

# **Coleman Supportive Oncology Initiative**

## **Survivorship Training Module**

### **Topic: Comprehensive Care for Cancer Survivors**

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Frank J. Penedo, PhD**

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# Learning Objectives

**By the end of this module you should be able to:**

- 1. Explain what is comprehensive follow-up care for cancer survivors**
- 2. Describe common models of survivorship care**
- 3. Identify major challenges of survivorship care**

# Comprehensive Follow-Up Care for Cancer Survivors



## Provider's Clinical Assessment

### **Cancer Surveillance and Screening**

- Detection and treatment of late malignancy recurrence or new second malignancies

### **Risk Reduction and Cancer Prevention**

- Life style changes to prevent cancer and risk assessment

### **Late / Side Effects Management**

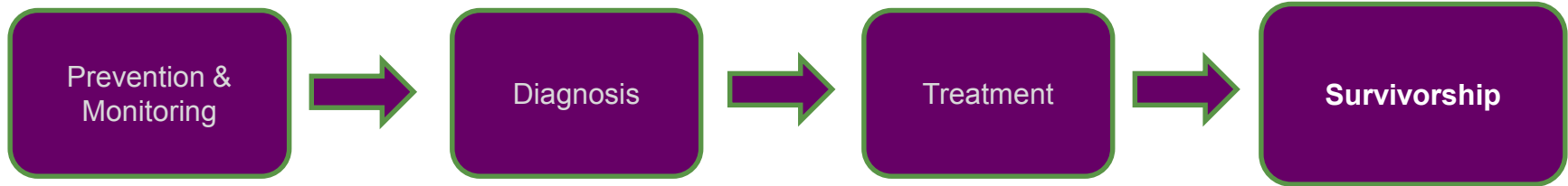
- Health maintenance and observation of vital organ function

### **Psychological Functioning**

- Psychological support services to maintain healthy relationships and restored life

