LONG-TERM SURVIVOR PROGRAMS
A PARADIGM FOR THE ADVANCED PRACTICE NURSE

The Role of the Pediatric Nurse Practitioner in Follow-up Care of Children, Adolescents, and Young Adults Cured of Childhood Cancer

The increasing cure rate for childhood cancers increases the numbers of children, adolescents, and young adults who are survivors. Follow-up care for these survivors goes far beyond the former 5-year plateau. The care necessary for the long-term survivor is more than just a history and physical examination. Pediatric cancer survivors require specific screening and assessment. Today, we recognize that care for this population must be lifelong. The trauma of cancer is not over just because the treatment phase has ended. Cancer is a "permanent life experience" as described in 1980 by Shanfield.

However, today resources in healthcare are stretched even to provide the care for patients who are actively being treated for their cancer. The increasing population of cancer survivors creates a further stress on health care professionals. It becomes increasingly difficult to follow long-term survivors with the number of medical professionals available today and the myriad problems these survivors face.

Childhood cancer survivors have expressed that they do not wish to burden physicians and loved ones with their issues that may seem insignificant compared to the life-threatening events of the treatment phase. (Leigh)

The following is a review of some of the phases described from the perspective of childhood cancer survivors.

- **Diagnosis**
  This is the period of time when the diagnosis is made. Tests, scans, laboratory studies, invasive and non-invasive procedures are performed. The patient and family are given extensive information. There is usually input from many sources. The family is asked to give consent for treatment.
- **Treatment**
  During this phase, the actual treatment occurs and may include surgery, radiation therapy, chemotherapy, immunotherapy, and any other therapy. Supportive care measures may be given. Acute side effects and toxicities occur during this treatment phase.
- **Intermediate survival**
  "When an individual completes initial cancer therapy, he or she enters an intermediate phase of survival where survivors walk a fine line between the land of the sick and well." (Leigh, p 194.) They are in a type of limbo when all signs of disease are gone. Although the actual treatments have been completed, there may be some lasting effects that make the survivor physiologically different, challenging other aspects of their lives.

  Psychologically, the patient (if old enough) and the family experience the stress of potential recurrence. Although there is a sense of relief that there are no further treatments, the anxiety and fear of the return of the disease can be overwhelming.

  Socially, the intermediate phase may be the hardest of all for the survivor and family. The supportive persons surrounding the family, as well as the healthcare providers, expect that all is normal and the child and family should return to life as it was before cancer. It is during

this phase that the child and family may find it difficult to speak with physicians for fear that they will be considered ungrateful, complaining, or difficult.

- **Long-term phase**
  During this time, the child and family begin to realize that cure may actually be a reality, as things really do return to a "normal" state. However, during this phase, long-term (chronic) and/or late (delayed) physiologic effects may occur. In addition, psychosocial issues may include issues surrounding reentry into the job market, school, peer friendships, and/or post traumatic stress disorder. (Hobbie, etal, 2000)

  The transition from being ill to being completely well is considered one of the stressful challenges that evoke anxiety. (MacLean, etal.) This transition must be acknowledged by caregivers, long-term survivors, and their families. It is important that there is ample time to help with the necessary adjustment.

"All survivors need follow-up care that is organized, systematic, and comprehensive, including physiologic and psychosocial components." (Hobbie, etal, 2002, p 426) The authors note that the goals of off-therapy programs include:

- Assessment of risk factors based on preexisting disease, the diagnosis, treatment, and acute effects;
- Obtaining a careful history, including psychosocial issues and well-being;
- Providing a thorough physical examination;
- Teaching health promotion and disease prevention strategies;
- Developing a specific plan for lifelong follow-up care that can be shared with other health care professionals.

THE HEALTHCARE ENVIRONMENT

The changes in the healthcare industry are very complex and are intertwined with providers, agencies, government, and society. The medical model which includes diagnosis, treatment, and cure is no longer a viable paradigm for today's society. Today, chronic disease, lifestyle-induced illness, and health and wellness issues have made it nearly impossible for cure to be the outcome of the medical model.

There is a new paradigm for healthcare delivery, which is more holistic. Disease and its associated symptoms are merely the information for healthcare providers rather than the focus. The patient, family, and society are all partners with the healthcare provider to ensure that self-care, self-reliance, and self-responsibility are part of the care emphasizing human values, cooperation, and mutuality. (DeBack & Cohen)

THE NURSE IN PEDIATRIC ONCOLOGY

The pediatric oncology nurse emerged in the late 1940s when children with cancer were diagnosed and soon succumbed to their disease. Nursing care consisted of "keeping the child clean, comfortable, and out of pain." (Foley & Fergusson, p.10). When chemotherapy was initiated as a treatment modality, the nurse developed into the tumor therapy nurse. Jean Fergusson was an early pioneer in oncology nursing. She worked with Dr. Sydney Farber and

others at Children's Hospital in Boston, helping to develop one of the first tumor therapy clinics in the United States for children with cancer. (Foley & Fergusson).

