## Transforming Care for the Critically III and the Dying





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Pioneering clinical studies that have changed end of life care.

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Most people would find the pressures of the intensive care unit overwhelming: the hospital's sickest patients are vulnerable to complications and death, and patient lives are at stake. Dr. Deborah Cook, however, thrives in the intensive care unit as a clinician scientist, bringing compassionate care to patients and families every day. She takes her work a step further by teaching and performing research in the intensive care unit as well, where she translates her experience in the field to research data that is used to improve patient care.



Dr. Cook works as a clinician scientist – she is a trained medical doctor but performs scientific research as well. She brings her experience in the intensive care unit to patient-centered research to provide better care to critically ill and dving patients. This unique opportunity to perform two roles has made her both a better clinician and scientist. Although she loves her work, there are still challenges to working in the intensive care unit; it is fast-paced and dynamic, and tensions can run high given the pressures of caring for critically ill patients. Critical care patients are supported by a team made up of many different professionals; bedside nurses, respiratory therapists, physiotherapists, pharmacists, dieticians, spiritual care providers, social workers, and physicians each make up an important part of the team. Patients benefit from the ideas and expertise of a wide range of individuals with diverse perspectives, and the teamwork involved in supporting patients has made Dr. Cook's job incredibly rewarding.

Dr. Deborah Cook felt drawn to the medical field because she sees the ability to restore health as incredibly impactful. Specifically, she was interested in critical care because these patients are the sickest in the hospital. When patients are critically ill, they are more vulnerable to complications and can die. She also saw a massive knowledge gap in terms of research; while there is plenty of animal and physiology research, patient-centered research in this field is lacking. When asked about the most fulfilling part of her work, Dr. Cook immediately said that it was looking after patients, as it is "an incredible honour to care for them at their most vulnerable."

Dr. Cook has played a key role in research of advanced life support, prevention of complications, research ethics, and end-of-life care. Unlike many scientists who focus on one specific problem, organ, or disease, Dr. Cook's research is highly multi-faceted. The unifying goal of her research is to enhance the quality of life and the transition to death for critically ill patients. She takes a two-pronged approach to supporting her patients. Firstly, she focuses on prevention of additional complications and death for patients while in the intensive care unit, and secondly, she focuses on how life support is administered or withdrawn as appropriate.



There are various methods that Dr. Cook and her team use to perform research in the intensive care unit. They use randomized clinical trials to test specific interventions against a placebo. In this type of research, some participants will be given the intervention, while others will receive a placebo, which is a substance or treatment known to have no medical effects. Another type of research she performs is observational studies. In these studies, researchers simply observe patients and collect their data in order to better understand the frequency of problems or interventions, risk factors, and consequences. Finally, Dr. Cook and her team also use surveys of practitioners, patients, and families. Survey data can be used both qualitatively and quantitatively to better understand different perspectives and get a comprehensive overview of the research topic.

Several avenues of her research include highly specific methods that improve advanced life support and reduce the likelihood of complications for intensive care unit patients. Another element of patient-centered research that Dr. Cook has investigated is research ethics. It is imperative that participation in research studies is ethical. When critically ill patients are eligible for participation in research studies, a coordinator will often need to speak to families and go through the process of obtaining informed consent. Consent must be freely given, well-informed, and is ongoing, so participants and their families can withdraw their consent to participate at any time. Dr. Cook has studied the consent process for critically ill patients and helped to determine the appropriate steps involved. Additional research ethics considerations are needed when participants are enrolled in more than one study at a time to ensure the studies will not conflict. Furthermore, Dr. Cook has highlighted the importance of a coordinated approach with the patient's clinical team, so they are providing the best care while obtaining data for the study.



Another of Dr. Cook's many endeavours is end-oflife care, which refers to the medical care and support provided in months, weeks, days, and hours surrounding death. Dr. Cook's favourite focus of teaching is end-of-life care, and she seeks to keep humanity alive amongst the technology. A substantial proportion of intensive care unit patients don't survive, and in working with these patients, Dr. Cook had a desire to learn more about them beyond their critical illness. She ensures that the care is patient- and family-centered, and always compassionate. Dr. Cook recognizes that additional care is needed for the loved ones of the dying patient and ensuring that patients and their families receive the extra care that they need, which can include physical comfort, mental or emotional needs, spiritual needs, and practical tasks.

Her first-hand experiences working in end-of-life care led to the creation of the 3 Wishes Program, which started as a project at a single hospital and has since expanded to many hospitals internationally. This program helps to create memories and celebrate and honour the lives of dying patients through the fulfillment of small but meaningful wishes. The 3 Wishes Program has shown that it doesn't require a large financial cost or a lot of time to improve the end-of-life experience for patients and families. In fact, the mean cost of patient's participation in this project was only \$27, and the impact of these actions was significant in supporting patients and families during an emotionally challenging time. Sometimes, wishes are designed to create a memory for the patient's loved ones to remember them by, such as a fingerprint keychain. Other wishes center more around creating a comfortable environment for the patient at the end of life, for instance decorating the room, bringing a bouquet of flowers, or playing music during their final moments. When asked about what some of the favourite wishes Dr. Cook had been a part of, she reiterated that it is the "simplest things that matter the most" and highlighted a wish where the family pet was brought in to curl up on the bed of the patient, and the joy and comfort that it brought them. Using surveys completed by the patients' families and members of their medical team, Dr. Cook has shown the incredible value of the program and its efficacy. The 3 Wishes Program brings together patients, their families, and medical teams to honour people's lives and bring peace to their final moments.

Another recent expansion in end-of-life care has been the increase in video technology during the COVID-19 pandemic. Compassion is at the forefront of Dr. Cook's practice in the intensive care unit, but during the COVID-19 pandemic, the ability to provide patient- and family-centered care was severely limited when visitor restrictions were imposed in hospitals. Videoconferencing technology helped to fill this gap in connection, and Dr. Cook's research into its implementation identified both drawbacks and benefits to videoconferencing technology in end-of-life care. The major drawbacks included inequitable access to technology, challenges for families setting the technology up, less authentic interactions with missed physical and non-verbal communication, and additional time required of staff. Despite these drawbacks, videoconferencing was demonstrated to be an excellent tool to support patients and families when in-person visits were limited. It was often the best option for creating moments of connection given the circumstances. Videoconferencing does bring more connection compared to other methods such as telephone calls because patients and families can still experience visual cues to connect with each other. The results of this research showed that while clinicians are hesitant to use videoconferencing technology to replace in-person interactions, it certainly plays an important role in keeping patients and families connected when in-person visits are not possible.



Dr. Deborah Cook has had an immense impact on improving patient care in intensive care units across the world throughout her career as a clinician scientist. She highlights the importance

of teamwork in many of her successes. Not only is teamwork characteristic of the intensive care provided in a hospital setting, but it has also been crucial to transforming the field of critical care research. Dr. Cook praised Canada's community of researchers who prioritize collaboration ahead of competition, foster growth and leadership in early career researchers, and embrace diversity to make teams stronger. This has created a strong foundation for further research to be conducted, as the field moves towards more patient-centered largescale clinical trials and works to fill the gap in patient-centered intensive care research. Dr. Cook has played an integral role in clinical research that has changed the way medical teams care for critically ill patients. Her efforts have transformed our approach to clinical care research both in Canada and internationally, resulting in better care and support for critically ill and dying patients.