RETHINKING FOLLOW UP CARE WHILE ADDRESSING BLADDER CANCER SURVIVORS NEEDS

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Disclosures

◦ I am a stockholder and advisor to Carevive Systems
◦ I will not discuss any drugs during this presentation
Objectives

- Examine cancer statistics
- Define cancer survivor and survivorship care
- Appraise survivorship issues bladder cancer survivors face
- Reframe follow-up care for bladder cancer survivors
- Describe needed survivorship research
Survivorship Over Time

“War” → “Competition” → “Journey”

1950 5-yr survival = 30%
1975 5-yr survival = 48%
1986
1996
2005
2007
2019 5-yr survival = 68%

3m
16.9 m

“Good Patient”
“Victims”
“Empowered Patient”
“Survivors”
More Than a Statistic

CANCER IN THE US
Top 10 Causes of Death: 1900 vs. 2010

1. Pneumonia or influenza, 202.2
2. Tuberculosis, 194.4
3. Gastrointestinal infections, 142.7
4. Nephropathies, 88.6
5. Accidents, 72.3
6. Cancer, 64.0
7. Diphtheria, 40.3
8. Senility, 50.2
9. Cerebrovascular disease, 106.9
10. Heart disease, 137.4

No. of Deaths/100,000

1900 vs. 2010

Figure 1. Number of deaths due to heart disease and cancer: United States, 1950–2014

NOTES: Leading cause is based on number of deaths. Access data table for Figure 1.
The number of cancer survivors is projected to increase by 31%, to almost 26 million, by 2040.

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By 2040, 73% will be ≥ 65
Survivors Projected in 2022

Over next 10 years, those living beyond 5 years will increase by 35%
Estimated Number of Cancer Survivors in the U.S., by Site

- **High Volume**
- **High Need**
Estimated Number of Persons Alive in the U.S. Who Were Diagnosed With Cancer, by Site (as of January 1, 2014)
Total Cancer Survivors, N=14.5M

- Female breast: 22%
- Prostate: 13%
- Colorectal: 7%
- Gynecologic: 7%
- Hematologic: 7%
- Urinary Bladder, Kidney, Renal Pelvis: 21%


Bladder Cancer

Statistics at a Glance

**At a Glance**

- **Estimated New Cases in 2019**: 80,470
- **% of All New Cancer Cases**: 4.6%
- **Estimated Deaths in 2019**: 17,670
- **% of All Cancer Deaths**: 2.9%

**Percent Surviving 5 Years**

- **2009-2015**: 77.1%
In 2016, there were an estimated 699,450 people living with bladder cancer in the United States.

### Five-year Relative Survival Rates (%) by Race, 2007-2013

<table>
<thead>
<tr>
<th>Site</th>
<th>White</th>
<th>Black</th>
<th>Absolute Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>All Sites</td>
<td>70</td>
<td>63</td>
<td>7</td>
</tr>
<tr>
<td>Breast (female)</td>
<td>92</td>
<td>83</td>
<td>9</td>
</tr>
<tr>
<td>Colorectum</td>
<td>67</td>
<td>59</td>
<td>8</td>
</tr>
<tr>
<td>Esophagus</td>
<td>22</td>
<td>12</td>
<td>10</td>
</tr>
<tr>
<td>Non-Hodgkin lymphoma</td>
<td>74</td>
<td>67</td>
<td>7</td>
</tr>
<tr>
<td>Oral cavity &amp; pharynx</td>
<td>69</td>
<td>49</td>
<td>20</td>
</tr>
<tr>
<td>Ovary</td>
<td>46</td>
<td>39</td>
<td>7</td>
</tr>
<tr>
<td>Prostate</td>
<td>&gt;99</td>
<td>97</td>
<td>3</td>
</tr>
<tr>
<td><strong>Urinary bladder</strong></td>
<td>79</td>
<td>65</td>
<td>14</td>
</tr>
<tr>
<td>Uterine cervix</td>
<td>71</td>
<td>58</td>
<td>13</td>
</tr>
<tr>
<td>Uterine corpus</td>
<td>85</td>
<td>65</td>
<td>20</td>
</tr>
</tbody>
</table>