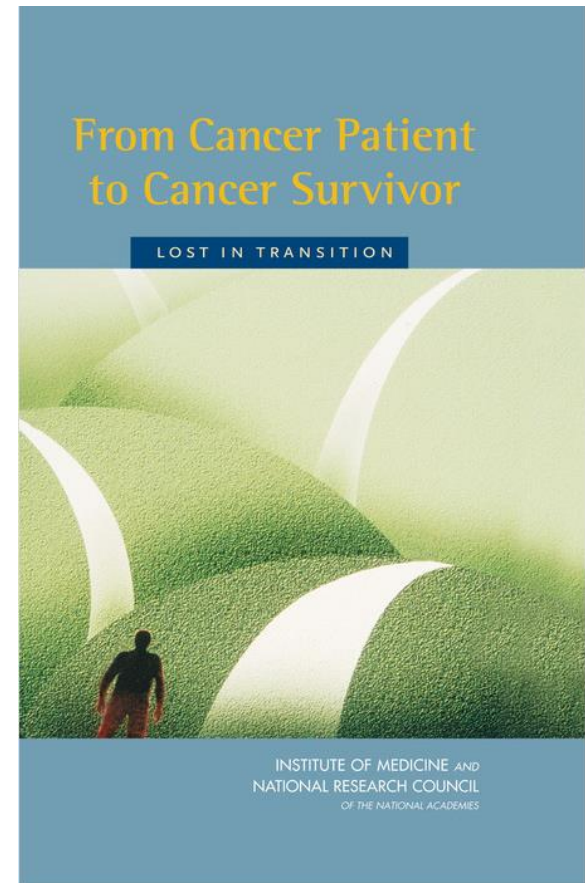
# Potential Models of Survivorship Care

Model	Description	Pros	Cons
<b>Provider Centered Model</b>	Each mid-level provider & MD is responsible for the survivorship care plan.	<ul style="list-style-type: none"> <li>• Team will know the patient the best and be most familiar with cancer type/recommendations.</li> <li>• Patient may respond best to primary team.</li> <li>• Can be done within existing appointment so no extra trip.</li> </ul>	<ul style="list-style-type: none"> <li>• Very time consuming for primary team (will take about 20 min. per patient to prepare + counseling time).</li> <li>• May not be feasible in some departments.</li> <li>• Will not capture billing if done at an existing visit.</li> <li>• Lack of consistency between providers.</li> </ul>
<b>Department Centered Model</b>	The mid-level provider in each department (surgery, med. onc., rad. onc., dermatology, geriatric onc., AYAO) is responsible for the survivorship care plan. Patients would see them as a separate visit.	<ul style="list-style-type: none"> <li>• Mid-level will still have some expertise in department.</li> <li>• Can still have some consistency between the mid-levels providing survivorship care plan (SCP).</li> <li>• Possible to more efficiently do research with a consistent group delivering SCP.</li> <li>• Bill for separate visit.</li> </ul>	<ul style="list-style-type: none"> <li>• Will need to hire mid-levels vs. determine if existing people have time.</li> <li>• Patient will have someone different from primary team delivering recommendations.</li> <li>• A separate trip for patients.</li> </ul>
<b>Survivorship Centered Model</b>	Central Survivorship Clinic along with a few mid-level providers (from each department) & MD see ALL patients in the cancer center as a separate visit.	<ul style="list-style-type: none"> <li>• We can have some consistency still between the mid-levels providing SCP.</li> <li>• Could more efficiently do research with a consistent group delivering SCP.</li> <li>• Bill for separate visit.</li> </ul>	<ul style="list-style-type: none"> <li>• Need to hire mid-levels.</li> <li>• Mid-level may not have specific expertise in each field (surgery, radiation).</li> <li>• Patient will have someone different from primary team delivering recommendations.</li> <li>• A separate trip for patients.</li> </ul>



## Institute of Medicine Report (2005)

- Lack of attention to survivors' needs
- Limited guidelines for follow-up
- Recurrence, second cancers and treatment late effects are of concern
- Providers lack adequate training
- Physical and psychosocial concerns are not well addressed



## Patient's Perspective of Survivorship

- **Livestrong Poll shows:**
  - 49% of survivors felt their needs as survivors were unmet
  - 70% felt their oncologists were unwilling to discuss survivor needs
  
- **53% reported secondary health problems:**
  - Cancer survivors have an average of 3 comorbidities after treatment
  - 23% of all survivors in the United States are breast cancer survivors

## Challenges of Cancer Survivorship for Patients

- **Treatment side effects can be chronic and debilitating, often necessitating psychosocial and medical care.**
- **Care can be complex and typically involves multi-disciplinary teams.**
- **Medical care can be fragmented: for example there may be limited continuity from medical oncology to primary care.**
- **Costs of care can present a financial burden to the patient.**
- **Treatment-related side effects can lead to functional limitations and interpersonal disruption, affecting personal, family, social and professional roles.**
- **In many cases, the disease course is uncertain.**
- **Ongoing monitoring can cause distress and fear of recurrence.**
- **Challenges of survivorship can impact all facets of quality of life (emotional, functional, physical and social well-being).**
- **Comorbid conditions and accelerated age-related declines in older patients add to the complexity of care.**



## Challenges of Cancer Survivorship Plan Delivery

- **Time: It takes a minimum of 20 minutes to prepare the care plan.**
- **Review with patient may be variable depending on treatment, stage, patient characteristics and other factors (e.g., literacy).**
- **Provider teams may find it difficult to incorporate this extra step into their existing workload.**
- **Reimbursement is limited and not specific to survivorship care services.**

## **Billing for Survivorship Care** (1 of 2)

- **Fee schedules are based off of national Medicare guidelines and reimbursement may vary by payer.**
- **Visits in a survivorship clinic may be billable.**
- **All visits should include appropriate key components such as a detailed history, exam documentation and medical decision-making.**

## Billing for Survivorship Care (2 of 2)

- **Documenting for Time-Based Visits**
  - Total time of visit
  - Total time spent counseling
  - Details of the discussion
  
- **Prolonged Service**
  - Document the start and end time
  - Document the details of the discussion
  
- **Smoking Cessation**
  - Document the start and end time
  - Document the details of the discussion
  
- **Treatment planning and coordination management for cancer care**
  - Document the start and end time
  - Document the details of the discussion
  - Archive an electronic copy of Survivorship Care Plan including date provided to patient

