Notice to CNE enrollees:
A closed-book, multiple-choice examination following this article tests your understanding of the following objectives:

1. Explain the concept of “parallel paths” as it relates to improving outcomes in patients with heart failure.
2. Describe the relationship between patients’ beliefs about their ability to control heart failure and their adherence to self-care behaviors.
3. Discuss barriers to delivery of effective heart failure education for patients with advanced heart failure and ideas for improving patients’ accuracy of illness beliefs and their adherence to guideline-recommended heart failure self-care behaviors.

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Gaps and disparities in delivery of heart failure education by nurses and performance in accomplishing self-care behaviors by patients with advanced heart failure may be factors in clinical decompensation and unplanned consumption of health care. Is nurse-led education effectively delivered before hospital discharge? Nurse leaders must understand the strength of nurses’ knowledge base related to self-care principles and important barriers to best practice. Nurses may not be comfortable teaching patients about dry weight, meal planning, heart failure medications, or progressive steps of activity and exercise. Further, clinical nurses may not have time to provide in-depth education to patients before discharge.

Equally important, research is needed to learn about factors that enhance patients’ adherence to heart failure self-care behaviors, because adherence to recommendations of national, evidence-based, heart failure guidelines improves clinical outcomes. Thus, nurses and patients are on parallel paths related to setting the foundation for improved self-care adherence in advanced heart failure. Through research, we found that nurses were not adequately prepared as heart failure educators and that patients did not believe they were able to control heart failure. In 2 educational intervention studies that aimed to help patients understand that they could control fluid management and follow a strict daily fluid limit, patients had improved clinical outcomes. Thus, misperceptions about heart failure can be overcome with interventions that move beyond communicating “what” self-care behaviors are recommended. Research results reflect that evidence matters! Systems and processes are needed to support nurses’ knowledge, comfort, and frequency in delivering self-care education before discharge, increase the accuracy of patients’ beliefs about controlling heart failure, and enhance patients’ desire to adhere to guideline-recommended heart failure self-care behaviors. This article describes the development of the parallel paths of nurse and patient programs of research and explores translation of findings into practice and development of clinical translational research. (American Journal of Critical Care. 2013;22:289-297)
n nursing school, as I rotated through different care environments, I quickly learned that I preferred the fast-paced, intense, technology-driven environment of critical care nursing. My first job after graduating from a diploma nursing program was in a mixed medical-surgical intensive care unit. The unit received patients with a variety of diagnoses, so I found it important to review the literature on medical and nursing care management of multiple diagnoses and surgical procedures. In addition to learning from nurse preceptors and colleagues, the knowledge I gained through a literature review became the spark that led me to ask questions of attending physicians during rounds. I wanted to have answers to discrepancies in care between the literature and the real world and did not want intuition and past practice to be the basis of current practice. Decades later, when I was the clinical nurse specialist for heart failure, cardiac dysrhythmias, and cardiac transplant services, the behavior of reviewing current evidence and challenging the status quo pushed me toward my role as a nurse scientist. I needed answers and could not find what I was looking for in the literature!

Before I provide some background about each of the parallel paths of my program of research, I want to make some general comments about being a nurse scientist, as it was never something I aspired to. Oh, sure, I had a great uncle who was a professor in sociology at the University of California, Los Angeles, and he was someone I looked up to. But, I looked up to him in a global way, not as a scientist. I had never met a nurse scientist in my years of diploma training, and although I met PhD nurses in my BSN and MSN programs, we never discussed their programs of research; the focus of communication was on class work. Because I worked full time and went to school part time to get my BSN and MSN, I did not take on a research assistant job at the college or get to know faculty beyond the classroom; I was simply too busy with work, school, buying land and building a house, and spending time with my husband.

