Perspectives of Cancer Survivors on their Transition from Active to Follow-Up Cancer Care

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The Research Process

- Define the Research Problem
- Literature Review
- Hypothesis Formulation
- Preparing Study Design
- Administer Instruments
- Data Collection
- Data Analysis
The Problem

• Patients are often lost in the transition from active treatment with their oncologist to follow-up cancer care with their primary care physician.

• This means their survivorship care needs may be inadequately met.\textsuperscript{14}
  • \textbf{Prevention} of new and recurrent cancers
  • \textbf{Surveillance} for recurrence of original or new cancers
  • \textbf{Interventions} for effects secondary to cancer and cancer treatment
  • \textbf{Coordination} between specialists and PCPs
The Cancer Care Continuum

<table>
<thead>
<tr>
<th>Prevention and Risk Reduction</th>
<th>Screening</th>
<th>Diagnosis</th>
<th>Treatment</th>
<th>Survivorship</th>
<th>End-of-Life Care</th>
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<tbody>
<tr>
<td>Tobacco control</td>
<td>Age and gender specific screening</td>
<td>Biopsy</td>
<td>Systemic therapy</td>
<td>Surveillance for recurrences</td>
<td>Implementation of advance care planning</td>
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<td>Diet</td>
<td>Genetic testing</td>
<td>Pathology reporting</td>
<td>Surgery</td>
<td>Screening for related cancers</td>
<td>Hospice care</td>
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<td>Physical activity</td>
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<td>Hereditary cancer predisposition/ genetics</td>
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<td>Sun and environmental exposures</td>
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<td>Alcohol use</td>
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<td>Chemoprevention</td>
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<td>Immunization</td>
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The Cancer Care Continuum. Figure adapted from the Institute of Medicine. From Committee on Improving the Quality of Cancer Care: Addressing the Challenges of an Aging Population, 2013 by the National Academy of Sciences, Courtesy of the National Academies Press, Washington, DC, USA
Background

- Number of cancer survivors is rapidly rising in the United States\textsuperscript{13}
- Information about follow-up care for patients is abundant\textsuperscript{3,4}
- Clinical practice reflects variation across care guidelines\textsuperscript{1}
- Shortage of oncologists and PCPs\textsuperscript{5}
- Oncologists lack time and resources\textsuperscript{5-12}
- New and significant demands on PCPs\textsuperscript{5-12}
- Lack of partnership between oncologists and PCPs
  - Lack of provider role clarity, information exchange, adequate compensation\textsuperscript{2}
Significance

• Patients are often left out of the equation in cancer care continuum studies
  • Need for focus on patient satisfaction, knowledge of disease, and subsequent patient behavior following education\(^1\)
• Lack of studies investigating survivorship care as a whole\(^1\)
  • Uptake and duration
  • Quality of Care
  • Resource Utilization
  • Cost
  • Outcomes
• Information about patient experiences and knowledge is essential in closing the gaps in caring for cancer survivors to increase quantity and quality of life
The Research Process

Define the Research Problem

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Literature Review

• 36 Publications Reviewed
• 13 Primary Research examples
  • Research question studied?
  • Suggestions for further research?
• 18 Secondary Research examples
  • 8 systematic reviews
  • Research questions studied?
  • Summary of past research?
  • Areas in need of further study?
• 5 Non-Research examples
  • Any useful information was extracted
Most Informative Articles

1. Adult Cancer Survivors Discuss Follow-Up in Primary Care: ‘Not What I Want, But Maybe What I Need’
   - Qualitative, semi-structured, in-depth interviews
   - Purposive sample of 42 early-stage breast and prostate cancer survivors
     - Stratified by age, race, and length of time from and location of cancer treatment
     - Survivors at least 2 years beyond completion of active cancer treatment

   - Results:
     - 52% preferred to receive follow-up care from their cancer specialists
     - Only 38% believed there was a role for PCPs in cancer follow-up care
       - Performing routine cancer screening tests
       - Supplementing cancer and cancer-related specialist care
       - Providing follow-up medical care when “enough time has passed”
Most Informative Articles

2. Health care needs of cancer survivors in general practice: a systematic review
   • RA Hoekstra, et al. *BMC Family Practice* 2014

   • Qualitative or quantitative studies
   • Sample: survivors of any cancer type, free of active disease, no longer receiving active treatment
   • 15 studies included – 12 qualitative

   • Results
     • Most mentioned general practice needs were psychosocial needs
     • Need for help with medical issues
     • Need for information on cancer, recovery, late treatment effects and adjusting to life after treatment
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Hypotheses

• In the transition from active treatment to on-going care with a PCP, cancer survivor patients experience poor communication and coordination between their oncology and primary care providers.