Pediatric oncology nurses were the unsung heroes in the 1950s. Their role was primarily to administer chemotherapy. There were stringent hospital rules preventing family visitation, except during limited, prescribed times. By the 1960s, improvements in outcome for the child with cancer became a reality with the use of improved therapeutic treatment strategies and supportive care methods. Family-centered care became important and pediatric oncology nurses became the link between the patient, parent and family, and the physician. The nurse provided clinical care, education, and support.

The nurse was educated and mentored by the physicians with whom she worked. Eventually continuing education programs were developed to provide the pediatric nurse with information and peer support. As progress in treatment improved through clinical trials' research, the pediatric oncologist needed a nurse to assist with data collection and patient evaluation.

Dr. Henry Silver, a pediatrician, and Dr. Loretta Ford, a nurse educator, envisioned the original role of the pediatric nurse practitioner (PNP) in 1967. They developed a continuing education program for nurses at the University of Colorado in Denver, CO, to provide health care screening, education, and common illness management to healthy children in areas with limited access to physicians.

In the early 1970s, Dr. Donald Pinkel, the first medical director of St. Jude Children's Research Hospital in Memphis, TN, and his colleagues, adapted the Colorado model to train selected nurses to perform physical assessment and advanced technical skills. At the completion of their training, they were awarded a certificate from St. Jude and were called nurse practitioners in pediatric oncology. (Foley & Fergussen)

At that time, there was a shortage of primary care physicians, which provided an impetus for the nurse practitioner to provide direct patient care to patients with increasing complexity of health care problems. When childhood cancer cure rates began to increase in the mid-1970s, a need arose for a new healthcare provider who would specialize in childhood cancer. Nurses recognized that this would be an innovative role for the nurse.

In 1976, Jean Fergusson, RN, DEd, at Children's Hospital of Philadelphia (CHOP) designed a two-semester educational program to train nurses as pediatric nurse practitioners with a specialty in pediatric oncology. In order to meet the qualification for certification, it was necessary for the program to provide designated didactic information and clinical practice in the area of pediatric primary care. These nurses were eligible to sit for the certification examination as PNPs.

Subsequently, as the nursing profession recommended that the PNP have an advanced nursing degree, the CHOP program developed a relationship with Widener College and later with University of Pennsylvania, to provide courses leading to a Master of Science in Nursing (MSN) degree. Many of the early graduates continued their education and to received a Master's degree. Presently, all states require that PNPs receive an advanced degree.

In 1987, the Association of Faculties of Pediatric Nurse Practitioner/Associate Programs delineated the scope of practice for the PNP: "wellness, prevention, and health promotion.

PNP/As perform physical examinations and developmental assessment, treat common childhood illnesses, coordinate care of common chronic illness in children, and help families meet their health needs."

Since that time the role of the PNP has evolved at a rapid pace forging new trails in health care delivery. The PNP can be found in such settings as intensive care units, inpatient units, schools, surgical centers, emergency rooms, and specialty outpatient clinics, to name a few. (Tobias & Klemt)

Many PNP graduates are certified by the National Board of Pediatric Nurse Practitioners/Associates and others are certified by the American Nurses Association (ANA). The name "advanced practice nurse" (APN) is used today to describe the combined and /or blended role of clinical nurse specialist (CNS), which traditionally was that of educator in a specialty area, and nurse practitioner (NP), as described above.

Each state has different licensure requirements for APNs. Many states recognize APNs as a separate and distinct entity for licensure. In many states, the APN may have prescriptive privileges if they are certified and meet the pharmacology requirements of that state's board of nursing. In some states, the APN has prescriptive privileges that may include controlled substances. After meeting the states' qualifications, the APN must maintain the privilege by meeting certain ongoing educational requirements.

Today, the APN in pediatric oncology is a licensed, registered nurse prepared with a minimum of a master's degree. This nurse has acquired advanced knowledge in pediatric oncology nursing with demonstrated competencies in all areas of basic practice in addition to the APN standards. Although there is no specific certification for the APN in pediatric oncology there is certification in primary care and advanced oncology nursing. The APN in pediatric oncology (APN/PO) should also be certified by the Oncology Nurses Certification Corporation (ONCC) as a Certified Pediatric Oncology Nurse (CPON). This certification test measures basic knowledge and requires that the nurse have clinical practice experience in pediatrics and pediatric oncology.

The role of the PNP is ever evolving. With the changes in health care delivery and the demonstrated ability of APNs to provide high-quality care, they are providing care to patients who are well, as well as those with complex health care needs. This new environment requires more APNs who can coordinate care, case manage, advise and council, triage and monitor, advocate, evaluate outcomes, utilize evidence-based care, and add to the body of knowledge through research. There is no end to the continuum of care services that can be provided by the APN. These changes call for adjustments in relationships with other healthcare professionals. Further interactions with all members of the healthcare team will facilitate these relationships.

