BACKGROUND
Between 2015 and 2019, the Hawai‘i State Comprehensive Cancer Coalition’s Quality of Life Action Team held “Journey Together: Helping to Shape Cancer Survivorship Care in Hawai‘i” conferences throughout the state to bring cancer survivors and stakeholders together to discuss challenges, gaps and needs around survivorship in Hawai‘i, to provide resources to survivors, and to identify ways to improve communication between survivors, caregivers, and healthcare providers. The purpose of this evaluation project (FY2018-2019 Project#2) was to create a summary report compiling the notes taken at the survivorship conferences to document the unique barriers and needs of rural and neighbor island cancer survivors in Hawai‘i, and to compare those needs to what has been documented in the literature. Notes and literature were used to develop a presentation, to be used at the Statewide Cancer Survivorship Conference in Honolulu in Summer of 2020, and to develop a survey, to be used to identify unique challenges and needs for survivors of neighbor island and rural communities in Hawai‘i, and to help survivors and stakeholders set priorities to address identified challenges.

SUMMARY REPORT
This summary report has three parts. In Part I, we synthesize the themes found in four sets of meeting notes along with insights about what we found in the relevant literature. Then, in Part II, we describe our findings considering the six articles about cancer survivorship barriers in Hawai‘i and what was similar and distinct from what was found in the survivorship notes. Finally, in Part III, we enumerate our findings from the literature about cancer survivorship challenges in rural communities generally, also describing what was similar and distinct from themes identified in the survivorship notes.

NOTES REVIEWED*
“Journey Together: Helping to Shape Cancer Survivorship Care in Hawai‘i - All on the Wall Activity”
   Location: O‘ahu
   Date: August 20, 2015

“Journey Together: Helping to Shape Cancer Survivorship Care in Hawai‘i – Hilo”
   Location: Hilo
   Date: November 3, 2017

“Journey Together: Helping to Shape Cancer Survivorship Care in Hawai‘i – O‘ahu, Maui, Kona, Hilo”
   Locations: O‘ahu, Maui, Kona, Hilo
   Dates: August 20, 2015 (O‘ahu), February, 18, 2016 (Maui), November 4, 2016 (Kona),
           November 3, 2017 (Hilo)

“Journey Together: Helping to Shape Cancer Survivorship Care in Hawai‘i Strengths, Challenges,
Opportunities, Threats (SCOT) Activity”
   Location: Kapa‘a, Kaua‘i
   Dates: February 22, 2019

*Notes from the O‘ahu conference were reviewed because neighbor island representatives were present at the meeting and neighbor island challenges were identified in those notes.
I. JOURNEY TOGETHER MEETING NOTES THEMES

We reviewed the four survivorship meeting notes listed above and grouped them into seven overarching themes, and smaller subthemes. Overarching themes included transportation and financial needs and challenges; access to social and emotional supports; knowledge and information needs; access to care and support services; complementary and alternative medicines; emotions, beliefs, or culture; and other challenges and needs. We then reviewed literature about needs and challenges faced by Hawai‘i cancer survivors and rural cancer survivors generally. In the literature, we found many similar themes to the seven themes and multiple subthemes we identified in the survivorship meeting notes, and noted them with relevant citations.

Note: We did not do systematic literature review, nor did we consider the full scope of barriers and challenges in health information, access to care, and health communication in cancer or health care in general as this was beyond the scope of this project. However, to validate the subthemes from the Journey Together meeting notes that were not identified as barriers or needs in the Hawai‘i or rural cancer survivorship literature, we looked through literature about general cancer survivorship challenges and use of alternative medicines for cancer survivors.

1. TRANSPORTATION AND FINANCIAL NEEDS AND CHALLENGES

Transportation costs related to traveling to other islands for care*
- Transportation/travel costs to neighbor islands (airfare, transportation, food)
- Need for financial assistance (e.g., assist caregivers with airline and ground transportation arrangements)
- Funding for family visit off island
*This theme was found commonly in the cancer survivorship literature for Hawai‘i1-3 and for rural communities.7-11

Transportation issues related to on-island care*
- Lack of rides/drivers to get to appointments or support groups, group transport issues, no gas money
*This theme was found also in the cancer survivorship literature for Hawai‘i3 and for rural communities.12