### Trends in Five-year Relative Survival Rates (%), 1975-2012

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>All sites</strong></td>
<td>49</td>
<td>55</td>
<td>69</td>
</tr>
<tr>
<td>Breast (female)</td>
<td>75</td>
<td>84</td>
<td>91</td>
</tr>
<tr>
<td>Colorectum</td>
<td>50</td>
<td>60</td>
<td>66</td>
</tr>
<tr>
<td>Leukemia</td>
<td>34</td>
<td>43</td>
<td>63</td>
</tr>
<tr>
<td>Lung &amp; bronchus</td>
<td>12</td>
<td>13</td>
<td>19</td>
</tr>
<tr>
<td>Melanoma of the skin</td>
<td>82</td>
<td>88</td>
<td>93</td>
</tr>
<tr>
<td>Non-Hodgkin lymphoma</td>
<td>47</td>
<td>51</td>
<td>73</td>
</tr>
<tr>
<td>Ovary</td>
<td>36</td>
<td>38</td>
<td>46</td>
</tr>
<tr>
<td>Pancreas</td>
<td>3</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>Prostate</td>
<td>68</td>
<td>83</td>
<td>99</td>
</tr>
<tr>
<td><strong>Urinary bladder</strong></td>
<td>72</td>
<td>79</td>
<td>79</td>
</tr>
</tbody>
</table>


Source: Surveillance, Epidemiology, and End Results (SEER) Program, National Cancer Institute, 2016.
Defining Survivors and Survivorship

The Face of Cancer
Cancer Survivor: An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. There are many types of survivors, including those living with cancer and those free of cancer. This term is meant to capture a population of those with a history of cancer rather than to provide a label that may or may not resonate with individuals.

- Adapted from the National Coalition for Cancer Survivorship
Survivorship Defined

- **Living cancer free**
  - For remainder of life
  - Experiences $\geq 1$ treatment complication
  - But dying after a late recurrence
  - But develops another cancer

- **Living with cancer**
  - Intermittent periods of active disease on/off treatment
  - Continuously without disease free period
Survivorship Definition and Attributes

- Defined as those who have lived through a potentially deadly or life altering event.
- It is a dynamic process
- It involves uncertainty
- It is a life changing experience
- It has duality of positive and negative aspects
- It is an individual experience with universality

BUMPS ON THE ROAD OF LIFE
‘Life is the at the same time more vibrant and more dispiriting, more rich and more challenging, more wonderful and more exhausting, more assured yet more uncertain.’
Models of Survivorship Care
Essential Components of Survivorship Care

- Prevention of recurrent and new cancers and other late effects
- Surveillance for cancer spread, recurrence or new cancers and assessment and mitigation of physical and psychosocial late effects
- Health Promotion
- Coordination between specialists and primary care providers to ensure that the survivors health needs are met
Adult Follow-up Care Models

- Multidisciplinary
- Disease specific
- Consultative service
- Integrated care model
- Risk-stratified and shared care

Risk-Stratified Shared Care Model for Cancer Survivors

Low Risk:
- All of the following:
  - Surgery only or chemotherapy that did not include radiation agent, anthracycline, bleomycin, or epipodophyllotoxin
  - No radiation
  - Low risk of recurrence
  - Mild or no persistent toxicity of therapy

Moderate Risk:
- Any of the following:
  - Cancer that developed before or during treatment with chemotherapy or radiation therapy
  - Prior diagnosis of cancer
  - Moderate risk of recurrent cancer
  - Moderate risk of treatment-related morbidity

High Risk:
- Any of the following:
  - High dose chemotherapy agent, anthracycline, bleomycin, or epipodophyllotoxin
  - High dose radiation
  - Allogeneic stem-cell transplant
  - Multi-organ persistent toxicity of therapy

Communication Points with Primary Care Physician:
- Cancer diagnosis and planned therapeutic approach; brief overview of chemotherapy, radiation therapy and/or surgery.
- Survivorship Care Plan: cancer diagnosis, cancer therapy, surveillance recommendations, contact information.
- Periodic update with changes in surveillance recommendations, and new information regarding potential late effects.
- Periodic update of survivor’s health for primary care physicians record.