## Summary of Points Covered

**In this training module we addressed:**

- **What comprehensive follow-up care for cancer survivors is and the components of a provider's clinical assessment**
- **Common models of survivorship care, as well as potential models of survivorship care**
- **The complex major challenges of survivorship care**

## Next Steps

For more detailed training on this topic, you can go to the following resources:

### National Comprehensive Cancer Network®

- [NCCN Clinical Practice Guidelines in Oncology \(NCCN Guidelines®\) for Survivorship](http://www.nccn.org/professionals/physician_gls/pdf/survivorship.pdf)  
http://www.nccn.org/professionals/physician\_gls/pdf/survivorship.pdf
- [Patient and Caregiver Resources, Taking Charge of Follow-Up Care](http://www.nccn.org/patients/resources/life_after_cancer/survivorship.aspx)  
http://www.nccn.org/patients/resources/life\_after\_cancer/survivorship.aspx

### American Society of Clinical Oncology, ASCO®

- [Cancer.Net, ASCO Cancer Treatment and Survivorship Care Plans](http://www.cancer.net/survivorship/follow-care-after-cancer-treatment/asco-cancer-treatment-and-survivorship-care-plans)  
http://www.cancer.net/survivorship/follow-care-after-cancer-treatment/asco-cancer-treatment-and-survivorship-care-plans

### American Cancer Society

- [National Cancer Survivorship Resource Center](http://www.cancer.org/treatment/survivorshipduringandaftertreatment/nationalcancersurvivorshipresourcecenter/index)  
http://www.cancer.org/treatment/survivorshipduringandaftertreatment/nationalcancersurvivorshipresourcecenter/index

### Journal of Medical Internet Research

- [An Internet Tool for Creation of Cancer Survivorship Care Plans for Survivors and Health Care Provider: Design, Implementation, Use and User Satisfaction](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2762859/)  
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2762859/

### National Cancer Institute, NIH

- [Office of Cancer Survivorship](http://cancercontrol.cancer.gov/ocs/)  
http://cancercontrol.cancer.gov/ocs/
- [Follow-up Care After Cancer Treatment](http://www.cancer.gov/about-cancer/coping/survivorship/follow-up-care/follow-up-fact-sheet)  
http://www.cancer.gov/about-cancer/coping/survivorship/follow-up-care/follow-up-fact-sheet

### Memorial Sloan Kettering Cancer Center

- [Survivorship Care Plans, Guides for Living After Cancer Treatment](https://www.mskcc.org/sites/default/files/node/4931/documents/survivorshipcareplans.pdf)  
https://www.mskcc.org/sites/default/files/node/4931/documents/survivorshipcareplans.pdf

## Next Steps (con't.)

For more detailed training on this topic, you can go to the following resources:

### Institute Of Medicine

- **[From Cancer Patient to Cancer Survivor: Lost in Transition](http://iom.nationalacademies.org/Reports/2005/From-Cancer-Patient-to-Cancer-Survivor-Lost-in-Transition.aspx?utm_source=Twitter&utm_medium=Tweet&utm_campaign=Hootsuite)**  
[http://iom.nationalacademies.org/Reports/2005/From-Cancer-Patient-to-Cancer-Survivor-Lost-in-Transition.aspx?utm\\_source=Twitter&utm\\_medium=Tweet&utm\\_campaign=Hootsuite](http://iom.nationalacademies.org/Reports/2005/From-Cancer-Patient-to-Cancer-Survivor-Lost-in-Transition.aspx?utm_source=Twitter&utm_medium=Tweet&utm_campaign=Hootsuite)
- **[Cancer Survivorship Care Planning](http://iom.nationalacademies.org/~media/Files/Report%20Files/2005/From-Cancer-Patient-to-Cancer-Survivor-Lost-in-Transition/factsheetcareplanning.pdf)**  
<http://iom.nationalacademies.org/~media/Files/Report%20Files/2005/From-Cancer-Patient-to-Cancer-Survivor-Lost-in-Transition/factsheetcareplanning.pdf>

### Survivorship Care Plan Resources

- **Journey Forward**  
[www.journeyforward.org](http://www.journeyforward.org)
- **Prescription for Living**  
[www.nursingcenter.com](http://www.nursingcenter.com)
- **Livestrong Survivorship Care Plan**  
[www.livestrongcareplan.org](http://www.livestrongcareplan.org)
- **Memorial Sloan Kettering**  
[www.mskcc.org](http://www.mskcc.org)
- **ASCO treatment summaries**  
[www.cancer.net](http://www.cancer.net)