Financial issues related to medical costs (e.g. medications and tests)*
- Costs of copays for medications and tests
- Rising costs of medical & threats of losing coverage
*This theme was found also in the cancer survivorship literature for Hawai‘i1-3 and for rural communities.10

General financial issues*
- Loss of income from time off work
- Need funding support - financial strain continues after treatment
- Financial burdens for caregivers and survivors
2. **ACCESS TO SOCIAL AND EMOTIONAL SUPPORTS**

**Need for social and emotional supports for survivors***
- Patient support groups (e.g., site specific, for neighbor islands, and for different types of cancer)
- Social support during treatment (care of kids)
- Help with changing thinking, overcoming fear of recurrence, and sharing your story to others who know nothing about it
- Emotional support
- Need for individual mentors/counselors and newsletters.
- Unsure what to do with emotional distress once it’s been identified.

*This theme was found also in the cancer survivorship literature for Hawai’i and for rural communities.*

**Need for religion and spiritual supports in cancer care**
- More church involvement, prayer

*This theme was found also in the cancer survivorship literature for Hawai’i and for rural communities.*

**Need for supports and information for caregivers***
- Caregiver education, literature, training, resources, etc.
- Buddy system for caregivers
- Caregiver support groups
- Respite care for caregivers
- Respite & support for caregivers when they also become diagnosed (i.e., when there is multigenerational cancer in the family)

*This theme was found also in the general cancer survivorship literature.*

3. **KNOWLEDGE AND INFORMATION NEEDS**

**Need for provider and patient education about long-term side effects (e.g., lymphedema, neuropathy)**
- Lymphedema awareness education
- Education for health professionals about post-treatment ongoing and long-term side effect, and how to improve that
- Knowledge of long-term side effects (e.g., Will they go away? Will they subside? Are they working on it?)
- I know what neuropathy means but was surprised to find out I needed 10 minutes to button a shirt

*This theme was found also in the cancer survivorship literature for rural communities.*
Need for information about treatment options so survivors can make informed decisions*

- Communication of side effects before treatment
- Knowledge of current and future treatment options
- Information of targeted therapy/ immune bio (e.g., info of testing, cost vs. covered by insurance, availability, side effects in survivorship, diet, labs, imaging)
- More informed decision-making
- Information of step-by-step planning (e.g., what is next after biopsy & what to do)
- Knowledge of treatment, side effects, step-by-step planning (e.g., after biopsy what is next, what to do) and relevant psychological support
- Information about treatment options can be intimidating to find and overwhelming to sift through.

*This theme was found also in the cancer survivorship literature for Hawai‘i¹ and for rural communities.¹⁰, ²¹

Information about services and resources that are available by island or community*

- I wish there to be a “catch all place” where communication of all concerns can be part of notification on new available resources – where to go
- Need for a one-stop shopping resource list
- Lack of information/resources of available services
- Create a resource directory for Hawai‘i (Hilo specific and/or Kona specific)

*This theme was found also in the cancer survivorship literature for Hawai‘i¹ and for rural communities.⁷, ⁹

Need for information about financial resources and supports (e.g., grants, financial planning)*

- Awareness of pharmaceutical assistance programs
- Knowledge of financial resources (grants, post treatment help, charitable organizations, funding for neighbor islands, information on insurance coverage)
- Support for financial planning, available grants, understanding out of pocket costs, or other services that could provide them with some financial relief.

*This theme was found also in the cancer survivorship literature for Hawai‘i³ and for rural communities.⁸

Need for information/help to understand insurance coverage*

- Continuous feedback sought of patient comprehension of medical plan –
- Dedicated case manager/social worker/patient navigator to help understand insurance coverage
- Support for financial planning, available grants, understanding out of pocket costs, or other services that could provide them with some financial relief.
- Need financial navigators
*This theme was found also in the cancer survivorship literature for rural communities.*

Need for information about palliative care eligibility and access to those resources*
- Definition and clarification of palliative care service and eligibility criteria
- The Hilo (Kupu care) Palliative care program (only one) is grant funded (not sustainable) working toward being a reimbursable service (in progress)
- Increasing access to palliative care or increasing information about palliative care/support care programs

*This overarching theme was found also in the general cancer survivorship literature.*

Other educational needs*
- Education support
- Educational materials in different languages

*This theme was found also in the cancer survivorship literature for Hawai‘i* and the general cancer survivorship literature.

