

CANCER LIBRARIANS SECTION NEWS

Issue No. 31
Spring 2002

NEWSLETTER OF THE CANCER LIBRARIANS SECTION OF THE MEDICAL LIBRARY ASSOCIATION

From the Chair

Hello Everyone,

Once again, our section is co-sponsoring a number of very interesting programs. Many thanks to Halyna Liszczyński. These programs underscore the reality that the person-to-person service we provide is needed, regardless of how many virtual resources and services we offer.

The next few years look very promising for cancer research and treatment. It is exciting to read about the investigation of anti-inflammatory drugs for their antineoplastic potential. Increasing knowledge of the natural molecule called TRAIL (tumor necrosis factor-related apoptosis-inducing ligand) and its use with ingredients found in foods such as red wine and turmeric is intriguing.

Motivation for more research in cancer epidemiology and prevention will probably include the recent reiteration that plastic containers release dioxins into your food when it is heated in microwave ovens, and the increased attention to the use of estrogens in beef and poultry to speed their growth (Pollan, 2002).

Gayle

Gayle Ablove
Roswell Park Cancer Institute
Chair, Cancer Librarians Section
gayle.ablove@roswellpark.org

(Pollan, Michael. Power Steer. New York Times Magazine, March 31, 2002. Cover story.)

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MEDICAL LIBRARY ASSOCIATION ANNUAL CONFERENCE 2002

Programs Sponsored by the Cancer Librarians Section May 17 – 23, 2002

Submitted by: *Halyna Liszczyński*

Delivering Genetics Information to Healthcare Consumers

Sunday, May 19, 2002

4:00 p.m. – 5:30 p.m.

Following the success of the Human Genome Project, the field of human genetics is expanding rapidly and having a massive impact on society. As political leaders debate issues of human cloning and stem cell research, advances in genetic diagnostics and therapy are beginning to change the practice of medicine. As information providers to patients and health care consumers, medical librarians must be prepared to help them cope with this new technology. Are medical librarians qualified? What are the best methods of delivering this type of information? What kinds of services and programs are medical libraries developing? What are the ethical issues involved with this type of knowledge? This session will consider these questions and others involved in the delivery of genetic information to health care consumers.

The invited speaker is Angela E. Scheuerle, MD, Clinical Director, Texas Birth Defects Research Center at the Texas Department of Health. Dr. Scheuerle teaches Clinical Ethics in Medicine in Dallas at the University of Texas, Southwestern Medical School in Dallas and is an adjunct Faculty member in Management and Policy Science at the School of Public Health, University of Texas - Houston. The other two speakers for this session will be librarians Kristine Alpi (Weill Cornell Medical Library) and Gail Hendler (New York University School of Medicine), speaking on the topic of "DNA Demystified: Online Genetics and Cancer Genetics Resources for Patients."



Joint Meeting of the Molecular Biology and Genomics SIG and the Cancer Librarians Section

Monday, May 20, 2002, 5:45 p.m. – 7:00 p.m.

Room to be announced.

Participating in the Genome Age: Present Research on Pharmacogenetics

Tuesday, May 21, 2002

3:00 p.m. – 4:30 p.m.

This session will feature invited speakers and contributed papers covering the topic of pharmacogenetics and its implications for future health care. Speakers and presenters will also talk about finding information in this interdisciplinary area. The invited speaker for this session will be Corinne C. Aragaki, PhD, Assistant Professor, University of Texas Health Science Center at Houston, School of Public Health, Dallas Satellite MPH Program. Her research interests include: gene-environment interactions, cancer epidemiology, genetic epidemiology, molecular epidemiology.

Cancer Librarians Section Business Meeting

Tuesday, May 21, 2002

1:00 p.m. – 2:30 p.m.

Room to be announced.

See you there!

Dealing with Tough Questions

Wednesday, May 22, 2002

9:00 a.m. – 10:30 a.m.

Librarians from all types of medical libraries are becoming more actively involved with consumer health and patient education. Speaker Gail Rink, MSW, award-winning hospice educator and counselor, will share techniques for dealing with questions about life and death issues, tough medical choices, and grief.

MEMBER UPDATES AND ACCOMPLISHMENTS

Sharon A. Lezotte, MHE, MLIS

New Contact Information:

Outreach & Consumer Librarian
Health Sciences Library and Informatics Center
University of New Mexico
Albuquerque, NM 87131-5686
Voice: 505.272.4943
FAX: 505.272.8254
Email: SLezotte@salud.unm.edu

Mark Vrabel, Librarian, Oncology Nursing Society,
Pittsburgh, PA.

