

Unmet Needs of Asian American and Pacific Islander Cancer Survivors

Asian American Health Research Roundtable
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Study Aims

1. Describe the unmet needs of a national sample of Asian American and Pacific Islander cancer survivors, using a community-based participatory research approach.
2. Identify demographic characteristics that can predict higher or lower likelihood of having unmet needs among Asian American and Pacific Islander cancer survivors.

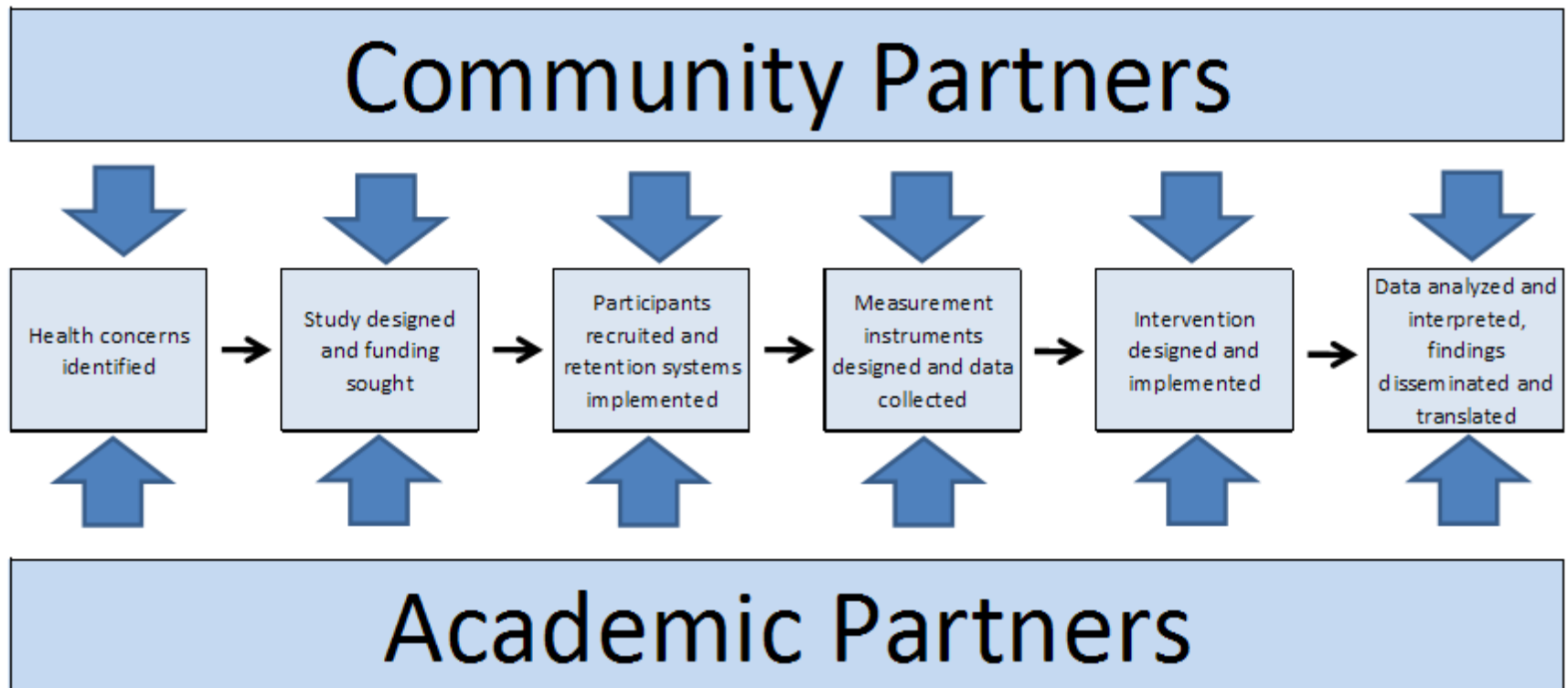
Research Design & Methods:

General Approach

- Study design is based on a community-based participatory research (CBPR) approach.
- This approach emphasizes collaboration between academic and community partners taking advantages of the strengths of all partners in a process of co-learning and mutual transfer of expertise, with shared decision-making and mutual ownership, through the research continuum.

