



Cancer Survivorship: Embracing the Future

Program Book



October 4 – 6, 2006 • Bethesda North Marriott Hotel & Conference Center • North Bethesda, MD

Dear Conference Participant,

On behalf of the Conference Planning Committee, welcome to the Third Biennial Cancer Survivorship Research Conference:

Cancer Survivorship: Embracing the Future.

Since our last conference in June 2004, attention to and investment in cancer survivorship research and care has grown enormously:

- The Institute of Medicine released its report on adult cancer survivorship, *From Cancer Patient to Cancer Survivor: Lost in Transition*;
- The National Institutes of Health has expanded its portfolio of cancer survivorship research from 179 to 236 grants (FY2003-2005);
- The National Cancer Institute's Strategic Plan included its intention to pursue research to "improve the quality of life for cancer patients, survivors, and their families;"
- The American Cancer Society (ACS) has included improvement in quality of life from the time of diagnosis and for the balance of life of all cancer survivors among its 2015 Challenge Goals;
- The Lance Armstrong Foundation (LAF) has launched five LIVESTRONG™ Survivorship Centers of Excellence;
- And the American Society of Clinical Oncology incorporated a special "Patient and Survivor Care" track at its annual meeting.

Also significant is the fact that this month the Office of Cancer Survivorship celebrates its tenth anniversary! In October 1996, the Office of Cancer Survivorship (OCS) was established by the NCI in recognition of the millions of individuals surviving cancer for longer periods of time and their unique and poorly understood needs.

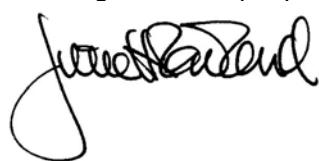
Since its inception, the OCS has been fortunate to be able to forge collaborations with valued partners like the ACS, the LAF and other cancer organizations to sustain the momentum and advancement in cancer survivorship research. This year we are especially pleased that the LAF has joined the NCI and ACS as a formal co-sponsor of the biennial cancer survivorship research conference.

Please join us in celebrating these milestones and recognizing the many partners who have championed cancer survivorship research and served as passionate advocates for survivors and their family members.

Over the course of our two days of meetings you will hear from some of today's leading scientists and clinicians about the progress we have made in a number of key areas and the challenges that remain to be addressed. Our intent is not merely to provide state-of-the-science information, but also to engage your thinking and energy in how we move forward our still young field of cancer survivorship research.

- What is the best way to communicate with survivors about their health?
- What should follow-up care after cancer look like, who should deliver it and where?
- What is the impact on families of living with a member who has had cancer?
- Why are there differences in who remains healthy after cancer and who becomes ill, and can we eliminate these?
- What resources do we need to conduct our research, deliver care and reach diverse populations?
- Critically, how are we going to measure the success of our efforts?

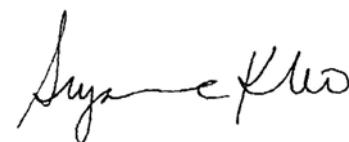
We hope that you will use this time to share ideas, plan collaborations, make new friends and network with long-time colleagues. We also hope that you will come away from these sessions energized and excited about the opportunities that lie before us. Only by working together can we continue to make strides in enhancing the quality and length of life of people affected by cancer.



Julia H. Rowland, Ph.D.
Director, Office of Cancer
Survivorship
National Cancer Institute



Michael Stefanek, Ph.D.
Vice President , Behavioral
Research Center
American Cancer Society



Suzanne Kho
Director of Grants
Lance Armstrong Foundation

CANCER SURVIVORSHIP: EMBRACING THE FUTURE

Bethesda North Marriott Hotel

Bethesda, MD

October 4-6, 2006

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AGENDA

CANCER SURVIVORSHIP: EMBRACING THE FUTURE
Bethesda North Marriott Hotel
Bethesda, MD
October 4–6, 2006

AGENDA

WEDNESDAY, OCTOBER 4

12:00 p.m. – 6:00 p.m. Conference Registration Opens
Grand Ballroom Foyer

PRE-CONFERENCE EVENTS

1:00 p.m. – 3:00 p.m. **Building a Career in Cancer Survivorship Research: A Training Workshop**
White Flint Amphitheater *(Grant Application Training Workshop) (Approved Pre-registered Participants Only)*

3:30 p.m. – 5:30 p.m. **Pre-Conference Orientation/Introduction to Cancer Survivorship Research**
Grand Ballroom – Salon A *(Survivor-Researcher Mentor Program) (By Invitation Only)*

6:30 p.m. – 9:00 p.m. **GROUP DINNER AND AWARDS CEREMONY**
Grand Ballroom – Salon E

Welcome and Opening Remarks

Julia Rowland, Ph.D.
Director, Office of Cancer Survivorship
Division of Cancer Control and Population Sciences
National Cancer Institute, National Institutes of Health
Bethesda, Maryland

Robert Croyle, Ph.D.
Director, Division of Cancer Control and Population Sciences
National Cancer Institute, National Institutes of Health
Bethesda, Maryland

Jerome Yates, M.D., M.P.H.
National Vice President of Research
American Cancer Society
Atlanta, Georgia

Mitchell Stoller
President and Chief Executive Officer
Lance Armstrong Foundation
Austin, Texas

Keynote Address

Ellen Stovall
President and Chief Executive Officer
National Coalition for Cancer Survivorship
Silver Spring, Maryland

THURSDAY, OCTOBER 5

7:30 a.m. – 8:30 a.m. **Registration and Continental Breakfast**
Grand Ballroom Foyer

8:30 a.m. – 9:00 a.m. **Welcome and Opening Remarks**
Grand Ballroom – Salon D

Julia Rowland, Ph.D.
Director, Office of Cancer Survivorship
National Cancer Institute, National Institutes of Health
Bethesda, Maryland

Michael Stefanek, Ph.D.
Vice President, Behavioral Research Center
American Cancer Society
Atlanta, Georgia

PLENARY SESSION: Communications and eHealth
Chair: Bradford Hesse, Ph.D.

9:00 a.m. – 9:15 a.m. **Introduction**
Grand Ballroom – Salon D

Bradford Hesse, Ph.D.
Acting Chief, Health Communication and Informatics Research Branch
National Cancer Institute, National Institutes of Health
Bethesda, Maryland

9:15 a.m. – 9:45 a.m. **The Passport for Care Program**
Grand Ballroom – Salon D

David Poplack, M.D.
Director, Texas Children's Cancer Center
Professor of Pediatric Oncology
Head, Hematology Section
Baylor College of Medicine
Houston, Texas

9:45 a.m. – 10:05 a.m. **BREAK**

10:05 a.m. – 10:30 a.m. **Cancer Survivors – Successfully Swimming or Struggling to Stay Afloat in a Sea of Cancer-Related Information?**
Grand Ballroom – Salon D

Neeraj Arora, Ph.D.
Social Scientist, Outcomes Research Branch
National Cancer Institute, National Institutes of Health
Bethesda, Maryland

10:30 a.m. – 10:55 a.m. **Using a Comprehensive Informatics Support System to Improve Survivor Outcomes**
Grand Ballroom – Salon D

David Gustafson, Ph.D.
Professor of Industrial Engineering and Preventive Medicine
Founding Director, Center for Health Systems Research and Analysis
University of Wisconsin–Madison
Madison, Wisconsin

THURSDAY, OCTOBER 5 – CONTINUED

PLENARY SESSION: Communications and eHealth – continued
Chair: Bradford Hesse, Ph.D.

10:55 a.m. – 11:25 a.m. **Cancer Survivor Panel Discussion**

Grand Ballroom – Salon D

Virgil Simons
Founder and President
The Prostate Net
Secaucus, New Jersey

Susan Lowell Butler
Executive Director
D.C. Cancer Consortium
Washington, District of Columbia

Gilles Frydman
Founder and President
Association of Cancer Online Resources
New York, New York

11:25 a.m. – 11:45 a.m. **Questions and Answers**

Grand Ballroom – Salon D

Wrap-Up

11:55 a.m. – 1:25 p.m. **GROUP LUNCH**

Grand Ballroom – Salon E

Progress Since the Institute of Medicine (IOM) Report—*From Cancer Patient to Cancer Survivor: Lost in Transition*

Sheldon Greenfield, M.D.
Professor of Medicine
Executive Director, Center for Health Policy Research
University of California, Irvine
Irvine, California

THURSDAY, OCTOBER 5 – CONTINUED

PLENARY SESSION: Post-Treatment Follow-Up Care for Cancer Survivors
Chair: Noreen Aziz, M.D., Ph.D., M.P.H.

1:35 p.m. – 1:55 p.m.
Grand Ballroom – Salon D

Introduction: Why Follow-Up Care Is Important

Noreen Aziz, M.D., Ph.D., M.P.H.

*Senior Program Director, Office of Cancer Survivorship
National Cancer Institute, National Institutes of Health
Bethesda, Maryland*

1:55 p.m. – 3:35 p.m.
Grand Ballroom – Salon D

Follow-Up Care in the Pediatric/Adolescent/Young Adult Survivor Setting

Kevin Oeffinger, M.D.

*Director, Living Beyond Cancer: A Program for Adult Survivors of Pediatric Cancer
Departments of Pediatrics and Internal Medicine
Memorial Sloan-Kettering Cancer Center
New York, New York*

Follow-Up Care in the Adult Survivor Setting

David Vaughn, M.D.

*Associate Professor of Medicine
Abramson Cancer Center, University of Pennsylvania
Philadelphia, Pennsylvania*

Developing Models of Care for Adult Cancer Survivors

Linda Jacobs, Ph.D., R.N.

*Director, Lance Armstrong Foundation Living Well After Cancer Program
Abramson Cancer Center, University of Pennsylvania
Philadelphia, Pennsylvania*

Realizing IOM Care Recommendations in Practice

Patricia Ganz, M.D.

*Professor of Health Services and Medicine
Division of Cancer Prevention and Control, Jonsson Comprehensive Cancer Center
UCLA Schools of Medicine and Public Health
Los Angeles, California*

3:35 p.m. – 3:55 p.m.
Grand Ballroom – Salon D

Questions and Answers

Wrap-Up

THURSDAY, OCTOBER 5 – CONTINUED

3:55 p.m. – 4:15 p.m. **BREAK**

BREAKOUT SESSIONS: (Sessions 1–3 are repeated on Friday)

4:15 p.m. – 5:45 p.m.
Grand Ballroom – Salon A

- 1. Emotional and Physical Long-Term and Late Effects – Moderator: Kevin Stein, Ph.D.**

Michael Andrykowski, Ph.D., Professor of Behavioral Science, Department of Behavioral Science, University of Kentucky College of Medicine, Lexington, Kentucky

Karen Syrjala, Ph.D., Co-Director of Survivorship Program, Director of Biobehavioral Sciences, Fred Hutchinson Cancer Research Center, Seattle, Washington

Craig Lustig, M.P.A., Executive Director, Children's Cause for Cancer Advocacy, Silver Spring, Maryland

Grand Ballroom – Salon B

- 2. Lifestyle Behavior Change – Moderator: Julia Rowland, Ph.D.**

Bernardine Pinto, Ph.D., Associate Professor of Psychiatry and Human Behavior, Centers for Behavioral and Preventive Medicine, The Miriam Hospital, Providence, Rhode Island

Chanita Hughes Halbert, Ph.D., Assistant Professor of Psychiatry, Community Cancer Prevention and Control, Department of Psychiatry, University of Pennsylvania, Philadelphia, Pennsylvania

Melinda Irwin, Ph.D., M.P.H., Assistant Professor, Division of Chronic Disease Epidemiology, Department of Epidemiology and Public Health, Yale University School of Medicine, New Haven, Connecticut

Anna Schwartz, F.N.P., Ph.D., FAAN, Professor, Scottsdale Healthcare, Endowed Research Chair, College of Nursing, Arizona State University, Cave Creek, Arizona

Linden Oak

- 3. Cancer Survival Toolbox – Moderator: Emily Heide**

Susan Leigh, R.N., B.S.N., Cancer Survivorship Consultant, National Coalition for Cancer Survivorship, Tucson, Arizona

Katherine Walsh, Ph.D., Professor, Springfield College School of Social Work, Springfield, Massachusetts

THURSDAY, OCTOBER 5 – CONTINUED

BREAKOUT SESSIONS: – continued

4:15 p.m. – 5:45 p.m.
Grand Ballroom – Salon C

- 4. Methodologic Issues I: Design – Moderator: Noreen Aziz, M.D., Ph.D., M.P.H.**

Graham Colditz, M.D., Dr.P.H., Professor of Medicine, Brigham and Women's Hospital and Harvard Medical School, Boston, Massachusetts

Ann Mertens, Ph.D., Associate Professor, Department of Pediatrics, University of Minnesota, Minneapolis, Minnesota

Michael Antoni, Ph.D., Professor of Psychology, Psychiatry, and Behavioral Sciences; Director, Center for Psycho-Oncology Research; Associate Director, Cancer Prevention and Control, Sylvester Comprehensive Cancer Center, University of Miami, Coral Gables, Florida

Brookside

- 5. Patient-Provider Communication – Moderator: Neeraj Arora, Ph.D.**

Ronald Epstein, M.D., Professor of Family Medicine and Psychiatry, Director of Research in Family Medicine, Family Medicine Research Programs, University of Rochester Medical Center, Rochester, New York

Neeraj Arora, Ph.D., Social Scientist, Outcomes Research Branch, National Cancer Institute, National Institutes of Health, Bethesda, Maryland

Richard Boyajian, R.N., M.S., A.N.P., Nurse Practitioner, Lance Armstrong Foundation Adult Survivorship Clinic, Perini Family Survivors' Center, Dana-Farber Cancer Institute, Boston, Massachusetts

Bradford Hesse, Ph.D., Acting Chief, Health Communication and Informatics Research Branch, National Cancer Institute, National Institutes of Health Bethesda, Maryland

Forest Glen

- 6. Employment and Economic Issues – Moderator: Nina Miller, M.S.S.W., O.S.W.-C.**

Cathy Bradley, Ph.D., Professor, Department of Health Administration, Massey Cancer Center Virginia Commonwealth University, Richmond, Virginia

Barbara Hoffman, J.D., Professor, Rutgers School of Law–Newark, Center for Law and Justice, The State University of New Jersey, Princeton Junction, New Jersey

Karen Pollitz, M.P.P., Project Director, Health Policy Institute, Georgetown University, Washington, District of Columbia

THURSDAY, OCTOBER 5 – CONTINUED

BREAKOUT SESSIONS: – continued

4:15 p.m. – 5:45 p.m.
Glen Echo

7. **Support Groups – Moderators: Lourie Campos, M.P.A., and Robert Hendrickson, L.C.D.R.**

Mark Salzer, Ph.D., Assistant Professor of Psychology, Department of Psychiatry, University of Pennsylvania School of Medicine and the Abramson Cancer Center, Philadelphia, Pennsylvania

Alyson Moadel, Ph.D., Assistant Professor, Department of Epidemiology and Population Health, Albert Einstein College of Medicine, Yeshiva University, Bronx, New York

Mitch Golant, Ph.D., Vice President, Research & Development, The Wellness Community, Los Angeles, California

White Flint Amphitheater

8. **Cancer and Aging – Moderator: Keith Bellizzi, Ph.D., M.P.H.**

Thomas Blank, Ph.D., Professor of Human Development and Family Studies, University of Connecticut, Storrs, Connecticut

Gary Deimling, Ph.D., Professor of Sociology, Cancer Survivor Research Program, Department of Sociology, Case Western Reserve University, Cleveland, Ohio

Deborah Boyle, R.N., M.S.N., AOCN, FAAN, Practice Outcomes Nurse Specialist, Banner Good Samaritan Medical Center, Phoenix, Arizona

William Bright II, Ed.D., US TOO Local Support Group, Alexandria, Virginia

6:00 p.m. – 7:45 p.m.
Grand Ballroom –
Salons F-G-H

RECEPTION AND POSTER SESSION

FRIDAY, OCTOBER 6

7:30 a.m. <i>Grand Foyer</i>	Conference Registration and Continental Breakfast
7:45 a.m. – 8:45 a.m. <i>Grand Ballroom – Salon A</i>	Continental Breakfast and Survivor-Researcher Mentor Program Discussions <i>(By invitation only)</i>

PLENARY SESSION: Cancer Survivorship among Underserved Populations

Chair: Diana Jeffery, Ph.D.

9:00 a.m. – 10:40 a.m. <i>Grand Ballroom – Salon D</i>	Keynote Address Harold Freeman, M.D. Senior Advisor to the Director, NCI National Cancer Institute, National Institutes of Health Bethesda, Maryland
	Facing the Reality of Cancer and Survivorship Merle Mishel, Ph.D., R.N. Kenan Professor of Nursing School of Nursing University of North Carolina at Chapel Hill Chapel Hill, North Carolina
	Social Determinants of Cancer across the Continuum Marjorie Kagawa-Singer, Ph.D., M.N., R.N. Professor of Public Health and Asian American Studies School of Public Health and Asian American Studies Center University of California, Los Angeles Los Angeles, California
	Equity of Care Claudia Baquet, M.D., M.P.H. Professor of Medicine Office of Policy and Planning University of Maryland School of Medicine Baltimore, Maryland
10:40 a.m. – 11:00 a.m. <i>Grand Ballroom – Salon D</i>	Questions and Answers Wrap-Up
11:00 a.m. – 11:30 a.m.	BREAK

FRIDAY, OCTOBER 6 – CONTINUED

BREAKOUT SESSIONS:

11:30 a.m. – 1:00 p.m.
Grand Ballroom – Salon A

1. **Emotional and Physical Long-Term and Late Effects – Moderator: Kevin Stein, Ph.D.**

Michael Andrykowski, Ph.D., Professor of Behavioral Science, Department of Behavioral Science, University of Kentucky College of Medicine, Lexington, Kentucky

Karen Syrjala, Ph.D., Co-Director of Survivorship Program, Director of Biobehavioral Sciences, Fred Hutchinson Cancer Research Center, Seattle, Washington

Craig Lustig, M.P.A., Executive Director, Children's Cause for Cancer Advocacy, Silver Spring, Maryland

Linden Oak

2. **Lifestyle Behavior Change – Moderator: Keith Bellizzi, Ph.D., M.P.H.**

Bernardine Pinto, Ph.D., Associate Professor of Psychiatry and Human Behavior, Centers for Behavioral and Preventive Medicine, The Miriam Hospital, Providence, Rhode Island

Chanita Hughes Halbert, Ph.D., Assistant Professor of Psychiatry, Community Cancer Prevention and Control, Department of Psychiatry, University of Pennsylvania, Philadelphia, Pennsylvania

Melinda Irwin, M.P.H., Ph.D., Assistant Professor, Division of Chronic Disease Epidemiology, Department of Epidemiology and Public Health, Yale University School of Medicine, New Haven, Connecticut

Anna Schwartz, F.N.P., Ph.D., FAAN, Professor, Scottsdale Healthcare, Endowed Research Chair, College of Nursing, Arizona State University, Cave Creek, Arizona

Forest Glen

3. **Cancer Survival Toolbox – Moderator: Emily Heide**

Susan Leigh, R.N., B.S.N., Cancer Survivorship Consultant, National Coalition for Cancer Survivorship, Tucson, Arizona

Katherine Walsh, Ph.D., Professor, Springfield College School of Social Work, Springfield, Massachusetts

FRIDAY, OCTOBER 6 – CONTINUED

BREAKOUT SESSIONS: – continued

11:30 a.m. – 1:00 p.m.
Grand Ballroom – Salon B

4. **Methodologic Issues II: Measurement and Assessment – Moderator: Noreen Aziz, M.D., Ph.D., M.P.H.**

Carol Ferrans, Ph.D., R.N., FAAN, Deputy Director, UIC Center for Population Health and Health Disparities; Professor, College of Nursing, University of Illinois at Chicago, Chicago, Illinois

Jay Piccirillo, M.D., Professor, Clinical Outcomes Research Unit, Otolaryngology Head and Neck Surgery, Washington University School of Medicine, St. Louis, Missouri

Kevin Oeffinger, M.D., Director, Living Beyond Cancer: A Program for Adult Survivors of Pediatric Cancer, Departments of Pediatrics and Internal Medicine, Memorial Sloan-Kettering Cancer Center, New York, New York

Grand Ballroom – Salon C

5. **Complementary and Alternative Medicine – Moderator: Meryl Sufian, Ph.D.**

Barrie Cassileth, Ph.D., Laurance S. Rockefeller Chair in Integrative Medicine; Chief, Integrative Medicine Service, Memorial Sloan-Kettering Cancer Center, New York, New York

Daniel Monti, M.D., Executive and Medical Director, Jefferson Myrna Brind Center of Integrative Medicine, Thomas Jefferson University, Philadelphia, Pennsylvania

Bobbi Brady, Member, NCI's Consumer Advocates in Research and Related Activities, Fairfax, Virginia

Caroline Peterson, M.A., ATR-BC, Clinical Research Coordinator, Jefferson Myrna Brind Center of Integrative Medicine, Thomas Jefferson University, Philadelphia, Pennsylvania

Glen Echo

6. **Pregnancy and Fertility – Moderator: Camille Hammond, M.D., M.P.H.**

Leslie Schover, Ph.D., Professor of Behavioral Science, Department of Behavioral Science, University of Texas M. D. Anderson Cancer Center, Houston, Texas

Kutluk Oktay, M.D., Associate Professor, The Center for Reproductive Medicine and Infertility, Weill Medical College of Cornell University, New York, New York

Tamika Felder, Founder and Chief Executive Officer, Tamika and Friends, Inc., Upper Marlboro, Maryland

FRIDAY, OCTOBER 6 – CONTINUED

BREAKOUT SESSIONS: – continued

11:30 a.m. – 1:00 p.m.
Brookside

7. Analytic Datasets and Research Resources – Moderator: Deborah Winn, Ph.D.

Ann Geiger, Ph.D., Associate Professor, Social Sciences and Health Policy, Division of Public Health Sciences, Wake Forest University School of Medicine, Winston-Salem, North Carolina

Ann Mertens, Ph.D., Associate Professor, Department of Pediatrics, University of Minnesota, Minneapolis, Minnesota

Michelle Holmes, M.D., Dr.P.H., Assistant Professor of Medicine, Harvard Medical School, Boston, Massachusetts

Linda Squiers, Ph.D., CIS Project Officer for Research, Office of Communications, National Cancer Institute, Bethesda, Maryland

1:15 p.m. – 2:15 p.m.
Grand Ballroom – Salon E

GROUP LUNCH

PLENARY SESSION: Family Caregiving as the Cornerstone of Survivorship: A Lifespan Approach
Chairs: Youngmee Kim, Ph.D., and Paige McDonald, Ph.D., M.P.H.

2:30 p.m. – 4:00 p.m.
Grand Ballroom – Salon D

Family Caregivers – Who Cares for Them?

Barbara Given, Ph.D., R.N., FAAN
University Distinguished Professor
College of Nursing
Michigan State University
East Lansing, Michigan

Young Caregivers

Gail Gibson Hunt
President and Chief Executive Officer
National Alliance for Caregiving
Bethesda, Maryland

Early-to-Middle Adulthood Caregivers

Victoria Raveis, Ph.D.
Associate Professor of Clinical Sociomedical Sciences
Co-Director, Center for Psychosocial Study of Health and Illness
Columbia University Mailman School of Public Health
New York, New York

Marriage after Cancer: State of the Science

Sharon Manne, Ph.D.
Senior Member and Director, Psycho-Oncology Program
Population Science Division
Fox Chase Cancer Center
Philadelphia, Pennsylvania

FRIDAY, OCTOBER 6 – CONTINUED

PLENARY SESSION: Family Caregiving as the Cornerstone of Survivorship: A Lifespan Approach – continued
Chairs: Youngmee Kim, Ph.D., and Paige McDonald, Ph.D., M.P.H.

4:00 p.m. – 4:20 p.m. Grand Ballroom – Salon D	Caregiver Panel and Discussant <i>Richard Schulz, Ph.D.</i> <i>Professor of Psychiatry</i> <i>Director, University Center for Social and Urban Research</i> <i>University of Pittsburgh</i> <i>Pittsburgh, Pennsylvania</i>
4:20 p.m. – 4:30 p.m. Grand Ballroom – Salon D	Questions and Answers Wrap-Up
4:30 p.m. – 4:45 p.m. Grand Ballroom – Salon D	Closing Remarks <i>Julia Rowland, Ph.D. and Michael Stefanek, Ph.D.</i>
4:45 p.m.	Adjourn

PLANNING COMMITTEE LIST

CANCER SURVIVORSHIP: EMBRACING THE FUTURE
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Planning Committee List

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As associate dean for policy and planning at the University of Maryland School of Medicine, Dr. Claudia R. Baquet serves as an advocate for better health care, including issues relating to the health needs and models for underserved communities, telemedicine and rural health initiatives. Dr. Baquet also serves as director of the Maryland Area Health Education Center Program, director of the Center for Health Policy/Health Services Research and director of the Center for Health Disparities. In 2003, she became director of the University of Maryland Comprehensive Center for Health Disparities. Dr. Baquet seeks to reduce and eventually eliminate health disparities.

In 2002, Dr. Baquet served as the chair of the Governor's Commission for the Prevention of Infant Mortality and received the Governor's Citation for the reduction of the Maryland infant mortality rate. Dr. Baquet is also the 2004 co-recipient of the U.S. Department of Health and Human Services' Best Practice Award for Increasing Availability of Community-Based Clinical Trials on the Eastern Shore. Dr. Baquet was formally recognized by the Maryland Senate for her work to reduce cancer disparities and most recently for her longstanding commitment to the community. Dr. Baquet's recent awards include NIH's Dr. Martin Luther King, Jr. Special Award for Closing the Health Gap in the Communities We Serve, the American Public Health Association's 2005 David P. Rall Award for Advocacy in Public Health, and the National Medical Association's Council on Concerns for Women Physicians Research Award. In 2006, Dr. Baquet received the Racial Justice Award from the YWCA of the Greater Baltimore Area.

Dr. Baquet received her M.D. in 1977 from Meharry Medical College in Tennessee and her M.P.H. in epidemiology in 1983 from Johns Hopkins University School of Hygiene and Public Health. Her residency was in pathology at St. Louis University and Wadsworth Veterans Administration Hospital.

Thomas O. Blank, Ph.D.

Professor
Human Development and Family Studies
University of Connecticut
Storrs, Connecticut

Dr. Thomas Blank has been at the University of Connecticut as professor of human development and family studies since 1988. He has a Ph.D. in psychology from Columbia University and had his postdoctoral training in social gerontology at the University of Missouri. He is a fellow of the Gerontological Society of America.

Dr. Blank's primary research areas concern psychological, social psychological, and behavioral aspects of aging and of cancer survivorship. He has published five books on various aspects of aging and numerous articles and presentations. His current research focuses on how people deal with diagnosis and longer-term aspects of cancer survivorship, with emphasis on understanding pathways to psychological growth. He completed a National Institute on Aging grant examining older men with prostate cancer and is co-PI on a grant from the Lance Armstrong Foundation to study younger adult cancer survivors from the perspective of psychological growth. Recent publications include a commentary on gay men and prostate cancer, published in Journal of Clinical Oncology, and an article based on his prostate cancer research in press at Cancer. Also, he is a 9-year prostate cancer survivor and as such has been a consumer reviewer for the DOD Prostate Cancer Research Program.

Richard N. Boyajian, R.N., M.S., A.N.P.

Nurse Practitioner
Lance Armstrong Foundation Adult Survivorship Clinic
Perini Family Survivors' Center
Dana-Farber Cancer Institute
Boston, Massachusetts

Mr. Richard Boyajian, nurse practitioner at the Lance Armstrong Foundation Adult Survivorship Clinic, has been caring for oncology patients at the Dana-Farber Cancer Institute since 1999. Mr. Boyajian has worked in a variety of oncology specialties including allogeneic stem cell transplant, lymphoma, immunology, nuclear medicine, and radiation oncology. He has been caring for cancer survivors since coming to Dana-Farber and has focused his practice in this area since the fall of 2004. Since that time he has been invited to lecture about the subject of survivorship, most recently at the ONS 2006 congress and the 2006 ASBMT/CIBMTR BMT Tandem Meetings. Clinically, Mr. Boyajian has developed documents to improve the care of survivors such as a personal needs assessment and a late effects organ system checklist. He has also created an electronic prototype database that will allow clinicians to create a care plan/treatment summary document for each patient as they complete treatment. In May of 2006, Mr. Boyajian participated in the Institute of Medicine national cancer policy forum workshop on implementing cancer survivorship care planning and has contributed chapters to the

2006 Clinical Manual for the Oncology Advanced Practice Nurse. Since 2001, he remains a patient advocate as member of the NCI/NIH CARRA program, participating in peer review of extramural research funding grants committees. Mr. Boyajian's 1996 experience as a matched unrelated donor bone marrow transplant recipient living with chronic graft vs. host disease has made him a provider with a unique perspective on patient and provider communication.

Deborah A. Boyle, R.N., M.S.N., AOCN, FAAN

Practice Outcomes Nurse Specialist
Banner Good Samaritan Medical Center
Phoenix, Arizona

An oncology nurse for more than 3 decades, Ms. Debi Boyle has held role as staff, clinic and research nurse, nurse educator, and clinical nurse specialist. She is the recipient of numerous honors from the Oncology Nursing Society, including the receipt of awards for her contributions to the oncology nursing literature and interventions to improve quality of life. In addition, she was chosen to deliver both the Schering Excellence in Clinical Practice and Mara Flaherty Excellence in Psychosocial Nursing Care lectureships. A graduate of Yale University, Ms. Boyle was honored as a Distinguished Alumnae in 1994. In 1999, she was inducted into the American Academy of Nursing, where she was cited for her contributions to the promotion of advance practice in oncology nursing and her advocacy of the needs of cancer survivors and the elderly. The author of more than 150 publications, Ms. Boyle co-authored one of the first texts on chemotherapy for nurses. She is a frequent speaker within the United States and abroad, having been a visiting nurse professor in Australia and Singapore and lecturing in the United Kingdom, the Netherlands, France Austria, Ireland, Switzerland, Germany, Italy, Korea, and Israel. In 2004, Ms. Boyle participated in the President's Cancer Panel addressing geriatric survivorship issues. Currently, she is the practice outcomes nurse specialist and project leader of the Gero-Oncology & Survivorship Nursing Studies Program at Banner Good Samaritan Medical Center in Phoenix.

Cathy J. Bradley, Ph.D.

Professor
Health Economics
Department of Health Administration
Virginia Commonwealth University
Richmond, Virginia

Dr. Cathy Bradley received her Ph.D. from the University of North Carolina and is currently a professor in the Department of Health Administration and the Massey Cancer Center. Dr. Bradley is a health economist, and her primary research focus has been on health outcomes with regard to cancer and its treatment. Within this broad area, she addresses research topics related to labor market outcomes and disparities in cancer care and survival among low-income populations—specifically those insured by Medicaid.

Barrie R. Cassileth, Ph.D.

Chief, Integrative Medicine Service
Laurence S. Rockefeller Chair in Integrative Medicine
Memorial Sloan-Kettering Cancer Center
New York, New York

As a researcher, educator, and planner, Dr. Cassileth has worked in alternative and complementary (integrative) medicine and psychosocial aspects of cancer care for more than 25 years. She has published extensively on these issues and has been invited to lecture on these topics throughout North and South America, Eastern and Western Europe, Asia, and Australia.

Dr. Cassileth developed prototypic programs in patient and family support, medical education, homecare and hospice, and research in integrative medicine while a faculty member in medicine and associate director of the Comprehensive Cancer Center at the University of Pennsylvania in Philadelphia.

She is editor-in-chief of the new Journal of Society for Integrative Oncology and founding president of the International Society for Integrative Oncology, associate editor or advisory board member of 11 medical journals internationally, and serves as reviewer for most major medical journals and as grant reviewer for government agencies in the United States and other countries. She was a founding member of the Advisory Council to the National Institutes of Health Office of Alternative Medicine. She was on the National Board of Directors and is now on the Eastern Board of the American Cancer Society. She is a member of national ACS committees on complementary medicine, quality of life and health promotions, and serves on ASCO Committees as well as on many NIH and other Federal and national panels and committees.

Her publications include 130 original papers in medical literature and 48 books and chapters for physicians, patients, and families. She has prepared and was filmed for numerous audio and audiovisual programs for patients and physicians. She received her Ph.D. in medical sociology from the University of Pennsylvania and had completed all but her dissertation toward a Ph.D. in psychology at Albert Einstein University in New York. She is a sought-after lecturer and has given numerous radio, television, and print media interviews. She is principal investigator of several NIH research protocols and also heads one of five NIH-supported Botanical Research Centers. Her center at Memorial Sloan-Kettering Cancer Center (MSKCC) addresses the study of immunomodulators.

Graham A. Colditz, M.D., Dr.P.H.

Professor of Medicine
Brigham and Women's Hospital
Channing Laboratory
Harvard Medical School
Boston, Massachusetts

Dr. Graham A. Colditz is professor of medicine at Harvard Medical School, a professor of epidemiology at the Harvard School of Public Health, and a senior epidemiologist in the Department of Medicine, Channing Laboratory, Brigham and Women's Hospital, and associate director of Channing Laboratory. He received his B.Sc., M.B.B.S., and M.D.

from the University of Queensland and his Dr.P.H. from Harvard University School of Public Health.

Dr. Colditz is principal investigator on the Nurses' Health Study, a cohort study of 121,701 nurses, and principal investigator on the Growing Up Today Study (GUTS), which focuses on the diet and lifestyle of 16,883 adolescents between the ages of 13 and 17. As director of the Harvard Center for Cancer Prevention, Dr. Colditz leads the effort to bring the growing body of knowledge on cancer prevention to the public. His work at the center includes the Harvard Cancer Risk Index (a compilation of interactive tools designed to assess individual cancer risk and encourage healthy lifestyle choices) and a breast health compendium written for the Susan G. Komen Breast Cancer Foundation. The Web-based risk assessment tool has been expanded and now provides tailored messages on strategies to prevent a range of chronic diseases among adults (www.yourdiseaserisk.harvard.edu). This Web site has been recognized in numerous ratings of leading medical and public health sites for the public. Under his leadership, the Harvard Center has become actively involved with the Massachusetts Colorectal Cancer Working Group, Massachusetts Skin Cancer Prevention Collaborative, and Boston's Crusade Against Cancer, three local cancer prevention efforts with potential for replication on a nationwide scale. His research focuses on breast cancer incidence, breast cancer prevention, and screening evaluation for breast and colon cancer. He recently led a collaborative effort to promote colorectal cancer screening in primary care practices.

Robert T. Croyle, Ph.D.

Director

Division of Cancer Control and Population Sciences

National Cancer Institute

National Institutes of Health

Bethesda, Maryland

Dr. Robert Croyle was appointed director of the National Cancer Institute's Division of Cancer Control and Population Sciences in July 2003. He previously served as the division's first associate director for behavioral research. Before moving to NCI in 1998, he was professor of psychology and a member of the Huntsman Cancer Institute at the University of Utah in Salt Lake City. Prior to that, he was a visiting investigator at the Fred Hutchinson Cancer Research Center in Seattle, visiting assistant professor of psychology at the University of Washington, and assistant professor of psychology at Williams College in Massachusetts.

Dr. Croyle received his Ph.D. in social psychology from Princeton University in 1985 and graduated Phi Beta Kappa with a B.A. in psychology from the University of Washington in 1978. He has published research in many areas of behavioral science and health. His recent research has examined how individuals process, evaluate, and respond to cancer risk information, including tests for inherited mutations in BRCA1 and BRCA2. His research has been widely published in professional journals in behavioral science, public health, and cancer, and he has edited two volumes: Mental Representation in Health and Illness (1991), and Psychosocial Effects of Screening for Disease Prevention and Detection (1995).

Dr. Croyle is a member of the Academy of Behavioral Medicine Research, a fellow of the Society of Behavioral Medicine, and a recipient of several awards for his research and

professional service. His efforts on journal editorial boards include being associate editor for *Cancer Epidemiology, Biomarkers, and Prevention* and consulting editor for *Health Psychology* and the *British Journal of Health Psychology*. Dr. Croyle received the NIH Merit Award in 1999 and 2002, and the NIH Director's Award in 2000.

Gary T. Deimling, Ph.D.

Professor of Sociology
Cancer Survivor Research Program
Department of Sociology
Case Western Reserve University
Cleveland, Ohio

Dr. Deimling is professor of sociology and associate professor of General Medical Sciences (Oncology) at Case Western Reserve University. His research focuses on the quality of life of older adult long-term cancer survivors. The National Cancer Institute has funded his research for 10 years. It concentrates on the psychosocial impact of this illness on individuals and their family members, and the successful adaptation of older adults to the associated stresses. Key aspects of this research address the ways that personal dispositions such as coping style and health beliefs, along with proactive behaviors such as health promotion and marshalling social and health care support, can buffer cancer survivors from chronic stressors associated with cancer survivorship. Another emphasis of his work is how the development of the "survivor identity" buffers the individual from some of the more profound effects of cancer. The presentation at this conference compares age-related and cancer-related factors as they impact health, functioning, and psychosocial quality of life.

Ronald M. Epstein, M.D.

Director of Research in Family Medicine, Professor of Family Medicine and Psychiatry
Family Medicine Research Programs
Department of Family Medicine
University of Rochester Medical Center
Rochester, New York

Dr. Ronald Epstein is professor of family medicine and psychiatry at the University of Rochester. He serves as director of research in the Department of Family Medicine, associate dean for educational evaluation and research, and is also a practicing family physician. His research focuses on communication in clinical settings and the patient-physician relationship, with special interest in caring for stigmatized populations, management of ambiguity, physician self-awareness and professional development. In medical education, he has published about teaching communication skills and assessing professional competence. Dr. Epstein directs the Rochester Center to Improve Communication in Health Care at the University of Rochester. Funded by grants from National Institute of Mental Health (NIMH), National Cancer Institute (NCI), Agency for Healthcare Research and Quality (AHRQ), and the Robert Wood Johnson Foundation, the Center's mission is to improve communication among members of health care teams, patients, and families. The center focuses on understanding how communication can reduce social, economic, racial, and ethnic disparities in health and health care. He has pioneered the use of unannounced standardized patients to study physicians' practice behaviors, the impact of patient-physician relationships on health and health care costs, management of ambiguity in the clinical practice, and the effect of direct-to-

consumer advertising on clinical care. He is also an experienced qualitative researcher. He has authored over 100 publications. He has received awards from the Robert Wood Johnson Foundation, NIMH, AHRQ, Department of Health and Human Services, the Pfizer-AAFP Foundation, the Koppaka Foundation, the Fulbright Foundation and other state and foundation sources. Dr. Epstein was named the first George Engel and John Romano Dean's Teaching Scholar at the University of Rochester, has been a visiting professor at more than 25 medical schools in the United States, South America, and Europe, and keynote speaker at over 30 national and international conferences on research and medical education. Dr. Epstein graduated from Wesleyan University with a major in music in 1976 and from Harvard Medical School in 2004. He completed residency in family medicine at the University of Rochester/Highland Hospital Family Medicine Residency Program in 1987. At home, Dr. Epstein is father of Eli (16) and Malka (13) and husband of Deborah Fox, a freelance lutenist. He enjoys playing the harpsichord, cooking, cycling, and cross-country skiing.