For the first 13 years of my career, I was in clinical and management tracks at a midsize, teaching, community hospital, and although understanding current research mattered to me, I was not exposed to physician or nurse scientists except when I attended national conferences. My first national conference was the American Association of Critical-Care Nurses National Teaching Institute in Cincinnati, Ohio, in 1981. What an eye-opener. I remember being in awe of some cardiac and critical care presenters and looking up to them from afar. They became indirect mentors in terms of helping me understand what I could aspire to. As I watched their careers develop and read manuscripts they authored, I started realizing that they were nurse scientists; they were changing nursing practice and making a difference in the lives of patients. But still, nurse scientists were physically very far removed from my midsize, teaching, community-based hospital. In my reality, it felt like a million miles away, because the information technology revolution had not yet begun.

After attending a national cardiac conference in my backyard, Cleveland, Ohio, I knew that I needed to work at a hospital that was involved in clinical research. The moment of truth came after listening to speakers discuss care management of bare metal stents that were still in clinical research at the time. I still did not aspire to be a nurse scientist. I just wanted to be in an innovative environment: one that fostered change, expected flexibility in clinical care, and encouraged nurse education about new patient management expectations based on clinical research findings. Once I made the move to Cleveland Clinic as nurse manager of the coronary care

Nurse scientists were changing nursing practice and making a difference in the lives of patients.
unit, I was excited that I would no longer need to wait for 5 years or more to learn about emerging cardiac science; I was now part of the emerging science process.

The singular factor that led to my introduction to nursing research was new relationships that emerged after my move to Cleveland Clinic. In my nurse manager role, I wanted to switch unit practice from thermodilution cardiac output to the continuous cardiac output method. The change in practice was proposed to decrease nurse workload in obtaining important hemodynamic data and decrease fluid intake, because many patients were on fluid restrictions and the continuous method did not require bolus injection of intravenous solution. The medical director of the unit, Steven Nissen, MD, did not believe in the accuracy of continuous cardiac output technology. He preferred the current standard of bolus thermodilution and asked me to conduct a research trial to compare cardiac output readings obtained between the 2 methods. The next thing I knew, I was reading manuscripts on writing a research proposal, teaching myself how to go about conducting a comparative research trial, and seeking advice from a statistician and medical scientists.

Leading the cardiac output methods study and seeing first hand how study results do not always match intuition was very valuable. Further, getting published spurred me to want to conduct more research; however, I still saw myself as a nurse manager on a path toward a leadership role. I did not think of myself as a nurse scientist; rather, I just wanted answers to nursing questions and was thrilled that my boss, Dr Gayle Whitman, provided me with the support I needed to perform multiple roles. As a note, I continue to be fascinated with research in hemodynamic monitoring; however, now my research questions are related to noninvasive hemodynamic monitoring using thoracic bioimpedance to assess cardiac output and thoracic fluid and whole-body impedance to detect total body water as a surrogate for weight monitoring (currently in data collection), since weight monitoring is not a very sensitive measure of fluid overload in patients with heart failure.

In 2000, I took a position as the manager of clinical investigations for cardiothoracic surgery at Cleveland Clinic. I said yes to the job because it combined leadership, research, and clinical nurse specialist responsibilities. The job also allowed me to administer a large corporately funded grant we received to implement a nurse-led program for heart failure disease management. The job encompassed facilitating, supporting, and assisting with internally funded clinical investigations, externally funded clinical trials, and registry-based research from a long-standing departmental registry maintained by our team.

I became a sponge while in this role, soaking up knowledge from my boss Eugene Blackstone, MD, and colleagues including our cardiology scientist Michael Lauer, MD, statisticians, informatics personnel, and heart failure specialists James Young, MD (medicine), and Patrick McCarthy, MD (surgeon). Working with quantitative research designs (my own and those of many physicians), ensuring the quality of multiple databases and registries, and dealing with proposal, data collection, analysis, and dissemination issues on a daily basis helped me develop greater competence in research.