Awarded:

- Credentialed by the Academy of Health Information Professionals (AHIP) at the Provisional Level.

Advanced Studies:

- Accepted to the Certificate of Advanced Study Post-Master's Program in Medical Librarianship/Medical Informatics at the University of Pittsburgh.

Published:

- Schulmeister, L. & Vrabel, M. (2002). Searching for information for presentations and publications. *Clinical Nurse Specialist*, 16(2): 79-84. This article outlines the steps in developing a search plan and locating and compiling relevant research and resources for the Clinical Nurse Specialist interested in disseminating information via publication or professional presentation. Coauthored with Clinical Journal of Oncology Nursing Editor Lisa Schulmeister, RN, MN, CS, OCN®, Mark's section focuses on searching the literature using PubMed. Standard topics such as MeSH Headings and Boolean operators are addressed, and sample nursing-related search strategies and examples are included.

Margaret Vugrin, Reference Librarian at Preston Smith Library, Texas Tech University Health Sciences Center.

Presentation:

- **Keynote Speaker:** *Librarians of the 21st Century - Presenting Better Professional Images*. Lubbock Area Library Association's 20th Anniversary Meeting. Lubbock, TX, April 2002.

Officer:

- Chair of the Educational Technology Taskforce for the CATCHUM Project for the last three years. The CATCHUM Project is a consortium comprised of the eight Texas Medical Schools. Its mission is to enhance undergraduate medical education in cancer prevention, screening and control. Margaret and her committee, which includes Educational Technology Ph.D's as well as three other librarians: Gale Hannigan (Texas A&M), Cathy Montoya (Baylor-Houston), and Melissa DeSantis (University of San Antonio Health Sciences Center), have been working on a new project this year, a web-based Cancer Course. The beta version is up and can be viewed at <http://www.catchum.utmb.edu/>.

New Section Officers Elected

The most recent election results are as follows:

Chair-Elect/Program Chair (5/02-5/03):

Margaret Vugrin, MSLS, AHIP – Reference Librarian at the Texas Tech Health Sciences Center, Preston Smith Library, Lubbock, TX.

Please Note: The bio sketch accompanying the recent election ballot erroneously listed Margaret as Chair of the South Central Chapter of MLA from 1999-2000. In reality, Margaret served as the Chair of the Chapter's Grants and Scholarship Committee during that time period.

Secretary (5/01-5/03):

Sue Felber, MSLS, AHIP, Coordinator of the Medical Library of the H. Lee Moffitt Cancer Center & Research Institute at the University of South Florida, Tampa, FL.

Section Council Representative-Elect (5/03-

5/06): Gail Hendler, MLS, AHIP, Coordinator of Outreach Services at the Ehrman Medical Library, New York University School of Medicine, New York, NY.

Thanks to all members who participated in this election by mailing in ballots by the deadline. Also, thank you to Cheryl Warren and Ann Marie Clark for serving on this year's Nominating Committee. Finally, the biggest thank you should go to the members who agreed to take on these new roles for the Cancer Librarians Section.

Submitted by:

Karen Albert

Nominating Committee Chair

Cancer Librarians Section

BEYOND "CANCER 101": THE LIBRARIAN'S CHALLENGE

Ruti Volk, M.S.I.

*Manager, Patient Education Resource Center,
Comprehensive Cancer Center University of
Michigan*

Introduction

Cancer is a complex disease that may have an unpredictable path with many twists and turns. Along this winding road the information needs of patients and their caregivers vary. Studies have found that the amount of information sought, the degree of detail, and the topics of interest shift during the course of the illness¹. The challenge for librarians working with cancer patients and families is to provide current, reliable, and comprehensive information on complex issues and cutting-edge therapies, written in lay language.

Newly diagnosed patients require basic, introductory level information that describes the disease, the common treatments for cancer, and some of the support/coping issues relating to persons affected by cancer. This type of "Cancer 101" information is easily accessible in brochures, books and websites geared toward patients and written in lay language. The American Cancer Society (ACS), the National Cancer Institute (NCI), and other cancer organizations, as well as commercial publishers, have created a sufficient and valuable body of literature to help newly diagnosed patients understand their diagnosis and make decisions during the initial stages of the disease.