• Poor communication and coordination exists between cancer survivor patients, their oncologist(s), and their primary care providers during their transition from active treatment to follow-up care with a PCP.
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Preparing Research Design

• Develop purpose of the study
• Complete implementation steps
Purpose of Study

1. Better understand the cancer survivor experiences and perceptions regarding their follow-up cancer care.

   - Type of doctor that fills “follow-up care” provider role
   - Extent of provider-patient communication
   - Provider responsibility for key aspects of follow-up cancer care
   - Confidence in provider knowledge and skills
   - Follow-up cancer care satisfaction
   - Patterns of seeking follow-up cancer care
   - Preference for type of provider for follow-up care and for how long
   - Rating of provider-provider follow-up cancer care coordination

This study is complementary to a Stephenson Cancer Center pilot study:

*Oncology and Primary Care Coordination: Perspectives of Care Providers, Kathleen Dwyer, PI*
Implementation Steps

• Finalize Protocol
  • Study Sample
  • Methods
• Finalize Instruments
  • Beta testing
• Consent Forms
• IRB Application
• FMC clinician commitment
• EMR review, cancer codes
• Ask clinician if selected patients fit criteria
Study Sample

• 25 cancer-diagnosed individuals who are active patients at the OUHSC Family Medicine Clinics (FMC)
  • ICD-9 Diagnosis codes: 140.0-208.9, for the prior five years
  • Agreement from specific FMC clinicians to approach eligible patients
  • “Pull” 2 week appointment schedules for those clinicians agreeing to participate

• Check with participating FMC clinicians if identified patients meet inclusion criteria
  • Completed treatment at least 1 year prior to study participation
Methods

• **Data Collection**
  
  • Closed-ended paper survey administered in person
    
    • Administered at time of scheduled FMC doctor’s appointment
    • Contact patients in advance prior to their participation in study
    • Obtain consent, administer survey at time of appointment
    • Incentive provided following completion of survey ($25 gift card)
  
  • Semi-structured interview administered by phone
    
    • Conducted with survey participants who volunteer
    • 6 questions
    • Aimed at supplementing the quantitative data obtained from the survey
Instruments

• Paper Survey
  1. **Survivor Experiences, Perceptions & Preferences:**
     • 14 topic questions composed of 57 total items
     • specific attention on the interface between the oncology care delivery system and the primary care delivery system
  2. **Survivor Profile:**
     • 10 demographic items
     • 8 items about patient’s cancer and health status

• Semi-structured phone interview
Beta Testing

• 3-5 cancer survivors will complete the survey
  • Clarity
  • Relevance
  • Important issues included?
  • Additions?
  • Deletions?
  • Length of time to complete the survey

• Beta testing will also be done with the phone interview questions

• Spoke with 2 participants this morning
Implementation Steps

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Supplemental Experiences
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• Shadowing at the Supportive Care Clinic
• Attending a cancer support group meeting
• Meeting with clinicians to discuss patient transition and instruments
Supportive Care Clinic

• Stephenson Cancer Center
  • 2nd floor – next to Breast Cancers Clinic

• Dr. Steve Orwig
Cancer Support Group Meeting

• Project31
  • Breast cancer support group
  • Sarah McLean

• Dr. Theobald
Clinician Meetings

• Dr. Doescher

• Dr. Tietze

• Dr. Salinas

• Common themes:
  • Large variety of cancer patients, Dr. Tietze mostly breast cancer patients
  • Patients are usually seen for other comorbidities and diseases
  • Summary letter from oncologists would greatly help the transition
  • Overall, patients want to feel better and to have someone LISTEN
  • Very little to no communication with oncologists
  • Patients often do not receive the psychosocial support they need

Tell us a little about the cancer patients you have in your care. What do your cancer patients see you for? What do they say? What would you have had in place to facilitate the transition process? What do you think patients want in their transition? How often would you say you have contact with oncologists regarding your patients? Where are your patients referred for psychosocial support? What would you like to know from patients making the transition?
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What’s Left?
Planned Analysis

• Descriptive statistics (Initially)
  • Including comparison of descriptive stat results for comparable questions across patient, PCP and oncology specialist surveys

• Further on with larger sample size:
  • Likely analysis via Chi-square statistics to assess bivariate associations between key variables
  • Likely multivariate regression analysis with those variables found to be statistically significant in bivariate analyses
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• Beta Testing participants
References


References


Questions?