

# Survivorship Research Symposium

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**Carolyn Eberle, MPH**

## **The Implementation and Initial Evaluation of a Physician Communications Skills Training Module to Enhance Transition to Survivorship in Lymphoma**

**Danielle Baum, BS; Carma Bylund, PhD; Kara McLarney, MPH; Matthew Matasar, MD; Steven Horwitz, MD; Smita Banerjee, PhD; Tomer Levin, MD; Susan Holland, MA; David Kissane, MD**

**Introduction:** Cancer survivors are commonly left with overwhelming feelings of uncertainty, worry and a lack of understanding of how to maintain their lives post cancer. Such anxiety can be attributed to the current lack of a structured standard of care during this “survivorship” period (Coleman and Shigamesa, 2007). For this study we have introduced an additional post-treatment physician- patient consultation strictly for purposes of survivorship transition. A physician focused Communication Skills Training (CST) module was developed to prepare physicians for this new consult. The module integrates an evidence-based standardized care plan document with standard Comskil Training practices.

**Methods:** Thirteen medical oncologists specializing in lymphoma treatment from Memorial Sloan-Kettering Cancer Center and the H. Lee Moffitt cancer Center (Tampa, Florida) participated in a five-hour survivorship CST workshop. The training included a didactic session, exemplary videos of the skills and tasks taught and an approximate two hour role-playing session. Physicians also participated in two 15-minute standardized patient assessments (one pre-training and one post- training). The effectiveness of the training was measured using a retrospective pre-post course evaluation. The participating physicians also rated various aspects of the module using the pre- post course evaluation.

**Results:** Using a paired t-test, the pre-post course evaluation methodology showed a significant increase in physicians’ confidence when discussing their patient’s transition to survivorship ( $t = -2.739$ ,  $p < 0.05$ ). In addition, 92% of the physicians found that each of the three elements of the module training process (didactic, exemplary videos and role-play) aided their learning somewhat or a lot, with 100% of physicians agreeing or strongly agreeing that the exemplary videos and role- play aided in their learning process. One hundred percent of physicians agreed or strongly agreed that they will use their newly acquired skills during future consultation. Lastly, 85% of physicians reported that the skills learned from the module will improve their patient care.

**Conclusions:** This study demonstrates the success of a survivorship communications skills training module for increasing the self-efficacy and confidence of physicians as they aid patients during their transition into their survivorship period. Through the utilization of a novel survivorship care-plan document and a Comskil-modeled survivorship training module, this new standard of care has the potential to increase the survivorship rate and overall well-being and quality of life in patients newly free of cancer. Future work will examine the effect of this new survivorship consult on patient outcomes.

## **Management of men post Radical Prostatectomy (RP) that develop a detectable Prostate-Specific Antigen (PSA) while enrolled in a Prostate Cancer Survivorship Program.**

**Anthony Delacruz, NP; Mary A. Schoen, NP; Robin Rawlins-Duell, NP; Melanie Bernstein. Memorial Sloan Kettering Cancer Center, New York City**

**Introduction:** It is estimated that there are nearly 2.8 million men living with a history of prostate cancer in the US and more than one-half (57%) of these men aged younger than 65 are treated with radical prostatectomy (RP). At MSKCC, men who undergo a RP are eligible to enter a nurse practitioner led survivorship program. Men are followed according to NCCN guidelines. While many patients may be cured, some will develop a detectable prostate-specific antigen (PSA) and there are no standard guidelines for the management of these patients. We report on a cohort of patients with a detectable PSA enrolled in a prostate cancer survivorship program. The algorithm involved in the management of these patients will be presented and patients referred for additional therapies will be reported.

**Design/Setting /Participants:** A total of 2,551 men were enrolled in the prostate cancer survivorship program from January 2007 to July 2012, each undergoing a RP at MSKCC. Standard clinicopathologic variables were recorded and entered into a secure database called Caisis. The patient's PSA was evaluated at each visit. The assay used at MSKCC is an automated enzyme immunoassay analyzer, AIA, from Tosoh. Undetectable PSA is defined as a value reported at <0.05ng/ml. Patients with a confirmed PSA value of  $\geq 0.05$ ng/ml were considered to have a detectable PSA. Management of these patients involves multiple variables: PSA at time of diagnosis, Gleason grade, stage, PSA kinetics, time to a detectable PSA, and patient's age.

**Results:** 155 (6.1%) patients had a confirmed detectable PSA. 64 for T2 disease (3.4% of all T2), 89 for T3 (13.6% of all T3) and 2 for T4 (20% of all T4). Median age at time of RP was 59 and median PSA was 6.07. Gleason scores of  $\leq 6$  accounted for 8.3%, 46 % for Gleason 3+4, 35.2% for Gleason 4+3, and 10.5 % for Gleason  $\geq 8$  of patients with a detectable PSA. The median time to detectable PSA was 4.08 years.

63 (41%) patients were referred to radiation oncology for consideration of salvage therapy (median age 63.2 and median time to detectable PSA 3.2 years). 17 (11%) referred to medical oncology (median age 64.9 and median time to detectable PSA of 4.4 years) and 37 (24%) referred to both radiation oncology and medical oncology for consideration of additional therapy. The total number of patients referred was 117 (75%) while 38 (25%) of patients remain in the survivorship program for continued surveillance.

**Conclusion:** We report on the largest cohort of men enrolled in a prostate cancer survivorship program and their rate and time to a detectable PSA. The management of these patients is complex; the algorithm we use will be presented. Many variables such as PSA at time of diagnosis, Gleason grade, stage, PSA kinetics, time to a detectable PSA, and patient's age are all variables that need to be analyzed to determine if a patient should go on to additional therapy or continued surveillance. Further research is recommended to determine the optimal management of patients with a detectable PSA.

## **New insights into the risk of breast cancer in childhood cancer survivors treated with chest radiation: A report from the Childhood Cancer Survivor Study (CCSS) and the Women's Environmental Cancer and Radiation Epidemiology (WECARE) Study**

Chaya S. Moskowitz, PhD, Joanne F. Chou, MPH, Suzanne L. Wolden, MD, Jonine L. Bernstein, PhD, Jyoti Malhotra MD, MPH, Danielle Novetsky Friedman, MD, Nidha Z. Mubdi, MPH, Tara O. Henderson, MD, Wendy M. Leisenring, ScD, Marilyn Stovall, PhD, Sue Hammond, MD, John D. Boice, ScD, Melissa M. Hudson, MD, Lisa R. Diller, MD, Smita Bhatia, MD, MPH, Joseph P. Neglia, MD, MPH, The WECARE Study Collaborative Group, Colin B. Begg, PhD, Leslie L. Robison, PhD, Kevin C. Oeffinger, MD

**Background:** The risk of breast cancer (BC) by age 50 among women treated for childhood cancer with chest radiation therapy (RT) and how this risk compares with that of *BRCA1* and *BRCA2* (*BRCA1/2*) mutation carriers is unknown.

**Methods:** We evaluated the risk of BC in a cohort of 1268 female 5-yr childhood cancer survivors treated with chest RT and estimated the cumulative incidence of BC non-parametrically treating death as a competing risk. The cumulative incidence of BC in *BRCA1/2* mutation carriers was estimated with the kin-cohort method using data from 4570 female first-degree relatives of women diagnosed with unilateral BC (probands) participating in the WECARE Study. Absolute Excess Risks (AERs) were estimated using population-based data from the SEER program.