SCOPE AND STANDARDS OF PEDIATRIC ONCOLOGY NURSING

The Scope and Practice of the APN in pediatric oncology was traditionally delineated on an individual basis. The APN and the collaborating physician(s) would develop standards for collaborative practice and write this as well as the job description under which the APN would function. The pediatric oncology nursing *Standards of Nursing Practice* was developed by the Association of Pediatric Oncology Nurses (APON) in 1978 and revised in 1987 to reflect nursing process and outcome standards. In 2000, APON developed a new *Scope of Practice and*

Outcome Standard of Practice for Pediatric Oncology Nurses in accordance with the American Nurses Association (ANA) standards. It was published by the ANA and includes the scope and standard for practice of the APN. It provides the guidelines under which an APN in pediatric oncology should practice. It is used to formulate the job description for the APN and provides a standard by which the APN can be evaluated.

The Advanced Practice Nurse in pediatric oncology nursing (APN/PO) is expected to practice according to the Scope and Standards of Pediatric Oncology Nursing Practice, 2000. The qualities of the nurse, the standards of care, and the performance standards are abstracted below.

Qualities for the APN/PO

- **Self-directed in the development and maintenance of competency**: The APN/PO seeks educational opportunities whenever possible. It is essential for the APN/PO to continue to learn and grow in all aspects of pediatric oncology care, as well as pediatric primary care. This includes knowledge about clinical trials, treatments, side effects, potential long-term effects, and much more. It is essential that the APN/PO attend continuing education programs, professional meetings, and conferences.
- **Member of professional organizations:** The APN/PO should be a member of appropriate professional organizations, such as the Association of Pediatric Oncology Nurses (APON), Oncology Nursing Society (ONS). This provides an avenue for interaction with colleagues and an opportunity to grow and develop in the professional aspects of the profession.
- **Certified in relevant areas**: It is essential for the APN/PO to be certified in the area of practice. The Oncology Nursing Certification Corporation (ONCC) offers certification as a. Oncology Certified Nurse (OCN), a Certified Pediatric Oncology Nurse (CPON), and Advanced Oncology Certified Nurse (AOCN). The National Board of Pediatric Nurse Practitioners and Associates (NBPNP/A) also offers certification as a Certified Pediatric Nurse Practitioner (CPNP).
- **Role model for clinical nurses and other healthcare professionals**: The APN/PO serves as a role model for other nurses and for healthcare professionals within an inpatient and outpatient setting. It is part of the professional commitment of the APN/PO to educate the public sector, as well.

Standards of Care for the APN/PO

- Assessment is the first standard of care for all healthcare professionals and includes data collection to determine physical, emotional, cultural, and social needs, as well as the well being of the child and family.
- Diagnosis is the next standard of care and it involves the systematic analysis of the assessment data to identify actual and potential diagnoses.
- Outcome Identification occurs when the APN/PO identifies expected outcomes based on the assessment and diagnoses of the patient and family, in collaboration with the multidisciplinary team when appropriate.
- Planning based on the diagnoses, involves the formulation and implementation of a plan of treatment, and interventions to achieve the desired outcomes.
- Implementation includes case management, consultation, health promotion, education, prescriptive authority, referral, and research to implement the appropriate plan of care.
- Evaluation is the last step that is an expected standard of care. It is essential that the APN/PO monitor and evaluate the response to the plan and the interventions provided.

Standards of Professional Performance for the APN/PO

- *Quality* is the basis for all of the care given by the APN/PO. The APN/PO develops criteria and evaluation for quality clinical outcomes and effectiveness.
- *Self-Evaluation* by the APN/PO is vital to continually assess one's own clinical practice in order to maintain competent care.
- *Continuing education* and integration of new knowledge and advances into their practice is required of all oncology APNs. (ONS Position Statement, The Role of the Advanced Practice Nursed in Oncology Care, 12/97.)
- *Leadership* roles by the APN/PO include functioning as a leader, role model, and mentor for the professional development of peers, colleagues, staff, and students. In addition, The American Academy of Nurse Practitioners notes that an important leadership function is participation in legislative and professional activities to promote professional advancement and health related social policies. (Nurse Practitioner as an Advanced Practice Nurse Position Statement, American Academy of Nurse Practitioners.)
- *Ethical practice* includes advocacy for the patient and family, including their rights, access to care, informed decision-making, autonomy, and developmentally appropriate information.
- The complexity of pediatric oncology care requires *coordination* and on-going *interaction* among the multidisciplinary team. The team includes other disciplines, as well as the patient and family.
- *Research and evidence-based practice* are incorporated into research activities and clinical practice.