Abbreviations:
- CA: Cancer diagnosis; Dx: Diagnosis; Off Rx: Completion of cancer therapy; PCP: primary care physician; LTFU: long term follow-up (survivor) program; Oncologist
- Primary responsibility for cancer-related care; PCP continues to manage non-cancer comorbidities and routine preventive health maintenance.
- Cancer Center or Oncology/radiation group practice or if there is not an LTFU Survivor Program available, care in the US is provided by the primary oncologist.

McCabe MS, et al. (2013) *Semin Oncol.*, 40:804-12

Risk Stratified Model National Cancer Survivorship Initiative

Supported self-management (patients at low risk for developing long-term and late effects of treatment):
- Patients are given the knowledge and skills to self-manage their care

Shared care (patients at moderate risk for developing long-term and late effects of treatment):
- Patients have regular contact with health-care professionals

Complex case management (patients at high risk for developing long-term and late effects of treatment):
- Patients need intensive support from health-care services to meet their needs

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Risk Stratified Shared Care Model

Patients at low risk of developing long-term and late effects of treatment
All of the following:
- Surgery only
- Non-alkylating chemotherapy
- No radiotherapy
- Low risk of recurrence
- Mild or no persistent toxicity of therapy

Patients at moderate risk of developing long-term and late effects of treatment
Any of the following:
- Low or moderate-dose alkylating agent
- Low or moderate-dose radiotherapy
- Autologous stem-cell transplantation
- Moderate risk of recurrence
- Moderate persistent toxicity of treatment

Patients at high risk of developing long-term and late effects of treatment
Any of the following:
- High-dose alkylating agent
- High-dose radiotherapy
- Allogeneic stem-cell transplantation
- High risk of recurrence
- Multi-organ persistent toxicity of therapy

Risk Stratified Model of Care

- Breast 70-80%
- Colorectal 50%
- Prostate 40-50%

http://www.evidence.nhs.uk/qipp
Lessons from Other Countries

- England and Northern Ireland (National Cancer Survivorship Initiative or NCSI)
  - Triage to one of three pathways based on risk of recurrence, subsequent cancers and late effects; severity of ongoing treatment sequelae; functional ability; psychosocial issues; health literacy and ability to self-manage:
    - Supported self-management
    - Shared care with self-management on provider (either PCP or Oncologist)
    - Complex care management
  - 14 sites in England for CRC, breast and prostate cancers
    - 50% CRC, 80% Breast and 50% prostate patients treated with curative intent → supported self-management
    - Projected savings of £90m/5 years with 58% breast patients supported self-management

Sustainable Cancer Redesign

Figure 1: The Recovery Package

Figure 3: Key breast cancer follow-up findings from the TCFU evaluation

- Enhance coordination and integration of care
  - 1,000 fewer patients receiving dual speciality follow-up (39% reduction)
  - More patients feeling various aspects of their care were well coordinated: 71%+78%
- Improve cancer patients' aftercare experience
  - Patients satisfied with the timing of appointments: 70%-80%
  - More patients feeling supported to manage the emotional impacts of their cancer: 64%-67%
- Improve resource utilisation
  - Release of almost 3,000 review appointments
  - 2,724 fewer patients on surgical review waiting lists (28% reduction)
  - 228 fewer patients on oncology review waiting lists (4% reduction)
  - More than 1,000 patients had received an HRA


Figure 6: % change in breast cancer surgical review waiting lists versus monthly incidence, Nov 12–Mar 16

- Initial TCFU project goes out of budget
- % change in no. of N.I. patients on breast surgical review waiting lists (vs Nov 2012)
- Linear (Unstandardised monthly incidence of breast cancer – all NI)
- Unstandardised monthly incidence of breast cancer – all NI

Source: Monthly incidence figures courtesy of the N. Ireland Cancer Registry. Incidence data are only available to December 2014.

https://www.nice.org.uk/savingsandproductivityandlocalpracticeresource?id=2632
Stratified pathways of care will be influenced by:

- Assessing the level of risk for disease related comorbidity and recurrence, dependent on the tumour type;
- Short, medium and long-term treatment sequelae;
- Existing comorbidities;
- Survivor ability and motivation to engage and self-manage;
- Level of professional involvement required.
Principles of Personalized Follow-up Care Pathways

- Triage into care pathways is influenced by more than risk of recurrence, subsequent cancers or late effects.

