Helping Patients Transition to Survivorship

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Objectives

1. Review the definition and stages of survivorship
2. Learn effective communication strategies to help patients identify themselves as survivors
Who Is a Cancer Survivor?

Evolving definitions of survivorship\textsuperscript{1}:

- Traditional: 5 years after diagnosis
- A more recent definition would be from completion of the first phase of treatment
  - Chemotherapy, radiation, surgery, or a combination of these
- A current definition would be from diagnosis through the end of life
  - A patient becomes a “survivor” as soon as he or she is diagnosed with cancer, and remains a survivor through the phases of treatment and afterwards until the end of life\textsuperscript{1,2}

\begin{itemize}
  \item \textsuperscript{1} President’s Cancer Panel. Living Beyond Cancer: Finding a New Balance. Bethesda, MD: National Cancer Institute; 2004.
\end{itemize}
Expanding Population of Survivors

• Whatever definition of survivorship we use, the number of survivors is growing
  – About 3 million people (1.5%) with a cancer diagnosis in the US in 1971
  – In 2006, there were more than 11 million Americans living with a history of cancer—approximately 3% of the US population

• 5-year survival rate:
  – 1970s: 50%
  – 1999-2005: 68% ($P < 0.05$)

Stages of Survival

**Acute**
- From diagnosis to the completion of initial treatment
  - Issues related to treatment, side effects

**Extended**
- From completion of initial treatment
  - Dominated by fear of recurrence

**Permanent**
- Evolving from an extended disease-free interval when the likelihood of the cancer recurring is small

Rachel: “My goose is cooked!”

• “Once you’re diagnosed with the big C, you’re finished!”

• “I should have done things differently. Now I won’t get to enjoy any of the retirement travel my husband and I planned.”
“Does this sound fair to you?”

- Rachel has many of the usual reactions to a cancer diagnosis
  - Feelings of fear and anxiety
  - Facing her own mortality
- Additional reactions:
  - A sense of being cheated
    - “Now I won’t get to enjoy retirement or being a grandmother.”
  - Feelings of self-blame and guilt
    - “I should have done more for others with cancer. Now I won’t have that opportunity.”
  - Feeling hopeless
    - “Why have I bothered eating right all these years? None of it mattered.”

Rachel’s Reactions

Rachel responds to her caregivers with the following statements:

- **To her primary care physician:** “Shoot me now.”
- **To the oncology nurse:** “What are you going to do with that needle? Hurt me again?”
- **To office staff:** “Don’t worry, soon you won’t have to schedule anything for me.”
- **To the social worker:** “Don’t you get tired of dealing with people like me?”
Emotional Needs at Diagnosis

- Understanding of illness, treatments, and services
  - Improved patient-provider communication
- Coping with emotions surrounding illness and treatment
  - Through counseling, psychotherapy, etc
- Managing illness and health
  - Comprehensive self-management/self-care
- Behavioral change to minimize disease impact
  - Behavioral/health promotion; eg, smoking cessation
- Managing disruptions to work, school, and family life
  - Family/caregiver education, assistance with activities of daily living
- Information related to financial assistance
Preliminary Interview
Preliminary Interview

• The treatment team’s social worker meets with Rachel
• Rachel asks: “Don’t you get tired of dealing with people like me?”
• The social worker responds: “We’re here to talk about you today. Tell me what’s going on.”
• Their conversation brings out a couple of issues:
  – When Rachel learned of her cancer, she had a new health plan and a new primary care physician
  – She recalled little of the diagnostic conversation with the oncologist: “He said they had found cancer and I didn’t hear anything after that.”
  – Although the oncologist went on to explain that there were effective treatment options, Rachel was too upset to listen
Patient Satisfaction With Diagnostic Discussions

<table>
<thead>
<tr>
<th>Method of disclosure</th>
<th>Setting of disclosure</th>
<th>Length of discussion</th>
<th>Discussion of treatment?</th>
</tr>
</thead>
<tbody>
<tr>
<td>In person</td>
<td>Personal</td>
<td>&gt;10 min</td>
<td>Yes</td>
</tr>
<tr>
<td>By phone</td>
<td>Impersonal</td>
<td>≤10 min</td>
<td>No</td>
</tr>
</tbody>
</table>

Mean patient satisfaction score

- In person: 68.2
- By phone: 47.2*
- Personal: 68.9
- Impersonal: 55.7*
- >10 min: 73.5
- ≤10 min: 54.1*
- Yes: 72.0
- No: 50.7*

* P < 0.001

Conveying the Diagnosis

- Diagnosis should be given face-to-face in a personal setting\(^1\)
- Plan to talk for longer than 10 minutes\(^1\)
- Include discussion of treatment options, if appropriate\(^1\)
- Using these communication strategies may help patients understand their situation\(^2\):
  - Use lay language and adjust your pace to the patient’s
  - Ask questions to discern patient comprehension
  - Use clear transitions between pieces of information
  - Explain relationships between pieces of information
  - Allow patients and companions to absorb each piece of information

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Reaching a Better Understanding

• After their conversation, the social worker alerted the entire oncology team, which helped Rachel in several ways:
  – Provided understanding of illness, treatments, and services
  – Identified the outdated nature of her belief that a cancer diagnosis must be an immediate death sentence
  – Introduced her to the concept of being a “survivor”

• The social worker also helped Rachel become more comfortable with her oncology team, enabling her to:
  – Cope with emotions surrounding illness and treatment
  – Manage illness and health
  – Make behavioral changes to minimize disease impact
  – Manage disruptions to work, school, and family life
  – Access information related to financial assistance
  – Receive individualized care and treatment plan

• Her feelings of anxiety and depression diminished over time
Transition to Survivorship

• During and after treatment, Rachel embraced new roles in advocacy:
  – *The Personal Advocate*: Rachel collected information about her cancer, sought second opinions when needed, asked questions, and closely scrutinized her care\(^1\)
  – *The Community Advocate*: Rachel became involved in local support groups and community fundraising. She later became a key member of a non-profit group that is using social media to create narratives in which cancer survivors tell their stories on online social platforms\(^2\)
  – *The National Advocate*: Rachel joined an activist committee formed to seek funding for research\(^1\)

Rachel as a Survivor
Rachel as a Survivor

“We as cancer survivors should pay attention to the food we eat, to our bodies through daily exercise, and our minds through things like art and music.

