

Highlights of the 2017 Cancer Survivorship Symposium: Part 1

The second Cancer Survivorship Symposium: Advancing Care and Research was held on 26-27 January 2017 in San Diego, CA, USA. Following on from the inaugural meeting held in January 2016, the American Academy of Family Physicians (AAFP), the American College of Physicians (ACP) and the American Society of Clinical Oncology (ASCO) once again collaborated to provide information about survivorship issues that both primary care physicians and oncologists are dealing with on a day-to-day basis, aiming to improve the care of the millions of cancer survivors around the world.

Throughout the Cancer Survivorship Symposium, and the “Evening for Cancer Survivors and Caregivers” which preceded it, a key theme was the importance of addressing all the needs of cancer survivors and their families, whether these be symptoms requiring treatment, psychosocial distress requiring intervention or financial difficulties which may impact their ability to remain in follow-up care programmes. The importance of a holistic approach to cancer treatment was another key focus of the meeting, including the consideration of spiritual needs and the use of integrative approaches. This report summarises information on these aspects of cancer survivorship which were shared during presentations and discussions.

An “Evening for Cancer Survivors and Caregivers” was organised the night before the Symposium began – a similar event had taken place in 2016, and this year’s event was even better attended.



The panel for this event brought personal and professional experience of a range of cancers and their stories clearly resonated with the audience of cancer survivors, caregivers, patient advocates and healthcare professionals working in the oncology field. Discussions were wide-ranging and included the need to support caregivers as well as patients, the importance of a holistic approach to cancer treatment and the need to provide every cancer survivor with a treatment summary and a survivorship care plan to facilitate good communication between healthcare providers.

The importance for cancer survivors of caring for both their mind and their body, as well as finding some purpose in their cancer experience, was discussed throughout the “Evening for Cancer Survivors and Caregivers” and the Symposium as a whole. Comments from the audience highlighted that many survivors continue to find the use of integrative approaches in conjunction with conventional medicine to be very beneficial both physically and psychologically.

Common symptoms in cancer survivors include fatigue and sleep disturbance

During the first day of the Cancer Survivorship Symposium, Dr Christine Miaskowski from the University of California, San Francisco examined the interesting and complex topic of identifying a symptom phenotype in cancer, using fatigue as the exemplar. Dr Miaskowski began by reminding attendees of **the huge symptom burden experienced by cancer patients – 30% to 50% have fatigue, 60% have sleep disturbance, 35% have anxiety/distress, 25% depression and 75% cognitive impairment.**

Dr Miaskowski described a large study in 582 patients with various tumour types examining morning and evening fatigue scores during two cycles of chemotherapy to identify diurnal variation (Kober KM et al, Support Care Cancer 2016). Various factors were predictive of higher levels of evening fatigue, including poorer functional status, a worse co-morbidity profile, a diagnosis of breast or lung cancer vs GI cancer or having childcare responsibilities, suggesting that specific interventions might be possible for these patients.

While most research focuses on one symptom, almost all patients have multiple symptoms – 9 to 15 on average. The oncology care team need to routinely assess survivors for common symptoms including fatigue, pain, sleep disturbance, cognitive impairment and depression. ASCO provide guidelines for management of common symptoms in cancer including fatigue, neuropathy, chronic pain and depression and anxiety (see below). In the future we may be better able to identify patients with clusters of symptoms and consider targeted interventions to improve resilience and coping strategies for those experiencing a high symptom burden.

ASCO guidelines on symptom management in cancer survivors

Andersen BL, DeRubeis RJ, Berman BS, et al. Screening, Assessment, and Care of Anxiety and Depressive Symptoms in Adults With Cancer Guideline Adaptation. J Clin Oncol 2014; 32: 1605-1619. Available at: <https://www.asco.org/practice-guidelines/quality-guidelines/guidelines/patient-and-survivor-care#/9656>

Hershman DL, Lacchetti C, Dworkin RH, et al. Prevention and Management of Chemotherapy-Induced Peripheral Neuropathy in Survivors of Adult Cancers. J Clin Oncol 2014; 32: 1941-1967. Available at: <https://www.asco.org/practice-guidelines/quality-guidelines/guidelines/patient-and-survivor-care#/9541>

Bower JE, Bak K, Berger A, et al. Screening, Assessment, and Management of Fatigue in Adult Survivors of Cancer Guideline Adaptation. J Clin Oncol 2014; 32: 1840-1850. Available at: <https://www.asco.org/practice-guidelines/quality-guidelines/guidelines/patient-and-survivor-care#/9546>