## Faculty Bio for Sheetal Kircher, MD

**Dr. Sheetal Kircher is a Medical Oncologist and Assistant Professor in the Department of Medicine at Northwestern University. Her clinical focus is the treatment of gastrointestinal malignancies. Dr. Kircher's research interests are to improve the quality of cancer care and cancer survivorship. Her work focuses on better understanding the trends in use and expenditure of services and medical treatments for cancer patients. She is particularly interested in the patient's experience of cancer treatment in relation to financial burden and the patient-provider communication about costs of care.**

**She currently serves as Northwestern Survivorship Institute Medical Co-Director and Director of the Survivorship Specialty Clinics where she oversees programmatic aspects of survivorship medical care across the Specialty Survivorship Clinics in the Lurie Cancer Center.**

**For additional information:**

<http://cancer.northwestern.edu/survivorship/institutemembers.cfm>



## **Faculty Bio for Javier Macias, BA**

**Javier Macias is the Multicultural Community Outreach Manager with The Leukemia & Lymphoma Society (LLS). He is tasked with the coordination of the Be Your Own Advocate (BYOA) Program and the Illinois Blood Cancer Conference. Throughout his 3-years tenure with LLS, Mr. Macias has built a reputation for implementing successfully a strategy for community outreach in under-represented communities in Illinois, primarily Latino and African American.**

**Prior to LLS, Mr. Macias worked as a Development Specialist and coordinating Community Programs with Easter Seals where he spent over 5 years working with donors and providing much needed services to people in the community.**

**Mr. Macias currently serves as member to the Survivorship team for the Coleman Supportive Oncology Initiative (CSOI). The CSOI focuses on enhancing supportive care services that improve quality of life for patients and families affected by cancer by reducing physical and emotional burdens throughout the care continuum, from diagnosis through survivorship and end of life.**

**For additional information:**

<http://www.lls.org/illinois>



## Faculty Bio for Frank J. Penedo, PhD

Dr. Frank J. Penedo is the Roswell Park Professor of Medical Social Sciences, Psychology and Psychiatry and Behavioral Sciences. He is also the Program Leader of the Cancer Control and Survivorship Program in the Lurie Cancer Center and the Director of the Cancer Survivorship Institute at Northwestern Medicine. He is trained in clinical psychology and behavioral medicine and his research has focused on evaluating the role of psychosocial, sociocultural and biobehavioral processes in adjustment, health related quality of life (HRQOL) and health outcomes in chronic disease populations with a major emphasis on diverse cancer survivors in regard to race, ethnicity and socio-economic status. Dr. Penedo has served as PI, co-PI or project leader on multiple NIH-funded studies addressing psychosocial and biobehavioral correlates of adjustment and the efficacy of psychosocial interventions in improving HRQOL, symptom burden and health outcomes in chronic disease populations. He has significant expertise in community based, cohort and intervention studies that target cancer survivors and involve collection and analyses of psychosocial and biological data. He has over 110 peer-reviewed publications, has served as associate editor of two major journals in his field, and some of his translational work has been disseminated as clinical intervention tools. Dr. Penedo currently serves as a standing member of the NIH BMIO study section and on the editorial board of several major journals in his field. He is the president elect of the International Society of Behavioral Medicine, a fellow of the Society of Behavioral Medicine and a member of the Academy of Behavioral Medicine Research. He has received numerous awards and also served on the advisory boards of community organizations such as the Wellness Community, the Intercultural Cancer Council and Salud America.

**Link to website with additional information about the faculty member:**

<http://www.feinberg.northwestern.edu/faculty-profiles/az/profile.html?xid=24719>

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[http://www.nccn.org/patients/resources/life\\_after\\_cancer/survivorship.aspx](http://www.nccn.org/patients/resources/life_after_cancer/survivorship.aspx). Accessed 01/13/2016

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Treatment. <https://www.mskcc.org/sites/default/files/node/4931/documents/survivorshipcareplans.pdf>. Accessed January 13, 2016.

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