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A Career of “Why?” and “Why Not?”

Donna L. Berry, PhD, RN, AOCN®, FAAN
2011 Distinguished Researcher Award

I am deeply honored by the Oncology Nursing Society's Distinguished Research Award. To my nominators and supporters, saying *thank you* seems woefully inadequate. Without my involvement with the Society, I certainly would not have been able to become the researcher I am today.

I would like to dedicate this article to Ellen DeBondt, my former oncology nurse colleague at the Seattle Cancer Care Alliance. At seven o'clock in the morning on March 6, 2011, as Ellen was going to do her excellent work as a nurse, a drunk driver crossed the line and smashed right into her car, taking Ellen's life. She and I had worked together clinically and on her literature review and poster presentations for Congress regarding use of medical marijuana. A second dedication is to Lloyd Kitchens, Jr., MD. He sparked my fledgling interest in medical treatment of cancer and was the first oncologist with whom I established a strong working partnership. Sadly, he passed away in 2001. Finally, to my mother, who passed away when I was three. She wanted to be a nurse and because of restrictive rules in schools of nursing at the time regarding married students, she did not achieve her dream. When I first began to talk, my mother transcribed my first words in my baby book, “What's that?” My destiny as an investigator unfolded from that point on.

To get through college, I had to work full-time; as a pharmacy clerk, I started asking many “why” questions. The pharmacists I worked with were thrilled to have a clerk in front of them that was interested in the medications we dispensed. Finally, I was able to care for hospitalized patients in the summer between my junior and senior year, and I was asking, “Why is adriamycin red, and why do you have to give it that way?” Dr. Kitchens would take me on his late rounds as he gave all the IV push chemotherapy—in those days, nurses did not give IV push chemotherapy in the hospital. I would say, “Why do you do it like that,

and how does that work?” And as we rounded on each patient, he would fill my head with answers to my questions.

After I graduated in 1978 with my BSN, I stayed on at Baylor University Medical Center in Dallas. The next year, we opened the first oncology unit. One of my biggest questions was regarding chemotherapy-induced nausea and vomiting. Our brand new, beautiful oncology unit was designed with a hub and spokes layout and it was a really long way to the end of that hall. So many call buttons were ringing and our patients telling us, “I'm really sick.” We would grab our syringes and we would run down the hall, give the Phenergan® (promethazine) and it didn't help. I'm thinking, “Why are we waiting until they are calling us to say they are so sick? Why are we waiting? Why not prevent that nausea and vomiting instead of treating it after it happens?” And so I'd sit in the nurses' station with the oncologists and I'd say, “Why aren't we doing this differently?” And they'd say, “OK, Donna; the order is ‘as needed to prevent or manage nausea’ and you can give it.” And then they said, “Donna, go to graduate school.” Maybe they were getting tired of me asking them all the questions, and they said, “We don't have the answers. The research-based answer doesn't exist. You need to go to graduate school, and then you can ask these questions.”

So, I went to the University of Texas Health Sciences Center in Houston. I was very bright-eyed, and I was asking a lot of “why” questions. I met Karen Heusinkveld, who became my thesis chairperson. I said to Karen, “Why not do a randomized clinical trial for my thesis? Doesn't everyone do that?” And then while I'm at it, why not do a double major? So, not only was I an oncology clinical nurse specialist major, I was a nursing education major at the same time. Why not? But then I was thinking, why am I lonely? There's something missing. Why not have a baby? And then, what is that Oncology Nursing Society (ONS) all about? Those were my

questions in 1981. Under Karen's guidance, we wrote an article based on my thesis results (Berry-Opersteny & Heusinkveld, 1983), my first peer-reviewed publication. Everything then went viral for me in the 1980s, as I had my first advanced practice position at the University of Texas Medical Branch in Galveston. I began to attend

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the ONS national meetings. I discovered, oh, they have chapters in ONS; but we don't have a chapter in Galveston. So, why not have our own ONS chapter? I became the charter president of the Galveston Bay Area Chapter.

I believed at the time I had the perfect advanced practice role in cancer care. I was in clinic every morning treating patients. However, the questions started again; "Why are we only asking drug versus drug questions in these clinical trials we're doing?" There were so many other issues for our patients. I had multiple mentors among the Southwest Oncology Group researchers, and that made a very big difference in my life. Not only was I enthusiastic about asking clinical questions of my mentors, but they introduced me to an entire world outside of nursing that had a lot more money, where you could ask really big research questions and conduct really big clinical trials.

I needed to make a transition, because I was asking questions to which no one knew the answers. My colleagues told me there is a way to ask these questions and get answers, but you're going to have to do something else in addition to what you are doing right now. I was asking, "Why do some patients do so much better than others on the same drugs?" And, "Why not study the experience of being a person with cancer while we're also trying to kill the tumor cells? Shouldn't that be important, too?" And, again, I was told, "You need money to ask those questions, Donna. You need to get a PhD or an MD."