**Results:** With a median follow-up of 26 yrs (range 5-39) for the CCSS cohort, 175 women were diagnosed with BC at a median age of 38 yrs (range 24-53) and a median latency of 23 yrs (range 7-38); the overall cumulative incidence of BC by age 50 was 24% (95% confidence interval [CI] 20-28%) and among Hodgkin lymphoma survivors was 30% (95% CI 25-35%). In comparison, among first-degree relatives of WECARE Study probands 324 were diagnosed with BC (median age at diagnosis, 55 yrs (range 26-90)). The estimated cumulative incidence by age 50 was 31% (95% CI 16-47%) and 10% (95% CI 2-23%) in carriers of *BRCA1* and *BRCA2* mutations, respectively. The population cumulative incidence of BC is 4% by age 50. Among the childhood cancer survivors, AERs for BCs diagnosed per 10,000 person-years of observation were respectively 34 (95% CI 18-52), 27 (95% CI 11-45), and 95 (95% CI 78-112) among women treated with 10-19 Gy (23%), 20-29 Gy (17%), and 30+ Gy (56%) of chest RT.

**Conclusions:** Women treated for childhood cancer with chest RT have a substantial risk of BC comparable to *BRCA1/2* mutation carriers and considerably greater than that of the general population. Women treated with 10-19 Gy RT had an increased excess risk warranting consideration of breast cancer surveillance strategies similar to the current recommendations for women treated with  $\geq 20$  Gy.

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## **Psychological Correlates of Sexual Dysfunction in Female Rectal and Anal Cancer Survivors: Analysis of Baseline Intervention Data**

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**Purpose:** Sexual dysfunction represents a complex and multifactorial construct that can affect both men and women and has been noted to often deteriorate significantly after treatment for rectal and anal cancer. Despite this, it remains an understudied, underreported and undertreated issue in the field of cancer survivorship. The current study examined the characteristics of women enrolled in an intervention trial to treat sexual dysfunction, and explored the relationship between sexual functioning and psychological well-being.

**Method:** There were 70 female post-treatment anal or rectal cancer survivors assessed as part of the current study. Participants were enrolled in a randomized intervention trial to treat sexual dysfunction and completed measures of quality of life (EORTC-30), sexual functioning (FSFI) and psychological well-being (BSI Depression and Anxiety, IES-R, CR-38 Body Image) prior to randomization.

**Results:** Women enrolled in the study intervention were on average 55 years old, predominantly Caucasian (79%), married (57%) and a median of 5 years post-primary treatment. For those reporting sexual activity at baseline ( $N=41$ ), sexual dysfunction was associated with a range of measures of psychological well-being in the hypothesized direction. The Sexual/Relationship Satisfaction subscale was associated with all measures of psychological well-being (all  $p<.01$ ). Body image was associated with five of the six subscales of sexual functioning (Desire, Arousal, Lubrication, Orgasm, Satisfaction; all  $p<.05$ ), while anxiety and cancer-specific post-traumatic intrusion were associated with four of six subscales (Desire, Arousal, Orgasm, Satisfaction; all  $p<.05$ ).

**Conclusion:** For sexually-active female rectal and anal cancer survivors enrolled in a sexual health intervention, sexual dysfunction was significantly and consistently associated with measures of psychological well-being in this understudied population. Sexual/Relationship Satisfaction was found to be most consistently associated with psychological well-being, while a global measure of quality of life was largely unrelated to sexual functioning domains. These results suggest that sexual functioning requires focused assessment by providers, and that attention to sexual/relationship satisfaction may be critical in the development and implementation of interventions.

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## **Work status and financial stability during treatment for early breast cancer: a pilot study of an ethnically diverse sample**

**Carolyn Eberle, MPH; Sang-Hee Min; Suyoung Jung, MA; Julia Ramirez; Sujata Patil, PhD; Francesca Gany, MD; and Victoria Blinder, MD**

**Background:** Black and Latina women have lower rates of return to work than non-Latina whites (NLW) after breast cancer treatment. We recently showed that stopping work during chemotherapy is associated with not returning to work for 5 years after treatment. Little is known about the impact of breast cancer on employment in other low-English proficiency (LEP) immigrant or minority groups. The ongoing longitudinal Breast Cancer and the Workforce study measures work status in LEP immigrants and ethnic minorities undergoing breast cancer treatment with curative intent. For this pilot, we assessed work status and financial stability during treatment.

**Methods:** Women aged 18-64, undergoing treatment for stage I-III breast cancer, employed at diagnosis, and able to consent in English, Korean, Mandarin, or Spanish were recruited at 3 community oncology clinics and MSKCC. Participants enrolled any time prior to completing their last treatment (chemo, XRT, or surgery) and self-administered web surveys with in-person assistance, as needed, in their preferred language. Demographic, financial, and pre- and post-diagnosis employment characteristics were analyzed using descriptive statistics.

**Results:** The sample (n=61) median age was 48 years. 20 (33%) were black, 14 (23%) NLW, 11 (18%) Latina, 8 (13%) Korean, 7 (12%) Chinese, and 1 (2%) other. 37 (61%) were foreign born, 35 (58%) had <college education, 30 (49%) had annual household income <\$50,000. 41 (69%) had private insurance, 14 (24%) Medicaid or Emergency Medicaid, and 2 (3%) Medicare/VA. Before diagnosis, 47 (78%) worked full time and 13 (22%) part time. 36 (60%) had white collar jobs (37% manager/professional, 2% arts/media, 22% sales/admin. support); 24 (40%) had blue collar jobs (5% fabricators/laborers; 35% service). 32 (52%) had paid sick leave available at work; 33 (57%) had disability pay. Most were undergoing active therapy: 44 (75%) receiving chemotherapy (7% neo-adjuvant), 3 (5%) post-surgery awaiting adjuvant therapy, 7 (11%) receiving XRT and 5 (8%) awaiting surgery.

When surveyed, 25 (41%) were working full time, 11 (18%) part time and 25 (41%) not working (13% on disability, 16% on paid sick leave, 12% other). 31 (51%) changed work status – stopped working or reduced hours. Of pre-diagnosis full-time workers (n=47), 23 (49%) changed work status – 4 (9%) to part-time, 8 (17%) sick leave, 7 (15%) disability and 4 (9%) stopped working. Of pre-diagnosis part-time workers (n=13), 6 (46%) changed status – 2 (16%) sick leave, 1 (8%) disability and 3 (23%) stopped working. Overall, 26 (43%) had less money to spend on food since starting treatment; 31 (53%) did not have enough money to cover their needs.

**Discussion:** In this pilot, 51% of women changed work status during breast cancer treatment. 41% stopped working, of whom almost a third did not have sick leave or disability. 43% experienced food insecurity during treatment, and 53% said they did not have enough money to cover their needs. Additional research is needed to understand factors that disrupt work during or soon after treatment, how these factors vary for low-income and minority groups, and to better define the impact of change in work status on financial stability.

