

Issue #1: (existing Objective #18) Connect cancer patients and caregivers with non-clinical support services.**ISSUE STATEMENT & RATIONALE/EVIDENCE BASED RESEARCH:**Psychosocial Needs (including Navigation):

- Survivors reporting any psychosocial care were more likely to be “very satisfied” with how their needs were met, (Forsythe LP, Kent EE, Weaver KE, Buchanan N, Hawkins NA, Rodriguez JL, Ryerson AB, Rowland JH. Receipt of psychosocial care among cancer survivors in the United States. *Journal of Clinical Oncology*. 2013 Apr 22:JCO-2012).
- An Institute of Medicine report concluded that attending to psychosocial needs should be an integral part of quality cancer care and that all cancer care should ensure the provision of appropriate psycho- social health services by facilitating effective communication between patients and care providers; identifying each patient’s psychosocial health needs; designing and implementing a plan that links the patient with needed psychosocial services, coordinates biomedical and psychosocial care, engages and supports patients in managing their illness and health; and systematically following up on, reevaluating, and adjusting plans, (Adler NE, Page AE, editors. *Cancer Care for the Whole Patient:: Meeting Psychosocial Health Needs*. National Academies Press; 2008 Mar 19).
- On population-based study found that 58% of survivors reporting being distressed about their finances during treatment, (*CancerCare. CancerCare Patient Access and Engagement Report*. New York: CancerCare; 2016).
- In a study of over 1800 cancer survivors in Vermont, one third of survivors reported a need for “A case manager to whom you could go to find out about services whenever they were needed,” but 32% of those also declared that need was unmet, (Geller BM, Vacek PM, Flynn BS, Lord K, Cranmer D. What are cancer survivors' needs and how well are they being met?. *The Journal of family practice*. 2014. Oct;63(10):E7-16).

Gaps in psychosocial care

- Despite the prevalence of emotional and financial distress among cancer patients, survivors reported few referrals by members of their care team to counseling services or other professionals for support, (*CancerCare. CancerCare Patient Access and Engagement Report*. New York: CancerCare; 2016).
- Data from a national population based survey in 2010 found that 55% of cancer survivors reported no discussions with providers or use of support groups to address psychosocial concerns, (Forsythe LP, Kent EE, Weaver KE, Buchanan N, Hawkins NA, Rodriguez JL, Ryerson AB, Rowland JH. Receipt of psychosocial care among cancer survivors in the United States. *Journal of Clinical Oncology*. 2013 Apr 22:JCO-2012).
- Comment from listening session: “Go beyond distress screening” and actually address the distress.”

Equity

- (in Aziz&Rowland, 2002)
- For some cancer survivors of color, finding culturally appropriate support services can be a challenge. One study identified that two specific challenges for women of color were finding prostheses that matched their skin tones and obtaining referral to culturally relevant support groups, (Wilmoth MC, Sanders LD. Accept me for myself: African American women's issues after breast cancer. InOncology nursing forum 2001 Jun 1 (Vol. 28, No. 5)).
- Patient navigation interventions are recommended as a strategy for eliminating cancer related health disparities. Navigators perform key tasks across the cancer care continuum to ensure that patients receive services that are Understandable, Available, Accessible, Affordable, Appropriate, and Accountable, (Braun KL, Kagawa-Singer M, Holden AE, Burhansstipanov L, Tran JH, Seals BF, Corbie-Smith G, Tsark JU, Harjo L, Foo MA, Ramirez AG. Cancer patient navigator tasks across the cancer care continuum. Journal of health care for the poor and underserved. 2012 Feb 1;23(1):398)
(Krebs LU, Burhansstipanov L, Watanabe-Galloway S, Pingatore NL, Petereit DG, Isham D. Navigation as an intervention to eliminate disparities in American Indian communities. InSeminars in oncology nursing 2013 May 31 (Vol. 29, No. 2, pp. 118-127). WB Saunders.)
- Economic hardship may be especially burdensome for minority cancer survivors and disparities in economic hardship may not be caused by cancer care costs alone. Expenses to maintain or improve quality of life, rather than expenses for the treatment itself, may be making a difference for survivors in the months after treatment, (Pisu M, Kenzik KM, Oster RA, Drentea P, Ashing KT, Fouad M, Martin MY. Economic hardship of minority and non-minority cancer survivors 1 year after diagnosis: Another long-term effect of cancer?. Cancer. 2015 Apr 15;121(8):1257-64.)
- (LS) Need to address financial resource piece – big need here...(*p.24)

