

Being there makes things bearable

An inside look at the role of a pediatric oncology nurse practitioner

By Susan Wessling, On Call Magazine, June/July, 2004

When he was asked recently on a college application to list the people he most respected, one young man who has been an oncology patient at Dana-Farber Cancer Institute's Jimmy Fund Clinic had no problem deciding who to put first. Arlene "Andy" Androkites, BSN, MSN, CPNP, topped the list. But he wasn't the only one to feel strongly about this nurse. His mother was so pleased with the care Androkites had provided her son that she wrote a letter to the president of Dana-Farber, saying, "Andy has to be one of the most competent, caring and lovely people we know."

Androkites, a pediatric oncology nurse practitioner, had been the young man's primary medical manager for two years. The boy's mother went on to say that since her son has experienced almost every imaginable side effect from the chemotherapy and radiation, things have not been easy. "Through all of this," she wrote, "Andy has always been there for us. Whether taking daily phone calls, whether being second-guessed, whether handling a hysterical mother, or just getting him to cooperate when he didn't want to anymore, Andy was there and made things bearable." Being there for people is what Androkites does in her role as a nurse practitioner at the Jimmy Fund Clinic.

A Bond of Trust Between Patient and Provider

The Jimmy Fund Clinic provides outpatient care for children with a suspected or diagnosed cancer and those who are at high risk for cancer. It is part of a collaboration between Dana-Farber Cancer Institute and Children's Hospital Boston. Inpatient care and pediatric subspecialty consultation are provided at Children's Hospital, but the two institutions function as one to provide a continuum of care. Androkites is one of many pediatric healthcare professionals at Dana-Farber and Children's Hospital who provide that care.

Each patient and their family members have a primary multidisciplinary team of providers at the clinic lead by a pediatric oncologist. Key members include a pediatric oncology fellow or nurse practitioner, an inpatient and outpatient primary nurse, a social worker or psychologist, clinical assistants, child life specialists, pediatric pharmacists, and other support staff. Karen Conley, RN, MS, AOCN, the nurse program manager for pediatric oncology at Dana-Farber, says Androkites epitomizes the NP role. Some NPs, according to Conley, focus only on the medical model. "Andy does a great job of upholding the clinical piece in the medical model," she says, "as well as the nursing model. I think that is hard to do, especially when you are held up to the same standard as physicians. It is hard to keep one foot in each camp."

Androkites, who began her nursing career in oncology, has been an NP for the past 22 years and has spent 20 of them at Dana-Farber. She says the increased responsibilities--primarily the ability to do physical assessment--is what drew her

into the role of nurse practitioner. "I love the teaching aspects and the time you can spend with a family and patient educating them about the illness, offering psychological support and being able to have a true impact on the course of illness," she explains. "Along with that is the ability to prescribe the chemotherapy and the associated medications that go along with it. So it was the additional challenges, the extra areas of care that helped me decide that this is what I wanted to do."

Androkites sees her nursing background as one of her most important assets. Families often bond with their provider, she says, especially since they meet them so early in the process. "It is actually a journey you go through together. You have a very close working relationship, so the relationship you have is very important. The trust is established early on. I think the advantage is that I have been here a very long time," she adds, "so I carry expertise and also [a] nursing background that really strengthens that role."

When she first became a nurse, Androkites says, "I wanted very much to go on to pediatrics, and there happened to be an opening in a pediatric oncology clinic. I started out in Children's Hospital in Philadelphia and I had no idea if I would like the role." But she was hooked from the start. "I think it is something you know immediately." At the time, she was working as a clinic nurse, so she was administering chemotherapy and helping manage side effects. "The whole day was basically spent doing IVs and supporting patients and helping with procedures. I loved it, and I knew it was my thing. There happened to be a program at Children's Hospital for education of nurses to become NPs, so I started taking classes. It all fell into place."

Helping Families Face the Issues in Spite of Fear

Eight nurse practitioners work in the Jimmy Fund Clinic, which treats children from newborns to 18-year-olds and also cares for adult survivors of childhood cancer. Androkites is one of three NPs--and the only full-time NP--who work in the General Oncology Clinic, which is held five days a week. The majority of her patients have Acute Lymphoblastic Leukemia (ALL). She also works with patients with lymphoma and Wilms' tumors.

Androkites manages a child's care from the time of diagnosis. She prescribes treatment and provides education. She also performs some procedures, such as bone-marrow aspirates and lumbar punctures. "From the time of diagnosis, you are doing physical examination," she says. "You are monitoring lab work, you're treating any side effects, fevers, or complications that occur as a result of immune suppression or the actual treatment. I also prepare the child and family for end-of-treatment issues and then I follow them off therapy, observing the patients for effects from treatment."

