

Highlights of the 2017 Cancer Survivorship Symposium: Part 3

During the Cancer Survivorship Symposium: Advancing Care and Research, many speakers and presenters described new approaches to the delivery of care for cancer survivors and their families. Sharing of experiences from different countries and regions within the US highlighted the challenges faced by patients and healthcare providers and provided learnings and examples of best practice. In addition, there was much discussion around different models of care and the use of online educational approaches for cancer survivors and healthcare providers. This report summarises information on these aspects of cancer survivorship which were shared during presentations and discussions.

The survivorship care plan is valuable for patients and healthcare providers

One of the key 'take home' messages from both the "Evening for Cancer Survivors and Caregivers" which preceded the Symposium as well as the meeting itself was **the importance of ensuring all survivors receive a treatment summary and survivorship care plan (SCP) which documents their precise diagnosis, specific treatments received, ongoing treatment, any symptoms or complications and recommended follow-up care / surveillance**. This should be filled out by their oncologist and shared with their primary care provider. ASCO provides a two-page template for the treatment plan and the SCP which can be used if institutions have not developed their own examples (<http://www.cancer.net/survivorship/follow-care-after-cancer-treatment/asco-cancer-treatment-and-survivorship-care-plans>).

During the Presidents' Panel on Day 2 of the meeting, representatives of ASCO, ACP and AAFP were all in agreement about the importance of the SCP and of collaborative approaches between oncologists and other physicians. The importance of providing clear and up-to-date guidelines was stressed – harmonisation of guidelines is an important goal. Available guidelines include those provided by ASCO on the management of specific cancer symptoms, as well as the tumour-specific guidelines provided in collaboration with the ACS (see Highlights of the 2017 Cancer Survivorship Symposium, Part 2).

A poster presented by researchers from St. Luke's Mountain States Tumor Institute (MSTI) in Idaho (Rosales A et al, Abstract 94) highlights that there is still some way to go in terms of broad SCP provision. Although MSTI has been providing patients and primary care physicians with SCPs for more than five years, a survey found **54% of physicians working in local primary care clinics have never received an SCP, although all are caring for cancer survivors. Moreover, 64% reported that they would like additional education about caring for cancer survivors**. An interesting poster on research conducted at Tufts Medical Center, Boston highlighted that "one size does not fit all" and **phase-specific SCPs may be useful for heterogeneous survivor populations whose needs will change over time** (eg for initial, 5- and 10-year visits for breast cancer survivors) (Parsons S et al, Abstract 61).

Dr Lisa Schwartz and colleagues described the development of a mobile application (app) for AYA survivors (AYA STEPS), which aims to improve survivorship self-management via a combined texting self-management programme (THRIVE 2.0) and an electronic SCP generator (Smart-ALACC [Smart-Adult Living After Childhood Cancer], hosted on Oncolink.org) (Abstract 74).

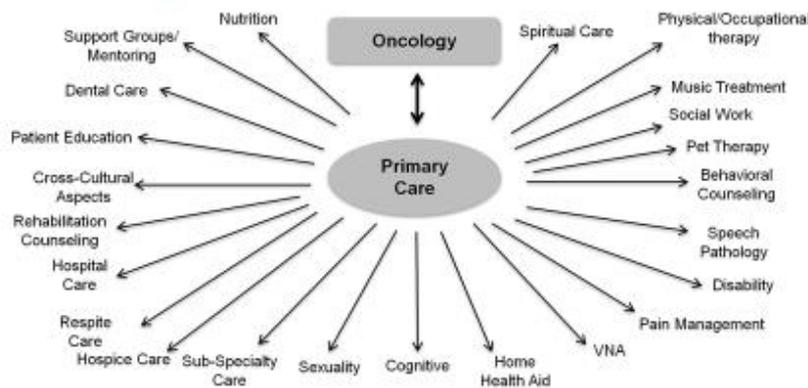


The app houses a copy of the SCP and in addition provides two-way text messages that are tailored to an individual's SCP and are designed to enhance uptake of the SCP with information, strategies for adherence, motivational messages, and appointment reminders. AYAs reported high acceptability for the app, especially the tailored text messages.