Unfortunately, information sought by patients with rare cancer types, or patients whose disease has progressed, is not so easily found. These patients have very specific questions on complex medical issues and new therapies still under investigation. For example, at the Patient Education Resource Center (PERC) at the University of Michigan Comprehensive Cancer Center, patients have requested information on topics such as:

- Burkitt's Leukemia
- Iressa for treatment of lung cancer
- Open vs. closed MRI: pros and cons

Easily accessible consumer-health publications such as brochures, books, videos, and websites offer only limited information, if any, in response to the above questions. While it is possible to answer such queries by searching MEDLINE to find articles in the peer-reviewed medical literature, the average person would find it difficult to understand and analyze articles written for professionals in technical language. The PERC is able to offer detailed

answers in lay language by providing current articles from periodicals indexed in its catalog and information from websites that offer news, *Questions and Answers* archives, and transcripts of lectures and webcasts.

Cancer Periodicals

Newsletters published by cancer organizations and cancer treatment centers contain information on complex medical issues, cutting-edge therapies, rare cancers, and specific subtypes of cancer diseases, written or reviewed by health professionals for lay people. These publications and the following three magazines: *Coping with Cancer*, *InTouch* and *MAMM*, comprise a body of authoritative, reliable, and current medical literature in lay language on topics not typically covered in other types of media. However, these publications are not indexed in any of the health indexes and databases available today, thus, access to them is very difficult. The PERC collects cancer organizations' newsletters as well as the three magazines mentioned above. To facilitate retrieval of cancer-related articles, the PERC librarian selectively indexes articles in the library catalog. The considerable time invested in indexing is well worthwhile, because it enables the PERC to provide lay-language information, instead of technical information, to almost all queries. The PERC library catalog is online at

<http://www.cancer.med.umich.edu/learn/leares.htm>.

Access is open and free to all.

In order to obtain the full text of the articles a library needs to collect the above mentioned cancer magazines; however, the full-text of many of the cancer newsletters is accessible on the Internet. A list of the newsletters indexed by the PERC with the URL's is provided at the end of this article (Appendix A).

While the PERC self-indexes seventeen newsletters and the three magazines, one library alone cannot invest the time and resources necessary to create a comprehensive database that would include all relevant publications. This database should ideally include cancer organizations' newsletters (if they are written or reviewed by medical professionals), as well as newsletters published by NCI-designated cancer centers. A large national organization, such as the ACS, NCI, or the National Library of Medicine would be in the best position to undertake this project, which would be beneficial to patients and families around the globe.

Advanced Cancer Information on the Web News and "Questions and Answers" Archives

News and "Questions and Answers" (Q & A's) archives of various cancer websites provide excellent starting points when looking for information on new therapies, drugs in clinical trials, and other specific topics. The ACS site (cancer.org), Cancer.gov (cancer.gov), MEDLINE plus (medlineplus.gov) and OncoLink (oncolink.com) offer databases of news on cancer. These include articles in lay language about new developments in cancer and newly published papers in the peer-reviewed scientific medical literature. In a way, these articles provide "translations" of medical articles from technical to lay language, and represent topics currently explored in cancer research.

The questions on these databases tend to relate to specific topics and personal situations; however, the same situations may apply to other patients.

OncoLink and CancerBACUP (cancerbacup.org.uk) have "Questions and Answers" databases that contain expert answers to questions asked by cancer patients and caregivers. The questions are answered by a panel of cancer specialists, and therefore are sources of authoritative, current information. The questions on these databases tend to relate to specific topics and personal situations; however, the same situations may apply to other patients. For example: a PERC user was considering stopping tamoxifen treatment because of low tolerance to the drug's side-effects. The "Cancer Q's" section of CancerBACUP provided an answer to a similar question, explaining, in lay terms, that clinical trials have demonstrated that taking tamoxifen for five years is more effective in breast cancer prevention than taking the drug for two years. Moreover, taking tamoxifen for ten years offers little or no more protection than taking it for five years. By stopping tamoxifen after less than five years, a patient would potentially lose a great deal of the protective benefit of the drug. This answer provided the PERC user with concrete and understandable information that helped her to make an informed decision.

CancerBACUP, cancer.gov, MEDLINEplus, and OncoLink offer a restricted search option, specific to the news archive or Q & A's areas. This important feature makes it possible to obtain a focused, relevant retrieval. (Note: unfortunately, the ACS site's restricted search has not been functioning properly in recent months. Hopefully this will be corrected soon.)

Webcasts, Lectures and Articles

Healthology.com contains transcripts of webcasts and lectures given by cancer specialists for patients. This content can be very useful for patients seeking more comprehensive, current, and in-depth information. Webcasts are virtual conferences that offer patients the opportunity to interact with cancer specialists through the Internet in real time, utilizing RealAudio or RealVideo software. During the webcasts oncologists provide detailed, lay language explanations of the diseases and new developments in research that have not yet been incorporated into books or brochures. After the live broadcasts the transcripts and video files of the event are posted on the site. Several sites that offer access to webcasts, lectures, and in-depth articles are listed at the end of the article (Appendix B).