- Patient-identified issues should guide the delivery of care.

- Remote monitoring should be used to imbed a survivor in a surveillance system to monitor them for the exacerbation of ongoing cancer-related symptoms or functional limitations, and for early recurrence, new cancer, or late effects detection.

- Shifting patients to supported self-management and reducing face-to-face clinic visits is critical for improving clinic utilization and cost outcomes.

- Coordination and information exchange among oncology, primary care, specialists and patients is essential.

- Engaging all stakeholders, securing their buy-in, and using change management and continuous improvement principles are critical for successful follow-up care transformation.
Continuing Care for Cancer Survivors

Prevalence by Phase of Care, All Sites, All Ages, Male and Female, in 2010 Dollars

National Costs of Cancer Care by Phase of Care, All Sites, All Ages, Male and Female, in 2010 Dollars

Assumptions:
- Incidence: Constant (2003 – 05 average rate)
- Survival: Constant (2005 rate)

Source: https://costprojections.cancer.gov
Estimates Of National Expenditures For Cancer Care, By Site

![Bar chart showing expenditures for various cancer care sites, with expenditures for bladder, stomach, and cervix highlighted in red.](image-url)
Cancer Survivors at Duke

January 1, 2016 – June 30, 2017 (18 months), the following unique patients were seen:

<table>
<thead>
<tr>
<th>Cancer Type</th>
<th>0-2.9 y</th>
<th>3-4.9 y</th>
<th>5-9.9 y</th>
<th>10-20 y</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brain</td>
<td>3143</td>
<td>826</td>
<td>1092</td>
<td>747</td>
<td>5808</td>
</tr>
<tr>
<td>Breast</td>
<td>4175</td>
<td>1713</td>
<td>2487</td>
<td>1972</td>
<td>10347</td>
</tr>
<tr>
<td>Cell Therapy</td>
<td>2826</td>
<td>1036</td>
<td>1523</td>
<td>976</td>
<td>6361</td>
</tr>
<tr>
<td>Endocrine</td>
<td>1250</td>
<td>352</td>
<td>394</td>
<td>238</td>
<td>2234</td>
</tr>
<tr>
<td>Eye</td>
<td>182</td>
<td>52</td>
<td>59</td>
<td>30</td>
<td>323</td>
</tr>
<tr>
<td>GI</td>
<td>5041</td>
<td>1099</td>
<td>1250</td>
<td>526</td>
<td>7916</td>
</tr>
<tr>
<td>GU</td>
<td>4495</td>
<td>1641</td>
<td>2635</td>
<td>1696</td>
<td>10467</td>
</tr>
<tr>
<td>Gyn</td>
<td>2160</td>
<td>772</td>
<td>968</td>
<td>467</td>
<td>4367</td>
</tr>
<tr>
<td>H&amp;N</td>
<td>1023</td>
<td>304</td>
<td>430</td>
<td>229</td>
<td>1986</td>
</tr>
<tr>
<td>Melanoma</td>
<td>1471</td>
<td>504</td>
<td>644</td>
<td>471</td>
<td>3090</td>
</tr>
<tr>
<td>Other sites</td>
<td>252</td>
<td>29</td>
<td>42</td>
<td>24</td>
<td>347</td>
</tr>
<tr>
<td>Sarcoma</td>
<td>563</td>
<td>201</td>
<td>269</td>
<td>152</td>
<td>1185</td>
</tr>
<tr>
<td>Thoracic</td>
<td>4658</td>
<td>827</td>
<td>925</td>
<td>367</td>
<td>6777</td>
</tr>
<tr>
<td><strong>Grand Total</strong></td>
<td><strong>31239</strong></td>
<td><strong>9356</strong></td>
<td><strong>12718</strong></td>
<td><strong>7895</strong></td>
<td><strong>61208</strong></td>
</tr>
</tbody>
</table>