Further, the department leadership team supported my involvement on national committees of many health care organizations. It was through relationships I developed at a national level that I found myself side-by-side with nurse scientists such as Barbara Riegel, RN, DNS, and Debra Moser, RN, DNSc. More importantly, these established nurse scientists involved me in their multicenter research on quality of life. I will always be grateful for having been involved in telephone and in-person discussions that raised my awareness of the multiple benefits of collaborative research. It was during my tenure in this job that I took a leap forward and entered a doctoral (PhD) program. My incentives were professional job growth and a desire to have a more global perspective at national forums so that I could contribute to the fullest.

The Initial Walk Down the Parallel Paths of Improving Heart Failure Outcomes

The first of 2 parallel paths involved my interest in nurses’ ability to deliver knowledge of guideline-recommended self-care principles to hospitalized patients with advanced heart failure. Research was sparked during collaborative meetings with nurses who worked in heart failure, nursing education, and home care. I was leading a team with a goal of developing a heart failure handbook for patients with common forms of heart failure. The handbook was intended for use among all system hospitals, ambulatory areas, and our home care program. When discussing the rationale for not placing calcium channel blocker therapy in the systolic dysfunction medication section of the handbook, a nurse stated that her physicians ordered calcium channel
as expected about heart failure self-care principles, and that it was not the nurse’s job to question therapy decisions, it was only to provide education.

Further in our discussions, the home care nurse manager stated that her nurses could not understand why physicians failed to respond when the home care nurse reported an episode of asymptomatic hypotension. I started to wonder if cardiac critical care and telemetry nurses unquestionably followed physician orders because they did not understand the nuances of heart failure pharmacologic therapies. For example, calcium channel blockers were contraindicated in systolic heart failure, but some calcium channel blocker agents were acceptable therapy for patients with heart failure and preserved ejection fraction. Further, I wondered whether critical care, telemetry, and home care nurses, who were so attuned to acute care patient evaluation, believed that adverse events during a hospital episode were similar to adverse events that surround usual activities of daily living at home. I also wondered if physicians who received nurses’ reports of perceived deterioration in a patient’s condition, such as an isolated episode of asymptomatic hypotension, responded by removing life-saving pharmacologic therapies, such as angiotensin-converting enzyme inhibitors or β-blockers.

The second parallel path in my research stems from my interest in factors that affect patients’ adherence to recommended self-care behaviors. This research interest was sparked by 2 emotional encounters with patients within days of each other. In both encounters, the patients had just been treated in a heart failure intensive care unit for acute decompensation of chronic heart failure. Nonadherence to guideline-recommended therapies was one of many factors in their decompensation. Both patients boldly asked me questions about death: “How long do I have to live?” and “Am I going to die?” They had both asked their physicians the same questions and received broadly worded, global statements. Both patients made commentaries about the inadequacy of their physicians’ responses.

As our conversations continued and I asked more questions, it became apparent that neither patient had a good understanding of heart failure, its timeline, consequences, or what they could do to control it. At the time, it seemed to me that the underlying themes were that patients based the seriousness of their condition on the level of current symptoms and relied on physicians to control their symptoms. Patients really did not know much about heart failure or what they should be actively doing to help themselves, other than to follow the medication plan of care. After my encounter with both patients, I started proactively asking patients questions. It did not take long to understand that patients had general misperceptions and inaccuracies about heart failure and self-care expectations. Further, messages patients received and repeated back about staying active and exercising, eating a low-sodium diet, and monitoring for worsening signs and symptoms were not perceived as “should or must dos”; rather, they were relegated to “okay to do if I want to.”

**Evolution of Improving Self-Care via Nurses’ Knowledge, Comfort in Educating Patients, and Frequency Delivering Education**

As a precursor to initiating research, it took no time at all to get serious about determining the knowledge base of nurses who educated patients with heart failure about the principles of self-care. In 1999, a literature review was completed, and to our surprise, we were only able to find 2 related studies in which nurses ranked perceived learning needs of patients with heart failure. We could not find any publications focused specifically on nurses’ knowledge base. Some nurse members of the heart failure handbook development team assisted in developing a 20-item true/false questionnaire. Self-care content themes used in the questionnaire were those discussed in the 1995 national heart failure management guidelines of the American College of Cardiology and American Heart Association, and some items were those known to be important because of the frequency with which they were raised in patient care. Through the results of the study, we learned 2 basic messages: nurses were not as knowledgeable as expected about heart failure self-care principles, and nurses were unaware that they needed more information on many principles of heart failure self-care.