Drug Information

Drug monographs published by the United States Pharmacopeia in the USP DI® Advice for the Patient® are available free on the Internet, through MEDLINEplus and other sites. Although they are written in lay language, these monographs are very concise with limited detail. More comprehensive drug monographs in lay language are posted on the vCure site at vcure.com. These monographs are written by faculty members of the University of Michigan's School of Pharmacy, and include more detailed explanations of how drugs work, how to take them, and how to deal with side effects. (Note: this site is still under development. As of February 21, 2002, only 75% of drugs are covered).

Conclusion:

Patients in later stages of the cancer journey require complex, specific and current medical information in order to understand the illness and treatment options. Easily accessible information sources, such as brochures, books, and websites, offer mostly basic, introductory information that would not satisfy the more comprehensive information needs of patients who have relapsed, patients in advanced stages of cancer, or patients with rare cancer types. In order to respond effectively to questions beyond the introductory level, librarians must be able to access cancer consumer-health periodicals and websites that offer news, Q & A's, webcasts, lectures, and in-depth articles.

1. Butow PN, Maclean M, Dunn SM, Tattersall MH, Boyer MJ. The dynamics of change: cancer patients' preferences for information, involvement and support. *Ann Oncol.* 1997 Sep;8(9):857-63.

Appendix A

List of newsletters collected and indexed in the PERC catalog. (These publications include educational articles on cancer research and coping with cancer. Newsletters that contain only information on fundraising and advocacy do not appear on this list)

Bone Marrow Transplantation

Blood and Bone Marrow Transplant Newsletter

A quarterly newsletter for bone marrow, peripheral blood stem cell and cord blood transplant patients and survivors. Full-text online at www.bmtinfonet.org.

Brain Tumors

The Challenge

Published by the Children's Brain Tumor Foundation (www.cbtf.org). Full-text not available online.

MessageLine

Published by the American Brain Tumor Association. PDF and HTML full-text files available at www.abta.org.

Neurotransmitter

Published three times per year by the Childhood Brain Tumor Foundation, this publication includes. PDF files available at www.childhoodbraintumor.org

Search

Published by the National Brain Tumor Foundation. PDF files available at www.braintumor.org.

Breast Cancer

Mission News from the Front (formerly *Frontline*)

Published by the Susan G. Komen Breast Cancer Foundation. Full text available at www.komen.org.

Living Beyond Breast Cancer

Published by LBBC. Full-text at www.lbbc.org/

NABCO News

Published by the National Alliance of Breast Cancer Organizations. Full-text at www.nabco.org.

Y-Me Hotline

Full-text at www.y-me.org.

Childhood Cancer

Candlelighters

Published by the Candlelighters Childhood Cancer Foundation. Full-text at www.candlelighters.org.

Head and Neck Cancer

News from S.P.O.H.N.C. (Support for People with Oral and Head and Neck Cancer)

Abstracts only are available at the organization's website at www.spohnc.org.

Hematologic Cancers and Disorders

Aplastic Anemia and MDS (Myelodysplastic Syndrome) International Foundation, Inc. Newsletter

Full-text at www.aamds.org.

Life-Lines

Published by the Children's Leukemia Foundation of Michigan. Full-text at www.leukemiamichigan.org.

Lymphoma Update

Published by the Lymphoma Research Foundation of America. Full-text at www.lymphoma.org.

Myeloma Focus

Published by the Multiple Myeloma Research Foundation. Full-text at: www.multiplemyeloma.org

Myeloma Today

Published by the International Myeloma Foundation. Full-text at: www.myeloma.org.

Lung Cancer

Spirit and Breath

Published by the Alliance for Lung Cancer. Excerpts from the current issue are available at www.alcase.org.

Appendix B

The following sites offer in-depth articles, transcripts and video files of cancer webcasts:

- www.healthology.com
Select the topic of interest from a pull-down menu at the Health Information Library section of the site. The same content may be accessible through www.alphacancer.com (breast, lung and colon cancers), www.komen.org (breast cancer) www.lymphomafocus.org (Hodgkin's and non-Hodgkin's lymphoma), and www.cancer411.org (leukemia, breast, colon, leukemia and lymphoma)
- www.cancereducation.com
Video files only include webcasts on cancer survivorship and coping and several cancer types.
- www.cancersmart.org
Audio files of webcasts and transcripts of online chats between patients and cancer specialists from Memorial Sloan-Kettering Comprehensive Cancer Center.