Every family has different needs and coping skills, which is part of the challenge of her position, Androkites says. For instance, the psychosocial issues are very different for young children than they are for teens, and, Androkites says, younger children seem to be more resilient. "The adolescent group is the most difficult to deal with because they want to live life normally, and body image is so important. The fact that they lose their hair or have fatigue or nausea or vomiting hits them harder." She adds, "When you take on a new family, you try to do the best you can to work with that family and get them through the cancer experience as unscathed as possible. You do get to know the child and the family very well. You do get an innate understanding of how you can help them and support them."

Addressing family issues such as child care, finances, and food during a visit is all part of the help-and-support equation. There can also be issues with siblings,

Androkites says. Oftentimes, other children feel they are not receiving enough attention or are extremely worried about their sibling's cancer. Parents sometimes get so busy with the medical needs and with keeping the family together that communication within the family suffers. In this kind of scenario, a psych/social team consult may be in order. "The other kids need to maintain normalcy, and yet they have fears, and they get jealous," Androkites says, "so it is really a lot for the parents to think about."

One of the more difficult issues in working in oncology involves reoccurrence of the cancer. "You never get used to the sadness that is involved," Androkites says. "The child is devastated; the parents are devastated; and you have to look for additional forms of therapy." Helping to strengthen the family so they can get through what lies ahead in this case is a challenge.

Care Based on Experience and Continuity

The rapport Androkites has with families is "phenomenal," according to Ann Marie Beauchemin, RN, BSN, CPON, a staff nurse at the Jimmy Fund Clinic and the primary nurse who works with Androkites. "Andy has a very gentle approach," Beauchemin says. "She doesn't rush anybody. She will answer questions in her room for an hour if that is what it takes to make the families comfortable." That type of care builds trust. "She invests the time up front, when it is most needed," Beauchemin says. "So then families will be more relaxed and the visits will be shorter over time."

In the adult world, Androkites says, the healthcare provider talks one-on-one with the patient, and that person chooses to bring others in for consultations. When it is a child, the provider's job includes educating the parents and siblings. "You do look at it as a family catastrophe," she says. At the same time, it's important for the child to understand his or her illness and the need for treatment from the beginning. "The child [needs to be] told as much as he can developmentally understand," Androkites says. And if the disease comes back, it is important for a child to realize it is not anyone's fault. In some cases, the fact that the child may not have an opportunity to recover needs to be addressed. "Then, at that point, the discussion changes with the parents," she says, "and the child is brought in then in really a very individual way." You don't want to frighten them, but at the same time you want to help them understand what is happening. I think you need to be able to talk openly about disease," Androkites says, "and the negative aspects of it, which can include death." She adds that some people know immediately they can't work with sick children. "Their hearts get broken."

Her nurse manager, Conley, says Androkites is medically very savvy and extremely competent as far as diagnosis and treatment goes. "She is so competent that she is a mentor to new nurse practitioners," Conley says, "and also contributes to training many of our fellows--physicians in training--on the intricacies of pediatric oncology. She has the medical piece down, but one of the beauties of Andy, and many nurse practitioners, is that she has that caring, compassionate nursing perspective as well."

Androkites works in the General Oncology Clinic four days a week. "Having the ability to reach me and to see me on multiple days is a positive thing for a family," she says. Patients at the clinic, she feels, get excellent care. "If I have an issue," she says, "there is medical backup, and we provide continuity, [and] the longer you work in an oncology setting, the more experience you have managing protocols. You can anticipate side effects and better prepare the family for the side effects because that is what experience teaches you."

Every Day Is Special

If there is a downside to her job, it is the emotional drain it can have on her. "I think you assert a tremendous amount of emotional energy, and I think, therefore, other areas of my life have been shortchanged," Androkites says. "You come home from a day in the clinic and there is an exhaustion that is difficult to explain. Oftentimes, you go home and you can't do anything but stare at a television or read a few pages in a book because you have really given so much of yourself during the course of the day."

Androkites admits she sometimes is jealous of friends with less stressful jobs. But, she adds, people who work in oncology have a very special appreciation for life. "The relationships you form in your personal life seem so much more important because you know within a day that relationship could be altered because of health reasons. Every day is special because the unknown is always around the corner."

In 2002, Arlene Androkites, BSN, MSN, CPNP won the President's Award for Nursing Excellence. The honor, bestowed by former recipients, is awarded to two nurses yearly at the Dana-Farber Cancer Institute.

How to Find Out More

The Dana-Farber Cancer Institute was founded in 1947. It is committed to providing cancer patients with state-of-the-art treatment while developing tomorrow's cures through cutting-edge research.

For more information contact:

Dana-Farber Cancer Institute
44 Binney Street
Boston, MA 02115
Tel. (866) 408-DFCI (3324)
E-mail:
Internet:

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