Research Design & Methods: General Approach

Model for Community Based Participatory Research



Research Design & Methods:

Community & Academic Partners

- San Francisco State University, Asian American Studies Department
- University of Pennsylvania, School of Medicine
- Asian & Pacific Islander National Cancer Survivors Network (the Network)
- Asian American Cancer Survivors Network (AACSN)

Research Design & Methods:

Survey Preparation

- Research team reached out to the National Advisory Council (NAC) for the Network and shared with them the domains of need described in the prior work by Barg et al. in the general population of cancer survivors.
- Research team then asked the NAC members to provide rankings to see how salient each of the domains is for AA&PI cancer survivors.

Research Design & Methods:

Survey Instrument

- Preliminary findings from our community experts were used to guide the research team to design a survey instrument.
- Study survey instrument was a modified survey used by Barg *et al.* for the Pennsylvania cancer study - comprised 92 items in categories of psycho-social need.
- Needs were assessed for the following categories:

Activities of Daily Living	Transportation	Financial Issues
Employment Issues	Insurance	Emotional Concerns
Relationship w/ Medical Staff	Cancer Information	Home Care
Treatment-Specific Issues	Social Relationships	Spiritual Issues

Methods

Survey:

- Cross-sectional survey conducted between May 2011 and March 2012
- Each survey took at least 20-25 minutes to complete
- Surveys were either self-administered or face-to-face
- Survey was in English, Chinese, and Vietnamese
- Participants received \$20 CVS gift card as compensation for their time, as well as referrals to local health and social service agencies after completing the questionnaire

Recruitment:

- Through referrals from the Network & AACSN

Eligibility Requirements:

- Asian American & Pacific Islander cancer survivors living in the United States
- Over 18 years old
- Ability to speak either English, Chinese, or Vietnamese

Data Analysis:

- For the paper-based response, research team manually entered the responses into the system so that everything was in a single database.
- Stata was utilized for data analysis

Results:

Sample Characteristics – AA&PI Cancer Survivors (n=119)

Participant characteristics	% or mean \pm SD *
DEMOGRAPHICS	
Age (years) [range 22 to 83]	56.6 \pm 13.3
Female	81.5%
Foreign born	72.5%
Age at immigration (years) [range 9 to 65]	31.9 \pm 13.1
Ethnicity	
Chinese	41.4%
Korean	11.2%
Vietnamese	11.2%
Filipino	10.3%
Japanese	10.3%
Chamorro	6.9%
Asian Indian	3.5%
Hawaiian	2.5%
Samoan	0.9%
Tongan	0.9%
Cambodian/Khmer	0.9%

Results:

Sample Characteristics – AA&PI Cancer Survivors (n=119)

Participants characteristics	% or mean + SD*
Living in city (vs. suburban/rural)	61.7%
Living alone	11.5%
Married/married-like relationship	71.2%
Graduated college	66.1%
Annual income \geq \$40,000	60.7%
Currently employed (at least part-time)	43.9%

LANGUAGE

English speaking ability	
Not at all	4.3%
Not well	18.8%
Well	30.8%
Very well/fluently like a native	46.1%
Speak English at home	46.6%
Prefer to receive printed cancer information in English	65.3%

INSURANCE

Private insurance with and without Medicare or Medicaid	66.4%
Medicare/Medicaid without private insurance	22.1%
No insurance	11.5%

Results:

Sample Characteristics – AA&PI Cancer Survivors (n=119)

Participants characteristics	% or mean + SD*
MEDICAL HISTORY	
Age at first diagnosis with cancer (years) [range 8 to 79]	48.4 ± 13.4
General health	
Poor	9.5%
Fair	32.7%
Good	50.9%
Excellent	6.9%
Cancer Type	
Breast cancer alone or combined with others	61.1%
Ovarian/uterus/cervix	8.0%
Prostate	7.1%
Blood	4.4%
Colon	2.7%
Lung	2.7%
Thyroid	2.7%
Bone	2.7%
Other (liver, head and neck, kidney, skin, stomach, brain, combined without breast)	8.6%

* Missing responses were excluded when calculating frequencies and means.

