The 2016 CancerCare Patient Access and Engagement Report

Understanding the Patient Experience

The Cancer Gap: Landmark Study Reveals Disconnects and Changing Pressure Points in Cancer Care 2016

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Welcome

I would like to thank OncoNav for sponsoring this webinar.

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Welcome to all of you and thanks for joining us.
Goals For Today

• Provide a summary of The 2016 CancerCare Patient Access and Engagement Report

• Promote discussion about the findings

• Provide an opportunity to network with colleagues
We welcome your comments and will take questions or comments at the end of the presentation.

Your experience as patient navigators, managers and administrators will contribute to building a valuable network to share ideas and information.

“A rising tide raises all ships.”
What Is CancerCare


For more than 70 years, CancerCare has been providing support services and educational programs to help people affected by cancer manage the emotional, practical, and financial challenges of the disease.
This study was conceived to better understand the unmet needs of cancer patients across the United States.

In 2015, Cancer Care initiated a research project to
• define engagement according to people diagnosed with cancer
• identify barriers to their engagement with care providers
• characterize the financial, emotional, social, and quality-of-life costs of cancer to patients and families.
Why, What, When, How It Was Done

CancerCare commissioned 6 nationwide online surveys in 2016

To gain a better understanding of and appreciation for the needs of survivors, their families, and caregivers—and how best to serve and engage them.

More than 3,000 unique adults shared their experiences and perceptions on a wide range of topics that span from diagnosis to survivorship.

Sample sizes of at least 500 respondents each, diverse in age, gender, ethnicity, education, income, geography, cancer type and stage.
This is not the only study

Let’s take a look.......
Highly respected agencies each undertaking major studies of the landscape of cancer care in the US

Cancer Care 2016 report is the patient perspective

IOM 2013 & 2008 reports are expert “in the field” perspective

Oncology Roundtable 2007 report is the expert “think-tank” perspective
Three Different Voices-Same Message

The Institute of Medicine- now known as The Health and Medicine Division of the National Academies of Sciences, Engineering and Medicine

*Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis*. 2013

*Cancer Care of the Whole Patient: Meeting Psychosocial Health Needs*-2008

CancerCare


Oncology Roundtable

*Inside the Mind of the Cancer Patient*-2007
A Brief Overview
The Health and Medicine Division of the National Academies of Sciences, Engineering and Medicine

Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis-2013

Coordination and organization of care

Outcomes reporting and quality metrics

Growing need for survivorship care, palliative care, and family caregiving

Complexity and cost of care

Payment reform and new models of care

Disparities and access to high-quality cancer care
Psychological and social problems created or exacerbated by cancer

Lack of information or skills needed to manage the illness

Lack of transportation or other resources

Disruptions in work, school, and family life cause additional suffering, weaken adherence to prescribed treatments, and threaten patients' return to health.
Examine which program attributes (clinical quality, customer service, facility design, efficiency, etc.) have the greatest impact on consumer choice of facility and the perceived quality of a patient’s care.

Survey of 750 current and former cancer patients, as well as numerous telephone-based interviews with cancer patients and survivors

- Decision making behind choice of hospital, surgeon, medical oncologist and radiation oncologist
- Use of and desire for clinical outcomes data to evaluate cancer programs
- Role of physician in driving facility and treatment choices
- Drivers of satisfaction, dissatisfaction with care experience
- Perceived value of specific cancer program offerings
CancerCare- 2016

• Defines engagement specifically as it relates to cancer patients

• Identifies barriers to cancer patient engagement with care providers

• Characterizes the financial, emotional, social and quality-of-life costs of cancer to patients and families

• Recommends strategies and programs to promote cancer patient access and engagement
The reports provide insight and context regarding many aspects of patients’ cancer experiences, highlighting:

• the gaps in care

• barriers to the patient’s engagement with care providers

• the physical, emotional, and financial toll of cancer
Why Another Study?

Good question
The Main Event

CancerCare Patient Access and Engagement Report

Executive Summary
Report components

Six distinct areas were identified and surveyed

Survey 1: Understanding the Diagnosis of Cancer
Survey 2: Treatment Planning
Survey 3: Communication With the Care Team
Survey 4: Financial and Insurance Issues
Survey 5: Symptoms, Side Effects, and Quality of Life
Survey 6: Survivorship
Take A Look……

Survey 1: Understanding the Diagnosis of Cancer - Key Findings

• Most patients understood and followed their physicians’ recommendations for diagnostic tests

• Nearly all respondents could access diagnostic testing and had confidence in the medical professionals who diagnosed them

• One-quarter of those ages 25 to 54 disagreed with some of their doctors’ recommendations for testing and did not follow them.