“I spent almost 30 years in business. I loved the people I worked with even when work was a grind. But when I was just about to retire, at the moment of freedom, doctors diagnosed my cancer. Trapped. No surprise I felt that way, but what do you do? After my treatment I turned my energy into tapestry as a fiber artist. You might pick up a guitar. Another person, Spanish cuisine. All of us survive by doing.”

— Rachel
Bill: “I can’t believe this is happening again”

• “But I’m only 51!”
• “I want to be there for my kids as they grow up.”
Fears Realized

• Many cancer survivors have persistent fears of cancer recurrence\textsuperscript{1,2}
• Patients have described feeling overwhelmed and devastated upon learning of a recurrence\textsuperscript{2}

“My wife could give me a hug, at least”

• Bill’s reactions to learning of his cancer recurrence included:
  – Sadness and bewilderment
  – Emotional withdrawal
  – Heightened feelings of anxiety and panic
  – Overwhelming feelings of guilt
  – Blaming his wife for insufficient affection
  – Unable to decide on recommended treatment course

• Patients like Bill may need help as they re-enter the acute phase of survivorship
Dominated by Fear

- “My wife is angry because she’s been after me to improve my lifestyle for years.”
- “I’ve found a lot of information on the internet and I’m scared about how I’ll look after surgery. If I survive…”
- In the midst of his worrying, Bill missed an appointment with his oncologist
- When the office contacted him, he came back a week later
Identifying Distress

• What signs might make you think a patient is feeling depressed?
• What do you do when you suspect psychological distress in a patient?
• You can encourage patients to express their concerns by¹:
  – Listening with an open mind
  – Not interrupting
  – Letting the patient lead the conversation
  – Acknowledging concerns and responding empathetically
  – Using appropriate questions and emotional words
  – Summarizing patient statements and clarifying their needs

Bill as a Survivor

• After undergoing extensive cancer treatment, Bill continued to see a counselor to ease his feelings of depression, distress over physical disfigurement, and fear regarding another recurrence
  – Bill has now achieved the “extended stage” of survivorship

• Healthcare providers can help survivors by\(^1\):
  – Allowing them to express their ongoing concerns
  – Supporting their use of additional services

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Survivorship Care Plans

• Aim to optimize continuity and coordination of care
• Components of a survivorship care plan include:
  – Clear protocol for surveillance for recurrence or new cancer
  – Describe common long-term and late effects of treatment
  – Specific lifestyle recommendations
  – Identify providers and roles (ongoing monitoring, non-cancer care, psychosocial support, etc)

Earle CC. Failing to plan is planning to fail: improving the quality of care with survivorship care plans. J Clin Oncol. 2006;24:5112-5116.
Bill’s Healthy New Lifestyle
Bill’s Healthy New Lifestyle

• Improvement in relationships with family members
• Focusing on improving lifestyle
• Makes time for exercise
• Spends time on favorite hobbies

BUT

• Continues to see a counselor to deal with feelings of depression and fear of recurrence
• Suffers from feelings of anxiety over body image
Extended-Stage Concerns

- Bill’s survivorship care plan includes:
  - Follow-up visits to monitor for recurrence
  - Regular primary care visits to assess for pain or other long-term side effects
  - Continued counseling to discuss concerns over physical changes
  - Recommendation to join a survivor support group

Earle CC. Failing to plan is planning to fail: improving the quality of care with survivorship care plans. *J Clin Oncol.* 2006;24:5112-5116.
Coping With Ongoing Distress

• Psychological costs:
  – Bill continues to feel anxious about his health, including his disfigurement
  – His altered body image has affected his feelings about sexuality with his wife

• Seeking support:
  – Bill joined a cancer support group
  – He found support from the other survivors here as he furthered his journey into survivorship
Understanding Survivorship

• Cancer survivorship affects a large and growing number of people in the United States\(^1\)

• Survivorship care planning should be recognized as an important component of quality cancer care\(^2\)
  – Healthcare team members should understand and communicate the importance of post-treatment care and adherence to follow-up recommendations

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2. Earle CC. Failing to plan is planning to fail: improving the quality of care with survivorship care plans. *J Clin Oncol.* 2006;24:5112-5116.
Encouraging Survivorship

- Open lines of communication, beginning with initial meeting
- Provide survivorship care plan
- Use compassionate communication to address concerns
- Help patients understand the choices ahead of them
- Celebrate life

**GOAL:** Improve the quality of life for cancer survivors and their families by providing them with a survivorship care plan
Cancer Survivorship Research Trends

- Identify and control/reduce adverse cancer diagnosis and treatment-related outcomes
- Manage, treat, and prevent comorbidities
- Promote healthy lifestyle interventions
- Define optimal follow-up and surveillance strategies
- Examine disparities in outcome across a range of demographics

References


References