Interval from Cancer Diagnosis

0-2.9 y | 3-4.9 y | 5-9.9 y | 10-20 y | Total

Source: Kevin Oeffinger, MD, Duke 4.19
Assumptions:
- 5% new cases/year
- 50% of all new cases will be followed long term.
- Follow-up begins year 2 with 4 visits, year 3=3 visits, year 4=2 visits, year 5-10=1 visit or 0 visits
Follow-up of 50% of new cases starting year 2 after diagnosis with 4 visits year 2, 3 visits year 3, 2 visits year 4 and annually thereafter.
The experiences of cancer survivors while transitioning from tertiary to primary care

B.B. Franco,* L. Dharmakulaseelan,* A. McAndrew BA RAd,* S. Bae MPH,* M.C. Cheung MD MSc,*a and S. Singh MD MPH,a

ABSTRACT

Purpose  In current fiscally constrained health care systems, the transition of cancer survivors to primary care from tertiary care settings is becoming more common and necessary. The purpose of our study was to explore the experiences of survivors who are transitioning from tertiary to primary care.

Methods  One focus group and ten individual telephone interviews were conducted. Data saturation was reached with 13 participants. All sessions were audio-recorded, transcribed verbatim, and analyzed using a qualitative descriptive approach.

Results  Eight categories relating to the main content category of transition readiness were identified in the analysis. Several factors affected participant transition readiness: how the transition was introduced, perceived continuity of care, support from health care providers, clarity of the timeline throughout the transition, and desire for a “roadmap.” Although all participants spoke about the effect of their relationships with health care providers (tertiary, transition, and primary care), their relationship with the primary care provider had the most influence on their transition readiness.

Conclusions  Our study provided insights into survivor experiences during the transition to primary care. Transition readiness of survivors is affected by many factors, with their relationship with the primary care provider being particularly influential. Understanding transition readiness from the survivor perspective could prove useful in ensuring patient-centred care as transitions from tertiary to primary care become commonplace.

Key Words  Primary care, transitions in care, patient-centred care, qualitative research, survivors

Actions *Oncology Clinicians* Can Pursue Now

- Clearly communicate to patients from the time of diagnosis that they will be expected to continue to be followed by their primary care provider and likely will transition back to predominately primary care after treatments ends.

- Examine current patient rosters, clinic utilization patterns, and new patient visit slots → consider how shifting care of low-risk/low-need survivors to primary care or advanced practice practitioners would affect these factors.

Actions Oncology Clinicians Can Pursue Now

- Reinforce expectations about follow-up by ongoing communication throughout cancer treatment.
- Shift follow-up appointments for patients off treatment so they are clustered.
- Support patients who are doing well in self-managing their health.
- Build bridges with primary care.

Challenge

- Reorganize your follow-up of patients off treatment to their own follow-up clinics → first integrate and then move fully to APP → transition to PCP over time.
- Get your institution to provide the numbers of follow-up visits by time since diagnosis.
- Identify PCP interested in taking care of survivors in your area.
- Discuss long-term plans of care with new patients throughout their care.
Survivorship Research

Picking up my pieces
Cancer Survivorship Research: Cancer survivorship research seeks to improve the health and well-being of cancer survivors and caregivers providing care to survivors.

It aims to improve understanding of the sequelae of cancer and its treatment and to identify methods to prevent and mitigate adverse outcomes, including functional, physical, psychosocial, and economic effects.

This research also includes and informs the design, delivery, and implementation of evidence-based strategies and the coordination of healthcare services to optimize survivors’ health and quality of life from the time of diagnosis through the remainder of the survivor’s life.