BARRIERS TO EDUCATION AND TRAINING FOR THE APN/PO

Several issues provide barriers for nurses to enter the APN arena. There is still a lack of definition of advanced practice nursing, variability in educational preparation, and lack of agreement among state boards of nursing related to privileges for APNs.

However, more importantly, there is a critical shortage of nurses. Presently, hospitals are coping with a shortage of 126,000 registered nurses (RNs), and it is predicted that this will increase to more than 400,000 by 2020. (Maes, 2002). The number of APNs is estimated to be 196,279, or 7% of the total RN population. Nurse Practitioners comprise 53% of this population, or 102,829 nurses. (O'Grady)

It is believed that a majority of pediatric oncology nurses are members of the Association of Pediatric Oncology Nurses (APON), as it is the only professional organization for pediatric oncology nurses. The statistics available from APON membership demographics indicate that of the 2000 members, there are 457 members with a Master's Degree; 192 indicate that they are nurse practitioners; 162 indicate that they are clinical nurse specialists. There are 865 members with Baccalaureate Degrees and 225 with Associate Degrees. It is possible that some of these nurses will further their education and become APNs in the future.

There are 29 masters' programs listed on the Oncology Nursing Society's (ONS) Website to educate the nurse as an APN with a specialty in adult oncology. (www.ons.org) However, there are relatively few programs for the nurse who wants to become an APN in pediatric oncology. In fact, careful review of the curricula of the colleges and universities that offer a Master's Degree in Nursing with a specialty in oncology reveal that some may outline that there is a pediatric advanced practice curricula, but in actuality there are no scheduled courses. There may be some

integrated lecture material or an adjunct lecture that is included in the course, but there are no programs with formal, full-time curricula in pediatric oncology. Emory University and the University of Pennsylvania and others may offer courses taught by an APN/PO experienced with long-term survivors, but these are usually on an adjunct basis. St. Jude Children's Research Hospital offers a distance learning program for pediatric oncology. Therefore, the pediatric nurse may have to enroll in a program that will provide a degree in pediatric primary care or adult oncology. Many programs offer clinical experiences in areas of desired future work, such as pediatric oncology. A student may contact a pediatric oncology program where there is a willing physician or ANP to function as preceptor. Occasionally a student may have the opportunity to see patients who have completed therapy and are followed in a late effects clinical setting. This is usually on a "hit-or-miss" basis. At the successful completion of these programs, a master's degree is bestowed and the nurse may sit for a certification examination.

Jackson, etal (2001) described the characteristics of employment, the children served, and the role functions of recent graduates of PNP programs. Of the 137 surveys returned (52% return rate) indicated that 70% of the respondents indicated they "often" or "sometimes" provided care to children with acute/critical conditions, and 77% reported caring for children with chronic conditions. This data suggests that PNPs function beyond the traditional areas required for the pediatric primary care education they may have received. The authors conclude that educational programs should address the changes in the care continuum provided by PNP graduates. It is necessary for more programs to provide curricula and clinical practice situations in keeping with these changes.

A survey was undertaken by the Advanced Practice Nurse Survey Team formed by the Oncology Nursing Society (ONS) Steering Council in May 2000 to ascertain critical issues inherent in advanced practice roles. (Lynch, etal.) A sample of 1000 APNs from the ONS membership received surveys with 368 surveys being returned (37% response rate). Fifty-eight percent of the respondents had not graduated from an oncology-specific graduate program.

There are several negative aspects of this scenario. First, in order to learn the basics of pediatric oncology, the nurse must glean information from preceptors. Formal classes are rare. Nurses are resourceful and should be able to garner necessary learning from preceptors and extrapolate data from adult to pediatric care. Nevertheless, this is a failing in the educational system. There is a need for more programs to train nurses to become APNs/PO.

It is possible with the myriad information a nurse needs to learn in masters' programs that there may never be time to see patients who are survivors of childhood cancer. In fact, it probably is not a priority for the student. It is crucial for the student to gain skills in history-taking and physical assessment and this is best accomplished during the general on-therapy clinic setting. Unless there is an integrated long-term survivor program, the student may not see patients who are off therapy.

Recently there has been increasing literature about long-term effects and childhood cancer survivors. This is a means for nurses to study and learn about the problems of survivors and their families. However, this too is not a formal method for learning. The nurse must obtain the information on an independent basis.

Nurses must be lifelong learners in order to give the best care to their patients, whether acute or follow-up care. Nurses have been instrumental in the research focused on various aspects of survivorship, including insurance and employment, marriage and relationships, fatigue, and post-traumatic stress disorder, as well as many others areas. However, constraints on healthcare dollars may effect the ability of the APN/PO to participate and attend continuing education programs.