Carol Estwing Ferrans, Ph.D., R.N., FAAN

Professor, Deputy Director
University of Illinois at Chicago
Chicago, Illinois

Dr. Carol Estwing Ferrans is the deputy director of the Center for Population Health and Health Disparities at the University of Illinois at Chicago (UIC) and professor in the UIC College of Nursing. Dr. Ferrans has been conducting studies focusing on quality of life and minority issues in health care over the past 20 years, funded by the National Cancer Institute and the National Institute for Nursing Research (NINR). She is well known for developing the Ferrans and Powers Quality of Life Index, which has been translated into 20 languages and has been used throughout the world in approximately 200 published studies. In addition, she has contributed to the conceptual development of the field of quality of life research, through her conceptual work focused on clarification of the construct. Dr. Ferrans has received a number of awards for her work and has been recognized as a Distinguished Research Fellow by the International Society for Quality of Life Studies (ISQOLS). Dr. Ferrans maintains an active program of research, studying the effects of illness and treatment on quality of life in cancer, cardiac disease, and other chronic illnesses. An important part of this research has focused on cross-cultural issues, including approaches to increase validity of data and participation in research for minority populations in the United States. This has included the development of culturally specific measures for African Americans and Hispanic Americans. Dr. Ferrans currently is the principal investigator for two large (R01) studies funded by NCI. One study examines cancer survivorship issues for African Americans, focusing on the impact on quality of life and barriers to cancer screening. The second study focuses on breast cancer delay in Black, Hispanic, and White Women. In addition, she is the mentor for NIH and ACS-funded postdoctoral and career-development awards, studying the effect of trust and cancer screening in African American women, prostate cancer screening in African American men, and the effect of trust in health care decision-making in African American caregivers of older adults.

Harold P. Freeman, M.D.

Senior Advisor to the Director, National Cancer Institute
President, Founder, and Medical Director, Ralph Lauren Center for Cancer Care
and Prevention
New York, New York

Dr. Harold Freeman is senior advisor to the director of the National Cancer Institute (NCI), Bethesda, Maryland. He is directly responsible for strategies to achieve NCI's 2015 goal to eliminate the suffering and death due to cancer in minority and underserved communities. Dr. Freeman is also president, founder, and medical director of the Ralph Lauren Center for Cancer Care and Prevention in New York, New York. He is a professor of clinical surgery at Columbia University College of Physicians and Surgeons, also in New York. For 25 years (1974–1999), Dr. Freeman was director of surgery at Harlem Hospital in New York and, for a 2-year period ending in 2001, Dr. Freeman served as the president and CEO of North General Hospital in New York.

Dr. Freeman currently is a diplomat of the American Board of Surgery and a fellow of the American College of Surgeons. He has been medical director of the Breast Examination Center of Harlem, a program of Memorial Sloan-Kettering Cancer Center, since 1979. Previously, he served as a member of the Executive Committee of the Board of Governors of the American College of Surgeons; on the Executive Council of the Society of Surgical Oncology; as chairman of the Surgical Section of the National Medical Association; and as a member of the Ethics Committee of the Board of Regents of the American College of Surgeons. Dr. Freeman is past chairman of the New York State Commission for a Healthy New York and past chairman of the New York State Breast Cancer Treatment Quality Advisory Panel. Dr. Freeman was elected to membership in the Institute of Medicine of the National Academy of Sciences in 1997.

Dr. Freeman has been actively involved with the American Cancer Society for many years, and from 1988–89 he served as its national president. He is the chief architect of the American Cancer Society's initiative on Cancer in the Poor and is a leading authority on the interrelationships between race, poverty, and cancer. The Society established the Harold P. Freeman Award in 1990 to recognize his work in this area. This award is presented annually by American Cancer Society divisions throughout the United States to individuals who have made outstanding contributions to the fight against cancer in the poor.

Dr. Freeman pioneered the "Patient Navigation Program," which addresses disparities in access to treatment, particularly among poor and uninsured people. This program is designed to assist medically underserved patients in navigating their way through a complex health system by overcoming barriers to timely diagnosis and treatment of cancer. The success of Dr. Freeman's Patient Navigation Program has led many other health care organizations to adopt similar initiatives. Based on this model, the Patient Navigator and Chronic Disease Prevention Act was signed into law by President Bush in June 2005.

Dr. Freeman is past chairman of the President's Cancer Panel to which he was appointed for four consecutive 3-year terms, first by President Bush in 1991 and subsequently by President Clinton in 1994, 1997, and 2000.

As a graduate of Catholic University of America, Dr. Freeman received the Harris Award for Outstanding Scholar, Gentleman, and Athlete. He later was recognized as

Outstanding Alumnus in the Medical Arts at Catholic University and was inducted into the Athlete's Hall of Fame of the University. In addition, he received the Daniel Hale Williams Award for Outstanding Achievements as Chief Resident while in medical school at Howard University.

Dr. Freeman was awarded honorary D.Sc. from Albany Medical College, Niagara University, Adelphi University, and Catholic University of America. He was also awarded the University of California at San Francisco Medal. Dr. Freeman's work has earned him several awards, including the Mary Lasker Award for Public Service; the Time, Inc. Health International Health and Medical Media Awards' Lifetime Achievement Award; the American Cancer Society's Medal of Honor; the CDC Foundation's Champion of Prevention Award; the Breast Cancer Research Foundation's Jill Rose Award; the American Society of Clinical Oncology's Special Recognition Award; the Susan G. Komen Breast Cancer National Foundation's Champion of Change Award; the International Spirit of Life Foundation and the Washington Cancer Institute's Spirit of Life Award; the Mayo Clinic Charles G. Moertel Memorial Lectureship Award; the Association of Community Cancer Centers' Achievement Award; the George Washington University Cancer Institute's Distinguished Public Service Award; and the 2006 Black History Makers Awards of The Associated Black Charities.

Patricia Ganz, M.D.

Professor of Health Services and Medicine

University of California, Los Angeles Schools of Medicine and Public Health

Division of Cancer Prevention and Control, Jonsson Comprehensive Cancer Center
Los Angeles, California

Dr. Patricia Ganz, a medical oncologist, received her B.A. magna cum laude from Radcliffe College (Harvard University) in 1969 and her M.D. from the University of California at Los Angeles (UCLA) in 1973. She completed her training in internal medicine and hematology/oncology at UCLA Medical Center from 1973–1978, where she also served as chief resident in medicine. She has been a member of the faculty of the UCLA School of Medicine since 1978 and the UCLA School of Public Health since 1992. Since 1993 she has been the director of the Division of Cancer Prevention and Control Research at the Jonsson Comprehensive Cancer Center. In 1999 she was awarded an American Cancer Society Clinical Research Professorship for Enhancing Patient Outcomes across the Cancer Control Continuum. In 2006, she was awarded funding to lead UCLA's Cancer Survivorship Center of Excellence as part of the LIVESTRONG™ Survivorship Center of Excellence Network.

Dr. Ganz is a pioneer in the assessment of quality of life in cancer patients, and is active in clinical trials research with the National Surgical Adjuvant Breast and Bowel Project (NSABP). She has focused much of her clinical and research efforts in the areas of breast cancer and its prevention, and was a member of the NCI Progress Review Group on Breast Cancer. At the Jonsson Cancer Center, she directs the UCLA Family Cancer Registry and Genetic Evaluation Program. Her other major areas of research include cancer survivorship and late effects of cancer treatment, cancer in the elderly, and quality of care for cancer patients. She is an associate editor for the Journal of Clinical Oncology, the Journal of the National Cancer Institute, and CA-A Journal for Clinicians. She currently serves on the NCI Board of Scientific Advisors, as well as the Board of Directors of the American Society of Clinical Oncology (ASCO).

Ann M. Geiger, Ph.D.

Associate Professor

Social Sciences and Health Policy

Division of Public Health Sciences

Wake Forest University School of Medicine

Winston-Salem, North Carolina

Dr. Ann Geiger is an associate professor in the Division of Public Health Sciences at the Wake Forest University School of Medicine, where she is also a member of the Cancer Control Program of the Comprehensive Cancer Center of Wake Forest University. She received an A.B. in biology from Harvard-Radcliffe College in 1987 and a M.P.H. (1992) and Ph.D. (1995) in Epidemiologic Science from the University of Michigan. For 10 years, Dr. Geiger served as a Research Scientist then Group Leader of Cancer Research in the Research and Evaluation Department of Kaiser Permanente Southern California, where she also held an adjunct appointment in the Department of Preventive Medicine at the University of Southern California–Keck School of Medicine. Dr. Geiger has led or participated as a co-investigator on multiple cancer-related projects, including a number of projects incorporating information from automated health system data, cancer registry data, medical records and surveys or telephone interviews. She has been involved with the Cancer Research Network since it began in 1999. In addition to currently leading one project and serving as a co-investigator on several others, she facilitates the Network's Survivorship Interest Group. Dr. Geiger's interests focus on cancer survivorship, particularly population-based studies of late treatment effects and the impact of health care on survival and quality of life.

Barbara Given, R.N., Ph.D., FAAN

University Distinguished Professor, College of Nursing

Senior Fellow, Outreach and Engagement

Michigan State University

Walther Cancer Institute Research Scientist

East Lansing, Michigan

Dr. Barbara Given is a University Distinguished Professor in the College of Nursing. She has been actively involved in research in long-term care, home care, chronic illness, and family care for more than 27 years with funding from the National Cancer Institute, National Institute on Mental Health, National Institute for Nursing Research, National Institute on Aging, Walther Cancer Institute, Michigan Department of Community Health, and the American Cancer Society to explore these issues. Topics of research center around functional outcomes, symptom control, patterns of care, utilization of care, and formal and informal cost of care for the chronically ill and their family caregivers, especially those with cancer. She is a reviewer for numerous professional journals and currently serves on the editorial board for Research in Nursing and Health, and Cancer Nursing. She has served as a grant reviewer for AHCPR, Psychosocial Research for the American Cancer Society, National Cancer Institute, NINR, Department of Defense, National Institute of Aging, California Cancer Research Program, and the Alzheimer's Association of Canada. Dr. Given testified to the President's Breast Cancer Commission and the President's Cancer Panel for Older Populations in 1997 and served on the Institute of Medicine's Department of Defense Panel to decide on priorities for breast cancer research funding. She serves on the Breast Cancer Integrating Panel for the Department of Defense and the psychosocial committee for NSABP. She also served on the Blue Ribbon Panel for ACS to set direction for research for Behavioral and

Psychosocial Research. She recently served on the Institute of Medicine to examine cancer care outcomes in Georgia. She serves on the Executive Committee of the Behavioral Cooperative Oncology Group of the Walther Cancer Institute. In 1994, she was the American Nursing Foundation Distinguished Researcher Award Recipient and in 1995, the ONS Distinguished Researcher and the Michigan Association of Governing Boards Distinguished Faculty Award recipient. In 2000, she received the College of Nursing Alumni Lifetime Achievement Award at Michigan State University. In 2001, she received the University Distinguished Professor award, the Sigma Theta Tau Elizabeth Williams Miller Award for Excellence in Research and the Friends of the National Institute for Nursing Research Pathfinder Distinguished Researcher Award. In 2005, she received the Oncology Nursing Outstanding Service Award.

Mitch Golant, Ph.D.

Vice President, Research & Development
The Wellness Community
Los Angeles, CA

Dr. Mitch Golant is a health psychologist and is vice president of research and development for The Wellness Community (TWC). He, along with Dr. Harold Benjamin, TWC's founder, traveled throughout the world introducing TWC's Patient Active Concept to international thought leaders and psychosocial oncologists. He has been with TWC for over 22 years, where he supervised and trained TWC's professional clinical staff. Dr. Golant is widely recognized as a pioneer in the use of information technology in cancer education and support through the delivery of online support groups. He was central to the launch of the award-winning Virtual Wellness Community in both English and Spanish and Group Loop: Teens. Talk. Cancer. Online. He has presented nationally and internationally on TWC's Patient Active programs and evidence-based research. He is the contributing editor to the Essentials of Psychosocial Oncology handbook 2006). In fall 2005 he, along with two colleagues from Memorial Sloan-Kettering Cancer Center, was selected to train 40 psychologists and psychiatrists from Poland's National Psychosocial Oncology Society. He is also the author of six books, including "What To Do When Someone You Love is Depressed," (Holt) and more than 20 peer-reviewed articles.

David H. Gustafson, Ph.D.

Professor of Industrial Engineering and Preventive Medicine
Founding Director of the Center for Health Systems Research and Analysis
University of Wisconsin–Madison
Madison, Wisconsin

Dr. Dave Gustafson is professor of industrial engineering and preventive medicine and founding director of the Center for Health Systems Research and Analysis at the University of Wisconsin–Madison. He received his B.S., M.S., and Ph.D. from the University of Michigan. He and his wife, Rea, have three children and 1.8 grandchildren, reputed to be the best grandchildren in the world.

Dave's interests in decision, change, and information theory applied to health systems come together in the design and evaluation of systems and tools to help individuals and organizations cope with major changes. Regarding individual change his research teams have created systems to detect suicidal propensity, help teenagers adopt healthy

behaviors, and help families facing major health crises cope more effectively. That work focuses on the Comprehensive Health Enhancement Support System (CHESS), a computer system to help people facing serious situations such as breast and prostate cancer, asthma, HIV/AIDS, heart disease, Alzheimer's disease, and sexual assault. CHESS has been tested in randomized trials and field tests involving several thousand people and provided insight into acceptance, use and impact of computer-based support systems on health, health-related behavior and health service use. Another of his research projects is examining the barriers to successful diffusion of these technologies.

His research on organizational improvement focuses on making and sustaining organizational change. He developed a computer system (QISS, the Quality Improvement Support System) to help organizations implement quality improvement. He developed new techniques for facilitating groups and understanding customer needs. Evaluating the computer systems led to new models to measure: customer satisfaction, severity, medical under-service and quality of care. His behavior change research led to models to predict and explain initiation of and adherence to organizational change.

Dr. Gustafson is the author of six books and more than 100 journal articles. He is a fellow of the Association for Health Services Research, a fellow and board member of the Institute for Healthcare Improvement, board chair of the eHealth Institute, and past chair of the Federal Government's Science Panel on Interactive Communications in Health. He is a member of the Athletic Board of the University of Wisconsin and national program director of a Robert Wood Johnson Foundation initiative to improve quality of services in substance abuse treatment agencies.

Robert Hendrickson, Commander (Sel)
Silver Spring, MD

Commander (Sel) Bob Hendrickson is a colon cancer survivor and 25-year veteran of the United States Coast Guard. He recently completed a tour as executive officer in the Coast Guard vessel "Decisive" and is presently assigned at Coast Guard Headquarters in Washington, D.C. Since his own battle with colon cancer from 2001–2002, Commander Hendrickson has been a robust advocate for cancer awareness and education. He works with a number of organizations such as the American Cancer Society and the Colon Club as well as personally mentoring dozens of cancer survivors, with a particular emphasis on active-duty military members battling the disease. He is currently working to improve administrative procedures/options for these men and women to ensure they are given every opportunity for continued service if they so desire. He has appeared on national television and in numerous other media outlets discussing cancer. In July of 2006, Commander Hendrickson bared his scar and posed for the "Colondar," a calendar featuring young men and women diagnosed with colon cancer before the age of 40. Most recently he sought appointment to the NCI Director's Consumer Liaison Group (DCLG)—at press time he was awaiting the selection results.

Bradford W. Hesse, Ph.D.

Acting Branch Chief

Health Communications and Informatics Research Branch, DCCPS

National Cancer Institute

National Institutes of Health

Rockville, Maryland

Dr. Bradford Hesse was appointed acting chief of the National Cancer Institute's Health Communication and Informatics Research Branch in August 2004 and is the director of NCI's biennial Health Information National Trends Survey (HINTS). For almost 2 decades, Dr. Hesse has been conducting research in the interdisciplinary fields of human computer interaction, health communication, medical informatics, and decision support technology (especially as an application of artificial intelligence research). He completed his graduate work in psychology at the University of Utah where he was funded jointly by the departments of Psychology and Medical Informatics. After completing his degree, he served as a member of the Committee for Social Science Research on Computing at Carnegie Mellon University in 1988, and then went on to co-found the Center for Research on Technology at the American Institutes for Research in Palo Alto, California, in 1991. Working in a contract environment before coming to NCI, he directed projects for the Departments of Education and Labor, the Centers for Disease Control and Prevention, and the National Institutes of Health. He has provided usability services to Apple Computer, Hewlett Packard, Xerox, Microsoft, Sun, and Netscape; and he serves on the board of advisors for the American Psychological Association's online resource, PsycINFO. Since coming to NCI, Dr. Hesse has focused his energies on bringing the power of health information technologies to bear on the problem of eliminating death and suffering from cancer; a cause to which he remains steadfastly dedicated.

Barbara Hoffman, J.D.

Professor

Rutgers School of Law-Newark

Center for Law and Justice

The State University of New Jersey

Newark, New Jersey

Professor Barbara Hoffman is a member of the legal research and writing faculty of Rutgers Law School–Newark. She is the founding chair of the National Coalition for Cancer Survivorship. She is the author of numerous book chapters, articles, Web content, and consumer booklets on the legal rights of cancer survivors, and is an Area Specialist to the Cancer Survival Toolbox. She is the editor of A Cancer Survivor's Almanac: Charting Your Journey, John Wiley & Sons (1998), a revised and expanded version of which will be published by John Wiley & Sons in March 2004.

Since the early 1980s, Professor Hoffman has advocated for the rights of cancer survivors and individuals with disabilities. She has spoken at more than 100 conference and programs about cancer survivorship. She has served as a consultant to the National Cancer Institute, comprehensive cancer centers, nonprofit organizations, and Web sites. She is a member of the Princeton University Alumni Schools Committee and the editorial board of CURE (Cancer Updates, Research & Education). Professor Hoffman is the recipient of the President's Award from the National Coalition for Cancer Survivorship and of an Image Award from DateAble, Inc.

Chanita Hughes Halbert, Ph.D.
Assistant Professor of Psychiatry
Community Cancer Prevention and Control
University of Pennsylvania
Philadelphia, Pennsylvania

Dr. Chanita Hughes Halbert received her Ph.D. in personality psychology from Howard University in 1997. In addition to her doctoral training, Dr. Halbert completed pre- and postdoctoral training at the Lombardi Cancer Center at Georgetown University. In 1995, she received a pre-doctoral supplemental award from the National Institutes of Mental Health to evaluate psychosocial and sociocultural influences on family communication about genetic testing and in 1997 she received a postdoctoral supplemental award from the National Cancer Institute to evaluate the process and content of family communication about genetic testing following disclosure of BRCA1 and BRCA2 test results. Currently, Dr. Halbert is an assistant professor in the Department of Psychiatry at the University of Pennsylvania. The goal of Dr. Halbert's research program is to identify sociocultural, psychological, and environmental determinants of cancer disparities and to translate this information into interventions to reduce cancer disparities in African Americans. She is director of the Community Cancer Prevention and Control Initiative at the Abramson Cancer Center and is principal investigator of a randomized trial funded by the Department of Defense to develop and evaluate a culturally tailored genetic counseling protocol for African American women. Dr. Halbert is also co-principal investigator for the Penn Center for Population Health and Health Disparities, which is funded by the National Cancer Institute. She is also director of the Community Outreach and Dissemination Core and is principal investigator for a project on Determinants of Ethnic Differences in Quality of Life within the Penn Center for Population Health. In addition, Dr. Halbert's research is addressing the lack of adequate instruments to assess cultural factors through an R01 funded by the National Cancer Institute to develop and evaluate a multidimensional cultural values instrument for cancer prevention and control behaviors among African Americans, Hispanics, and Caucasians. The results of Dr. Halbert's research have been published in influential journals in the fields of cancer prevention (Cancer Epidemiology, Biomarkers, and Prevention), clinical oncology (Journal of Clinical Oncology), medicine (Archives of Internal Medicine), genetics (Genetics in Medicine), and public health (Preventive Medicine).

Gail Gibson Hunt
President and CEO
National Alliance for Caregiving
Bethesda, Maryland

Ms. Gail Hunt is president and CEO of the National Alliance for Caregiving (NAC), a nonprofit coalition dedicated to conducting research and developing national programs for family caregivers and the professionals who serve them. Prior to heading NAC, Ms. Hunt was president of her own aging services consulting firm for 14 years. She conducted corporate eldercare research for the National Institute on Aging and the Social Security Administration, developed training for caregivers with AARP and the American Occupational Therapy Association, and designed a corporate eldercare program for EAPs with the Employee Assistance Professional Association. Prior to having her own firm, she was senior manager in charge of human services for the Washington, D.C., office of KPMG Peat Marwick. Ms. Hunt attended Vassar College and graduated from Columbia University in New York.

Melinda L. Irwin, Ph.D., M.P.H.

Assistant Professor

Department of Epidemiology and Public Health

Yale School of Medicine

New Haven, Connecticut

Dr. Melinda Irwin is an assistant professor in the Department of Epidemiology and Public Health at Yale School of Medicine. She received a B.S. in kinesiology from the College of William and Mary, a M.S. in exercise physiology from the University of North Carolina at Chapel Hill, and a Ph.D. in exercise physiology from the University of South Carolina. She received an M.P.H. in epidemiology from the University of Washington in Seattle, and also completed a postdoctoral research fellowship at the Fred Hutchinson Cancer Research Center in Seattle, WA. Dr. Irwin is experienced in the design and conduct of randomized controlled exercise trials and population-based prospective cohort studies in women with and without breast cancer. She has received funding from the American Cancer Society, the Susan G. Komen Breast Cancer Foundation, and the Lance Armstrong Foundation to conduct two exercise trials examining, in breast cancer survivors, the effect of exercise on a number of biological markers associated with breast cancer prognosis. Dr. Irwin also is a co-investigator on the recently funded Transdisciplinary Research on Energetics and Cancer Coordination Center grant, and a co-investigator on a multi-site cohort study in breast cancer survivors (the HEAL study) that is following 1,185 incident breast cancer cases to determine the effects of weight, body composition, physical activity, diet, genetics, and serum hormones on recurrence and survival. She also is currently the chair of the American College of Sports Medicine Cancer Interest Group. Dr. Irwin has published numerous papers in peer-reviewed journals on the effect of exercise on breast cancer biomarkers, influence of physical activity on obesity, and physical activity measurement issues. She also has considerable experience with the development and validation of physical activity surveys and objective measures of physical activity such as motion sensors and cardiorespiratory fitness.

Linda Jacobs, Ph.D., R.N.

Director, Lance Armstrong Foundation Living Well After Cancer Program

Abramson Cancer Center, University of Pennsylvania

Philadelphia, Pennsylvania

Dr. Linda A. Jacobs received her undergraduate and doctoral degrees from the University of Pennsylvania. She is board certified as an oncology and primary care nurse practitioner, and the recipient of numerous clinical and teaching awards. She is the director of the multidisciplinary Lance Armstrong Foundation Living Well After Cancer Program at the Abramson Cancer Center at Penn, and she consults with institutions across the country developing similar programs. She also works with the Lance Armstrong Foundation, the American Society of Clinical Oncology, the Institute of Medicine, the American Cancer Society, and the Oncology Nursing Society on cancer survivorship-related projects.

Marjorie Kagawa-Singer, Ph.D., M.N., R.N.

Professor

UCLA School of Public Health and Asian American Studies

University of California, Los Angeles

Los Angeles, California

Dr. Marjorie Kagawa-Singer is a professor at the UCLA School of Public Health and Asian American Studies Department. She has a master's degree in nursing from the UCLA School of Nursing and master's and doctorate degrees in anthropology from UCLA. Her clinical work and research has been in oncology, focusing upon the disparities in physical and mental health care outcomes of ethnic minority populations with cancer: primarily with the Asian American and Pacific Islander communities. She serves on multiple local, state, and national committees addressing impact of ethnicity on health care and health outcomes, and has published and lectured extensively on cross-cultural issues in health, cancer, pain, grief and bereavement, end of life decision-making, and quality of life. Her current cancer studies include intervention studies to promote mammography in Southeast Asian and Pacific Islander women, quality of life, spirituality, and doctor/patient communication with Hispanic, African American, and Asian American women post-breast and cervical cancer. She also focuses her efforts on the impact of culture on health outcomes, and developing standards of cultural competence in health care.

Dr. Kagawa-Singer is also principal investigator of the Los Angeles site for the NCI funded national Asian American Network on Cancer Awareness, Research and Training (<http://www.AANCART.org>). She is co-PI for study on end-of-life care for ethnic minority individuals in California, Associate Director the c UCLA EXPORT Center of Excellence to Eliminate Health Disparities, PI of the UCLA/NCI-funded Minority Training Program for Cancer Control Research, community director of UCLA's Jonsson Cancer Center Survivorship Program, and a member of the **LIVESTRONG™** Survivorship Center of Excellence Network.

Susan Leigh, R.N., B.S.N.

Oncology Nurse

Cancer Survivorship Consultant

Tucson, Arizona

Ms. Susan Leigh is a founding member of the National Coalition for Cancer Survivorship (NCCS) in 1986, and has been consulting, speaking, writing, and advocating for issues around living with cancer across the continuum, including long-term survival. She speaks from personal experience as a cancer survivor, and also from professional experience as an oncology nurse. She has numerous publications in both peer-reviewed journals (Seminars in Oncology Nursing, Oncology Nursing Forum), oncology textbooks, AJN, and consumer publications.

Craig Lustig, M.P.A.

Executive Director

Children's Cause for Cancer Advocacy

Silver Spring, Maryland

Mr. Craig Lustig is a 12-year survivor of pediatric brain cancer, an active volunteer, and cancer patient advocate. Mr. Lustig is vice president, survivorship programs, at The Children's Cause for Cancer Advocacy, a national childhood cancer advocacy

organization. Mr. Lustig's strong volunteer commitment includes serving on the boards of the Children's Brain Tumor Foundation and the North American Brain Tumor Coalition, and formerly, the National Coalition for Cancer Survivorship. His professional experience includes serving as presidential management intern at the National Institutes of Health and as deputy director at the University of Maryland Center on Aging. He was also an advertising executive for more than a decade, focusing on public health, health care, and consumer products clients at a number of international marketing firms. He serves as the co-chair of the Alliance for Childhood Cancer, and as a patient representative to the FDA's Oncology Drug Advisory Committee and the NCI's Consumer Advocates in Research and Related Activities program. He completed his M.P.A. in health policy at the Columbia University School of International and Public Affairs in 1998.

Ann C. Mertens, Ph.D.

Associate Professor, Childhood Cancer Survivor Study Project Director
Department of Pediatrics
University of Minnesota
Minneapolis, Minnesota

Dr. Mertens, a pediatric cancer epidemiologist, received an M.A. biostatistics in 1987 and a Ph.D. in epidemiology in 1994 from the University of Minnesota. She joined the faculty at that time in the Department of Pediatrics, within the Division of Epidemiology and Clinical Research. She is currently an associate professor of Pediatrics at the University of Minnesota. Dr. Mertens' research involves etiology, statistical methods, and survivorship issues in childhood cancer research. Her major focus is on behavior change and the development of education strategies among adult cancer survivors diagnosed and treated during childhood and adolescence. She is the project director of the Childhood Cancer Survivor Study, a multi-institutional consortium evaluating a cohort of more than 20,000 5-year survivors of childhood cancer. She has extensive experience in grants that focus on specific issues that affect cancer survivors as they reach adulthood.

Merle Mishel, Ph.D., R.N.

Kenan Professor of Nursing, Professor, Cancer Prevention and Control
School of Nursing, UNC Lineberger Comprehensive Cancer Center
University of North Carolina at Chapel Hill
Chapel Hill, North Carolina

Dr. Merle Mishel has an M.S.N. from UCLA and a Ph.D. in social psychology from Claremont Graduate School. She is currently a Kenan Professor and Director of the doctoral and postdoctoral programs in the School of Nursing, University of North Carolina at Chapel Hill. She has been well funded for her research on patients' experience of uncertainty in illness. As the developer of the uncertainty in illness theory and the scales to measure uncertainty, she has been invited to numerous countries to present her research findings and to discuss her theory and use of the uncertainty scales. She and her colleagues have conducted four intervention studies funded by either NCI or NINR on managing uncertainty. The studies have included Caucasian and African American men with prostate cancer or women with breast cancer. She and her research team are currently funded for an intervention study on decision-making under conditions of uncertainty in men recently diagnosed with localized prostate cancer.

Alyson Moadel, Ph.D.

Assistant Professor

Department of Epidemiology and Population Health
Albert Einstein College of Medicine, Yeshiva University
Bronx, New York

Dr. Alyson Moadel is assistant professor in the Department of Epidemiology & Population Health at the Albert Einstein College of Medicine, as well as director of the Psychosocial Oncology Program of the Albert Einstein Cancer Center (AECC), Bronx, NY. As a health psychologist, Dr. Moadel applies a career in research, teaching, and clinical training to her interest in the psychological, social, and cultural factors associated with quality of life (QOL) after cancer among underserved patients. She received her Ph.D. in health psychology from Yeshiva University in 1995, after which she received her postdoctoral training (1995–1997) in psycho-oncology at Memorial Sloan-Kettering Cancer Center. Since then, she has been involved in studying the efficacy of various mind-body interventions on QOL after cancer. She is currently conducting two clinical trials including a randomized-controlled trial of yoga (funded by the National Cancer Institute and Langeloth Foundation) and a randomized-comparison trial of psycho-education vs. psycho-spiritual group support (funded by the American Cancer Society). As representative of the Bronx population, the majority of the patients enrolled in her trials are African American and Hispanic.

Daniel A Monti, M.D.

Director

Jefferson Myrna Brind Center of Integrative Medicine
Thomas Jefferson University Hospital
Philadelphia, Pennsylvania

Dr. Daniel Monti is the director of the Jefferson-Myrna Brind Center of Integrative Medicine at Thomas Jefferson University Hospital, where he also is an associate professor in the Department of Psychiatry and the Department of Emergency Medicine. His most recent research efforts have focused on the effects of stress and stress-reduction on the health outcomes of cancer patients. In addition, he has published and lectured extensively on mind-body medicine and integrating promising complementary therapies into the current medical model.

Dr. Monti recently received a grant from the NCI Office of Survivorship to study a novel stress reduction program for cancer patients called Mindfulness-Based Art Therapy (MBAT).

Kevin C. Oeffinger, M.D.

Member

Living Beyond Cancer: A Program for Adult Survivors of Pediatric Cancer
Department of Pediatrics and Internal Medicine
Memorial Sloan-Kettering Institute for Cancer Research
New York, New York

Dr. Kevin Oeffinger is a family physician, the Medical Director of Living Beyond Cancer: A Program for Adult Survivors of Pediatric Cancer, and member and attending in the Departments of Pediatrics and Internal Medicine at Memorial Sloan-Kettering Cancer

Center. Prior to arriving at MSKCC in July 2005, he was a professor of family medicine and pediatrics at the University of Texas Southwestern Medical Center in Dallas and the director of the After the Cancer Experience (ACE) Young Adult Program. In addition to providing survivorship health care, Dr. Oeffinger has been actively involved in survivorship research. As an independently supported NCI R01 investigator, his two main areas of research are cardiovascular risk in survivors of childhood leukemia and facilitating and enhancing risk-based health care of pediatric cancer survivors. He currently serves on the Childhood Cancer Survivor Study Steering Committee and the Children's Oncology Group Late Effects and Cancer Control Steering Committees. Dr. Oeffinger also served as a consultant for the Institute of Medicine report, Childhood Cancer Survivorship: Improving Care and Quality of Life.

Kutluk Oktay, M.D.

Associate Professor

Fertility Preservation Program

The Center for Reproductive Medicine

Weill Medical College of Cornell University

New York, New York

Dr. Oktay is a tenure track associate professor and director of the Fertility Preservation Program at the Center for Reproductive Medicine and Infertility, Weill Medical College of Cornell University. He is best known for his contributions in the field of fertility preservation, especially the development of ovarian tissue cryopreservation and transplantation, and novel ovarian stimulation protocols for cancer patients. He has also conducted key work on early stages of ovarian follicle development and holds an NIH grant to study the molecular aspects of early ovarian follicle development. Dr. Oktay has published over 70 articles and book chapters, some of them in top journals such as NEJM, JAMA, Lancet, and Journal of Clinical Oncology; continuously lectures around the world; and has been recognized with numerous scientific and clinical awards. He is currently the president of the Fertility Preservation Interest Group at the American Society of Reproductive Medicine.

Caroline Peterson, M.A., ATR-BC

Research Associate

Jefferson Myrna Brind Center of Integrative Medicine

Thomas Jefferson University

Philadelphia, Pennsylvania

Ms. Caroline Peterson, is a board certified therapist and mindfulness-based stress-reduction program instructor with the Jefferson Myrna Brind Center of Integrative Medicine at Thomas Jefferson University Hospital, where she is also a research associate in the Department of Emergency Medicine. Her ongoing work has been the development of the multi-modal Mindfulness-Based Art Therapy (MBAT) intervention and as a researcher on the effect of the MBAT intervention on the health outcomes of men and women with cancer. Ms. Peterson is a co-investigator on the current research study of MBAT, funded by NCI's Office of Survivorship, for which Daniel A. Monti, M.D., is the principal investigator.

Jay F. Piccirillo, M.D.

Professor

Clinical Outcomes Research Unit
Otolaryngology Head and Neck Surgery
Washington University School of Medicine
St. Louis, Missouri

Dr. Piccirillo is professor and director of Clinical Outcomes Research Office, Department of Otolaryngology, Medicine, and Occupational Therapy. He is a practicing clinical otolaryngologist and a member of the Washington University Faculty Practice Plan. He trained in clinical epidemiology and health services research at Yale University with Dr. Alvan Feinstein as a Robert Wood Johnson Clinical Scholars Fellow. He is the coursemaster for the first- and second-year medical student course in Scientific Methods in Clinical Medicine and Research. He is program director for the NIH-sponsored T32–Pre-doctoral Clinical Research Training Program, a new clinical research training program that provides stipends for medical students and pre-doctoral students enrolled in training programs in audiology, occupational therapy, physical therapy, social work, and biomedical engineering. He is also a co-director for the Doris Duke Clinical Research Fellowship, K30–Core Curriculum in Clinical Investigation and the K12–Multidisciplinary Clinical Research Career Development Program. The T32, K12, and K30 programs are all part of the NIH Roadmap Initiatives in Clinical Research Workforce Training. As a result of his roles as coursemaster, program director, and co-program director, Dr. Piccirillo interacts each year with nearly a hundred pre-professional students, residents, fellows, and junior faculty engaged in clinical research training. He is prognostic investigator for the NCI/NIA-sponsored project “Comorbidity Prognostic Impact in Elderly Cancer Research” (RO1CA104979-01) and the NCI-sponsored project “Comparison of Comorbidity Collection Methods” (RO1CA114271). He is a member of the National Quality Forum Technical Panel (expert on comorbidity).

David G. Poplack, M.D.

Director, Professor of Pediatric Oncology, Head Hematology Section
Texas Children's Cancer Center
Texas Children's Hospital
Baylor College of Medicine
Houston, Texas

Dr. Poplack is director of the Texas Children's Cancer Center. Dr. Poplack holds the Elise C. Young Chair of Pediatric Oncology at Baylor College of Medicine (BCM) and serves as the chief of the Hematology/Oncology Section in the Department of Pediatrics. Dr. Poplack is training director of the BCM Pediatric Hematology-Oncology Fellowship Training Program, and is the PI/program director of a K12–Pediatric Oncology Clinical Research Training Program and a T32–Pediatric Oncology Training Program, both funded by the National Cancer Institute. He is also PI of the NIH-funded Pediatric Pharmacology Research Unit at BCM. Dr. Poplack is Chairman of the GCRC Scientific Advisory Committee at BCM. He is a member of the American Society of Clinical Investigation and has served on numerous editorial boards as well as on committees for the National Institutes of Health, the Food and Drug Administration, and the Institute of Medicine. He is also a member of the External Scientific Advisory Board of the Children's Oncology Group (COG). He has authored 348 publications. Prior to joining BCM, Dr. Poplack served as deputy branch chief of the Pediatric Branch of the NCI and head of its Pharmacology and Experimental Therapeutics section. His research interests

include childhood leukemia, cancer survivorship, and the clinical pharmacology of anticancer agents in children. Dr. Poplack is the co-editor of Principles and Practice of Pediatric Oncology, the major textbook in the field, now in its fifth edition. He has an extensive track record of successful mentorship. Many of the trainees previously mentored by Dr. Poplack are now leaders in the field of pediatric oncology.

Victoria H. Raveis, Ph.D.

Associate Professor of Clinical Sociomedical Sciences, Co-Director
Center for Psychosocial Study of Health and Illness
Columbia University Mailman School of Public Health
New York, New York

Dr. Victoria H. Raveis is an associate professor of Clinical Sociomedical Sciences at Columbia University and co-director of the Center for Psychosocial Study of Health and Illness. Dr. Raveis has been engaged in a comprehensive program of research examining the psychological, social, and practical challenges seriously ill or dying persons and their family caregivers' experience. She has received funding from NCI, NIMH, NINR, HRSA, the DOD, and various foundations. Her work has documented the diversity and scope of the family caring unit, demonstrated the importance of attending to societal and cultural factors in caregiving situations, and informed programs, practice, and policy in this area. Her recent research has examined breast cancer survivorship and family care provision, focusing on caregiving relatives at increased familial risk for cancer (i.e., mothers, sisters, and daughters). Dr. Raveis is currently evaluating the efficacy of a family caregiver education and skill-training program in facilitating symptom management during cancer survivorship.

Julia Rowland, Ph.D.

Director, Office of Cancer Survivorship, DCCPS
National Cancer Institute
National Institutes of Health
Bethesda, Maryland

Dr. Julia Rowland was appointed director of NCI's Office of Cancer Survivorship in September 1999. Before coming to DCCPS, she was the founding director of the Psycho-Oncology Program at the Lombardi Cancer Center at Georgetown University (1990–1999). Prior to that, she trained and worked for 13 years in psycho-oncology at Memorial Sloan-Kettering Cancer Center (MSKCC). Dr. Rowland received her Ph.D. in developmental psychology from Columbia University in 1984 and was one of the first two postdoctoral fellows at MSKCC to receive NIH-supported training in the then newly emergent field of psychosocial oncology. While at MSKCC, where she held joint appointments in pediatrics and neurology, Dr. Rowland helped establish and was the first director of the Post-Treatment Resource Program.