SERVING THE INFORMATION NEEDS OF THE ONCOLOGY NURSE

Mark Vrabel, MLS, AHIP
Oncology Nursing Society

Oncology nurses rely upon library resources and services in a variety of ways. “When we form project teams around specific topics, I often request literature searches from the librarian in order to identify those individuals possessing expertise, in addition to current research findings – promotion of evidence-based practice is a significant component of the Oncology Nursing Society Strategic Plan,” said ONS Director of Education Laura Fennimore, RN, MSN. According to Executive Director of the Oncology Nursing Certification Corporation Cynthia Miller Murphy, RN, MSN, CAE: “In our certification bulletin, it is imperative that the selected references for our OCN[®], AOCN[®], and CPON tests be up-to-date – the library is easily able to verify editions as being current, and to check the status of forthcoming editions. And when we hold item-writing workshops, the library is able to provide our item writers with additional copies of referenced publications via interlibrary loan.” “When I was responsible for coordinating a Knowledge Management initiative, the librarian offered assistance in developing a Knowledge Management Resource Guide on the ONS Intranet,” stated Executive Director of the Oncology Education Services Michele McCorkle, RN, MSN, OCN[®].

Although the information needs of the oncology nurse may overlap with those of other healthcare professionals, they do pose some special considerations. Library requests frequently pertain to standards of practice or scope of authority in a given area. For example, the nurse responsible for administering methotrexate may require not only the information on dosage, etc. found in standard drug manuals, but also the professional guidelines or recommendations regarding administration authority; rather than performing a standard “Methotrexate/Administration & Dosage” MEDLINE or CINAHL search – which will retrieve many clinical trials and other citations not necessarily of interest – the librarian needs to consult publications such as the *Chemotherapy and Biotherapy Guidelines and Recommendations for Practice* (Oncology Nursing Society, 2001) or locate specific relevant statements within published articles, such as “ED nurses in her department administer methotrexate only via the intramuscular route; otherwise, a certified chemotherapy nurse administers it,” (Blazys, 2000, p.46). Professional guidelines and scope and standards of practice are vital tools for the practicing oncology nurse.

Oncology nursing research, literature, educational offerings, and publications are generally more symptom-oriented than those of other professional disciplines. Essential comprehensive texts such as *Cancer Nursing: Principles and Practice**** (Jones and Bartlett, 2000) and *Oncology Nursing: Assessment and Clinical Care**** (Mosby, 1999) include sections on fatigue, pain, and other symptoms in addition to treatment modalities and site-specific content. The same holds true for online information sources such as ONS Online[®] (<http://www.ons.org>) and CancerSourceRN (<http://www.cancersourcern.com/>). There are works devoted entirely to symptom management, such as *Cancer Symptom Management**** (Jones and Bartlett, 1999), and others devoted to specific symptoms, such as *Fatigue in Cancer: A Multidimensional Approach*** (Jones and Bartlett, 2000) and *Pain Management Nursing: Official Journal of the American Society of Pain Management Nurses*.

Librarians working with oncology nurses should be familiar with the following publishers: Oncology Nursing Society (publication catalog available at http://www.ons.org/xp6/ONS/Information.xml/ONS_Catalogue.xml); Jones and Bartlett (“Nursing: Oncology” category of publication catalog available at <http://catalog.jbpub.com/titles.cfm?d=Nursing%20%2F%20NLN%20Press&s=Oncology>); Lippincott Williams & Wilkins (“Nursing: Oncology” category of publication catalog available at <http://www.lww.com/browseby specialty/1,2252,90,00.html>); and W.B. Saunders and Mosby (<http://www.harcourthealth.com>). Every title listed in the “Nursing” section of the “Core Cancer Library” (http://www.selu.com/cancerlib/core_list_2001.pdf) from the Cancer Librarians Section of the Medical Library Association is attributed to one of these publishers. Other associations offer relevant materials as well. The Infusion Nurses Society (<http://www.ins1.org>) publishes *Infusion Nursing Standards of Practice and Policies and Procedures of Infusion Nursing*, and the Association of Pediatric Oncology Nurses (<http://www.apon.org>) publishes *Essentials of Pediatric Oncology Nursing: A Core Curriculum****, to name a few.

