Learning Experiences of Malay Muslim Women Breast Cancer Survivors at a Cancer Resource Center

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OBJECTIVES:

❖ To understand the learning experiences at a Cancer Resource Center (CRC) from the perspective of Malay Muslim women breast cancer survivors.

❖ To explore how the context of culture shaped their experiences with the CRC.
METHODOLOGY

Study Design
- Qualitative study
- In-depth Interview

Sampling technique
- Purposive sampling - to locate information-rich subjects
- Recommended by CRC

Criteria of Selection
- Diagnosed with breast cancer
- Have visited and experienced with CRC in Hospital X.
- Access to the researcher
- Willing to participate and share experience
Location

- Hospital X. Why ?:
  - 1st CRC in Malaysia
  - Oldest CRC
  - 1st in MOH Hospital
  - Model for other CRC
  - Different setting/way to operate

Data Collection

- In-depth interview
- Probing techniques
- Audio tape recorded

Data Analysis

- Transcribing verbatim
- Constant comparative method
CRC Hospital X

CaRE, UPM
OUTCOMES 1: Learning Experiences

1. Motives
2. Content
3. Strategies
4. Benefit and Challenge
1. Motives to be at CRC

Need more information on cancer
(Diagnosis, treatment/diet- to reduce anxiety and fear)

Share experience with others:
- Nurses
- Peer survivors

To socialize
(similar/share experience)
2. Learning contents

- Coping strategies
- Cancer recurrence
- Food/Diet
- Cancer disease
- Cancer treatment & side effect
3. Learning strategies

- Utilizing Print Media: Brochures/Books
- Peers/fellow patients/survivors
- Utilizing internet
- CRC Nurses
- CRC education activities
4. Experience using CRC

**Benefits:**
- Gained knowledge & information
- Get Psychological support
- Shared feelings, problems & experience
- A place to socialize/ connect with others/friends/peers.
- A **second HOME**:
  "I feel like I am at home. Comfortable and calm. We can talk, drink and eat together".

**Challenges:**
- Internal : (transportation/time)
- External : (distance/hospital systems : eg parking)
How does Malaysian context shaped their experience with the CRC?

<table>
<thead>
<tr>
<th>Disease Context</th>
<th>Learning strategies or preference context</th>
<th>Culture context</th>
</tr>
</thead>
</table>
| Cancer is a stressful and challenging disease: need to share fears/problems/feelings with others. | - Depend on doctors and health professionals as main source of learning and not CRC.  
- Hospital is not a platform for learning but to get treatment.  
- Self directed, non-formal and experiential learning | - Relationship oriented.  
- Preferred learning via talking, sharing experience & socialized with others.  
- Learn better via their social network: nurses/peers/volunteers from the support group. |
CONCLUSION

CRC played a vital role as an effective learning platform towards improving the quality of life of breast cancer survivors.
Recommendations

- The establishment of new CRC needs to consider the culture context and the organizational factors.
- The health care providers need to access patient’s profile and their information, psychological and emotional needs before implement any intervention activities.
- CRC need to tailor the activities not only to focus on cognitive but also incorporate affective component (eg coping skills).
- Support the establishment of support group eg **KanWork** - The volunteers as the health promoters/agent of change.
- CRC should be equipped with the latest, adequate and appropriate cancer education materials.
- CRC need to have well trained nurses and volunteers.
- Promote the existing CRC and fully support the establishment of new CRC- provide supportive services : compliment the cancer management
Thank You

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Lost in Translation
Exploring the nature of information and support accessed by non-English speakers to an Australian Cancer Helpline

Katherine Lane¹, Amanda Vittiglia, Clare Sutton, Meg Chiswell, Dr. Anna Boltong
1. Head of Cancer Information and Support Services, Cancer Council Victoria, Australia
Background

- Victoria is Australia’s most culturally diverse state – ¼ population born overseas, nearly ½ have a parent born overseas
- 2016 Census data shows Victorians:
  - come from >200 countries
  - speak >300 diverse languages, and;
  - follow >130 religious faiths
- Increased challenge in how we provide information and support that meets the needs of each cultural group
Background cont.

