



Health Literacy & Communication Strategies in Oncology National Cancer Policy Forum

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Strategies for Communicating Health Information in Survivorship Care

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Cancer Survivorship

Someone impacted by cancer from the time of diagnosis through the balance of life.

(NCCS, NCI, ACS, etc.)

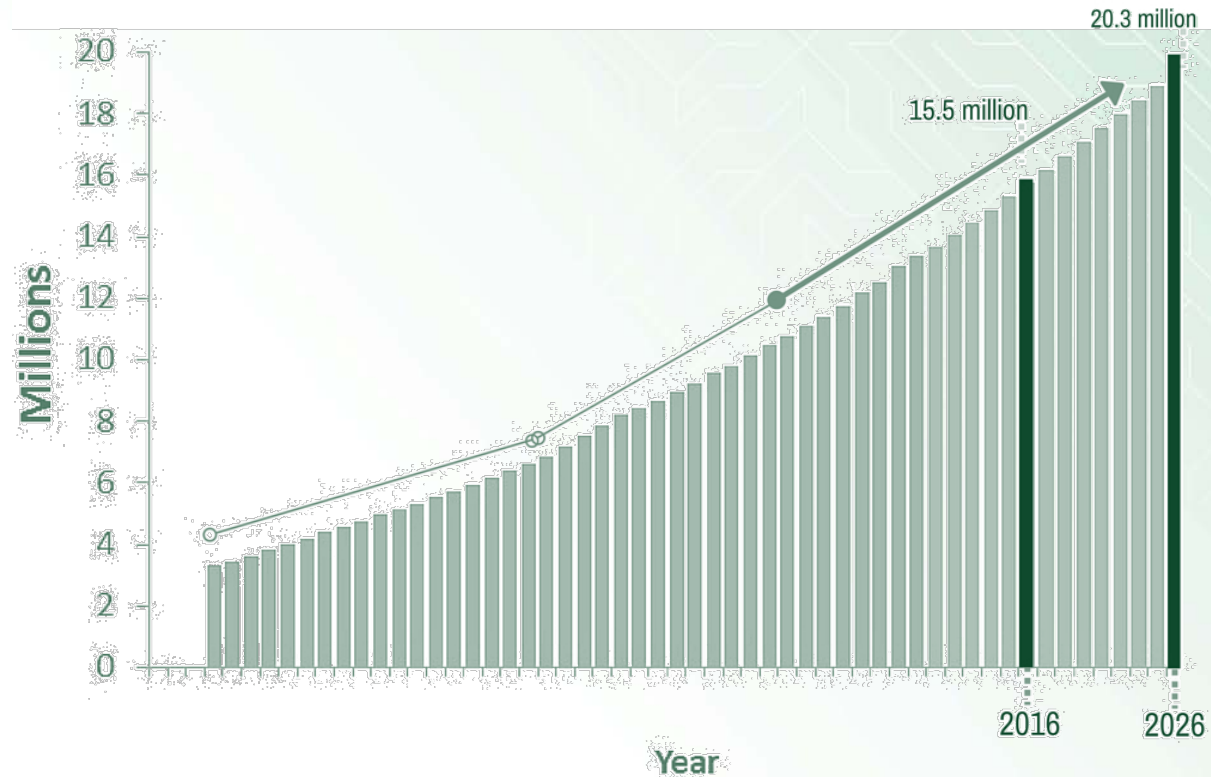
Advances in early detection & treatment have led to a growing number of cancer survivors:

In U.S.:

1970: ~50% 5-year survival

2016: ~70% 5-year survival

Estimated Cancer Survivors in the U.S.



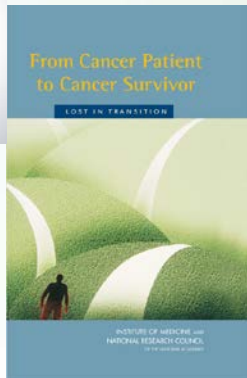
Source: Miller, K. D., et al. Cancer treatment and survivorship statistics, 2016. CA: A Cancer Journal for Clinicians. June 2, 16.

Why the emphasis on Survivorship research & care?

