APIAHF
ASIAN & PACIFIC ISLANDER
AMERICAN HEALTH FORUM

MAKING CANCER SURVIVORSHIP CARE PLANS MORE INCLUSIVE OF ASIAN AMERICAN, NATIVE HAWAIIAN, AND PACIFIC ISLANDER COMMUNITIES

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ABOUT APIAHF

The Asian & Pacific Islander American Health Forum (APIAHF) is a health justice non-profit organization dedicated to improving the health and well-being of more than 21 million Asian Americans, Native Hawaiians, and Pacific Islanders (AAs and NHPIs) living in the United States and its jurisdictions. APIAHF works with local and state-based CBOs in over 20 states and territories who provide services and advocate for AA and/or NHPI communities.

Since 1986, APIAHF has worked with community advocates, public health leaders, and policymakers to generate policies, programs, and systems changes to improve the health of AA and NHPI communities. APIAHF strongly believes that all persons have the right to be healthy, the right to live in a thriving community, and the right to quality, affordable, and accessible health care.

APIAHF's Mission

APIAHF influences policy, mobilizes communities, and strengthens programs and organizations to improve the health of Asian Americans, Native Hawaiians, and Pacific Islanders.

ABOUT APINCSN

The Asian and Pacific Islander National Cancer Survivors Network (APINCSN) is a network of cancer survivors, their family members, health care providers, researchers, health advocates, community members and organizations who are concerned about the issue of cancer and survivorship in Asian American, Native Hawaiian and Pacific Islander (AA and NHPI) communities.

APINCSN links AAs and NHPIs with critical resources, such as contact with other survivors, referrals to cancer support and survivorship services, access to multi-lingual cancer materials, and supportive and educational networking opportunities.

APINCSN's Mission

To minimize the burden of cancer and improve the quality of life of Asian Americans, Native Hawaiians, and Pacific Islanders by dispelling myths, reducing disparities and providing hope.

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INTRODUCTION

Cancer is the leading cause of death for Asian Americans, Native Hawaiians, and Pacific Islanders (AAs and NHPIs). AAs and NHPIs experience higher rates of cancer than other racial groups. In addition, they continue to experience the lowest screening rates and are less likely to be diagnosed with cancer at a localized stage. Some of the reasons that explain this include the lack of health insurance and access, financial concerns, lack of linguistically and culturally competent health care, and distrust or fear of the health care system due to certain cultural norms or beliefs. "More than 15.5 million children and adults with a history of cancer were alive on January 1, 2016, in the United States."[i] Due to advances in early detection and treatment, more people are surviving from cancer than ever before. By 2026, the population of cancer survivors in the U.S. will increase to nearly 20 million.

Cancer care does not end with the completion of treatment. There is a high risk of cancer recurrence involved, as well as the potential development of a new or different type of cancer. "Patients are not receiving care that prepares them for---or supports them after---the end of cancer treatment. Few health care providers are familiar with the short-and-long-term consequences of a cancer diagnosis and treatment, and there is a lack of clear evidence about what constitutes best practices in caring for patients with a history of cancer. This is especially true in underserved populations."[ii] AA and NHPI cancer patients are among the many that get lost in the health care system after treatment. Too many cancer survivors get lost in the transition from cancer patient to cancer survivor. Post treatment care often consists of inconsistent communication and coordination among the survivor and their health care team, fragmented and/or duplicated services, and insufficient attention to the side effects and after effects of the treatment received.

The 2005 Institute of Medicine (IOM) report, From Cancer Patient to Cancer Survivor: Lost in Transition, recommended that all patients completing primary cancer treatment receive a comprehensive treatment summary and a survivorship care plan (SCP) during end-of-treatment consultations by 2015. "Such plans would summarize information critical to the individual's long-term care, such as the cancer diagnosis, treatment, and potential consequences; the timing and content of follow-up visits; tips on maintaining a healthy lifestyle and preventing recurrent or new cancers; legal rights affecting employment and insurance; and the availability of psychological and support services."[iii]

In 2012, the Commission on Cancer (CoC), a program of the American College of Surgeons (ACoS) released a new standard focused on the delivery of survivorship care plans in Cancer Program Standards 2012: Ensuring Patient-Centered Care."[iv] Disseminating survivorship care plans to Stage I, II, and III cancer patients that completed therapy became a factor in facilities obtaining CoC accreditation. The CoC mandated that the new standard (standard 3.3) was to be implemented by 2015, but a survey that was disseminated to CoC's accredited programs in early 2014 found that "only 37% of responding cancer programs felt "completely confident" that their program would be able to implement the standard and only 21% indicated that a survivorship care plan had been developed. In response, the CoC updated the scope and timing of its standard. By January 1, 2015: implement a pilot survivorship care plan process involving 10% of eligible patients; by the end of 2016: provide survivorship care plans to 25% of eligible patients; by the end of 2017: provide survivorship care plans to 50% of eligible patients; by the end of 2018 and beyond: provide survivorship care plans to 75% of eligible patients; and by January 1, 2019: provide survivorship care plans to 100% of eligible patients."[v]

There are many other problems associated with SCPs including the lack of research to show the impact on cancer survivorship outcomes, not addressing unique cultural needs and not being provided in-language. Not addressing cultural needs and not being provided in-language are specific ways that survivorship care plans are not culturally and linguistically competent or inclusive of AA and NHPI communities. These factors will be addressed later in the findings section of this report.