- Cancer Council Victoria receive thousands of calls from English-speaking Victorians every year
- A small proportion of non-English speakers access our 13 11 20 telephone-based information and support service, via an interpreter
- Nurses report inconsistencies in working with interpreters and how support is delivered
- Interpreting Service provided by Australian Government’s Department of Health
Aims

This QA project aimed to assess:

- Accuracy of interpretation of information between nurse and caller
- Barriers or facilitators to smooth conversation flow
- Whether these calls are conducted using the same therapeutic communication model as calls between the nurse and English-speaking callers
Methods and results

- 16 calls in 2016 were isolated and transcribed in language
  4 languages represented: Cantonese, Mandarin, Vietnamese, Greek
- 289 pairs of dialogue analysed for accuracy and consistency
  Caller to nurse = 65% accuracy
  Nurse to caller = 73% accuracy
- Transcripts were assessed for quality issues, impacts on therapeutic communication and the provision of holistic information and support
Quality issues and impacts on provision of information and support

- Non-compliance with best practice principles when working with interpreters
  
  *cross-talk, long conversation segments, exclusion of nurse or caller from conversation, omission or incorrect paraphrasing of information*

- Impacts on ability to provide quality information and support
  
  *difficulty providing therapeutic communication – conveying empathy, compassion, or exploring emotional concerns in enough detail*
Conclusion & next steps

- Provision of highly skilled interpreters with knowledge of medical terminology and complexities is paramount
- Tailored training to be developed for both nurses and interpreters providing phone-based cancer information and support
- Results to be shared with DHHS and other Cancer Councils
Thank you.
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Living Stronger than Cancer:
Building an ecosystem that combines human touch and digital tools to improve the quality of survivorship
By Sharon Lee

www.cancer.org.my
Rooted on Insights: Survivors 2015

“What would have been important to know?”

Practical help
Preparation for the hospital
Patients’ rights

Directory of resources
- List of hospitals
- Home nursing
- Directory of resources
- Palliative care
- Support groups
- Financial avenues

Financial avenues
- List of hospitals
- Home nursing
- Directory of resources
- Palliative care
- Support groups
Rooted on insights: Community survey 2015 - 2017

Q: If you/your family member is diagnosed with cancer, what would be your top 2 concerns?

<table>
<thead>
<tr>
<th>Concern</th>
<th>All (n=327)</th>
<th>CS (n=5)</th>
<th>CP (n=3)</th>
<th>CG (n=22)</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) The cost of treatment</td>
<td>180</td>
<td>2</td>
<td>2</td>
<td>15</td>
</tr>
<tr>
<td>b) The side effects from the treatment</td>
<td>153</td>
<td>4</td>
<td>2</td>
<td>12</td>
</tr>
<tr>
<td>c) How are they going to cope (physically and mentally)</td>
<td>209</td>
<td>3</td>
<td>0</td>
<td>14</td>
</tr>
</tbody>
</table>
Rooted on insights: Patients, Survivors, Caregivers: 2018

- Empathy
- Approachability
- Fast & accurate
- Experienced in onco. & BMT
- Information knowledgebase
- Check list
- Self service technology
- Cultural sensitivity
- Languages 4 main languages
- Genuine desire to make a difference
- The flex to speak to different levels of the community
- Communication skills: tone & manner
Next level challenge: Cultural sensitivity

Appealing to the majority

- The largest community makes up 67% of the population.
- Lower to mid level income.
- Goes to the public hospitals but with reported high drop out rate.
- Strong inclination towards alternative / herbal remedies.
- Male centric and submissive to the wishes of fathers/spouse, often agreeing to alternative remedies versus surgery.
- Prefer to discuss with people within the community.