Paice JA, Portenoy R, Lacchetti C, et al. Management of Chronic Pain in Survivors of Adult Cancers. J Clin Oncol 2016; 34: 3325-3345. Available at: <https://www.asco.org/practice-guidelines/quality-guidelines/guidelines/patient-and-survivor-care#/13021>

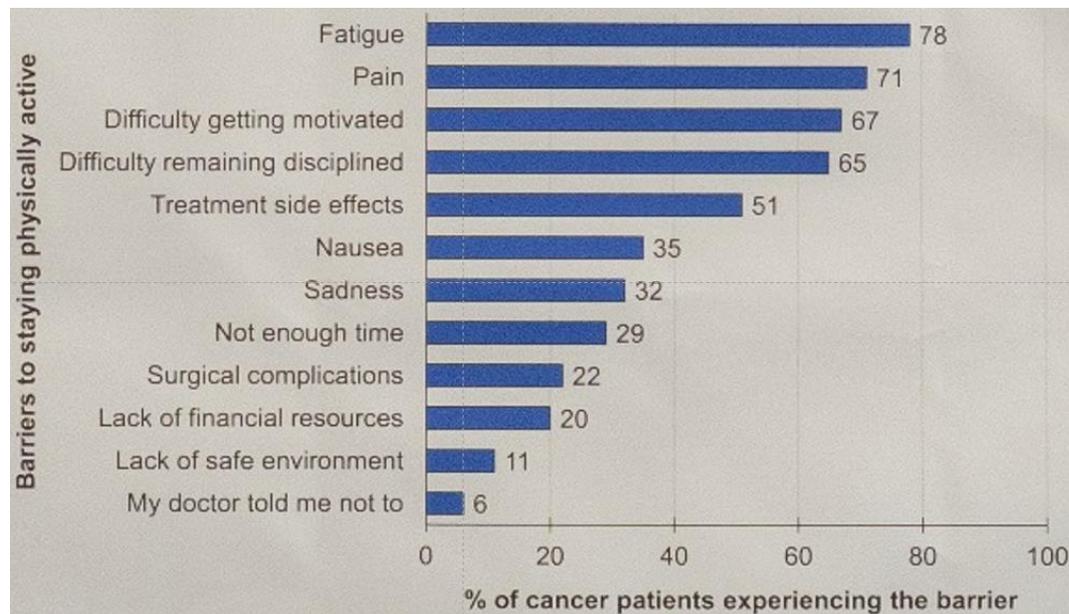
Exercise can improve outcomes for cancer survivors

There is now robust evidence that exercise can improve outcomes for cancer survivors; this topic was mentioned by several presenters and covered in a number of posters. ACS/ASCO's recent breast cancer survivorship guidelines recommend that providers **encourage all patients to engage in regular physical activity after cancer treatment (eg 150 minutes of moderate or 75 minutes of vigorous aerobic exercise per week with strength training exercises at least two days/week)** (Runowicz C et al. J Clin Oncol 2015). This is consistent with the guidelines on physical activity and nutrition for cancer survivors provided by the ACS (Rock C et al. CA Cancer J Clin 2012).

Dr M Tish Knobf and colleagues at Yale School of Nursing reported on outcomes in 148 breast cancer survivors who participated in the Yale Fitness Intervention Trial (Abstract 165). **The incidence of metabolic syndrome – a strong risk factor for cardiovascular disease – was significantly reduced after 12 months of an aerobic fitness intervention conducted at community fitness centres (p=0.0005).**

However, it should be remembered that factors associated with a cancer diagnosis can provide barriers to physical activity, as discussed in a poster by Dr Sally Romero and colleagues from the Bendheim Integrative Medicine Center at Memorial Sloan Kettering Cancer Center (Abstract 162).

In a one-time survey among 662 patients with common cancers who were being treated at 11 community hospitals and one academic medical centre, **the majority of survey respondents (75%) reported that they had decreased their physical activity levels since receiving a cancer diagnosis**, while 16% maintained pre-diagnosis activity levels and 4% increased physical activity. A variety of barriers to physical activity were reported and additional research is needed to better understand how clinicians and survivors can work together to maintain physical activity levels.