• Fewer than half discussed costs

• African American and Hispanic patients had 35% more post diagnosis conversations with their medical team than their white counterparts.
Conclusions and Recommendations-Survey 1

Conclusions
• Large numbers of patients with cancer do not receive adequate information about their disease
• High insurance deductibles, copayments, and other costs are important barriers
• Patients must have access to resources to help address financial concerns
• Patients need access to the practical and psychosocial support services that can help them cope

Recommendations
• Awareness among medical professionals that patients are foregoing diagnostic testing and treatment due to financial distress
• Clinicians should direct patients toward support services
  – to help them navigate financial challenges
  – prepare them practically and emotionally to engage with providers in treatment planning.
Survey 2: Treatment Planning—Key Findings

- Two-thirds reported having adequate information about benefits of their treatment plan, potential side effects, or the reasons the treatment was recommended.
- Only 13% felt adequately informed about clinical trial opportunities.
- **Less than 50%** felt they had enough information about the emotional impact of cancer, work-related concerns or the cost of care.
- **Less than 50%** got a second opinion.
- Majority trusted their physicians and felt they were getting the best care.
- About 50% were asked about distress level.
- Patient satisfaction was low around clinical trial information and new treatment options.
Recommendations-Survey 2

- Discuss patients’ values and priorities in the context of treatment planning, ensuring that they have sufficient knowledge to make informed decisions,

- Foster a partnership approach to care

- Encourage patient participation during office visits, eliciting details about the patient’s lifestyle routines, and checking for patient understanding
Take A Look......

Survey 3 Communication with the care team- Key findings

• Most were satisfied with their clinical care coordination, understood discussions with providers about their cancer and its treatment

• Were able to connect with members of their health-care team in a reasonable amount of time.

• White patients were more likely than African American and Hispanic patients to report that they had confidence in their ability to talk to their physicians about their concerns

• Conversely, African American respondents were significantly more likely to report that their physicians listened to their concerns and asked for their opinions.
Survey 3 Communication with the care team - Key findings

- About 20% of African American and Hispanic respondents experienced serious communication problems with their clinical care team:
  - Lack of translation services
  - Difficulty understanding what their doctors said about their treatment
  - Discomfort talking about how cultural, religious, and personal values affected their treatment.

- Most patients considered their oncologists and primary care physicians part of their cancer care. Nearly half included nurses.

- They generally chose to discuss treatment-related issues with their oncologists. For lifestyle concerns they preferred talking with their primary care physicians:
  - Diet and exercise
  - Sexuality and intimacy
  - Work, emotional distress
  - Questions about end-of-life issues
Survey 3 Communication with the care team- Key findings

- Fewer than half were asked by a member of their care team if they were feeling distressed by their cancer or its treatment.

- Despite the prevalence of emotional and financial distress respondents reported few referrals by members of their care team to counseling services or other professionals for support.
Conclusions and Recommendations

Conclusions
• Low level of patient referrals for emotional, physical, or financial distress counseling.

• Ages 25 to 54 were significantly less positive about their clinician communication than those 55 and older,

• 5% to 17% of African American and Hispanic respondents reported major lapses in effective communication from their providers.

Recommendations
• IOM Report on Health Professions and Training underscored the importance of communication training for clinicians and members of the health-care team

• Ongoing collection of patient feedback and behavior data can help identify where providers could benefit from training

• Need for open communication and coordination of care between oncology providers and the primary care doctor
Survey 4: Financial and Insurance Issues-Key Findings

- Only about **one-half** reported understanding their health insurance coverage for their cancer care “completely” or “very well.”
- Twenty-five percent of patients between the ages of 25 and 64 stopped working during active treatment
  - 13% switched from full-time to part-time employment.
  - Only **one-third** continued working fulltime during treatment.
- 58% of respondents reporting being distressed about their finances
- 25% of those ages 25 to 64 said their medical care team never considered their financial situation during treatment planning
  - 34% said it was only “sometimes” considered.
- Many patients **used care-altering strategies** to reduce their expenses, some of which may have compromised their cancer treatment.
Survey 4: Financial and Insurance Issues

• To afford treatment, **one-third** of respondents ages 25 to 54 reported cutting back on daily essentials
  – groceries and transportation
  – borrowing from family members and friends

• **21%** missed a utility bill payment; **17%** missed a rent or mortgage payment.

• Average monthly out-of-pocket spending for treatment-related expenses:
  – non-elderly respondents reported spending $1,112, nearly twice as much as those 65 and older.

• Among those ages 25 to 64, **44%** were concerned that they would lose their insurance if they were unable to work.
Conclusions

- People with cancer frequently have difficulty understanding their insurance coverage and the extent to which the cost-share burden may be passed along to them.
- 20%-30% of patients had difficulty estimating their out-of-pocket costs before incurring medical expenses.
- A third have to borrow money to meet their needs.
- Most concerning of all is that the financial burden placed on patients caused them to take care-altering steps to save money.

Recommendations

- More open discussions with patients about the cost of their care can lead to greater understanding of patients’ financial and personal circumstances.
- Discuss treatment costs and patients’ ability to meet those costs when recommending treatment options.
- Refer patients in need to patient support organizations and patient assistance programs.
- Check in with patients at each visit regarding how well they are coping—emotionally, physically, and financially.
Take A Look……

Survey 5: Symptoms, Side Effects, and Quality of Life-key findings

• Moderate to severe fatigue was most common; nearly half of women reporting that it interfered with their daily activities.