Her research has focused on both pediatric and adult cancer survivorship. She has published extensively on women's reactions to breast cancer, as well as on the roles of coping, social support, and developmental stage in a patient's adaptation to cancer. She co-edited the groundbreaking text, *Handbook of Psycho-Oncology: Psychological Care of the Patient with Cancer* (1989), and is the author of more than 75 scientific articles, reviews, and book chapters. She is also a frequent speaker to both lay and professional audiences on issues related to quality of life and health after cancer.

Dr. Rowland is a member of several advisory boards, including that of the National Coalition for Cancer Survivorship and the American Psychosocial Oncology Society. Her service on journal editorial boards includes being editor of the survivorship department for *Cancer Investigation*, and contributing editor for *Breast Diseases: A Yearbook Quarterly*. Since coming to NCI, Dr. Rowland has been awarded an NIH Plain Language Award, two NIH Merit Awards, and was appointed co-champion of NCI's Extraordinary Opportunity in Cancer Survivorship.

Mark Salzer, Ph.D.

Assistant Professor of Psychology in Psychiatry
Center for Mental Health Policy and Services Research
University of Pennsylvania School of Medicine and the Abramson Cancer Center
Philadelphia, Pennsylvania

Dr. Mark S. Salzer is an assistant professor in the Department of Psychiatry at the University of Pennsylvania School of Medicine, a member of the University of Pennsylvania Abramson Cancer Center, and a Senior Fellow of the Leonard Davis Institute of Health Economics. Dr. Salzer is the director and principal investigator of the University of Pennsylvania Collaborative on Community Integration of Individuals with Psychiatric Disabilities (www.upennrrtc.org), a Rehabilitation Research and Training Center funded by the National Institute on Disability and Rehabilitation Research. He obtained his Ph.D. in clinical psychology from the University of Illinois at Urbana-Champaign, and completed his pre-doctoral clinical internship at the Yale School of Medicine and NIMH postdoctoral research fellowship at Vanderbilt University. He is a licensed psychologist in Pennsylvania.

Dr. Salzer has studied patient-run, peer support interventions for almost 2 decades. His research includes studies of professional perceptions and support of these interventions for persons with mental illnesses, a study examining the benefits of these interventions for those who provide support to another with similar issues (Helper-Helpee principle), and studies that have found decreases in hospitalizations associated with participation in peer support programs. He has also conducted randomized, controlled studies of peer support for persons treated for depression in primary care and persons with co-occurring mental health and substance use disorders. He was the steering committee chair for a multi-site study funded by the Substance Abuse and Mental Health Services Administration/Center for Mental Health Services on consumer-operated services for persons with mental illnesses.

Dr. Salzer is interested in patient-run, peer support efforts in all health care areas. He is the principal investigator of an NCI-funded study involving a randomized, controlled design to examine outcomes associated with participation in Internet peer support of women newly diagnosed with breast cancer. Results from this study will serve as the basis for his presentation at this conference. He has also recently initiated another federally funded randomized, controlled study of Internet peer support for persons with psychiatric disabilities.

Leslie R. Schover, Ph.D.

Professor of Behavioral Science

Department of Behavioral Science

The University of Texas M. D. Anderson Cancer Center

Houston, Texas

Fertility after Cancer (John Wiley and Sons, Inc., 1997) is a self-help guide for cancer survivors to overcoming problems with sexuality and infertility. She has also written Overcoming Male Infertility: Understanding Its Causes and Treatments (John Wiley and Sons, 2000) with her co-author, Anthony J. Thomas, Jr., M.D.

Dr. Schover has served in the past on the President's Cancer Panel and for the Office of Cancer Survivorship at the National Cancer Institute. In 2004, she chaired a national conference on Parenthood after Cancer: Today's Options and Tomorrow's Hopes, sponsored by the National Institutes of Health, the Lance Armstrong Foundation, and Fertile Hope. In 2006, she was a member of the American Society of Clinical Oncology's Technology Panel on Fertility Preservation.

Anna Schwartz, F.N.P., Ph.D., FAAN

Professor, Scottsdale Healthcare, Endowed Chair

College of Nursing

Arizona State University

Cave Creek, Arizona

Dr. Anna L. Schwartz is a professor and holds the Scottsdale Healthcare Endowed Research Chair at Arizona State University. Her program of research focuses on exercise interventions to reduce the acute and chronic physical and emotional effects of cancer and its treatment. Her book, Cancer Fitness: Exercise Programs for Patients & Survivors, published by Simon & Schuster, brings the science of cancer and exercise to patients, survivors, and their families. Dr. Schwartz has received funding from the NCI, NINR, Department of Defense Breast Cancer Research Initiative, Oncology Nursing Foundation, and industry. She is a cancer survivor and holds two world records in bicycling.

Linda Squiers, Ph.D.

CIS Project Office for Research

Office of Cancer Information Service

National Cancer Institute

National Institutes of Health

Rockville, Maryland

Dr. Linda Squiers is the project officer for research at the National Cancer Institute's Cancer Information Service. Since 2003, she has led the CIS Research Program, a collaborative research venture through which investigators partner with the CIS to plan, implement, and disseminate the findings from studies that further the field of health communication. The results of these studies will help the CIS develop evidence-based interventions for effective communication approaches to educating the public about cancer.

Dr. Squiers has more than 15 years of experience working in health communication research and evaluation and has overseen studies involving telephone surveys, in-depth interviews, and data analysis. She has expertise in program planning, program evaluation, and questionnaire design. In addition, she has designed media analysis studies, analyzed qualitative and quantitative data, and written numerous evaluation reports for both the NCI and the Centers for Disease Control and Prevention (CDC). Dr. Squiers' current research interests focus on health information seeking and social marketing.

Before joining NCI's staff, Dr. Squiers worked as an NCI contractor to develop a 5-year comprehensive evaluation plan for the CIS. She also assisted NCI's Office of Education and Special Initiatives in planning the evaluation of its Clinical Trials Education Series and Survivorship Series of publications. She has developed and implemented health communication evaluations for other Government agencies, such as the National Institute of Drug Abuse's (NIDA) National Youth Anti-Drug Media Campaign, the CDC's Youth Media Campaign for VERB, CDC's National Folic Acid Communication Campaign, and CDC's Life Preserver Campaign.

Dr. Squiers obtained her Ph.D. in health education from the University of Maryland.

Michael Stefanek, Ph.D.

Vice President, Behavioral Research Director
Behavioral Research Center
American Cancer Society
Atlanta, Georgia

Dr. Michael Stefanek has been vice president of behavioral research and director of the Behavioral Research Center of the American Cancer Society (ACS) since April 2006. Prior to that, Dr. Stefanek was Chief of the Basic Biobehavioral Research Branch in the Division of Cancer Control and Population Sciences at the National Cancer Institute (NCI) from 1998–2006. Before joining NCI, he was Director of Adult Psychology at the University of Maryland Department of Psychiatry, and Coordinator of Psychosocial Services at the Greenebaum Cancer Center at the University of Maryland. He was on the faculty as instructor and assistant professor, Johns Hopkins University School of Medicine, from 1985–1994, with a full-time appointment with the Johns Hopkins Oncology Center. He was co-founder and co-director of the Johns Hopkins Breast Surveillance Service, a research-focused clinical program of the Johns Hopkins Oncology Center. He has received funding from the NCI and ACS, served on several NCI and ACS grant review boards, and served on institutional review boards at both Johns Hopkins and the University of Maryland Cancer Centers. He was also a recipient of an NCI training grant.

Dr. Stefanek received his M.S. and Ph.D. in psychology (1984) from Virginia Polytechnic and State University and his M.A. in Behavior Therapy and Analysis from Southern Illinois University in 1976. He completed his pre-doctoral internship at Johns Hopkins in the Division of Medical Psychology. His research has focused on psychosocial and behavioral oncology, and he has published extensively on issues related to women at high risk of developing breast cancer and other psychosocial areas. He is the author of numerous scientific articles and has presented nationally and internationally in areas related to behavioral oncology.

He was founder and first chair of the Society of Behavioral Medicine Cancer Special Interest Group. He has also served on the Behavioral Oncology Steering Committee of the American Society of Preventive Oncology (ASPO), and currently serves as chair, Task Force on Behavioral Science for the American Association of Cancer Research (AACR).

Mitchell R. Stoller

President and Chief Executive Officer
Lance Armstrong Foundation
Austin, Texas

Mr. Mitchell R. Stoller joined the Lance Armstrong Foundation (LAF) as president and chief executive officer in January 2004, bringing to the LAF more than 20 years of nonprofit management and fundraising experience. He oversees the LAF's efforts to fulfill its mission to inspire and empower people affected by cancer. He works with Team LAF and the Foundation's board of directors to establish long-range goals and strategic plans to help people with the physical, emotional, and practical challenges of cancer through the Foundation's advocacy, public health, and research programs. Prior to his work at the LAF, Mr. Stoller served as president and chief executive officer of the Christopher Reeve Paralysis Foundation for more than 10 years. He also served as the executive vice president and chief operating officer of the Sudden Infant Death Syndrome Alliance (SIDS) and on the boards of the CJ Foundation for SIDS, Temple Har Shalom, Ridge Sports Foundation and the National Health Council.

Mr. Stoller holds a B.S. from Frostburg State University and an M.A. in Philanthropy and Development from Saint Mary's University of Minnesota.

Ellen L. Stovall

President and Chief Executive Officer
National Coalition for Cancer Survivorship
Silver Spring, Maryland

Ms. Ellen L. Stovall is a 34-year survivor of two bouts with cancer. In 1992, Ms. Stovall became president and CEO of the National Coalition for Cancer Survivorship (NCCS), a survivor-led organization that advocates for quality cancer care for all Americans.

Ms. Stovall also is a member of the Institute of Medicine's (IOM) National Cancer Policy Forum, established in May 2005 to succeed the National Cancer Policy Board. This Forum is designed to allow government, industry, academic, and other representatives to meet and privately discuss public policy issues that arise in the prevention, control, diagnosis, and treatment of cancer. Prior to the establishment of the Forum, Ms. Stovall was vice-chair of the National Cancer Policy Board's (NCPB) Committee on Cancer Survivorship. As vice-chair of the survivorship committee, Ms. Stovall co-edited the Institute of Medicine's recently released report titled, *From Cancer Patient to Cancer Survivor: Lost in Transition*, which addressed the issues adult cancer survivors face.

Currently, Ms. Stovall serves as vice-chair of the Robert Wood Johnson Foundation's National Advisory Committee for Pursuing Perfection: Raising the Bar for Health Care Performance. From 1997–2004, Ms. Stovall chaired The Robert Wood Johnson Foundation's National Advisory Committee to Promote Excellence in Care at the End of

Life. Ms. Stovall is also a member of the Board of Directors of the National Committee for Quality Assurance (NCQA) and The Leapfrog Group and participates on a Steering Committee of the National Quality Forum (NQF) to establish consensus around Cancer Care Quality Measures. Ms. Stovall sits on advisory panels, working groups, and committees of the National Cancer Institute (NCI), American Association for Cancer Research (AACR), and the American Society of Clinical Oncology (ASCO).

Ms. Stovall was founder and president of THE MARCH...Coming Together to Conquer CancerSM. Through her leadership, this yearlong, national public awareness campaign focused both national and regional media attention on the issues of cancer research and quality cancer care for all Americans. Ms. Stovall also served for 6 years on the National Cancer Advisory Board (NCAB), an appointment she received in 1996 from President Clinton.

Recognizing a need for the voice of cancer survivors to be heard during the national debate over health care reform, the Cancer Leadership Council (CLC) was convened in 1993 under her direction; today the CLC is comprised of nearly 29 patient advocacy organizations, professional societies and voluntary organizations.

Staffs of the United States Congress and the Administration frequently call upon Ms. Stovall to work on a variety of cancer-related policy issues, most notably access to quality cancer care.

Karen L. Syrjala, Ph.D.

Co-Director of Survivorship Program and Director Biobehavioral Sciences
Fred Hutchinson Cancer Research Center
Seattle, Washington

Dr. Syrjala is director of the Biobehavioral Sciences Department and co-director of the Survivorship Program at the Fred Hutchinson Cancer Research Center (a member of the **LIVESTRONG** Survivorship Center of Excellence Network). As part of the Psychiatry/Psychology Consult Service, she provides clinical services to oncology patients. She has been on 10 journal editorial boards and among other national responsibilities. She has chaired the Annual Advisory Panel for the Behavioral Research Center of the American Cancer Society, and has been elected a director-at-large for the American Pain Society. She has contributed to the development of a number of national cancer treatment guidelines, particularly in pain and symptom management and for graft versus host disease. Her research and clinical care have focused most recently on examining long-term outcomes and late effects of treatment for hematopoietic stem cell transplant survivors. In these longitudinal, prospective studies, survivors have been followed for 5 to 10 years and will continue to be followed for 20 years. In addition to evaluating general quality of life, her research has focused on measurement of distress and sexual function, neuropsychological outcomes of treatment, and interventions to reduce long-term survivor interventions that can be provided through long-distance methods of providing risk-adapted self-care guidelines for managing long-term and late needs of transplant survivors.

David J. Vaughn, M.D.

Associate Professor of Medicine
Hematology/Oncology Division
Abramson Family Cancer Research Institute
University of Pennsylvania
Philadelphia, Pennsylvania

Dr. David J. Vaughn received his M.D. at Harvard Medical School. After his internal medicine residency at New York Hospital-Cornell, he completed hematology/oncology fellowship training at the University of Pennsylvania. He is associate professor of medicine at the Abramson Cancer Center of the University of Pennsylvania. He is medical director of the Abramson Family Cancer Research Institute. Dr. Vaughn is a practicing medical oncologist with expertise in the management of patients with testicular, bladder, and prostate cancers. He is a member of Penn's Lance Armstrong Foundation Living Well After Cancer Program, where he directs the Testicular Cancer Survivorship Program. He is co-chair of the American Society of Clinical Oncology's Cancer Survivorship Guideline Panel. His research interests include studying the late effects of testicular cancer chemotherapy.

Katherine Walsh, Ph.D., M.S.W.

Springfield College School of Social Work
Springfield, Massachusetts

Dr. Walsh is a professor at the Springfield College School of Social Work in Springfield, Massachusetts, where she designs and teaches courses in social work practice with vulnerable and resilient populations, family treatment, and loss and grief. She has practiced as an oncology social worker for 25 years in a variety of settings including as a senior social worker and student supervisor at the Dana-Farber Cancer Institute, director of Psychosocial Services at Hospice/VNA Alliance of Hampshire County and as a provider of individual, group, and family therapy in private practice. She just completed a 2-year term as president of the Association of Oncology Social Work and is a co-author of the C-Penn Award winning Cancer Survival Toolbox, a collaborative project of AOSW, the Oncology Nursing Society and the National Coalition for Cancer Survivorship. In 2000, Dr. Walsh-Burke received a Social Work Leadership Award from the Project on Death in America and has developed curriculum in end-of-life care for master's and post-master's level social workers as well as allied health professionals. Dr. Walsh serves on the Medical Advisory Committee of the Northeast Division of the American Cancer Society. Her publications include Grief and Loss: Theories and Skills for Helping Professionals (2006), Allyn and Bacon. Zebrack, B. and Walsh-Burke, K. (2005) "Advocacy Needs Adolescent and Young Adult Survivors of Cancer: Perspectives of Pediatric Oncology Social Work Leaders, Journal of Psychosocial Oncology, Walsh-Burke, K. (2005). "Mental Health Risk Assessment" in Berzhoff, J. and Silverman, P. (eds.) Social Work and End of Life Care, Oxford Press.

Jerome Yates, M.D., M.P.H.
Behavioral Research Center
American Cancer Society
Atlanta, Georgia

Dr. Jerome Yates attended Lawrence University as an undergraduate, received his M.D. from the University of Illinois at Chicago, and obtained his M.P.H. from Harvard University. He was trained in medical oncology and is certified by the American College of Physician Executives.

Early in his oncology career, he conducted studies of patients undergoing aggressive treatment or bone marrow transplantation for acute leukemia at Roswell Park Cancer Institute. The 7&3 therapy for acute myelocytic leukemia (AML) was conducted and published in the early '70s and was standard therapy for the next 20-plus years. During that time, he participated as an American Cancer Society (ACS) volunteer, speaking widely in Ohio, Pennsylvania, and New York as well as national meetings.

For the next phase of his career Dr. Yates was in Vermont, where he ran the clinical and cancer control services at the Cancer Center. He was instrumental in the development of the Request for Proposals and participated in the oversight of the study sponsored by both HCFA and the Robert Wood Johnson Foundation. He was a hospice physician at that time.

Subsequently, Dr. Yates became the Associate Director for Centers and Community Oncology at the National Cancer Institute (NCI). He, along with others, developed the Community Clinical Oncology Program (CCOP), which now accounts for the majority of the accrual to the cooperative group clinical trials supported by the NCI. He also pushed for evaluation of the CCOPs and other NCI programs to generate information that could maximize the return on investment.

From there Dr. Yates returned to Roswell Park to be the Senior Vice President for Clinical Affairs and also ran the Prevention and Cancer Control programs. After 14 years, he came to the American Cancer Society (3 years ago). Presently, Dr. Yates is recruiting leadership for the BRC and adding new talent to the center for statistics and evaluation.

Dr. Yates has served on a variety of advisory committees for cancer centers in the United States and internationally, has served on a variety of peer review committees, and has approximately 100 peer-reviewed publications.

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Fox Chase Cancer Center

Presentation Title: Passport For Care (PFC)

Author: David G. Poplack, M.D.; Marc Horowitz, M.D.; Michael Fordis, M.D.

Description:

The PFC is an innovative project that addresses the need to provide patients and survivors of childhood cancer with increased access to their medical information/healthcare guidelines. This interactive Internet resource provides the user accurate, timely, and individualized healthcare information on a "just-in-time" basis. It is anticipated that eventually the PFC will offer a model that address the needs of individuals with a wide range of medical conditions, including adult cancers.

The PFC is being developed in collaboration with the NCI, Children's Oncology Group, and the National Childhood Cancer Survivor Study to address the needs of the estimated 270,000 long-term survivors of childhood cancer in the United States. The IOM and President's Cancer Panel have identified the provision of comprehensive follow-up medical care to long-term survivors of cancer as an important national health priority. Child and young adult survivors are often at risk for serious medical problems that result from cancer and its treatment; obtaining consistent medical follow-up for cancer survivors is confounded by several factors.

Our goal is to develop a national resource to address the health management needs of childhood cancer survivors. Initially, the PFC will be tested in a population of survivors and their healthcare providers to determine whether its use improves physician and survivor knowledge of, and compliance with, the best available surveillance recommendations. The implementation, testing, and modification of the PFC will be an iterative process with the eventual goal of producing an effective instrument that optimally serves the healthcare information needs of this growing population.

Grant Number and Funding Source: Abell Hanger Foundation, Alexander, Joan and Stanford Foundation, Armstrong, Lance Foundation, Bass, Harry W. Foundation, Hearst Foundations, Huffington Foundation, Meadows Foundation, Ronald McDonald House Houston, Ronald McDonald House Charities of Greater Houston/Galveston, Inc., Ronald McDonald House Charities, Texas Cancer Council, private individuals

References:

Poplack, DG, Horowitz, ME, Fordis, M, et al. (2006). The Passport for Care (PFC), Improving the Lives of Childhood Cancer Survivors: Development of a Novel Internet Resource for Managing Long-Term Health Risks. *Implementing Cancer Survivorship Care Planning: A National Coalition for Cancer Survivorship and Institute of Medicine National Cancer Policy Forum Workshop In Partnership with The Lance Armstrong Foundation and The National Cancer Institute*. Washington, D.C.: National Academies Press; in press.

Presentation Title: Cancer Survivors—Successfully Swimming or Struggling to Stay Afloat in a Sea of Cancer-Related Information?

Author: Neeraj K. Arora, Ph.D.; Ellen Beckjord, Ph.D.; Bradford W. Hesse, Ph.D., Division of Cancer Control and Population Sciences, National Cancer Institute

Description:

The purpose of this presentation is to provide insights for supporting the information needs of cancer survivors and individuals with a family history of cancer. We will use data from multiple population-based surveys to highlight the information needs of cancer survivors, to understand their information seeking behavior and experiences, and to compare the information management strategies used by cancer survivors and individuals with a family history of cancer.

We examined information needs of cancer survivors by analyzing data collected from 1,033 cancer survivors diagnosed in California with non-Hodgkin's lymphoma, leukemia, bladder, or colorectal cancer, 2-5 years prior to responding to a mailed questionnaire. The most commonly reported information needs were about medical tests/treatments (70%), followed by health promotion (67%), late-effects of treatment (63%), interpersonal/emotional issues (54%), insurance (42%), and sexuality/fertility problems (31%). Women reported more interpersonal/emotional information needs than men ($p<0.01$), and survivors 3-4 years post-diagnosis reported the most sexuality/fertility information needs ($p<0.05$). Non-White race and quality of follow-up care ratings of less than "excellent" were significantly associated with higher needs in all six information categories.

We assessed the information seeking behavior and experiences of cancer survivors and individuals with a family cancer history by analyzing data from the 2005 Health Information National Trends Survey (HINTS). There were significant differences in information management across survivorship status. For example, cancer survivors were more likely to use health care providers (HCPs) as sources of cancer information ($p<0.01$), but trust in HCPs was equal across groups. Internet use was uniform, but cancer survivors reported greater trust in the Internet ($p=0.05$). Individuals with a family history of cancer were significantly more frustrated in their search for information and it took them more effort to find needed information compared to cancer survivors (both $p<0.01$). Information management, however, did not differ within survivors by time since diagnosis.

We will conclude by highlighting the implications of our empirical findings for creating an environment of unfailing and ongoing support that would facilitate the efforts of cancer survivors and their family members to successfully meet their information needs.

Funding source: National Cancer Institute

Presentation Title: Using a Comprehensive Informatics Support System to Improve Survivor Outcomes

Author: David H. Gustafson, Ph.D., University of Wisconsin–Madison

Description:

This presentation will present a theory-based vision for an informatics-based support system that will serve to meet patients' and caretakers' needs. It will summarize ongoing research with the Comprehensive Health Enhancement Support System, illustrating how comprehensive support systems can be used to empower patients during the interstitial "down time" between doctors visits. It will also offer one vision for how the informatics systems of tomorrow will not only support information needs, but will offer support for emotional needs, instrumental needs, and self-agency needs.

Presentation Title: Post-Treatment Follow-Up Care for Cancer Survivors

Author: Kevin C. Oeffinger, M.D., Memorial Sloan-Kettering Institute for Cancer Research

Description:

Survivors of pediatric cancer are a vulnerable and at-risk population unfamiliar to many clinicians. Studies have shown that they have an excess risk of mortality due to second cancers and cardiac or pulmonary disease. Almost half of young adult survivors of pediatric cancer have moderately to severely diminished health status. By 30 years following cancer diagnosis, almost three-fourths of survivors are likely to experience a chronic health condition, while over 40 percent experience a serious health problem, and one-third experience multiple conditions. The incidence of health conditions experienced by this population increases with time and does not appear to plateau. Therefore, monitoring with close follow-up is important to maximize the health of childhood cancer survivors.

In recent years, the concept of risk-based health care of survivors has evolved. Risk-based health care is anticipatory and proactive care that includes a systematic plan of prevention and surveillance based on risks associated with the cancer therapy, genetic predispositions, lifestyle behaviors, and comorbid health conditions.¹ Using the *Children's Oncology Group Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers*,² risk-based care is delivered through multidisciplinary Long-Term Follow-Up (LTFU) programs.³

In addition to describing the current status and future directions of risk-based survivorship care of pediatric cancer survivors, barriers of care and innovative methods to facilitate care will be discussed.

Grant Number and Funding Source: DHHS/NIH/NCI U24-CA-55727, CA100474, and CA106972

References:

- Oeffinger KC. (2003). Longitudinal risk-based health care for adult survivors of childhood cancer. *Curr Probl Cancer* 27(3):143-67.
- Landier W, Bhatia S, Eshelman DA, et al. (2004). Development of risk-based guidelines for childhood cancer survivors: the Children's Oncology Group Long-Term Follow-Up Guidelines. *J Clin Oncol* 22:4979-90.
- Aziz NM, Oeffinger KC, Brooks S, Turoff AJ. (2006). Comprehensive long-term follow-up (LTFU) programs for pediatric cancer survivors. *Cancer*; in press.

Presentation Title: Follow-Up Care in the Adult Survivor Setting

Author: David J. Vaughn, M.D., University of Pennsylvania

Description:

With increasing numbers of long-term adult cancer survivors, the development of effective models for post-treatment follow-up care is important. Testicular cancer has been called a “model for a curable neoplasm.” Likewise, testicular cancer provides an excellent platform for the development of a model post-treatment follow-up care program for these adult cancer survivors. Presently, approximately 95 percent of patients diagnosed with testicular cancer will be cured. However, testicular cancer survivors confront a variety of post-treatment issues including late physiologic effects of treatment, second neoplasms, and psychosocial late sequelae.

The Lance Armstrong Foundation Living Well after Cancer Program at Penn’s Abramson Cancer Center is a clinical care and research center focused on adult cancer survivors. A major component is the testicular cancer survivorship program. In this presentation, the testicular cancer survivorship program will be described and will serve as a model for follow-up care in the adult survivor setting.

Grant Number and Funding Source: Work supported in part by 1R21-CA097255-01A1 (NCI) and the Lance Armstrong Foundation.

References:

Vaughn DJ., Gignac GA., Meadows AT. (2002). Long-term medical care of testicular cancer survivors. *Annals of Internal Medicine* 136(6):463–70.

Vaughn DJ., Meadows AT. (2002). Cancer survivorship research: the best is yet to come. *Journal of Clinical Oncology* 20(4):888–90.

Presentation Title: Developing Models of Care for Adult Cancer Survivors

Author: Linda A. Jacobs, R.N., Ph.D., Abramson Cancer Center

Description:

Adult Cancer Survivorship

Nearly 10 million cancer survivors in U.S.¹

• 3–4% of entire U.S. population

14% of cancer survivors diagnosed \geq 20 years ago²

For adults diagnosed with cancer, 5-year survival 60%²

Adult cancer survivors at risk for late effects of treatment³

Models of Care: Examples

- Primary vs. oncology provider
- General oncology vs. separate survivorship
- General vs. disease or treatment specific
- Consultative model vs. practice model

Grant Number and Funding Source: Funding provided by the Lance Armstrong Foundation

References:

- Institute of Medicine Report, 2006
 - www.iom.edu
(Hewitt M, Greenfield S, Stovall E. *From Cancer Patient to Cancer Survivor: Lost in Transition*. Washington, D.C.: The National Academies Press; 2006.)
- COG (2004) Long-Term Follow-up Guidelines for Childhood, Adolescent, Young Adult Survivors
 - www.survivorshipguidelines.org
- 2006 ASCO Guidelines (not yet published)
 - www.asco.org

Presentation Title: Impact of the Institute of Medicine Report on Follow-up Care and Research

Author: Patricia A. Ganz, M.D., Jonsson Comprehensive Cancer Center, UCLA Schools of Medicine and Public Health

Description:

In November 2005, the Institute of Medicine (IOM) issued a report from a committee study of adult cancer survivors that focused on the time after acute treatment ends and at which time patients must transition to a period of extended survival. The report drew attention to some of the known late effects of cancer survival (physical, emotional, social, and economic), as well as structural problems in the health care system that interfere with coordinated and comprehensive care for adult cancer survivors. It also called for additional research to better understand the consequences of cancer survivorship and to conceptualize this disease within the chronic disease model of care.

An important recommendation from the IOM report was the call for an end-of-treatment summary and survivorship care plan to be given to each patient at the end of primary treatment as well as communicated to the primary care physician. This presentation will update this audience on the progress that has been made in addressing this latter recommendation, especially among oncology clinicians. Additional efforts are underway to make the larger medical community aware of the needs of cancer survivors, with educational sessions at scientific meetings, development of educational curricula that focus attention on survivorship concerns, and the development of new models to address survivorship care in the community. This presentation will update the audience on work accomplished since the issuance of the IOM report.

Grant Number and Funding Source: This work is supported in part by an American Cancer Society Clinical Research Professorship award to Dr. Ganz, and a **LIVESTRONG** Center of Excellence Grant to UCLA and the Jonsson Comprehensive Cancer Center.

References:

Hewitt M, Greenfield S, Stovall E. (2005). From Cancer Patient to Cancer Survivor: Lost in Transition. Washington, D.C., The National Academies Press.

Earle DD, Schrag D, Woolf SH, Ganz PA. (2006). The Survivorship Care Plan: What, Why, How and for Whom. American Society of Clinical Oncology Educational Book, 42nd Annual Meeting. Michael C. Perry (ed.), ASCO: Alexandria, pp. 525–531.

Presentation Title: Psychological and Emotional Late Effects of Cancer Diagnosis and Treatment

Author: Michael A. Andrykowski, Ph.D.

Description:

It is well known that cancer diagnosis and treatment can trigger a variety of psychological and emotional responses. The experience of some degree of distress is not uncommon during the period following cancer diagnosis and through completion of primary cancer treatment. While research suggests that distress diminishes over time and that most cancer survivors reestablish their pre-diagnosis psychological and emotional equilibrium, the cancer experience can impact the long-term psychological and emotional functioning of survivors; such psychological and emotional "late effects" can be either negative or positive in nature.

In this presentation, the nature, prevalence, and magnitude of various psychological and emotional late effects commonly evidenced by cancer survivors will be briefly reviewed. In addition, some psychological mechanisms potentially underlying the development and maintenance of these late effects will be described.

References:

- Stark, D., Kiely, M., Smith, A., Velikova, G., House, A., & Sclby, P. (2002). Anxiety disorders in cancer patients: Their nature, associations, and relation to quality of life. *Journal of Clinical Oncology* 20:3137–3148.
- Massie, M.J. (2004). Prevalence of depression in patients with cancer. *Journal of the National Cancer Institutes Monographs* 32:57–71.
- Cordova, M.J., & Andrykowski, M.A. (2003). Responses to cancer diagnosis and treatment.

Presentation Title: Promoting Physical Activity After Cancer

Author: Bernardine M. Pinto, Ph.D., Centers for Behavioral and Preventive Medicine, Miriam Hospital and Brown Medical School

Description:

Patients who have been treated for cancer are exposed to various treatment-related sequelae, increased risk for other diseases such as cardiovascular disease, obesity, hypertension, and increased risk of recurrence or new cancers. There have been various efforts to explore the role of physical activity during cancer treatments and post-treatment, and its potential benefits. This presentation will focus on research in the recovery phase of cancer treatments. Issues such as establishing interdisciplinary collaboration, patient safety, and addressing challenges in recruitment and retention of participants in intervention trials will be discussed.

Grant Number and Funding Source: American Cancer Society Research Scholar Grant, Lance Armstrong Foundation National Cancer Institute (CA101770)

References:

- Pinto, B. M., Frierson, G., Rabin, C, Trunzo, J. & Marcus, B. (2005). A home-based physical activity intervention for breast cancer patients. *Journal of Clinical Oncology* 23:3577–3587.
- Demark-Wahnefried, W., Aziz, N., Rowland, J. & Pinto, B. M. (2005). Riding the crest of the teachable moment: Promoting long-term health after the diagnosis of cancer. *Journal of Clinical Oncology* 23:5814–5830.

Presentation Title: Experiences with and Reactions to Weight Change following Treatment in African American Breast Cancer Survivors

Author: Chanita Hughes Halbert, Ph.D.; Frances K. Barg, Ph.D.; Benita Weathers, M.P.H.; Kiyona Brewster, M.A.

Description:

Each year thousands of African American women are diagnosed with breast cancer. Weight gain is a common side effect of breast cancer treatment that may have significant medical and psychological implications. Despite prior research showing that African American breast cancer survivors are significantly more likely to gain weight following diagnosis and treatment, limited information is available on the psychological and behavioral reactions to post-treatment weight change in this population. The purpose of this study is to characterize experiences with and reactions to post-treatment weight change in African American breast cancer survivors. Participants were African American breast cancer survivors ($n=34$) who were diagnosed with stage I-IIIA disease and had completed primary treatment. Women participated in structured focus group discussion sessions designed to identify psychological and behavioral reactions to post-treatment weight change. Women reported complex experiences with weight change following treatment. These included experiencing initial weight loss followed by substantial, rapid gains in weight. Initial weight loss was attributed to changes in eating behavior resulting from loss of appetite, taste changes, or mouth sores during treatment while subsequent weight gain was attributed to loss of energy and fatigue following treatment, which contributed to reduced physical activity. Reactions to weight changes depended on pre-diagnosis weight. Women who were overweight or obese before diagnosis viewed weight loss somewhat favorably whereas women who were normal weight before diagnosis reported distress about weight gain following treatment. In addition, most women indicated that they had made changes in terms of their dietary and physical activity behaviors in an effort to lose weight. These reactions suggest that larger body sizes may not be universally acceptable to African American women.

Grant Number and Funding Source: NCI grant #R21CA098107

References:

Rock CL, Flatt SW, Newman V, et al. (1999). Factors associated with weight gain in women after diagnosis of breast cancer. *J Am Diet Assoc* 99:1212–1218.

Weathers W, Barg FK, Collier A, Halbert CH. (2006). Perceptions of weight change among African American breast cancer survivors. *Psycho-oncology* 15:174–179.

Presentation Title: Physical Activity Interventions in Breast Cancer Survivors

Author: Melinda L. Irwin, Ph.D., M.P.H., Yale School of Medicine

Description:

Many studies have shown that women who are overweight or obese when they are diagnosed with breast cancer (BC) are more likely to die from BC than women who are healthy weight. High insulin levels also are associated with a two- and three-times higher risk of developing a recurrence or dying of BC. Furthermore, women who are physically active after a BC diagnosis are at lower risk of a recurrence and poor survival. However, these studies are observational and may be influenced by other factors (e.g., healthy diet). No randomized trials have examined the effect of physical activity (PA) on biological mechanisms related to BC, BC recurrence, or survival. Given these findings, we received funding from the Susan G. Komen Breast Cancer Foundation, the American Cancer Society, and the Lance Armstrong Foundation to conduct two different exercise trials in BC survivors: The Yale Exercise and Survivorship Study and The IMPACT Study. The purpose of our presentation will be to discuss our exercise trials, the rationale, our preliminary findings, and future research. Both studies are examining the effect of exercise on body fat, hormones associated with tumor growth, and quality of life. The Yale Exercise and Survivorship Study recruited 75 women who have completed adjuvant treatment (except for hormonal therapy), while the IMPACT Study recruited 50 women recently diagnosed (i.e., before treatment begins) with BC. Both studies involve randomizing women into one of 2 equal-sized groups: an Exercise Group or a Control group. Preliminary results show significant decreases in body fat and fasting insulin levels among exercisers and increases in controls ($p < .05$). Results from these trials will provide important data for future studies examining the long-term effect of PA on BC recurrence and survival, and could influence the way cancer survivors are managed in the future.

Grant Number and Funding Source: Komen Foundation BCTR0201916, ACS MRSG-04-006-01-CPPB, Lance Armstrong Foundation

References:

Irwin ML, McTiernan A, Bernstein L, Gilliland G, Baumgartner R, Baumgartner K, Ballard-Barbash R. (2004). Physical activity levels among breast cancer survivors. *Med Sci Sports Exerc* 36(9):1484-1491.

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Irwin ML, Ainsworth BE. Physical Activity Interventions Following Cancer Diagnosis: Methodologic Challenges to Delivery and Assessment. (2004). *Cancer Investigation* 22(1):30-50.

Presentation Title: Physical Activity Following Cancer Treatment

Author: Anna Schwartz, F.N.P., Ph.D., FAAN, Arizona State University

Description:

Cancer and its treatment are associated with numerous acute and long-term physical and psychological adverse effects. Research examining the effects of physical activity during and following cancer treatment has demonstrated beneficial physical and psychological effects. A growing body of evidence supports exercise as an important component of cancer treatment and rehabilitation.

As our treatments become more effective and there are more and more survivors, the face of cancer care may change to include physical activity as part of the "new" standard of care for cancer patients. To meet this end, future research needs to look at the cost benefits of keeping survivors active and able from the perspectives of employment productivity, insurance costs, health care utilization, and the survivor. Educational programs are needed to train health care professionals what to tell their patients about physical activity and how to prescribe exercise.

Grant Number and Funding Source: NIH T32 NR07071-04; U.S. Army DAMD 17-96-1-6171; NIH F31 NR07159-0; NIH R29 NR04945-01. NIH R01 05084, Oregon Cancer Inst. Ca 69533-05; PHS Grant 5 M01; Oncology Nursing Foundation; Schering Pharmaceuticals; University of Utah Research Fellowship, Eccles Foundation

References:

Galvao, D and Newton, RU. (2005). Review of exercise intervention studies in cancer patients. *Journal of Clinical Oncology* 23(4), 899-909.

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Presentation Title: The Cancer Survival Toolbox

Author: Susan Leigh, B.S.N., R.N., and Katherine Walsh, M.S.W., Ph.D.

Description:

This workshop will introduce the *Cancer Survival Toolbox®* (CST), a free audio-based resource program designed to help cancer survivors and caregivers develop practical skills to deal with the diagnosis, treatment, challenges, and consequences of cancer. The CST is also available to healthcare professionals and advocacy organizations for local distribution or for educational purposes. As this is a joint collaboration among four national oncology organizations: The National Coalition for Cancer Survivorship (NCCS), the Oncology Nursing Society (ONS), the Association of Oncology Social Work (AOSW), and the National Association of Social Workers (NASW). Multiple perspectives are represented, including those of cancer survivors.

The Basic Skills module includes the following topics: communicating, finding information, making decisions, solving problems, negotiating, and standing up for your rights. Separate modules that incorporate the basic skills include the following themes: caring for the caregiver; finding ways to pay for care; topics for older persons; and the latest addition, living beyond cancer. These learning tools can be read, listened to, or ordered as a set of CDs via the Toolbox Web site.

At the completion of this activity, participants will be able to:

1. Identify six basic self-advocacy skills for cancer survivors.
2. Articulate the basic research methods and findings that guided the development of the Cancer Survival Toolbox.
3. Utilize the Cancer Survival Toolbox as a resource to increase access to quality cancer care.
4. Contrast the need for basic skills in both the treatment and post-treatment phases of cancer care.