ACS guideline on physical activity and nutrition for cancer survivors

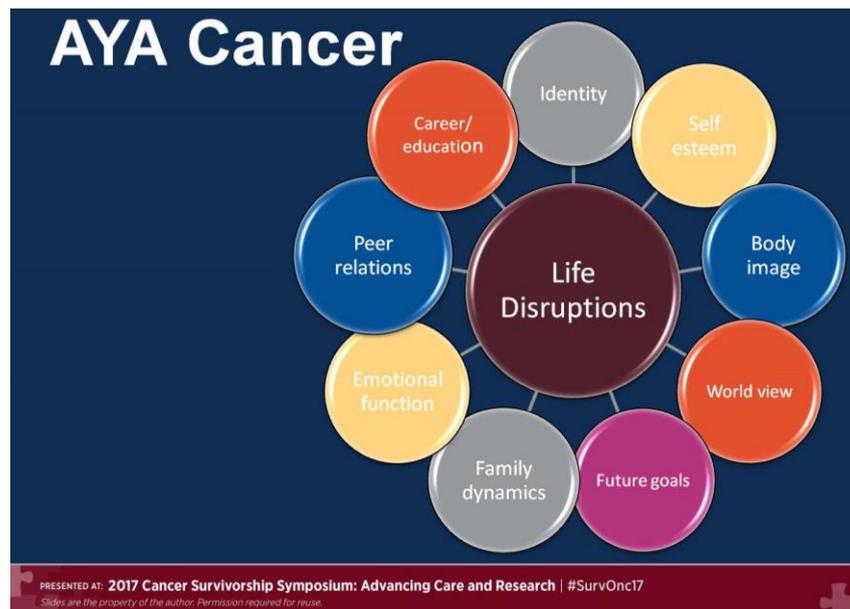
Rock CL, Doyle C, Demark-Wahnefried W, et al. Nutrition and Physical Activity Guidelines for Cancer Survivors. CA Cancer J Clin 2012; 62: 242-274. Available at: <http://onlinelibrary.wiley.com/doi/10.3322/caac.21142/epdf>

Psychosocial distress can be a major problem for cancer survivors with some groups at particularly high risk

Identifying and addressing psychosocial distress in cancer survivors also featured heavily throughout the meetings. During the “Evening for Cancer Survivors and Caregivers”, the panel highlighted the value of attending classes and seminars, which can provide an opportunity to express feelings and reduce isolation.

Dr Zeina Nahleh from the Texas Tech University Health Sciences Center in El Paso gave an oral presentation about a survivorship programme designed to improve quality of life in Hispanic/Latina women (Abstract 183). Breast cancer is the leading cause of cancer death in Hispanic/Latina women and American Hispanic breast cancer survivors have high rates of fatigue and depression. Women who were 1-5 years post-diagnosis and attending a clinic in El Paso received training in mindfulness based stress reduction (MBSR), with two hours of training weekly for eight weeks provided in Spanish and English and a workbook provided for practising at home. **At 12 months, there was a clear and statistically significant decrease in scores on the Generalised Anxiety Disorder (GAD)7 (p=0.0027) and the Patient Health Questionnaire (PHQ)9 (p=0.0031).** Dr Nahleh concluded that this small non-randomised study suggests that the MBSR model should be further evaluated in breast cancer survivors.

During a breakout session on “Unique Issues Affecting Adolescent and Young Adult (AYA) Patients” Dr Karen Fasciano from the Dana-Farber Cancer Institute highlighted the large number of life disruptions which may be experienced by the AYA cancer survivor.



AYA survivors are more vulnerable to mental health issues and to alcohol and substance use disorders and some develop symptoms of PTSD. A large study found that **12% of AYA survivors reported clinically significant chronic distress throughout the first 12 months after diagnosis** and a further 15% had delayed distress (Zebrack B et al. Psycho-Oncology 2014). Psychosocial interventions for AYA survivors seek to provide coping mechanisms, improve resilience and educate on healthy behaviours.