Any cancer survivorship research should clearly identify the type of survivor being studied (e.g. age, type and stage of cancer, time since diagnosis) and the outcomes of the research (e.g. function, quality of life, health care utilization, costs, survival).
Adapted from Nekhlyudov, L., Mollica, M., Jacobsen, P., Mayer, DK, Shulman, LN, Geiger, AM. (2019). Developing a Quality of Cancer Survivorship Care Framework: Implications for Clinical Care, Research and Policy. JNCI, epub ahead of print
Review of 165 eligible grants:
- 88.5% were funded by the National Cancer Institute followed by NINR, NIH OD, and NIA
- 85.6% of NCI studies funded by DCCPS
- 66.7% were investigator-initiated (R01) mechanism
- 84.2% focused on adult survivors
- 47.3% focused on breast cancer survivors
- 64.2% focused on <2 years since diagnosis
- 57.3% were observational in nature (57.3%)
- 4.8% older adults and 3% rural populations
- Topics included:
  - 75.8% physiologic outcomes
  - 37.6% psychosocial outcomes
  - 35.7% health behaviors
  - 35.7% patterns of care
  - economic/employment outcomes
NIH Survivorship Research Portfolio Analysis (2016)

Research recommendations:

• Increase diversity of cancer sites
• Greater ethnoculturally diverse samples
• More older (>65 years) and longer-term (>5 years) survivors
• Need to address effects of newer therapies
NCI Future Directions in Cancer Survivorship Research: Workshop priorities and Webinar endorsements

- Identify and present the research gaps in the recommended components of survivorship care and important next steps that were identified at a recent NCI meeting; and

- Gather feedback on the identified strategic research priorities (SA-SD).
Survivorship Research Priorities

Prevention and Surveillance
(87% Agree)

◦ Surveillance schedules
  ◦ Testing optimal frequency, risks and benefits and bundled screening
  ◦ Evidence-based guidelines consistent across organizations

◦ Reducing disparities among different populations

◦ Adding longer surveillance for existing, relevant clinical trials

◦ Enhancing SEER, State Registries and National Cancer Databases

Physical Late/Long-term
(91% Agree)

◦ Measurement of symptoms, functional impairments, comorbid conditions and needs as core measures by disease

◦ Profiles of natural history of late/long-term effects in prevalent cancers

◦ Frame intervention development using chronic disease model (CDM) as it is multilevel and is patient and family focused at its core and spans risk reduction, rehabilitation and self-management support
Survivorship Research Priorities

Psychosocial Late/Long-term
(89% Agree)

- Implementation of psychosocial interventions in real-world settings (e.g. community oncology, primary care) → integration of psychosocial services into existing community systems.
- Prevention and mitigation strategies that include risk-stratification

Health Behaviors
(87% Agree)

- Mechanisms and biomarkers for health behaviors
- Integration of exiting and emerging technologies for health promotion in cancer survivorship care
- Multi-level research studies addressing health behaviors in cancer survivors
Survivorship Research Priorities

Care Coordination
86% Agree

- Identify key outcomes to assess quality care coordination
- What are optimal models to promote risk-based care coordination?
- What are key strategies to support vulnerable populations?
- How to engage IT in care coordination

Economic
90% Agree

- Longitudinal studies to understand risk factors for financial hardship, employment limitations and other economic effects.
- Studies to understand the impact of financial hardship, employment limitations and other economic effects on functioning, clinical outcomes, quality of life and healthcare utilization.
- Conduct new interventions to address economic effects and leveraging implementation science to ensure effective interventions are disseminated.
- Leverage data infrastructure, linkages, and methods
- Leverage technology to collect data and deliver interventions.
Conclusions

- Current cancer can not be sustained
- More survivorship research to help prevent or mitigate long term and late effects
- There is no one solution to address this issue but all require culture change in cancer care delivery.
- Projections for staff and facilities must go beyond # new cases and beyond the next 1-2 years.
- Shifting model for follow-up survivorship care is part of the solution but needs to be based on risk stratification, collaboration between PCP and Oncologists, team based care, and supported self-management.
- Multiple strategies need to be tested.
- We need to develop and implement a range of evidence-based programs that do not require 1:1 face-to-face interventions.
Additional References


When Life Is Sewn Back Together, It Has Changed