4. **ACCESS TO CARE AND SUPPORT SERVICES**

Issues around access to care (e.g., clinical trials, on-island shortages of care)*
- Location issues (lack of access to and availability of treatment – need to travel to the NI)
- Concern of timeliness of treatments
- Lack of providers (due to turnover)
- Identified gap: under-usage of APRNs to broaden survivorship care
- Shortage of care plans and clinical trials
- Access to and information on clinical trials, especially for rare cancers.
- Kaiser patients living on Moloka‘i must go to O‘ahu for treatment rather than Maui. (The challenge is due to what insurance you have.)

*This theme was found also in the cancer survivorship literature for Hawai‘i* and for rural communities.

Issues around access to supportive care services for patients/survivors (e.g. psycho-social services, nutrition services, tailored PT services)*
- Shortage of oncology psycho-social services and support (e.g., shortage of social workers trained in oncology, oncology social services, oncology psych providers, tele-psych, certified nutritional support)
- Opportunity for psych evaluation for cancer patients
- Post-treatment care (tailored program for PT, exercise, nutrition, mind/meditation resources).
- No support for nutritional on-going care
- Appropriate exercise regimen
- More interventional research to improve side effects or quality of life
Need for access to other resources/services*

- Legal services
- Outreach facilities

*This was not identified as a barrier in the literature for Hawai‘i or rural communities, but the Institute of Medicine recommends that survivorship care plans provide information about legal services and outreach services.25

5. COMPLEMENTARY AND ALTERNATIVE MEDICINES (CAM)

Lack of access to and information about alternative medicines*

- Lack of discussion between patient and provider about alternative treatments (e.g., providers don’t want to talk about it)
- Lack of coordination between naturopathic doctors’ healers with clinicians
- Need experts in alternative medicine
- Not FDA approved (e.g., data on effectiveness, anecdotal information)
- Provider issues: no financial incentive for MDs to include/consider CAM
- Lack of knowledge by MDs and survivors around CAM
- No funding for complementary resources – healing touch, acupuncture
- More funding needed for research on oils, hemp, herbs, etc., for ongoing health.

*This theme was found in cancer survivorship literature for rural cancer survivorship9, 10, 12, 20 and the general cancer survivorship literature.26, 27

Preferences for traditional healing*

- Hawaiian traditional medicine

*This theme was found in cancer survivorship literature for Hawai‘i2, 6 and for rural communities.11

6. EMOTIONS, BELIEFS, OR CULTURE

Cultural factors*

- Fear/shame after being diagnosed with cancer
- Not wanting to identify as a survivor
- Do not want to burden others with their illness & treatment
- Not feeling comfortable sharing/private
- Trust issues with the health care systems

*This theme was found in cancer survivorship literature for Hawai‘i1-4, 6 and rural communities,7 and the general cancer survivorship literature.11, 22, 29
Patient attitudes, feelings, beliefs toward cancer*
- Fear of being diagnosed/lack of education that prevents them from getting screened
- Fears of recurrence
- Feeling overwhelmed so don’t do some things
- Losing friends and members in the group to cancer can be deflating to the remaining survivors

*This theme was found in cancer survivorship literature for Hawai‘i2, 3, 6 and rural communities, 10 and in the general cancer survivorship literature.25, 29

7. OTHER CHALLENGES AND NEEDS

Issues around coordination of care*
- Coordination of care among providers – different EMRs, different systems

*This theme was found also in the cancer survivorship literature for Hawai‘i1 and for rural communities.11

Issues relating to nutritious foods*
- Nutrition – nutritious food on Maui is more expensive
- Unhealthy foods/ fast foods are easily accessible

*The high costs of nutritious foods was not specifically identified as a barrier in the Hawai‘i or rural survivorship literature. However, Hawai‘i patient navigators helped cancer survivors with accessing food assistance.3 Access to affordable, healthy food is a documented challenge in Hawai‘i.28

Need legislative support and advocacy for cancer issues*
- Need to increase advocacy for cancer issues from Kaua‘i perspectives
- Need more active lobbying for Hawai‘i Island cancer issues