Grant Number and Funding Source: The Toolbox is made possible by unrestricted educational grants from the Amgen Foundation and the Eli Lilly and Company Foundation

References:

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Presentation Title: Design of the Childhood Cancer Survivor Study

Author: Ann C. Mertens, Ph.D., University of Minnesota

Description:

The Childhood Cancer Survivor Study (CCSS) is a 10-year multi-institutional collaboration supported by a grant from the National Cancer Institute designed to investigate long-term effects among 5-year survivors of childhood and adolescent cancer. The CCSS is a study of individuals who met the following eligibility criteria: a) diagnosis of leukemia, CNS tumors (all histologies), Hodgkin's disease, non-Hodgkin's lymphoma, kidney tumor, neuroblastoma, soft tissue sarcoma, or bone tumor; b) diagnosis and initial treatment at one of the 25 collaborating CCSS institutions; c) diagnosis date between January 1, 1970, and December 31, 1986; d) age less than 21 years at diagnosis; e) survival five or more years from diagnosis. At the inception of this study, a major focus was on the development of research strategies to develop and maintain a cohort study of adult cancer survivors that was both geographically and socio-economically diverse.

Since 1994, CCSS has successfully established and followed 14,370 5-year survivors of childhood and adolescent cancer, and a sample of 3,737 sibling controls. Self-reported data were collected for members of the study cohort using mailed questionnaires designed to capture a wide range of information including demographic characteristics, health habits, frequency of diagnosed medical conditions, surgical procedures, recurrent cancer, subsequent new neoplasms, and quality of life related outcomes. For all CCSS participants who returned a signed medical release, information concerning primary cancer therapy was collected, including initial treatment, treatment for relapse, and preparatory regimens for bone marrow transplantation (if applicable).

Grant Number and Funding Source: National Cancer Institute, U24 CA55727

References:

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- Robison LL, Mertens AC, Boice JD, Breslow NE, et al. (2002). Study Design and Cohort Characteristics of the Childhood Cancer Survivor Study: A Multi-Institutional Collaborative Project. *Med Pediatr Oncol* 38:229-39.
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Presentation Title: Stress Management Effects on Psychological and Physiological Adaptation During Breast Cancer Treatment: Lessons Learned and Next Steps

Author: Michael H. Antoni, Ph.D., Sylvester Comprehensive Cancer Center, University of Miami

Description:

Adjusting to a new diagnosis of cancer, dealing with surgery, and anticipating the physical challenge of adjuvant therapy are multiple stressors that can overwhelm the adaptation efforts of women dealing with breast cancer. Poorer psychosocial adaptation may be evident in emotional and interpersonal disruptions that do not resolve and these may be accompanied by poorer physiological adaptation evident in elevations in hypothalamic pituitary adrenal (HPA) hormones such as cortisol and decrements in cellular immune indicators, which could have effects on future health. This presentation will provide information on methodological issues involved in the design of psychosocial interventions in breast cancer in order to test effects on psychological adaptation, physiological adaptation and mediational process that might explain the effects of the intervention on these outcomes. Over the past decade we developed and tested the effects of a group-based Cognitive Behavioral Stress Management (CBSM) intervention on psychosocial and physiological adaptation among over 300 women diagnosed with early-stage breast cancer recruited in the midst of their medical treatment. These studies are present in order to show how one designs research studies to test the efficacy and mechanisms underlying psychosocial interventions in the context of breast cancer treatment. The CBSM intervention was chosen since it provides training in relaxation coping skills and other stress management techniques, in a supportive group. These elements were all deemed optimal for women being treated for breast cancer.

In choosing a sample, we wanted to include participants who were dealing with a particularly stressful point in their treatment. Therefore, these studies recruited women with Stage I-III disease who were then randomized 4–8 weeks after surgery to either a 10-week CBSM group or a 1-day CBSM seminar and followed across the period of adjuvant therapy to test whether stress management can facilitate psychosocial and physiological adaptation after adjuvant therapy. Assessments were made at baseline and 6 and 12 months follow-up using indicators of positive and negative psychological adaptation and physiological adaptation. Analyses focused first on establishing the efficacy of the intervention, then testing hypothesized mediators and ultimately using this information to conduct dismantling studies to isolate active ingredients and formulate cost-effective, shorter, and more portable versions of the intervention. Using Latent Growth Modeling analyses these studies showed that the 10-week CBSM intervention decreased depression, negative affect, and intrusive thoughts about cancer; and increased positive psychosocial outcomes such as optimism, benefit finding and positive affect. The intervention also affected physiological adaptation indicated as decreased evening serum cortisol levels and increased indicators of cellular immune system functioning including lymphocyte proliferation and T-helper Type 1 (th1) cytokine production. Mediational analyses showed that increased in emotional processing and perceived relaxation skills during the intervention were associated with greater increases on a number of these psychological outcomes, while increases benefit finding predicted changes in endocrine and immunologic functioning. Secondary analyses revealed that women who attended 4–6 CBSM sessions showed similar effects to those attending 8–10 sessions suggesting that at shorter form of the intervention might be effective. A recently initiated study will dismantle the elements of this multi-modal intervention by comparing the effects of a 5-week relaxation training group, a 5-week cognitive behavioral group and a 5-week attention control group on similar indices of psychosocial and physiological adaptation in women undergoing treatment for breast cancer. These studies represent a process of testing first for intervention efficacy, testing mediational hypotheses during efficacy trials, and then doing dismantling studies where proposed mediators are manipulated experimentally.

Presentation Title: Patient-Centered Communication Research in Cancer Survivorship: A Conceptual Framework

Author: Ronald M. Epstein, M.D., University of Rochester Medical Center

Description:

Communication challenges in cancer are magnified compared with other clinical conditions because it is a potentially curable life threatening illness in which there are numerous treatment options, both too much and too little data, and uncertainty about prognosis. This session will present a conceptual model that takes into account features of communication (mutual influence, adaptability, context-dependence, etc.), communication functions (building relationships, exchanging information, exploring emotions, managing uncertainty, making decisions and enabling patient self-management), intermediate process-of-care outcomes and the effects of communication on health and societal outcomes. We will also examine factors affecting communication such as the type and phase of the illness, clinician and patient characteristics, family, culture, the health care system, other sources of information and use of electronic media. Finally, using the model, we will indicate areas in which research has and has not been conducted, and important areas for future investigation in cancer survivorship.

Funding Source: This work was conducted as part of a contract from the National Cancer Institute.

Presentation Title: Follow-up Cancer Care: Adequacy of Patient-Physician Communication about Medical Tests and Symptoms/Side-Effects Management

Author: Neeraj K. Arora, Ph.D., Division of Cancer Control and Population Sciences, National Cancer Institute

Purpose: Conducting medical tests for ongoing surveillance and treating symptoms and late/long-term effects of cancer treatment are key functions of follow-up cancer care. We examined cancer survivors' perception of the adequacy of communication they received from physicians about these two functions as part of their follow-up care.

Methods: We analyzed survey data from 774 survivors diagnosed with leukemia, bladder, or colorectal cancer in Northern California, 2-5 years prior to the study. 623/774 received follow-up care in the past 12 months, 595 (96%) of whom received medical tests and 164 (26%) were bothered by symptoms/side-effects and had discussed them with their physician. Bivariate chi-square analyses and t-tests as well as multivariate logistic and linear regression analyses were conducted.

Results: About 27% of the cancer survivors who received medical tests reported that they did not "always" get the results in a timely manner, nor were the results "always" explained to them in a way they could understand. Similarly, more than 40% of those who discussed their symptoms/side-effects with their physician did not "always" receive the help they needed, nor were they "always" given clear instructions about what to do if their symptoms got worse or came back. Survivors who perceived their physician to have a better knowledge about their medical history, personal life, and the impact of the cancer on their quality of life reported receiving significantly better communication about both tests and symptoms management ($p<0.001$). While almost all of the survivors either shared control (43.1%) or deferred to their doctor (49.5%) regarding the decision about medical tests, patient roles were more evenly distributed for the decision about treating symptoms/side-effects with 31.1% leaving the decision to their doctor, 42.1% making the decision together, and 26.8% taking primary responsibility for the decision. Despite variation in patient roles, for both decisions, survivors who engaged in shared decision-making also reported significantly better communication compared to the physician control and patient control groups ($p<0.01$). Better communication about medical tests and symptoms management was also associated with more positive survivor ratings on the quality of care they received ($p<0.001$). In contrast, survivors who reported poorer communication about tests and symptoms management were significantly more likely to need additional information in these areas ($p<0.05$).

Conclusion: While not a majority, many cancer survivors report sub-optimal communication on two key functions of follow-up cancer care (approximately 1 in 4 for medical tests and 1 in 3 for symptoms/side-effects management). Our results highlight the salience of patient-clinician communication and suggest that better communication is likely to facilitate shared decision-making, enhance patient satisfaction with care, and result in fewer unmet information needs for cancer survivors.

Funding Source: National Cancer Institute

Presentation Title: Building Therapeutic Relationships between Cancer Survivors and Oncology Providers, How to Navigate this Poorly-lit Two-way Street

Author: Richard Boyajian, M.S., R.N., A.N.P., Dana-Farber Cancer Institute

Description:

In Oncology the current patient centered model focuses on empowerment of the cancer survivor to make their own informed decisions regarding their care. One of the biggest challenges to this "team approach" is finding a common ground in regards to the survivor's ongoing health care management. This session will attempt to answer the question "who is the best judge of the cancer survivor's interest". The presenter's perspective as both a survivor and a nurse practitioner leads him to only one logical conclusion, both are. The patient and providers are experts in their specialty. The provider has the medical knowledge that allows them to inform on the current options available to the survivor. The cancer survivor has the unique knowledge of their own being and will need to process the provider's expert opinion taking their emotions, hopes, fears, and past experiences into account. We will also highlight some of the communication challenges faced by a team of clinicians working in the setting of a dedicated adult survivorship clinic and discuss how it might differ from a traditional model. Case studies and patient interviews will also provide insight into the communication needs of actual cancer survivors.

Funding Source: The basis for this session was extracted from the presenter's work as a nurse practitioner in the Lance Armstrong Foundation Adult Survivorship clinic at the Dana Farber Cancer Institute.

Presentation Title: Cancer, Employment, and Health Insurance

Author: Cathy J. Bradley, Ph.D., Virginia Commonwealth University

Description:

This presentation reviews empirical findings regarding employment and health insurance from approximately 500 women newly diagnosed with breast cancer. Women were interviewed 6, 12, and 18 months following diagnosis. The months immediately following diagnosis are particularly critical for women with breast cancer because treatment-related morbidity. A regimen of surgery and, depending on type of surgery provided, a regimen of radiation, hormonal therapy, and/or chemotherapy for all stages of breast cancer is recommended. These treatments can last 6 to 9 months and their toxic side effects can cause both short- and long-term disability. At 6 months following diagnosis, relative to women who did not have cancer, employed women with breast cancer were less likely (17 percentage points, $p<.05$) to work 6 months following diagnosis. Approximately 12 percent of the women with breast cancer reported being disabled or too sick to work at 6 months following diagnosis. Furthermore, relative to White women, breast cancer's influence on the transition from employment to non-employment appeared to be twice as strong for previously employed African American women, but the reason for this difference was unclear.

At 6, 12, and 18 months following diagnosis, women with breast cancer and health insurance through their spouse's employer were more likely to have quit work than those who depended on their own employer for health insurance ($p<.05$). Furthermore, at each time period, among women who remained working, women who were dependent on their spouse's policy reduced their weekly hours worked by more than women who had health insurance through their own employer ($p<.05$). Even women who required aggressive treatment were more likely to remain attached to their job if their job was the source of their health insurance. It was striking that women with health insurance through their spouse were less likely to be employed even at 18 months following diagnosis, when all treatments should be complete. Clearly, health insurance influenced women's labor supply post-diagnosis; it could, therefore, also have affected the time they spent in treatment and recovery. The health toll on individuals who remained working is unknown, but conceivably work could negatively influence treatment compliance and recovery.

Grant Number and Funding Source: R01-CA86045-01A1 and N01-PC65064

References:

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Bradley, C.J.; Neumark, D.; Luo, Z.; Bednarek, H.L. (2005). Employment-Contingent Health Insurance, Illness, and Labor Supply of Women: Evidence from Married Women with Breast Cancer. National Bureau of Economic Research Working Paper: 11304.

Presentation Title: Employment and Economic Issues

Author: Barbara Hoffman, J.D., Rutgers School of Law-Newark

Description:

Fighting a cancer diagnosis can be a full-time job. Yet few adults have the financial stability to abandon their employment during and after their cancer treatment. Most survivors need to retain their employment status for obvious financial benefit, as well as for accompanying health insurance, self-esteem, and social support.

Significant progress has been made since the early 1990s to improve the employment opportunities of cancer survivors. With the passage of Federal laws such as the Americans with Disabilities Act and the Family and Medical Leave Act, as well as the expansion of many state laws, cancer survivors have gained new legal rights and remedies. Additionally, the rise of cancer survivorship advocacy has helped dispel the myths that fuel survivors' employment problems and empowered survivors with information about their rights.

Despite this progress, much more should be done to increase employment opportunities for cancer survivors. Federal and state laws should be expanded to provide broader financial and employment rights. Additionally, national cancer education should be addressed to all survivors, caregivers, and advocates, and should focus on current, practical information to empower survivors to preserve their financial and employment opportunities.

Presentation Title: Health Insurance Issues Facing Cancer Survivors

Author: Karen Pollitz, M.P.P.

Description:

This presentation will discuss health insurance issues facing cancer survivors under age 65, challenges people may face finding available, affordable, and adequate health coverage, and implications for access to health care.

Presentation Title: Internet Peer Support for Women with Breast Cancer: Findings from a Randomized, Controlled Trial

Author: Mark S. Salzer, Ph.D., University of Pennsylvania School of Medicine and the Abramson Cancer Center

Description:

Peer support is consistently found to benefit women with breast cancer in their emotional adjustment and functional status. The Internet has emerged as an exciting and potentially valuable tool in delivering psychosocial and educational interventions, including peer support, to persons with cancer and other illnesses. It does not require travel and is accessible 24-hours a day/7 days a week, plausibly making it a more accessible and more preferred mode of intervention for some. Millions of people with illnesses already participate in Internet peer support, including groups that are not facilitated by professionals. Yet little is known about how they operate, their benefits, and their potential harms.

This presentation will discuss initial findings from a randomized, controlled study of an Internet peer support group for women with newly diagnosed (within 1 year), Stage 1 and 2 breast cancer. Examples of mutual aid processes as they occur online will be presented along with participant ratings of perceived benefits associated with participating in the group. Finally, preliminary psychosocial outcomes will be presented comparing those participating in the group versus those in the control group.

Grant Number and Funding Source: 1R21CA098888-01A1 from the National Cancer Institute (Salzer, PI)

Presentation Title: Psychosocial Interventions for Underserved Cancer Patients: Recruitment, Retention, and Quality of Life Outcome

Author: Alyson B. Moadel, Ph.D., Albert Einstein College of Medicine, Yeshiva University

Description:

Research indicates that cancer patients from underserved and/or ethnic minority populations may be at greater risk for specific impairment in quality of life (QOL). For example, Hispanic patients appear to be at risk for high levels of psychological distress, while African Americans seem to be more vulnerable to social disruption and inadequate support. A large body of research conducted with primarily White, middle-class cancer patients has shown that psychosocial interventions (e.g., support groups, relaxation, exercise) can provide benefit to many aspects of QOL, including physical, emotional and social well-being (Rehse et al. 2003). While little intervention research has been directed to ethnic minority and low-income patients, the use of psychosocial techniques among such populations is widespread. Among African American and Hispanic breast cancer survivors, the most common techniques used include spiritual healing and prayer, meditation/imagery, and support groups (Lee et al. 2000).

The Bronx, New York has a population of nearly 1.4 million with the major racial/ethnic groups including Hispanics (48%), African-Americans (36%), and non-Hispanic whites (15%). According to the 2000 U.S. Census data, the Bronx is the poorest borough in New York City, with 31% living below the poverty line. As with most disadvantaged, minority populations in the United States, the Bronx suffers from high cancer morbidity and mortality rates. According to the American Cancer Society (2005), over 5,000 new cases are diagnosed in the Bronx annually, with incidence rates rising.

This presentation will describe two clinical trials examining the effects of psychosocial interventions (e.g., support groups, yoga) on the QOL of cancer patients from the Bronx, most of whom are from ethnic minority background. It will discuss the use of interventions that incorporate spiritual, meditative, and supportive elements that reflect the interests of the population. Preliminary results and challenges to recruitment and retention will be presented.

Grant Number and Funding Source: American Cancer Society – Research Scholars Grant (TURSG PBP-105665)

“Spiritual vs. Educational Intervention on QOL in Low-Income Cancer Patients”

PI: A. Moadel

Jacob and Valeria Langeloth Foundation

“Evaluation of a Yoga-Based Cancer Rehabilitation Program”

PI: A. Moadel

National Cancer Institute R03 CA88598-01A1

“Effects of Yoga on Quality of Life during Breast Cancer.”

PI: A. Moadel

References:

American Cancer Society, Bronx County, New York Cancer Burden Profile, 2005, 2005.

Lee MM, Lin SS, Wrensch MR, et al. (2000). Alternative therapies used by women with breast cancer in four ethnic populations. *Journal of the National Cancer Institute* 92(1):42-47.

Rehse B, Pukrop R. (2003) Effects of psychosocial interventions on quality of life in adult cancer patients: Meta analysis of 37 published controlled outcome studies. *Patient Education & Counseling* 50(2):179-86.

United States Census Bureau. <http://factfinder.census.gov> 2000.

Presentation Title: The Virtual Wellness Community Online Support Groups for People with Cancer—Theory and Practice

Author: Mitch Golant, Ph.D.

Description:

The Wellness Community (TWC) is the largest community-based psychosocial support program in the United States dedicated to providing free emotional support, education, and hope for people with cancer and their loved ones. TWC's program is based on the Patient Active Concept, where people with cancer are empowered to make active choices in their recovery and reduce the three most significant psychosocial stressors that people with cancer face—unwanted loneliness, a loss of control, and a loss of hope.

Since 1998, TWC has provided over 1,200 professionally facilitated support groups over the Internet to people coping with a cancer diagnosis. In this session, I will describe our experiences delivering both real-time and bulletin-board online support groups and advances in user interfaces we develop in these interactions. I will describe our underlying theoretical orientation and the data on the online support groups. I will provide a model of online support group supervision and key elements of facilitator training. I will also highlight findings from our recent experiences with online support groups with teens with cancer and an innovative computer-training program to increase access to eHealth information and support for Hispanics/Latinos with cancer. Finally, the Internet offers the opportunity to reach underserved populations worldwide. I will describe our experiences translating this model across international borders through a collaborative research and training program with the Canadian Institute for Health Research.

Presentation Title: Age, Aging, and Psychological Impacts of Prostate Cancer Survivorship: Lifespan, Life Course, and Comorbidity as Influences

Author: Thomas O. Blank, Ph.D.

Description:

Despite the fact that most persons are diagnosed with cancer when they are older, and even more long-term survivors are older, until recently there has been little discussion of how aging processes and one's "placement" in age (e.g., age at diagnosis or currently) affect survivorship. What evidence there is indicates consistently that older age is associated with less impact on quality of life (QOL), both positive and negative. Yet, there has been little attention to why that may be, and, indeed, most discussions of age differences emphasize problems of increasing comorbidity with age. Thus, it is important to explore multiple explanations of the "age effects" on QOL and to disentangle comorbidity from age to see how aging leads to fewer negative outcomes despite increasing comorbidity. After discussing potential influences, a study that allows for comparison of effects of comorbidity and of age on QOL will be described.

In the study, 490 men treated for prostate cancer from 1–8 years earlier ($X=4$ yr.), ranging in age at diagnosis from 47 to 85 (X age=65.4), answered questionnaires related to positive and negative impacts of QOL and well-being. Linear regression analyses examined impacts of personality, age, and comorbidities. Generally, comorbidity levels were low to moderate. Age and comorbidity were moderately related, as expected. However, relationships to outcomes were very different. Older age was generally related to lower impact in both negative (e.g., impact of cancer) and positive (e.g., positive affect, adaptive changes) ways, whereas higher comorbidity was quite strongly related to both lower positive (benefits, happiness) and higher negative outcomes (e.g., depression, negative affect). Thus, although comorbidity is related to aging and although it can make management, treatment, and survivorship of prostate cancer more difficult for older persons, it is independent of age in terms of QOL. Increasing age appears to diminish psychological impact, whereas presence of comorbidities has an overall negative effect. Age and comorbidity, thus, provide distinct challenges to follow up and survivorship. Life span developmental, life course, and expectation patterns all lead to more difficulty with having cancer for younger persons, in effect counterbalancing the potential negative impacts related to aging processes and comorbidity.

Grant Number and Funding Source: National Institute on Aging, 1-R03177288

References:

Blank, T. O., & Bellizzi, K. M. (2006). After prostate cancer: Predictors of well-being among long-term prostate cancer survivors. *Cancer*, 106, 2128-2135.

Bellizzi, K.M. & Blank, T. O. (2006). Understanding the dynamics of post-traumatic growth in breast cancer survivors. *Health Psychology*, 25, 47-56.

Presentation Title: The Impact of Cancer and Comorbidities on the Health Quality of Life of Older Adult, Long-Term Survivors

Author: Gary T. Deimling, Ph.D., Case Western Reserve University

Description:

This presentation proposes and tests a conceptual model of how cancer and treatment sequelae combine with comorbidities to influence the health and functioning of older adult (≥ 60), long-term survivors (5yrs +) of breast, prostate, and colorectal cancer. As survivors age, they may experience a variety of health problems that are unrelated to cancer, but which have implications for physical functioning and their ability to continue to perform the activities they enjoy. Additionally, as survivors of cancer, they may also experience persistent symptoms of either the disease or its treatment. These current cancer-related symptoms represent additional threats to health and functioning that are beyond those that are considered part of "normal" aging. To understand the role cancer plays in the QOL of long-term survivors, it is important to separate cancer-related factors from other health problems and functional difficulties.

Empirical testing of the model with a sample of 321 cancer survivors found that the number of current co-morbidities was the best predictor of functional difficulties and also a significant predictor of participation restrictions. Cancer stage at diagnosis and continuing cancer symptoms were found to have direct effects on functional difficulties, and indirect effects through functional difficulties on participation restrictions. The implications for these findings for clinicians working with older adult survivors are discussed.

Presentation Title: Seniors Surviving Cancer

Author: Deborah A. Boyle, R.N., M.S.N., AOCN, FAAN

Description:

Seniors, like children, have novel developmental challenges that must be considered and integrated into cancer care planning. However, seniors, unlike children, have not benefited from deliberative inquiry and investigation into these unique vulnerabilities. Historically, widespread assumptions have prevailed about elders facing cancer. These suppositions have influenced seniors' treatment options, screening recommendations, distress management, and decision-making capabilities. When considering survivorship issues, seniors can best be characterized by their paradigm of "double jeopardy." As older adults, their cancer experience has generally been ignored. Along with the general cohort of adult cancer survivors, elder's plight associated living with and beyond cancer, has been disregarded.

Of the 9 million cancer survivors in the United States, nearly two-thirds (62%) are over age 65 and approximately one-third (32%) is age 75 or older. Seniors present unrivaled challenges along the survivorship trajectory. Some of these include die prominence of co-morbidity and associated polypharmacy, cumulative loss, and fatalism that may prompt health surveillance aversion, anxiety, depression and grief, neurosensory compromise that may impair information reception and assimilation, adherence problems, loss of social support network, and functional decline or dependence. This presentation will highlight the author's efforts to address some of these common corollaries of being old and surviving cancer. Examples include the development of a cancer-specific comprehensive geriatric assessment inventory, compilation of a coping instrument specific to older adults, and testing of short screening tools appropriate for use in acute and ambulatory care practice settings.

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Boyle D. (2006). Survivorship. *Clinical Journal of Oncology Nursing* 10(3): 407421.

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Oncology Nursing Society and Geriatric Oncology Consortium. (2004). Oncology Nursing Society and Geriatric Oncology Consortium joint position on cancer care in the older adult. *Oncology Nursing Forum* 31(3): 1-2.

Presentation Title: Aging and Cancer: Are They Compatible?

Author: William E. Bright II, Ed.D.

Description:

The presenter will give his story of prostate cancer diagnosis in 2003 at the age of 65, his treatment, and recovery. Issues confronting the survivor through all phases of this journey will be addressed. Particular emphasis will be directed to how the aging process has cast a light on the phases of his journey and how it affected those around him. Recent published research findings will be considered as specific suggestions are brought forward.

Presentation Title: Assessing the Quality of Life of African American Cancer Survivors

Author: Carol Ferrans, R.N., Ph.D., FAAN, University of Illinois at Chicago

Description:

In large cancer survivor studies, the proportion of African Americans has been approximately 5–10 percent. These cohorts have been too small to break out for examination of survivorship issues for African Americans. Studies are needed that will identify the cancer-related problems specific to African Americans and to determine how their quality of life differs from African Americans who have not had cancer, as well as non-minority cancer survivors. The purpose of this presentation is to describe the assessment methods for an NCI-funded study designed to determine the prevalence of long-term effects of cancer in African Americans, and to describe their impact on quality of life and participation in cancer screening. This study examines issues specific to cancer survivorship for African Americans and makes comparisons with African Americans who have not had cancer to identify the differential impact of cancer on their lives. Comparison with African Americans who have not had cancer makes it possible to (1) examine cancer-related problems that are specific to African Americans, which are not as relevant for the majority population; (2) tease apart the experience of cancer from the experience of being African American; and (3) examine issues for African Americans across the entire range socio-economic status, rather than only the lower end.

The model used in this study to assess the quality of life of African Americans contains variables found to be important in other survivor studies, but have been interpreted in a culturally specific manner. The model also includes culturally specific variables such as spirituality, trust in health care providers, life stress/felt racial discrimination, and cultural beliefs about cancer. In the model, cancer and treatment are viewed as stressors and adaptation is the outcome. Cancer and treatment affect physical health and functioning, in terms of health status, comorbidities, fertility, and reproductive problems. Mediating variables, such as individual characteristics, social support, and economic resources, further exacerbate or ameliorate the stress of the experience of cancer and treatment. These variables are viewed as influencing the outcome variables reflecting adaptation: satisfaction with life, psychological distress (anxiety, depression, hostility), fear/anxiety about cancer, and participation in cancer screening.

Grant Number and Funding Source: NCI R01 CA89418 Quality of Life of African American Cancer Survivors

References:

- Ferrans, C. E. (2005). Definitions and conceptual models of quality of life. In J. Lipscomb, C. C. Gotay, & C. Snyder (Eds.), Outcomes Assessment in Cancer (pp. 14–30). Cambridge University Press.
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Presentation Title: Grading Long-Term and Late Effects

Author: Kevin C. Oeffinger, M.D., Memorial Sloan-Kettering Institute for Cancer Research

Description:

In addition to determining the prevalence and incidence of long-term and late effects associated with cancer therapy, it is essential to assess the severity of these conditions. The Common Terminology Criteria for Adverse Events version 3 (CTCAEv3) is a standardized and reproducible approach for grading the severity of long-term and late effects.¹

CTCAEv3 is a comprehensive scoring system developed through the National Cancer Institute by a multidisciplinary group and intended for use in scoring both acute and chronic conditions for cancer patients and survivors of all ages. There are five grades: grade 1 – mild; grade 2 – moderate; grade 3 – severe; grade 4 – life-threatening or disabling; and grade 5 – death.

CTCAEv3 is the standard used to report toxicity of side effects of patients on active cancer therapy. However, many survivorship-focused researchers are unfamiliar with the CTCAEv3 and its potential as a measurement instrument for grading long-term and late effects. Recently, through the Childhood Cancer Survivor Study (CCSS), we used the CTCAEv3 to score the severity of chronic conditions in 10,397 adult survivors of pediatric cancer and 3,034 of their siblings. This experience and use of the CTCAEv3 in future retrospective or prospective observational studies of survivors of both adult and pediatric cancer will be discussed.

Grant Number and Funding Source: DHHS/NIH/NCI U24-CA-55727

References:

Cancer Therapy Evaluation Program, Common Terminology Criteria for Adverse Events, Version 3.0, DCTD, NCI, NIH, DHHS; March 31, 2003 (<http://ctep.cancer.gov>), Publish Date: December 12, 2003.

Presentation Title: Complementary and Alternative Medicine

Author: Barrie R. Cassileth, Ph.D., Memorial Sloan-Kettering Cancer Center

Description:

"Integrative Oncology," a new subspecialty, addresses the use of data-based complementary therapies that reduce symptoms associated with cancer and cancer treatment. Integrative Oncology is a synthesis of the best of mainstream cancer care and prevention, and useful complementary modalities. The study and application of herbs and other botanicals, as well as dietary nutrients, is also encompassed here. We distinguish between rational, evidence-backed therapies and so-called "alternatives," which remain a serious problem around the world: there are no viable "alternatives" to mainstream cancer treatment, but thousands of products are falsely claimed to prevent and cure cancer.

This presentation will provide an overview of both Integrative Oncology and of the purported "alternatives," their claims, use, and realities.

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Presentation Title: Research Evidence for CAM Interventions

Author: Daniel A. Monti, M.D., Thomas Jefferson University Hospital

Description:

Although advancements in cancer care have led to increased cure rates and survival times, those coping with a long-term cancer diagnosis often report high levels of distress, poor health-related quality of life, and unmet psychosocial needs. The perceived shortcomings of the conventional biomedical system at sufficiently addressing these chronic illness issues are a primary reason that many patients turn to complementary and alternative medicine (CAM).

There are thousands of CAM modalities and treatments, many of which have been used by cancer patients, either as a complement to conventional cancer treatments, or in some cases, as an alternative to conventional care. The focus of this presentation is the former, with an emphasis on reviewing some CAM treatments that may potentially complement standard care in cancer survivors and those with chronic cancer-related illness. The treatments chosen have at least some supportive studies or encouraging preliminary data. The goal is to provide participants with an overview of a few modalities that might be used in conjunction with standard conventional care to enhance comfort and quality of life. The three general categories of complementary modalities to be discussed are 1) Traditional Chinese Medicine (TCM) treatments, including acupuncture and qigong; 2) Mind-Body Medicine treatments, including meditation and hypnosis; and 3) Therapeutic Massage. The presentation will conclude with references to credible sources of information, such as the NIH/NCCAM Web site, NIH consensus panels, and a brief description of the difference between anecdotal reports and controlled, peer-reviewed studies.

Grant Number and Funding Source: 1 RO1 CA111832-01A1; NIH/NCI RO-1, Office of Cancer Survivorship

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Presentation Title: Research Evidence for CAM Interventions: Mindfulness-Based Art Therapy Experiential

Author: Caroline Peterson, M.A., ATR-BC

Description:

Although advancements in cancer care have led to increased cure rates and survival times, those coping with a long-term cancer diagnosis often report high levels of distress, poor health-related quality of life, and unmet psychosocial needs. Mindfulness-Based Art Therapy is a multi-modal group therapy that is designed to maximize the potential for women with cancer to develop internal and external coping mechanisms that will lend to diminished stress and enhanced quality of life.

MBAT combines (1) the core curriculum of a well-studied 8-week mindfulness-based stress reduction (MBSR) program, (2) standardized art therapy tasks, and (3) a supportive group therapy milieu. These combined modalities provide opportunities for self-regulation on multiple levels of information processing not confined to verbal processing alone. For example, one aspect of the MBAT intervention, mindfulness meditation, provides standardized tools to help women observe, assess, and negotiate their objective and subjective representations of the illness and other experiences. The art therapy component of the intervention provides concrete tasks for expressing and transforming representations in a tangible and personally resonant form. The integration of these approaches, combined with verbal processing in the group, supports self-evaluative skills, greater ease in relation to psychological and physiological stressors as well as meaning filled personal transformation.

The experiential component of this presentation will allow participants to experience & taste of the MBAT intervention through non-verbal creative expression and an introduction to guided mindfulness meditation practice.

Grant Number and Funding Source: 1 RO2 CAU1832-01 AI; NIH/NCI RO-1, Office of Cancer Survivorship

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Peterson, C; Art Therapy, In: Rakel B, MacKenzie E (Eds). Complementary and alternative medicine for older adults: Holistic approaches to healthy aging, (pp. 111-134) Springer 2006.

Presentation Title: Pregnancy and Fertility After Cancer

Author: Leslie R. Schover, Ph.D., University of Texas M. D. Anderson Cancer Center

Description:

Infertility is increasingly recognized as a major negative consequence impacting quality of life in younger cancer survivors. In the past 2 years, guidelines relating to cancer and infertility have been issued by the President's Cancer Panel, the Ethics Committee of the American Society of Reproductive Medicine, and a special technology panel of the American Society of Clinical Oncology. About 7 percent of cancers are diagnosed before the age of 39, resulting in an incidence of 1 in 71 men and 1 in 51 women. One in 1,000 women diagnosed with cancer is pregnant, yielding an estimated 6,000 new cases of cancer in pregnant women each year in the United States. Despite a variety of options to cryopreserve gametes and embryos for people about to begin cancer treatment, many do not get the information they need within the narrow window of time between diagnosis. Sperm banking has been available to men before cancer treatment for many years but became much more practical with the success of in vitro fertilization with intracytoplasmic sperm injection, since only a few live sperm needed to survive to be used in assisted reproductive treatments. Although about 50 percent of young men bank sperm in countries like Norway and Japan that have national health care, only about 25 percent of men in the United States do so. Rather than cost being the most common barrier to men who would like to bank sperm, about 25 percent in a survey we conducted said they had not gotten the information they needed in time. Only about 60 percent recalled being informed of the risk of infertility with their cancer treatment.

Fertility options for women are unfortunately even more problematic, with an array of mostly experimental options. Women may undergo a cycle of in vitro fertilization before cancer treatment and cryopreserve embryos, but patients without a male partner have to use donor sperm to take advantage of this option. Women with breast cancer can utilize new protocols that may limit exposure of cancer cells to high estrogen levels by adding aromatase inhibitors to the ovarian stimulating drugs. Cryopreservation of mature, unfertilized oocytes is another choice, but has resulted in only around 100 births worldwide. Ovarian tissue can be frozen in the hopes that later autotransplantation or even xenotransplantation will yield healthy, mature oocytes. For some malignancies, cancer cells could theoretically be harbored in the ovarian tissue, however. Attempts remain controversial to protect the ovaries during cancer treatment by using GnRH-agonists to create a temporary menopause, with randomized trials needed. Women with early stage or low grade gynecologic cancer may be able to preserve fertility by having limited surgery or transposition of the ovaries to remove them from a field of pelvic irradiation.

Better doctor/patient communication about fertility preservation is strongly needed. The advocacy organization Fertile Hope has made an excellent start in developing patient education materials (www.fertilehope.org).

Grant Number and Funding Source: NCI: 4 R44 CA088088 02 Martinetti (PI) Interactive Media on Banking Sperm before Cancer Therapy; NCI/NCI: R13 CA103826-01 Schover (PI) Parenthood after Cancer: Today's Options and Tomorrow's Hopes

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Journal of the National Cancer Institute Monographs 2005;34 Proceedings of the Conference Parenthood after Cancer: Today's Options and Tomorrow's Hopes.

Schover LR, Brey K, Lichtin A, Lipshultz LI, Jeha S. Knowledge and experience regarding cancer, infertility, and sperm banking in younger male survivors. J Clin Oncol. 2002;20:1880-1889.

Presentation Title: Assisted Reproduction Techniques for Young Women with Cancer: What is Feasible, What is Safe?

Author: Kutluk Oktay, M.D., Weill Medical College of Cornell University

Description:

There are over 75,000 women sterilized as a result of chemotherapy and radiotherapy in the United States alone. Tens of thousands of women are sterilized due to surgery performed for gynecological cancer. It is against this backdrop that there is an increased demand for new assisted reproductive technologies to preserve fertility. When patients have at least 3–4 weeks prior to treatment, and if there is no contraindication for ovarian stimulation, in vitro fertilization and embryo cryopreservation can be used to preserve fertility.

However, in the case of an estrogen-dependent cancer (i.e., breast cancer) ovarian stimulation with conventional regimens is contraindicated. In that instance, tamoxifen can be used for ovarian stimulation, in vitro fertilization, and embryo cryopreservation. With tamoxifen, embryo yield can be increased by 2–6 folds compared to natural cycle-IVF, where no simulation is performed. In the case of endometrial cancer, tamoxifen cannot be used because of its stimulatory effect on endometrium. In which instance, aromatase inhibitors can be used for ovarian stimulation. Recent work has shown that aromatase inhibitor drugs can induce multiple ovarian follicle development and result in pregnancy rates comparable to other oral ovulation induction agents. Yet they can completely block estrogen production during ovarian stimulation and thus will not stimulate estrogen-dependent cancer. When the patient is single and does not want to use donor sperm, another strategy is to cryopreserve unfertilized oocytes. However, the pregnancy rates from frozen-thawed oocytes have historically been lower than that of obtained from frozen-thawed embryos. When feasible, we encourage our patients to cryopreserve embryos rather than oocytes.

Recent reports on the other hand, showed improved success rates with oocyte freezing, and in the future, oocyte freezing may become equally acceptable. In many cases, there is not enough time to perform an ovarian stimulation prior to cancer treatment. In that case, we perform ovarian cryopreservation for later auto-transplantation. We have performed 6 cases of ovarian transplantation, which resulted in ovarian function for as long as nearly 6 years. The most practical approach for ovarian transplantation is grafting of ovarian cortical pieces underneath the forearm or abdominal skin. With this approach, ovarian tissue can be closely monitored, tissue can be inserted and removed under local anesthesia, and oocytes can be collected percutaneously for in vitro fertilization. Until now, embryo development and live birth were achieved in two patients. Ovarian transplantation can not only preserve fertility but also reverse menopause, and this may be an added benefit for some.

Finally, recent evidence suggested that ovarian primordial follicle can be renewed in postnatal mammals. Our labs generated some evidence in support of this hypothesis in humans.

In conclusion, there is a multitude of options for fertility preservation; to make the best use of these options these patients should be referred to an assisted reproduction center as soon after the diagnosis as possible. For those who have not been able to preserve fertility and who have undergone ovarian failure as a result of cancer treatments; however, oocyte donation and surrogacy may be the final resort.

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Presentation Title: Unique Survivorship Research Opportunities in Integrated Health Care Delivery Systems

Author: Ann M. Geiger, Ph.D., Wake Forest University School of Medicine

Description:

An integrated health care delivery system typically encompasses a network of health care providers, facilities and an insurer that provides a full spectrum of health care services on a pre-paid basis. Such systems are characterized by coordinated delivery of health care; explicit quality and cost management programs; an emphasis on preventive care and improved health outcomes; and extensive record-keeping. The NCI-funded Cancer Research Network illustrates how integrated health care delivery systems provide a unique foundation for cancer survivorship research. The Network's overarching goal is to transform cancer care and prevention through a collaborative program of research using the diverse membership, delivery system and automated data resources of the 12 participating systems. As of May 2006, 19 of 36 funded Network proposals incorporate at least one aim pertinent to cancer survivors. These studies address topics such as follow-up care, health disparities, prognostic factors, treatment effectiveness, late treatment effects and quality of life. Data collection modalities employed include automated data extraction, medical record review, pathology specimen review, mailed surveys, telephone interviews, qualitative interviews and focus groups. Using studies from the Cancer Research Network as examples, this presentation will provide attendees with insight into the unique survivorship research capacities of integrated health care delivery systems, emphasizing the potential for studies of follow-up care and health disparities. In addition, the presentation will touch on methodological and collaborative considerations, and describe the activities of the Network's Cancer Survivorship Interest Group.