# Survivorship Research Symposium

## Poster Session

Authors	Title
<b>Sadana Balachandar, MD;</b> Ira Dunkel, MD; Yasmin Khakoo, MD; Suzanne Wolden, MD; Jeffrey Allen, MD; Charles Sklar, MD	Ovarian Function (OVF) in Survivors of Medulloblastoma (MB): Impact of Reduced Dose Craniospinal Radiation (CSI) and High Dose Chemotherapy with Autologous Stem Cell Rescue (ASCR)
<b>Marie Barnett, MA;</b> Jennifer Ford, PhD; Elyse Shuk, MA; Francine Conway, PhD	Self-Disclosure of Cancer among Adolescent and Young Adult Cancer Survivors
Elizabeth Blackler, LCSW; <b>Caraline Craig, BA;</b> Tatiana Starr, MA; Maria Farberov, MPA; Lee Krug, MD; Marjorie Zauderer, MD; Valerie Rusch, MD; Jimmie Holland, MD; R. Garrett Key, MD	The Psychosocial Impact of Mesothelioma: A Pilot Study Examining Patient Needs and the Promise of an Internet-Based Discussion Group
<b>Alyssa Fischer, BA;</b> Vishal Saggarr, BS; Xianzhong Wu, MD, PhD; Mario Lacouture, MD	Dermatologic Adverse Events in Breast Cancer Survivors Receiving Aromatase Inhibitor Adjuvant Hormonal Therapy: A Meta-Analysis
<b>Jennifer Ford, PhD;</b> Joanne Chou, MPH; Charles Sklar, MD	Attendance at a Survivorship Clinic: Impact on Knowledge and Psychosocial Adjustment
<b>Danielle Friedman, MD;</b> Eric Lis, MD; Charles Sklar, MD; Kevin Oeffinger, MD; Marina Reppucci; Megan Harlan Fleischut, MS; Jasmine Francis, MD; Brian Marr, MD; David Abramson, MD; Ira Dunkel, MD	Whole Body Bone Marrow MRI as Surveillance for Second Malignancies in Survivors of Hereditary Retinoblastoma: A Pilot Study
<b>Jyoti Malhotra, MD, MPH;</b> Emily Tonorezos, MD, MPH; Marina Rozenberg, MD; Gloria Vega, PhD; Charles Sklar, MD; Joanne Chou, MPH; Chaya Moskowitz, PhD; Robert Ross, PhD; Peter Janiszewski, MPH; Kevin Oeffinger, MD	Atherogenic Low Density Lipoprotein (LDL) Phenotype in Long-Term Survivors of Childhood Acute Lymphoblastic Leukemia
Victoria Leonichev, BS; Jurgen Rademacher, MD; Jennifer Liu, MD; <b>Matthew Matasar MD, MS</b>	Correlation between Carotid Ultrasonography, Coronary Calcium Score, and Coronary CT Angiography in Survivors of Hodgkin Lymphoma
<b>Jo Anne Maynard, DNP-BC, RN, AOCNP;</b> Debra Sansoucie, Ed.D, NNP-BC	What is the Relationship between Cancer Worry, Perceived Risk of Recurrence and Health Related Quality of Life in Breast Cancer Survivors
<b>Helen Catherine Miller, BS;</b> Amie Scott, MPH; Amy Belonick; Marwan Shouery, MS; Ethan Basch, MD; Peter Cordeiro, MD; Andrea Pusic, MD, MHS	Feasibility and Acceptability of Patient-Reported Outcomes Data Collection for Clinical Care Following Breast Reconstruction

Authors	Title
<b>Joseph Narus DNP, APRN, NP-BC</b> ; Christian Nelson PhD; John Mulhall, MD	Development of a Content-Validated Standardized Patient Education Teaching Tool (SPETT) Regarding Post-Radical Prostatectomy Sexual Dysfunction to Improve Nursing Knowledge and Patient Satisfaction
<b>Elizabeth Ryan, PhD</b> ; Hali Wood, BS; Julia Fallon, MA; Elana Cook, BA; Yuelin Li, PhD; Clifford Hudis, MD; Tiffany Traina, MD; Kemi Bolutayo, BA; Tim Ahles, PhD	Rehabilitation of Cognitive Changes in Breast Cancer Survivors
<b>Vishal Saggar, BS</b> ; Xianzhong Wu, MD, PhD; Maura Dickler, MD; Mario E Lacouture, MD	Incidence of Alopecia from Endocrine Therapies in Cancer
<b>Talya Salz, PhD</b> ; Mary McCabe, RN, MA; Erin Onstad, MPH; Kevin Oeffinger, MD	Survivorship Care Plans: Is There Buy-in from Oncology Providers?
<b>Tammy Schuler, PhD</b> ; Errol Philip, PhD; Katherine DuHamel, PhD; John Mulhall, MD; Larissa Temple, MD; Sabrina Jennings, MA; Christian Nelson, PhD	Sexual Self-Schema Covaries With Sexual Dysfunction in Male Colorectal and Anal Cancer Patients
<b>Emily Tonorezos, MD, MPH</b> ; Kim Robien, PhD; Debra Eshelman-Kent, RN, MSN, CNP; Chaya Moskowitz, PhD; Timothy Church, MD, PhD; Robert Ross, PhD; Kevin Oeffinger, MD	Contribution of Diet and Physical Activity to Metabolic Parameters among Survivors of Childhood Leukemia



# **OVARIAN FUNCTION (OvF) IN SURVIVORS OF MEDULLOBLASTOMA (MB): IMPACT OF REDUCED DOSE CRANIOSPINAL RADIATION (CSI) AND HIGH DOSE CHEMOTHERAPY WITH AUTOLOGOUS STEM CELL RESCUE (ASCR)**

Sadana Balachandar, MD<sup>1</sup>, Ira Dunkel, MD<sup>2</sup>, Yasmin Khakoo, MD<sup>2</sup>, Suzanne Wolden, MD<sup>3</sup>, Jeffrey Allen, MD<sup>4</sup> and Charles A. Sklar, MD<sup>2</sup>. <sup>1</sup> Department of Pediatrics, Weill Cornell/New York Presbyterian Hospital, New York, NY; <sup>2</sup> Department of Pediatrics, Memorial Sloan-Kettering Cancer Center, New York, NY; <sup>3</sup> Department of Radiation Oncology, Memorial Sloan-Kettering Cancer Center, New York, NY; <sup>4</sup> Department of Pediatrics, New York University Medical Center, New York, NY.

## **Introduction:**

Data on OvF in MB survivors is limited, with most studies describing outcomes in survivors treated with CSI doses > 2400 cGy +/- standard chemotherapy. The purpose of this study is to report on OvF 1) across a range of CSI doses and 2) following high dose chemotherapy with ASCR.

## **Methods:**

Retrospective chart review of all MB female survivors who received treatment from 1980 to 2010, and are followed in the Long-Term Follow-Up Clinic at Memorial Sloan-Kettering Cancer Center. Subjects were divided into 3 groups based on treatment: CSI > 3500 cGy +/- standard chemotherapy (n=11); CSI ≤ 2400 cGy +/- standard chemotherapy (n=18); ASCR with (n=4) or without (n=2) CSI.

## **Results:**

35 subjects were evaluated. Their median age at diagnosis of MB was 6.8 years (0.80-26.6) and median age at last evaluation was 16.5 years (4.0-33.2). In the > 3500 cGy group, 7 of 11 subjects had evidence of primary ovarian dysfunction (POD) (LH or FSH ≥ 15 mIU/mL). Of these 7 subjects, 4 normalized their ovarian function and/or developed spontaneous puberty, including 1 with precocious puberty, while 3 (27%) developed premature ovarian failure (POF) requiring hormone replacement therapy (HRT). In the ≤ 2400 cGy group, 8 of 18 subjects had evidence of POD. Of these 8 subjects, 7 normalized their ovarian function and/or experienced spontaneous puberty, including 1 with precocious puberty, while 1 (5%) developed POF requiring HRT. In the ASCR group, 5 of 5 evaluable subjects had evidence of POD; 3 (60%) developed POF requiring HRT.