Organizations such as the International Society of Pediatric Oncology (SIOP), American Society of Pediatric Hematology-Oncology (ASPHO), Association of Pediatric Oncology Nurses (APON), Oncology Nursing Society (ONS), as well as the Children's Oncology Group (COG) offer conferences and educational seminars directed toward nurses and/or physicians specializing in pediatric hematology-oncology. There may be one or two sessions included in these conferences about long term survivors of childhood cancer. Often this is the only information nurses can obtain on the subject.

There is only one pediatric oncology nursing textbook: Nursing Care of the Child and Adolescent with Cancer (Baggott, etal.) Included in the book is a fine overview of survivorship, covering physiologic and psychosocial issues. It speaks to many issues, but is by no means complete. Principles and Practice of Pediatric Oncology, (Pizzo and Poplack), is the foremost text directed toward pediatric oncology physicians. It includes chapters on physiologic late effects and on psychosocial issues including the late effects of childhood cancer, educational and financial issues in pediatric cancer, advocacy, insurance, education, and employment issues.

There is literature emerging on the topic of long-term survivors. An Internet search of literature using the description "childhood cancer survivors" found on "PubMed" shows 161 articles from 1998 to 2002. In fact, the literature has changed from general topics to specific issues of survivorship ranging from the physiologic to the psychosocial.

Networking with nurses from other comprehensive follow-up programs will help with mutual problem solving and in collaborating for the development of nursing research studies and educational materials. Through oncology nursing organizations such as the Association of Pediatric Oncology Nurses (APON), and Oncology Nursing Society (ONS), as well as the Children's Oncology Group (COG), there is a method to further collaboration that can assist in following long-term survivors throughout their lifespan. Although this is not a formal educational methodology, it provides nurses with an arena for discussion, mentorship, informal education, and collaboration.

LONG-TERM SURVIVORS' CLINICS

Three major pediatric medical organizations, International Society of Pediatric Oncology (SIOP), American Society of Pediatric Hematology-Oncology (ASPHO), and American Academy of Pediatrics (AAP) endorsed standards for long-term follow-up care for childhood cancer survivors. They advocated for the establishment of specialty clinics oriented to the preventive care that not only focused on maintaining an absence of disease or dysfunction, but also psychosocial and socioeconomic health and productivity. Survivors must be evaluated in a systematic manner to determine the full impact of cancer and its treatment.

Models for Long-term Survivors' Programs

There is no real knowledge of the number of programs that exist today to follow long-term survivors throughout the United States. However, it is estimated from a 1998 article by Oeffinger, etal, in a survey of the Children's Cancer Group and the Pediatric Oncology Group (now merged to form the Children's Oncology Group) that 96 institutions had some form of long-term survivor follow-up program.

Harvey, etal pointed out that it is essential that all of the team members involved in long-term survivor programs be "committed to the program and understand the unique issues of long-term survivors of childhood cancer." (p. 120). This provides an atmosphere that is safe for the survivor who may have medical and psychosocial concerns and fears. Understanding the developmental issues facing the adolescent and young adult is a very important. Blending the normal developmental issues with those of the long-term survivor may be a daunting responsibility for caregivers.

The size of the follow-up program usually dictates the type of program and the staffing requirements. Small-sized programs often are not able to have dedicated staff for the long-term survivor program. Financial and personnel constraints determine the organization of the program. Most importantly, it is imperative that the caregivers involved are familiar with the potential adverse effects of treatment.

Several program models exist for the follow-up care of long-term survivors. Regardless of the type of program utilized, the basic principle is to provide multidisciplinary care to the survivor and the family. This team should include the APN/PO, social worker and/or psychologist, and pediatric oncologist. Subspecialty caregivers from radiation oncology, endocrinology, gynecology, cardiology, neurology, and genetics, to name a few, may be present in the clinic or called on a referral basis. (Harvey, etal.)

<u>Shared Programs</u>

When long-term survivors are integrated with patients in all phases of the health/illness continuum, it is known as a shared program. Many programs, especially small and medium-sized programs use this model. The shared program offers many positive features. For instance, patients who are undergoing therapy have the opportunity to see and speak with patients and their families who have survived the ordeal. It demonstrates to the on-therapy patient that there really are long-term survivors and that this can be a reality for them as well. In addition, the caregiver may appreciate having long-term survivors integrated into the daily routine as it gives a hopeful perspective, especially during times of stress. A shared program can give an opportunity for a mentorship program between survivors and newly diagnosed patients and their families. This type of program assists the new patient with knowledge about what to expect, and, in turn, it provides the survivor an opportunity to "give back" to those who helped.