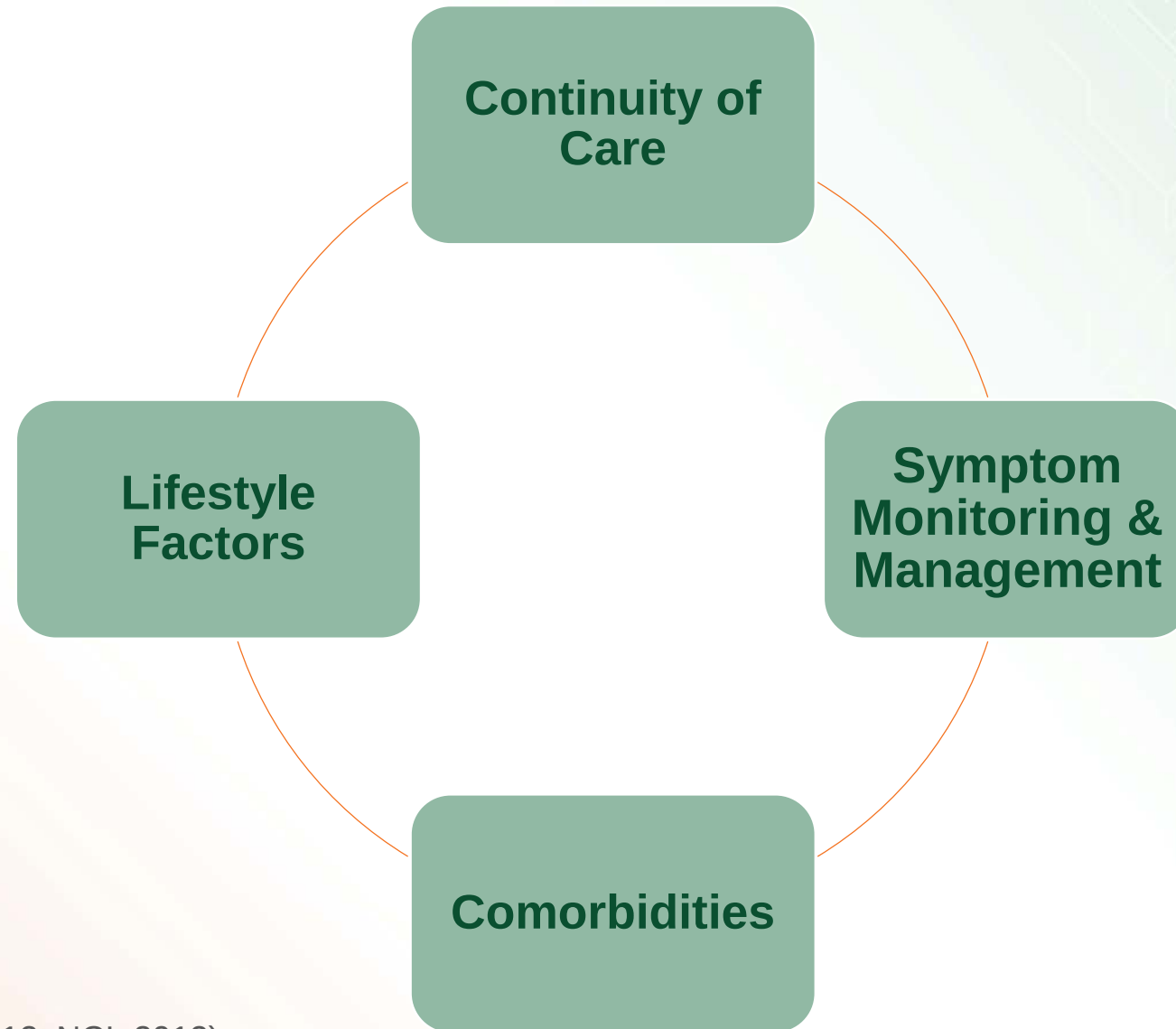
- **Survival offset by multiple challenges**
 - Chronic treatment side effects
 - Functional limitations & interpersonal disruption
 - Older population—comorbidities & lifestyle factors
 - Care is complex, expensive & often fragmented; financial burden
- **Psychological distress is common (~30%)**

- **Limited attention to survivors' needs (IOM/NAS):**
 - Physical, Emotional, Social, Financial & Care Coordination
 - Research and care delivery

(IOM, 2005, 2008, 2017; ACS, 2012; NCI, 2012)



Essential Focus Areas in Cancer Survivorship Care



(IOM, 2005, 2008, 2017; ACS, 2012; NCI, 2012)



AMERICAN COLLEGE OF SURGEONS

Inspiring Quality:

Highest Standards, Better Outcomes

100+years



Standards of Care

Revisions are coming?

STANDARD 3.2

Psychosocial distress screening, documented discussion and referral—at a pivotal point during the care continuum.

Expected
Compliance:

100%

During Active
Treatment?

STANDARD 3.3

Survivorship Care Plan—a comprehensive care summary and follow-up plan to patients with cancer who are completing cancer treatment.