Presentation Title: The National Cancer Institute's Cancer Information Service Research Program

Author: Linda Squiers, Ph.D., National Cancer Institute

Description:

The National Cancer Institute's Cancer Information Service (CIS) partners with investigators to develop and implement collaborative, mutually beneficial research projects that will further the field of cancer communication, inform CIS service delivery, and bridge the chasm between research and service. The CIS Research Program is unique in that it tests health communication interventions within an existing information infrastructure that directly serves cancer patients, their friends and family members, health professionals, the media, and the general public. In addition, the CIS is well positioned to participate in community-based participatory research through collaborations with partner organizations that reach minority and medically underserved populations.

In early 2005, the CIS Research Program launched a National Research Agenda, which is heavily focused on cancer health disparities among minority and medically underserved populations. The Research Agenda addresses four areas of interest: 1) testing innovative cancer communication and education interventions; 2) increasing access to and appropriate use of cancer-related information and education; 3) discovering effective models for disseminating successful cancer communication and education interventions; and 4) understanding information seeking. In addition, the CIS Research Program has developed a new research infrastructure to support its applied research program. This infrastructure includes four doctorally prepared Senior Research Coordinators that assist researchers in developing and implementing research proposals that address research questions on the CIS Research Agenda and investigators' research needs. The CIS has a formalized data collected system that researchers can incorporate into studies of cancer information seekers. Data from 2005 on cancer survivors who contacted the CIS will also be presented.

Often called a "living laboratory for cancer communication research," the CIS offers researchers a unique opportunity to partner on cancer communication studies that further the field of health communication and cancer control.

Presentation Title: Family Caregivers – Who Cares for Them?

Author: Barbara Given and Charles W. Given

Description:

In this paper, the current state of our knowledge about family caregivers caring for their patients will be discussed. The cancer-specific literature is limited and focuses primarily on the caregiver outcomes of depression, burden and coping. Interventions for caregivers have been focused on strategies to assist the caregivers to ameliorate depression, burden and enhance coping. Few studies have focused on the quality and how appropriateness of family members' care contributes to improved cancer patient outcomes. At this time there is little research on how caregivers acquire skills for assuming their care role. Finally, the research on family caregiving roles during survivorship phase of care is sparse. Recommendations for future research will be presented.

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Presentation Title: Marriage After Cancer: State of the Science

Author: Sharon Manne, Ph.D., Fox Chase Cancer Center

Description: The majority of literature on the impact of cancer on families conceptualizes spouses as caregivers to patients with cancer and focuses on comparing distress levels of patients and spouses. In this talk, I will take the viewpoint that this singular focus on caregiving and making comparisons of distress levels misses the crucial issue of the ways that cancer affects the marital relationship and how couples negotiate the cancer experience together. I will also discuss the diagnosis of cancer in one partner as an opportunity for couples to grow closer, and I will discuss how the study of the marital relationship during and after cancer informs the larger literature on the dynamics of relationship intimacy in mid-life, informs theoretical formulations of social support, and provides important information regarding the efficacy of family-based psychological interventions.

Grant Number: K05 CA 109008, Facilitating Marital Support for Couples Coping with Cancer

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Family Functioning after Childhood Cancer: Perspectives of Adolescent Survivors, Parents, and Siblings

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Background: It is widely accepted that childhood cancer causes disruptions in family functioning within 1 year of diagnosis. The purpose of this poster is to investigate long-term functioning in survivor families.

Method: Adolescent survivors (N=144), their mothers (N=144), fathers (N=104), and siblings (N=95), representing 149 families, completed the Family Assessment Device. Families were 1–12 years post-cancer treatment ($M=5.3$ years). Survivors and siblings were between the ages of 11 and 19.

Results: Table 1 displays the percentages of respondents reporting “unhealthy” functioning on the FAD subscales. For families with complete data from all eligible members (N=112), a family mean was created and the cut-scores applied.

Table 1: Percentage of Respondents Indicating “Unhealthy” Functioning

	Survivors	Mothers	Fathers	Siblings	Family Mean
Problem Solving	39%	17%	19%	41%	33%
Communication	62%	34%	37%	62%	42%
Roles	35%	36%	30%	43%	38%
Affective Responsiveness	47%	20%	36%	56%	38%
Affective Involvement	60%	44%	42%	56%	48%
Behavioral Control	54%	22%	28%	51%	34%
General Functioning	50%	35%	38%	55%	38%

Among families with complete data, respondents' scores were compared. Children tended to indicate more dysfunction than adults. Total number of subscales in the unhealthy range was calculated: 30% of families had no evidence of unhealthy functioning; 29% self-rated as unhealthy on 1-3 subscales; and 41% self-rated as unhealthy on 4 or more subscales.

Conclusions: A surprisingly large percentage of survivor families indicate that their families are having difficulties with functioning. More attention should be paid to long-term family adjustment after childhood cancer.

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Exercise and Dietary Change after Diagnosis and Cancer-Related Symptoms in Long-Term Survivors of Breast Cancer: CALGB 79804

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Background: A subgroup of breast cancer survivors experience persistent, debilitating, cancer-related symptoms including fatigue and depression. Increasing exercise and healthy eating are important for disease prevention among survivors and may decrease these symptoms. However, persistent symptoms may limit survivors' ability to make these positive changes. This analysis examined the relationships between self-reported changes in diet and exercise after a breast cancer diagnosis and fatigue and depression symptoms among survivors who participated in a clinical treatment trial of adjuvant chemotherapy coordinated by the Cancer and Leukemia Group B (CALGB 8541) 9–16 years previously.

Methods: Eligible survivors (n=245) completed a mailed survey assessing demographics, changes in exercise and dietary behaviors since diagnosis, and current symptoms of fatigue (SF-36) and depression (CES-D).

Results: Of the 227 participants with complete data, 32% reported increasing their exercise behavior after diagnosis. Reports of positive dietary changes were common including decreasing fat (44%), increasing fiber (42%), and increasing fruit and vegetable consumption (43%). Analysis of variance results, adjusted for demographic and clinical characteristics, revealed that women who reported increasing their exercise behavior after diagnosis reported less current fatigue compared to women who had not increased their exercise behavior ($p<.05$). There were non-significant trends for decreased depression symptoms among women who reported increasing exercise and for decreased fatigue among women who reported increasing fruit and vegetable consumption (both $p<.10$).

Conclusions: Changes in exercise and diet are common after breast cancer. Even 9–16 years after diagnosis, these positive lifestyle changes appear to be correlated with decreased cancer-related symptoms.

Funding Source: This study was funded by NIH grants AG16602, CA79883, and CA57707.

Preventing Lymphedema with Tailored Exercise: Exploratory Results from the RESTORE Trial

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Background: Lymphedema after breast cancer surgery can cause lifelong reduced function, physical discomfort, psychological distress, and cosmetic disfigurement. There is little data on prevention, especially behavioral interventions. Maintaining arm movement and strength through structured guided exercise may optimize lymph flow and prevent the onset of lymphedema.

Objectives: Using observational data collected from a study of 103 women with stage I to III breast cancer (RESTORE), we explored the association of fitness and physical activity levels on lymphedema at 3 months to 18 months post surgery. Lymphedema was assessed by measuring arm volume, using water displacement, of both involved and non-involved arms. Other assessments included measures of grip strength, range-of-motion, physical activity recorded by pedometer and recall, 6-minute walk, and health-related quality of life.

Results: Adjusting for clinical covariates of age, weight, radiation or chemotherapy, and baseline arm volume, predictors of increased arm volume over the study period were larger body habitus (assessed from BMI), older age, lower grip strength ($p=.008$), and fewer steps walked ($p=.008$) (as recorded on the pedometer). Not associated with change in arm volume was the 6-minute walk and physical activity recall (frequency and caloric expenditure). Predictive ability of adjusted models was good (min Adjusted $R^2 = 0.90$ in cross-sectional analyses).

Conclusion: These data suggest that targeted intervention to increase upper body strength and maintain ideal body weight may be effective in preventing or reducing onset of lymphedema in the year after breast cancer surgery.

Funding Source: Department of Defense; Grant Number A-10918.3

Using Electronic Diaries with Couples Coping with Metastatic Breast Cancer

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Background: Few studies adequately characterize the physical symptom experiences of patients coping with advanced cancers or the impact of physical symptoms on spousal relationships and quality of life. This is surprising since the heaviest burden of care often falls to patients' spouses and families, particularly at the end-of-life.

Methods: Sixteen female metastatic breast cancer patients and their male spouses used electronic diaries to record physical symptoms 6 times daily for 14 consecutive days.

Results: On average, spouses underestimated patient pain and fatigue. Results of a series of repeated-measures multilevel models using SAS Proc Mixed showed that when patients and spouses had greater concordance on daily ratings of patient pain, patients reported greater spouse attentiveness, greater emotional and tangible support, greater satisfaction with spousal support, and less pain interference ($p < .05$). Couples who had greater concordance were also less likely to report avoiding cancer-related discussions.

Conclusion: To our knowledge, this is the first study to use electronic diaries with couples coping with metastatic cancer in an effort to obtain a real-time picture of the associations between physical symptom reports and patient and spouse quality of life. Results suggest that couples who openly discuss the patient's physical symptoms may be better equipped to handle the challenges of advanced cancer, together. Specifically, spouses who have an accurate picture of the patient's symptoms may be better able to provide social support that is adequately matched to the patient's needs.

Funding Source: A multidisciplinary postdoctoral award from The U.S. Army Medical Research and Material Command under W81XWH-0401-0425 01; Hoda Badr, Ph.D., Principal Investigator.

Enhancing Survivorship for Couples Facing Breast Cancer: A Pilot Study of a Couple Based Cognitive-Behavioral Intervention

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Breast cancer poses short- and long-term challenges for both women and their romantic partners, including individual psychological difficulties such as depression and anxiety. The cancer diagnosis also frequently leads to maladaptive interaction patterns between women and their partners and sexual difficulties.

Given couples' challenges, we developed a cognitive-behavioral intervention for couples with early stage breast cancer. In this pilot study, 14 couples were randomly assigned either to cancer-focused relationship enhancement (RE) or treatment-as-usual (TAU). RE consisted of six sessions between a couple and health educator focused on the following: (a) decision-making regarding cancer, (b) emotional support regarding cancer, (c) sexuality and body image, and (d) benefit finding. TAU couples received a list of community resources to access. Couples were assessed at pretest, posttest, 6- and 12-month follow-ups in the following domains: (a) individual psychological well-being, (b) physical well-being, and (c) relationship functioning.

Between group effect sizes (ES) demonstrated that women receiving RE showed notably greater improvements than TAU women in psychological (Average ES= .58) and relationship functioning (Average ES= .61) at both posttest and twelve month follow-up; RE women also demonstrated fewer cancer-related physical symptoms at posttest (Average ES= .73). Men likewise benefited from RE, showing improved psychological (Average ES= .41) and relationship functioning (Average ES= .69) at posttest and twelve month follow-up compared to TAU men.

The findings suggest that couple-based interventions for breast cancer can be beneficial for both partners long-term. This pilot study is currently being replicated in a large NCI-sponsored randomized, controlled intervention.

Funding Source: This study was funded by a grant from Lineberger Comprehensive Cancer Center, Grant Number LCCC0313.

Motivational Interviewing Increases Physical Activity in Long-Term Cancer Survivors

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Purpose: Many cancer survivors report persistent fatigue, even years after completion of cancer treatment. This study tested a motivational interviewing (MI) intervention to increase physical activity and improve aerobic fitness, physical health, mental health, and fatigue in long-term cancer survivors. A secondary purpose was to evaluate whether the effect of MI on physical activity depended on self-efficacy for exercise.

Methods: Fifty-six (56) underactive, fatigued, adult cancer survivors (mean age 57 years, mean 42 months since completion of treatment) were randomly assigned to two groups. The MI intervention consisted of one in-person counseling session followed by two MI telephone calls over six months. Control group participants received two telephone calls without motivational content. Outcomes were measured at baseline, 3 months, and 6 months. Data were analyzed using multi-level modeling.

Results: Individuals in the MI intervention group started with lower levels of regular physical activities, but increased more than control group individuals, controlling for time since completion of cancer treatment ($p<.05$). Aerobic fitness, physical health, mental health, and fatigue outcomes were not different between groups. In the intervention group, individuals with high self-efficacy for exercise at baseline increased physical activity more than those with low self-efficacy ($p<.05$). In the control group, increases in physical activity did not depend on self-efficacy.

Conclusions: MI may be useful to increase physical activity in long-term cancer survivors, especially in persons with high self-efficacy for exercise. Future studies with larger samples or more intense MI interventions may show changes in aerobic fitness, physical health, mental health, and fatigue.

Funding Source: Lance Armstrong Foundation

Qualitative Study of BMT Spouse-Caregivers in the Extended Recovery Phase

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Spouse-caregivers are critical to the recovery and well-being of blood and marrow transplant (BMT) cancer survivors, yet few studies have examined the spouse experience. We used Pennebaker's expressive writing protocol to learn about the spouses' experience during the transition from transplant center to home for continued convalescence and reintegration into life and society. Thirty-three spouse-caregivers (24 female) wrote about their deepest thoughts and feelings about caregiving and being the spouse of a BMT survivor for 15 minutes, once a week, for four weeks. To insure compliance, scheduled writing sessions were initiated and ended with a phone call. Completion rate was 98.5%. A multi-step method was used for content analysis. Writings were broken into separate utterances and reviewed by four raters who generated code book categories. After writings from ten participants were coded, the code book was consolidated. Remaining writings were coded and the first ten recoded. Thirty-six distinct categories were developed with varying levels of differentiation of subthemes. The two most frequent categories with greatest demarcation were "caregiver burden" and "negative emotions." Fewer utterances were found related to neutral/positive caregiver experiences or positive emotion. Other frequent themes included "normalcy" and positive/negative support. Writings varied by length (102–820 words, Mean 313 words) and language used—e.g., future-based versus past-based; fact-focused vs. emotion-focused; and acceptance vs. questioning/wondering. Themes were consistent with the caregiver literature however categories were noticeably more delineated. These BMT spouse-caregivers appear to focus more on negative, than positive, aspects and on a desire to return to "normal" life. Themes not in the caregiver literature included emotional labor.

Funding Source: American Cancer Society; IRG-01-188-01

Volunteer Satisfaction among Survivors

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The American Cancer Society's ("ACS") Volunteer Satisfaction Study ("VSS") provides an in-depth measure of satisfaction with community volunteering for the Society, actionable results for improving volunteer management practices, and a mechanism to track satisfaction over time. Differences across subgroups of volunteers provide an opportunity to tailor relationships to specific needs. The VSS is a self-administered survey among a random selection of "active" volunteers. The basic research design includes a preliminary letter, survey questionnaire, and reminder postcard via U.S. mail.

Analyses of the 2004–2006 Satisfaction data for 1,011 cancer survivors across six ACS divisions reveals important differences compared to 2,374 volunteers who have not had cancer. The typical survivor volunteer is older, more likely to live in suburbia, and less likely to be "very satisfied" as a volunteer compared to other volunteers. With many of the survivors being Reach to Recovery volunteers, the data supports the idea that survivors' engagement with ACS is centered on work with cancer patients rather than the broader community or an affinity to the mission of ACS per se. For example, survivors place higher importance on "helping cancer patients," training, having necessary materials, using skills, and staff communication; and less importance on leadership opportunities, opportunities to be involved with the community, "helping ACS meet its mission," fundraising, and recognition. Survivors also differ from other volunteers in their communication preferences, preferring the U.S. mail and face-to-face meetings over e-mail.

This study sheds light on unique issues impacting survivors' volunteer engagement and suggests ways to improve engagement.

Funding Source: American Cancer Society

Real-Time Data Capture of Post-Surgical Recovery in Stage I Lung Cancer Patients: A Feasibility Study

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Post-surgical recovery from cancer entails dynamic physical and psychosocial processes that can set the stage for longer-term adjustment and quality of life (QOL). Understanding individual differences in coping, affect, and physical symptoms may help to explain variation in post-treatment QOL outcomes.

Methods: We examined the feasibility of assessing these variables using real-time data capture methodology (RTDC) within a larger trial studying QOL in Stage I lung cancer patients treated surgically. Prior to hospital discharge, patients were trained to use a handheld computer (named "LUCY") programmed to administer two daily assessments randomly for 14 consecutive days after hospital discharge.

Results: Of 88 eligible patients (mean age = 68; 63% female), 17 (19%) declined participation, primarily due to perceived burden, 3 either did not pass the proficiency test for using LUCY or withdrew soon after starting LUCY, and 2 did not return LUCY. Technical problems, e.g., low battery power, occurred with 12 (18%) of the remaining 66 patients. For those not experiencing technical problems, the median percent of completed assessments was 67%. Patients evaluated their LUCY experience with a 5-point scale (1=not at all, 5=extremely). They found LUCY very comfortable ($M=3.8$) to use, moderately convenient ($M=3.0$), interesting ($M=2.6$), and overall "living with LUCY" was moderately satisfying ($M=2.8$).

Conclusion: We believe that RTDC is a promising method for assessing dynamic processes early in post-treatment, but patient burden and technical problems may limit its utility. We will present pros and cons of RTDC in this study, suggest refinements, and illustrate with findings.

Funding Source: Supported by a grant from Steps for Breath Fund to Jack Burkhalter, Ph.D.

Spousal Relationship Satisfaction Buffers the Association between Patient and Spouse Psychological Distress when Facing Lung Cancer

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Background: When couples face chronic disease, one partner's psychological distress may exacerbate that of the other. We explored whether the quality of the spousal relationship could buffer the association between patient and spouse distress in couples facing lung cancer.

Methods: Baseline data from 169 patients and 167 spouses from a 6-month longitudinal psychosocial study in newly diagnosed lung cancer are presented.

Results: Patients were predominately male (63%), white (88%), retired (51%), and married (98%); average age was 53. Results from the Brief Symptom Inventory (BSI) indicated that 34.6% of patients and 36.4% of spouses were psychological distress cases. The correlation between patient and spouse BSI global distress was low ($r=.19$; $p=.02$); however, other indices of psychological distress were more highly correlated. Using SAS Proc Mixed and the Actor-Partner Interdependence Model for analyzing dyadic data, relationship functioning buffered the association between each partner's level of psychological distress on 3 BSI symptom dimensions, controlling for age, gender, and participant role (patient versus spouse). The interactions approached significance for global distress ($p=.07$) and depression ($p=.08$).

Conclusion: Results suggest there are high rates of distress in patients and spouses, and the association between each partner's distress is lower in couples with higher relationship functioning. Results underscore the importance of targeting the couple, instead of the patient alone, when delivering psychosocial interventions. Such interventions may minimize spousal relationship distress, and ultimately, allow the spouse to better meet the patient's needs at the end of life and assist in a healthy bereavement following the patient's death.

Funding Source: National Cancer Institute

Reproductive and Psychosocial Concerns of Women Treated with Fertility Preserving Radical Trachelectomy for Cervical Cancer

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Background: Radical trachelectomy has been established as a fertility preserving surgery for young women diagnosed with early stage cervical cancer, with low morbidity and encouraging gynecologic and fertility outcomes. However, little is known about its quality of life impact on cancer survivorship.

Objective: To report the reproductive concerns of women treated with fertility preserving surgery for early stage cervical cancer.

Methods: twenty-nine women diagnosed with early stage cervical cancer between 18-45 yrs. undergoing trachelectomy were enrolled in the study. Surveys were completed preoperatively, 3 & 6 months post-operatively.

Results: Participants were predominantly Caucasian (90%), with some college education (86%, n=26) and married/or cohabitation (62%) at study enrollment. Childbearing was the primary factor for undergoing trachelectomy; however, decision-making was also guided by their doctors (41%), reproductive concerns (41%), and/or personal initiative (28%). Preoperatively, 90% of the women expressed concern about getting pregnant in the future; by 6 months this increased to 100%. Reproductive concerns centered on fears of conception, miscarriage, carrying a pregnancy, and time factors. Pre-operatively 85% percent provided a relatively high rating (50-100%) of future conception success, but this changed over time with one-third projecting lower rates post-op (40%-3 months, 38% -6 months). Preoperatively, all participants showed mild/moderate levels of distress which improved over time, with 81% at 3months and 45% at 6 months.

Conclusions: Trachelectomy offers hope of future fertility, but distress and reproductive concerns exist for many following fertility preserving surgery. Ideally, patients should be identified for additional support in the pre- and post-operative period.

Funding Sources: The TJ Martell Foundation and Philanthropic Funds Presented to the Gynecology Service.

Menopausal Symptom Relief with Acupuncture

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A consequence of breast cancer treatment for younger women is the abrupt onset of menopause and its related symptoms. Menopausal symptoms (hot flashes) contribute to the disruption of usual activities, alteration in sleep and decreased quality of life. Non-hormonal approaches such as acupuncture hold promise as an approach to hot flash reduction.

This study was a randomized clinical trial, to test the effect of acupuncture on menopausal symptoms. A 3 group design (site-specific needling, control needling, and enhanced usual care) of 74 women was used. Data were recorded in a Daily Symptom Diary. Site-specific acupuncture treatment consisted of specific acupuncture body points related to the menopausal symptoms, such as hot flushes and sleep disturbances. Controlled needling acupuncture treatment consisted of needling at acupuncture points identified in the literature as irrelevant to menopausal symptoms. Enhanced usual care treatment included educational sessions related to menopausal symptoms and healthy life activities. Each group had 12 sessions.

Results included a significant decrease in hot flashes over time in both acupuncture groups ($F=4.77$, $p=.0002$), with a significant group x time effect of acupuncture over enhanced usual care ($F=2.10$, $p=.0382$). Sleep improved in both acupuncture groups ($F=2.41$, $p=.0007$) and quality of life showed improvement over time for both acupuncture groups ($F=37.05$, $p=.0001$).

Acupuncture may help to reduce the impact of menopausal symptoms on quality of life for menopausal symptom management for women who are breast cancer survivors and potentially for women who choose not to use ovarian hormones following menopause.

Funding Source: National Cancer Institute; Grant Number R01 CA80625

Physical Activity across the Cancer Trajectory among Lung Cancer Survivors

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Background: Despite the potential benefits of regular physical activity, no previous research has examined lung cancer survivors' patterns of physical activity across the cancer trajectory. We addressed this research gap and also examined the demographic and medical characteristics of lung cancer survivors who do not engage in regular physical activity.

Methods: 107 individuals (M age = 68.9 years, 61% female) who were from 1-5 years post-treatment (M=3.7 years) for stage I non-small cell lung cancer completed a one-time telephone survey of their pre-diagnosis, short-term post-treatment, and current levels of physical activity.

Results: The results of a repeated-measures ANOVA (Wilks' lambda=.77, F(2,105)=15.54, p<.0001) and follow-up pairwise comparisons (ps<.0001) indicated that survivors' average weekly minutes of moderate/strenuous physical activity decreased from pre-diagnosis (M=92.0 minutes) to post-treatment (M=35.9 minutes) and then increased in the longer-term post-treatment period (M=103.2 minutes). Post-treatment moderate/strenuous physical activity was particularly low (M=19.7 minutes/week) among individuals who had one or more treatment-related complications. Less than a third (29.9%) of lung cancer survivors currently met national guidelines for regular weekly physical activity. Lower rates of meeting physical activity guidelines were found among individuals with lower levels of education, those with poorer lung diffusing capacity, and those who were current or former smokers (ps<.05).

Conclusions: Treatment for lung cancer adversely affects engagement in regular physical activity. Few lung cancer survivors engage in regular physical activity. Future research is warranted to examine the role of physical activity in ameliorating post-treatment symptoms and quality of life impairments among lung cancer survivors.

Funding Source: National Cancer Institute

Prevalence of Joint Symptoms in Postmenopausal Women on Aromatase Inhibitors for Early Stage Breast Cancer

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Background: Aromatase inhibitors (AIs) are increasingly used as adjuvant therapy in postmenopausal women with hormone-sensitive breast cancer. Breast cancer patients receiving AIs have a higher incidence of musculoskeletal symptoms, particularly joint pain and stiffness. In large adjuvant trials, the incidence of musculoskeletal disorders was 20-30% and nearly 5% of patients discontinued therapy because of toxic effects. However, the prevalence and severity of this syndrome in the community has not been well described.

Materials and Methods: In the academic practice at Columbia University, 192 consecutive postmenopausal women receiving adjuvant AIs for early stage breast cancer were screened. Of these women, 152 completed a 25-item self-administered survey asking about the presence of joint symptoms in the preceding week, if symptoms started or worsened after initiating AIs, and the location and severity of symptoms using a 0-10 scale. Patients were also asked whether they were using medications and/or non-pharmacologic interventions for symptom relief. Baseline demographic and clinical characteristics were collected, including disease stage, tumor characteristics, duration of AI treatment, and prior breast cancer treatments.

Results: A total of 152 women were surveyed; median age: 62.5 (35-90); White/Black/Hispanic/Asian (%): 63/11/23/3; median years since menopause: 13 (0.2-47); median BMI (kg/m^2): 27 (18-44); anastrozole/letrozole/exemestane (%): 66/16/17; median months on AI: 17.5 (1-66). Joint pain was experienced during the week prior by 70% of participants and joint stiffness was reported by 62%. Of patients reporting joint pain, 67% attributed their pain to AIs; 51% reported worsening of baseline pain and 49% developed pain after initiating AIs. Similarly for joint stiffness, 74% attributed this to the AI; 39% had worsening of baseline stiffness and 61% developed stiffness after starting AIs. The three most common sites of arthralgia, in descending order, were knees, hands/wrists, and shoulders. Of patients who experienced AI-related joint symptoms, the median score of severity on a scale of 0 to 10, was 5 for both pain and stiffness. 54% of patients with AI-associated joint symptoms reported taking medications or supplements for relief, including acetaminophen (30% of all patients taking analgesics), NSAIDs (58%), and other (49%). The median score of relief from oral medications was 7 (0-10). In addition, 51% used non-pharmacologic interventions, mainly exercise, to alleviate joint symptoms.

Discussion: Our study suggests that AI-induced joint symptoms are more prevalent and more severe than described in clinical trials. Because the success of AI therapy depends upon patients' ability to adhere to treatment recommendations, further studies of interventions that may alleviate these symptoms and increase patients' quality of life are needed.

Funding Source: None

Cancer Coping Style among Survivors Reporting for Diet and Exercise Interventions: Are there Differences between “Fatalists” and “Fighting Spirits” in the FRESH START Trial?

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Background: The FRESH START trial currently is in-the-field, testing the long-term efficacy of individually-tailored vs. standardized mailed materials on changing diet and exercise behaviors of 543 breast and prostate cancer survivors.

Methods: During recruitment, we conducted screening interviews on 678 individuals; most had “fatalistic” (57%) or “fighting-spirit” (36%) cancer coping styles.

Results: Several significant differences (p -values<.01) were observed. Compared to “fighting-spirits,” “fatalists” were older (59.8 ± 10.4 vs. 55.0 ± 10.2 years); of minority status (21% vs. 9%); overweight (68% vs. 55%); from “Bible-Belt” states (77% vs. 55%); without college education (13% vs. 7%); and with incomes <\$60K (49% vs. 37%). “Fatalists” also were less likely to report treatment with chemotherapy (20% vs. 33%) and depressive symptomatology (1.79 ± 2.78 vs. 2.49 ± 3.65), and more likely to report “good-to-excellent” health (91% vs. 82%); higher quality-of-life (93.9 ± 10.8 vs. 89.6 ± 12.8) and intakes of 5+ fruits and vegetables/day (56% vs. 45%). No group differences were observed on gender, social support, marital or smoking status, co-morbidity, exercise, dietary fat, or other treatment types. Higher proportions of fighting spirits (84%) vs. fatalists (77%) were enrolled, since we screened-out individuals already practicing healthful behaviors. Once on-study, the 204 fighting spirits and 297 fatalists did not differ on attrition, completion of assignments or dietary change, however “fighting-spirits” reported greater change in exercise at 1-year follow-up (+65 vs. +38 minutes/week; p <.003).

Conclusions: Differences between “fatalists” and “fighting-spirits” may be important when conducting behavioral interventions; longstanding differences in behavioral practices, differential performance and the potential for ceiling effects on quality-of-life outcomes (among fatalists) should be considered.

Funding Source: National Cancer Institute, Grant Number R01 CA81191, the Susan G. Komen Foundation, and the American Institute for Cancer Research

Feasibility of the Rural Breast Cancer Education Intervention to Improve Quality of Life

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Background: Rural breast cancer survivors are vulnerable to being lost in transition. Lack of access to survivorship services are exacerbated by communication obstacles, rendering them at increased risk for poor quality of life (QoL). Few intervention studies address rural cancer survivors' needs. This study reports on: (1) the feasibility of the Rural Breast Cancer Survivor Intervention, a psychoeducational QoL intervention specifically designed for rural breast cancer survivors; and (2) examined the feasibility of telephone communication.

Methods: Fifty-three rural subjects were included. Twenty-seven rural subjects were assigned to Experimental (EX), and 26 subjects assigned to Wait Control (WC) group. Subjects completed baseline QoL measures (QoL-Breast, BPI, POMS) and at 3 and 6 months post intervention. The intervention consisted of 3 education and support sessions, followed by 3 telephone and 2 in person sessions. Data Generalized Estimating Equation (GEE) techniques were used to compare intervention effects at baseline and follow up.

Results: There were no significant differences in primary measures between the EX and WC at baseline. At Month 3, EX reflected significant improvement in overall QoL and WC reflected slight but non-significant deterioration in QoL. Significantly more WC subjects reported pain than EX subjects (57.7% versus 33.3%). At Month 6, both EX and WC showed significant improvement in QoL. Even though both groups showed significant improvement at Month 6, the EX still reflected statistically significantly better QoL ($p<.05$).

Conclusion: Rural breast cancer survivors benefit from a survivorship plan. The telephone is a feasible communication medium for rural survivors.

Funding Source: National Institute of Nursing Research and Office of Cancer Survivorship, National Cancer Institute; Grant Number 5R01-NR005332-04

Body Mass Index, Weight, Smoking and Alcohol Use are Associated with 7-year Overall Survival after Breast Cancer Diagnosis

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Relatively few studies have examined the relationship between modifiable risk factors and survival after breast cancer diagnosis. The purpose of this study was to investigate whether smoking, alcohol use, height and weight at diagnosis, abstracted from the medical records, influence overall survival after breast cancer diagnosis. Follow-up data, vital status, stage, age at diagnosis, ER/PR status, race, and SES were ascertained from a cancer registry for women diagnosed with breast cancer between July 1, 1996, to June 30, 1997 (n=360 pre-menopausal; n=855 post-menopausal). Cox proportional hazards models [included BMI and/or weight, alcohol and smoking, stage, age, race, ER/PR status, and SES], were used to measure the relationship between lifestyle risk factors and the risk of dying after breast cancer diagnosis. We found that for post-menopausal women, the risk of dying increased as weight increased ($p=0.04$) and the association with BMI was borderline significant (Beta:0.03; $p=0.06$). Also, smokers had an almost 2 times greater risk of dying over the 7-year follow-up period compared to non-smokers (HR:1.94, 95%CI:1.21-3.10). In addition alcohol users were at a reduced risk of dying compared to non-users (HR:0.702, 95%CI:0.51-0.97). A similar relationship was found in pre-menopausal women for alcohol use only (HR:0.542, 95%CI:0.30-0.97). The results suggest that weight, smoking and alcohol use have the potential to decrease the risk of dying after diagnosis and if modified they could have implications for survivorship for women diagnosed with breast cancer.

Funding Source: National Cancer Institute/UCI Cancer Center; Grant Number 2P30CA62203-04

Quality of Life of Breast Cancer Survivors: General Population, Ethnicity, and Urban vs. Suburban Neighborhoods Comparisons

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To better meet the needs of breast cancer survivors for health services, we need to understand the differences in quality of life (QOL) among various groups. This study compared the QOL of breast cancer survivors with women from the general population, and examined the effect of ethnicity and location of residence (urban vs. suburban). Data were collected by mailed questionnaire. Cancer survivors ($n = 522$) were drawn from three oncology practices throughout Illinois. The general population sample ($n = 270$) were women drawn randomly from telephone directory information.

The QOL of cancer survivors was significantly better than women in the general population. Cancer survivors reported positive changes in their lives, contributing to improved QOL. Cancer survivors living in urban neighborhoods had a significantly lower QOL than those living in suburban areas. This was the case even though the urban group was significantly younger. This was found for both Caucasians and African Americans, demonstrating that living environment and socioeconomic status had a greater effect on QOL than ethnicity. In fact, the Caucasian women living in urban neighborhoods had a lower QOL than the African Americans in similar neighborhoods. Greater depression and social isolation may have contributed to the poorer QOL of the urban Caucasian group. The findings demonstrated that the cancer survivors living in urban neighborhoods had a greater need for supportive services than those in suburban areas. The results of this study can be used to help identify differences in needs for breast cancer survivors, particularly those in urban areas.

Funding Source: University of Illinois at Chicago, Campus Research Board

Quality of Life Disparities for African American and White Breast Cancer Survivors: A Pilot Study

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Purpose: This pilot study compared health related quality of life (HRQOL) between African American (AA) and white breast cancer survivors (BCS). We hypothesize that HRQOL is differently experienced by AAs and whites 6 months after surgery.

Background & Significance: Nearly half of all BCS is AA. African Americans have a higher BC death rate, are disproportionately underinsured and socioeconomically disadvantaged relative to whites. While survival has been extensively studied, little has examined whether survivorship disparities exist for AA BCS.

Data & Methods: We use a convenience sample of AA ($n_{AA}=5$) and white ($n_{whites}=22$) BCA survivors from academic and community medical settings. HRQOL was measured with the Functional Assessment of Cancer Treatment – Breast + 4 (FACT-B+4). We use descriptive statistics to report sample characteristics for the overall and subscales (physical well-being [PWB], functional well-being [FWB], social/family well-being, and emotional well-being) FACT-B+4 prior to and 6 months after BC surgery.

Results: On average, participants are 54 years old and 73% received lumpectomy. All participants had pre-surgical diagnostic biopsy, 4% received axillary lymph node dissection and the remainder either received or did not require sentinel lymph node biopsy. Overall FACT-B+4 scores were similar for AA and whites, yet 100% of AAs report a decline in PWB compared to 33% for whites.

Conclusions: This pilot study indicates preliminary support of our hypothesis that AA and white BCS differently experience HRQOL especially related to physical recovery. Physical therapists can improve PWB and FWB in terms of proven effective exercise interventions and patient/family education programs. A follow-up study involving a larger sample is in development.

Funding: National Cancer Institute; Grant Number U54 CA91408-04

Cancer Survivors' Health Information Seeking

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Although there is research identifying cancer patients' information needs, there are no comprehensive studies focused on health information seeking among a large number of survivors. In this study, we examine health information seeking among 711 cancer survivors (28% breast cancer, 13% prostate cancer, 13% melanoma). The data for this study are from the Health Information National Trends Survey (HINTS), a national probability survey of the U.S. adult population conducted in 2005 by the National Cancer Institute. Participants in the HINTS were selected using random-digit dialing and completed a telephone or Internet survey. All statistical analyses were conducted using SUDAAN. On average, survivors were 50 years old ($SD=20$) when diagnosed and were 11 years post-diagnosis ($SD=15$). Sixty-four percent of survivors reported looking for information about cancer and about half of these last looked for this information during the prior 6 months. Survivors most often reported that they consulted their health care provider (44.4%) or the Internet (32.5%) for cancer information. Of those survivors who used the Internet for cancer-related information, 90% found the information to be somewhat or very useful. Survivors reported that in the future their first source of cancer information would be a health care provider (70.8%). Overall, survivors were confident that they could get advice or information about cancer (71.5%), even though almost half (47.6%) were concerned about the quality of health information they received when they last looked for information. Additional analyses will examine barriers to cancer information seeking and information seeking among subgroups of cancer survivors.

Funding Source: None

The Community Health Advisors in Action Program (CHAAP): A Community-Based Breast Cancer Patient Navigation Intervention for Low-Income, Medically Underserved, and Minority Women

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Background: African American women are 1.2 times more likely to die from breast cancer compared to white women, and the 5-year survival rate is 75% for African-American women vs. 89% for Caucasian women. Some contributing factors for these differences include limited access to care, late diagnosis, and psychosocial challenges that interfere with adherence to therapeutic regimens.

Methods: The CHAAP intervention is based on the Community Empowerment and Community Health Advisors Network (CHAN) models, and seeks to develop, implement, and evaluate a community-based strategy for increasing adherence to appropriate diagnostic/medical follow-up care and treatment, primarily among medically underserved and low-income African-American and Caucasian women who present with breast abnormalities, or positive breast cancer screening results. A network of experienced volunteers were identified and received 16 hours of peer-patient navigation training. Navigators gained preparation to serve as referrers, health system navigators, and lay case managers. Navigators work one-on-one with patients to overcome barriers that impede treatment compliance.

Results: Peer-Patient Navigators (36) were successfully trained, and 128 patients have been enrolled. Majority of patients are 40 and older; African American, have incomes $\leq \$10,000$; unemployed; and need help with insurance. Presently, patient treatment and appointment compliance rate is 94%, with 936 of 1000 medical appointments kept. Patients reported feeling less fearful when assisted by a navigator.

Conclusion: This intervention is unique in that it engages patients while they are both inside and outside the healthcare setting. It reaches underserved women who have been difficult to reach through traditional methods designed to increase compliance/retention.

Funding Source: The AVON Foundation

Using the Breast Cancer Surveillance Consortium for Research About Breast Cancer Survivors

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Background: When considering a new research question about breast cancer survivorship, locating a population-based sample can be challenging.

Methods: The National Cancer Institute supports the Breast Cancer Surveillance Consortium (BCSC), currently 5 registries across the nation, with representative ethnic and racial diversity with data from 1994 to present. Women in the BCSC represent about 5% of the U.S. population. Data are collected during breast imaging visits and women are tracked longitudinally. Advantages of using the BCSC are 1. current data collection; 2. registry-specific permission to invite women into studies on prevention, RCT treatment, or survivorship; 3. demographic and risk factor data available for segmenting populations; and 4. breast imaging and pathology/cancer data and possible access to benign and malignant tissue. The BCSC collects self-reported breast cancer history and age at diagnosis enabling identification of women along the cancer survivorship continuum. In addition, the BCSC links with pathology laboratories and cancer registries.

Results: From 1994–2004, 82,825 of 1,453,912 women reported a history of breast cancer. BCSC data have been used to identify women for studies about understanding psycho-social issues of surveillance mammography, quality of life, complementary therapy use, hereditary breast cancer, tissue samples studies, quality of care, factors associated with recurrence, second primary cancers and mortality.