There are some negative aspects of this type of program. The caregiver may not have enough time to spend with the patient and family during the busy clinic when patients are receiving treatment and protocol/treatment decisions must be made. Many topics must be covered beyond the history and physical examination for the long-term survivor. The caregiver many not have the proper mind-set for the myriad issues facing the off-therapy patients, if patients on and off

therapy must be seen at the same time. For the patient, interactions between survivors and on-therapy patients may perpetuate feelings of survivor's guilt. Also, caring for survivors in a pediatric setting may make the older patient feel uncomfortable among youngsters going through treatment. These older teens and young adults may become noncompliant in their follow-up visits.

Stand-alone Programs

The stand-alone program usually has dedicated time and/or space for the long-term survivor program. In this type of program, patients have the opportunity to interact with one another and share experiences. The caregiver can set the time and mood of the clinic and spend as much time as necessary without taking away from patients who are receiving treatments. Program planning, evaluation, and research efforts are made easier by amassing patients with common needs. (Hollen & Hobbie) However, in this type of program the patient and family lose the opportunity to act as a role model for others.

Large programs can support a stand-alone program. With many survivors and personnel to care for them, there are enough resources to provide appropriate follow-up. Insurance carriers may not reimburse for the specialized evaluation by many caregivers, counseling, and coordination of service that is part of the follow-up for long-term survivors.

Interdisciplinary Programs

In the interdisciplinary model for the long-term survivor program, caregivers from all disciplines are present to see patients and their families. These may include social worker, psychologist, neurologist, radiation oncologist, physical and/or occupational therapist, and others. This type of program offers the patient and family the opportunity to see all of the needed specialists with one visit, rather than going to many different appointments. Careful coordination and scheduling is required to provide continuity of care for the patient, family, and all of the needed specialists. It may also be necessary for the program coordinator to plan for the required tests, x-rays, and follow-up studies prior to the actual patient visit so the team members can discuss results and plan for the impending visit.

Transition Programs

Transition programs may include adult healthcare providers—internist, medical oncologist, family practitioner, and/or an adult/family nurse practitioner who specializes in oncology. This model helps the survivor and family become familiar with specialists who care for adults and who are familiar with oncology. Ideally, for a period of time, in this program, the APN/PO would continue to be involved in the care of the survivor as it relates to issues that pertain to the past history of the pediatric cancer. Through education and mentorship, the adult/family nurse practitioner would learn about the late effects of the childhood cancer and begin to establish a rapport with the patient and family.

This model presents the concept of an interdisciplinary transition program based in an adult-oriented ambulatory care setting that links the expertise of the pediatric oncology team, with the necessary pediatric and adult subspecialists. (Oeffinger, etal 2000) Underscoring this model is

the opportunity to have the patient followed for all of their adult years as new issues and problems arise that are outside the expertise of the pediatric team.

This transition model provides survivors with freedom to move away from their parents and treating institutions. Good communication between pediatric and adult APNs can provide continuing care at any site as long as the patient is considered at risk for potential future physiologic and psychosocial problems.

Other benefits of transition have been noted by Rosen.

- *A sense of future*: Pediatric-centered care may give a subtle message that adulthood may be an unrealistic expectation. Transition to adult-centered care suggests an ongoing future.
- *A valued member of society*: The move to adult health care gives a signal that the survivor is indeed a valued member of society. It may serve to emancipate the survivor, to be more self-reliant, and to decrease emotional regression and risk-taking behaviors.
- *Age-appropriate health care*: The transition to adult-centered care assures that the overall health care needs of the survivor will be provided.
- *Ongoing medical surveillance*: Continuity of care is maintained through linkages between the pediatric and adult providers.

The transition program is an ideal rather than a reality. Logistically it is very difficult to have the healthcare providers from both pediatrics and adult medicine (or adult oncology) to maintain a joint venture. Financially, it is unlikely that insurance companies would provide reimbursement to all involved healthcare providers.

Another barrier to a transition program is the lack of education of healthcare providers. The future of these programs rests with the appropriate education of community-based practitioners. It is important that all survivors be provided with the essential information about their disease and treatment. Regardless of the type of follow-up care the survivor receives, having complete information empowers survivors to advocate for themselves. (Hobbie & Ogle) A multidisciplinary team approach is the standard for pediatric oncology programs. It should provide the model for adult follow-up programs.

The APN/PO in Long-term Survivors' Programs

The nurse is in a very special position because of the basic nursing education and the experience in the practice of holistic care to the patient and family. The APN nursing education includes physical assessment, pharmacology, interpretation of laboratory findings, pathophysiology, disease management, critical thinking, and specific issues in pediatric oncology. The nurse's education provides a focus on developmental issues. In fact, because the nurse is educated and trained to care for persons of all ages as part of basic nursing training, the APN/PO can recognize appropriate behaviors, as well as deviations through the lifespan.