*This unique theme from Journey Together notes did not come up as a challenge in the survivorship literature for Hawai‘i, rural communities, or the general cancer survivorship literature. However, legislative advocacy for cancer survivors is a key activity conducted by many cancer stakeholder organizations, such as the American Cancer Society, the American Society of Clinical Oncology, National Coalition for Cancer Survivorship, etc.
II. LITERATURE REVIEW OF NEEDS AND CHALLENGES FOR HAWAI’I SURVIVORS

We reviewed six articles for Hawai’i specific needs and challenges. Most of the articles we reviewed were studies by the ‘Imi Hale Program who collected information through focus groups and interviews with Native Hawaiian, Samoan, and Micronesian cancer survivors, as well as patient navigators. Publication dates ranged from 2002-2012. Literature confirmed many of the themes that were gathered at the survivorship conferences. (See Section A below). Native Hawaiian and Hawai’i resident survivors have needs and challenges related to both arranging and affording travel from the neighbor islands to O’ahu, arranging transportation to on-island care, financial issues related to medical care costs, and general financial issues. They felt there is a lack of social supports for cancer survivors, especially for Native Hawaiians, and expressed a need for spiritual supports in cancer care. Knowledge and information needs were also identified in the Hawai’i literature, specifically around needs for information about cancer and treatment options to make decisions, available resources, and financial supports, and needs for culturally tailored and in-language materials. In terms of access to care and support services, the literature showed that Hawai’i survivors felt they lacked access to providers on-island, and needed access and referrals to supportive care services like palliative and hospice care. Hawai’i survivors also had preferences for traditional Native Hawaiian and Samoan traditional healing practices. Emotions, beliefs and cultural factors identified in the literature included things like feeling alienated by Western Healthcare, feelings that cancer is a white man’s disease and feeling ashamed to have it, feeling that talking about cancer will bring it on. Other challenges and needs that corroborated the Journey Together notes, included a lack of coordination of care within the cancer system.

Issues identified in the Hawai’i specific literature that were not raised in the Journey Together notes included: lack of insurance or underinsurance (perhaps due to changes in insurance policies since these articles were published); barriers in the patient-provider relationship (including communication issues, provider insensitivities, and provider dismissals); challenges related to side effects and disfigurements; issues balancing treatment with other obligations; and needing help signing up for food assistance. These challenges and needs are shared in Section B below for their possible relevance in Hawai’i.

A. HAWAI’I CHALLENGES OR NEEDS SIMILAR TO THE JOURNEY TOGETHER MEETING NOTES

1. TRANSPORTATION AND FINANCIAL NEEDS AND CHALLENGES

Transportation costs related to traveling to other islands for care
- Travel costs and fatigue
- Need to travel to O’ahu
• Inability to leave families or work to travel to Oʻahu
• Time and cost of transportation
• Distance from screening and treatment facilities
• Need for financial supports for travel for survivors and family
• Difficulties arranging or affording off-island travel
• Housing issues

Transportation issues related to on-island care
• Difficulties arranging on-island transportation

Financial issues related to medical costs
• High cost of care, copays, and/or medications
• Costs of care

General financial issues
• Poverty
• General financial issues

2. **ACCESS TO SOCIAL AND EMOTIONAL SUPPORTS**

Need for social and emotional supports for survivors
• Lack of social supports
• Lack of support groups specifically for Native Hawaiians

Need for religion and spiritual supports in cancer care
• Stressed the importance of religion and a need for spiritual supports in cancer care

3. **KNOWLEDGE AND INFORMATION NEEDS**

Lack of information about cancer and treatment needed for decision-making
• Lack of information to make good choices
• Limited knowledge of cancer
• Not knowing what questions to ask
• Lack of information about clinical trials

Need for information about available resources and services
• Lack of knowledge of/referral to other resources

Need for information about financial supports
• Patients needed referrals from their patient navigators to general financial resources (e.g., rent, utilities, food assistance), and for cancer care (e.g., treatment, assistive devices, pharmaceuticals, travel)

Other educational needs
• Need for culturally tailored and in-language education/materials
4. **ACCESS TO CARE AND SUPPORT SERVICES**

   **Lack of access to quality care**
   - Lack of providers on-island\textsuperscript{1,3}
   - Lack of physicians, specialists, and second opinions\textsuperscript{1}