## **Conclusion:**

While POD is common in MB survivors who received CSI ≤ 2400 cGy +/- standard chemotherapy, in most cases it was transient and only a small minority required HRT. High dose chemotherapy with ASCR is associated with a high incidence of POF requiring HRT.

## Self-Disclosure of Cancer among Adolescent and Young Adult Cancer Survivors

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**Background:** The majority of adolescents and young adults (AYAs) diagnosed with cancer will become long-term survivors. Survivorship presents multifaceted medical and psychosocial late effects that may interact with normative milestones for this cohort, including the development of a greater sense of self and social relationships. The integration of AYAs' cancer experience has been shown to be an important element of psychological growth after treatment. Self-disclosure (SD), the communication of one's personal thoughts, feelings, and experiences, is an essential dimension of close relationships. Family and peer support has also been identified as salient for AYA survivors. Minimal research to date has examined cancer-related disclosure in this population, and its role as a mechanism for increasing social support and positive outcomes, such as posttraumatic growth (PTG) or benefit finding.

**Method:** As part of a larger study, we used mixed methods identify and describe cancer-related SD patterns of AYA survivors to explore the relationship between disclosure with perceived social support and post-traumatic growth. Semi-structured individual interviews were conducted (n=26; 62% female) utilizing open-ended questions about disclosures of their cancer experience. Survivors were between ages 16-24 ( $M=19.6$ ;  $SD=2.8$ ), and diagnosed with cancer between ages 14-18 ( $M=15.6$ ;  $SD=1.3$ ). Participants were mainly 2-5 years (50%) or less than 2 years (31%) posttreatment ( $M=3.2$  yrs). Most common diagnoses included lymphomas (31%) and leukemias (19%), and 65% of participants received multi-modal treatment. Inductive thematic content analysis was conducted with multiple coders (Inter-rater reliability >80%).

Informed by the qualitative analyses, cancer-related SD measures are being administered (ongoing data collection) to 150 AYA survivors (41% female; ages 16-24;  $M=21.3$ ) diagnosed with cancer between ages 14-21 ( $M=16.8$ ), and who completed treatment at least six months prior to the interview. Most common diagnoses include lymphomas (34%) and sarcomas (25%), and 75% of participants received multi-modal treatment.

**Results:** Qualitative analysis reveal three major themes and eight related subthemes: decision- making (don't ask/don't tell, depends if there is a shared experience, and depends on the relationship potential), views of others (perceived apprehension, neutral/positive responses), and methods of disclosure (verbal, written, behavioral). No significant gender differences emerged, though females identified a greater number of disclosure experiences.

Analyses of the survey data will examine patterns of cancer-related SD. The relationship between cancer-specific and general disclosure styles will also be explored. Finally, the relationship between cancer-related SD, perceived social support, and posttraumatic growth (benefit finding) will be examined.

**Conclusion:** With the increasing AYA cancer survivor population, exploring cancer-related SD patterns can target ways SD can be used to promote growth, facilitate transitions and social relationships, and aid the design of meaningful interventions.

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## **The Psychosocial Impact of Mesothelioma: A Pilot Study Examining Patient Needs and the Promise of an Internet-Based Discussion Group**

Elizabeth Blackler, LCSW; Caraline Craig, BA; Tatiana Starr, MA; Maria Farberov, MPA; Lee M. Krug, MD; Marjorie Zauderer, MD; Valerie Rusch, MD; Jimmie Holland, MD; R. Garrett Key, MD

**Background:** Mesothelioma is often caused by asbestos traceable to a specific point of exposure. This unique pathophysiology and identifiable cause can lead to blame and anger directed at the party responsible for exposure. Few studies have examined the psychosocial burden of mesothelioma and little is known about how patients cope or interventions to improve their psychosocial symptoms.

**Methods:** The aim of this two-part study is to assess the quality of life (QOL) in a sample of patients with pleural mesothelioma and explore the feasibility and promise of an Internet-based discussion group for this population. We approach patients with a diagnosis of pleural mesothelioma who are able to read and speak English and are being treated at Memorial Sloan-Kettering Cancer Center (MSKCC). Patients with significant cognitive dysfunction or severe psychiatric disturbance are ineligible to participate.

Part 1 consists of a set of questionnaires assessing coping, interpersonal support, mood, anxiety, and overall QOL. Part 2 is a weekly, six session Internet-based discussion group facilitated by a social worker. Part 2 participants are assessed three times: baseline, approximately 1 week after group completion, and approximately 4 weeks after group completion in addition to a satisfaction survey. Part 1 participants are not required to participate in Part 2. The recruitment goal is 90 Part 1 participants and 30 Part 2 participants.

### **Results:**

Of 64 participants enrolled thus far in Part 1, 56 have completed the questionnaires. Thirty-eight were male and 18 were female. The median age is 66.5 years old (range 35-83). In baseline assessment of wellbeing, participants on average indicated the most distress in functional wellbeing, which includes the ability to work, enjoy life, accept illness, and be content with current QOL. Overall, participants showed the least distress in social well-being, indicating feelings of closeness and high emotional support and communication with family and friends. In baseline assessment of coping, participants on average indicated emotional support and acceptance as the most common methods of coping.

Thirteen of the 22 participants enrolled to Part 2 have completed participation and 4 participants are pending completion of sessions. Five participants dropped from the discussion group before participating in any sessions. Thus far, 11 of 13 completed participants reported that the group met or exceeded their expectations.

**Conclusions:** Early data show a decrease in wellbeing for lung function and emotion. Given the typical rapid progression of disease, the worsening of lung wellbeing scores is expected. The decrease in emotional wellbeing is difficult to interpret without comparison data for patients who did not participate in the discussion group. The subjective comments indicate benefit for most participants which conflicts with the numerical data gathered. The discordance between the two data sets suggests an opportunity for more detailed study. Information from this pilot study could prove helpful in developing a way to connect these geographically dispersed, disabled, and distressed patients.

# **Dermatologic Adverse Events in Breast Cancer Survivors Receiving Aromatase Inhibitor Adjuvant Hormonal Therapy: A Meta-analysis**

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**Introduction:** Women who have survived early breast cancer are treated for an additional 5 years with adjuvant hormonal therapies. Recently, aromatase inhibitors (AIs) such as anastrozole, letrozole, and exemestane have been shown to reduce the risk of recurrent disease in women with steroid-hormone-receptor-positive early breast cancer when compared with selective estrogen-receptor modulators (SERMs) such as tamoxifen. However, these treatments lead to a wide range of adverse events (AEs) that diminish patients' quality of life (QoL). We performed a systematic review of the literature and meta-analysis to determine the incidence and risk of dermatologic adverse events in women receiving AIs as adjuvant therapy.

**Methods:** Databases from PubMed and Web of Science from January, 1998 until September, 2012 and abstracts presented at the American Society of Clinical Oncology annual meetings from 2004 through 2012 were searched to identify relevant studies. The incidence and relative risk (RR) of dermatologic adverse events, namely alopecia, peripheral edema, rash, and sweats, were calculated using random-effects or fixed-effects model depending on the heterogeneity of included studies.