2016 –25%

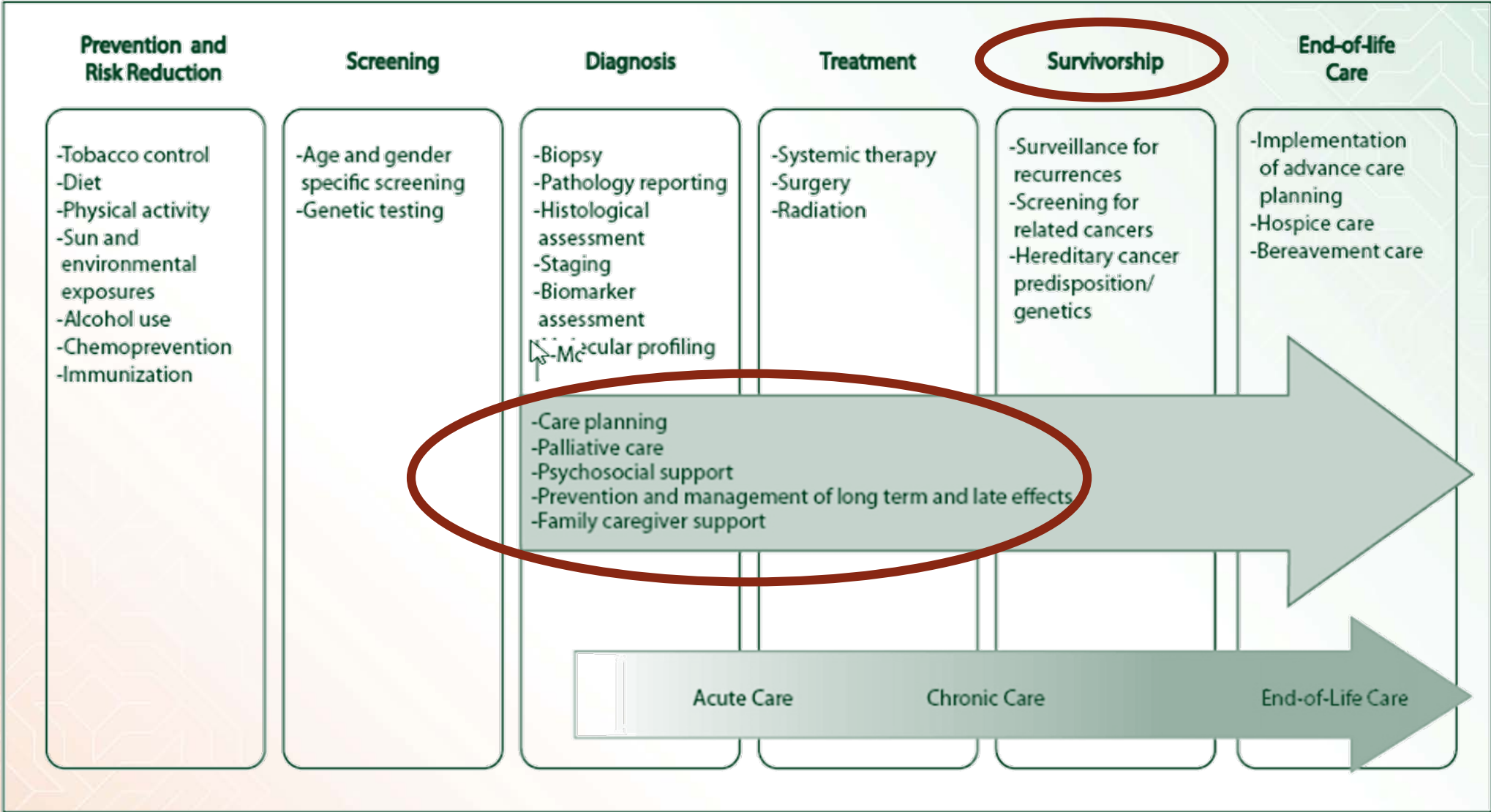
2017 –50%

2018 –50%

2019 –50%

Optional?

