Culture is Healing

Supporting Aboriginal and Torres Strait Islanders affected by breast cancer

Danielle Spence
Directory Advocacy, Policy and Programs
Breast Cancer Network Australia

- More than 120,000 members
- 300 support groups
- 1,200+ affiliated health professionals
Disparities in outcomes

- The gap in health outcomes between Indigenous and Non-Indigenous Australians
- What are the contributing factors to the disadvantage?
  - Social determinants
  - Risk factors
  - Rural/remote isolation
Breast Cancer Network Australia
What we’re doing so far

– 2017 Think Tank
– Current Action Plan
– Aboriginal and Torres Strait Islander Reference Group
– Partnerships
– Development of RAP
Culture is Healing

- Three Year project funded by Cancer Australia
- Increase engagement and improved the survivorship experience
- Self determination and local solutions
- Increased community awareness around best practice survivorship care
Culture is Healing – The Possum Skin Cloak

- Collaboration with Peter MacCallum Cancer Centre Melbourne Victoria and the Victorian Aboriginal Community Controlled Health Organisation (VACCHO)
- Funded by Cancer Australia
Culture is Healing – The Possum Skin Cloak

On a cultural basis there is a connection amongst women when significant cultural garments are made for the continuation of culture and healing.

It was such a positive healing experience to participate with the Aunties and other women.

Support was led by Aboriginal women for Aboriginal women with generosity of non-aboriginal women in a shared journey.

• Link to video
How we can improve the lives of disadvantaged or vulnerable cancer patients
Increasing inequality in health

Life expectancy in Denmark from 1987-2011
Inequality in cancer survival

Education and 5 years survival after cervical cancer
Equality vs. equity
Presentations

How can we improve the lives of ethnic minority cancer patients, socioeconomically disadvantaged cancer patients and men with cancer?
Department Head Laila Walther and Project Manager Stine Scheuer, Patient & Relative support the Danish Cancer Society, Denmark

"Culture is Healing": Improving survivorship for Aboriginal and Torres Strait Islanders.
Director Advocacy, Policy and Programs Danielle Spence, Breast Cancer Network Australia

Caring for displaced persons and refugees - Jordanian perspective
MD, MBA, Consultant, Hospice & Palliative Medicine, Chairman of Palliative & Home Care Services Omar Shamieh, King Hussein Cancer Centre, Jordan
How can we improve the lives of ethnic minority cancer patients, socioeconomically disadvantaged cancer patients and men with cancer?
The telephone cancer information service and the cancer counselling centres

CALL 80 30 10 30
Weekday: 09.00 am – 09.00 pm
Weekend: 12.00 noon – 05.00 pm
The typical user of our patient support services:

- Women
- Medium long or long education
- Ethnic Danes
Socioeconomically disadvantaged cancer patients
Socially vulnerable cancer patients are matched with a navigator (volunteer) who support them during a 6 month period based on the patients needs:

- 87% participate in consultations (lay representative)
- 78% emotional support
- 48% strengthen network
Brian, 61 years, lung cancer

- Former alcoholic
- No contact to the family
- Diabetes, blood clots and cannot feel his leg
- Early retirement benefit
- Smokes
- Has difficulties breathing
- Has a big temper
- Cannot remember what the doctors or nurses say
WHO-5 Well-being Indeks. Percentage who has 0-35 points, 36-50 points and above 50 points at baseline and 6-month follow-up (n=84)
Health literacy

- 60% are better at finding information about their disease
- 70% are better at preparing for consultations at the hospital
- 67% has become better at keeping track of and follow-up on consultations at the hospital
“The navigator is a major support. They help to ensure that the patient comes to treatment and follow-up and that the patient understand what is being said”

“Having the opportunity to call my navigator. For the most part it has been enough that I knew I could call if everything feel apart. It is the knowledge that there is someone out there who can handle it if I cry”

– Quote: Nurse at the hospital

– Quote: Patient
Men & cancer
Men & cancer

Men’s preferences in relation to patient support

- The support should come immediately after diagnose
- The hospitals should refer
- The support should be together with other men
- It should be self-organized
- No women should participate
- The support should focus on facts
Men: Mentor & network events

MENTOR
• Newly diagnosed are matched with a male volunteer (former or current cancer patient)
• The match is based on diagnosis or similar experiences
• Exchange knowledge and experiences
• Introduce the cancer counselling center and the network events

NETWORK EVENTS
• Every 14 days in the evening
• Open for all men with cancer
• Community of interest (rather than a focus on disease)
• Presentations, dinner and networking
• Organized by the men themselves
Ethnic minority cancer patients
Ethnic minorities

- Heterogenous group
- Low social status
- Lower mental health status
- Small network
- Cancer is stigmatized
- Low knowledge of cancer
- Low knowledge of the Danish Cancer Society
What works?

Following is important when targeting individuals with another ethnic background than Danish:

- Arrange events in local settings
- Find key individuals
- Cooperate with existing services and associations
- Use role models
Ambassador corps

AIM
• Increase knowledge of cancer and the patient support services.

TWO APPROACHES
• Communication activities
• Informations activities in local settings.
Thank you!

Contact information:

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