Objective : to improve survivorship

1. Target the largest community with the support ecosystem
2. Set up a task force to tackle inclination towards alternative remedies in the community
The support ecosystem

- CIS
- Emails
- Chat forums
- Websites
- Support group
- Wellness Centre
- NCSM Help Desk

- Community Health Ambassadors
- Patients into hospitals
- Data in PNS
- Care Navigator & Interactive System
- Track journey to closure
Learnings

Did well

1. Rooted on insights that leads to local content
2. Localizing content of existing knowledge base
3. Hiring for diversity & experience
   - 4 major languages
   - Oncology experience
   - Excellent communication skills over the phone
   - Embrace technology
4. CIS provided an avenue for communication, helpful for an inhibitive community
5. 5% of callers received deeper support from subsequent F2F counselling and wellbeing programmes

Continuous improvement

1. Review mobile app strategy as downloads are low. Does not command broad base interest.
2. Fizziness of digital tools – keeping it Top of mind
3. Knowledge bank – continuous addition / update of information
4. System & report automation
5. Quantifying the impact
THANK YOU

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Nuclear Weapons Testing in the Marshall Islands

Implications for CA Screening & CA Health Seeking Behaviours

UICC
Kuala Lumpur, Malaysia
October 3, 2018

Neal A. Palafox MD MPH
John A. Burns School of Medicine, University of Hawaii
US Thermo-nuclear Weapons Testing - Marshall Islands

- Operation Crossroads
- 1946 – 1958 (12 years)
- 67 total thermo-nuclear devices
- Testing done above ground & in atmosphere
- Total megaton yield = 7200 Hiroshima bombs.
  - An average of more than 1.6 Hiroshima bombs per day for the 12 yr nuclear test program
Nuclear Legacy
OUTCOMES

- Moved off ancestral lands - their homes
- Direct fallout on people of several atolls
- CA, rad burns, fetal death and abnormalities
- Destruction of ancestral lands
- Disrupting lineage
- Community breakdown
- Food chain contamination
- Ongoing radiation contamination of atolls
Is Nuclear Testing Associated with Cancer?

  - Biologic Effects of Ionizing Radiation (BEIR) VII

- 2004 US NCI (report Marshall Is Nuc testing)
  - 530 excess cancers due to nuclear testing
  - 250 may be latent, onset 40-60 yrs after exposure
  - Radiation exposure to all of Marshall Islands
Cultural Perspective
(Destruction of Islands)

Islands
- focal point of social structure
- social hierarchy
- basis of indigenous cultural values
- land rights
- nutrition / dietary staples
Impact of Culture on a Person’s Experience of CA

- nuclear events integrated into cultural fabric


- Generalization: Are all cancers in Marshall Islanders caused by the nuclear testing? Diabetes? HTN?

- Trust: Do I believe the US scientist? Who should I believe about the effects and reasons for nuc testing?

- Cultural Healing: Can damage, including cancer, be undone? How will the cultural trauma be addressed?
Influence of Culture on CA screening, & Health Seeking Behaviours

- Understanding: Risk? Radiation? Cancer?
- Accountability: Who is responsible for cancers? Who pays the bill? What standard of care do I deserve / receive?
- Compensation: Should I be compensated if I get cancer? How much?
  - What is “my” personal responsibility for CA prevention?
Barriers to Cancer Prevention and Care

- Structural
  - Political and Economic Relationships
  - Accountability

- System and Provider
  - Standards of Care
  - Who bears cost

- Patient
  - Cultural Trauma
  - Literacy re radiation and CA
Cultural Trauma

- loss of identity / meaning, associated with a traumatic event (s) affecting a group of people
- Identity formation of a group of people is grounded in collective memory of the event(s)
  - Not have to be present or alive at time
  - cancer will be viewed through a collective memory
Conclusion

Nuclear Legacy affects –

- cultural context and perceptions of cancer
- health seeking (screening, treatment) cancer behaviours

Barriers to be addressed

- Structural Barriers
- Personal Barriers
  - Cultural Healing
  - Healing of trauma
  - What does justice look like
Komol Tata– Thank you

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“Cancer”...a Ma’I Palagi (European Illness) - How Samoan people view cancer and how this affects their health seeking behaviour in the context of Cancer.