Other important topics usually incorporated in the APNs education include reimbursement and health care financing, outcomes' management, administrative issues, and research skills. This education, as well as the years of experience in the field of pediatric oncology, are the prerequisites for the PNP to become involved in the care of long-term survivors. The APN has developed roles that encompass clinical care, patient/family education (including development of websites and other media), professional and public education, consulting, community relations,

advocacy, program development, and fund-raising. This background, experience, and education make it a logical choice that the APN/PO has become the leader of the team in caring for long-term survivors. Oeffinger, etal (1998) noted that the APN/PO is most appropriate to be included in long-term survivors' programs and to lead the team caring for the long-term survivor.

Traditionally, programs in pediatric oncology include the APN. Depending upon the size of the program, this nurse may practice either in- or outpatient or both. The APN is often the closest caregiver to the family from diagnosis to off-therapy. The APN begins the relationship with the family at the time of the initial diagnosis. Traditionally, the APN is involved in the initial discussion meeting with the parents. "The PNP plays an invaluable role at this point in the family's lives." (Christensen and Akcasu, p. 60) The APN is often the primary source of information and assurances, thus establishing a rapport which sets the tone for the potentially long, positive relationship with the child and family. The PNP is consistently available to provide comprehensive management across the inpatient and outpatient continuum and is the consistent person upon whom the family can rely. This provides a holistic approach to care and allows the APN to better care for and advocate for patients. This role enhances communication with the healthcare team across settings and provides seamless health care.

APN/POs traditionally have taken the lead in the care of long-term survivors of childhood cancer. The increased intensity and complexity of cancer care requires more rigorous monitoring, coordination of services, ongoing communication between the patient, family, the community, school, employer, etc, and the healthcare professional. Pediatric oncology nurses are in an essential position to continually measure and improve the outcomes of pediatric oncology nursing care.

Central to the team is the APN/PO who can carry out myriad responsibilities for the long-term survivor program and functions in many different roles during each clinic session. In pediatric oncology, the care needs of the child and family drive role definition for the APN. (Baggott & Kelly). The APN/PO provides clinical case management for survivors and their families through coordination of services among disciplines, monitoring for actual and potential late effects, and taking a leadership role in assisting with navigation through the healthcare system. (Hobbie & Hollen)

- The APN/PO acts as facilitator of the long-term survivor program and reviews charts before patients are seen. It is especially important to have the medical record organized in order to determine what treatments were given, what side effects and complications the patient had, and what complications might be expected. A review of past visits is essential as long-term survivors usually only come for annual visits.
- The APN/PO provides the history and physical examination at the time of the visit.
- The APN/PO functions as an educator for the patient, family, as well as other healthcare professionals.
- As case manager, the APN/PO can provide the recommended follow-up care, summarize the visit, and assure that there is a letter to the primary care physician and the patient. (Harvey, etal).
- The APN/PO is also a researcher, identifying research questions and assisting with all aspects of research to help understand the biopsychosocial needs and long-term effects of childhood cancer and its treatment.

Therefore, the APN is a resource and problem solver allowing for collaborative management as the patient and family move through the healthcare continuum. In pediatric oncology, APN roles are diverse and vary greatly between institutions. The focus is usually on clinical practice, consultation, education, leadership, theory, and research.

CONCLUSION

The APN as a facilitator in long-term follow-up care can be instrumental in overcoming the barriers to care that face the childhood cancer survivor. As a patient advocate, consultant, educator, and leader, the APN can focus on the psychosocial, financial, and medical needs of their patients and families. In many programs, the same nurse has been involved in the assessments and treatments of the patient during the treatment phase. This nurse is in the unique position to have gained the trust of the child and family for the years of treatment. It is very beneficial if that same nurse is involved in the care of the child and family as they transition to the status of long-term survivor. At the very least, the nurse should introduce the family to the new healthcare professionals who will continue their follow-up care. At best, the APN should continue to follow these families in a transition program that coordinates efforts of the pediatric and adult teams.

A barrier to providing nurse-driven follow-up care to pediatric cancer survivors is a lack of formal educational opportunities. Research and articles on issues of long-term survivorship is increasing and there are continuing education programs on the topic. These provide a means of education for nurses. It is suggested by MacLean, etal, that the American Cancer Society takes a leadership role in the development of workshops and other educational activities for the primary healthcare provider.

Lastly, the nursing shortage is predicted to continue since fewer nurses enter the profession and more nurses reach retirement age. There will be a shortage in all nursing specialties, but as cancer statistics increase, there will be fewer oncology nurses available to care for the adult patients and even less in pediatric oncology nursing. With fewer nurses in the workforce, there will be fewer APNs who will specialize in pediatric oncology and therefore fewer APN/POs able to care for long-term survivors.

Bibliography

American Academy of Nurse Practitioners. *Nurse practitioner as an advanced practice nurse: Role position statement*. http://www.aanp.org/np_advanced_practice.htm, 2002.

American Academy of Pediatrics, Section on Hematology Oncology. Guidelines for the pediatric cancer center and role of such centers in diagnosis and treatment. *Pediatrics*, 99(1), 1997: 139-141.