Eligible studies were prospective trials that described all-grade adverse events for patients who received the following adjuvant therapies at the approved dose: anastrozole 1 mg daily; letrozole 2.5 mg daily; exemestane 25 mg daily.

**Results:** Of 333 studies initially identified, 8 met the selection criteria and were included for the study. Two were excluded because they were analyses of a study previously reported. A total of 25,529 patients were included for analysis, of which 13,518 were treated with AIs.

The summary incidences of all-grade sweating, all-grade peripheral edema, and all-grade rash were 16.4% (95% CI: 14.6-18.4%), 14.4% (95% CI: 13.1-15.8%), and 1.4% (95% CI: 0.9-2.2%) respectively. From randomized controlled trials, patients who received AIs did not have a significantly increased risk of developing all-grade dermatologic AEs in comparison with placebo, with a RR of 1.15 (95% CI: 0.974-1.277,  $p=0.115$ ), while comparison with tamoxifen revealed a decreased risk, with a RR of 0.890 (95% CI: 0.818-0.968,  $p=0.006$ ), which was significant.

**Conclusion:** The reported incidence of dermatologic adverse events in breast cancer survivors receiving adjuvant hormonal therapy with AIs is low, but the decreased risk relative to tamoxifen, the previous mainstay of adjuvant therapy, is significant. However, there is inconsistency in AE reporting between studies, with 15 adjuvant trials excluded because they did not report any dermatologic AEs. It is likely that dermatologic AEs are more prevalent, yet under-reported in adjuvant trials, which have focused on effects such as bone density, lipid profile and thromboembolic, cardiovascular, gynecologic or gastrointestinal events. Nevertheless, one study by Fontein et al., analyzed non-compliance in the IDEAL trial, and reported that of 154 patients who discontinued treatment due to adverse events, 17 (11%) did so because of dermatologic/skin related AEs. These events are significant for the early breast cancer survivors who are free of disease, but must continue to take hormonal therapies to prevent disease recurrence. These women should be encouraged to report dermatologic AEs in order to receive proper management and improve QoL.

## **Attendance at a survivorship clinic: Impact on knowledge and psychosocial adjustment**

**Jennifer S. Ford, Ph.D., Joanne F. Chou, M.P.H., Charles A. Sklar, M.D.**

Memorial Sloan-Kettering Cancer Center

**Background:** Approximately two-thirds of young adult survivors of cancer will develop some type of medical complication or disability that can be directly attributed to their previous cancer treatment. Due to their heightened risk of developing late-occurring adverse outcomes, pediatric cancer survivors are advised to receive follow-up care in specialized Survivor Clinics (SC). This study serves as an initial step in assessing the differences between those who attend a SC and those who do not on knowledge, perception of risk, and psychosocial adjustment.

**Methods:** We assessed 102 survivors who attended a SC and 71 survivors never seen in a specialized clinic (non-SC) who were matched on gender, age at cancer diagnosis, date of diagnosis, diagnosis, and race. All survivors were diagnosed at least 5 years prior to the assessment, were at least 20 years old, and had no evidence of disease. Surveys included sociodemographics, knowledge of their cancer diagnosis/treatment, health status, health behaviors, perceptions of health risks, and psychological distress.

**Results:** On average, participants were 30 years old at the time of questionnaire ( $SD=6.1$ ) and had been diagnosed with cancer around age 12 ( $SD=6.0$ ). A majority were female (60%), non-Hispanic White (79.8%) and were highly educated (72% had a college degree). The most common cancer diagnoses included leukemia (30.1%) and Hodgkin's Lymphoma (16.2%). There were no significant sociodemographic differences between the two groups of survivors.

Around two-thirds (60%) of SC survivors accurately knew they had been seen in a specialized clinic. Non-SC participants reported they did not attend a SC because they were not aware of such a clinic (71%), while only 16% stated they were "not interested." Both groups were able to accurately report their cancer diagnosis and whether they had undergone chemotherapy and/or radiation, but not specific agents or dosages.

Survivors in both groups reported being in good health. A significantly greater proportion of survivors in the SC group reported hormone or endocrine problems (40.2% vs. 17.4%). Survivors' perceptions of their risks of late effects (cancer, infertility, heart and/or pulmonary problems), compared with physician-rated risk revealed moderate accuracy (range: 55%-82%) with both groups similarly underestimating their risks.

The majority reported that they receive a general physical examination at least once every two years (82-88%); however, they were less likely to report breast self-examination, monthly testicular examination, or receiving a check up from a cancer-related specialist. No significant differences were observed between groups, but there were trends suggestive of increased surveillance in the SC group.

While there were no significant differences between groups on psychological or emotional problems, both groups reported that they had psychological or emotional problems (16-18%), met criteria for PTSD (4.2%-6.9%) and/or met clinical cutoff for psychological distress (7.8-19.7%).

**Conclusions:** Survivors are in need of continued education about their specific cancer treatments, recommended follow-up practices, the importance of survivorship care and their specific risks for late effects. Additionally, we found that being part of a SC did not increase health-related anxiety or distress.

This research was supported in part by the Langeloth Foundation (Sklar) and American Cancer Society MRSG-07-165-01-CPPB (Ford).

## **Whole body bone marrow MRI as surveillance for second malignancies in survivors of hereditary retinoblastoma: a pilot study**

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**Introduction:** Individuals with hereditary retinoblastoma (RB) are at very high risk of developing subsequent malignant neoplasms (SMN) of which osteosarcoma (OS) is one of the most common. We hypothesized that surveillance imaging using whole body bone marrow (BM) MRI in asymptomatic survivors of hereditary RB might allow earlier detection of SMN.

**Methods:** Retrospective review of the results of a whole body MRI screening program in hereditary RB survivors. Primary outcome was detection of SMNs. Data are reported as of June 10, 2012.

**Results:** Whole-body BM MRI studies were ordered on 34 patients with hereditary RB between 2008 - 2012. Twenty-four patients (70.6%) had at least 1 BM MRI performed (range: 1-4). First whole body BM MRI was performed at a median age of 16 years (range: 8 -24 years). Whole-body BM MRI detected new osseous abnormalities in 4 patients: 2 were diagnosed with high-grade OS of the extremity and 2 were found to have benign osseous abnormalities after further testing was performed. One patient was diagnosed with secondary OS 3 months after normal screening whole body MRI exam.

**Conclusions:** Whole body BM MRI screening may detect SMN in survivors of hereditary RB, but it appears to have limited sensitivity and specificity. Detection of abnormalities that do not represent SMN may result in additional medical procedures and increased anxiety. A larger cohort of patients would be required to determine whether surveillance whole body BM MRIs can decrease SMN-related mortality in this population.

## ATHEROGENIC LOW DENSITY LIPOPROTEIN (LDL) PHENOTYPE IN LONG-TERM SURVIVORS OF CHILDHOOD ACUTE LYMPHOBLASTIC LEUKEMIA

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**Introduction:** Childhood acute lymphoblastic leukemia (ALL) survivors have increased risk of coronary artery disease. Small density lipoproteins (sdLDL) are atherogenic and have not been studied in this population.

**Aims:** 1) Determine prevalence of sdLDL phenotype in ALL survivors, and identify associated treatment factors. 2) Assess relationship between different measures of body fat and sdLDL.