Study Results:

Unmet Needs of Asian American and Pacific Islander Cancer Survivors (n = 119)

Domain of unmet needs	Frequency (%)*
DAY-TO-DAY ACTIVITIES (≥1 unmet need in this domain)	51.9%
Preparing meals or doing light housework or yard work	41.8%
Getting transportation for medical treatments	22.9%
Getting transportation for work or household activities	22.0%
Other problem with everyday activities or transportation	32.4%
FINANCIAL EXPENSES (≥1 unmet need in this domain)	43.3%
Paying for prescription medications	24.4%
Paying for other medical treatments	34.8%
Meeting basic living expenses	36.6%
Other financial problems	34.6%
EMOTIONAL CONCERNS (≥1 unmet need in this domain)	51.8%
Feeling down or depressed	42.1%
Difficulties with family or spouse	32.5%
Difficulty dealing with illness	43.6%
MEDICAL TREATMENT (≥1 unmet need in this domain)	36.6%
Feeling you did not have enough say in decisions about your medical treatment	25.0%
Wondering if the medical staff was being honest	24.1%
Feeling as though medical staff was uncaring or insensitive	27.9%

Study Results:

Unmet Needs of Asian American and Pacific Islander Cancer Survivors (n = 119)

CANCER INFORMATION (≥1 unmet need in this domain)	32.1%
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Getting information about treatments or medications	25.9%
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Knowing which information is most reliable and up-to-date	31.3%
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HOME CARE (≥1 unmet need in this domain)	29.5%
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Learning how to care for your medical needs at home	20.2%
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Knowing how to access groups or agencies that could help you at home	25.7%
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NUTRITION (≥1 unmet need in this domain)	42.3%
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Changes in weight	35.4%
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Knowing what foods to eat	34.2%
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PHYSICAL CONCERNS (≥1 unmet need in this domain)	66.0%
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Getting tired easily	51.4%
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Changes in physical appearance	40.5%
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Nausea or vomiting	31.6%
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Pain	41.4%
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FAMILY RELATIONSHIPS (≥1 unmet need in this domain)	43.0%
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Increased tension or arguments at home	38.6%
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Increased emotional problems at home	38.6%
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SPIRITUALITY (≥1 unmet need in this domain)	
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Feeling a need for spiritual help	22.4%
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Discussion

- Approximately 8 out of 10 AAPI cancer survivors in this study reported experiencing at least 1 unmet need. This is slightly higher than the 75% observed in Barg et al.'s study conducted among the general population of cancer survivors.
- Physical concerns (66.4%) are primary area of unmet needs for AAPI cancer survivors, while emotional concerns are tertiary need (52.3%).
- More than 1 in 4 participants stated that they do not have enough authority in making medical decisions regarding their health. Language & cultural barriers may shed light on this issue.

Discussion

- Notably, less than a quarter of our respondents reported unmet needs surrounding payment for prescription medications (24%), but a slightly higher percentage (36%) of our participants indicated that they are having difficulty meeting basic living expenses.
- A significant number (44%) of AA&PI cancer survivors expressed difficulty dealing with their illness.

Conclusion & Implication:

- Some findings from our study suggests that AA&PI cancer survivors have both different and similar unmet needs in relation to the general population of cancer survivors.
- It also suggests that culturally specific and linguistically appropriate interventions are essential to addressing the unmet needs of AA&PI cancer survivors effectively.
- Larger sample size.
- Future study should include health care providers, family, and caregivers.
- Importance of CBPR.