

*Special Issue in Honor of J. Randall Curtis, MD, MPH*

# J. Randall Curtis's Legacy and Scientific Contributions to Palliative Care in Critical Care



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## Key Words

*Critical care, palliative care, end-of-life care, interventions, communication, decision making, outcomes measurements, institutional culture*

## Introduction

J. Randall Curtis ("Randy") has had a profound impact on the culture and state of the science of palliative care in serious illness, particularly in the critical care setting. He has accomplished this by bringing rigorous and innovative empirical research into understanding and improving communication, decision-making, and culture around end-of-life care in the intensive care unit (ICU). His legacy extends far beyond his scientific contributions through the personal impact of his compassion, creativity, and visionary brilliance on the cultures of ICUs and hospitals around palliative care. The goal of this narrative essay of Randy's contributions to palliative care in the ICU extends beyond a review of his scientific contributions. Many of the characteristics which make him an extraordinary and beloved colleague and mentor are incompletely visualized through his publications. To gain additional insights, one of us (E.D.) interviewed several of Randy's colleagues and mentees to understand the relationships and inspirations that underly his career. Through these interviews, we highlight how his impact has broad ripple effects on generations of researchers and his indelible impact on the field of palliative care and critical care.

## Early Research Career Influences

Randy's motivations for a career in palliative care research arose from his deep conviction that we were not doing patients and families justice near the end of

life. He was drawn to the practice of critical care medicine for several reasons including the interprofessional teamwork that critical care required.<sup>1</sup> In this setting, he found a natural fit between this clinical work and his research goals of improving communication and support for seriously ill patients and their families. He first arrived to palliative care research through his interest and commitment to HIV/AIDS research, which arose from personal experiences with and a profound empathy and compassion for those affected by the disease. His early qualitative research identified barriers and facilitators to communication around end-of-life care in patients with AIDS.<sup>2</sup> This would inform his future work around quality of communication and in outcome measurements.<sup>3</sup> He found mentorship and encouragement from Leonard (Len) Hudson and Donald Patrick.

In 1997, Randy joined the Open Society Institute's Project on Death in America (PDIA) Faculty Scholars Program,<sup>4</sup> which Kathleen (Kathy) Foley, Director of PDIA, described as creating a cohort of clinicians, researchers, and educators who would, "be the Trojan horses within an institution to improve end-of-life care." At the time, critical care research was heavily focused on basic sciences, and physiology. Kathy described the state of the science of palliative care in the 1990s as:

"All of us who cared about end-of-life care knew these things mattered, but we had not convinced the rest of the world that they mattered...most of the

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deans in the medical schools could have cared less. There wasn't money to do this kind of work and we didn't have all the methodologies to do it well."

As such, PDIA was deeply influential for many of its scholars because as James Tulsy reflected, it was a place they found support and community "at a time when there were not many avenues for thinking outside of the box in medicine."

Randy came to PDIA already established as a rising star in critical care research. That same year, he won the Parker B. Francis Fellowship, a prestigious award in pulmonary research. This gave him the legitimacy to promote palliative care and qualitative research methods. Kathy reflected that this was important in allowing palliative care research to become accepted in the ICU:

"... as a respected intensivist, it was possible for him to open the door to understanding what the other factors were that were impacting care and to argue that the care wasn't good and that we weren't meeting the needs of these people. They were charting a new course in a field that was heavily medicalized and they were broadening the medicalized into a social cultural... model of palliative care. It was much more acceptable for Randy to get up at grand rounds and say, 'I'm going to talk about communication.'"

Maintaining his primary professional home in critical care, with leadership roles including serving as the president of the American Thoracic Society (ATS) in 2009, was important to bringing palliative care into critical care.

### ***Changing the Culture and Developing the Science of Palliative Care in the ICU***

Early in Randy's career, he was presented with an opportunity to edit the book, "Managing Death in the ICU: The Transition from Cure to Comfort" with Gordon Rubinfeld, who at the time was a Robert Wood Johnson fellow with Randy.<sup>5</sup> Gordon reflected, "Randy thought it would be a good idea, and as with many things, his advice about doing things that seem like they'd be fun to do with people you think would be fun (was right)."

This book, published in 2001, had an outsized impact on the broader culture and acceptance of palliative care in the ICU – an impact that Randy anticipated but Gordon did not: "I told Randy it would no doubt sit on the desk somewhere and gather dust, but I was wrong... it's turned out to be a huge deal." This book was the first to discuss palliative care in the ICU and the gaps in the field within specific diseases that had been less receptive to palliative care. Gordon described how authors in some sub-specialties initially asked why there was even a need for a chapter in their

field. These chapters became the first to consider, for example, what to do with implantable defibrillators when delivering end-of-life care.

One example of how this directly impacted a future mentee is how this book landed in the hands of Doug White, then a second-year critical care fellow at UCSF, "John Luce gave me that book and I was like, 'Look at this. This is worth studying'... that was my intro to the field. This is a topic that is a credible research topic and area of focus." Doug recalled it being difficult to convince some of his department leaders that this was an area that could be rigorously studied through empirical methods. This book helped convince Doug that they were wrong.

### ***Measurement to Advance the Science of Palliative Care***

In 1999, Randy was connected by Donald Patrick to Ruth Engelberg, who would become a long-time collaborator and co-director of the University of Washington (UW) End-of-Life Care research program. This was the start of a prolific collaboration that would span over twenty years and continues to this day. Their first projects together focused on developing outcome measurements including the "quality of dying and death" (QODD) and the "quality of communication" (QOC) instruments. Ruth described Randy's motivation coming from his realization during his qualitative work on the experiences near the end of life for people with HIV that, "it was really important to figure out how we measure this, because we're not going to move the science if we don't measure it."

Creating the QODD as an outcome measure enabled research on the determinants of high quality dying and to evaluate interventions that sought to improve the quality of the dying.<sup>3</sup> The QODD measured the "degree to which a person's preferences for dying and the moment of death are consistent with observations of how the person actually died as reported by others."<sup>6</sup> Data collected from QODD surveys helped empirically demonstrate that improved communication was associated with a better quality of dying. Subsequently Randy and Ruth focused on patient-centered outcome measures around quality of communication around end-of-life care, which was previously absent from the literature.<sup>7</sup>

### ***Understanding the Dynamics of Family Conferences in the ICU***

Randy's next work arose from a desire to see what was happening in the ICU around communication in family meetings. His paper on, "Missed Opportunities During Family Conferences about End-of-Life

Care in the ICU” drew from a rich qualitative dataset of 51 audiotaped family conferences.<sup>8</sup> This data set was seminal because it was the first empirical study that gave insight into what was actually happening in family conferences. He found that physicians missed opportunities to listen and respond to family, acknowledge and address emotions, and pursue key principles of medical ethics and palliative care.

Gordon recalled that the theme of “missed opportunities” was completely unexpected and not one they had thought to identify until it emerged from the data. He recalled how unusual rigorous qualitative research was in critical care medicine then, “It was just unheard of. And it wasn't done because no one thought you could get it published. . . . But Randy totally brought it to the fields of pulmonary and critical care and raised it to the point where people really understood its value.” This paper highlights a major thread that spans his career - his ability to connect and bring different methodologies into his work.

Ruth feels that this was one of their most seminal studies, in part because it was influential in its impact on other investigators. Randy was generous in sharing their data and methodologies which helped the next generation of researchers get established. Doug, for example, reflected:

“I read (the paper) and a light bulb went off . . . before looking at this paper and engaging with Randy, I had really been struggling to figure out methodologically how to pursue a line of research that was satisfying and clinically important, and also one that could sustain an academic career in medicine. . . . I look back on that first conversation as the starting point of the line of research that I have pursued that brings an empirical focus to things that have not previously had much empirical focus in terms of communication practices.”

This work was foundational to understanding decision-making between clinicians and families in the ICU. Doug and Randy went on to find that shared-decision making in the ICU was often incomplete and that higher levels of shared decision-making were associated with greater family satisfaction.<sup>9</sup> Studies like this laid the groundwork to show the value of shared decision-making in the ICU.

### ***Changing the Culture of End-of-life Care in the ICU Through Research, Education, and Mentorship***

After pioneering advances in outcome measurements and in the understanding the nature of family

conferences, Randy conducted several important trials to improve end-of-life care in the ICU. Some of these trials were negative, but the conclusions Randy drew from them reflect his ability to find valuable lessons regardless of whether a study is positive or negative. As Elie Azoluay, a long-time collaborator in France reflected on Randy's nuanced thinking,

“Randy always has a very strong qualitative eye and ear . . . in the way he listens to others. . . . He would maybe think about what changes (were made) at the bedside and what improved for family members and patients (in the study). . . . Randy understand that the impact of an intervention varies across settings. He understands that many of the studies that are considered negative. . . . could have been positive in other countries or settings.”

These trials also had a snowball effect on the culture of end-of-life care through Randy's influence on the next generation of researchers and educators who brought palliative care principles into the ICU setting and beyond. Randy's first major trial was a cluster-randomized trial of a quality improvement intervention that targeted multiple components to integrate palliative care into the critical care setting.<sup>10</sup> While the intervention did not improve quality of dying or family satisfaction with care and therefore, it was a “negative” trial, it created a robust dataset of over 2300 patients who had died in the ICU with several surveys and process measures, from which Randy's mentees could begin their careers in research.<sup>11–14</sup>

Another important trial that Randy led was a study that examined the effect of communication skills training for medical residents, subspecialty fellows, and nurse practitioners on the quality of communication with patients with serious illness.<sup>15</sup> They found that the simulation-based communication training (“Code Talk”) did not improve quality of communication or quality of end-of-life care when compared with usual education as assessed by patients, families, and clinicians. Despite having successfully changed clinician behaviors and improved communication as assessed by standardized patient encounters,<sup>16,17</sup> it was possible that patient-assessed outcomes may have been measured too far downstream to see an effect. Randy also suggested that patients and families may need to be trained to provide these kinds of skills assessments.

Erin Kross reflected that the trial and Randy's advocacy for communication skills training as an integral part of medical training had a significant and long-standing influence on the culture at UW. Many training programs at UW value communication skills training, which subsequently influenced generations of clinicians who then move to other institutions and brought their learning there. It was shortly after this trial when Elizabeth (Liz) Dzeg visited Harborview

Medical Center, UW's public hospital and the hospital where Randy is based, in 2013 to conduct interviews for her doctoral thesis. She encountered a hospital culture that was profoundly different from what she had experienced during residency training. There was a striking culture of understanding around palliative care.<sup>18</sup> She heard from several interviewees that a driving force for that culture was the research and education that Randy and his colleagues led:

"Randy's work here has made it easier for residents to talk with patients upfront. . . I think it has really changed a lot. Over the seven years (I've been here) I've seen a bit of growth in terms of acceptance. The residents coming through now are very open and aware of it up front. I think a lot of that has come out of the Code Talk stuff that Randy did. . . that has to do with Randy's discussion of these topics frequently and making people feel okay with that being an option." (Pulmonary Critical Care Fellow, interview conducted November 5, 2013)

Randy's impact transcends research, into mentorship, education, and clinical excellence. Susan Merel corroborates that Randy, his colleagues, and those they trained all helped create a culture in the ICU that valued excellent serious illness communication and supported the emotions of trainees, "As a resident, what I remember most is that he would always take time to check in when it was clear that we were struggling with the human impact of caring for seriously ill patients in the ICU."

### *Learning and Building Upon Prior Studies*

Subsequent studies that arose from these trials reflected the way that Randy thought about things and the ways he draws inspiration from various sources. Ruth reflected that:

"he's such a big picture thinker. . . always visionary, always listening to what was going on in the field and thinking through what went wrong not only for us, but for other studies. . . it is his analytic way of approaching things. It's a very comprehensive view of the state of the science. . . He's always been so curious and able to hear what other people are doing, very engaged in mentoring, which brings ideas and thoughts. It came from our findings and our failures and how we tried to correct things when we realized we had gone astray. Like why didn't we find significant findings in our educational intervention? That led to Jumpstart. We decided we have to do a lot more than teaching. You got to really give people skills in the moment."

These trials, as well as advances in implementation sciences, provided important insights, particularly

around the importance of creating interventions that were sensitive to local institutional cultures. This work provided experience in health systems interventions and highlighted the importance of the need to obtain buy-in with stakeholders at all levels of the healthcare system. Ruth reflected that Randy's realization over the course of these studies was that:

"It wasn't enough to show good science, but that we had to test interventions that were health service and health system implementable to change health systems. . . so we moved from the ICU to the outpatient setting. I think that there was a feeling at that point that we really wanted to encourage goals of care discussions, not just documentation of advanced care planning. . . that brought us to the current outpatient Jumpstart Initiative."

### *Recognizing the Importance of Intervening Upstream to the ICU*

Ruth and Randy are currently working on the "Jumpstart" intervention, which seeks to promote and improve goals of care discussions for patients with serious illness. Randy first collaborated with David Au on a cluster-randomized trial of clinicians and patients with COPD.<sup>19</sup> The intervention was refined based on feedback from patients and clinicians leading to a PCORI-funded cluster randomized trial of clinicians caring for patients with diverse chronic illnesses. Ruth explains,

"Giving people an educational curriculum is great but it's hard to show change. Let's make the change at the level of the patient encounter. Let's tell the doctor these are things you could say. . . We gave them words. This way, they had the words right there in front of them at the time of the encounter. What was so nice about the outpatient (study), is that these were now people who knew their patients. The patients knew them. We gave them the prompts - the patients had prompts, the families had prompts, and the clinicians. That was very effective in changing goals of care discussions, so that was cool. We saw real progress, and we were very excited."

This trial showed that Jumpstart increased goals of care discussions during routine clinic visits from 31% in usual care to 74% with the intervention and also increased patient-assessed quality of communication.<sup>20</sup> They have further adapted Jumpstart to the inpatient setting and are currently testing it, along with supporting additional brief educational interventions with faculty and trainees at the study sites.<sup>21,22</sup> This setting has brought new challenges, though initial pilot data suggests that they have been successful in changing goals of care discussions in the ICU.

### ***Improving ICU Communications in France and International Collaborations***

An important aspect of Randy's career and personal life has been his collaborations in France, which began through his work at ATS where he first got to know Elie Azoulay in the early 2000s. Elie was immediately struck by Randy's unique thinking and his commitment to inter-professionalism. They collaborated on a trial using a communication strategy and brochure focused on bereavement that decreased anxiety, depression, and PTSD symptoms for family members of patients who died in the ICU.<sup>23</sup> This was an especially notable study because in France, there was little focus on communication, and family conferences were not the standard of care at the time.

They continued to collaborate and exchange ideas, particularly through Elie's role as the Editor-in-Chief of *Intensive Care Medicine*, where he recruited Randy to be the managing editor for the ethics section. Elie illustrates one of Randy's quintessential characteristics of being so giving beyond what was required and without need for recognition: "even when the papers were rejected, he was very positive and inclusive, spending time to help people and to guide them to say what should be improved for the paper so it can be published elsewhere." Randy then took a sabbatical from 2017 to 2018 where he was a Professeur Associé at the Hôpital Saint-Louis. This was a special time for Randy and his family, and a productive one professionally.<sup>1</sup>

While on sabbatical, Randy and Nancy Kentish-Barnes, a French researcher working with Elie, conceptualized and submitted two separate grants in the United States and France which were both funded to conduct the same cluster-randomized trial in both countries.<sup>24</sup> These studies build on an earlier trial which showed that the intervention – an ICU communication facilitator – reduced intensity of end-life care with similar or improved levels of family distress.<sup>25</sup> The intervention currently being tested incorporates feedback received from families from the prior trial and utilizes nurse communication facilitators to support, model, and teach communication strategies to patients and families to improve goal-concordant care and reduce family symptoms of distress. What has been particularly striking about these collaborations is that Randy has brought his focus on inter-professionalism and his recognition of the importance of nurses to his work in France. Nancy recalled this being one of the most notable lessons from her collaboration with Randy, especially when she visited Seattle to observe the nurse facilitators training:

"In France, nurses don't benefit from the same social recognition as they do in the Anglo-Saxon health-care system. It was important for me to see how over there; nurses are part of the team just like any other

clinicians or the same as doctors...everyone was respected in what they had to say. There was no hierarchy. We are definitely involving nurses much more in our research group because we've learned to value nurses much more."