**Methods:** We conducted a cross-sectional analysis of 110 ALL survivors (median age, 23.5 years). Lipid sub-fractions were measured with Vertical Auto Profile-II (Atherotech, Birmingham, AL). Patients with >50% of LDL-c in sdLDL fractions (LDL<sub>3+4</sub>) were classified as having atherogenic pattern. Visceral and subcutaneous adipose tissue (VAT, SAT) volumes were measured by abdominal CT. Analyses were adjusted for age, gender, smoking and hypertension. Fischer's exact test and multivariate linear regression were used for statistical analyses.

**Results:** While the mean LDL-c was 108.7±26.8 mg/dl, 36.4% (40/110) ALL survivors had the atherogenic pattern. Atherogenic pattern was more common in males (26/47) than females (14/63; 55.3% vs 22.2%;  $P=0.01$ ). Among the 32.7% (36/110) survivors who had a normal body mass index (BMI: 18.5 to 24.9 kg/m<sup>2</sup>), 11.1% (4/36) had an atherogenic pattern. In contrast, among the 67.3% (74/110) survivors with BMI ≥25 kg/m<sup>2</sup>, 48.7% (36/74) had an atherogenic pattern ( $P<0.001$ ). Visceral pattern of obesity (VAT/SAT ratio≥0.4) was associated with the atherogenic phenotype (14/19, 73.7%) as compared to those without visceral pattern of obesity (24/85, 28.2%;  $P=0.03$ ). In a linear model including all survivors, VAT was strongly associated with LDL<sub>3+4</sub> (sdLDL),  $\beta=0.1$ ; 95% CI 0.04-0.1;  $p<0.001$ . Controlling for BMI, waist circumference or SAT did not yield any additional information about the variation in LDL<sub>3+4</sub> with increasing VAT.

**Conclusion:** We report a high prevalence of atherogenic phenotype in ALL survivors. Prevalence of atherogenic pattern in young adults in the general population is 7.5% in females and 22.9% in males (Watson TD, Arterioscler Thromb, 1994). Further studies are warranted to elucidate underlying mechanisms associated with the development of sdLDL phenotype in this population.

## **Correlation between carotid ultrasonography, coronary calcium score, and coronary CT angiography in survivors of Hodgkin lymphoma**

Leonichev VB, Rademacher J, Liu J, Matasar MJ

**Background:** Hodgkin lymphoma (HL) is an uncommon cancer that is highly curable with chemotherapy or combined-modality therapy. Long-term survivors of HL who received mediastinal radiation therapy (RT) as a component of care face significantly increased risk of premature coronary artery disease (CAD), myocardial infarction (MI), stroke, and all-cause cardiovascular mortality. Despite these risks, there exists no guidelines for how best to monitor asymptomatic patients, and the optimal surveillance strategy is unknown. While routine surveillance techniques in healthy patients may include carotid ultrasonography (CUS) with measurement of the intima-media thickness (IMT), measurement of the coronary calcium score (CCS), or CT coronary angiography (CTCA), the utility of these tests in previously irradiated patients is unknown.

**Methods:** We analyzed a convenience sample of 8 HL survivors who had undergone screening CUS, CCS, and CTCA as part of routine care; MSKCC institutional database search was approved by the institutional review board. All patients had received mediastinal RT of at least 36 Gy at ages 9-24 years. All patients were without recurrence 5+ years post-treatment and without symptoms of cardiovascular disease at time of screening. Descriptive statistics were applied in comparing CUS, CCS, and CTCA in this small patient sample.

**Results:** Eight survivors of HL treated with mediastinal radiotherapy (with or without chemotherapy) who had undergone CUS, CCS, and CTCA were identified. Age at treatment ranged from 9 to 24 years, and age at screening ranged from 34 to 54 years. All had been treated with at least 36 Gy of radiation, and none required second-line chemotherapy in treatment of relapsed or refractory disease. Of the eight patients, five had results of CTCA consistent with coronary artery disease (CAD), with degree of stenosis ranging from 30 to 70%. In comparing CCS to CTCA, of the five true-positive CTCA examinations, all five had abnormal CCS, but of the three normal CTCA examinations, two had abnormal calcium scores, yielding an estimated specificity of 33% and sensitivity of 100%. Comparing carotid ultrasonography to CTCA, of the five patients with abnormal CTCA results, two had normal carotid ultrasounds, one without plaque and one without plaque and a normal IMT. Of the three patients with normal CTCA findings, one had an abnormal carotid ultrasound, with 50% stenosis noted despite a normal IMT. These results yield an estimated sensitivity and specificity for CUS, using CTCA as gold standard, of 60% and 67%, respectively.

**Conclusion:** In this small, and highly selected, patient sample, CTCA is able to detect abnormalities in coronary arterial vasculature in survivors of HL treated with mediastinal radiotherapy. Coronary calcium scores were universally elevated in those with underlying CAD, but two of the three patients with normal CTCA results had an abnormal CCS, suggesting that a staged strategy of CCS followed by CTCA if abnormal may have limited utility. Additionally, CUS had limited sensitivity and specificity in comparison to the de facto gold standard CTCA; careful assessment of the impact of specific radiotherapy fields (e.g., inclusion of carotid vessels in the treated field) on these findings is required and will be included in the final presentation. These data offer support for a broader investigation of the relative utilities of these modalities in screening asymptomatic long-term HL survivors for underlying CAD.



## **What is the relationship between cancer worry, perceived risk of recurrence and health related quality of life in breast cancer survivors**

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**Background:** Due to advances in early detection and medical technology women with breast cancer are living longer. Researchers have documented that at least 20-30% of breast cancer survivors have experienced psychological distress. This distress does decrease over time however, many survivors report that they are haunted by ongoing fears that their disease will recur. Cancer worry and fear of recurrence unlike overall psychological distress do not dissipate over time and may impact negatively on health related quality of life. It is felt that the psychological concerns of breast cancer survivors are very often not addressed and are unmet in clinical practice. In busy oncology practices these psychological variables are very often not addressed. This may be due in part to the fact the oncology health care providers focus mainly on the physical aspects of the patient's disease. The patient's tumor response to treatment and the management of the physical side effects are the main concern of the oncology team. In addition many oncology physicians and nurses are not qualified to manage the psychological issues related to the disease.

**Purpose:** To provide a systematic investigation of the relationship between cancer worry, perceived risk of recurrence and health related quality of life in breast cancer survivors, to provide scientific evidence that these variables do alter in a negative way breast cancer survivors health related quality of life.

**Methods:** A convenience sample of 61 breast cancer survivors recruited from a private oncology hematology private practice in eastern Long Island were included in the study. Eligible participants scored study instruments including a demographic tool, the modified Concerns About Recurrence Scale and the Quality of Life-Breast Cancer version instrument during their regular office visit. Both descriptive and correlational analysis was performed.

**Results:** The results of this investigation revealed a statistically significant relationship between cancer worry and perceived risk of recurrence and breast cancer survivor's health related quality of life. Cancer worry and perceived risk of recurrence may negatively affect breast cancer survivors health related quality of life. Correlation of the subscales revealed a statistically significant relationship between cancer worry and perceived risk of recurrence and distress and fear.