   **Need for access to supportive care services**
   - Patients needed referrals from patient navigators to supportive care services like hospice and palliative care and emotional supports\textsuperscript{3}

5. **COMPLEMENTARY OR ALTERNATIVE MEDICINES (CAM)**

   **Preferences for traditional healing practices**
   - Preferences for Native Hawaiian or Samoan traditional healing practices\textsuperscript{2,6}

6. **EMOTIONS, BELIEFS OR CULTURE FACTORS**

   **Cultural factors**
   - Cultural barriers in the system\textsuperscript{1}
   - Feeling alienated by Western healthcare\textsuperscript{2}
   - Feelings that cancer is a white man’s disease and shame about having it\textsuperscript{6}
   - Feeling that talking about private parts is inappropriate, related to cervical and breast cancers\textsuperscript{4}

   **Patient attitudes and beliefs toward cancer**
   - Fatalistic perceptions of cancer\textsuperscript{2}
   - Beliefs that saying the word cancer can bring it on\textsuperscript{2,3}

7. **OTHER CHALLENGES AND NEEDS**

   **Lack of coordination within the cancer system**
   - Running around between providers offices and facilities in the course of diagnosis and treatment\textsuperscript{1}
   - Not knowing who is in charge of treatment\textsuperscript{1}
B. POSSIBLY RELEVANT HAWAI‘I CHALLENGES OR NEEDS NOT FOUND IN THE JOURNEY TOGETHER MEETING NOTES

The challenges and needs identified below were subthemes that were not brought up in the Journey Together discussions. However, they are shared for their potential relevance to Hawai‘i cancer survivors.

1. TRANSPORTATION AND FINANCIAL NEEDS AND CHALLENGES

Lack of insurance or underinsurance
- Lack of access to insurance or underinsurance\(^1,2\)
- Insurance issues\(^3\)

7. OTHER CHALLENGES AND NEEDS

Barriers in the patient-provider relationship
- Poor communication between patient and provider\(^1\)
- Patients’ feelings of intimidation\(^1,2\)
- Insensitivity and poor communication by providers\(^1\)
- Provider’s dismissal of concerns (indicated by rural communities on the NI)\(^3\)
- Feelings of being discriminated against\(^4\)
- Poor attitudes of providers and staff\(^3\)
- Dropped referrals/transfers\(^1,3\)
- Lost paperwork\(^1,3\)

Other challenges
- Side effects and disfigurements\(^2\)
- Seeking care when busy with other obligations\(^1\)
- Patient navigators helped Hawai‘i cancer survivors to sign up for food assistance\(^3\)
III. LITERATURE REVIEW OF NEEDS AND CHALLENGES FOR RURAL CANCER SURVIVORS GENERALLY

We also reviewed 19 articles about cancer survivors in various rural communities in the United States (rural Eastern North Carolina, Kentucky, Utah, etc.) as well as in rural Australia and Canada. Despite the fact that Hawai’i’s rural communities are unique in terms of demographics and geography, many of the needs and challenges identified in these rural studies were similar to those identified in the survivorship conference notes and in the Hawai’i specific literature. Rural themes similar to the notes included challenges around transportation, including costs; financial issues related to medical costs and in general (e.g., higher health-related unemployment rates in rural survivors); needs for social and emotional supports for both patients and caregivers; need for religion and spirituality to be included in cancer care; need for information about side effects (to improve them and make treatment decisions), palliative care, financial supports, and insurance coverage; issues around access to quality care, supportive care services, and other resources; lack of access to and information about alternative medicines; preferences for traditional healing; and cultural and emotional factors, such as shame, alienation from Western healthcare; and fear of stigma. (See Section A below.)

Themes that were not raised in the Journey Together meeting notes are shared for their potential relevance to Hawai’i. (See Section B below.) These themes include other issues related to transportation (time away from family and isolation due to travel); issues related to health insurance; the need for information about cancer and treatment generally; the need for information about sexual and fertility issues; the lack of access to health promotion resources; and barriers in the patient-provider relationship (like lack of empathy and trust or provider turnover in rural communities). Finally, although there were mixed findings in the literature about if rural survivors have more psychological distress than urban survivors do, the theme came up in the literature often, so we have shared those findings as well. As previously noted, we also reviewed 11 articles that were not specific to rural cancer survivorship needs. These pertained to challenges and needs for cancer survivors and their caregivers generally and the use of alternative medicines for cancer survivors. Information from these non-rural articles are noted with **.