The following table illustrates a core collection of oncology nursing periodical publications (this is not intended to be an all-inclusive listing, but rather a baseline selection in which oncology nursing is the predominant scope):

Title	Frequency	Publisher
Canadian Oncology Nursing Journal	Quarterly	Canadian Association of Nurses in Oncology
Cancer Nursing: An International Journal for Cancer Care*	Bimonthly	Lippincott Williams & Wilkins
Cancer Practice: A Multidisciplinary Journal of Cancer Care	Bimonthly	Blackwell Science
Clinical Journal of Oncology Nursing	Bimonthly	Oncology Nursing Society
European Journal of Oncology Nursing	Quarterly	Churchill Livingstone
International Journal of Palliative Nursing	Monthly	Mark Allen Publishing
Journal of Infusion Nursing*	Bimonthly	Lippincott Williams & Wilkins
Journal of Hospice and Palliative Nursing	Quarterly	Hospice and Palliative Nurses Association
ONS News	Monthly	Oncology Nursing Society
Oncology Nurses Today	Quarterly	Excerpta Medica
Oncology Nursing Forum***	10 Times Per Year	Oncology Nursing Society
Oncology Nursing Updates: Patient Treatment and Support	Quarterly	Lippincott Williams & Wilkins
Pain Management Nursing: Official Journal of the American Society of Pain Management Nurses	Quarterly	W.B. Saunders
Seminars in Oncology Nursing*	Quarterly	W.B. Saunders

*Included in the Brandon/Hill Selected List of Print Nursing Books and Journals (*Nursing Outlook*, January/February 2000, pp.10-22)

**Included in the "Core Cancer Library" (http://www.selu.com/cancerlib/core_list_2001.pdf) from the Cancer Librarians Section of the Medical Library Association

***Included in both Brandon/Hill and the "Core Cancer Library"

Reference:

Blazys, D. (2000). Clinical nurses forum: Methotrexate administration. *Journal of Emergency Nursing*, 26(1), 46-7, 88-92.

13th Annual National Cancer Institute - Cancer Patient Education Network Meeting

The Kaleidoscope of Cancer Education: An Evolving Practice

June 12-15, 2002

Mayo Clinic Cancer Center, Rochester, Minnesota

This year's speakers include James S. Gordon, MD, and Michele L. Deck, MEd, RN.

For more information, contact Matrix Meetings, Inc. at 507-288-5620

LYMPHEDEMA: OVERVIEW AND RESOURCES

Cheryl Warren, MSLS, AHIP

*ValleyCare Health Library & Ryan Comer Cancer
Resource Center*

Lymphedema is an accumulation of lymphatic fluid in the subcutaneous tissue causing swelling of the affected area, usually the extremities. The condition is divided into two broad categories: 1. Primary lymphedema, caused by congenital abnormalities in the lymph system; and 2. Secondary lymphedema, acquired through injury to the lymph system. The more common secondary lymphedema is generally a side effect of cancer treatments that affect the lymph nodes. This non-curable condition seriously impacts patient quality of life.

The medical community cannot yet predict which patient will develop lymphedema. Neither is screening for the condition routine. There is no real cure once the condition has started. Risk factors for developing lymphedema, however, have been identified: lymph node dissection, radiation treatment, uncontrolled chronic venous insufficiency and recurrent cellulitis. Triggering events for people at risk include infection, trauma or injury, and constriction, such as tight clothing. Once lymphedema occurs control can be difficult. Treatment is lifelong. Treatment options include physical therapy, moderate exercise, compression garments, pneumatic compression devices, and a last resort surgery.

The importance of awareness and prevention is underscored by the fact that lymphedema can occur, not just immediately after the operation, but weeks, months, even years later. Left untreated or undertreated, mild lymphedema can progress to severe lymphedema. Lymphedema swelling often leads to pain, loss of skin elasticity, limb heaviness, loss of mobility and numbness. Psychological factors can include anxiety and depression as well as sexual and self-image problems. Because prevention and early intervention are such crucial components for the at-risk patient's well being, patient education has an important role. The National Lymphedema Network, a well-known advocacy group, has a reproducible patient education sheet called *The 18 Steps for Prevention*. Available from their web site (<http://www.lymphnet.org/prevention.html>), this is a very readable, detailed list for patients to consider. The oncology nurse is in a key position for assessing and monitoring the condition, as well as providing most of the patient education and coping techniques. The following article, excerpted from the *ONS Lymphedema Management Special Interest Group Newsletter*, 2001; 12(3):2, highlights problems faced by oncology nurses dealing with lymphedema.



Reprint permission by

Christine Rymal, NP, AOCN
Karmanos Cancer Institute, Detroit, MI

Ask the Expert Column

Teach Your Patient About Lymphedema Precautions

Question from Maureen Giffin, RN, Penobscot, ME.: How can I respond to physicians who claim that lymphedema precautions are not necessary, and should not be practiced by professionals nor taught to patients?