Conclusions: We invite researchers to apply to use BCSC data. The size and the longitudinal nature of the data make the BCSC a rich resource for research in breast cancer survivorship. Visit: <http://breastscreening.cancer.gov/> for more information about the BCSC and the process for working with the BCSC.

Funding Source: NCI-funded Breast Cancer Surveillance Consortium co-operative agreement (U01CA63740, U01CA86076, U01CA86082, U01CA63736, U01CA70013, U01CA69976, U01CA63731, U01CA70040); however, all opinions and findings are the sole responsibility of the authors. The views expressed do not necessarily represent those of the U.S. Government.

Primary and Specialty Care Models of Follow-Up Care Delivery among Colorectal Cancer Survivors

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Background: The Institute of Medicine recommends the health care system consider both primary and specialty care models in delivering follow-up care to cancer survivors.

Methods: Cancer survivors in Northern California were surveyed 2–5 years after diagnosis. Three hundred and fifty (350) colorectal cancer survivors were asked the specialty of the follow-up care physician they saw in the past 12 months. We assessed specialty differences in patient characteristics (number of comorbidities and time since diagnosis) and patient perceptions of the quality of follow-up care (communication, care coordination, and office staff interactions).

Results: A minority (15.9%) of colorectal cancer survivors stated that the doctor they most often saw for follow-up cancer care was a primary care physician (PCP). Among survivors who most often saw a subspecialty physician, 62.2% saw an oncologist; 12.9%, a gastroenterologist; and 9.1%, a surgeon. PCPs were more likely than subspecialty physicians to provide follow-up care to survivors with ≥ 3 comorbid conditions (40.7% vs. 25.3%, $p=.020$) and to see patients ≥ 4 years after cancer diagnosis (46.3% vs. 32.1%, $p=.043$). There were no detectable specialty differences in the quality of follow-up care in relation to communication, care coordination, or office staff interactions.

Conclusions: Models of health care delivery should consider the integration of care for cancer survivors with complex medical problems and the timing of transition from subspecialty to primary care. Colorectal cancer survivors who see primary care physicians do not perceive lower quality of care, although a primary care model is uncommon and should be tested more widely.

Funding Source: None

Positive and Negative Social Support, Traumatic Stress Symptoms, and Posttraumatic Growth in Colorectal Cancer Patients

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Background: Positive support from family members is critical for cancer survivor well-being, however, few studies have examined the negative aspects of social support, such as having conflict with family, in the face of cancer. This study examines preliminary baseline data from a longitudinal study of newly diagnosed colorectal cancer patients. Specifically, we examined the relationship of positive and negative aspects of family social support with indices of psychological adjustment.

Methods: Immediately after diagnosis but prior to surgery, participants (N=59) completed self-report measures of: positive and negative social support, distress reactions at the time of cancer diagnosis, cancer-related traumatic stress symptoms (TSS), and cancer-related posttraumatic growth (PTG).

Results: Approximately 1/3 of patients were diagnosed with colon cancer and 2/3 with rectal cancer; 51% had advanced disease. Patient sample was 57.6% men, 76.3% Caucasian, mean age 56.1 years ($SD=13.8$), and 61% college educated. ANOVAS (2 X 2) were conducted, which included main effects for positive social support (high vs. low) and negative social support (high vs. low), as well as the interaction of positive support X negative support. Patients indicating high (vs. low) negative support reported significantly greater distress at the time of cancer diagnosis ($F=8.8$, $\eta^2=.12$, $p=.008$) and greater TSS ($F=7.5$, $\eta^2=.14$, $p=.023$), while patients indicating high (vs. low) positive support reported significantly greater PTG ($p<.05$, $\eta^2=.10$).

Conclusions: These preliminary data suggest patients with high levels of negative social support and family conflict may have more difficulties in adjusting to colorectal cancer, while positive support from family may help promote posttraumatic growth.

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Effects of Coping and Stress on Physical Activity among Caregivers of Newly Diagnosed Colorectal Cancer Patients

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Purpose: Cancer is a major stressor to patients as well as to their caregivers and may affect the maintenance and achievement of a healthy lifestyle. Studies have addressed the association between exercise and stress but have not examined the potential for a buffering effect of coping styles among caregivers. We hypothesized that an active coping style would buffer the adverse effect of caregiving stress on exercise.

Methods: Caregivers of newly diagnosed colorectal cancer patients at community hospitals ($n = 155$) participated in the study, responding to measures of caregiving stress (Pearlin Stress Scale), coping styles (B-COPE), and physical activity (Godin Scale). Participants were middle-aged (mean age 52.6), 76% female, 45% African American; 24% had high school or less education, and 19% had < \$40,000 household income.

Results: Results from hierarchical linear regression analyses support the hypothesis, showing that increased use of active coping, such as planning and emotional expression, buffered the adverse effect of caregiving stress on strenuous physical activity ($p < .01$). This finding was significant after controlling for sex, age, race, income, education and main effects of stress and coping styles. The association was not significant for mild and moderate levels of physical activity. Dichotomizing strenuous activity above and below the recommended levels of 60 minutes per week, logistic regression revealed the interaction effects between active coping and stress ($p < .01$) and between passive coping and stress ($p = .019$).

Conclusions: The findings support the stress-coping theory, which suggests that caregiving stress can be buffered by utilizing active types of coping strategies. Caregivers may benefit from programs that encourage the use of active coping strategies, such as participation in physical activity, to maintain their own health during a loved one's cancer diagnosis and treatment.

Funding Source: American Cancer Society; Intramural Funding

Comparing Stress among Prostate and Breast Cancer Survivors: A URCC CCOP Report

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Background: Stress in cancer survivors can negatively impact quality of life, and, ultimately, survival. This study characterizes and compares stress reported by breast (BCS) and prostate (PCS) cancer survivors, 6–24 months post treatment, and identifies correlates of stress within each group.

Methods: Breast (N=353; mean age=50) and prostate (N=313; mean age=66) cancer survivors recruited for two randomized controlled trials conducted by the University of Rochester Community Clinical Oncology Research Base provided information on stress, as assessed by the POMS and MAC (Mental Adjustment to Cancer scale).

Results: PCS reported lower levels of stress, specifically, tension, depression, anger, fatigue, confusion, fatalism, helplessness, anxiousness, and avoidance, but higher levels of vigor compared to BCS (all p<.01). Despite less stress, PCS reported lower fighting spirit compared to BCS (p<.01). Age was inversely correlated with fighting spirit (BCS r=-0.234; PCS r=-0.192) and anxiousness (BCS r=-0.260; PCS r=-0.281) among both groups (all p<.01). Income was negatively correlated with depression, helplessness, and avoidance, but positively correlated with fighting spirit among both groups (all p<.05). Income was also inversely correlated with confusion and fatigue among PCS (all p<.05).

Conclusions: These data suggest that prostate cancer survivors have less post-treatment stress compared to breast cancer survivors. However, stress seems to be significantly associated with age and income among both groups. More research is needed to determine the role of specific survivor characteristics (e.g., diagnosis, age, income) on post-treatment levels of stress, and future randomized controlled trials are needed to examine the efficacy of individualized interventions.

Funding Source: National Cancer Institute; Grant Number U10 CA37420

Traditional Masculinity and Psychosocial Coping Processes

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Background: Male cancer patients who espouse traditional notions of masculinity may have significant psychosocial distress as a result of their cancer experience. The goal of this study was to examine the relationships between masculine gender role conflict (or conflict that exists from the endorsement of traditional masculinity ideology) and psychological outcomes, as well as the potential mediating influences of emotional expression and constraints in social relationships.

Method: Participants included 151 male cancer patients who ranged in age from 31 to 94 years ($M=67.4$, $SD=10.5$). All participants were being treated at an outpatient oncology clinic at a veteran's hospital in a major metropolitan area. Participants were asked to complete written assessments by clinic staff.

Results: There were five endogenous variables in the path analysis model: emotional expression, social constraints, constraints with medical providers, cancer-specific distress, and general distress. Gender role conflict was the sole exogenous variable. Slight modifications were made from the hypothesized model based on modification and fit indices. The final model had a good fit to the data, $\chi^2(4, N = 151) = 3.07$, $p = .55$, ns (CFI = 1.00; RMSEA = .00, 90% CI = .00-.11; SRMSR = .03). According to the final model, conflict associated with a traditional masculinity ideology is associated with increased levels of cancer-specific and general distress and this relationship is partially mediated by emotional expression and constraints in social relationships.

Conclusions: Interventions that accommodate masculine ideologies yet challenge assumptions should be designed and tested to determine how practitioners can foster the expression of emotion without significant threat to masculine identity.

Funding Source: Partial funding for this research was granted by the Arizona State University Office of the Vice-President for Research and Economic Affairs.

Fitness and Quality of Life Issues for Endometrial Cancer Survivors

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Background: Obesity and sedentary behavior are risk factors for endometrial cancer; thus endometrial cancer survivors are more likely to experience comorbid health and quality of life problems related to these conditions. Because endometrial cancer has a high cure rate, methods to enhance quality of survivorship are a priority research area.

Methods: Endometrial cancer survivors who were post-treatment were recruited as part of a pilot study for a larger study on exercise after endometrial cancer. Assessments included quality of life (MOS SF-36), anthropometrics, and aerobic capacity (submaximal cycle ergometer).

Results: To date, 17 participants (mean age, 58.1 years), have completed assessments. The participants were below normal in aerobic capacity and can be categorized as borderline obese as determined by body mass index (BMI) standards. Specifically, 30% were of normal BMI; 30% were overweight; and, 40% were obese. The mean predicted aerobic capacity expressed as VO₂ max was 19.6 (SD=4.1), which is below the 10th percentile value as published by the American College of Sports Medicine. Fifty-four percent of the participants were below the median for their age on the SF-36 Physical Component Scale (PCS), and 48% were below the median on the SF-36 Mental Component Scale (MCS). PCS score was negatively associated with BMI ($r = -.52$, $p < .05$).

Conclusions: The initial data suggest that this sample of survivors has poor fitness and could benefit from a physical activity intervention designed to reduce BMI and increase aerobic capacity. A reduction in BMI may have a positive effect on physical well-being.

Funding Source: National Cancer Institute; Grant Numbers R01 CA1099919, R25 CA57730, P30 CA016672

Physical Activity and Sleep Disturbance in Cancer Survivors: Is there a Relationship?

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Background: Physical activity has been found to influence quality of life in cancer survivors. Little research has explored whether regular physical activity may also impact the sleep disturbance that occurs following a cancer diagnosis. This study aimed to explore this relationship between sleep disturbance and physical activity levels in cancer survivors.

Method: Posters and study flyers were placed in cancer-related medical waiting rooms. Patients could complete the survey during an interview or by mail.

Results: Participants were 91 breast (35%) and prostate (65%) cancer patients (mean age= 61 years). Poor sleep was reported by 57%. There were significant differences in sleep quality by age; those <50 years reported the poorest sleep ($F(2,79) = 4.54$, $p<.014$). Women reported greater disturbance of sleep ($M=10.5$) compared to men ($M=7.8$; $F(1,87) = 12.4$, $p<.001$). Poor sleepers reported 69% less minutes of physical activity in the last week (63) compared to those reporting good sleep (201; $F(1,81) = 11.8$, $p<.001$). Those reporting the least activity had a greater problem with sleep latency (1.7 versus 0.7; $F(1,85) = 7.4$, $p<.008$).

Conclusion: This is one of the first studies examining the effects of physical activity on sleep disturbance following cancer. If regular activity is found to influence sleep, there are important implications for improving quality of life, particularly as those who reported poor sleep also reported depressive symptoms. To inform on the causal nature between physical activity and sleep quality, future studies need to examine this relationship prospectively.

Funding Source: Australian Research Council postdoctoral fellowship; Grant Number DP450144.

The Meaning of Cancer Survivorship for Hispanic Adolescents: A Qualitative Pilot Study

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Background: Hispanic adolescents with cancer have poorer outcomes and receive more inconsistent care than their non-Hispanic counterparts (Bhatia et al. 2002). Lack of health care and insurance coupled with family poverty can create significant barriers to health care for adolescents of color in general (Hoberman et al. 1997). Language/cultural barriers continue to present problems for Hispanic children to access health care in the United States (Spector 2004). Due to disparities in access to health care, Hispanic adolescents with cancer have been underserved /understudied

Hispanic adolescents may have a significantly different experiences of cancer survival based upon cultural values. While the term “Hispanic” encompasses many cultures and ethnicities, traditional values such as importance of family, respect for others, honor, loyalty, ethnic pride, courage, and strong religious faith may deeply influence the ways in which Hispanic adolescents make meaning of their cancer experience as compared to their non-Hispanic counterparts (Harrison et al. 1996, Holleran & Waller 2003, Marin & Marin 1991).

Methods: Using a phenomenological approach, 10–15 Hispanic adolescent cancer survivors (ages 12–21) were interviewed about the meaning they assigned to surviving cancer. Interviews were conducted at University of New Mexico Children’s Hospital and the Children’s Hospital of Austin. Phenomenology allowed the researchers to gain a deep understanding of the lived experiences of the survivors. Interviews were audiotaped, transcribed and entered into Atlas.ti, a qualitative software program.

Results: Preliminary findings indicate that Hispanic adolescents’ experiences of cancer are grounded in cultural values. Implications for interventions will be discussed.

Funding Source: National Institute of Nursing Research; Grant Number P30 NR005051 to the Center for Health Promotion Research.

Late Effects of Treatment for Long-Term Cancer Survivors: Qualitative Analysis of an Online Support Group

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Background: Ten million cancer survivors in the United States are at increased risk for developing late effects of treatment. Due to a lack of consistent follow-up care, many long-term cancer survivors use the Internet as a source of information and support. Research on online support for this cohort is lacking. The purposes of this study were to report late effects of treatment, as described by members of an online cancer survivor support group, and to identify major themes related to long-term cancer survivorship.

Methods: Qualitative descriptive methodology was utilized. Content analysis was employed to evaluate the raw data for thematic threads. Descriptive analysis was used to determine gender, type of cancer, years as a cancer survivor, and late effects of treatment.

Results: Seventy-five long-term cancer survivors posted 300 messages online over an eight-week period. They reported multiple late effects of treatment including neurological impairment, cardiomyopathy, pulmonary dysfunction, gastrointestinal problems, musculoskeletal pain, endocrine/hormone imbalances, anxiety, and secondary cancers.

Three categorical schemes were identified: information exchange, symptomatology, and frustration with healthcare providers. Members often sought or gave information related to their disease and all reported multiple late effects of treatment. Many expressed frustration related to a lack of surveillance and follow-up by healthcare providers.

Conclusions: Late effects of cancer treatment may be numerous and cause considerable disability. Results of this study suggest that healthcare providers are not using available guidelines for assessment and follow-up for long-term cancer survivors. Comprehensive and ongoing educational programs are essential in order to address this informational gap.

Funding Source: None

Pregnancy after Breast Cancer and Survival

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Background: As age at first birth in the United States is rising, more women are being diagnosed with breast cancer prior to beginning childbearing. Because breast cancer is a hormone dependent disease, clinicians have been concerned that pregnancy after diagnosis may increase the risk of recurrence and death.

Methods: Retrospective follow-up study of breast cancer cases younger than age 45 at diagnosis who were enrolled in a Kaiser Permanente prepaid health care plan. Cases without subsequent pregnancy (n=347) were matched to cases with subsequent pregnancy (n=108) using the following criteria: 1. age at diagnosis; 2. year of diagnosis; 3. stage at diagnosis; 4. months of survival prior to initiation of subsequent pregnancy; and 5. disease status at initiation of subsequent pregnancy. Risk was assessed using Cox Proportional Hazards models controlling for age at diagnosis, treatment history, prior pregnancy, oophorectomy, and breast cancer family history.

Results: Risk of recurrence or death did not differ among cases with pregnancy after diagnosis compared with cases without subsequent pregnancy [adjusted HR recurrence: 1.3 (0.8, 2.1); adjusted HR death: 1.2 (0.7, 2.1)].

Conclusion: These data support previous research that pregnancy subsequent to breast cancer does not significantly impact risk of recurrence or death.

Funding Source: Department of Defense; Grant Number DAMD17-96-1-6122.

Screening for Hepatitis C Virus (HCV) Infection in Long-Term Pediatric Cancer Survivors: A Report from the Childhood Cancer Survivor Study (CCSS)

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Background: The Children's Oncology Group recommends HCV screening for all pediatric cancer survivors treated prior to 1993. Study aims were to determine the proportion of adult survivors of pediatric cancer who report having been tested for HCV and to identify modifying factors associated with testing.

Methods: The CCSS is a cohort study that tracks health outcomes in long-term survivors of childhood cancer who were diagnosed between 1970 and 1986. Adult participants (N=8443) were asked a series of questions about transfusion history and HCV testing.

Results: 47.5% reported a previous transfusion, 35.9% reported not having one, and 16.6% were not sure. Of those who reported a previous transfusion, 38.9% reported HCV testing (leukemia survivors, 34.5%), 31.4% reported no testing, and 29.7% were not sure. Of those tested, 15.9% of leukemia survivors and 6.7% of other cancer survivors were HCV positive. Multivariate analysis identified three factors that predicted an increased likelihood of testing: diagnosis of leukemia (odds ratio [OR], 1.5; 95% confidence intervals (CI), 1.3-1.7); care in the previous two years at a cancer center (OR, 1.5; 95% CI, 1.3-1.7); and some college education or vocational training beyond high school (OR, 1.2; 95% CI 1.1-1.4). Gender, race, ethnicity, income, and health insurance status did not predict likelihood of HCV testing.

Conclusion: Though universal screening for HCV is recommended in this population, less than one-third of participants report knowledge of previous testing. Thus, there is a potentially large population of pediatric cancer survivors with undetected chronic HCV, representing a serious public health issue.

Funding Source: National Cancer Institute; Grant Number U24-CA-55727.

The Impact of an Exercise Intervention on Body Composition, Fat Distribution, and Weight in Breast Cancer Survivors

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Background: Recent research has demonstrated that obesity increases a woman's risk of breast cancer recurrence. Although the mechanism is not well understood, it is known that obese women have higher levels of insulin and other hormones related to energy balance. In this study, we sought to explore the impact of an exercise intervention on body composition, fat distribution, weight, and insulin levels in a population of breast cancer survivors.

Methods: Women with early stage breast cancer who had completed adjuvant treatment were randomized to a 16-week exercise intervention or a normal care control group. The exercise intervention consisted of 2 supervised strength training sessions and 90 minutes of unsupervised cardiovascular exercise each week. Anthropometric measurements and fasting insulin levels were collected at baseline and after 16 weeks in both groups.

Results: Ninety-nine women have been randomized; complete anthropometric data are currently available for 67. Exercise participants experienced a nonsignificant decrease in body weight, body fat, and circumference at the waist and hip, as compared to control patients. Participants completed a median of 84% of scheduled strength training sessions and performed an average of 114 minutes of cardiovascular exercise per week. Strength increased by an average of 40% during the exercise intervention. Prior studies have demonstrated significant inter-assay variability in biomarker testing, thus insulin testing will be performed when all patients have completed the protocol.

Conclusions: Compliance with the exercise intervention was good. Women in the exercise group experienced non-significant changes in anthropometric measures, and increased strength during the 16-week intervention.

Funding Source: This project was supported by funding from the Lance Armstrong Foundation and an ASCO Career Development Award.

Pain among Long-Term Survivors of Childhood Cancer: A Preliminary Report from the Childhood Cancer Survivor Study (CCSS)

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While increased rates of cancer survival have focused attention on the detection of late effects, few studies have investigated pain as a late effect in long-term survivors of childhood cancer. Pain outcomes (i.e., pain and pain-related disability) were assessed using the bodily pain scale of the Short-Form 36 (SF-36) in 9034 childhood cancer survivors participating in both CCSS baseline and follow-up surveys (approximately seven years after). Survivors' mean age was 31.8 ± 7.57 (range 17-54) years at follow-up, and at diagnosis was 8.2 ± 5.84 (range 0-21) years. At follow-up, 22.3% reported moderate to very severe pain; 14.3% reported moderate to extreme pain interference. Among survivors diagnosed with leukemia, Hodgkin's lymphoma, soft tissue sarcoma, and bone cancer, the percentages of reporting moderate to very severe pain were 20.2%, 23.0%, 26.2% and 33.3%; and the percentages of reporting moderate to extreme pain interference were 12.6%, 16.6%, 17.07%, and 23.4%. On average, the three diagnostic groups reported more pain and pain-related disability compared with the leukemia group (p 's < 0.01). Those who received Alkylating and Anthracycline agents reported more pain related disability than those who received other chemical agents (bonferroni correction $p=0.004$); those who received radiotherapy reported more pain-related disability than those without radiotherapy ($p=0.02$). Bivariate analyses revealed that older age, lower income, more psychological distress and attributing pain and anxiety to cancer at baseline were also associated with more pain and pain-related disability at follow-up ($ps<0.01$). Multivariate analyses are underway to further examine the diagnosis- and treatment-related pathways to pain in childhood cancer survivors

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Fertility and Pregnancy Outcome in Cancer Patients

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Introduction: Because of the increased survival rates in cancer patients, post-treatment infertility has become a major concern. This study compares the overall (all first childbirths ever after age of 16 years) and post-diagnosis fertility rates (all first child births after diagnosis in previously childless individuals) among cancer patients (Part I), and obstetric and perinatal complications for a cancer patient's two first childbirths (Part II) with comparable figures in the normal population.

Methods: The series was established by linkage of three registries covering births after 16 week pregnancy from 1967 to 2004: 1) Patient registry of the RRMC, 2) MBRN, 3) Cancer Registry of Norway. A control group was established from the normal population.

Results: *Part I:* 149 (53%) of the 284 females with cancer reproduced overall as compared to 63% in the normal population ($p=0.007$). 193 (42%) of the 463 males with cancer reproduced overall compared to 45% in the normal population ($p=0.41$). Compared to controls the post-diagnosis fertility was reduced both among male and female cancer patients with no children prior to diagnosis (<0.001). *Part II:* Female cancer patients had significantly increased rates of low birth weight and pre-term deliveries in children born post-diagnosis. Children of male cancer patients were significantly more often conceived after assisted fertilisation. Compared to controls children born post-diagnosis to male cancer patients had increased levels of malformations, but the difference lost its significance when adjusting for time-period of birth.

Conclusions: Female cancer patients have decreased reproduction-rates overall, and more often children with low birth weight and pre-term delivery. The overall reproduction rate for a male cancer patient is not significantly decreased, but they more often conceive by in vitro fertilisation. For both genders post-diagnosis fertility rates are decreased. The rates of malformations need to be analysed in larger series.

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Symptom Burden among U.S. Cancer Survivors Compared to Other Populations: A Population-Based Study

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Background: Previous research among specific cancer populations has shown high but variable symptom burden; however, very little is known about its extent and pattern among the entire population of U.S. cancer survivors as compared to other groups.

Methods: To determine the prevalence of recurring symptom distress among cancer survivors and compare it with the general population and populations suffering from other chronic diseases, we analyzed data from the 2002 National Health Interview Survey, which included 1,904 cancer survivors and 29,092 controls. Main outcome measures included self-reported ongoing pain, psychological distress, and insomnia. Multivariate logistic regression models were used to adjust for confounders and test for interactions.

Results: The rates of recurring pain, psychological distress, and insomnia among cancer survivors were 34%, 26%, and 30% respectively and were significantly higher (all $p<0.001$) than individuals without a history of cancer (18%, 16%, and 17%). A greater symptom burden was seen in cancer survivors of both recent (within 1 year) and distant diagnoses (>10 years). In addition, cancer survivors were more likely to report recurring pain (odds ratio [OR] 1.26, 95% confidence interval [CI] 1.07-1.49) and psychological distress (OR 1.26, 95% CI 1.06-1.49) than individuals with other chronic medical illnesses such as heart disease and diabetes adjusted for social-demographic factors and other co-morbidities.

Conclusions: The symptom burden among cancer survivors is substantial and persistent, even compared to other chronic diseases. Effective symptom assessment and treatment by health care providers are important to help eliminate the suffering of cancer.

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Breast Cancer as a Life Process: Psychosocial Experiences of Latina and White (non-Latina) Long-Term Breast Cancer Survivors

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Breast cancer is the most common form of cancer in women living in the United States across most ethnic groups. Although the psychosocial impact of breast cancer has been studied, there is little information on women from diverse ethnic and socioeconomic backgrounds. This study aims at understanding the psychosocial experiences of long-term breast cancer survivors using qualitative methodology. In depth interviews were conducted with 25 Latina long-term (5 years since diagnosis) and 28 White non-Latina breast cancer survivors. Breast cancer survivors' perceptions about breast cancer related challenges and changes to their body, their identity and social relations were explored. Latina and White (non-Latina) women were compared and contrasted. Women's perceptions and issues of concern were related to: fear of recurrence, embodying breast cancer, and changes in social relationships, femininity and sexuality, and social identities. Latinas compared to White (non-Latinas) reported more issues of concern related to access to quality health care and the need for social support, communication barriers with their health care providers, negative impact on their femininity and sexuality, and the importance of spirituality. This study contributes to our understanding of ethnic differences and similarities in the long-term impact of breast cancer survivors' psychosocial health and quality of life. Last, this research is important for the provision of culturally sensitive health care, and support services to benefit breast cancer survivors and their families.

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Physician Visits 1998–2000 in a Population-Based Cohort of Young Cancer Survivors: Report of the Childhood/Adolescent/Young Adult Cancer Survivor (CAYACS) Program

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Background: Health services utilization among childhood and adolescent cancer survivors is not well described. For a population-based survivor cohort in British Columbia (BC), Canada, we examined frequency of physician visits, compared visit patterns to that of a similar aged general population sample; and examined the impact of demographic, socioeconomic and diagnosis variables.

Method: We linked BC fee-for-service physician claim data for 1998–2000 to provincial registry demographic, socioeconomic, physician type, and diagnosis information for a cohort of 856 individuals diagnosed with cancer under 20 years from 1981–1992, and surviving 5 years or more, and a population sample of 16,754 individuals.

Results: Survivors had a median of 18 physician visits in the period, compared to a median of 13 visits in the population sample ($p<0.0001$). Median frequency of both general practitioner (GP) (11 vs. 10; $p<0.001$) and specialist (5 vs. 2; $p<0.001$) visits were significantly higher among survivors. Specialist visit types differed between groups. Socioeconomic status, region of residence, and urban/rural location of survivors did not affect survivor visit frequency. Results adjusted for potentially modifying factors will be presented.

Conclusions: Physician visits are an indicator of long-term surveillance for, and treatment of, late effects. In our cohort, survivors visited both general practitioners and specialist physicians more often than the general population. Our research resource of record-linked, person-based, longitudinal administrative care datasets for a total geographically defined survivor population, within a publicly-funded health care system, can generate a comprehensive documented description of care patterns of cancer survivors, and factors affecting care.

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Optimizing Survivorship in Myeloproliferative Patients: Obstacles and Opportunities

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Background: The myeloproliferative disorders (MPDs) are a group of chronic leukemias in which patients suffer from thrombosis, cytopenias, splenomegaly, constitutional symptoms, acute leukemia and death. Survivorship in MPDs needs to target improving quality of life, since no therapy has positively impacted survival or fatigue over the long disease course. We hypothesize that increased activity may abrogate the morbidity of the MPDs, and undertook a patient survey to identify the barriers optimizing survivorship in MPD patients.

Methods: A multi-center international web based survey of patient characteristics, clinical course, fatigue (FACT-An, Brief Fatigue Inventory), constitutional symptoms, and physical activity (Godin) was undertaken.

Results: 1179 MPD patients reported fatigue (80.7%; worse than published controls ($p<0.001$)), pruritus (52.2%), night sweats (49.2%), bone pain (43.9%), fever (13.7%), and weight loss (13.1%) from their disorder. Symptoms restricted participation in social functions (68%), 34.5% of the patients needed assistance with activities of daily living and 11.2% reported MPD-associated medical disability. Respondents reported significantly less physical activity than published control on the Godin Scale (MPD = 25.1 METS vs. 45.8 METS for controls ($p<0.001$)). Barriers to activity were reported as fatigue (69.2%), dyspnea (30.8%), pain-legs (24.9%), pain-back (17.7%), numbness (15.6%), and splenomegaly (8%). The majority of respondents (70.8%) felt that walking was an option but used less than desired.

Conclusions: Fatigue leads to a vicious cycle of decreased physical activity and worsening fatigue in MPD patients. Long-term improvement of survivorship in these patients might be improved by directly targeting fatigue through pharmacologic and non-pharmacologic (i.e., exercise) interventional trials.

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Cancer-Related Fatigue (CRF) and Shortness of Breath (SOB) among Survivors: A Prospective URCC CCOP Study

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Background. Suffering experienced by cancer survivors resulting from side effects can impair quality of life and survival. As part of a multi-center longitudinal survey of patients beginning cancer treatments, we prospectively investigated the frequency and severity of self-reported problems with CRF and SOB.

Methods. 596 Cancer patients receiving chemotherapy and/or radiation (mean age=61) from 17 NCI CCOPs reported problems at their worst with CRF and SOB using an 11-point Likert Scale (0 = "Not present" to 10 = "As bad as you can imagine") for 5 days prior to treatment (T1), during the entire course of treatment (T2), and for 5 days approximately 6 months following treatment (T3). A side effect level ≥ 7 was classified as "severe."

Results. Results. CRF was reported by 70% at T1 (6% severe), 92% (41% severe) at T2 and 81% (17% severe) at T3. SOB was reported by 32% at T1 (2% severe), 59% at T2 (12% severe) and 49% (6% severe) at T3. A repeated-measures MANOVA revealed a significant treatment group (chemotherapy, radiation, or both) by time interaction with the severity of both symptoms higher among survivors receiving chemotherapy compared to radiation alone ($p<.001$). Severity of CRF and SOB increased from T1 to T2, decreased from T2 to T3, and remained significantly higher at T3 compared to T1 ($p<.001$).

Conclusion: Patients receiving chemotherapy, compared to radiation alone, reported more severe CRF and SOB. The frequency and severity of CRF and SOB in survivors 6 months after completing treatment remained higher than pre-treatment levels.

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Unmet Needs of Family Caregivers of Colorectal Cancer Patients

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Background: Over 10 million Americans have a history of cancer, the majority of whom have at least one person who provides care to them. Informal cancer care involves the caregiver meeting the multidimensional needs of the patient as well as their own needs. The degree to which caregivers' needs are not met may affect their ability to care for the patient as well as their own quality of life.

Method: A total of 158 caregivers (45% African American) of persons newly diagnosed with colorectal cancer participated in the American Cancer Society's Study of Informal Cancer Care (M=60 years old). Demographic correlates were analyzed against a measure examining unmet caregiver needs.

Results: A general linear modeling analysis tested significant associations between the caregiver's age and ethnicity and the types of unmet needs. Results showed that 32.9% of caregivers identified "helping the survivor's emotional distress" and 31.1% reported "getting information about cancer" as unmet needs. Younger caregivers reported more unmet needs categorized as informational, daily activities, financial/legal, medical, social/relationship, and spiritual ($p<.05$). Non-African American caregivers indicated that mainly their emotional needs were unmet ($p=.04$). We found no significant associations between gender and income level and the different needs.

Conclusion: The findings suggest that family caregivers have various types of needs and among those, the prevalence of informational and emotional needs are paramount. These findings also provide useful information about subgroups of caregivers who will benefit from services tailored to help them meet their needs while providing care.

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Lymphedema and Physical and Functional Dimensions of Quality of Life

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Background: Shortcomings in studies of lymphedema incidence, severity, and effect on quality of life (QOL) prompted recommendations for new prospective studies with easy-to-use, reliable, quantifiable assessment of lymphedema using self-report. Earlier, we developed a short questionnaire classifying lymphedema as none, mild or moderate/severe based only on perceived size differences between the limbs, which had excellent criterion validity compared to physical therapists' measurement-based assessments. Then, in a population-based study of 649 newly diagnosed breast cancer survivors, 10% with moderate/severe, 25% with mild, and 65% with no lymphedema after two years, based on our questionnaire, we examined the correspondence between lymphedema and several independent dimensions of QOL.

Methods: One QOL scale measured self-reported frequency, severity and distress of symptoms confined to the arm on the surgical side, such as tired, thick or heavy limb, and pain. Range-of-motion was measured by self-reported difficulty with activities involving upper extremities, such as combing hair.

Results: At the 2-year follow-up, the percent of women experiencing each symptom decreased from moderate/severe, to mild, to no lymphedema, e.g. for "hand/arm felt tired thick or heavy", 82% moderate/severe, 51% mild, 7% none. Perceived severity and distress increased from mild to moderate/severe lymphedema. For range-of-motion, 83%, 58%, and 41% of women with moderate/severe, mild and no lymphedema, respectively, experienced problems. Although age, race, BMI, pain, and chronic conditions were also associated with range-of-motion, they did not confound the association between it and lymphedema ($p=0.0002$).

Conclusion: Reinforcing the validity of our short questionnaire assessment of lymphedema, independently measured physical and functional QOL decreased with increasing lymphedema.

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Self-Identity Following Cancer: Implications of “Victim” vs. “Patient” vs. “Survivor”

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Background: For some, cancer survivorship may imply radical transformations of self-identity. However, research has yet to address how the different types of self-labeling might influence how individuals function following their active cancer treatment. This study examined the extent to which different self-identifiers were related to each other and to both behavioral and psychological adjustment following cancer.

Methods: 151 younger adult cancer survivors (\bar{X} time since completion of treatment = 2.8 years; age = 20-52 (\bar{X} = 46.7), 89% Caucasian, 70% women) completed questionnaires including one that asked the extent to which participants considered themselves a victim of cancer, a cancer patient, and a survivor of cancer. Each question was asked separately, so that self-labels were not mutually exclusive.

Results: Participants identified themselves, at least “somewhat”, as survivors (82.5%), patients (59%), and victims (17%); the labels were not correlated with each other or with time since active treatment ended. Extent of identifying as a victim was related to lower sense of control, poorer mental and physical health-related quality of life, higher perceived risks for recurrence, lower satisfaction with life, spiritual well-being and positive affect, and higher intrusive thoughts and negative affect. Identifying oneself as a survivor was related to higher levels of positive affect and spiritual well-being and lower levels of negative affect. Identifying as a patient was unrelated to adjustment. Both identifying as victim and as survivor were related to centering one’s identity around cancer and participating in cancer-related activities. Identifying as a victim was related to belonging to cancer organizations and advocacy, while identifying as a survivor was related to contributing money to cancer-related causes.

Conclusions: Identifying as a victim of cancer appears to be strongly related to poorer adjustment following cancer treatment, while identifying as a survivor has some apparent advantages in terms of psychological well-being. Having a patient identity appears to be neutral vis-à-vis well-being.

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Psychological Screening for Adult Survivors of Childhood Cancer: Validation of the Computer-Assisted Survivor Screening (CASS)

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Background: The Computer-Assisted Survivor Screening (CASS) was developed as a patient-administered computerized psychological screen for adult survivors of childhood cancers.

Methods: Using computerized adaptive testing (CAT) CASS administers a brief two-step screening. Respondents complete the SF-12, demographic and treatment items in Step I. Based on these items, CASS calculates the probability of respondent distress, terminating screening for survivors with low probability of distress, and administering the BSI-18 (Step II) to survivors with significant risk. Results of a validation study comparing CASS to the SCL-90-R are reported here.

Results: CASS was administered to 131 survivors (57 male, 74 female) at three centers. Subjects ranged from 18–45 years ($M = 23.8$) and averaged 15.6 years off-treatment. CASS screened 73 survivors at Step I only; 58 received the Step II screen. The SCL-90-R classified 38 survivors as significantly distressed, and ROC analysis showed CASS prediction models had good discrimination at Step I ($AUC = .82$), and excellent discrimination at Step II ($AUC = .98$) compared to the SCL-90-R. Overall, CASS correctly classified 82.4% of subjects (sensitivity = 79%; specificity = 84%). Lower than expected sensitivity resulted from distressed cases missed at Step I, largely because of incorrect patient-reported treatment information. With corrected treatment information, sensitivity improved to 89%. Patient acceptance was high: >90% reported CASS was easy to use.

Conclusions: CASS can effectively deliver a valid psychological screening in a survivor clinic. CAT administration allows CASS to deliver in-depth screening to distressed survivors without overburdening the majority of survivors who are not.

Funding Source: Lance Armstrong Foundation

Diagnosis and Treatment of Lymphedema Following Breast Cancer: A Population-Based Study

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Background: Of the 2.3 million breast cancer survivors in the United States, 1 out of 3 will suffer from lymphedema. Evidence suggests lymphedema is under-treated, despite the availability of effective interventions. The aim is to examine incidence of lymphedema and variation in treatments. The study takes advantage of a population-based, prospective study collecting information on lymphedema care and outcomes for over 700 women with lymphedema secondary to breast cancer (BC).

Methods: The study follows elderly (65+) women identified as having BC surgery in 2003 in 4 states. Data from patient interviews are supplemented with Medicare claims and state Tumor Registries.

Results: 731 survivors interviewed. 9.4% were diagnosed with lymphedema by a doctor. An additional 2.7% reported symptoms consistent with lymphedema despite the absence of a diagnosis. Diagnosed: 20.3% received the recommended complete decongestive therapy (CDT) including: manual lymphatic drainage (MLD), bandaging, compression sleeves, skin care, remedial exercises; 7.3% received MLD only; 8.4%—bandages, sleeves or a pneumatic pump only; 56.5%—only skin care or exercise; 7.3% received no treatment at all. Multivariate regressions revealed that incidence of lymphedema did not differ by the patient's age or race. There were no differences by age, race, or state in patient's probability of receiving CDT or no treatment at all.

Conclusions: Preliminary results suggest lymphedema is under-diagnosed and under-treated. Our ultimate goal is to identify components of care that impact outcomes, identify gaps in service delivery and barriers to patients' adherence to treatment and quality of life among survivors with lymphedema.

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Low Adherence to Preventive Swallowing and Dental Regimens in Head and Neck Cancer Survivors in a Multidisciplinary Cancer Center

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For oropharyngeal cancer patients, adherence to preventive regimens during radiation greatly impacts quality of life during the post-treatment survivorship phase. Radiation of the tumor and surrounding tissue results in high rates of dry mouth, dysphagia, and trismus (permanently locked jaw). To compensate for lack of saliva during radiation, patients are prescribed complicated dental regimens to prevent oral infection, which can in turn lead to necrosis of the mandibular bone. Specifically, dental oncologists instruct our patients to brush, floss, and rinse after every meal and wear fluoride trays before bed. Similarly, to prevent trismus and promote muscle tone, speech pathologists instruct our patients to perform seven different swallowing exercises (taking 10 min per session) several times a day. We assessed self-reported adherence during radiation at 1-week post-radiation treatment and during the 6-week post-treatment period. In a preliminary analysis of 12 patients, there was a high rate of nonadherence to the swallowing regimens and mixed adherence with the dental exercises. At 1-week post-treatment, 54.5% reported complete nonadherence to all seven exercises of the swallowing regimen, while 0-70% reported nonadherence to the dental behaviors (brushing nonadherence = 0% and nonadherence to the fluoride trays = 70%). At 6-weeks post-treatment, adherence to the dental and swallowing regimens were worse for all exercises and behaviors. The most oft-cited reasons for nonadherence were fatigue, pain, and lack of knowledge. These preliminary results underscore the need for a coordinated and sustained effort among different health disciplines during treatment and beyond to promote adherence to difficult preventive regimens.