A. RURAL CHALLENGES AND NEEDS SIMILAR TO THE JOURNEY TOGETHER MEETING NOTES

1. TRANSPORTATION AND FINANCIAL NEEDS AND CHALLENGES

Transportation costs
- Rural youth cancer survivors in Canada needed more information about financial supports for lodging and fuel than their urban counterparts.
- Costs of accommodations and travel

Financial issues related to medical costs
- Challenges with costs of care

General financial issues
- Loss of ability to work
o Rural cancer survivors tended to go into early retirement and were less likely to go on paid disability than their urban counterparts.13
o Rural survivors had more health related unemployment than urban survivors.14
  • Challenges paying for non-treatment related bills10
  • Survivors had needs for financial assistance.8

2. ACCESS TO SOCIAL AND EMOTIONAL SUPPORTS

Need for/lack of access to social and emotional supports
  • Need for more support groups7,15
  • Rural patient navigators helped young adult and adolescent survivors with emotional supports8
  • Lack of professional support services in rural communities15,21,24
  • Access to fewer mental health resources15,16
  • Need for psychosocial supports (coping with emotions, changing thinking, understanding changing relationships)16
  • Need for childcare support to attend long-term follow up appointments8

Need for religion and spirituality to be included in cancer care
  • Other studies of African American survivors found that they wanted their provider to acknowledge their faith in God or spirituality in their cancer treatment10
  • Multiple studies found that rural African American survivors relied on spirituality throughout the diagnosis and treatment of cancer10,12

Need for supports and information for caregivers**
  • Needs for caregiver education, literature, training, etc.19
  • Caregivers experience psychosocial, social, material and coping challenges17,18

3. KNOWLEDGE AND INFORMATION NEEDS

Lack of education/information about side effects
  • Pain, body aches, neuropathy, lymphedema, memory loss, tooth loss, weight gain10
  • Lymphedema, hormonal side effects, fatigue, sexuality, and body image20

Lack of information about side effects when making treatment decisions20

Need for information about and having issues around access to palliative care
  • Lack of knowledge of services, costs, lack of trust, cultural barriers, etc.17**
Need for information about financial supports
  • Survivors had needs for financial assistance

Need for information or help to understand insurance coverage
  • Patients needed guidance from patient navigators in understanding their insurance policies

4. ACCESS TO CARE AND SUPPORT SERVICES

Issues around lack of access to quality care
  • Limited access to new and effective therapies and technologies
  • Long distances from treatment – geographic isolation
  • Lack of access to specialty care
  • Issues around access to different types of treatments
  • Issues around access to medical providers and health information
  • Not having access to a regular GP
  • Delayed access to adjuvant treatments post-surgery
  • Studies showed that distances from cancer centers makes it less likely to receive optimal cancer treatment
  • Rural survivors have later access to screening leads to more advanced cancer and more extreme treatments
  • Rural physicians lacked continuing education to be aware of current treatments

Issues around access to supportive care services
  • Rural residents have less access to cancer support groups, education, and health promotion programs.
  • Compared with non-rural cancer survivors, rural survivors were less likely to report access to psychologist or support groups within 30 miles from their home and were less likely to report they could access supports if they wanted to.
  • Rural breast cancer survivors with poorer adjustment (on psychological factors on survey items) to breast cancer had more weight gain. Gaps in access to mental health services in rural communities is one contributing factor.
  • Shortages of mental health care resources in rural communities in general (not specifically for cancer).

Need for access to other resources/services
  • The Institute of Medicine recommends that survivorship care plans provide information about legal services and educational outreach services.
5. **COMPLEMENTARY OR ALTERNATIVE MEDICINES (CAM)**

Lack of access to and information about alternative medicines

- Studies have shown a lack of communication around CAM use between patient and clinician, due to lack of disclosure by patient and lack of inquiry by the clinician.\(^{29}\)
- Aboriginal cancer survivors interviewed said access to traditional healing was challenging. They either had to travel to remote areas to access it or make arrangements to bring a bush healer to them.\(^{30}\)
- Some Aboriginal cancer survivors indicated they didn’t know how to contact a traditional healer.\(^{30}\)