Different community-based models of survivorship care: one size does not fit all

A lively and well-attended early afternoon plenary session during the first day of the symposium focused on community-based models of survivorship care. Dr Jay Burton, an AML survivor, described the establishment of The Primary Care Cancer Survivorship Program of Western New England and Survivor Journeys which is a community-based support network of professionals in western Massachusetts and northern Connecticut. **Participants derive from a range of backgrounds and include physicians, behavioural health specialists, integrative treatment providers, cancer survivors and community leaders.**

The Essence of Primary Care Cancer Survivorship



Presented By Jay Burton at Cancer Survivorship Symposium 2017

Like many of the speakers and attendees at the Cancer Survivorship Symposium, Jay Burton brings the dual perspective on cancer survivorship from both a patient and physician point of view. He is passionate about the need to improve primary care for all cancer survivors and emphasises the importance of a treatment summary for all survivors, which includes as a minimum the exact

diagnosis, treatment received, any ongoing treatment for cancer or complications and recommended surveillance for secondary malignancies and late effects of treatment.

“To have ‘a past diagnosis of lymphoma’ on someone’s case record is just not good enough”

Dr Burton highlighted that Survivor Journeys includes cancer-specific support groups as it can be particularly beneficial to talk to other people with the same diagnosis as you. The support groups take place in the community – in libraries and churches, for instance – meaning survivors do not have to go back to a hospital environment. **Another important element of Survivor Journeys is a mentoring programme – this allows cancer survivors to give back and is empowering.** Dr Burton hopes that Survivor Journeys could become a national network across the US, sharing knowledge and best practice.

Dr Keith Argenbright from the Moncrief Cancer Institute described the Mobile Cancer Survivor Clinic which is supporting around 15 000 underserved cancer survivors living in nine counties in rural Texas.

Mobile Cancer Survivor Clinic



- ★ Custom-designed
- ★ \$1.1 million initial cost
- ★ First-of-its-kind mobile clinic
- ★ Targets underserved in rural communities



Presented By Keith Argenbright at Cancer Survivorship Symposium 2017

The mobile clinic provides consultation rooms and an exercise area and services include mammography, telemedicine (eg with hospital specialist or genetic counsellor), cervical smears and phlebotomy. The clinic has been featured on television news programmes and its impact on patient outcomes is currently being studied.

Dr Becky Lowry from the University of Kansas Medical Center described building an Adult Transition Clinic with the aim of improving outcomes for childhood cancer survivors. **A survey of 272 survivors aged 18 years or older detected significant unmet needs – more than 80% reported at least one late effect, 72% did not have a treatment summary, 52% wanted more information on late effects and, most concerning of all, 25% said they did not routinely see any healthcare providers.**

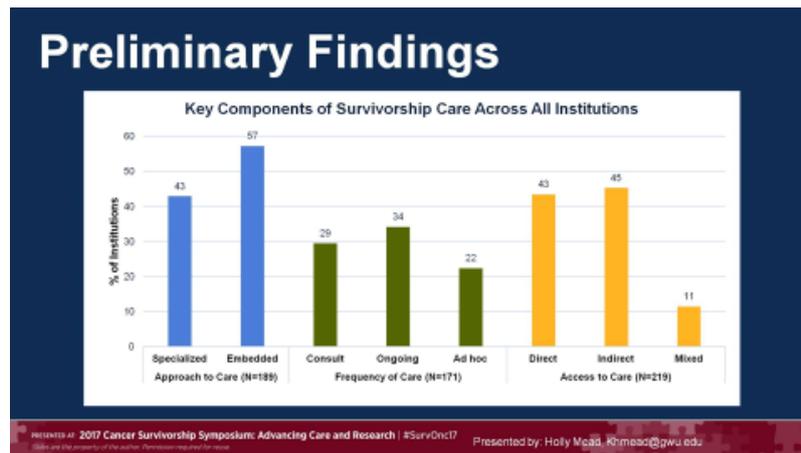
Philanthropic and institutional support was provided to set up an Adult Transition Clinic. A crux role was a shared nurse navigator – a unique position that goes between the paediatric and adult care providers and provides a point of continuity, fostering active collaboration. The largest group of attendees is now self-referrals (37%) and these patients generally do not have summaries or SCPs.