Response by Christine Rymal, MSN, RN, CS, AOCN, Lymphedema SIG Coordinator-Emeritus, Nurse Practitioner in lymphedema care.

The persistence of this issue warrants a thoughtful commentary regarding lymphedema precautions following lymph node dissection and/or radiation.

Lack of scientific evidence

No one has studied whether lymphedema precautions have their intended effect, i.e. lymphedema prevention. There is no evidence that at-risk patients who develop lymphedema have abused their limbs, nor that at-risk patients who do not develop it have protected theirs. An experimental study (protection versus "abuse") would be unethical to perform, as one group would be subjected to procedures and activities assumed to be dangerous.

Basis for practice

Though scientific evidence is the most desirable basis for medical and nursing practice, there are many medical practices without basis in evidence. Rather, many medical practices are logically derived from physiology or are based on tradition. The two bases for lymphedema precautions are interrelated. The first is physiologic: to maintain a balance between lymph production and lymph transport, by avoiding lymph over production and by avoiding reduced lymphatic output (lymphatic constriction or reduced stimulation to lymph flow). The

second is clinical: specific activities, conditions, and procedures are documented as immediately preceding the onset of lymphedema in many at-risk patients, suggesting them to be “precipitating events.” It is not coincidental that these events either cause increased lymph production or decreased lymph outflow. My informal survey of lymphedema therapy centers indicates that a precipitating event has been identified in only half of their secondary lymphedema cases.

Legal Issues

Health care providers and institutions are liable for harm caused by action or inaction that runs counter to the standard of care. Medical and nursing literature proscribes limb precautions for at-risk patients (Petrek & Lerner, 2000; Whitman & McDaniel, 1993). Tanner’s (1998) illustrates how courts uphold these standards: following bilateral axillary lymph node dissections, a woman developed lymphedema after receiving intravenous chemotherapy in her arms. She had not been offered an implanted port. Also, she had not been informed of the risk for lymphedema. Following the testimony of a lymphedema expert, the court made the following ruling: 1) It identified the I.V.’s to be the “proximal cause” of the lymphedema; 2) It held the hospital liable for damages; and 3) The patient was unable to give informed consent to the

procedure, as the doctor had failed to describe the risks associated with the chemotherapy administration.

Commentary

One can see that direct evidence is only one factor shaping medicine and nursing practice. Nurses are responsible for their professional practice, and are primarily responsible to the patient. The power of nurses to teach lies in their state’s Nurse Practice Act. Michigan’s encompasses “teaching about health, illness, and its treatments.”

Please send questions or comments to Christine Rymal at crymal@earthlink.net, or 313.745.2760. Thank you.

Bibliography

Petrek, J. & Lerner, R. Lymphedema. In J.R. Harris et al. (eds.), *Diseases of the Breast*, 2nd Ed., (pp. 1033-1040), Philadelphia: Lippincott Williams & Wilkins, 2000: 1033-1040.

Tanner, M. Lymphedema Patients Win Legal Battles. *NLN Newsletter*, 1998 10 (2): 5-6.



Librarians in the consumer/patient resource center setting can be prepared to assist patients or family members with timely information on this condition. Various resources that provide information suitable to the patient’s learning style can be identified and collected. Librarians can also be aware of current resources to support nurses with their information needs.

Web Sites

American Cancer Society

ACS features a good explanation of what lymphedema is as well as pointers on prevention and control the condition.

<http://www.cancer.org/>

National Lymphedema Network (NLN)

This excellent site provides lymphedema information to patients, health care professionals and the concerned public. NLN offers numerous educational fact sheets, a quarterly newsletter, support group contacts, research and legislation information, treatment center list, and an equipment supplier directory.

www.lymphnet.org/

National Cancer Institute

NCI’s website contains a summary on lymphedema with a version for healthcare professionals and one for patients. The site links to Pubmed, Cancerlit and PDQ for those interested in finding clinical trials and searching the biomedical literature.

<http://www.cancer.gov/>

Oncolink

Site features a small section with lymphedema information including ask the expert, coping tips, and current news items.

<http://oncolink.upenn.edu/>

Print Resources

Coping With Lymphedema / Joan Swirsky, Diane Sackett Nannery. Avery Penguin Putnam, 1998. ISBN: 0895298562

Written by a breast cancer survivor and a clinical nurse specialist, this is a very readable book with detailed sections on various issues including how to choosing a lymphedema therapist. Very advocate oriented.

Lymphedema: A Breast Cancer Patient's Guide to Prevention and Healing / Jeannie Burt, Gwen White, Judith R. Casley- Smith. Hunter House, 1999. ISBN: 0897932641

Written by a breast cancer survivor and a physical therapist who specializes in lymphedema, the book uses personalized stories to explain the causes of lymphedema and treatment options. Simple line drawings add to the discussion and exercises.