We translated our findings locally by educating newly hired hospital-based cardiac nurses and home care nurses on heart failure self-care principles and specifically discussed signs and symptoms of worsening condition from both acute and ambulatory care perspectives. Over the years, while we were offering nurse education as a fix to inadequate knowledge about self-care principles, the Nurses Knowledge of Heart Failure Self-Care Principles tool was replicated in similar and different nursing populations. Published results involving hospital-based nurses reflected a lack of improvement in
knowledge about heart failure self-care over time, even though some researchers provided education before nurses participated in the research.

I decided to change perspectives to ensure that patients received the right type and amount of heart failure education before hospital discharge. The new focuses were to assess nurses’ level of comfort for specific self-care education content and nurses’ frequency in delivering education to patients during the hospital episode. Nurses could pass a true/false knowledge test but still be uncomfortable educating patients. Using education themes discussed in 2 national guidelines for management of chronic heart failure in adults, an 88-item assessment tool with 8 themes was created. The tool also asked nurses to provide the average range of time in minutes that they spent delivering heart failure education to patients before discharge.

Although the Joint Commission mandates educating patients before discharge, the depth and breadth of routine education typically delivered by nurses has not been reported. The assumption is that education delivery happens, but questions remain. How much time is devoted to education? Is education superficial or individualized and detailed? Is patients’ education long enough to allow time for assessing patients’ understanding of the education delivered? Can improvements in delivery of heart failure education reduce hospital readmission rates? Critical care, cardiac step-down, telemetry, and internal medicine nurses from 3 centers and multiple work environments provided data to answer some of those questions.

In heart failure, hospitalization rates have been an ongoing issue. Heart failure is the leading cause of adult hospitalizations, the rates of which have not declined between 2000 and 2010. After discharge, patients with heart failure are likely to be rehospitalized within 30 days. One potential rationale for the stagnant hospitalization rate revolves around the average amount of time allotted to heart failure education. In our sample of 118 nurses, more than 55% of participants spent less than 15 minutes educating hospitalized patients, regardless of the data collection site. Moreover, the frequency of educating patients about heart failure medications, low-sodium diet, activity and exercise, and heart failure illness beliefs were below Joint Commission expectations.

Disseminating and translating research results internally are important components of evidence-based practice. I made time to get on the schedules of both the cardiac and internal medicine leadership team meetings. When called upon to participate in system-level changes in heart failure education, I communicated study results in the hope of raising awareness of changes needed to ensure that patients are adequately educated before discharge. Leaders listened; multiple nurse- and patient-focused interventions were initiated to overcome time and comfort barriers to education delivery and enhance patients’ understanding of heart failure self-care expectations. Pharmacists began providing 2 education sessions to patients during the hospital episode: within a few days of admission and on the day of discharge. Our heart failure handbook was revised to simplify wording and focus on important concepts. A 1-page zones handout (a discharge discussion tool) was revised to match revised weight-monitoring concepts and postdischarge communication. A clinical nurse specialist colleague co-developed (with a dietician and pharmacist) a group education class for patients and their families that is provided multiple times per week on a cardiac telemetry unit on our main campus as a supplement to individualized education.

Finally, throughout the health care system, hospital nurses who care for patients with heart failure complete a 1-hour self-study computerized class with a quiz. The class content and quiz covers specific principles of heart failure self-care that scored low in nurses’ comfort in educating patients and frequency in delivering education. It was exciting to know that nursing leaders and health care system administrators paid attention to research findings and devoted time and funding toward creating realistic education expectations for nurses and new systems for patients. Leadership support for improvements and change provided visible support that evidence matters.