Arceci RJ, Reaman GH, Cohen AR, Lampkin BC. Position Statement for the need to define pediatric hematology/Oncology programs: A model of subspecialty care for chronic childhood diseases. *J Pediatr Hematology Oncol*, 20(2), 1998: 98-103.

Association of Pediatric Oncology Nurses, American Nurses Association. Scope and Standards of Pediatric Oncology Nursing Practice, American Nurses Publishing, Washington, DC: 2000.

Baggott CR, Kelly KP. Interdisciplinary collaboration. In Baggott, etal, (Eds) Nursing Care of Children and Adolescents with Cancer, (3rd Ed), W.B. Saunders Company, 2002: 626-639.

Christensen J, Akcasu N. *The role of the pediatric nurse practitioner in the comprehensive management of pediatric oncology patients in the inpatient setting*. J Pediatr Oncol Nurs, 16(2), 1999: 58-65.

DeBack V, Cohen E. The new practice environment. In Elaine L. Cohen (Ed.), Nursing Case Management in the 21st Century, St. Louis: Mosby-Year Book, Inc., 1996.

Foley GV, Fergusson JH. History, issues, and trends. In In Baggott, etal, (Eds) Nursing Care of Children and Adolescents with Cancer, (3rd Ed), W.B. Saunders Company, 2002: 2-23.

Harvey J, Hobbie WL, Shaw S, Bottomley S. Providing quality care in childhood cancer survivorship: Learning from the past, looking to the future. *J Pediatr Oncol Nurs*, 16(3), 1999: 117-125.

Hobbie WL, Hollen PJ. Pediatric nurse practitioners specializing with survivors of childhood cancer. *J Pediar Health Care*, 7, 1993: 24-30.

Hobbie WL, Ogle S. Transitional care for young adult survivors of childhood cancer. *Seminars in Oncol Nurs*, 17(4) 2001: 268-273.

Hobbie WL, Ruccione K, Harvey J, Moore IM. Care of survivors. In Baggott, etal, (Eds) Nursing Care of Children and Adolescents with Cancer, (3rd Ed), Philadelphia: W.B. Saunders Company, 2002: 426-464.

Hobbie, WL, Stuber M, Meeske K, etal. Symptoms of Posttraumatic stress in young adult survivors of childhood cancer. *J Clin Oncol*, 18(24), 2000: 4060-4066.

Hollen PJ, Hobbie WL. Establishing comprehensive specialty follow-up clinics for long-term survivors of cancer: Providing systematic physiological and psychosocial support. *Support Care Cancer*, 8, 1995: 1-6.

Jackson PL, Kennedy C, Sadler LS, etal. *Professional practice of pediatric nurse practitioners: Implications for education and training of PNPs*. *J Pediatr Health Care*, 15, 2000: 291-298.

Leigh SA. The long-term cancer survivor: A challenge for nurse practitioners. *Nurse Practitioner Forum*, 9(3), 1998: 192-196.

Lynch MP, Cope DG, Murphy-Ende K. Advanced practice issues: Results of the ONS advanced practice nursing survey. *Oncol Nurs Forum*, 28(10) 2001: 1521-1544.

MacLean WE, Foley GV, Ruccione K, Sklar C. Transitions in the care of Adolescent and young adult survivors of childhood cancer.*Cancer*, 78(6), 1996:1340-1344.

Maes, S. The Nursing Shortage: Part I. Healthcare Community Tries Innovative Approaches to Solving a National Crisis. *ONS News*. 17(5) 2002:1, 4-6.

O'Grady, ET. The nursing shortage: Why nurse practitioners should embrace the problem. *Am J for Nurs Practitioners*, April 2002: 31-36.

Oeffinger KC, Eshelman DA, Tomlinson GE, Buchanan GR. Programs for adult survivors of childhood cancer, *J Clin Oncol*, 16(8), 1998: 2864-2867.

Oeffinger KC, Eshelman DA, Tomlinson GE, etal. Grading of late effects in young adult survivors of childhood cancer followed in an ambulatory adult setting. *Cancer*, 88(7), 2000: 1687-1695.

Oncology Nursing Society. *The role of the advanced practice nurse in oncology care*. http://www.ons.org, 1997.

Pizzo, PA, Poplack, DG (Eds). Principles and Practice of Pediatric Oncology. Philadelphia: Lippincott Williams & Wilkins, 2002.

Rosen DS. Transition to adult health care for adolescents and young adults with cancer. *Cancer Supplement*, 71(10), 1993: 3411-3414.

Shanfield SB: On surviving cancer: Psychological considerations. *Comprehensive Psychiatry*, 21, 1980:128-34.

Tobias NE, Klemt CS. Pediatric advanced practice nursing. Nursing Clinics of North America, 35(1), 2000: 1-169.