Preferences for traditional healing

- Aboriginal survivors had preferences for traditional healing because it is more holistic and spiritual\(^{11}\)

6. **EMOTIONS, BELIEFS, OR CULTURAL FACTORS**

Cultural factors

- Cultural barriers in the system\(^{17,29-31}\)
- Multiple Aboriginal studies identified a lack of culturally appropriate communication and care from health professionals and a need for survivorship programs tailored for Indigenous people.\(^{11}\)
- Aboriginal studies talked about perceiving cancer as the “white man’s disease” and felt shame around having cancer.\(^{11}\)
- Both African American and Aboriginal rural cancer survivors had social role disruptions due to their cancer/treatment. Both also had a lack of trust in the health system.\(^{7,11}\)
- African American Breast Cancer Survivors in rural communities had fears about disclosing cancer diagnosis to family and friends to protect their loved ones and felt that community members had negative perceptions of cancer.\(^{29}\)
- Feeling alienated by Western healthcare\(^{22**}\)

Patient attitudes and beliefs toward cancer

- Fatalism\(^{10,20,32}\)
- Fear of stigma\(^{10,20}\)
B. POTENTIALLY RELEVANT RURAL CHALLENGES OR NEEDS NOT FOUND IN THE JOURNEY TOGETHER MEETING NOTES

The challenges and needs identified below were subthemes that were not brought up in the Journey Together discussions. However, they are shared for their potential relevance to Hawai‘i cancer survivors.

1. TRANSPORTATION AND FINANCIAL NEEDS AND CHALLENGES

Other transportation challenges
- Time away from family\textsuperscript{11}
- Discomfort with long journeys\textsuperscript{7}
- Feelings of isolation & displacement due to needing to travel to get care\textsuperscript{7}

Issues with health insurance
- Lapses in insurance affecting adherence to follow-up appointments\textsuperscript{10}
- Lack of health insurance impacted screenings\textsuperscript{12}

3. KNOWLEDGE AND INFORMATION NEEDS

Need for cancer-related education/information
- Need for general cancer-related information\textsuperscript{8}
- Rural survivors lacked knowledge about their cancer and stage\textsuperscript{21}
- Rural survivors needed health literacy about diagnosis, treatment, & side effects\textsuperscript{10}

Need for information about sexual issues and fertility
- Young adult and adolescent rural survivors wanted information about fertility preservation\textsuperscript{8}
- African American rural breast cancer survivors were hesitant to discuss sexual issues\textsuperscript{10}

4. ACCESS TO CARE AND SUPPORT SERVICES

Lack of health promotion resources (e.g., physical activity resources)\textsuperscript{21}

7. OTHER CHALLENGES AND NEEDS

Barriers in the patient-provider relationship
- Feelings that providers lacked empathy and patience\textsuperscript{20}
- Lack of patient-provider trust\textsuperscript{12}
- Providers lacking of respect for the role of spirituality in the treatment\textsuperscript{10}
• Provider turnover related to rurality lead to having to adjust to a new provider during or after treatment due to their oncologist leaving the facility.10
• Rural survivors had more satisfaction with care when their provider listened to them and felt the provider respected them.7
• African American cancer survivors in general felt discriminated against based on their SES and education.22**
• Possible miscommunication due to different language/cultures22**

**Mixed findings about rural survivors having more psychological distress**
• Multiple studies showed that rural patients have more psychological distress than their urban counterparts do.13,14,21,2433
• Literature discussed that delays in screenings for rural cancer patients lead to more extreme treatments (e.g., mastectomies) and therefore more psychological distress.7,1021
• One study found that rural survivors had more abnormal sleep scores than urban counterparts. 34
• A couple of studies showed no differences based on living in rural or urban communities, but that distress and depression were related to case-specific factors (type of cancer, stage of disease, physical symptoms, age of survivor, if they had a partner, etc.).34-37
REFERENCES

NATIVE HAWAIIAN & HAWAI’I LITERATURE


RURAL CANCER SURVIVOR & GENERAL SURVIVORSHIP LITERATURE REVIEWED**


**These 11 articles were articles about general cancer survivorship (not specific to rural communities). They were reviewed and cited because they validated what was identified as a theme from the Journey Together meeting notes.**