The large area covered in Kansas requires the use of telemedicine approaches. As well as enabling direct patient management, second opinions, consultations, tumour boards and professional education, telemedicine can also provide a range of patient support programmes and even real-time health coaching.

Models of survivorship care: a spectrum of global experiences

In an oral presentation, Dr Holly Mead from George Washington University presented research on identifying models of cancer survivorship care across the US, noting that little formal guidance has been provided, leading to an unsystematic approach to developing models of care.

Providers across the US (CoC-accredited cancer centres) were asked about their approach to cancer survivorship care (specialised vs embedded), the frequency of care (one-time consultative, ongoing longitudinal or ad hoc per patient request) and the route of access to services (directly through survivorship, indirectly via referral, or mixed).



While there is much variability in how survivorship care is organised, the models emerging as the most prominent were: 1. specialised consultative care with direct access; 2. specialised ongoing care with direct access; and 3. embedded ongoing care with direct access. Next steps are to examine whether outcomes differ between the models provided.

Presented By Holly Mead at Cancer Survivorship Symposium 2017

Dr Lauren Wallner from the University of Michigan gave an oral presentation on the topic of preferences and expectations for which clinicians handle various aspects of care after primary cancer treatment (Abstract 99). A weighted random sample of patients newly diagnosed with breast cancer in Georgia or Los Angeles in 2014-15 were surveyed approximately six months after diagnosis (N = 2342, 70% response rate). The majority of women preferred to see oncologists for mammograms (93%) and second cancer detection (92%), while they preferred to see primary care physicians for general preventive care (78%) and co-morbidity care (83%). **Minority women (black or Hispanic) were more likely than white women to want the oncologist to handle all aspects of oncology care, with a similar pattern being seen in women with less education compared with those who had a college-level education.**

Dr Nurdan Tacyildiz from the Ankara University School of Medicine began her oral presentation by highlighting that five-year survival for childhood cancer in Turkey is 65% and there is a need to close the gap with other developed nations such as the US. A questionnaire was developed to identify barriers and solutions, in particular problems around transition from childhood to adult care. Of 33 canters surveyed, 21 responded and only one had a (very new) survivorship clinic. Patients generally have a low awareness of possible complications and side effects of treatment and problems often arise after the age of 18 years when healthcare is no longer covered by the government. The Turkish Pediatric Oncology group has developed a simple and usable survivorship guideline which will be available soon and the organisation is also looking into developing simple booklets for patients and families.

Barriers of Turkish Pediatric Oncology Centers for LTFU of Pediatric Cancer Survivors

All centers have barriers;

	n	%
* Lack of enough care providers	14	66.6
* Lack of time	12	57.1
* Financial problems of center	7	33.3
* Lack of health insurance (after 18yrs old)	9	42.8
* Transportation problem of patients	12	57.1
* Lack of providing knowledge to patients	8	38.1

Tacyildiz N. et al. Questionnaire survey for LTFU, 2017 (Unpublished data)

Presented at: 2017 Cancer Survivorship Symposium: Advancing Care and Research | #SurvOn17

All centres were monitoring childhood survivors for cardiotoxicity, renal toxicity and second cancers without difficulty, but other aspects such as sexual function, psychosocial and financial difficulties were not monitored well due to a lack of providers and a lack of time.

Presented By Nurdan Tacyildiz at Cancer Survivorship Symposium 2017

Dr Jonathan Sussman from Hamilton, Canada is a family physician who became an oncologist. He began his oral presentation by highlighting that in the Canadian population of 35 million people who live in 10 provinces there are approximately 190 000 new cancers per year and 1.2 million survivors, meaning figures are around 1/10th of those in the US. Essential healthcare services are publicly funded for all Canadian residents and these are federally mandated and provincially administered.

Cancer survivors in Canada receive support from oncologists, family physicians, nursing, supportive care, rehabilitation and peers. Primary care is the backbone of care in Canada.

Dr Sussman described a propensity matched cohort study – 3000 transitioned patients were compared with controls who were not transitioned. Patients who were transitioned received better surveillance, with more mammograms performed and fewer unnecessary tests (CT and MRI scans). Costs were \$200 per person less in the transitioned group and survival appeared to be better.