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Quality of Life of Survivors of Adult Non-Hodgkin's Lymphoma

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This presentation will detail the reported quality of life (QOL) of long-term survivors of adult non-Hodgkin's lymphoma (NHL), with particular emphasis on psychological distress as defined by post-traumatic stress disorder (PTSD). Study subjects were identified through two tumor registries (the University of North Carolina Lineberger and the Duke Comprehensive Cancer Centers). Approval for contact was obtained from each patient's physician. Participants completed the mailed survey, which contained several standardized measures: PTSD Checklist (PCL-C); Functional Assessment of Cancer Therapy (FACT-LYM); MOS Short Form (SF-36); Impact of Cancer (IOC); and Post-traumatic Growth Inventory (PTGI).

Of the 1195 eligible survivors, 884 (74%) participated. Participants ranged from 25 to 92 years of age (mean = 63 yrs, SD = 13.4) and were from 2 to 44 years post-diagnosis (mean = 10 yrs, SD=7.1). While the majority (69%) reported good QOL (i.e., with mean FACT-G scores \geq the general population norm), 7-8% of the sample reported symptomatology consistent with a full PTSD diagnosis, and 17% overall reported two or more PTSD symptoms that were moderately to extremely bothersome. Factors associated with increased PTSD symptomatology and poorer QOL included having received multiple types of treatment, lower levels of social support and income, and more negative appraisals of treatment intensity and life threat.

These and further findings from our continuing data analyses will be useful to inform providers from multiple disciplines about the survivorship experience of individuals with NHL and to design interventions aimed at reducing risk factors and enhancing QOL among members of this expanding population.

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Comparison of Self-Referred *versus* Cancer Registry Subjects Accrued to the FRESH START Diet and Exercise Trial for Cancer Survivors: Differences in Baseline Characteristics and Performance at One-Year Follow-Up

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Subjects self-referring to behavioral intervention trials may have dissimilar characteristics and subsequent performance than those accrued through cancer registries. We explored this hypothesis in FRESH START, a lifestyle intervention trial testing the effectiveness of individually tailored versus standardized (control) print materials in improving diet and exercise behaviors of breast and prostate cancer survivors. After 1-year, tailored and control arms experienced significant improvements (p -values $< .05$), with the tailored arm showing significantly greater increases in exercise, fruit and vegetable intake (F&V) and fat (saturated) restriction. Given behavior change in both arms and adequate distribution of self-referred ($N=209$) versus registry-accrued ($N=334$) participants, we compared characteristics, adherence, and behavior change between groups. Subjects who were self-referred versus registry-ascertained differed significantly (p -values $<.05$) by age (54.1 ± 10.4 vs. 58.7 ± 10.7 years), “fighting spirit” coping style (50% vs. 30%), quality-of-life (88.2 ± 15.1 vs. 92.0 ± 12.9), co-morbid conditions (1.87 ± 1.60 vs. 2.24 ± 1.78), treatment with chemotherapy (40% vs. 19%), and consuming 5+ F&Vs daily (35% vs. 45%). There were no significant differences by gender, race, education, income, social support, marital or smoking status, perceived health, depression, baseline levels of exercise or dietary fat intake, weight, other treatments, attrition, assignment completion, or change in dietary fat intake. Self-referred subjects reported significantly (p -values $< .01$) greater increases in exercise (61.8 ± 132.1 vs. 41.3 ± 108.8 minutes), F&V consumption (1.3 ± 2.2 vs. 0.6 ± 2.2), and were more likely to adopt 2+ lifestyle behaviors (32% vs. 22%). Thus, self-referred subjects differ from those who were actively recruited, and may be more likely to demonstrate greater response to behavioral intervention trials.

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Prospective Neuropsychological Function in the 5 Years after High-Dose Treatment for Hematologic Malignancies, with Case-Matched Controls at 5 Years

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Background: We and others have documented significant cognitive decline after high dose treatment followed by allogeneic stem cell transplant, with partial recovery by one year. Our aim was to determine the extent of long-term cognitive recovery, and risk factors for deficits at 5 years. We hypothesized improvement between 1 and 5 years, and risk factors including type of treatment before transplant, and duration of immunosuppressant medications.

Method: Before high dose treatment 142 adults completed neuropsychological testing. Survivors were re-tested at 3mo., 1 and 5 years. A neuropsychologist traveled to test each of N=67 5 year survivors and case-matched controls.

Results: Generalized estimating equations indicated that function declined from pretreatment to 80 days and improved by 1 year ($p<.01$ between times on all tests). However, function was below normative levels at 1 year on verbal memory (Hopkins Verbal Learning Test; HVLT), verbal fluency (Controlled Oral Word Association Test; COWAT), and motor speed and dexterity (Grooved Pegboard). Between 1 and 5 years, verbal fluency improved ($p=.001$). But by 5 years, motor dexterity (37% impaired) and verbal memory (28% impaired) did not improve ($p>.20$), remaining below norms ($p<.001$) and controls ($p<.055$ verbal memory; $p<.001$ motor dexterity). Risk factors for poorer verbal function included history of intrathecal chemotherapy or cranial irradiation ($p<.05$ for HVLT and COWAT) and immunosuppression longer than 12 months for impaired motor dexterity at 5 years ($p=.03$).

Conclusion: Neuropsychological function improved between 1 and 5 years, but focal deficits remained for over a third of survivors.

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Pediatric Oncologists' Discussion of Fertility Preservation with Patients and Family

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As the number of survivors of children's cancer increase, the prevalence of iatrogenic infertility caused by chemotherapy and/or radiotherapy increases as well. However, the extent to which fertility preservation (FP) options are discussed by pediatric oncologists with patients and families is unknown. The present study examined knowledge, behavior, and attitudes about the discussion of FP among pediatric oncologists. Qualitative data were collected using open-ended, in-depth interviews with 24 pediatric oncologists. Providers worked across the state of Florida, practiced between 0-35 years, treated most types of pediatric cancers, and were generally board certified in pediatrics and pediatric hematology/oncology. Their average patient was 9 years (± 2) of age, but ranged from age 0 to 21. The majority of pediatric oncologists report discussing FP with patients and families. The main factors associated with pediatric oncologists' knowledge about FP options were related to practicing in large urban areas and having in-house FP facilities. The primary option discussed/offered for males was sperm banking and oophoropexy for females. However, physicians perceived that financial constraints may prevent families from using FP options, since insurance may not cover certain procedures. Physicians may hesitate to fully discuss this issue with female patients, as they perceive FP options are limited. This study indicates that pediatric oncologists in certain practice settings may benefit from education about FP options for pediatric cancer patients. However, to increase discussion of FP with pediatric cancer patients and their families, barriers related to availability and affordability of FP resources must also be addressed.

Funding Source: This research was supported in part by the Pediatric Clinical Research Center of All Children's Hospital and the University of South Florida, and the Maternal and Child Health Bureau, R60 MC 00003-01, Department of Health and Human Services, Health Resources and Services Administration.

Short-Term Clinical Outcomes of a Nutrition and Exercise Intervention on Lifestyle and Quality of Life in Obese Endometrial Cancer Survivors

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Background: Obesity is the largest risk factor for endometrial cancer (EC). The purpose was to examine the feasibility of a 6 mos nutrition and exercise counseling intervention in obese EC survivors.

Methods: 23 patients (pts) with stage I / II EC were randomized to the intervention (I) group and 24 to a control (C) group. Quality of life (QoL), measured by the FACT-G and SF-36, exercise (Leisure score index) and eating patterns (food records) were assessed at baseline, 3 and 6 mos.

Results: At 6 mos, the I group (n=15) lost weight and increased exercise habits as compared to controls (n=16, Table). Food records demonstrated the I group consuming fewer calories ($p<0.05$), less total fat ($p<0.01$) and more lycopene ($p<0.01$). At baseline, decreased QoL scores were observed in morbidly obese pts ($BMI \geq 40$) as compared to pts with a $BMI < 40$ (FACT-G: 78.0 vs. 83.7; $p=0.14$; physical SF-36: 40.6 vs. 49.1 $p=0.008$). At 6 mos, pts with higher LSI reported increased QoL scores for FACT-G physical, social and fatigue domains and physical SF-36 score.

Conclusions: Preliminary data suggest nutrition and exercise counseling can lead to short-term weight loss, increased exercise and improved nutrient intake and QoL. Future studies will measure long-term assessments as well as changes in recurrence, morbidity and mortality.

Table: Six-month clinical outcomes by group

	Intervention group	Control Group	p value *
Weight Change (median)	-4.7 kg (10.3 lbs)	0.85 kg (1.87 lbs)	$p=0.018$
Exercise (LSI) Change (median)	22.0	0.0	$p<0.01$

* Mann-Whitney U non-parametric test

Funding Source: Lance Armstrong Foundation

Fractures and Fracture Risk Factors in Premenopausal Breast Cancer Survivors with Chemotherapy-Induced Amenorrhea

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Fracture risk increases with low bone density (BMD) and a propensity to fall. Premenopausal BCS who experience chemotherapy-induced amenorrhea (CIA) may have elevated fracture risk due to both chemotherapy and hypoestrogenism. To our knowledge, no study has evaluated both bone health and fall risk in BCS. Our pilot study aimed to describe fractures, falls and bone health in BCS with CIA (N=47; mean age: 46 yrs; 12.2±4.5 mos. post-chemo). Baseline and one year follow-up data describe changes in fractures and risk factors over time. Data on premenopausal, cancer-free controls (N=30; mean age: 41 yrs) were used as a reference group. Using T-scores derived from spine and hip BMD, bone health was categorized as either normal (≥ -1) or low (< -1). Baseline fall and fracture history were assessed retrospectively by questionnaire and prospectively over 12-months by monthly postcards. In BCS, 11% had a history of fracture, 42% had fallen in the last year, 39% and 26% had low spine and hip BMD, respectively. In controls, 3% had a history of fracture, 50% had fallen previously, 17% and 26% had low spine and hip BMD, respectively. Over one year, 70% of BCS reported one or more falls, compared to 43% of controls. Two BCS (5%) and two controls (6%) reported a fracture and bone status did not change. Our pilot data suggests that within two years after treatment, BCS with CIA have a greater history of fractures, falls and low spine BMD compared to their premenopausal cancer-free counterparts. Larger studies must confirm these observations.

Funding Source: This project is supported by PHS Grant 5 M01 RR00334 and the OHSU Medical Research Foundation.

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Peer Counseling by Phone for Older Women with Breast Cancer: Challenges and Opportunities

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Background: Senior peer counseling aims to establish a foundation between two older adults, for support in times of crisis or transition. The potential role of senior peer counselor volunteers (PC) in providing telephone support to older women with breast cancer has not been reported in the literature.

Methods: A partnership was established between a community-based senior service agency and a hospital-based breast center. The objective was to test a telephone intervention by PC for older women after breast cancer surgery. Participants were randomized to one of three call schedules: (1) shortly after surgery (immediate contact/IC); (2) 6 weeks after surgery (delayed contact/DC); (3) on request (request contact/RC). Participants completed questionnaires on satisfaction with the intervention and other resources. PC also rated the intervention. Field notes of weekly PC supervision were recorded.

Results: To date, 140 women have been enrolled; 76 have completed the study. Of the 42 women randomized to RC, 10 have requested peer counselor contact. Qualitative analyses of satisfaction questionnaires suggest PC and a majority of patients valued the intervention.

Conclusions: Peer counseling by phone can be an extension and enhancement of the health care team, providing women with an additional resource for access to information, support, and care. Phone contacts were perceived as an expression of caring from the health care team. Furthermore, diversity in the narrative comments of PC and participants, and peer supervision field notes reflect different perspectives on the breadth, depth, and meaning of the intervention.

Funding Source: Supported by funding from the Avon Foundation.

Latino Caregivers of Cancer Patients: Identifying Unmet Needs

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Background/Methods: Cancer is the leading cause of death among Latinos. Although the research in Latinos is scant, studies of Anglos suggest that caregivers can suffer from long-term physical and emotional distress. We conducted in-depth Spanish-language interviews in the Washington, D.C., area with 20 Latina breast cancer patients (median age = 50) and 10 primary caregivers. Patients within 1 year of diagnosis were recruited from physicians and a Spanish support group. Twelve of the patients spoke little or no English and only two of 20 had private insurance. Over half were married and almost all had children. Most of the women were employed when diagnosed; however, many suffered financial difficulties because they were unable to return to work after treatment.

Nine patients had a spouse as their primary caregivers. A few had mothers travel from Central America to stay with them during treatment. In most cases, there was no additional extended family available to the patient or her caregiver. Often, children translated for their mothers at medical visits. Patients expressed concern about financial and emotional burdens on their caregivers.

Results and Conclusion: Extended family networks, a traditional resource for Latinos, were not available to the women we interviewed. As a result, caregivers were vulnerable in the face of competing roles and responsibilities, such as childcare and wage earning. These results suggest the need for the development of bilingual and culturally competent services to support Latino cancer caregivers. Outreach to Latinos must account for cultural barriers such as reluctance to seek services outside the family.

Funding Source: This work was supported by National Cancer Institute Cooperative Agreement #U01 CA86114-05.

Family Distress Findings in a Longitudinal Quality of Life (QOL) Study of Hematopoietic Stem Cell Transplant (HSCT) Recipients

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Background: At UNMC, a longitudinal study of HSCT recipients is being conducted to determine the relationship between patient, disease, and transplant characteristics and QOL.

Methods: Participants complete three standardized instruments, including the City of Hope (COH) QOL in Bone Marrow Transplant Survivors, at baseline (pre-HSCT), day 100, and annually years 1-4 post-HSCT. The COH social concerns subscale includes questions regarding family, finances, relationships, affection, sexuality, employment, and support. We report results from this subscale for 94 autologous HSCT recipients transplanted between 9/2001 and 6/2004. Most (98%) are White, non-Hispanic, 51% are male, and median age at HSCT is 55 years (range 20-73).

Results: The item, "How distressing has your illness been for your family?" (FD) ranked lowest (indicating greatest distress) among all subscale items at all time points.

	FD mean score (SD)
Baseline	3.3 (2.4)
Day 100	3.3 (2.3)
1 Year	3.7 (2.6)
2 Year	4.4 (2.6)

There is no change in FD scores between baseline and 1 year; however, a statistically significant increase is seen from 1 to 2 years. The magnitude of the increase (0.46 SD) is clinically important since it exceeds the distribution-based minimally important difference. Restricting the analysis to patients who remained disease-free did not alter the findings.

Conclusions: While scores improve after 1 year post-HSCT, family distress to illness remains a significant problem. Additional studies are needed to determine if FD continues to improve beyond 2 years post-HSCT and to identify the types of distress experienced by families to enable timely interventions and support.

Funding Source: No funding source.

Mother-Daughter Breast Cancer Communication, Psychosocial Constructs, and Preventive Behaviors

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Background: Family history is a primary risk factor for breast cancer (brca). How mother-daughter brca communication may be related to daughters' preventive practices is not fully known. This study examined the relationship of brca mother-daughter communication with daughters' preventive behaviors, closeness to mothers and cancer worry.

Methods: Adult daughters were recruited through a university homepage and brca clinics. Daughters of women with brca (n=150) were surveyed by telephone about mother-daughter communication, closeness to mother, cancer worry, and preventive practices. Difference tests were performed and regression analyses were run to determine differences in outcome variables by level of communication while controlling for potential confounders.

Results: Daughters in the study sample averaged 38 years old (range = 18 to 69) and most had a college degree (68%). Mean closeness to mother ($p=0.01$) and cancer worry scores ($p=0.04$) were significantly higher in daughters who had communicated more vs. less often, as was daily vegetable consumption, ($p=0.03$) in bivariate analyses. Only closeness to mother and vegetable consumption remained significant in adjusted analyses. There were no significant differences by communication level for any other preventive behavior including recent mammography.

Conclusions: Higher level of mother-daughter communication was related to significantly increased odds of being close to mother and of consuming ≥ 1 serving/day of vegetables, but not with other brca preventive practices. These results indicate that women with a primary relative with breast cancer may need targeted interventions for weight control, mammography and other healthy lifestyle practices to maximize breast cancer risk reduction.

Funding Source: Massey Cancer Center peer review grant program Virginia Commonwealth University

Assessing the Health Care Needs of Adolescent and Young Adult (AYA) Cancer Patients and Survivors

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Background: Improvements in cancer outcomes observed for the U.S. population as a whole are not experienced as such by adolescent and young adult (AYA) patients. This study identified important health and supportive care needs specific to AYA patients and survivors.

Methods: Fifty-seven oncology professionals (oncologists, nurses, social workers, psychologists) and 47 young adult cancer survivors (ages 18–44; diagnosed between the ages of 15–39) participated on a modified Delphi panel. Through three iterative rounds of mailed surveys, participants identified, rank ordered, and rated the importance of various issues.

Results: The oncology professionals and survivors converged with regard to ratings of many medical and supportive care needs for AYA patients and off-treatment survivors, including agreement to the relative importance of having adequate health insurance and a multi-disciplinary approach to care that addresses the unique developmental characteristics of this population. They also agreed to the importance of establishing clinical trials for cancers diagnosed within this age range. Notable differences included young adults ranking the importance of opportunities to meet other young adult survivors at a relatively higher level than did health professionals, and higher than the importance of support from family and friends.

Conclusion: These findings provide oncology professionals and young adults with insight into the others' values and perspectives. These findings also suggest areas in which to target investments of resources to promote quality health care and appropriate informational and supportive care services, and to overcome the deficit in survival improvement that has occurred in young adults and older adolescents with cancer.

Funding Source: Project funded by the Lance Armstrong Foundation.

Addressing Cancer Disparities via Navigation Outreach

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Rationale: The Rationale of this study is to better understand the barriers that African American cancer patients face when they are seeking cancer information. Specifically, this study attempts to identify if there are differences between African American cancer patients who seek cancer information and those who do not. It is our hope that the results of this study will be used to develop a culturally tailored Navigation model, which will deliver cancer information to the African American population. Furthermore, by partnering with the Bureau of Community Health Promotion, the American Cancer Society (ACS) plans to reduce health disparities and build relationships of trust and services within the Milwaukee African American community. We further hope to increase the number of African Americans who use the American Cancer Society's Navigation channels and other cancer services.

Methods: The target population for this study is a sample of individuals, both male and female African American cancer patients whom live in the city of Milwaukee, are 40 years or older, and who have had a cancer diagnosis within the last five years. Participants for this study will be and have been recruited from various hospitals, churches, cancer centers, support groups and community centers throughout the Milwaukee area. Data will be collected via trained research assistants using a survey questionnaire and focus groups.

Recommendations/Evaluation: Recommendations will be made to the National ACS Board, Midwest Board of Directors, Sankofa Leadership Team, and Midwest Division Disparities Team. These recommendations will include suggestions from focus group participants on how to enhance the current Navigation model.

Funding Source: Funding for this project is provided by an American Cancer Society mission division funding proposal.

Underserved Populations Survivorship Program

Margaret Allen Elbow, Texas Tech University & Erika Ponce, YWCA, Lubbock, TX

The American Cancer Society and three local cancer centers in the Texas Panhandle-South Plains region offer a variety of psychosocial survivorship services but reach only a small proportion of ethnic minority groups and residents of rural areas; African Americans and Latinos comprise nearly 38% of the county's population, but their participation in psychosocial survivorship programs is approximately 10%. Our program addresses this discrepancy by eliciting the expertise of underserved persons to define needs and find solutions.

The Texas Cancer Council (Project number 06-64) provides funding to the local Y.W.C.A. to conduct focus groups and establish a coalition composed of survivors, leaders within underserved communities, clergy, and service providers to identify service needs and generate solutions. Within the first five months of operation, the program reached over 1,000 persons from underserved communities through outreach efforts, facilitated 3 focus groups, and held three coalition meetings. Two solutions generated through this process have been initiated: a free exercise and massage program and a survivorship skills workshop for clergy. We are developing a mentoring program for patients and caregivers, producing bilingual informational DVDs, and designing a survivor advocate program to ensure that psychosocial services are offered in an adequate and ethical manner to all individuals. Funding has been secured for all but the survivor advocate program. Impact assessment is part of each program element.

Knowledge of survivorship derived from focus groups and coalition meetings will be disseminated to service providers and university students. In September 2006, the program will expand into eight rural counties.

Funding source: None indicated.

Overcoming Barriers to Dental Care for Head and Neck Cancer Survivors

Richard Hara, Ph.D.; Jacqueline Zahora, L.C.S.W.; Forrest Buckman, CancerCare

Rationale: Patients with head and neck cancer often develop dental problems after treatment. Although these long-term treatment sequelae compromise the oral health and quality of life of head and neck cancer survivors, medical insurance covering dental issues is limited. While the knowledge base for medical and dental practices with this population has begun to grow, research to identify and address the psychosocial needs of this under-served population is needed to ensure full access to available care.

Methodology/Protocol: Recognizing the financial barriers to dental care that affect head and neck cancer survivors, CancerCare instituted a discretionary fund dedicated to this need in 2003, as a subdivision of its nationwide financial assistance program. Applicants provided basic demographic, financial, and medical information for case assessment and disposition of funds. Clients were also referred to a program-dedicated oncology social worker for further practical assistance and counseling as needed; assessment and intervention were documented in the computer-based client database as per agency standards in both narrative and standardized forms.

Evaluation/Assessment of Project Impact: The aims of this project were primarily descriptive and exploratory. Qualitative data obtained through clinical interviews describes the systemic barriers to dental care for this population such as lack of dental insurance coverage. Demographic data for head and neck cancer clients served by CancerCare are consistent with the incidence/prevalence rates of this cancer in the general population. Compared with aggregate data across diagnoses, a higher proportion of this population receives financial assistance, but average smaller disbursements, suggesting that factors other than sheer financial need drive them to service at this organization.

Funding source: None indicated.

Nueva Vida's Mental Health Program for Latinas with Breast Cancer

Adriana Kaufman, M.A., Nueva Vida; Lidia Carnota, M.D., Nueva Vida

Purpose: Nueva Vida, a nonprofit established in 1996 by survivors and health specialists, informs, supports, and empowers Latinas whose lives are affected by cancer. A breast cancer diagnosis can be devastating when a woman lacks family and social support, as is often the case for Latinas in our community. Most of them face their disease far from family and friends, in a foreign environment and often in poverty. The *Survivorship Program* offers comprehensive, caring and culturally expert mental health support through a range of psychosocial interventions in the continuum of breast cancer survivorship including diagnosis, treatment, and recovery.

Methods: Programs include: intake interview to assess women's needs; general and stress reduction support groups; therapeutic group for women in treatment; individual counseling for women in crisis or with advance disease; peer support for women recently diagnosed or in treatment.

Evaluation: Individual progress is measured with BSI-18 (Brief Symptom Inventory 18) administered at four-month intervals; participant's experience is assessed with a comprehensive, anonymous end-of year survey. Program use is measured with the number of participants and retention rates in program activities. During 2005, 187 women participated in programs (peer support: 38; individual counseling: 18; support groups: 127; women in treatment group: 25).

Summary: Latina clients typically present with limited social support, family relationships under stress, much misinformation about their disease, difficulty in their interaction with healthcare providers and measurable levels of depression and anxiety. Psychological distress impacts quality of life and adherence to treatment.

Funding Source: S.G. Komen Foundation; IDB; IMF; Cafritz Foundation; Stuart Trust Foundation

We Celebrate Tomorrow: Latinas Living Beyond Breast Cancer/Celebramos el Mañana: *Latinas que Sobreviven el Cáncer del Seno: A Model of Psychosocial Support and Outreach*

Rosales A, Living Beyond Breast Cancer, Ardmore, PA

Background: To address the identified disparities in the diagnosis and treatment of breast cancer in Latina women, Living Beyond Breast Cancer (LBBC) set out to create a bilingual, culturally relevant resource, specifically designed to educate and support Latina women facing a diagnosis of breast cancer and to provide health professionals with a tested, culturally competent resource.

Methods: A consumer-based participatory approach was used featuring 1) an Advisory Committee of breast cancer survivors and professionals working with Latinas; 2) a needs assessment survey; 3) focus groups comprising Latina breast cancer survivors and their supporters; and 4) a bilingual, low-literacy project consultant, hired to facilitate focus groups and write the publication.

Results: Using focus group data and input from the Advisory Committee, *We Celebrate Tomorrow: Latinas Living Beyond Breast Cancer/Celebramos el Mañana: Latinas que Sobreviven el Cáncer del Seno*, a bilingual educational resource, was developed. The publication addresses women's experiences in facing a diagnosis of breast cancer, obtaining the best care and support, and life after breast cancer. LBBC provides interactive educational trainings for health professionals to provide a cultural overview of barriers impeding delivery of quality health care and to address the impact of a breast cancer diagnosis on Latina women and families.

Conclusions: Without affordable and linguistically-sensitive care, Latinas face the high likelihood of being diagnosed at a later stage of breast cancer, complicating treatment and leading to higher mortality rates. Providing health professionals with a culturally competent resource to use with Latina women can foster trusting relationships.

Funding source: None indicated.

The Comadre a Comadre Project: Improving Access to Cancer Services and Education for Hispanic/Latina Breast Cancer Survivors and Their Loved Ones

Elba Saavedra

Background: In NM, Hispanic/Latina women who are diagnosed with breast cancer experience language and socio-cultural barriers putting them at higher risk for poorer outcomes in the evaluation and treatment of breast cancer. The Comadre a Comadre Project was developed with the participation of breast cancer survivors who expressed a need for a program that would provide support in a culturally sensitive manner.

Methods: The Project developed planning and implementation phases which included focus groups with breast cancer survivors, recruitment and training of breast cancer survivors to serve as peer mentor-“comadres” patient navigator at the facility level and one-on-one peer mentor comadres in the community. Internal ORACLE data management and tracking of patient contact and evaluation measures of Project were also developed.

Results: Successful recruitment strategies and impact in the community will be discussed, showing of Project produced psychosocial bilingual video, entitled “Adelante Con Esperanza-Going Forward with Hope” and outreach and collaborative efforts of Project in the community will be presented. In addition, Project evaluation measures and data will be presented.

Conclusion: Findings from this project have implications for health care professionals working with Hispanic/Latino cancer patients, discussion on involving breast cancer survivors in the planning and implementation process; discussion on the applicability of patient navigator model in this project.

Funding source: None indicated.

Until My Change Comes: Breast Cancer Survivorship and the Transformation of African American Women's Health Advocacy

Elizabeth Williams

Breast cancer represents a major health issue for women of color in the United States. More Euro-American women are annually diagnosed with the disease, yet more African American women with breast cancer succumb. Numerous explanations suggest why breast cancer disparities exist between African American and other American women. Significant among these are: poverty, treatment seeking delays, discrimination in treatment delivery, and differing cultural understandings of cancer.

Some public health and social science literatures regarding African American women and breast cancer present "culture" (whether implicitly or explicitly) as counter-productive to health. However, prevailing ideas about African American women's culturally determined responses to breast cancer do not match the reality of many African American breast cancer survivors' experiences. Instead of a detriment, "culture" particularly aids many African American survivors' coping abilities. "Culture" also helps other survivors attain a higher quality of life during survivorship by transforming their health advocacy in ways they once perceived as unavailable to them.

Based on a critically informed anthropological approach, including thematic analysis, and 17 months of ethnographic fieldwork, this paper describes the complex psychosocial and transformative benefits of "culture" for African American survivors. The findings from this qualitative study indicate the need for more nuanced understandings of the relationship between "culture" and cancer survivorship, notably for women of color.

Funding source: None indicated.

Increasing MMU Survivor Representation in Comprehensive Cancer Control Planning

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Basis of the Study: Racial/ethnic and socioeconomic disparities in cancer survival are well documented but inadequately addressed. One of the major outcomes of the National Action Plan is to “increase awareness among the general public, policy makers, researchers, advocates, survivors, and others of the role public health can play in advancing cancer survivorship issues and to stimulate organizations to take action.” As part of a larger collaboration with the Lance Armstrong Foundation, the Intercultural Cancer Council engaged in a research project to develop a technical assistance program to increase participation of minority and medically underserved (MMU) survivors in the state comprehensive cancer control plans (CCCPs).

Methods: The research methods included:

- A. Review of written materials, including:
 - a. Journal articles
 - b. National publications
 - c. Content analysis of state plans
- B. Key informant interviews with:
 - a. CCCP National Partners
 - b. State level professionals involved with CCCPs
 - c. Survivors (especially MMUs) involved with CCCPs

Results: The research reveals several barriers to the participation of MMU survivors in CCCPs. This includes issues such as access, lack of awareness, funding limitations, and lack of trust towards governmental/“majority” programs by MMUs. However, many states have active or developing survivors’ networks as well as some MMU representation at the table.

Conclusions: Challenges in including MMU survivors:

- 1. Resource limitations of CCCPs in implementation and outreach
- 2. MMUs face lack of access, awareness, and trust issues regarding the CCCPs

Technical assistance must focus on communication, trust, and access and build on existing efforts.

Funding Source: Lance Armstrong Foundation

Survivor-Provider Communication: Not on the Same Page

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Background: Increasing breast cancer survivorship means more women are managing symptoms of original treatment such as fatigue, requiring effective survivor-provider communication. Yet survivors report ongoing communication problems such as enduring chronic symptoms they do not mention to providers.

Methods: This cross-sectional study investigated associations between the amount of patient-centered communication (indicating the amount of provider attention to survivor initiated concerns), survivor fatigue, uncertainty, mood state, and survivor *perception* of the amount of patient-centered communication. Follow-up oncology visits for 60 recurrence-free breast cancer survivors 2+ years post-treatment (26% African American, 74% Caucasian) were audio-taped.

Results: Results were interpreted using Uncertainty in Illness Theory, and the dimensions of a patient-centered relationship. Most women reported fatigue, with 20% reporting moderate to extreme fatigue, yet content analysis demonstrated only 58% of women mentioned fatigue to providers. There was no difference in fatigue levels between those who did and those who did not mention fatigue to providers ($t = 1.06$; df 53; $p = 0.29$). Survivor fatigue level and conversation about symptoms were associated with survivor uncertainty, mood state, and survivor *perception* of the amount of patient-centered communication. Despite objective data showing low patient-centered scores, survivors perceived their visits were highly patient-centered.

Conclusions: This paradox between low patient-centered communication scores, especially for discussions of symptoms, yet a survivor *perception* of highly patient-centered conversation suggests that survivors assign high importance to biomedical conversation about symptoms. One explanation may be uncertainty about recurrence and the need for medical reassurance. Further, fatigue remains a prevalent symptom that is frequently unaddressed.

Funding Source: 1. American Nurses Foundation: 2004 Jean E. Johnson, R.N., Scholar; 2. Postdoctoral Fellowship; T-32 Institutional National Research Service Award: Interventions For Preventing and Managing Chronic Illness. NIH - NINR T-32 NR07091, UNC-CH School of Nursing

Survivorship in Italy: A Challenging Issue

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Rationale: There are 1.5 million cancer survivors in Italy. The information and economic needs of these survivors and their families have been overlooked. AIMaC, a volunteer and survivor-based association, is assessing survivors' needs and developing programs to fill this gap.

Methodology: A needs survey was administered to 328 cancer survivors at 21 cancer units. The responders were primarily women (59%), and had breast (39%), colon (21%), lung (17%) and other cancers (21%). The results indicate a need for information about physical symptoms, employment, financial assistance, psychological support, diet, and CAM. AIMaC developed four interventions to address some of these needs: 1) *lobbying* the government to enact two major employment laws: one to shift full-time employment to part-time until adequate recovery, and provide job security, and one to provide financial benefits for temporary disability; 2) *psychological support* groups for survivors and their families; 3) written materials about CAM use, co-produced with the U.S. NCI and NCCAM; and 4) development/dissemination of pamphlets addressing survivorship concerns.

Evaluation/assessment: We are currently monitoring 16 hospital information desks, our cancer helpline, and website hits to evaluate information needs of Italian cancer survivors and their families. Presently, we have 50 calls/day to the helpline, 3,500 Web site hits/day, and have distributed >35,000 educational pamphlets. Thus far, 85% of those receiving the written material find it "useful" or "very useful." To date, 34 survivors and their family members have participated in support groups at three cancer centers. Workshops addressing the needs of cancer survivors also are being planned.

Funding source: Italian Ministries of Health and Welfare; private donations

Cancerous Citizens: Metaphors, Accounts, and Testimonies

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How has surviving cancer become a virtuous aim and the means of producing citizens that embody this positive moral evaluation? This study attempts to answer this question by examining the discursive practices of metaphors, accounts, and testimonies, and how each impacts an individual's personal, social, and public sense-making procedures. The critical analytical method employed combines autoethnographic "criteria" (Ellis 2000) with the "principles" (McKerrow 1989) of criticism, and effectively produces, as well as agitates, a naturalized understanding of cancer.

Results: revealed that personal level metaphors deal primarily with how "fields of knowledge" (Foucault 1985) work to silence or displace a cancer patient's voice. Social level accounting practices were shown to give rise to "types of normativity" (Ibid). These norms included the transformation of health and emotional well being into personal responsibilities, and the rise of the socially accepted attitude that cancer is a positive and/or necessary life event. Public testimony exposed the ways in which cancer survivors have legitimated their voice or "form of subjectivity" (Ibid). Three distinct movements of the cancer survivor's voice, which included the introduction of a minority group and leader, the expansion of the group through rites of passage, and the transformation of local problems into national issues, were also uncovered.

Conclusion: This study concluded that sense-making practices work together to transform cancer survivors into citizen-survivors, who have certain rights and responsibilities, and can be mobilized to advocate for community rights by agencies like the Lance Armstrong Foundation, and produce similar discursive regimes that strengthen existing governmental structures.

Funding source: No Funding Source.

Guo-Lin Qi-gong Exercise for Cancer Survivorship: A Review

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Exercise has proven very effective in managing cancer-related symptoms, but most published studies only employed conventional Western exercises and the benefits of Asian body-mind exercises (e.g., Tai Chi & Yoga) have not been fully explored. Significant efforts have been made in China since the 1960s to apply Guo-Lin Qi-gong to cancer care/recovery. Invented by Guo Lin, a cancer survivor, this version of Qi gong is the only exercise regimen specifically designed for cancer care/recovery. Efforts have been made to study its effects, but most studies were published in Chinese. As a result, Guo-Lin Qi-gong remains a well-kept secret from the West. This study was to conduct a literature review of Guo-Lin Qi-gong and examine its health benefits. In addition to 30 case studies, a total of 33 studies were identified. It was found that practicing Guo-Lin Qi-gong proves helpful for improving quality of life of cancer survivors, as well as likelihood of cancer survival although the long-term survival rates varied from study to study. Guo-Lin Qi-gong has been practiced by all kinds of cancer survivors with different stages of cancer. The intervention dosage varied greatly from one study to another. Several limitations were observed: (a) most of these studies were conducted under loosely controlled research designs; (b) the mechanism of Guo-Lin Qi-gong (e.g., energy expenditure characteristics) has not been carefully studied; and (c) dose-response relationship between Guo-Lin Qi-gong and health outcomes has not been systematically studied. Before introducing this exercise to U.S. cancer survivors, these issues should be addressed.

Funding Source: None indicated.

Patterns of Physical Activity among Young Adult Survivors of Childhood Cancers

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Background and Purpose: Lifestyle choices in combination with late effects put childhood cancer survivors at risk for premature development and accelerated progression of chronic diseases. Engaging in regular physical activities may ameliorate some of these risks. The purpose of this study was to examine the feasibility of using pedometers and Web-based physical activity (PA) logs to measure a 7-day period of PA in young adult survivors of childhood cancer.

Methods: Fifty-one young adult cancer survivors were recruited through Web-based advertisements, long-term survivor clinics, and cancer camp alumni databases. Participants completed Web-based surveys, wore pedometers, and recorded daily physical activities using Web-based PA logs.

Results: Survivors were Caucasian (94%), mostly female (69%), well educated (78% completed at least some college), and off treatment for at least 2 years (M, 10.7; SD, 6.6). Over half (59%) of the participants were leukemia and lymphoma survivors. Other cancer types included CNS, renal tumors, sarcomas, and germ cell neoplasms. Forty-one survivors completed both logs and step counts. The majority (76%) of participants were satisfied with the online survey and PA logs. Daily step counts ranged from 3,209-15,181 (M, 8078; SD, 2657). Weekly minutes spent in moderate PA ranged from 190-4,335 (M, 1377; SD, 948).

Conclusions: Although all participants reported moderate PA levels that met national PA guidelines (\geq 150 minutes/week), only 25% of participants had mean daily step counts that were consistent with active lifestyles (\geq 10,000 steps/day). Further exploration of the relationship between pedometer step counts and self-reported minutes of PA is warranted.

Funding source: None indicated.

Social Cognitive Mediators in the “Fresh Start” Trial

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Background: “Fresh Start,” a health promotion program aimed at increasing fruits and vegetables (FVs), physical activity (PA), and decreasing % fat, has recently been shown to be efficacious at improving these behaviors among cancer survivors. To better understand the factors that explained change in behavior, this study evaluated the effects of the intervention on social-cognitive mediators.

Methods: The outcomes of FV intake, % fat, and PA were measured at baseline and at 1-year follow-up. Mediation was tested using a series of linear regression models. Depending on individual's need/priority, participants received only dietary assistance (i.e., help with fat and FV intake) (n=135: c = 68; t = 67) or PA assistance combined with one of the dietary modules (i.e., help with PA and fat intake or help with PA and FV intake) (n = 384: c = 198; t = 186).

Results: For the group receiving only dietary assistance, the result indicated that the intervention had direct effects on FV self-efficacy ($\beta = .43$), fat self-efficacy ($\beta = .35$), and change in these variables also had direct effects on F&V ($\beta = .48$) intake and % fat intake ($\beta = -.78$). For the group that received assistance with PA, the results indicated that the intervention had direct effects on PA barriers ($\beta = .48$) and change in this variable had direct effects on PA levels ($\beta = -10.21$).

Conclusions: The results support the use of strategies to increase dietary self-efficacy and decrease PA barriers. Continued work is needed to strengthen intervention affects.