METHODOLOGY

APIAHF staff and the APINCSN National Advisory Council (NAC) reviewed four survivorship care plans including: American Society of Clinical Oncology (ASCO), City of Hope (COH) Center of Community Alliance for Research and Education (CCARE), Journey Forward, and LIVESTRONG. Each of the NAC members were asked to read all four of the SCPs and utilize an assessment tool to score the areas of content, clarity, utility, cultural responsiveness, and sociological responsiveness. The assessment tool had a ranking scale of 1 to 4 with 1being poor, 2 being average, 3 being good, and 4 being excellent for each of the 21 questions. The scores on the assessment tools were discussed during conference calls with the NAC on four different occasions and a list of recommendations on how SCPs could be more inclusive of AA and NHPI communities was compiled.

Assessment Tool Questions

CONTENT

1. How detailed is the information presented?
2. How relevant is the SCP to quality of follow-up care?
3. How well does the SCP provide additional information about SCPs?

CLARITY

4. How well does the format make the document easy for providers to use?
5. How well does the format make the document easy for survivors to use?
6. How clear is the information presented?
7. How well does the SCP explain the role and function of the SCP?

UTILITY

8. How well does the SCP help survivors follow the medical and surveillance guidelines?
9. How well does the SCP help survivors follow the health advisories or quality of life (QOL) guidelines?

CULTURAL RESPONSIVENESS

10. How culturally sensitive is the information presented in the comorbidity section?
11. How culturally sensitive is the information presented in the health advisories section?
12. How culturally sensitive is the information presented in the quality of life (QOL) section?
13. How well does the information presented fit the needs of cancer survivors?
14. Is the SCP written in language that cancer survivors can understand?
15. Is the SCP linguistically responsive to non-English speaking cancer survivors?

SOCIOLOGICAL RESPONSIVENESS

16. Does the follow-up care section adequately cover the follow-up care needs relevant to cancer survivors?
17. Does the comorbidity section adequately cover the health concerns common/relevant to cancer survivors?
18. Do the health advisories adequately cover information and resources relevant to cancer survivors?
19. Does the quality of life section adequately cover information and resources relevant to diverse cancer survivors?
20. How well does the SCP present resources that are relevant to diverse cancer survivors?
21. Is the SCP written at a reading level that most cancer survivors can understand?

SURVIVORSHIP CARE PLANS REVIEWED

American Society of Clinical Oncology

ASCO developed the cancer treatment plan and survivorship care plan to help cancer patients keep track of the treatment that they have received, as well as be informed about the medical care that they may need in the future. The cancer treatment plan is a document that provides information about a patient's cancer, treatment, and follow-up care needs. The SCP contains information about treatments given, and the need for follow-up and future testing. In addition, it provides information about improving health and quality of life. The ASCO SCP template meets the CoC Standard for survivorship care plans and can be used for all types of cancer. The SCP template was designed to be delivered at the time of diagnosis in order to communicate the planned course of care for the patient. The SCP template is web-based and is a brief record of a patient's cancer treatment that is to be filled out by a member of the oncology care team.

City of Hope

The COH survivorship care plan is intended to be filled out by the patient, their oncology team, and may include their primary care provider. This SCP addresses certain concerns cancer survivors have regarding treatments that are most effective and the potential side effects, follow-up care needed, and how to improve health and well-being. "The City of Hope SCP empowers the cancer survivor to ask questions such as- What treatments are most effective for me and what are the possible side effects?; What follow-up care do I need from my oncology and primary care team?; What actions and behaviors should I practice to improve my health and well-being?"[vi]

Journey Forward

Journey Forward is a free online program (Survivor Care Plan Builder 4.0) for cancer survivors that help medical professionals and patients who have recently completed cancer treatment to work together to create custom SCPs. This online tool meets the CoC Standard for survivorship care plans and can be used for all types of cancer. The online tool is a collaborative effort by the National Coalition for Cancer Survivorship, UCLA Cancer Survivorship Center, Wellpoint Inc., and Genentech.

LIVESTRONG

The LIVESTRONG survivorship care plan is a free online tool that is intended to empower cancer survivors to customize their SCPs by inputting information regarding their diagnosis, treatment, and symptoms. This SCP is a tool to help cancer survivors' work with their oncologist and primary health care provider to address the medical and psychological challenges that may arise post-treatment. The LIVESTRONG SCP is a collaborative effort by the University of Pennsylvania, Abramson Cancer Center, OncoLink, and LIVESTRONG.