What factors & barriers contribute to this issue? Below are comments from the listening sessions:

- Resources are available, but patients, providers or caregivers) don't know about them
 - * (LS) We have many that come to physical therapy that have been suffering for years and did not know there were options available to help them deal with the side effects of cancer treatment
 - * (LS) "Information on where to go for financial help."
 - * (LS) "Practitioners were not aware of the resources of the community. Having a packet of up-to-date referrals to community resources available at multiple locations (e.g., clinic, library, religious institutions, city hall) would be beneficial."
- Resources are not relevant (culturally, eligibility wise, timing)
 - * (LS) "Diagnosed patients have a beautiful folder with information but don't qualify for payment for treatment, don't understand what is going on, don't know what to do; provider lays out treatment plan and sends them on their way."
 - * (LS) "We need more culturally competent navigators."
 - * (LS) "People who are newly diagnosed with cancer need a lot more attention on emotional aspect; let new person know where to go for support ASAP"

*(LS) “When care plan information is given to patients, it needs to be distributed over time (years) as the patient can absorb it.”

- Resources are provided, but not understood by patient (health literacy)
 - * (LS) Use verbal and written directions for things even as simple as how to go from one area of the hospital to another.”
- Barriers to accessing resources (internet, language, reading level, format of resource, transportation, lack of insurance coverage, eligibility criteria (e.g. only for breast cancer) etc.)*
 - * “The support groups are not always in a convenient location.” (listening session)
 - * “Get health insurance companies to expand coverage towards prevention programs, with more equity in coverage policies between insurance providers.”
 - * (LS) “Do more than just hand out a form or list of resources. Actual person-based counseling and navigation.”
- (Coordination) Keeping resource lists up-to-date (and local)
- (Coordination) Barriers – lack of coordination or ownership of resource list

What are the gaps in policy, systems and services that give rise to this issue?

- Involving survivors in development and dissemination of resources
- Lack of **coordination** between specialists, family practice, etc.
- **Needs change depending on “season of survivorship”**, how to follow through over time
- **Distance** to care – location of providers and services
- Inequities in **funding** (e.g. inadequate funding of Indian Health Services)

What are the **POLICY** opportunities to address the identified factors, and racial, economic, geographic, and other barriers that contribute to this issue? What are the **POLICY** opportunities to address the identified gaps?

From listening sessions:

- Sick leave policies can be greatly improved – most cancer survivors can’t take paid time off, there are people that aren’t eligible for disability insurance *(p.24)
- Locating and then understanding different expertise – for e.x. medical, financial, insurance, legal, emotional, education, social (homelessness, etc.) - look into model developed for LA

What are the **STRATEGY** opportunities to address both the barriers and the gaps relating to this issue?

Patient Navigators:

- Checklist for navigators – general categories of the type of resources a survivor may need over time
- Navigators hired by insurance company or public health organization to be on-call by centers in area

- Reimbursement for navigator services

Resource hub – that is kept up to date – presented in different formats

- Current resource pages are difficult to navigate, confusing eligibility criteria

Partner with Primary Care providers

- Many survivors choose to discuss treatment-related issues with their oncologists, for lifestyle concerns, they preferred to talk with their primary care physicians. (CancerCare. CancerCare Patient Access and Engagement Report. New York: CancerCare; 2016).

1. Who are the existing partners/organizations already working on this issue?

- American Cancer Society
- George Washington Cancer Institute (GWCI)
- Native American Cancer Research (NACR) - specifically a resource for American Indian survivors
- American Indian Cancer Foundation (AICAF)
- LIVESTRONG

2. Which partners/organizations should work together to address this issue?

- State and national resources

Which strategies promote health equity?

- Culturally specific patient navigators
- Offering resources and education in multiple languages.