I wrote in my application to go back to graduate school that I wanted to be a "clinical trials architect in oncology nursing." I asked myself, why not move to Seattle and attend the University of Washington? And once there, the faculty went to work on me. I conducted research on cancer treatment side effects and returning to the workplace with a cancer diagnosis. I finished my PhD in 1992, at a time when health care was reeling from a round of "right sizing." Creating a new position as a nurse researcher, a clinical trials architect in Seattle, was not going to happen.

I found myself back at the University of Washington. Again I contemplated, why not have two programs of research? Why not study cancer symptoms and side effects, but at the same time, study cancer treatment decision making? I began as a research assistant professor. The guidance and mentorship I received at the University of

Washington, under the leadership of Nancy Woods, PhD, RN, and Margaret Heitkemper, PhD, RN, were phenomenal and continue today. My research is all about creating opportunities for our patients, for patients with cancer to fully express themselves regarding their healthcare issues, and to participate fully in their health care. As junior faculty, I worked very hard to get these programs of research off the ground. At the same time, I was longing for the experiences of clinical practice I had left behind. Fortunately, the School of Nursing was right next door to the University of Washington Medical Center.

Electronic Self-Report Assessment–Cancer

I volunteered in the University of Washington Cancer Center on one of the clinical teams as a discussant. We met regularly to discuss interesting clinical situations with our patients and to try to bring evidence from the literature to those discussions. One focus for our discussions was "Why does it take so long to discover our patient's problems in the clinic?" So, in 1999, we assembled a group of volunteers who planned a way to address this. We were able to get \$50,000 from the ONS Foundation's Priority Research in Symptom Management initiative to develop a prototype solution for collecting cancer symptom and side effect information. We formed a very dynamic research team of oncology clinicians from three different disciplines and students. Ultimately, we developed a successful prototype for patient-reported symptom and quality-of-life information that worked well in our clinic.

Those preliminary data gave us segue into the National Institute of Nursing Research–funded randomized clinical trial for electronic self-report assessment–cancer (ESRA-C). In that first randomized trial, we wanted to compare the clinical impact of using ESRA-C to usual care; not just in one cancer diagnosis, but the whole house. We wanted to know the effect of the intervention on communication of symptoms and quality-of-life concerns, on action taken for therapies to address the symp-

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toms, and what referrals were made. We randomized 660 patients with all diagnoses and stages. Long story short, our primary outcome was analyzed in the 590 patients for whom we had not only their symptom report at two time points, but also an audio recording of patient/provider conversations during a clinic visit. We found that symptoms and quality-of-life concerns were addressed significantly more often when the ESRA-C was made

available, more often when there actually was a problem with that symptom and that this outcome differed between symptoms, because not every symptom receives the same attention. This report came out in March 2011 in the *Journal of Clinical Oncology* (Berry et al., 2011).

Today, there are many sons and daughters of ESRA-C and secondary, interim analyses conducted by all kinds of folks. We have an analysis of the concerns of transplantation patients conducted by a direct care nurse at Seattle Cancer Care Alliance, Cindy Klein, RN, and this is now being prepared as a manuscript by a doctoral student at the University of Massachusetts in Boston. Cognitive dysfunction was studied by Erica Machol,

We need to ask *why* again and ask new research questions.

ARNP, acceptability by Seth Wolpin, PhD, RN (Wolpin et al., 2008), and Joseph Tariman, PhD, APRN (Tariman, Berry, Halpenny, Wolpin, & Schepp, 2011), and feasibility of depression screening in the ESRA-C, first authored by our psychiatrist on the team (Fann et al., 2009). Sleep disturbances were first evaluated by our high school student who worked with us in the summer of 2009, Bianca Valcarce, and now submitted in manuscript form by Mary Lou Siefert, DNSc, RN. And finally, Lisa Kennedy Sheldon, PhD, APRN, has published a secondary analysis of the ESRA-C evaluating patient/provider conversations regarding emotional stress (Kennedy Sheldon, Hilaire, & Berry, 2011). Carmen Chan, PhD, RN, replicated the pilot work with a Chinese version of ESRA-C in a feasibility study in Hong Kong (Chan et al., 2010) and Wei-Wen Wu, PhD, RN (Wu, Johnson, Schepp, & Berry, 2011) transformed ESRA-C into an adolescent version that was successfully piloted at Seattle Children's Hospital's ambulatory oncology service.

There are implications and further questions based on results with the ESRA-C program of research. What would it take to promote appropriate clinician responses? Because we learned that not every symptom was discussed as often as others, clinicians may have avoided discussions of those symptoms they were either unsure how to address (e.g., cognitive dysfunction) or uncomfortable discussing (e.g., impact of treatment on sexual activities). We really need enhanced training, notably for psychosocial issues, and Dr. Sheldon is going to move forward with this area. We need smooth access to resources for clinicians, and we're working on that at Dana-Farber Cancer Institute. We need to ask *why* again and ask new research questions. Can patients be prompted not only to raise the issue with the clinical team, and give the beginning of the subjective component of a symptom analysis? And, can patients engage in and adhere to self-care strategies? And finally, can we improve their symptom outcomes? So, stay tuned.