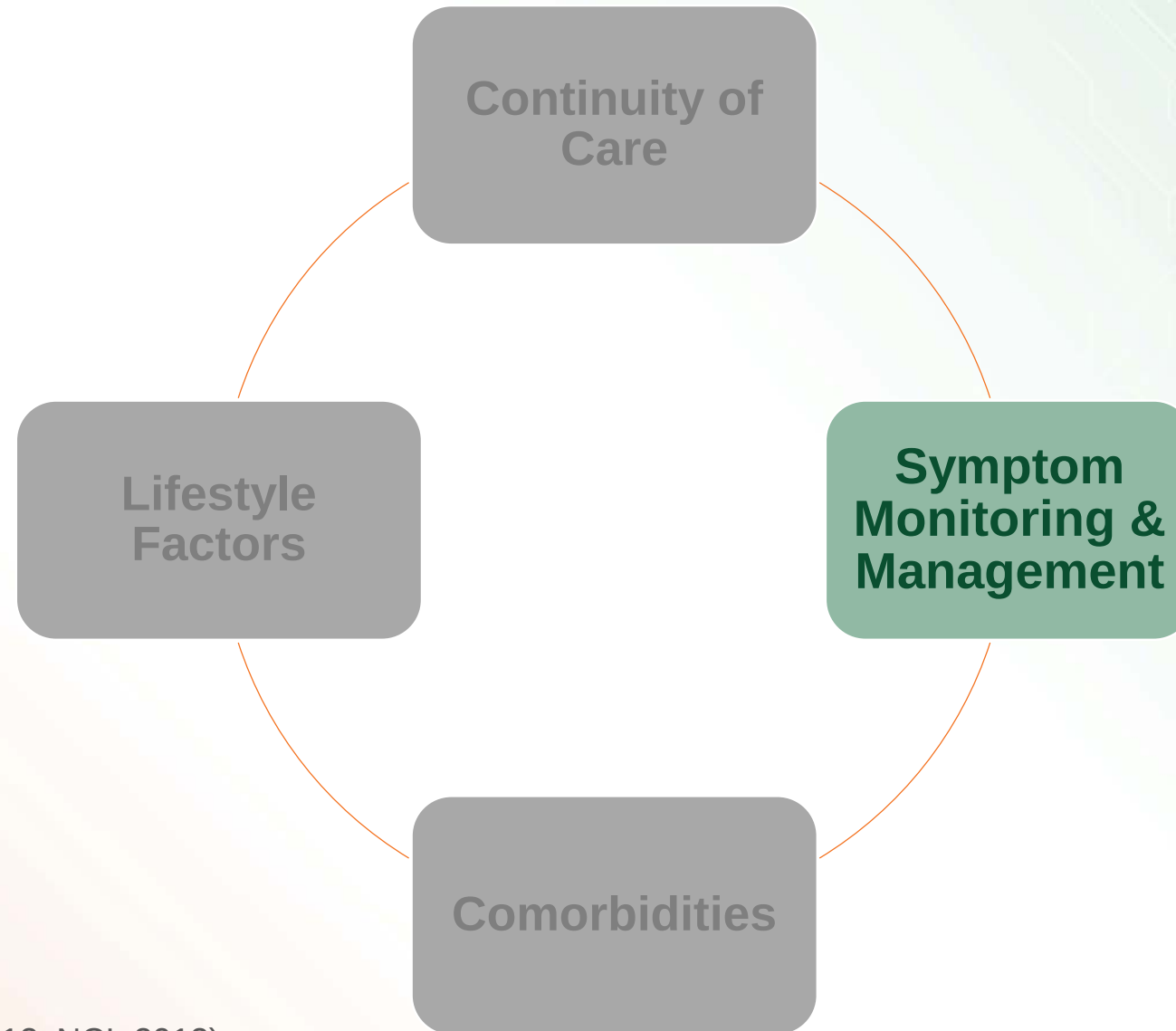
Survivorship Care



Survivorship Care: Communication Challenges

- How do we engage patients?
- Discussions typically *begin post-active treatment*—is earlier better for treatments planned with curative intent?
- Survivorship implies, for many, *5 years disease free*—is there a better term?
- Lack of provider *education and/or understanding* of survivorship care.
- *Provider resistance* to communicate services centered around the concept of survivorship—e.g., stem cell transplant
- *Cultural and contextual (e.g., SES, literacy) barriers* to overall care also impact patient engagement and understanding of survivorship

Essential Focus Areas in Cancer Survivorship Care



(IOM, 2005, 2008, 2017; ACS, 2012; NCI, 2012)

Measurement & Management of Patient-Reported Outcomes (PROs) in Oncology

- Evaluation and treatment of a patient's symptoms, function and quality of life are essential to quality medical care.
- Clinician ratings of symptom severity are often lower than that reported by patients, especially for subjective symptoms (e.g., anxiety, fatigue).

Benefits of Capturing Patient Experiences via Patient-Reported Outcomes:

- Promote individualized patient care *(Precision Care)*
- Enhance patient-physician communication *(Communication)*
- Facilitate shared health decision-making *(Patient Engagement)*
- Help patients measure progress over time *(Patient Engagement)*

Patient engagement → Outreach, engage & track patients



Organizing care teams of clinical and non-clinical staff under a value-based delivery sets a solid foundation for a value-based setting. Teams track patients throughout their care cycle, and establish a tailored process for patient outreach and engagement. By considering the patient's experience beyond the office, care teams can take a longitudinal approach to care delivery to meet value-based care delivery targets.

Technology

→ Collect, analyze pt. data



Managing the overall health and care delivery for a patient population requires an effective technology solution to effectively collect, aggregate, and analyze patient data. In addition to aiding in predictive modeling and implementing evidence-based care plans, collecting clean, quality data helps strengthen your reporting to ensure you receive appropriate payments and incentives—while avoiding costly penalties.

Workflow

→ Best practices, care requirements



Establishing effective clinical workflows—both at the micro and macro levels—ensures clear lines of responsibility, establishes best practices for effectively collecting and reporting on required data, and understanding the comprehensive care requirements for patients and patient populations.

Value-Based Care

Value-based care is the intersection of cost and quality.

Shifts the care delivery focus from volume to value and redefine financial incentives toward reduced costs.

Teams must think about the entire **patient experience** among all care settings and between episodic visits.

The provider mindset shift to address this model involves steps in terms of **patient engagement, technology and workflow** are the key first steps to value-based success.

<https://www.wellcentive.com/what-is-value-based-care/>

UHealth PRO: EHR-Integrated Screening, Management & Referral

Facilitating Communication of Symptoms & Practical Needs



With MyUHealthChart, your medical records are at your fingertips

Question Domains for Cancer Clinics

- Physical function
- Pain Interference
- Fatigue
- Depression
- Anxiety
- PRO-CTCAE
- Other PROs (clinic driven)
- Practical/psychosocial needs
- Nutritional needs

Assessment Criteria Utilized

- Patient population automatically selected by diagnosis code—contacted via email & text
- Assessment sent no more than 1x per month, starts at 2nd visit

Overall Functionality

- Assessment at home via UChart or in clinic
- Minimal disruption to regular clinic workflow
- Response routing to appropriate providers
- Real-time access to results and data within EPIC

PROMIS - Anxiety

https://uhemrmychlb1t.med.miami.edu/MyChartPOC/inside.asp?mode=questionnaire&src=ech

MyUHealthChart.com Bob Health Visits Messaging Billing Resources

eCheck-In

Personal Info Insurance Questionnaires Medications Allergies Health Issues

Emotional Well-being A

For an upcoming appointment with Joseph Pearson, MD on 4/5/2019

In the past 7 days

I found it hard to focus on anything other than my anxiety

Never
Rarely
Sometimes
Often
Always

CONTINUE CANCEL

Practical & Psychosocial Needs Assessment

https://uhemrmychlb1t.med.miami.edu/MyChartPOC/inside.asp?mode=questionnaire&src=ech

MyUHealthChart.com Mychart Health Visits Messaging Billing

eCheck-In

Personal Info Insurance Questionnaires Medications Allergies Health Issues Sign Documents

Practical & Psychosocial Needs

For an upcoming appointment with Joseph Pearson, MD on 4/5/2019

Indicates a required field.