Funding Source: National Cancer Institute; Grant Number CA081191

The Impact of Sense of Coherence and Coping on Quality of Life, Endocrine Reactivity, and Natural Killer Cell Activity in Breast Cancer Survivors

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Background: Despite several research studies with mixed results on breast cancer patients and survivors, little is known about long-term psychological complications surrounding life after a cancer diagnosis in this population.

Method: This study was cross-sectional in nature and relied on self-report data tapping Sense of coherence (SOC), approach and avoidance coping, and quality of life (QOL) in 60 breast cancer survivors from the Birmingham, Alabama, metro area. All participants had finished active chemotherapy and/or radiation therapy treatment and were at least one year post-diagnosis. All participants viewed a 27-minute video on the cancer experience that was designed to evoke an emotional stress response.

Results: It was found that SOC directly predicted QOL. It was also found that avoidance coping partially mediated the SOC-QOL relationship such that women who were higher on SOC used fewer avoidance coping strategies and, in turn, experienced better QOL. In addition, it was shown that, in response to the video stressor, those with high SOC reported experiencing less subjective emotional distress.

Conclusion: SOC may be a tool that can be used to predict which breast cancer patients are more likely to benefit from extended psychological support and follow-up. In this way, clinicians may be better able to target resources more accurately toward those in need of extended psychological support and longer follow-up by medical practitioners.

Funding Source: This study was made possible as part of an NCI-funded Cancer Prevention and Control Training Grant received through the interdisciplinary team of Nutrition Sciences, Department of Epidemiology in the UAB School of Public Health, and School of Health Related Professions, all in affiliation with the UAB Comprehensive Cancer Center.

The Impact Variant of Glutathione S-Transferases (GSTs) on Self-Reported Long-Term Toxicities in Testicular Cancer Survivors (TCSs)

Jan Oldenburg

Background: Genetic variations in cisplatin-detoxifying enzymes may contribute to the observed variations in long-term toxicities. We aimed to elucidate the impact of polymorphisms in the glutathione s-transferases (GSTs) *GST-P1*, *-T1* and *-M1* among TCSs.

Methods: One hundred and ninety-six (196) TCSs, treated between 1980 and 1994 with cisplatin-based chemotherapy at the Norwegian Radium Hospital, took part in a questionnaire-survey during the years 1998 to 2001. Treatment-induced toxicities were assessed by a validated scale, composed of six items: Peripheral sensory neuropathy (at hands or fingers/feet or toes), Raynaud's phenomenon (at hands or fingers/feet or toes), and ototoxicity (tinnitus/impaired hearing). Each item's score had four categories: not at all, a little, quite a bit, and very much. For all TCSs, DNA was extracted from peripheral blood samples and submitted to genetic analysis. Known functional polymorphisms (positive (+)/ negative (-)) in *GST-T1* and *GST-M1*, and (codon 105 A/G (Ile/Val) in *GST-P1* were analyzed by multiplex PCR, followed by restriction enzyme cutting, and separated by gel electrophoresis.

Results: Only five of the 31 TCSs (16%) with homozygous *GST-P1-GG* reported to have tinnitus at all as compared to 97 of the 165 TCSs (55%) without this genotype. Only 13% (4/31) TCSs with *GST-P1-GG* genotype reported to have suffered "quite a bit" or "very much" of white and cold feet compared to 30% without this genotype. No significant associations were found for *GST-M1* or *-T1*.

Conclusion: The *GST-P1-GG* genotype seems to protect against long-term tinnitus and Raynaud's phenomenon in the feet.

Funding source: None indicated.

Arm and Hand Swelling Among Long-Term Breast Cancer Survivors: CALGB 79804

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Background: Lymphedema is an under-reported and debilitating consequence of axillary node dissection among breast cancer survivors. The goal of this paper is to describe the characteristics of arm and hand swelling, including treatment-seeking behavior and effects on quality of life (QOL), among a population of breast cancer survivors who participated in a clinical trial coordinated by the Cancer and Leukemia Group B (CALGB 8541) 9 to 16 years ago.

Methods: Three hundred thirty-one eligible survivors of CALGB 8541 were contacted and asked to complete a mailed survey assessing questions about demographics, quality of life, arm and hand swelling, sexuality, breast cancer anxiety, spiritual beliefs, and depression.

Results: Of the 245 women who completed a survey, 75 (31%) reported ever having arm/hand swelling since their surgery. Of the women who ever experienced swelling, 75% reported current swelling, and half reported constant swelling, mainly in the upper arm. Self-reported swelling was either mild or moderate in 88% of the women. Women perceived the causes of their swelling to be removal of lymph nodes (73%) and general arm use (23%). Swelling interfered with wearing clothing (36%) and perceptions about general appearance (32%). Few women (37%) sought treatment for swelling. No effects of swelling on quality of life were observed.

Conclusions: Arm/hand swelling is still a significant problem for long-term survivors of breast cancer, and few women seek treatment for it.

Funding Source: This study was funded by National Cancer Institute grants AG16602, CA79883 and CA57707.

Lymphedema Occurrence During Survival: The First 24 Months Following Breast Cancer Treatment

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Breast cancer survivors are at lifetime risk of developing lymphedema (LE). Quantification of LE has long been problematic. Because of difficulties in measurement and diagnosis, the reported incidence of LE varies greatly among breast cancer survivors.

The research goal was to describe LE occurrence among breast cancer survivors. Participants were enrolled at pre-op with baseline limb volume (LV) and symptom assessment and followed at post-op and every 3 to 6 mos for 30 mos. Of 315 participants, 140 had completed data from pre-op to 24 mos post-op at the time of this analysis. LV changes (LVC) were evaluated by 3 measurement methods: (a) limb girth at 4 cm intervals; (b) perometry; and (c) symptom report. Four diagnostic criteria were used: 200 ml perometry LVC; 10% LVC; 2 cm girth increase; and report of heaviness or swelling.

Trends will be reported for analysis of data from 140 participants at 6, 12, 18, and 24 mos. LE occurrence ranged from 7%–46% and 38%–82% over the 6 to 24 mos, depending on the definition applied. In the absence of a “gold standard,” we can only say that the different LE definitions are not equivalent, but cannot say which is “best.” From these data, it appears that 10% LVC is more conservative, while the 2 cm difference is more liberal.

These preliminary findings also document the importance of baseline (pre-operative) anthropometric and symptom data and monitoring of changes over time. Further investigation of LE occurrence over an extended time period is warranted.

Funding Sources: Research funded in part by National Institutes of Health R01 # NR05432.

Proteomic Technologies for Cancer Research: Technology Assessment and Resource Development

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The National Cancer Institute (NCI) established the Clinical Proteomic Technologies Initiative for Cancer (CPTI, <http://proteomics.cancer.gov>) to accelerate the translation of proteomics from a research tool into a reliable and robust clinical application.

Complimentary to this initiative, a Mouse Proteomic Technologies program was developed as a component of the NCI's larger proteomics initiatives. This program addresses the technical challenges associated with the introduction of new technologies used to identify proteins/peptides in complex mixtures by developing protocols, metrics, and standards that help improve the accurate measurement of proteins/peptides linked to cancer processes. Advantages of using mouse models of human cancer is that certain genetically modified mice provide an *in vivo* model for cancer development that more closely resembles the human model than do cell lines and tissue samples, and the ability to genetically manipulate mice yields proteins associated with a specific tumor. The NCI Mouse Proteomic Technology program consists of an Eastern and Western Consortia comprised of eight research institutions (University of Michigan, Fred Hutchinson Cancer Research Center, Harvard Partners Center for Genetics & Genomics, Dana-Farber Cancer Institute, Van Andel Research Institute, Memorial Sloan-Kettering Cancer Center, Institute for Systems Biology, and Pacific Northwest National Laboratory). A total of 12 mouse models are being investigated that include breast, lung, prostate, ovarian, gastrointestinal, skin, and pancreatic cancer. Technologies/methodologies evaluated include different fractionation schemes, serum and plasma analysis, mass spectrometry (e.g., ESI-TOF MS) and affinity-based platform analysis. Resources disseminating from this program that will be made available to the broader scientific community include mouse models of human cancer, biospecimens, reagents (proteins, peptides, and antibodies), standardized protocols, open-source proteomics software (e.g., CPAS, msInspect, and X!Tandem), and data. The data from this program will be applied to CPTI and made available through the National Cancer Institute Center for Bioinformatics.

Funding source: National Cancer Institute

Lower Use of Surveillance Mammography among Older Breast Cancer Survivors at Risk of Recurrence

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Background: Information on surveillance mammography among older breast cancer survivors is limited. We examined factors associated with mammography use in this population.

Methods: Women in this study were 65 or older when diagnosed with early invasive breast cancer from 1990 to 1994 while enrolled in an integrated healthcare system. This report includes women who were alive, recurrence-free and enrolled in their health plans for at least 15 months after cancer treatment. We assessed mammography use during each of 4 years of follow-up, using generalized estimating equations to account for repeated measurements.

Results: Of the 1,762 women studied, 79% had mammograms during the first year after treatment; the percentage declined to 67% in the fourth year of follow-up. Women aged 80 or older and those with multiple comorbid conditions were less likely to have yearly mammograms. Controlling for these factors in multivariate analysis, women who were at high risk of recurrence were less likely to have yearly mammograms, including those diagnosed at stage II (odds ratio (OR) 0.73, 95% confidence interval (CI) 0.60-0.88) and those receiving breast conserving therapy without radiation (OR 0.53, CI 0.40-0.71). Women with visits to a breast cancer surgeon or oncologist were much more likely to receive mammograms (OR 7.0, CI 5.0-8.3).

Conclusion: Older breast cancer survivors who are at greater risk of recurrence are less likely to receive surveillance mammograms. Further study is needed to understand whether this paradox arises from patient refusals, less than standard care, or the presence of competing medical risks.

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Survivorship Education for Quality Cancer Care

Marcia Grant, R.N., D.N.Sc., FAAN, City of Hope National Medical Center

Background: Health care professionals frequently lack the background to address health care and quality of life issues of cancer survivors.

Methods: Four annual courses to educate professional caregiver teams on improving quality care for cancer survivors are planned. Competitively selected, two-person interdisciplinary teams were chosen based on stated interests, 3 projected goals, and letters of commitment from administrators. The curriculum framework included three concepts: institutional change, adult education principles and the City of Hope Quality of Life Model (COH-QOL). Expert national faculty taught the course. Participant team goals were refined during the course and will be evaluated at 6, 12, 18 months for goal implementation.

Results: An overwhelming 100 teams applied. The participants were selected and represented 52 cancer care settings from 28 states. The first course was held July 12–15, Pasadena, California. Teams included Nurses (48.1%), Social Workers (20.7%), Physicians (18.8%), Directors/Administrators (6.6%), Psychologists (2.8%), and others (3%). The institutional barriers identified by teams were lack of survivorship knowledge (94 %), financial constraints (61%), lack of administrative support (6%), and staff philosophy that excluded survivorship (15%).

Results for the first course revealed course satisfaction: Clarity (4.6%), Quality (4.6%) and Value to practice (4.5%) based on a scale of 1 – 5 (5=best).

Conclusion: This educational program, focused on 2 member teams with planned goals and structured follow-up at 6, 12, and 18 months will improve survivorship care in the participants' settings. Results of 6-month goal analysis will be presented.

Funding source: National Cancer Institute

Longitudinal Predictors of Lymphedema-Related Negative Affect Among Breast Cancer Survivors

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Background: Approximately 20–30% of breast cancer survivors develop Lymphedema (*LE*) following breast cancer treatment; *LE* is associated with psychological distress. Little is known about predictors of *LE* associated psychological distress over time.

Methods: Guided by the Cognitive-Social Health Information Processing model, we are conducting a longitudinal study to assess *LE* outcomes among breast cancer survivors currently unaffected by *LE*. Baseline predictors included personal *LE* risk perception, *LE* severity perception, *LE* self-efficacy (perceived ability to perform recommended behaviors and regulate negative affect associated with *LE*), *LE* knowledge, and *LE* related negative affect at baseline. The outcome for these analyses was *LE* negative affect at 6 months.

Results: Sixty women completed the baseline and 6-month follow-up surveys. Longitudinal hierarchical regressions were conducted for *LE* related negative affect. The final model accounted for 56% of the variance in *LE* negative affect, $\Delta R^2 = .38$, $\Delta F (6,44) = 6.33$, $p < .001$. Women who reported higher levels of *LE* negative affect at baseline reported significantly higher levels of *LE* related negative affect at 6 months ($B = .40$, $p < .05$). In addition, women who were older ($B = -.36$, $p < .05$) and women who reported higher levels of *LE* self-efficacy ($B = -.29$, $p < .05$) at baseline reported significantly lower levels of *LE* negative affect at 6 months.

Conclusions: Women with higher levels of *LE* self-efficacy may experience less *LE* related emotional distress over time. Interventions that increase *LE* self-efficacy may help breast cancer survivors cope with the possibility of developing *LE* and may improve the uptake of *LE* minimization practices.

Funding source: This work was supported by Department of Defense Grant # DAMD17-02-1-0382.

Supporting Nurse-Patient Interactions via Secure Internet Message Boards

Nathan Homitsky

Rationale: Each year, 25,400 women are diagnosed with ovarian cancer, the 5th most deadly cancer for U.S. women. Ovarian cancer has both a high [75%] rate of late diagnosis and a high rate of recurrence [80%]. After that first recurrence, most women enter an ongoing cycle of treatment-remission-recurrence-treatment for the rest of their lives. Women with recurrent ovarian cancer experience an average of 12 concurrent symptoms and these symptoms directly influence QOL. The process of trying to manage multiple symptoms is overwhelming to patients and health care providers. An innovative symptom management intervention, *WRITE Symptoms*[®], has been developed based on the Representational Approach to Patient Education.

Protocol: *WRITE Symptoms*[®] is delivered by nurses via Internet message boards in order to help women better manage their multiple symptoms. The message boards provide a private space for patients to interact with a nurse from the comfort of her own home at times that are convenient to her. It also provides a “place” for both patients and nurses to keep discussions organized and accessible for review and reflection.

Evaluation: The message board system has been developed in an iterative manner with ongoing feasibility and acceptability evaluations. These evaluations began with role play between research team members, expanded to healthy middle-aged women (n=3), progressed to ovarian cancer survivors (n=3), and is now being evaluated in a randomized clinical trial. Key aspects of the message system will be demonstrated along with feasibility and acceptability data.

Funding source: None indicated.

Psychosocial and Demographic Factors Associated to CAM Use Among Colorectal Cancer Survivors

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Background: Previous reports have suggested that complimentary and alternative medicine (CAM) use may be associated with psychological distress and poor quality of life (QOL) in the chronically ill. This study sought to examine correlates of CAM use among survivors of colorectal cancer (CRC), an understudied population that experiences many physical and emotional burdens.

Methods: The sample was 191, predominantly Caucasian, survivors of CRC (mean age = 59.9 ± 12.6) who were members of a colon disease registry at a NYC metropolitan hospital. Participants completed assessments of sociodemographic characteristics, psychosocial factors (e.g., psychological functioning, cancer specific distress, social support (SS), QOL) and past CAM use (e.g., chiropractic care, acupuncture, relaxation, hypnosis, herbal preparations, homeopathy).

Results: Seventy-five percent of participants reported using at least one type of CAM; most frequently reported was home remedies (37%). Younger ($p < .01$) or female patients ($p < .01$) were more likely to participate in CAM than their older male counterparts. Among psychosocial factors, poorer perceived SS ($p = .00$), more intrusive thoughts ($p < .05$) and poorer overall perceived QOL ($p < .05$) were associated to CAM use. In a linear regression model (including age, gender, SS, intrusive thoughts, and perceived QOL) only age remained significant predictor of CAM use.

Conclusion: These findings demonstrate that CAM use is prevalent among CRC survivors and should be assessed routinely by providers. CAMs may serve as a relevant adjunct to treatment among CRC patients as well as an indication of need for additional SS, especially among younger patients.

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Late Effects of Cancer Treatment Among Women 5-Year Survivors of Head and Neck Cancer

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Purpose: With improvements in treatment, larger numbers of head and neck cancer patients are living longer and experiencing the consequences of their life-saving treatment not all of which are positive. The purpose of this study was to assess the effects of treatment among female 5-year cancer survivors.

Methods: Using telephone survey methodology, two types of matched control groups were used to assess differences; friend nominated and listed sample.

Results: There were no significant differences on the mean age of the 3 groups. There were no significant differences among the three groups on smoking patterns, depression, fatigue, alcohol use, trait anxiety, self-consciousness. The women cancer survivors reported significantly higher oral pain scores and significantly lower quality of life than the control groups. Questions about changes in taste during the past 5 years showed that compared to controls the women patients reported that sour and bitter tastes were more intense whereas there were no differences between the controls and the patient survivors on salty or sweet taste. Thirty-nine percent (39%) of the cancer survivors reported a metallic taste in their mouth compared to 13% of the peer control and 10% of the listed sample.

Conclusion: These results suggest that as a part of treatment, the 9th cranial nerve may have been damaged releasing taste inhibition on the 7th nerve and pain inhibition on the 5th nerve. This explanation is consistent with the location of the tumors, most were at the base of the tongue, soft palate, or tonsil region.

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Cancer Survivors' Screening and Health Behaviors

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Background: The purpose of this study is to describe and compare the screening and health behaviors of cancer survivors (CaSurvivors, n=619) with a NoCancer control group (n=2141).

Methods: This retrospective secondary data used the National Cancer Institute's 2003 Health Information National Trends Survey I (HINTS I). Screening behaviors included age and gender appropriate pap smear, mammogram, prostate specific antigen (PSA), and colorectal cancer (CRC) screening. Health behaviors included smoking, exercise, and fruit and vegetable (F/V) intake, and body mass index. Univariate statistics and multivariate logistic regressions were conducted.

Results: There were significant differences between CaSurvivor and NoCancer; the CaSurvivor group was older, in poorer health, and had greater health care access.

<i>CaSurvivors and NoCancer Screening and Health Behaviors</i>		
	NoCancer	CaSurvivors
N	2141	619
Screening		
Had Pap Smear (all women)	91.6% (1027/1121)	98.7% (405/412) ***
Had Mammogram (women \geq 40)	84.9% (299/352)	91.8% (205/323) **
Had PSA (men > 50)	58.7% (177/302)	76% (100/132) **
Had CRC* (men and women \geq 50)	69% (374/542)	84.6% (362/428) ***
Health Behaviors		
Current smoker (all)	18.4% (284/1729)	22.5% (101/446)
Eats $>$ 5 F/V/d (all)	14.9% (332/2141)	18% (122/603)
Exercises $>$ weekly (all)	52.6% (1170/2141)	45.3% (273/597) ***
BMI \geq 25 (all)	54.9% (1068/2141)	58% (378/619)

* Ever having had sigmoidoscopy or colonoscopy or FOBT for colorectal cancer screening (CRC)

+ p<.05, ++ p<.01, +++p<.001

There were no differences in health behaviors when controlling for significant demographic variables. When controlling for age, race/ethnicity, and health care access, being a CaSurvivor *did not* significantly influence three of the four screening tests (pap smears, mammograms, or PSA but *did* influence CRC screening. Screening adherence exceeded national prevalence data (BRFSS) and Healthy People 2010 goals for both groups. Only 7.4% of CaSurvivors and 6.4% of NoCancer reported positively on all three health behaviors and had a healthy weight.

Conclusions: All screening rates exceeded current recommendations for individual tests. Being a CaSurvivor influenced screening for CRC. Neither groups met current recommendations for not smoking, exercise, or fruit and vegetable consumption; the majority was also overweight.

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Female Sexual Quality of Life after Cancer: A Quantitative Methodological Review

Sara McClelland

Sexuality and intimacy have been shown to play important roles in long-term survivorship. However, there is growing concern that the construct of sexual quality of life (SQoL) has not been adequately measured for female cancer survivors, including female sexual response, fertility, and menopausal status. This study addresses key questions regarding the conceptualization and measurement of SQoL for female cancer survivors using systematic review techniques.

This study reviewed 45 instruments that have been developed for use within medical, psychological, and clinical settings to assess female sexual quality of life. The measures were coded systematically for the presence of 11 themes at the *item*-level, including assessments of sexual desire, the presence/role of the partner, the role of illness, as well as aspects of pain and physical changes. Each of the items within the 45 measures was coded by two raters; inter-rater reliabilities were good ($> .85$).

Although sexual functioning is important to women in the post-surgery phase, psychological aspects of sexuality may be key components of adjustment and are largely missing from current measures. Current measures reflect an assumption that frequency of sexual intercourse is an adequate measure of sexual quality of life. However, assessing only the frequency of sexual intercourse obscures other important aspects of SQoL, such as sexual satisfaction. In addition, there is inadequate attention paid to the changes in sexual functioning that occur with illness, treatment, and aging. These areas represent important item gaps that should be addressed in future item development aimed at assessing female SQoL.

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Cancer as a Chronic Illness: Has the Time Come?

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Living with cancer throughout the lifespan is an idea warranting scientific consideration and theoretical development. Improvements in diagnosis and treatment have increased the five-year cancer survival rate to over 60%, altering the view of cancer as a death sentence. As individuals learn to live as survivors, the time has come for development of new theoretical frameworks to understand the survivorship experience is clear. This view facilitates conceptualizing cancer as a chronic illness, where management of ongoing symptoms, side effects, and emotional, relational, and physical changes must be integrated into daily life. The survivorship process includes acute periods of treatment, an extended period of survivorship to the critical 5-year marker, longer-term survivorship, as well as potential final life stages. All of these stages include uncertainty, fear of recurrence, preventative behaviors, treatment of secondary disease, resulting from or facing conditions resulting from treatments of the initial cancer. In designing an initial theoretical model, factors unique to cancer and the psychological research in cancer are discussed, including the development of a common nomenclature for the periods of survivorship. In addition, various established models of chronic illness (e.g., heart disease, diabetes, HIV, and rheumatoid arthritis) and long-term disability models are used to provide context and background. Constructs such as quality of life, perceived social support, influences of pain and fatigue, cognitive performance, goal changes (e.g., family planning, career), and demographic factors (e.g., age, ethnicity) are discussed within a framework that espouses cancer survivorship as a chronic condition and a lifelong process of survival and adaptation.

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Radiation Dose Delivered To Cardiovascular Structures In Patients Receiving Modern Mediastinal Radiation Therapy For Hodgkin's Lymphoma

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Diverse cardiovascular complications, including coronary artery disease, valvular heart disease and cardiomyopathy, significantly impact morbidity and mortality in long-term cancer survivors who received mediastinal radiation treatment for Hodgkin's disease (HD). Modern radiation therapy has sought to decrease cardiac irradiation; however, little is known about the amount of radiation currently delivered to specific cardiac structures which contribute to these diverse complications. Therefore, in 13 consecutive adult HD patients treated with modern mediastinal radiation at Brigham and Women's Hospital/Dana Farber Cancer Institute between April 2003 and June 2005, we identified and contoured the specific cardiovascular structures shown below on computed tomography scans from simulation treatment plans. With use of an external beam planning program (Eclipse 6.5, Varian Medical Systems), dose-volume histograms were calculated for each structure in all subjects (Table 1). The mean irradiation dose was significantly different among the cardiovascular structures (ANOVA, p<0.001). The aortic and pulmonary valves, thoracic aorta, and left main and right coronary arteries were found to receive the highest doses. The left and right ventricles and tricuspid valve were found to receive significantly smaller doses. Among the cardiac valves, the tricuspid valve received significantly less radiation than the mitral valve (p<0.05) and the aortic valve (p<0.001). This anatomic assessment of radiation therapy dose may yield more detailed risk assessment for common late cardiovascular complications and help tailor screening regimens for recent HD survivors treated with mediastinal radiation.

TABLE 1.

Cardiac structure	Average dose (Gy)
Aortic valve	27.2 ± 6.8
Pulmonary valve	31.8 ± 3.2
Mitral valve	14.5 ± 11.5
Tricuspid valve	5.8 ± 7.1
Thoracic aorta	33.6 ± 2.9
Left main coronary artery	30.5 ± 3.7
Right coronary artery	30.9 ± 4.0
Left atrium	22.9 ± 10.3
Right atrium	12.7 ± 11.6
Left ventricle	2.3 ± 2.1
Right ventricle	4.7 ± 5.1

Funding source: None indicated.

Predictors of Unmet Psychosocial Need among Cancer Survivors

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Understanding the psychosocial needs of cancer survivors is essential to planning services, and identification of factors which predict unmet needs may allow targeting of services to those at increased risk of poor outcomes. We conducted a population-based survey of 614 cancer survivors to describe level and predictors of unmet need among survivors 3-4 years post-diagnosis. Participants completed questionnaires, indicating unmet needs since treatment on a 93-item measure assessing 16 domains encompassing Psychological, Social, Spiritual, Informational, Physical, Financial, Medical, and ADL needs.

Our sample was primarily middle-aged ($M=57$ years), White (90%), Urban Residing (71%), and presented with Localized (56%) or Regional (21%) disease. Fifty-six percent were female. Level of unmet need was moderate, with an average of 7.7 unmet needs reported ($R = 0 - 83$). Sixty-five percent reported at least one unmet need, and 23% reported 11 or more. Unmet need varied across domains, with 39% reporting unmet Emotional and 38% reporting unmet Physical needs while only 6% reported unmet Spiritual needs. In multivariate analysis, total number of unmet needs was positively related to Staging at Diagnosis and Number of Comorbidities, but negatively related to Age and Income. Only Age and Comorbidity produced a significant interaction, and younger survivors with a greater number of comorbid conditions reported between 2.75 and 4.25 times the level of unmet need of other individuals (overall $R^2 = 27\%$). Our data suggest that lower income and staging relate to unmet need, but younger individuals with additional comorbid physical conditions may be at highest risk.

Funding source: Supported by the Pennsylvania State Department of Health.

Change in Unmet Need among Cancer Survivors: 1986–2005

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In the mid-1980s Houts and colleagues surveyed 629 people with cancer in Pennsylvania to determine how well existing resources and services were meeting patients' psychosocial needs. Results indicated that 59% of people with cancer in Pennsylvania reported at least one unmet need in the year following diagnosis, with the most common needs being in the Emotional, Financial, and Social realms. Progress in cancer treatment and supportive care since that time may have changed the relative importance of some issues, but has likely led to new psychosocial needs as well. Using semi-structured interviews with recent cancer survivors we revised the Houts et al. survey to better assess current needs. Next, as part of a larger, registry-based study we compared the level of unmet psychosocial need in 2005 with that identified by Houts and colleagues in 1986.

We assessed 614 recent cancer survivors, weighing our sample to approximate statewide incidence, and compared the proportion of individuals reporting at least one unmet need in various domains from our sample to those same domains in the Houts et al. sample. Findings indicate a significant increase in unmet need in six of nine categories: Emotional; Financial; Insurance; Employment; Information; and Home Care; as well in the proportion of individuals reporting at least one unmet need (all $\chi^2(1) \geq 4.41$; all $p < .05$). There was no significant difference in unmet need between time points in Spiritual, Transportation, and Communication with Medical Staff categories. Results suggest that unmet needs remain prevalent among cancer survivors.

Funding source: Supported by the Pennsylvania State Department of Health

Oncologists' Perceptions of Barriers to Fertility Preservation Discussion with Cancer Patients

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While risks may vary by cancer site, treatment, and gender, infertility is an expected consequence of cancer treatment for many survivors. Despite this established risk, limited data suggest the majority of cancer survivors of childbearing age do not recall a discussion of their treatment's impact on their future fertility. The present study explored factors (e.g., patient, provider, system) that may contribute to provider discussion of fertility preservation using qualitative research methods. Sixteen physicians at an NCI designated cancer center in the southeast participated in in-depth interviews, which examined physician knowledge, attitude and behavior, related to discussion of fertility preservation with cancer patients of childbearing age. Providers ranged in years of experience from 1 to 30 years as a board certified MD in their specific field, and specialized in treating a variety of site-specific cancers. All reported seeing at least 5–10 patients of childbearing age annually. Preliminary analysis indicates that although the majority of physicians report discussing fertility preservation with their patients, they have limited knowledge about available (although experimental) fertility preservation methods for female cancer patients. In general, they are unaware of local resources or patient information preferences for fertility preservation options. Respondents varied in attitude towards the priority level of this conversation with newly diagnosed patients. Few referred males of childbearing age for sperm banking and even fewer females for consultation with an infertility specialist. Study findings indicate physicians may benefit from educational tools that address current knowledge gaps related to fertility preservation for cancer patients.

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Clinical Cancer Proteomic Technology Assessment, Development, and Reagents Resource

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Implemented in research laboratories across the globe, proteomic technologies such as mass spectrometry and affinity-capture have provided a wealth of fundamental information on the mechanisms underlying cancer and other diseases. However, in order to complete the bridge from discovery to the patient; proteomic platforms, reagents and data analysis must meet rigorous performance criteria to assure their acceptability for clinical application. This requires the development of laboratory techniques that are rapid, accurate, reproducible, robust and reasonably economical. Yet many challenges exist in achieving this goal, such as pervasive problems with research design, data analysis, reproducibility, and comparability of research results; a lack of common reagents and highly qualified public data sets; and the inability to manage and interpret large quantities of pre-processed data. In an effort to accelerate the development of clinical protein detection systems, the NCI has recently established the Clinical Proteomic Technologies for Cancer Initiative. This program is designed to accelerate the translation of proteomics from a research tool into a reliable and robust clinical application by improving protein measurement capabilities and evaluating promising technologies for applicability in both analytical and clinical validation studies. This is to be achieved through identifying major sources of experimental variability and optimizing existing proteomic platforms in order to enable laboratories to compare data and results; developing innovative and advanced proteomic technologies capable of identifying rare cancer-related proteins circulating in body fluids such as blood or urine; and developing a much needed clinical reagents and resources core of well-characterized biological samples, reagents, reference sets, and standards available to the scientific community. Information on this program and how the NCI is addressing these issues of reproducible and reliable metrology will be presented. In addition, other background materials including educational tutorials are located at the program's Web site (<http://proteomics.cancer.gov>).

Funding source: National Cancer Institute

Adoption of Tamoxifen and Aromatase Inhibitors among Breast Cancer Survivors: A Population-Based Prospective Study

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Introduction: Although new data are available regarding adjuvant hormonal therapies, little is known about current use of these agents by breast cancer survivors.

Methods: This report comes from a population-based cohort study of 3,000 older breast cancer survivors from 4 States (California, Florida, Illinois, and New York) who had surgery for breast cancer in 2003. Cases were identified through a validated algorithm using Medicare claims and confirmed by self-report. Participants will be interviewed at 4 time points. Patient quality of life and medication use are obtained from patient report. Physician and hospital variables will be ascertained from Medicare databases and tumor variables from State tumor registries.

Results: We report on the initial 731 subjects (mean age 73.0 years, SD 5.3) interviewed a mean of 28.8 months (SD 2.4) post-diagnosis. Among the cohort, 70.9% reported use of a hormone therapy (HT); 24.5 % (n=179) tamoxifen only, 33.7% (n=246) an aromatase inhibitor (AI) only, and 12.2% (n=89) both tamoxifen and an AI. Of the 335 who used an AI, 279 (83.3%) used anastrozole, 29 (8.7%) exemestane, and 52 (5.5%) letrozole. The drug discontinuation rate for those who used tamoxifen only was 14.5% (n=26) and for those who used AI's only was 16.7% (n=41), p=0.52.

Conclusions: The use of AI exceeded the use of tamoxifen in the first 2.5 years of survivorship among a breast cancer cohort diagnosed in 2003, suggesting early adoption of guidelines including the use of AI.

Funding source: None indicated.

Predictors of Service Utilization during Chemotherapy

Paula Sherwood

Background: Severe changes in both patients' and caregivers' physical and emotional health can result when patients undergo chemotherapy, yet how these changes affect healthcare service utilization is unknown. The purpose of this study was to determine how patient and caregiver factors predict whether or not a patient will use oncologist office, emergency room, and hospital services during the first 10 weeks of chemotherapy.

Methods: Patients (>21 years) receiving chemotherapy for a solid tumor and their family caregivers (N=123 dyads) participated in two telephone interviews (at the beginning of chemotherapy and 10 weeks later). Logistic regression models evaluated potential predictors of healthcare service utilization (patient-related predictors: diagnosis, stage, age, CES-D, symptom severity; caregiver-related predictors: number of care tasks, limitations imposed by caregiving, bother associated with caregiving, and caregivers' gender, age, CES-D, mastery, and relationship to patient).

Results: Patients' stage of cancer ($p=.05$) was the only predictor of hospitalization. Stage of cancer ($p=.05$) and patient age ($p=.05$) predicted use of oncology office visits. Stage of cancer ($p=.03$) and symptom severity ($p<.01$) predicted use of the emergency room. No caregiver-related variables predicted patients' use of services.

Conclusions: Patients' stage of cancer is a key predictor of healthcare service utilization during chemotherapy. Future work should address the role of caregiver assistance with symptoms and involvement in care and how such activities may contribute to improved patient management, ultimately leading to reductions in the need to use formal services in response unmanaged symptoms and related issues at home.

Funding source: None indicated.

The Role of Problem-Solving Appraisal in Predicting Psychosocial Adjustment and Coping Effectiveness in Breast Cancer Survivors with Lymphedema

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Psychological research over the last 20 years has strongly indicated that problem solving and coping play important roles in adaptive responses to stress, and subsequently psychosocial health. Although problem solving has also been implicated in successfully fighting cancer progression, Meyer and Mark (1995) concluded what constitutes effective problem solving with cancer is still largely unexplained. At present, no one can reliably identify which problem solving strategies are most successful for breast cancer survivors, and consequently a lack of empirically supported effective psychosocial interventions to promote psychosocial health. The purpose of this study guided by a biobehavioral model was to examine the prospective role of breast cancer survivors' problem-solving appraisal in prospectively predicting both psychosocial adjustment and physical health over time.

The sample was 212 women diagnosed with breast cancer. Data was collected immediately post operation as well as at one year following their operation. As predicted, problem-solving appraisal was strongly predictive of psychological distress, adjustment to chronic illness, and overall life satisfaction immediately after their medical intervention, often accounting for up to 30% of the variance; moreover, this pattern of findings was largely maintained one year later. A key issue for many breast cancer survivors is quality of life, or "How well will I live?" The results from this rigorous prospective study with little patient attrition provides a promising direction for assisting breast cancer survivors to cope more effectively by developing specific interventions aimed at altering their problem-solving style and coping effectiveness which affect their quality of life.

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Health-Related Quality Of Life (HRQL) in Cancer Survivors: Chronic Co-Morbidity (Mb) Matters

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Purpose: In a general population sample (GenPop) to compare HRQL of cancer survivors with that of individuals without cancer, evaluating the impact of Mb, (hypertension/diabetes) [HDI] and (anxiety/depression) [ADe].

Methods: In 2004, 1127 males (response rate 32%) and 1370 females (response rate 39%) from the GenPop completed the mailed EORTC QLQ C-30 questionnaire and recorded their current medications for Mb. They also answered a question whether or not they ever had cancer, without documenting further details concerning the type and course of the malignancy. Five groups were constructed related to cancer and Mb: 1: Ca+/Mb+ (84); 2: Ca+/Mb- (114); 3: Ca-/ADe (176); 4: Ca-/HDI (475); 5: Ca-/Mb- (1648). Sixty-six cancer survivors of group 1 had HDI and 18 ADe. The present analysis evaluates physical- (PF), social- (SF), role- (RF) and emotional function (EF), fatigue (FA) and pain (P) together with global quality of life (GQoL). Statistically significant differences required a p value <0.01. Differences of ≥ 10 points were considered clinically significant.

Results: No clinically significant differences emerged between group 2 and 5 for any of the HRQL dimensions in spite of statistically significant differences for PF and RF. Clinically significant differences for most assessed HRQL dimensions were, however, observed between group 1 and group 2. Anxiety/depression, in particular, was associated with poorer HRQL dimensions. Previously demonstrated associations between GQoL and age, gender and education were confirmed in cancer survivors.

Conclusions: Co-morbidity, but not the malignant diagnosis itself, is essential for HRQL in cancer survivors. The prevention of co-morbidity is thus essential for the maintenance of satisfactory HRQL in cancer survivors. The term "cancer survivors" should not be used without specification of minimum characteristics as age, gender and co-morbidity.

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“I Made It Through”: Pride and Resilience in BMT Survivors

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Introduction: Although cancer diagnosis and treatment can be traumatic, these experiences can also promote positive psychological changes for survivors. The current qualitative study examined sources of strength and resiliency among BMT/SCT survivors, who undergo particularly aggressive treatment and face high mortality rates. Participants were asked what about their transplant experience they are most proud of (Q1), and what advice they would give someone else going through the same experience (Q2).

Methods: One hundred and eight (108) BMT/SCT survivors (Age X=54.9; 52.8% male; 80.2% White, 12–36 months post-treatment) participated in telephone interviews. Items were transcribed by the interviewer and/or recorded and transcribed verbatim. Responses were coded by two independent raters.

Results: Twenty-six (26) codes were identified for Q1 [most proud of], most commonly: coping and “staying positive” during treatment (34%), surviving (28%), keeping faith (12%), supportive friends/family (11%), and “moving on” (9%). 22 codes were identified for Q2 [advice], most commonly: stay positive (38%), have support (23%), follow doctor’s advice (19%), maintain faith (18%), and know that they will feel better in the future (18%).

Conclusions: Patients’ most common responses paralleled cognitive-behavioral approaches for minimizing distress, and also empirical models of adjustment that emphasize social support and spirituality. The questions themselves appeared to facilitate cognitive processing of a positive self-image as a survivor; only one patient found “nothing” to be proud of. Interestingly, nearly one-third took pride in their physical survival, even though that may not have been under their control. Future work will explore longitudinal associations between these beliefs and measures of distress and well-being.

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The Activities of Five National Organizations in Achieving the Goals of the National Action Plan for Cancer Survivorship

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Background: *The National Action Plan for Cancer Survivorship* (NAPCS 2004) articulated a foundation for public health activities in cancer survivorship by identifying goals and strategies within four domains: surveillance and applied research, communication and education, programs and policy, and access to care.

Methods: We developed and administered a structured interview to capture the survivorship-related programs and services of five national organizations and assessed the extent to which these activities were meeting the goals and strategies of the NAPCS.

Results: Although the programs we assessed were meeting many NAPCS goals related to communication and education, most lacked an evaluation component. A few organizations were involved in advocating for legislative changes to improve cancer survivors' access to care; however, most did not identify policy development as part of their mission. Many activities of the five organizations emphasized the value of quality care, especially palliative care. The role of the organizations in the development of survivorship guidelines was mainly advisory to work being done by a clinical professional organization.

Conclusions: We found that no one organization addressed every NAPCS goal, indicating the usefulness of having multiple national organizations striving to meet the needs of cancer survivors. Our assessment did not capture current survivorship surveillance and research efforts well due to selection bias towards organizations focused on programs and services. Overall, we found a need for the evaluation of current programs and activities and for advocacy to improve care and surveillance of cancer survivors.

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