FINDINGS

A literature review of cancer survivorship care plans was conducted and it revealed many interesting details including the lack of research regarding their impact on cancer survivorship outcomes, the lack of cultural and linguistic competency, barriers to implementation, and suggestions for improvement.

Lack of Research Regarding Survivorship Care Plans

There have been a few randomized, controlled trials that have shown that health care professionals have found that survivorship care plans have been helpful in bridging communication for better coordination of care. However, the impact of SCPs on cancer survivorship outcomes is still unknown as research on SCPs is still ongoing. There is a strong belief that SCPs can empower cancer survivors by providing the tools to make them active participants in their cancer care. The hope is that the level of impact SCPs have on cancer survivorship outcomes will be revealed as more cancer programs meet the CoC's Standard. If SCPs are proven to have a positive impact on survivorship outcomes, the rate at which they are created and disseminated to cancer patients/survivors will increase.

Lack of Culturally and Linguistically Competent Survivorship Care Plans

Although a small percentage of SCPs have been developed, there are limited examples of SCPs that are culturally and linguistically appropriate to underserved communities, including AAs and NHPIs. Of the few SCPs that are available, most are written in English and Spanish. "Patient-centered SCPs that are presented in a bilingual format are necessary to achieve the intended goals of an SCP including appropriate patient information, education, and resources pertaining to their treatment, potential side effects, and recommended surveillance and follow-up care for limited English proficient (LEP) patients."[vii] Not being provided in-language, and not addressing cultural needs or aspects such as meditation, spiritual faith, and cultural foods are specific ways that survivorship care plans are not inclusive of underserved communities, including AAs and NHPIs.

Barriers to Implementation of Survivorship Care Plans

Many barriers to SCP implementation exist. Some of these barriers include:

- Treatment guidelines in SCPs are not standardized (no gold standard for the information to include in an SCP).

- The best timing for distribution of SCPs to patients is unclear.

- Developing and reviewing an SCP with a patient is time intensive.

- There is a lack of financial support and reimbursement.

- There is a lack of physician and provider support.

- There is lack of institutional commitment.

- There is a lack of knowledge among both patients and health care providers about the importance of survivorship care plans.

How to Improve Survivorship Care Plans

- Standardize the information to be collected and included in SCPs (gold standard).

- Provide guidelines or best practices for the timing of SCP distribution.

- Provide reimbursement for the time spent creating SCPs.

- Increase physician/provider support.

- Increase institutional commitment.

- Increase training and education for health care professionals and survivors regarding the importance of SCPs.

- Include underserved communities in the development of SCPs.

- Provide SCPs in-language.

RECOMMENDATIONS

- SCPs should be provided in-language and not primarily in English and Spanish. SCPs should at least be provided in the Asian languages most commonly spoken in the U.S.- Tagalog, Vietnamese, Chinese, Japanese and Korean; and the most prominent Pacific Islander languages- Hawaiian, Samoan, and Tongan.

- AAs, NHPIs, and other underserved communities should be included in the development of SCPs. Documents and programs that have been developed and evaluated with active community input have proven to be the most successful.

- SCPs for limited English proficient (LEP) AA and NHPI survivors should be utilized with interpretation and culturally and linguistically appropriate patient navigators to improve quality of care.

- SCPs should be culturally competent/ culturally sensitive. For example, spirituality is a critically important issue in many cultural groups and should be included in SCPs, along with the benefits of meditation and eating cultural foods.

- SCPs should be written in a way that is less technical and simple to understand.

- SCPs should not be limited to being completed online. Many AAs and NHPIs, especially the elderly or the poor, often times may not have access to computers or do not have the skill set to work on them.

- More research needs to be done on the impact of SCPs on cancer survivorship outcomes.

CLOSING

Survivorship care plans and the included treatment summary may be helpful to survivors who need to discuss their cancer experience with their primary care provider or new members of their health care team. The effects of SCPs on cancer survivorship are still being studied. Although there is a belief that SCPs may improve the quality of cancer care, this has not been proven. However, a few randomized, controlled trials have shown that health care professionals have found SCPs helpful in coordinating care for their patients. SCPs are still a new concept for many U.S. cancer programs and still continue to be phased in. For many existing SCPs, changes or improvements are suggested in order to make them more culturally competent and culturally sensitive to vulnerable populations. The survivorship care plan review team has made the recommendations outlined in this report and is confident that SCPs will become more inclusive of underserved communities including Asian Americans, Native Hawaiians, and Pacific Islanders in the near future.

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*   Asian Pacific Partners for Empowerment, Advocacy and Leadership (APPEAL)

*   Reaching Asian Americans & Pacific Islanders through Innovative Strategies to Achieve Equity in Tobacco Control and Cancer Prevention (RAISE) Network

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