I would like for a treatment team member to contact me for help with (check all that apply):

Select all that apply.

No needs at this time
Transportation resources
Support to help me cope with my illness and/or manage stress
Advance directives: medical actions to be taken if my health prevents me from making decisions (living will, power of attorney)
Financial/Insurance concerns about my health care
Oncofertility (ability to have children)
Child Care
Housing needs/concerns
Work/school concerns
Family Problems/Family Health concerns
Spiritual/Religious concerns
Sexual Health concerns
General education about my illness and assistance with treatment decisions

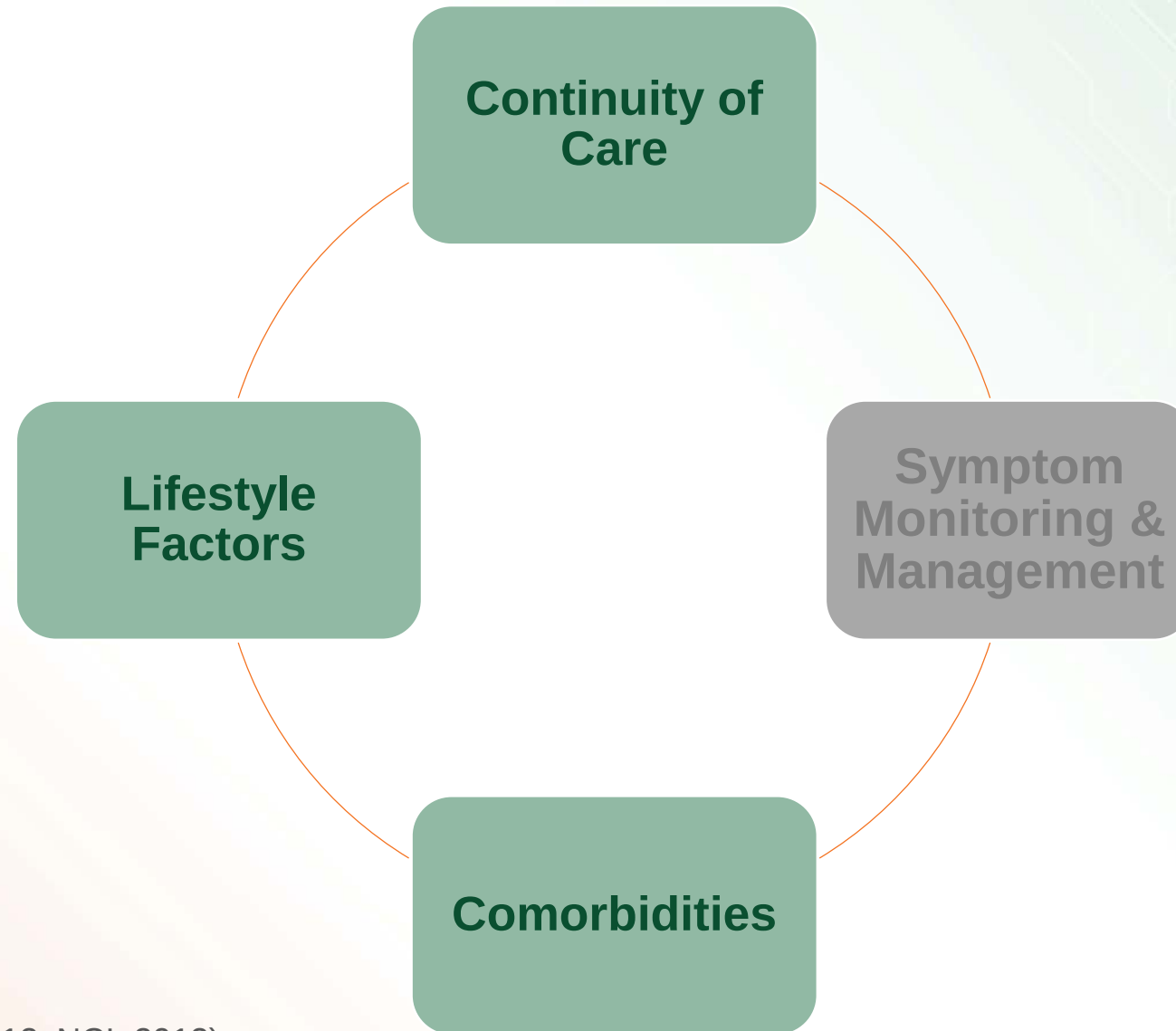
CONTINUE FINISH LATER CANCEL

Trending of PROs in the EHR to Optimize Patient Care

- Trends
- “Normal Range”



Essential Focus Areas in Cancer Survivorship Care



(IOM, 2005, 2008, 2017; ACS, 2012; NCI, 2012)

Essential Components of Survivorship Care

Prevention

- Lifestyle changes prevent new cancers and recurrent cancer

Surveillance

- For cancer spread, recurrence or second cancers

Intervention

- For consequences of cancer and its treatment (symptom burden, psychosocial distress)

Coordination

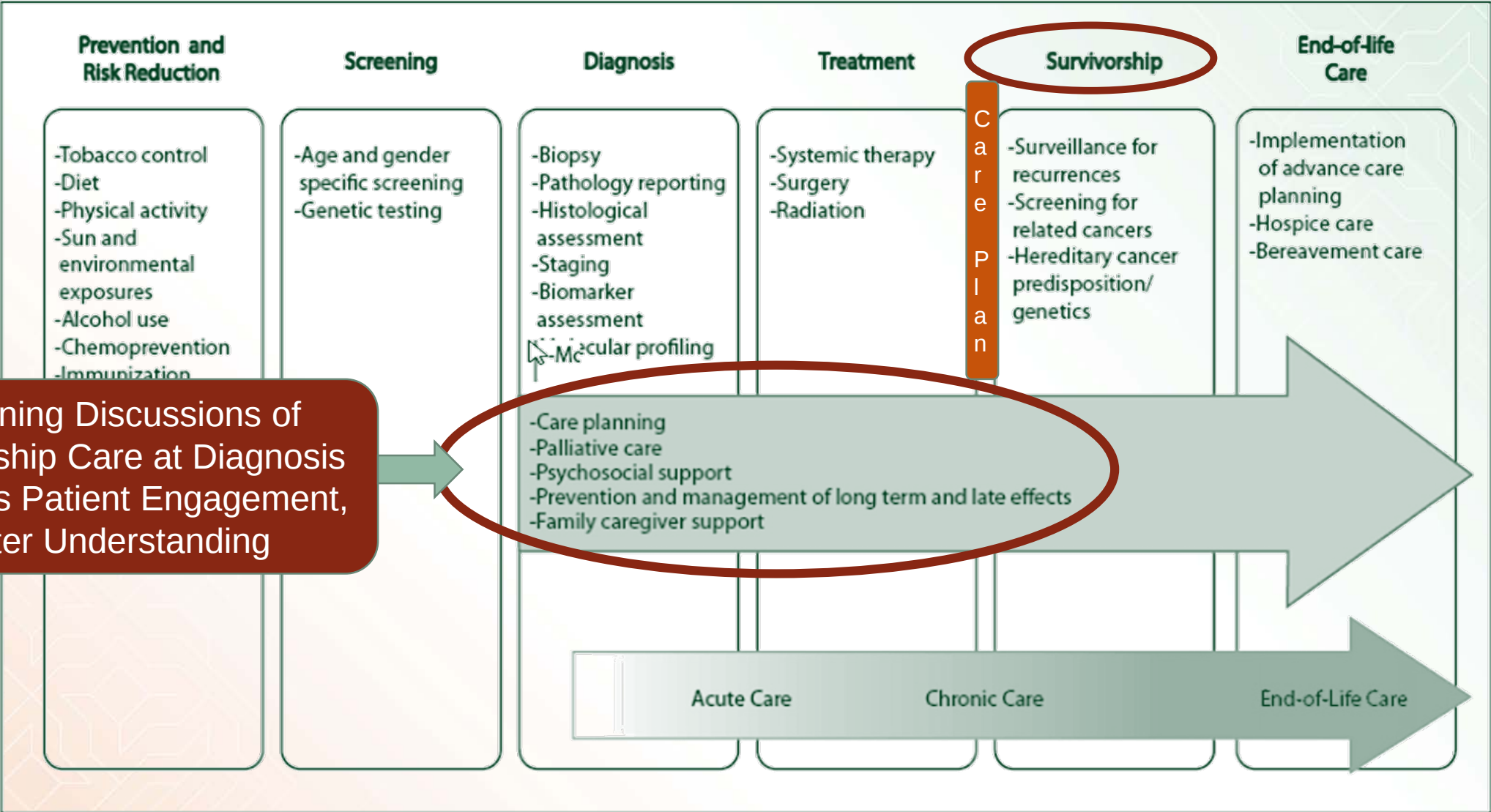
- Between specialists and primary care providers

Required Components of Survivorship Care Plans

- Contact info (institution/providers)
- Diagnosis, histologic subtype
- Stage
- Surgery (date, procedure)
- Chemotherapy (agent, end date)- including dose, regimen
- Radiation (body area, end date)- include dose
- Ongoing toxicities at end of treatment
- Genetic risk factors, predisposing conditions, if applicable with results of any genetic testing
- Need for any ongoing, adjuvant therapy
- Schedule of follow-up related clinical visits
- Schedule of cancer surveillance tests for recurrence
- Screening for early detection of new primaries
- Possible symptoms of recurrence
- A list of all possible clinically significant late effects
- General statement regarding importance of diet, exercise, tobacco cessation, alcohol use

Survivorship Care

Communicating the Concept of Cancer Survivorship Care



Has the Quality of Patient-Provider Communication About Survivorship Care Improved?

- Assess whether the quality of patient-provider communication on key elements of cancer survivorship care changed between 2011 and 2016.
- (N = 2,266). Participants reported whether any clinician ever discussed different aspects of survivorship care.
- "Did not discuss at all" to "Discussed it with me in detail"

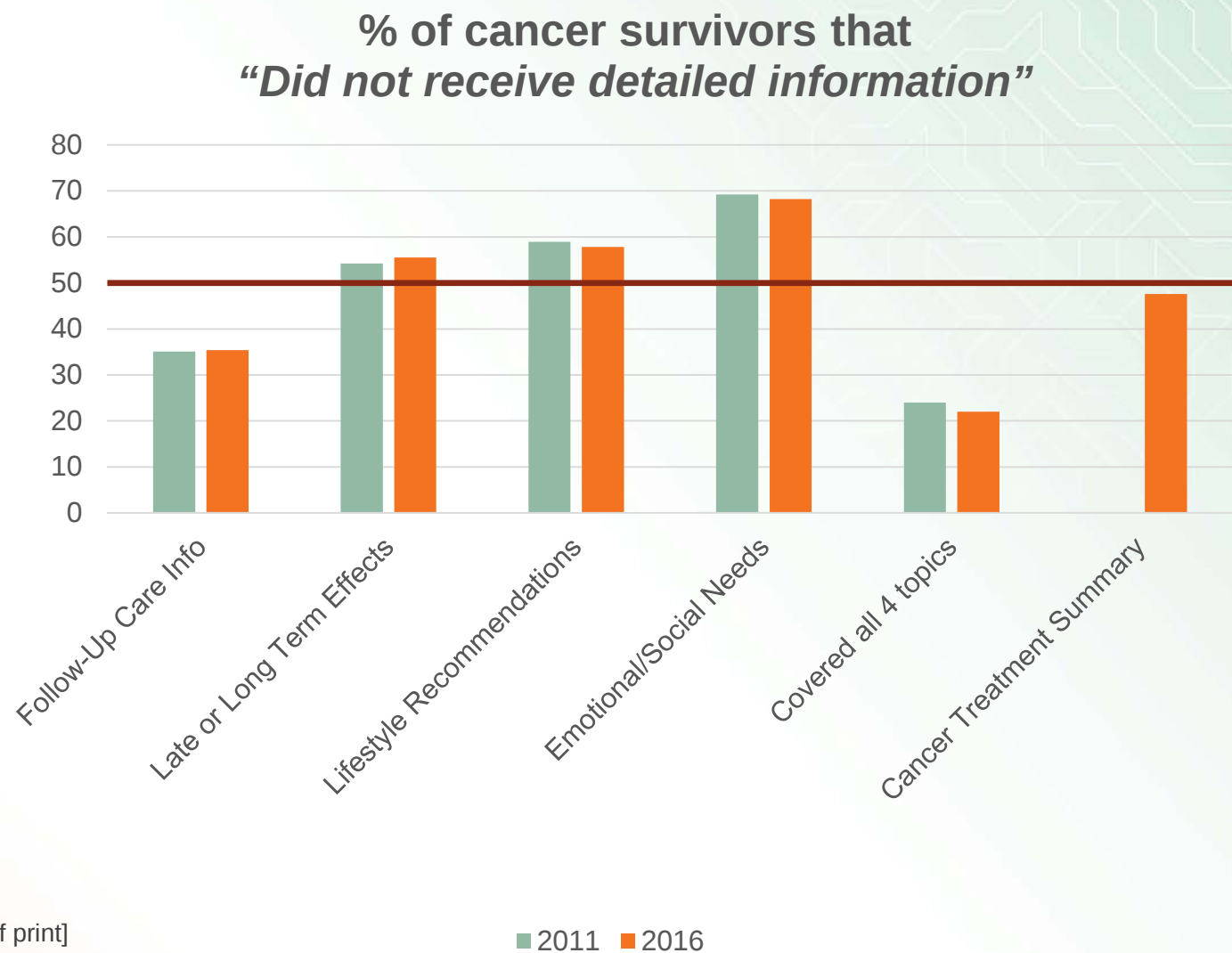


TABLE 1.
Patient-Centered Communication Strategies for Cancer Survivors

Function	Domains	Strategies
Responding to emotions	- Assess and recognize emotional distress - Validate emotions; express empathy and support - Provide tangible help for dealing with emotions	- Ask about survivor's <u>concerns and worries</u>; clarify understanding - Listen for verbal and <u>non-verbal cues</u>; avoid interruptions - Provide realistic reassurance; eg, quality-of-life issues; commitment to support survivor <u>Provide information; explore preferences for dealing with distress.</u> - Identify resources and facilitate referrals; eg, support groups, mindfulness-based practices; behavioral health
Managing uncertainty	- Assess and understand source of uncertainty - Use emotion-focused management strategies - Use problem-focused management strategies	- Address anxiety caused by uncertainty <u>Provide reassurance and information based on preferences</u> - Formulate a plan to reduce uncertainty; eg, decision trees - Recommend resources and facilitate referrals
Exchanging information	- Explore knowledge, beliefs, and information needs - Share information - Provide information and help survivors evaluate resources - Facilitate understanding	<u>Assess survivor's understanding; use everyday language</u> - Help survivor articulate information needs and preferences <u>Use support materials and encourage note-taking</u>
Enabling self-management	- Learn and assess survivors' motivation and ability to self-manage - Share, prioritize, and plan based on survivor's needs and priorities - Prepare, implement, and assist - Arrange, follow-up, and assist with navigating the system	- Tailor guidance; address psychosocial issues and barriers that impact self-management <u>Collaborate on goals, plans, and priorities</u> - Teach self-care, problem-solving skills, and support for symptom management; lifestyle modifications - Reassess progress and goals; update plan at each visit - Share SCP with primary care and other providers