Dr Malama Tafuna’I
Senior Clinical Lecturer
National University of Samoa
World Cancer Congress Kuala Lumpur 2018
Samoa

- Setting
- Health services

Samoa: Cultural beliefs and health seeking behaviour

- Traditional healers vs Western medicine

How Samoans view “cancer”

Understanding cultural beliefs and values is key to developing culturally sensitive and appropriate services that meet needs of indigenous people – findings from research
Samoa

- Pacific nation lying in Polynesia, Oceania.
- 2,821 square kilometres of land and ten square kilometres of water.
- 179th largest nation in the world.
- Independent state in 1962 after gaining its sovereignty from New Zealand.
- Two main islands: Upolu and Savaii.
- Apia is the capital of Samoa, located on the island of Upolu.
- Developing country in the upper middle-income group.
- Determined by its Gross National Income per Capita.
Samoa’s Health System

- Traditional Medicine and Healers
  - 1800’s missionary’s
    - Belief that Samoan traditional medicinal beliefs went underground
  - German Administration
    - First hospital 1905
  - New Zealand Administration
    - 1918 – Spanish flu
    - Western public health model
  - Western model
    - Centralised (1980’s)
      - 1 main hospital in Apia – 200 beds
      - Smaller hospital on Savaii – 20 beds
      - 10 rural health facilities
      - 6 Upolu
      - 4 Savaii
  - No stakeholder consultation
    - No attempt to understand indigenous people’s beliefs around sickness/health
    - No discussion with existing traditional healers
Cancer in Samoa

- Overwhelming burden
  - Anecdotally - clinicians seeing more cancer everyday and in younger people
  - No cancer register
  - No pathologist - doctor in training
  - People present at advanced stages of disease
    - Not appropriate for biopsy
    - Almost all have seen a traditional healer and undergone some type of traditional medicine/management
  - Health workers strongly suspect MANY do not present to hospital but instead present to traditional healers
  - Traditional healers play an important part in our peoples health care
  - Estimate 80% first point of call
Understanding of Cancer

Cancer did not exist before Europeans came to Samoa

- “A new illness brought by Europeans” (Hubbell et al 2005 Am Samoa)
- Meleisia 1987 “Illness often explained as a punishment by ancestral Gods for behaviour which spoilt the honour of the family”
- Capstick et al 2009
  - Literature review of health and culture in the Pacific
    - “Health and well being about the presence of culture” vs biomedical model
    - For “Samoans, it is inaccurate to conceptualise health as absence of illness and illness as absence of health - instead illness is seen as an inevitable though potent disruption to life and social systems”
    - “no words in Polynesian languages equivalent to the biomedical constructs of ‘health’ and ‘disease’ and that Pacific ideas of health are instead linked closely to cultural identity”
- Puaina et al 2007 (Samoan community in America)
  - “embarrassment” “Shy” “taboo” to discuss personal health issues esp sensitive issues ie genitalia, sex etc
  - Disrespectful to healthworker
Acceptability of HPV self-sampling tests amongst health workers and women from both urban and rural communities in Samoa.

Themes that came out of study:
- Education
- Significance of cultural beliefs and values,
- The value of benefits,
- The concerns with literacy and health literacy,
- The need for options,
- The different challenges that they face and empowerment.
Acceptability of HPV self-sampling tests amongst health workers and women from both urban and rural communities in Samoa.

- Lack of awareness
- Cancer European Illness = Ma’I Palagi
- Shocked to hear cancer affected other parts of the body other than lungs and breast
- Rural women struggled to understand how female genitalia could be affected and in particular the “cervix” - could not relate to this as could not see it/ wasn’t tangible
- Difference in explaining HPV causal effect and cervical cancer between urban and rural women
- Ambiguity of language and translation
- No Samoan words for some body parts / Health concepts
- Difficulties in translation
  - Health workers vs lay people
- Embarrassment/Shy/ taboo to discuss sensitive issues?
Cultural Beliefs and Values

- Imposed Western health model with westernised beliefs about illness
  - Samoans still consult traditional healers first
  - