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Symposium Editor

**Interview With Barbara J. Daly, RN, PhD, FAAN,
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Advances in disease management and health care technology have greatly impacted health care providers' ability to rescue critically ill patients who just a few years ago would not have survived. A consequence of these advances is the emergence of a population that may survive the immediate critical illness crisis, only to face challenges because of complications, prolonged dependence on technology, and need for extensive medical and nursing care. This population has become known as the chronically critically ill (CCI). Barbara Daly is a pioneer in the investigation of the systems of care and outcomes in the chronically critically ill. Since the Special Care Unit project in 1989, Dr Daly and her research associate, Dr Sara Douglas, have studied this patient population and their caregivers. Dr Daly has led the only research team to conduct 3 intervention studies in the CCI. These have included the Special Care Unit Study (1989-1994), the Disease Management Study (2001-2005), and the Intensive Communication Intervention Study (2005-2008). The Disease Management Study evaluated the effect of a postdischarge, 8-week disease management intervention by advanced practice nurses on readmission and other outcomes in the CCI and their caregivers. The effect of an intensive communication structure in the intensive care unit (ICU) phase of care on CCI patient resource use and family decision-maker satisfaction was tested in the Communication Study. Dr Daly has published and lectured extensively on topics related to the care of the CCI. As an introduction to Advanced Critical Care's symposium on "Caring for the Chronically Critically Ill," Clareen Wiencek, Symposium Editor, interviewed Dr Daly about this unique population.

Wiencek: Since the late 1980s, your research career has focused on the chronically critically ill (CCI), including 3 federally funded intervention studies. How did you become interested in studying this population?

Daly: We knew that these patients were a problem because they were outliers when compared to the typical ICU patient. Their profile and needs did not fit the usual acute care, short-stay focus of the ICU, and we did not do a very good job in caring for them.

Wiencek: The Special Care Unit project, conducted from 1989 to 1994, examined the differences between CCI patients cared for in traditional ICUs and a

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Wienczek

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nurse-managed special care unit. What did you learn about the CCI from this intervention study?

Daly: We learned that, as we suspected, this subgroup of the ICU population can be effectively cared for without use of the usual procedures and “high-tech” interventions that are part of critical care routines. In contrast, the essential aspects of care for these patients are explicit discussions of goals of care and benefits and burdens of treatment, close attention to support of basic biologic functions such as sleep, nutrition, mobility, and active involvement of family members as partners in care. We also observed that the patients who survived hospitalization and their families continued to need ongoing support and interventions as they continued to face challenges and health crises.

Wienczek: Advanced practice nurses were utilized in both your Disease Management and Intensive Communication projects. What finding or findings are most relevant for APNs to integrate into their practice when caring for the CCI?

Daly: This population is characterized by several features that have important implications for the role of the APN. First, most of the CCI have multiple comorbidities and consequently have multiple healthcare providers involved in their care, both in the hospital and after discharge. Unfortunately, our health care system today is marked by fragmentation and lack of effective coordination and communication among providers. The APN, with his or her broad preparation in both the pathophysiologic and psychosocial aspects of care, accompanied by system expertise, is ideally positioned to be the coordinator or care manager. As the discussion of Lee and Higgins’ article illustrates, most of the supportive care components are those that APNs can direct. Second, because of the generally poor outcomes of chronic critical illness, it is essential that early, sensitive discussions be held with patients and their families about goals, preferences, and values. Education about options and support

and guidance in decision making can be a key role for APNs, who often have more consistent, closer, and more intimate relationships with patients and families.

Wienczek: Due to the 20 years of research by your team and work of other groups, the profile of the CCI is now better defined. Has the profile changed in any substantive ways since you first started studying this group?

Daly: The profile of the patients themselves, as a population, has not changed. However, there have been changes in therapies and hospital facilities that have resulted in differences in care patterns. Most specifically, earlier extubation, probably associated with improvements in anesthetic techniques and use of evidence-based protocols, and availability of out-of-hospital weaning facilities (long-term acute care hospitals), have resulted in shorter hospital stays for these patients. This has also resulted in changes in hospital mortality rates.

Wienczek: What has your body of research revealed about caregivers of the CCI and what intervention by APNs could be most effective in supporting caregivers?

Daly: The family caregivers of CCI are a particularly vulnerable group. In general, most CCI patients were living at home, independent in activities of daily living. Following some form of medical crisis, families are then unexpectedly and relatively suddenly thrust into the role of decision maker and must cope with the significant effect this will have on their lives, as well as facing the possible loss of a loved one. Not surprisingly, they demonstrate high rates of depression and difficulty in managing their new role as caregiver, as noted by Hickman and Douglas. The interventions that we have found to be needed include counseling, referral to mental health services for some, education and preparation for the tasks ahead, guidance in making decisions, and emotional support.

Wienczek: As you know, there is no universally accepted definition of the CCI for research or clinical purposes, though prolonged mechanical





ventilation is a hallmark of the syndrome. How important is the refinement of a universal definition for the CCI?

Daly: Consensus about definitions and criteria are important for several reasons. First, gaining an understanding of this syndrome, identifying predictive factors, and measuring effectiveness of interventions all require precision and consistency in how researchers define the target population. Thus far, there has been an impressive growth in research related to CCI, but the use of varying definitions has made it very difficult to draw reliable conclusions or apply findings. Equally important, lack of generally accepted diagnostic criteria can contribute to underrecognition of the pattern of CCI and delayed reevaluation of treatment goals. As Wiencek and Winkelman note in this symposium, there are a number of promising interventions that are likely to be most effective if implemented in the first week of the ICU stay, such as early mobilization protocols and setting up regular communication systems. Incorporating these into ICU care routines requires early identification of patients at risk for developing chronic critical illness.

Wiencek: What are future priorities or directions in research on chronic critical illness?

Daly: There are 2 general goals for research in chronic critical illness: identifying effective ways to reduce the incidence of CCI (either through early interventions with patients proceeding toward CCI or identifying patients most likely to develop CCI) and identifying effective interventions to improve outcomes for patients and families who do experience CCI. Continued advances in our ability to “rescue” persons who have suffered some form of health catastrophe will undoubtedly continue to result in growing numbers of persons who have survived the crisis but who are unable to recover and thus develop chronic critical illness. I believe that technologic improvements are unlikely to have a significant impact on the course of CCI and that more work will need to be done on interdisciplinary models of care that assure continuity, restorative therapies, and psychosocial interventions, including supporting patients and families in identifying preferences and values that can direct decision making.