• Women were more likely than men to report experiencing anxiety, having difficulty exercising, staying physically active, and suffering from nausea or vomiting.

• Majority reported feeling satisfied with how well their clinical care team prepared them for cancer-related symptoms and side effects.

• 35% of those ages 25 to 44 reported feeling “very” or “somewhat dissatisfied
Survey 5: Symptoms, Side Effects, and Quality of Life-key findings

• Respondents most often discussed cancer-related symptoms and side effects with their physicians.

• To a lesser extent with a physician assistant, nurse practitioner, or nurse.

• Nearly 40% did not report symptoms or side effects because they did not want to “bother” their doctors.

• Nearly 40% were required by their insurers to follow a “fail-first” regimen in treating symptoms and side effects. For most this required that they use a non-preferred medicine for 2 to 3 months.
Survey 5: Symptoms, Side Effects, and Quality of Life-key findings

• **One-quarter** of respondents used cancer-specific counseling or support services to help them cope.

• Those between the ages of 25 and 44 and in active treatment were twice as likely to have used these services.

• **One-quarter to more than one-third** said their ability to perform day-to-day activities—working, exercising, entertaining, caring for children, and preparing meals—was dramatically compromised.

• **One-third** reported that they did not have a caregiver to support them through treatment, help with their activities of daily living and household responsibilities.
Conclusions and Recommendations-Survey 5

Conclusions

• Screening for distress is inconsistent and not widespread despite the attention given to it by the Institute of Medicine, the Commission on Cancer, and the America Society of Clinical Oncology

• Nearly half had severe to moderate fatigue and other debilitating cancer-related symptoms and side effects that interrupted daily activities and work life.

• More than one-third of those ages 25 to 44 were dissatisfied with the way their clinical care team prepared them for the symptoms and side effects of their cancer and its treatment.

Recommendations

• More preparation will likely support patients in better managing their symptoms and may also reduce emergency room visits, which were reported by more than half of survey respondents in active treatment.

• Clinicians and support organizations can fill this void by providing and encouraging patients to access a range of informative materials early in the treatment process.

• It would be helpful for patients to keep a log of treatment side effects to bring to medical appointments.
Survey 6: Survivorship-key findings

• Living with cancer brings about profound physical, emotional, financial, social, and spiritual changes for most patients, but is especially true for younger patients between the ages of 25 and 54.

• Women were much more likely than men to report that cancer had a positive effect on at least some part of their lives, including relationships with family members and friends.

• Cancer caused significant stress for most; they reported the impact the disease had on their family members to be the most stressful element.

• In all aspects of life, respondents ages 25 to 54 were significantly more likely than those ages 55 and older to report being “highly” or “extremely distressed”
Survey 6: Survivorship-key findings

• Receiving a cancer diagnosis prompted a considerable proportion of respondents under age 45 to have end-of-life discussions with family members.
• A significant proportion ages 45 and older had not communicated their wishes about these topics to family members or friends.
• After being diagnosed with cancer, about one-third of respondents younger than age 45 had some form of legal document in place that detailed their end-of-life wishes: health-care power of attorney, health-care proxy, living will, or last will and testament.
• Respondents older than 45, between 29% and 46% had not taken steps to complete at least one of these legal documents.
• Respondents from all age groups had widespread misconceptions about palliative and hospice care.
Conclusions and Recommendations-Survey 6

Conclusions
• This survey clearly shows the profound impact cancer has on the lives of survivors.
• The emotional, physical, financial, and spiritual side effects of cancer and its treatment last many years.
• This can be especially challenging for younger survivors.
• Greater focus on end-of-life education and planning.
• Confusion about palliative care and hospice.

Recommendations
• Comprehensive survivorship care plans should address clinical surveillance necessary for recurrence, late effects of treatment, secondary cancers, financial, physical, psychosocial consequences of cancer.
• Focus on end-of-life education and planning, so patients’
• Need for significant patient education about palliative care and hospice.
• Introduce palliative care early in treatment.
• Recognize the importance of inclusion and coordination among patient’s team of health-care providers such as PCP’s.
Many Key Take-Aways

- Each hospital, cancer center, facility, provider needs to decide how this information is relevant to you

- Where do you stand with your ability to meet the needs as expressed in the report

- What key take-aways are most important to you

- What will you do with this information
“Knowing is not enough; we must apply. Willing is not enough; we must do.”

—Goethe
Zig Ziglar said “I believe success is achieved by ordinary people with extraordinary determination.”
Resources

CancerCare
www.cancercare.org
http://www.cancercare.org/accessengagementreport

National Academies Press
www.nap.edu

The Advisory Board
www.advisory.com
Extraordinary people doing extraordinary work.

We at OncoNav thank you for the extraordinary work you do everyday.

www.onco-nav.com