## **Feasibility and acceptability of patient-reported outcomes data collection for clinical care following breast reconstruction**

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**Background:** To date, systematic measurement of patient-reported outcomes (PROs) has played an important role in cancer research, but not in routine clinical care. Our objective was to evaluate the feasibility of developing and piloting an electronic PRO data collection in clinical care among breast reconstruction patients using the BREAST-Q, a previously developed condition-specific PRO measure for breast surgery patients that measures quality of life (e.g. psychosocial, physical and sexual well-being) as well as patient satisfaction (e.g. satisfaction with breasts, with information, with surgeon).

**Methods:** The BREAST-Q was loaded to the MSKCC WebCore, a generic electronic patient-reporting platform adhering to strict privacy and security standards. Patients attending visits at the MSKCC Breast Reconstruction Clinic were asked to complete the BREAST-Q electronically prior to scheduled visits. For patients with email addresses, a reminder with web-link to the questionnaire was emailed automatically prior to the visit.

**Results:** Over a 9 month start-up period, BREAST-Q surveys were completed by 1442 patients. Patients completed the questionnaire at set time points before and after surgery. A total of 2340 BREAST-Q surveys were completed overall. Mean completion time was 5:53 minutes. Acceptability was high with both patients and clinical staff contributing positive comments along with suggestions for improvement via email.

**Conclusions:** This pilot experience suggests that ePRO data can be efficiently collected among outpatient breast surgery patients with high acceptability. In the next phase of this project, we will introduce real-time individual patient reports to the clinical team and evaluate the impact of this information on clinical care and quality improvement.

## **Development Of A Content-Validated Standardized Patient Education Teaching Tool (SPETT) Regarding Post-Radical Prostatectomy Sexual Dysfunction to Improve Nursing Knowledge and Patient Satisfaction**

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**Objectives:** A major side effect of a radical prostatectomy (RP) is sexual dysfunction (SD). No research exists on the nature and impact of pre-operative patient education by nurses addressing post-RP sexual dysfunction. As part of a doctorate in nursing practice program, an initiative to improve nursing knowledge on post-RP SD was implemented, which lead to the development of a content-validated SPETT for nurses to review with patients.

**Material and Methods:** Urological surgical nurses attended a 60-minute educational program to improve their knowledge and assess confidence and comfort in discussing and management of post-RP SD. The nurses completed a pre and post-program questionnaire developed for this study and reviewed by experts in sexual medicine and urology. The questionnaire assessed knowledge of post-RP SD, and confidence and comfort in discussing SD with patients. Survey findings supported the development of a SPETT reviewed by a multidisciplinary group of 6 clinical experts in medicine/surgery, nursing, and psychology for content validation.

**Results:** There were 23 nurses who attended one of 8 educational program sessions. Mean knowledge scores (range, 0-17; 0 low, 17 high) improved from baseline ( $11.60 \pm 2.8$ ) to post-program ( $16.61 \pm 0.9$ ,  $p < 0.01$ ). An improvement in mean nurse confidence scores (range 1-5; 1 strong agreement, 5 strong disagreement) was also noted (pre =  $3.04 \pm 1.2$ ; post =  $2.39 \pm 1.1$ ,  $p < 0.05$ ) with no change in mean nurse comfort scores (range 1-5; 1 strong agreement, 5 strong disagreement) (pre =  $2.65 \pm 1.2$ ; post =  $2.22 \pm 1.0$ ,  $p = \text{ns}$ ). A content validation index (CVI) for relevancy and clarity of the 13 items on the SPETT was established (relevancy CVI [range=0.88-1]) and clarity CVI [range=0.96-1]) and relevancy of the tool as a whole CVI=0.96. A CVI  $\geq 0.83$  defined content validity.

**Conclusions:** The findings demonstrate improved nursing education about post-RP sexual dysfunction from a continuing education program and supported the development of a content-validated SPETT by clinical experts. Future research will involve the implementation of the SPETT and evaluation of patient and nurse satisfaction.

## **Rehabilitation of Cognitive Changes in Breast Cancer Survivors**

Elizabeth Ryan, Hali Wood, Julia Fallon, Elana Cook, Yuelin Li, Clifford Hudis, Tiffany Traina, Kemi Bolutayo and Tim Ahles

**Introduction:** Cognitive deficits following chemotherapy have been seen in 20-30% of breast cancer survivors up to 12 months post-chemotherapy and can continue up to ten years post-chemotherapy. Notably, survivors complain of problems in working memory, the ability to retain and retrieve information stored over a very short period of time. The study seeks to determine the feasibility of utilizing rehabilitation software to improve cognitive side-effects potentially related to chemotherapy. Cogmed Working Memory Training is a software program designed to improve working memory via tasks that involve the temporary store and manipulation of either visuo-spatial and/or verbal information. The task difficulty is adapted to the participants' working memory span by increasing in difficulty as participants improve and/or adjusting for difficulties by decreasing working memory load. This software has shown efficacy in select populations (ADD, CVA, and pediatric cancer patients) leading to better working memory and reduction in inattention.

**Methods:** Breast cancer survivors (1-10 years post-chemotherapy) who demonstrate a decline on a cognitive screening test administered via telephone are randomized to two treatment arms: (1) an experimental group (n=19) which uses the adaptive software training program as described above or (2) an active placebo condition, the nonadaptive group (N=17) wherein task difficulty is static throughout the training. The overall project aim is to determine whether Cogmed Working Memory Training software leads to improvement on neurocognitive tests and decreased report of cognitive symptoms. In each condition, the software program is used for 30 minutes a day, 5 days a week for 5 weeks. Participants were assessed at baseline and following the training. A final follow-up assessment is done three months following the initial follow-up to determine if there is maintenance of any cognitive gains.

**Results:** Overall, preliminary results show that using the rehabilitative software is feasible in breast cancer survivors. This is evidenced by an 87% completion rate of those recruited to the study, positive reports regarding ease of use, and the relative likelihood of patients showing deficits deciding to enroll in this pilot study.

In our small sample (N=36), we see preliminary evidence of trends in improved neurocognitive functioning. There was significantly improved performance in working memory and sustained attention for survivors in the adaptive condition as compared to the nonadaptive, active placebo condition. Furthermore, those randomized to the adaptive training program perceived significant functional improvement and increased quality of life at follow-up.

Data collection of this pilot study is ongoing. We have recruited 75% of our sample and 83% of those recruited have finished their final 3-month follow-up assessment.

**Conclusions:** Cogmed Working Memory Training software appears to be a feasible rehabilitative program for use with breast cancer survivors. Preliminary data suggests the software improves neurocognitive functioning, decreases cognitive symptoms, and improves QOL.

## **Incidence of alopecia from endocrine therapies in cancer**

Vishal Saggar, Shenhong Wu, Maura Dickler, Mario E Lacouture

**Introduction:** Whereas alopecia to cytotoxic chemotherapies is a well described event, hair loss in patients treated with endocrine therapies (anti-estrogens, aromatase inhibitors) has not been systematically investigated. These agents are widely used in the treatment and prevention of many types of solid tumors, including those of the breast. Endocrine therapy has become a mainstay of treatment for hormone-receptor-positive breast cancers, which constitute the majority of cancers of the breast. We performed a systematic analysis of the literature in order to determine the frequency of alopecia for each of these drugs, in order to provide information that is critical for counseling and interventions against alopecia, a major quality of life issue for many patients.