Various initiatives are under way in Canada including a collaborative residency training programme and functional integration with an electronic platform for SCPs. The electronic pilot was well received by primary care physicians and patients. **During the collaborative residency programme, trainees in family medicine and oncology are to learn together about survivorship care via a blended learning approach – online modules are completed followed by a three-hour workshop looking at case studies.** So far, 300 residents have completed the training which has been very well received.

Dr Purna Kurkure, Emeritus Professor at the Tata Memorial Hospital reminded the audience that the Indian Cancer Society (ICS) was set up in 1951 and in 1954 it began the first cancer registry in Asia. The ICS has been conducting awareness programmes and mobile detection clinics since 1982. ICS is currently focusing on survivorship and wants this to be integrated with rehabilitation.



Ugam is a survivor support group which has been running since 2009 and now has 250 members. Ugam helps with job placements, career advice and educational scholarships.

International Survivorship Efforts 3 “Tiers” of Development

- Tier 1: The United States, Canada, Australia, and Western and Northern Europe
–Extensive research infrastructure, emerging policies, practices and guidelines
- Tier 2: Eastern/southern Europe, Asia (primarily Japan & Korea), parts of Latin America (e.g. Brazil)
–Limited research infrastructure, few survivorship oriented policies or practice, no guidelines
- Tier 3: Low-to-middle income (LMI) countries: Asia, Africa, the Caribbean, Central America
–Very limited research, almost no focus on survivorship, focus on treatment and pain management

PRESENTS AT 2017 Cancer Survivorship Symposium: Advancing Care and Research | #SurvOnc17
Presented by: Dr Purna Kurkure

International co-ordination of survivorship efforts is currently limited and there are essentially three “tiers” of development. In India there is no national or state level policy that addresses the employment/financial needs of cancer survivors.

Presented By Purna Kurkure at Cancer Survivorship Symposium 2017

A key component of survivorship care in India is a late effect follow-up clinic run at the Tata Memorial Hospital by a specialist in late effects. This is the After Completion of Therapy (ACT) clinic which was first set up in 1991, and monitors for late effects, growth development and psychosocial problems. As of Dec 2016, 1845 survivors have been followed (1335/510 male/female which reflects that culturally the male child is given preference).

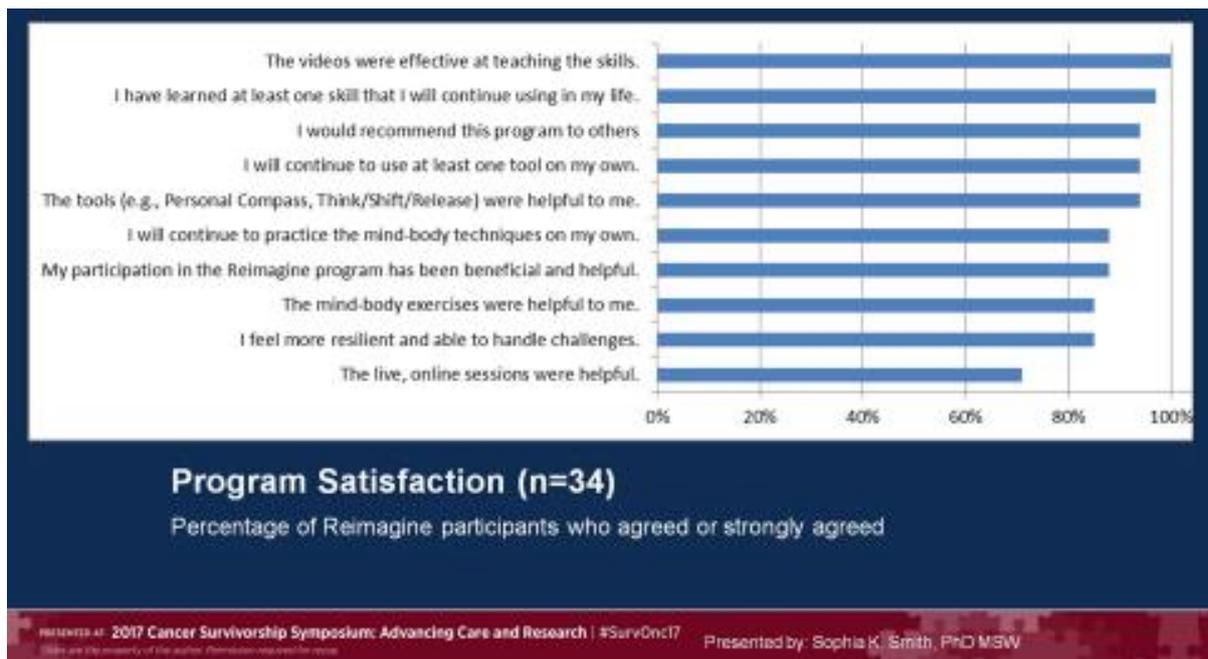
Project PICASSO aims to optimise survivorship care in India, with Stage 1 focusing on childhood cancers, Stage 2 on adolescents and young adults and Stage 3 on adults. The key challenges are the establishment of survivorship as a distinct entity, getting funding and raising awareness. It has the potential to improve the quality of life for thousands of cancer survivors.