**Evolution of Factors That Affect Patients’ Adherence to Recommended Self-Care Behaviors**

After having conversations with patients about what heart failure means and its consequences, and coming to realize that patients often had little understanding of how to control heart failure, even when they could repeat facets of self-care monitoring, such as the need to weigh themselves daily, I went on a hunt for a behavioral model that matched what I was hearing from patients. I spent months reading about various models in search of the right fit, to no avail. Becker’s Health Belief model, Pender’s Health Promotion model, self regulation and...
locus of control constructs, the transtheoretical model of behavior change, Mishel’s uncertainty theory, and the coping behavior model each had some features that seemed to fit my patients’ perspectives. However, none of the models precisely matched what I was looking for. Then, fate intervened. I received an e-mail from a nurse who asked me to give her feedback on a manuscript she had just seen in a cardiac journal. When I went to the table of contents to download the article, the article directly before it intrigued me. It contained the phrase “illness beliefs” in the title. Even though that article’s subject population was asthma and chronic pulmonary disease, I became excited—the kind of excited that creates goose bumps and shivers! The excitement grew more powerful when I started reading about Leventhal’s Common Sense Model of Illness. I connected immediately; it was visceral! Once I felt like I was on track with a model that matched my thoughts about behavior, I went to the library and obtained all publications on the model’s principles and research findings on its use.

Finding the right theoretical model to explain patients’ behavior was part of the “high” of embarking on this parallel program of research. Then came “work” as I realized that the only tool available to assess the illness beliefs model was long (72-item) and generic, not specific to heart failure beliefs. Like most chronic conditions, there is generally no cure for heart failure (except a transplant); however, heart failure is dissimilar to some chronic illnesses in that it is progressive, worsens silently, has a short timeline, and requires ongoing adherence of patients to self-care behaviors, even when asymptomatic. I thought that a specific measurement tool that assessed the accuracy of the patient’s perceptions of illness beliefs, based on contemporary medical knowledge, would provide more useful knowledge in terms of future interventions.

By this time, I was in my PhD program and I knew that I needed to have a valid and reliable tool before I could complete my dissertation. So, I set about making something (an assessment tool) out of nothing. Many heart failure specialists I worked with gave expert feedback on illness belief items for content validity testing, and my PhD program statistics professor conducted the statistical analysis used in psychometric testing of the new tool. Once I had a valid, reliable tool, I was ready to start collecting evidence on patients’ beliefs about controlling heart failure. When studying results of early research on illness beliefs, there were some ah-ha moments that helped shape the direction that this program of research would eventually take. For example, from my dissertation results, we learned that objective cues of advanced heart failure, as perceived by health care professionals (hospitalization within the preceding 30 days, moderate to severe symptoms, cardiac transplant listed, having a heart failure specialist provider, and being involved in medical heart failure research), were not a match with patients’ perceptions of a serious medical condition and were not associated with self-efficacy for heart failure low-sodium diet behaviors. Patients with more symptoms of depression had greater accuracy of beliefs about the prognosis for heart failure, but greater inaccuracy of beliefs about how to control it. Illness beliefs of African Americans were inaccurate and were independently associated with social support and education level.

After interpreting results of research on illness beliefs, we knew we needed to create an intervention that would help increase the accuracy of illness beliefs, including patient-initiated actions that would help control heart failure. I was leery of a traditional education intervention, especially one that required education by staff nurses in a hospital setting. Around that time, a company that markets videos for patient education had asked for my expert opinion on a heart failure video they had produced. The video had short, repetitive segments (similar to a commercial) between self-care themed chapters that reinforced important self-care behaviors such as communicating changes in daily weight to a health care provider and the importance of reading food labels. We conducted a randomized, controlled trial of video education versus usual care after hospital discharge on health care consumption (hospitalization, emergency care, and urgent office visits), adherence to self-care behaviors, and symptoms and functional status. Results served as a catalyst for next steps and pushed me to create a patient intervention that went beyond new knowledge.