Data from Epstein and Street,⁵ Dean and Street,¹⁸ and McCormack et al.²⁶

Communicating Cancer Supportive & Survivorship Care in Hispanics/Latinos

- Semistructured focus groups with 74 Hispanic/Latina BC survivors
- 50% low SES, uninsured
- Most had later-stage disease at diagnosis, some attributed this to linguistic and cultural barriers
 - Spiritual beliefs regarding cancer, prioritizing their familial role over their own health, passive interactions with health care providers due to their respect for the authority of health care providers.
- Expressed confusion regarding future care needs after primary cancer treatment concludes.
- Many misinterpreted survivorship care as plans to help their families carry on after they were gone.
- Social and cultural determinants of health shared with other racial/ethnic minority groups

Recovering Latina breast cancer patients report big gaps in 'survivorship' care [news release]. Oregon State University web site. <http://oregonstate.edu/ua/ncs/archives/2016/dec/recovering-latina-breast-cancer-patients-report-big-gaps-survivorship-care>. December 1, 2016. Accessed December 5, 2016. Tisnado DM, Mendez-Luck C, Metz J, Peirce K, Montañó B. Perceptions of survivorship care among Latina women with breast cancer in Los Angeles County. *Public Health Nurs.* 2016 Nov 2. doi: 10.1111/ohn.12299.

Hispanic/Latino Sociocultural Processes/Themes: Implications for Communicating Survivorship Care

Cultural Factors	Cultural Process	Psychosocial Implication	How to Optimize Communication: Culturally Informed Framing	
Familism	Strong attachment /interdependence with nuclear & extended family	▪ <i>Benefits of care must extend to family network</i>	▪ <i>Identifying how engagement in proper care benefits extended family</i>	▪ <i>Importance of self-care to maintain a strong family</i>
Simpatía & Power Distance	Non-confrontational interactions & conformity / powerful others as authority figures to respect	▪ <i>Authority figures (e.g., health care providers) not questioned</i>	▪ <i>Assertiveness skills, distinction between assertive vs. confrontational styles</i>	▪ <i>Demystifying powerful figures/others</i> ▪ <i>Rights as a patient to seek or clarify information</i>
Fatalism & External Locus of Control	Destiny is beyond one's control	▪ <i>Very little one can do to change the future</i>	▪ <i>Build self-efficacy via patient empowerment and engagement</i>	▪ <i>How culture can shape fatalistic beliefs</i> ▪ <i>More attention to controllability and modifying outcome expectancies—if one engages in proper care, benefits may be gained</i>
Male Gender Roles	Strong masculine pride and identity	▪ <i>Seeking supportive care as major threat to identity</i>	▪ <i>Address multiple aspects of a masculine role—and benefits to family</i>	▪ <i>Attention to how benefits of care support masculine role</i>

symposium article

Patient-centered care: the key to cultural competence

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Annals of Oncology 23 (Supplement 3): iii33–iii42, 2012
doi:10.1093/annonc/mds086

Table 1. Models of effective cross-cultural communication and negotiation [25]

Kleinman's questions [12]

- What do you think has caused your problem?
- Why do you think it started when it did?
- What do you think your sickness does to you?
- How severe is your sickness? Will it have a short or long course?
- What kind of treatment do you think you should receive?
- What are the most important results you hope to receive from this treatment?
- What are the chief problems your sickness has caused for you?
- What do you fear most about your sickness?

BELIEF [27]

- Beliefs about health (What caused your illness/problem?)
- Explanation (Why did it happen at this time?)
- Learn (Help me to understand your belief/opinion.)
- Impact (How is this illness/problem impacting your life?)
- Empathy (This must be very difficult for you.)
- Feelings (How are you feeling about it?)

Eliciting patient information and negotiating [28]

- Identify core cross-cultural issues
- Explore the meaning of the illness
- Determine the social context
- Engage in negotiation

LEARN [29]

- Listen with sympathy and understanding to the patient's perception of the problem
- Explain your perceptions of the problem
- Acknowledge and discuss the differences and similarities
- Recommend treatment
- Negotiate treatment

Survivorship Care: Recommendations

- Establish & implement clear guidelines for timely introduction of survivorship care
- Clarify/revisit the terms we use?
- Educate both patients & providers, foster a health system culture of survivorship
- Culturally informed and targeted approaches to optimize patient engagement
- Metrics to track progress—patient and system (*e.g., PCC measures; Street et al., 2016*)
- Stakeholder perspective (*Mazor et al., 2013*)
- Care delivery research initiatives focused on communication, linkage to care, continuity of care and patient/system level outcomes

Thank You!
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