Lymphedema Management Special Interest Group (SIG) Newsletter / Oncology Nursing Society (ONS)

Lymphedema Management Newsletter is published three times a year. The newsletter includes current information for nurses and coping /management strategies for patient use. Contact is available at ONS web site, www.ons.org. The newsletter will eventually be available on their web site.

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Primer on Lymphedema / Deborah G. Kelly. Prentice Hall, 2001. ISBN: 0130224103

Although written for the healthcare professional, this concise book has sections suitable for the educated consumer. Included are discussions of the lymph system, case studies, illustrations, intervention options, resources and other issues concerning the healthcare professional practicing in this area.

Kalinowski BH "Lymphedema." **Cancer Symptom Management**. Eds. Yarbro CH, Frogge MH, Goodman M. 2nd ed. Sudbury, MA: Jones and Bartlett, 1999.

This chapter provides a nice overview of lymphedema ending with self-care guides or sheets that can be copied. Patient education sheets address prevention and feature exercises. There are also education sheets describing mild, moderate and severe lymphedema.

Annotated Bibliography

Davis BS. Lymphedema after breast cancer. *AJN* 2001; 101(4): p24AAAA-24DDDD.

Reviews current practices and provides a nice summary of the role of the nurse as caregiver and advocate. Practical tips and suggestions for the patient are included in the article.

Harris SR et al. Clinical practice guidelines for the care and treatment of breast cancer: 11. Lymphedema. *CMAJ: Can Med Assoc J* 2001; 164(2): p191-200.

A literature review, the article concludes with a guide that physicians can use with the patient in the form of common questions and answers.

Loudon L, Petrek J. Lymphedema in women treated for breast cancer. *Cancer Practice* 2000; 8(2): 65-72.

Authors cover pathophysiology, risk factors, assessment, prevention cautions and various treatment options including a good discussion on complete decongestive physiotherapy (CDP).

McElrath TJ, Runowicz CD. Preventing and managing lymphedema. *Con OB/GYN* 2000; 45(5):115-25.

This very readable article details the need for patient education. Prevention, treatment options and risk factors are all discussed. Includes a patient information section in the form of questions and answers.

Petrek JA, Pressman PI, Smith RA. Lymphedema: current issues in research and management. *CA Cancer J Clin* 2000; 50(5):292-306.

Gives an overview of current practices, emphasizing the need for a multidisciplinary approach and for more research into risk factors, treatment modalities that reduce the risk of lymphedema and improved treatments of the condition.

NATIONAL CANCER INSTITUTE LAUNCHES REDESIGNED WEB SITE, CANCER.GOV

On January 22, 2002, the National Cancer Institute (NCI) unveiled its newly revised site, Cancer.gov (www.cancer.gov), into which two former NCI sites, CancerNet and CancerTrials, have merged. The new site provides one-stop shopping for answers to questions on cancer in English and Spanish, tips to prevent cancer, methods for quitting smoking, and ways to obtain informational materials for the general public and health professionals. The main content areas on Cancer.gov include the following: cancer information, clinical trials, statistics, research programs, and research funding. Another improved feature to the site is the searching capability; one can do a simple or advanced search. Additionally, NCI has created "Best Bets," which retrieves the most pertinent information for searches on many topics. Those who find the Cancer.gov site difficult to navigate can utilize the site map or the LiveHelp service. LiveHelp allows users to instant message with a trained Cancer Information Specialist and get assistance in navigating the site or answering questions on cancer. This service is available Monday through Friday, 9:00 a.m. to 5:00 p.m. Eastern time. Cancer librarians may consider signing up for NewMediacy, a new NCI listserv. This one-way listserv provides links and information on healthcare communication. To subscribe, just type "subscribe newmediacy" (without quotation marks) in the BODY of an e-mail message and send it to LISTSERV@LIST.NIH.Gov. Or, e-mail zellerp@mail.nih.gov.

To find out more about Cancer.gov

<http://newscenter.cancer.gov/pressreleases/Cancergovlaunch.html>

To find out more about LiveHelp

www.cancer.gov link at the lower right hand corner of the page

To find out more about NewMediacy

<http://dccps.nci.nih.gov/eocc/newmediacy.html>

To find current News Releases from NCI

<http://newscenter.cancer.gov/>

Submitted by: Ilyse Rosenberg, student of library science at Queens College Master program.

The opinions expressed are my own and do not reflect those of any institution or organization ilyse01@yahoo.com