Keeping up with the research literature is a wonderful way to get research ideas. In 2009, Italian researchers published results of a comparative trial of 3 groups of patients who received various combinations of diuretic dose, low-sodium diet restriction, and fluid restriction. I was intrigued that a strict fluid restriction (1000 mL/day) combined with a moderate, rather than strict, low-sodium diet and high diuretic dose provided the best clinical and biological outcomes at 6 months. Because the researchers had used a combination intervention, it was impossible to determine if fluid restriction
was independently meaningful in improving outcomes. Fluid restriction is theoretically easier to control than diet; it is easy to measure total daily fluid volume, and thirst can be quenched with hard candy or suckers. We used the illness belief model to create our education about the intervention and thought life was good . . . but that feeling did not last long. We should have known there would be issues when a cardiologist told me (emphasis) that he would never accept a 1000 mL/day fluid restriction. When we tried to enroll patients, some physicians would not allow us to approach their patients, as they feared their patients would not want a tight fluid restriction. Some patients also rebelled at the idea. Patient comments ranged from “Are you nuts?” to “There’s no way I could do that!”

Needless to say, enrollment for the randomized controlled trial moved at a snail’s pace. Moreover, 40% of patients randomized to the 1000 mL/day fluid restriction did not follow the intervention during the entire 60-day postdischarge trial period. The good news was that the intervention group had significantly better quality of life than the usual-care group, even though some participants had poor adherence.21 And, I learned valuable lessons about planning timelines in longitudinal experimental designs.

This program of research continues. We recently completed enrollment in a study to determine predictors of activity and exercise in ambulatory patients.22,23 In addition, we used the Common Sense Model of Illness Beliefs in a quasi-experimental study with a pre-post design of hospitalized patients with heart failure. The intervention included educating patients about illness beliefs and giving patients’ control of fluid management by using a 3-step method. We found statistically significant differences in health care consumption 6 months after discharge (abstract in progress). Finally, we are planning a randomized controlled trial that involves a diet intervention. The goals of newer studies and those being planned are to increase the accuracy of patients’ beliefs about heart failure, examine predictors of self-care behaviors (in advance of designing an intervention study), and alter self-care behaviors, ultimately leading to improved clinical outcomes.

**Maintaining Forward Momentum**

The beauty of being a nurse scientist in a hospital setting is that there is always something new to learn that involves updating research processes, understanding and explaining results, and determining a plan for translation of findings into practice. Additionally, determination to do the best job possible, curiosity about and questioning of daily life events, and a desire to overcome gaps, issues, and barriers to optimal care all become fodder for research and innovative ideas. New drugs, technology, techniques, and processes can also provide the seeds of developing nursing research and innovative ideas.

In a hospital environment, there are always expert clinicians and researchers and willing patients in close proximity to discuss or validate research ideas and to ensure evidence-based decision making. I am fortunate to work in a quaternary care medical center with an executive nurse leader who understands the importance of critical thinking, reflective practice, and achieving excellence through new knowledge and innovations. She fully supports nursing research activities and also understands that maintenance of clinical skills can facilitate new clinical research ideas and foster data collection (just today I was in the heart failure intensive care unit obtaining cardiac output readings and a wedge pressure as part of data collection for a hemodynamic study).

External funding is always a goal, but internal funding allows us to focus on generating new knowledge, even when the research plan is not easily fundable externally. Further, a reliable, intelligent nursing research team is integral to valid, trustworthy results. I am blessed with a wonderful support staff (research nurses, statisticians, nurse scientists, and clinical colleagues) and external research mentors and colleagues. Our nursing leadership may not fully understand what we do every day, but they understand and support evidence-based nursing practices that are founded on high strength and quality of research evidence. We are expected to be national leaders in generating new evidence that promotes optimal nursing practices and outcomes for patients. Ultimately, evidence matters!

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