Cancer Treatment Decision Making

My other program of research addresses cancer treatment decision making. A diagnosis of localized prostate cancer (LPC) leads a man to one of the most difficult decisions, if not the most difficult treatment decision, in the cancer setting today. Men are given the burden and the responsibility to choose a therapeutic approach. When I started this program of research that evolved out of my dissertation, we knew very little about how men come to a decision. We knew that one out of six men would have prostate cancer. We knew that survival rates and complication rates are not easily interpreted because there were no randomized clinical trials between modalities. We didn't know what the best treatment was in 1997. In 2011, we know only a little more; men with high-risk tumors appear to live longer after having surgery versus watchful waiting.

My very first study funded by the National Institutes of Health was an R29, a mechanism for new investigators that doesn't exist today. I planned a five-year, multimethod study in which we started with qualitative methods with both our patient and physician participants and went on to quantitative. We learned that the theme of the decision process for men with LPC was *making the best choice for someone like me* (Berry et al., 2003). We ultimately developed an intervention called the Personal Patient Profile-Prostate (P3P), with a little help from the National Cancer Institute and then from the National Institute for Nursing Research. The P3P is a completely Web-based system to teach and coach men, based on their personal factors, values, and prefer-

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ences, as they prepare for the treatment decision (Berry et al., 2010). In P3P, the man with LPC answers a series of questions and, based on his answers, a menu of options is delivered: customized, tailored education and coaching, including video clips specific to that man's race and that man's ethnicity and that man's language (English or Spanish), and it delivers this intervention to him on screen or on paper and provides worksheets for use during the doctor's options review consult. The purpose of our last multisite trial was to test this innovative measure of personal factors and customize decision support system and evaluate its effect on decisional outcomes, and we hypothesized we would see lower levels of decisional conflict in the intervention group, plus a higher perception of preparedness and higher levels of satisfaction with decision.

We conducted our trial in Seattle, WA, Philadelphia, PA, Augusta, GA, and San Antonio, TX with 494 eligible

men. Using the P3P, we significantly reduced decisional conflict over time compared with the control group for the total score of decisional conflict and for the two subscales, decisional uncertainty and factors contributing to uncertainty, and borderline for effective decision making. We also saw that the acceptability of the program was highly rated by our participants (Berry, 2010).

Throughout both my programs of research, I have been blessed with some very dedicated coinvestigators and research team members. My research teams are large and full of cancer care clinicians and researchers from nursing, medicine, social work, and informatics. We have competitive renewals being submitted for both programs this year. I have added new colleagues from Dana-Farber and submitted the next generation of the Personal Patient Profile approach. Hopefully we are going to have P3-Ovarian and P3-Myeloma.

I have spent many years engaged in various ONS roles and projects. I was the chairperson and principal investigator of the ONS research agenda from 2003 to 2008. Our research conference process gathered clinician, consumer, and researcher input. We came together with both quantitative and qualitative data, a multimethod consensus approach to develop our priority research topics, and finally came up with our research agenda. After publication, priority research results were applied and evaluated within practice; then we completed a cycle in which new ideas are generated from those practice settings and become the future research priorities. Key to this process is the successful application of new knowledge to practice and evaluation of the application success.

Science and Practice Aligned Within Nursing

I had always pondered how to bring about that successful application of new knowledge and raise the level of scholarly practice. In 2003, I was able to be a part-time, clinically based nurse researcher at the Seattle Cancer Care Alliance. I dedicated myself to the possibility of science and practice aligned within nursing, or SPAWN®. Nursing is a practice discipline, and every day, oncology nurses face people who have great needs; they must have the best evidence at their fingertips. They have to hear from the people who have developed that evidence, and they have to hear from people who know how to deliver it to them. They have to hear it at

every conference, not just a research conference. It is not enough to just learn interesting facts and findings that someone else has synthesized for you. We must take concrete actions to bring the findings to our care, find out if they will work well for us in our own settings. We need clinical researchers to get involved in doing that, and we need to make it known that our findings make a difference. There is only one way to do that, and that is to get into the clinical setting, do it and evaluate it—not just throw it on a Web site, not just put it in an article, not just have an hour-long lecture.

At Dana-Farber Cancer Institute, not only is the nursing department and our chief nursing officer, Patricia Reid Ponte, DNSc, RN, FAAN, committed to such a process, but also the physician leadership. Edward Benz, Jr., MD, president of the Institute, is one of our strongest supporters. With the resources made available by the Dana-Farber Cancer Institute, my colleagues in the Phyllis F. Cantor Center and I have begun to align science and practice in oncology nursing.

I would like to finish with a quote from a book my high school nurse gave me, *Come Climb My Hill*. "It is the sense of mystery that gives to life its majesty" (Abbott, 1976, p. 7). Thank you from the depths of my heart and soul.

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