**Methods:** An independent search of citations was conducted using the PubMed database for all available literature as of July 2012 (earliest relevant citation from 1986). The terms “tamoxifen,” “toremifene,” “raloxifene,” “anastrozole,” “letrozole,” “exemestane,” “fulvestrant,” “leuprolide,” “flutamide,” “bicalutamide,” “nilutamide,” “fluoxymesterone,” “estradiol,” “octreotide,” “megestrol,” and “medroxyprogesterone acetate” were used as keywords in the search. Results were restricted to only include Phase II and III clinical trials. The primary restriction in the study selection involved finding trials that included rates of alopecia in the context of endocrine therapy for cancer, without confounding variables such as concurrent treatment with additional biological therapy or chemotherapy.

**Results:** A total of 19,430 patients from the 35 clinical trials (representing 2.5% of 1384 search results) were available for analysis. Of these 19,430 patients, 13,415 patients received specific endocrine therapies, while 6,015 patients received control treatments. The incidence of all-grade alopecia ranged between 0% and 25%, with 25 percent of patients experiencing alopecia in a phase II trial documenting use of anastrozole and goserelin to treat breast cancer. Upon analysis of all trials, the overall incidence of all-grade alopecia was 11.1% (95% CI: 10.2%-12.2%), according to the random-effects model. The Relative Risk in comparison to placebo was found to be statistically significant.

**Conclusions:** Alopecia is a common, yet underreported side effect secondary to endocrine agents used against cancer, especially those of the breast. The long-term use of these agents heightens the importance of this adverse event on patients' quality of life. Knowledge of the incidence of alopecia represents the first step towards the understanding and management of this frequently occurring untoward event that may affect many people receiving these therapies.

## **Survivorship care plans: Is there buy-in from oncology providers?**

Talya Salz, PhD; Mary McCabe, RN, MA; Erin Onstad, MPH; Kevin Oeffinger, MD.

**Background.** The Institute of Medicine (IOM) proposed that oncology providers give survivorship care plans (SCPs) to cancer survivors and their primary care providers to inform ongoing care. Although survivors, primary care providers, and survivorship experts generally endorse the use of SCPs, the use of this intervention has been limited. We aimed to assess community oncology providers' opinions about the use of SCPs.

**Methods.** We invited oncology providers (nurse practitioners, clinical nurse specialists, physician assistants, medical oncologists, and radiation oncologists) from 14 National Cancer Institute Community Cancer Centers Programs to complete a brief questionnaire, which elicited perceptions of: barriers to SCP use, the importance of SCPs, and the responsibility of oncology providers to provide SCPs. We also listed strategies to ease implementation of SCP and asked whether they were used and, if so, the perceived value of the strategy. In the questionnaire, SCPs were broadly defined as written reports that included information on the topics in SCPs: summaries of diagnosis, summaries of treatment, recommendations for ongoing care, and information about what the oncology practice will follow up with their patients.

**Results.** With a response rate of 70%, 245 oncology providers completed the survey. Fewer than half of respondents, 38-49%, reported that they always or sometimes provide information on the topics in SCPs. The most widely endorsed difficulty in implementing survivorship care plans was having personnel to complete the SCP (N=170, 69%), followed by time to collect information to complete the SCP (N=156, 64%). The most common strategy used was to delegate the completion of a SCP to a single person (N=82 out of 183 who provide SCPs, 45%). Of those who used each strategy, most (74-94%) found it helpful. The most widely endorsed strategy was the use of a template with pre-specified fields (94%). While 87-89% of respondents felt it was very important for primary care providers to receive the topics summarized in an SCP, only 58-65% of respondents felt it was very important for patients to receive the topics summarized in a SCP. Further, 33-38% of respondents had mixed feelings about whether it was the oncology providers' responsibility to provide summaries of each topic in an SCP.

**Conclusions.** Despite broad approval of SCPs by survivors and primary care providers, uptake of this intervention will likely remain limited unless resources, particularly personnel and time, are made available to overcome significant barriers in implementation for oncology providers. We found somewhat limited buy-in for SCPs among oncology providers, particularly in terms of the perceived value of the SCP for the survivor and the idea that oncology providers are responsible for providing SCPs to patients.

## **Sexual Self-Schema Covaries with Sexual Dysfunction in Male Colorectal and Anal Cancer Patients**

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**Background:** Colorectal and anal cancer patients show high rates of sexual dysfunction following treatment. However, the majority of sexuality research in cancer focuses on female patients. Sexual self-schema, or sexual self-view, is a social-cognitive construct known to relate to sexual behaviors, responses, and attitudes in female cancer patients and prostate cancer patients. Even so, these relationships remain unstudied in male colorectal and anal cancer patients.

**Method:** Men ( $N=55$ ) diagnosed with colorectal/colon/rectal cancer (91%) or anal cancer (9%) at a major cancer center completed the Men's Sexual Self-Schema questionnaire (Andersen et al., 1999) derived from its 45 development items, the International Index of Erectile Function, and the Self-Esteem and Relationship Questionnaire. Measures were completed at the baseline assessment of a sexual-health education intervention pilot study for colorectal and anal cancer patients. Two-tailed Pearson product-moment correlations examined relations between variables.

**Results:** The average patient was middle-aged (mean=57.5;  $SD=9.0$ ), Caucasian (89%), and married (87%). The majority had Stage III (46%; vs. Stage I or II) cancer and had received surgical (95%), chemotherapy (91%), and radiation treatment (86%). A view of the sexual self as more powerful and aggressive covaried with worse erectile and orgasmic functioning ( $r=-.320$  and  $-.304$  respectively,  $p<.025$ ) and lower intercourse satisfaction ( $r=-.309$ ,  $p=.022$ ). A view of the sexual self as open-minded and liberal, however, was associated with higher self-esteem and a better sexual relationship ( $r=.310$  and  $.295$  respectively,  $p<.030$ ).

**Conclusions:** Data suggest the potential utility of addressing sexual self view in the context of sexual-health interventions for male colorectal and anal cancer patients.

## Contribution of diet and physical activity to metabolic parameters among survivors of childhood leukemia

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**Introduction:** Determine the relationship between diet and metabolic abnormalities among adult survivors of childhood acute lymphoblastic leukemia (ALL).

**Methods:** We surveyed 117 adult survivors of childhood ALL using the Harvard Food Frequency Questionnaire. Physical activity energy expenditure (PAEE) was measured with the SenseWear Pro2 Armband. Insulin resistance was estimated using the Homeostasis Model for Insulin Resistance (HOMA-IR). Visceral and subcutaneous adiposity were measured by abdominal CT. Adherence to a Mediterranean diet pattern was calculated using the index developed by Trichopoulou. Subjects were compared using univariate and multivariate analysis.

**Results:** Overall, greater adherence to a Mediterranean diet pattern was associated with improved visceral adiposity ( $P=0.03$ ), subcutaneous adiposity ( $P=0.005$ ), waist circumference ( $P=0.02$ ), and body mass index ( $P=0.03$ ). For each point higher on the Mediterranean Diet Score, the odds of having the metabolic syndrome fell by 31% (OR 0.69; 95% CI 0.51, 0.93;  $P=0.015$ ). Higher dairy intake was found to worsen HOMA-IR ( $P=0.014$ ), but other individual components of the Mediterranean diet, such as low intake of meat or high intake of fruits and vegetables, were not significant. PAEE was not independently associated with metabolic outcomes in the multivariate model, although higher PAEE was associated with lower body mass index.

**Conclusions:** Adherence to a Mediterranean diet pattern improves metabolic and anthropomorphic parameters among ALL survivors.