### ***Randy's Legacy***

As we tell the story of Randy's scientific career, what emerges is his intrinsic positivity, enthusiasm, kindness, and inclusivity that is consistent across all aspects of who he is as a person and researcher - from his deep-seated dedication to improving the quality of care for those with serious illness, to the way he creates consensus in his collaborations and seeks agreement and compromise, to the way he cares for his mentees, and to the way that he embraces and brings in different professions, disciplines, and methodologies. His human qualities are fundamental to the success of his research career, as illustrated by these testimonials:

"Randy's superpower is convincing you that his brilliant ideas were actually your idea, and then letting you take credit for them." -Gordon

"Someone will say something where the obvious answer is 'no' or 'it's impossible.' But Randy never says 'no.' He says 'yes,' and he brings people to understand how the 'yes' can become 'yes,' or explain that the 'yes' has some conditions for the 'yes' to be realistic." – Elie

"Randy always says that our job is to get to the other side of no." -Ruth

Randy is extraordinary in his inclusivity and cross-pollination between different fields, disciplines, and professions – be it critical care and palliative care; doctors, nurses, and other clinicians; or diverse research methods. He is always thinking about potential opportunities that might be good fits for his mentees and collaborators. By doing so, his legacy is the networks of collaborators and disciplines that he has brought together.

While talking about Randy's career, Gordon referenced the "Erdős number."<sup>26</sup> Erdős was a prolific Hungarian mathematician and the Erdős number refers to the "collaborative distance" between him and another mathematician. A direct co-author would have an Erdős number of one and a distinct collaborator with that co-author would have an Erdős number of two. Gordon thought that we should create a "Curtis Number," which illustrates Randy's extraordinary impact on the field. Fig. 1. illustrates just some of Randy's networks of collaborators, demonstrating his tremendous reach, and connections.

His legacy lives on through the hundreds of collaborators and mentees he has touched. For those of us who have been so lucky to have a Curtis number of one,

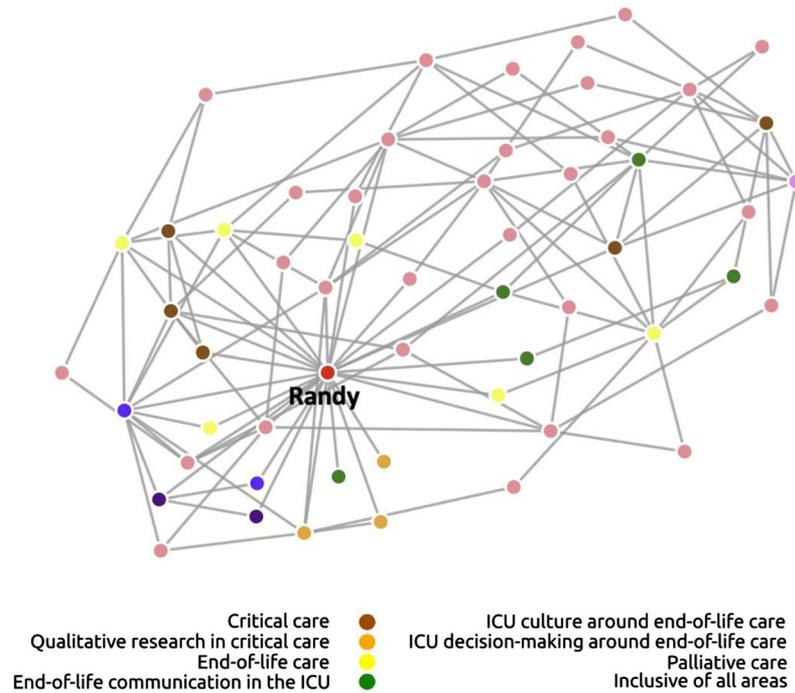


Fig. 1. Illustration of Randy's collaborative network across disciplines demonstrating his prolific reach. Each node represents a co-author with increasingly greater Curtis numbers as nodes radiate from the central red node representing Randy (Figure created by Quiyu "Amber" Wang.) (Color version of the figure is available online.)

reflecting on the ripple effects of his wisdom and teachings brings us much gratitude. The downstream consequences of Randy's influences are seen in the studies his mentees and collaborators design which reflect his emphasis on inter-professionalism and multiple methodologies. We, the authors, consider Randy one of the most impactful people in our lives, both personally, and professionally. Erin considers Randy a singular force in changing the trajectory of her career and life. Susan especially appreciates Randy's importance as a teacher, a clinical colleague, and a strong supporter of her as a clinician-educator. To Liz, Randy has been an important model for mentoring excellence; her gratitude for his responsiveness and compassionate mentorship translates into a commitment to pay it forward to her own mentees. These are but three examples of the profound impact Randy have had on the countless mentees and colleagues he's influenced over the years. The aggregate ripple effects of his influence on all these people and the field over the years is his ultimate legacy.

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