Resources for AYA survivors

NCCN Guidelines for Patients. Adolescents and Young Adults with Cancer. Available at: <https://www.nccn.org/patients/guidelines/aya/#90>
 Stupid Cancer®. Available at: <http://stupidcancer.org/>
 Moving Forward video series for young adults with cancer from ASCO and the LIVESTRONG Foundation. Available at: <http://www.cancer.net/navigating-cancer-care/young-adults>

Caregivers need support and education

The theme of recognising the needs of the caregiver was discussed in several posters presented during the Cancer Survivorship Symposium. Researchers from Johns Hopkins University School of Medicine reported on focus groups conducted with cancer survivors and caregivers which identified caregiver needs both from the caregivers themselves and from the perspective of survivors (Tolbert E et al, Abstract 84). Cancer survivors identified the need to provide caregivers with more information about side effects and how best to navigate healthcare systems, as well as giving support in the management of their own emotional distress and physical health. **Caregivers expressed uncertainty about their role in survivorship care planning and highlighted that both survivors and caregivers have to adjust to “a new normal”.**

Cancer-related financial toxicity is a growing problem

An oral presentation highlighted that data from the Health and Retirement Survey, a longitudinal survey in over 37 000 adults aged over 50 years show **that Black/African-Americans with a new diagnosis of cancer were significantly more likely than White/Caucasians to have household debt including high levels of debt and to develop new financial insolvency (6.8% vs 1.6%) or a ≥50% decline in net worth (27.3% vs 15.9%)** (Castellanos E et al, Abstract 03).

A summary of information presented at the 2017 Cancer Survivorship Symposium: Advancing Care and Research, co-sponsored by AAFP, ACS and ASCO, 26-27 January 2017, San Diego, CA, USA

Dr Aditi Narayan presented a poster on the results of an online survey conducted by LIVESTRONG in 2015 to learn more about the financial impact of treatment on cancer survivors and their loved ones (Abstract 10). **Fifty-nine per cent of survivors reported that they experienced a lot of or some financial problems as a result of cancer.** Twenty-seven per cent of survivors reported that they spent between \$10 000 and \$24 999 on out-of-pocket costs and **many described financial sacrifices such as using retirement savings and spending less on day-to-day living expenses.**

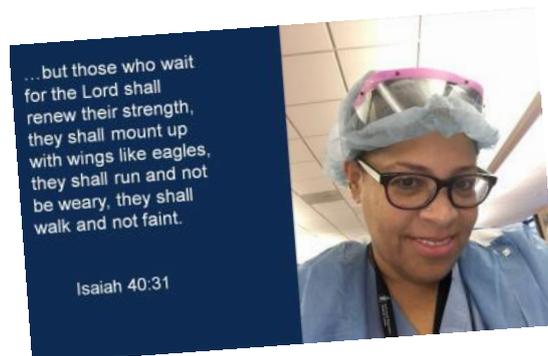
How can their experience as cancer survivors inform healthcare providers' roles?

The final plenary session of the Cancer Survivorship Symposium was entitled “One of Our Own – Insights of Health Care Providers on Coping with Cancer” and considered the various perspectives of four different cancer survivors.

Yvonne Gomez-Carrion, an Assistant Professor in ObGyn, was diagnosed with breast cancer in 2015 and found that **identifying her spiritual assets helped her to cope with her diagnosis and decreased her need for pharmaceuticals.** Dr Gomez-Carrion requested that all physicians should ask their patients about spirituality using prompts such as:

- Tell me about customs that might affect your healthcare
- What role does religion and spirituality play in your life?
- Which spiritual or religious beliefs (if any) might interfere with your undergoing certain tests or treatments?

“Medicine was my destiny... I now have my health ministry”



Richard Dickens, Director of Client Advocacy at CancerCare (a network of professional oncology social workers), was diagnosed with Stage IV indolent NHL in 1991. He believes that in our suffering we become one with the suffering of the world and our heart opens to compassion. The resilience of the human spirit is tremendous. We are all wounded and we have chosen caring professions. We can share our broken hearts to help people find healing.

Bret Sohn from Northwell Health is a survivor of retinoblastoma and had various chemotherapy and radiotherapy treatments and enucleation of his right eye. He chose to be a “Champion”, by which he means being proud and self-confident, setting aspirational goals and giving his life purpose and

meaning. Dr Sohn uses his experience as a patient to inform his role as a provider, being empathetic towards patients and their families and having strong attention to detail about all aspects of care including how he approaches a patient and the appearance of his office. He knows that he has a “true” understanding of what his patients with cancer are going through and believes that he has a responsibility to live life to the fullest.

“Adversity does not build character – it creates it”



The final speaker, Wendy Harpham from the Presbyterian Hospital of Dallas, told the audience that her understanding of hope changed soon after her 36th birthday when she was diagnosed with indolent lymphoma. An interesting discussion on the meaning of hope included the point that not all realistic hopes are healing hopes, but healing hopes can help you through uncertainty, helping you to act and to wait. For instance, hoping that check-ups will detect symptoms early or hoping that taking care of the body will keep you healthy.

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