In response to a question from the audience, Drs Kurkure and Tacyildiz stated that in India and Turkey primary care physicians are too busy to take a significant role in survivorship care and it is the oncologists who need to be targeted first to champion survivorship care before extending it into primary care. Dr Kurkure commented that – as happened in survivorship care in the US – in India “children would lead the way”.

Online educational approaches for survivors and healthcare providers

Dr Sophia Kustas Smith from the Duke School of Nursing gave a presentation on the impact of an online, symptom self-management curriculum (Reimagine) on key health outcomes. Adult breast cancer survivors with chronic pain were recruited from the Susan Love Army of Women volunteer registry and randomised 1:1 to the treatment or usual care condition. Treatment arm participants accessed content online and required activities included viewing online videos, attending online group meetings and completing cognitive reframing exercises. **There was a significantly greater reduction in depression scores ($p=0.035$) and improvement in fatigue scores ($p=0.038$) in patients receiving the intervention compared with usual care**, although no significant differences were found in the change in pain outcomes for treatment and usual care conditions. **Most treatment arm participants (94%) would recommend Reimagine to others and 85% felt more resilient at study completion.**

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



In discussing the data presented by Dr Smith, Dr Tara Henderson from the University of Chicago noted a recent publication from Fleisher and associates (Internet Interv 2015), which reported that, **while around 60% of patients used an eHealth tool, more than 90% reported reading print materials, indicating that we must ensure patients can access complementary channels of resources.** Comments from the audience during the panel discussion reinforced the themes addressed by the presenters and discussants, in particular highlighting the wide variation in comfort with using eHealth tools in people of different ages and racial backgrounds.

Useful online survivorship resources

Shapiro CL, Jacobsen PB, Henderson T, et al. ASCO Core Curriculum for Cancer Survivorship Education.

Available at: <http://ascopubs.org/doi/pdf/10.1200/JOP.2015.009449>

Focus Under Forty: Survivorship. Online training provided by ASCO University. Available at:

<http://university.asco.org/survivorship>

Anti-cancer treatment toxicities. Online training provided by ASCO University. Available at:

<http://university.asco.org/anti-cancer-treatment-toxicities>

Cancer Survivorship Series Courses provided by The University of Texas MD Anderson Cancer Center. Available

at: <https://www.mdanderson.org/education-training/professional-education/professional-oncology-education/survivorship.html>

National Cancer Survivorship Resource Center (developed by ACS and the GW University). Available at:

<https://www.cancer.org/health-care-professionals/national-cancer-survivorship-resource-center.html>

Cancer.Net's survivorship section. Available at: <http://www.cancer.net/survivorship>

References

Abstracts from the Cancer Survivorship Symposium. Available at:

<http://meetinglibrary.asco.org/subcategories/2017%20Cancer%20Survivorship%20Symposium>

Cancer Survivorship Symposium Meeting Program. Available at: <http://survivorsym.org/program/program>

Fleisher L, et al. Development and utilization of complementary communication channels for treatment decision making and survivorship issues among cancer patients: The CIS Research Consortium Experience. Internet Interv 2015; 2: 392-398.