory and Critical Care Medicine*.

"Increasing emphasis on patient and family-centred care in critical care and awareness that patients' and families' experiences in the ICU have long-term effects upon their health and well-being have incited interest in engagement as a means to improve their experiences and outcomes," explains the article.

Notably, healthcare institutions and research funding agencies now strongly encourage clinicians and researchers to work actively with patients and their families to advance clinical care and research. Engagement is increasingly mandated by healthcare organisations and is becoming a prerequisite for research funding.

Moreover, the literature suggests support and enthusiasm for engagement. However, as the article points out, most studies of critical care engagement have focused on individual encounters (vs. involvement at an organisation level) and direct assessments of patient experiences are scarce in number.

Despite international guidance documents on engagement in research, the article notes, only few studies report how patients and families were engaged or demonstrated impact on the conduct and quality of the study.

Engaging families in care can improve health literacy, self-care in chronic disease management, clinical decision-making, and patient safety. In the ICU, the article reiterates, engagement has been associated with improved caregiver psychological recovery and well-being, reduced post-traumatic stress disorder and depression, and increased satisfaction with care.

At the individual level, patients and families most often engage with healthcare providers by stating their preferences, goals, and values during shared decision-making. "Recognising the complex relationships and dynamics that exist between patients, families, and the multiprofessional ICU staff involved in patient care, special consideration is needed to ensure that patients and families have a clear understanding of the available care options to engage decision-making," the article explains.

At a system level, Patient and Family Advisory Councils, in which patients and families formally partner with healthcare teams on practice and policy decisions, have emerged to increase patient and family influence on ICU organisation and policies. Many of these groups, according to the article, have published their accounts of these experiences to foster stakeholder engagement in other ICU settings.

Despite increased focus on standards for patient and family engagement in research, there is little guidance regarding which engagement strategies have the greatest potential to impact favourably on research processes.

To advance engagement, the article urges clinicians and researchers to develop the science behind engagement in the ICU context and demonstrate its impact on patient and process-related outcomes.

"Despite the call for increased patient and family engagement, the science behind 'how to engage' patients and families is not well-developed. Although engagement has been shown to have positive effects on health outcomes, patient safety, quality of care, and healthcare costs in other settings, limited data exist to demonstrate whether similar benefits can be realised in the ICU. Future ICU research should aim to explicate the impact that engagement activities have on both patient and process-related outcomes," the article emphasises.

Source: [American Journal of Respiratory and Critical Care Medicine](#)

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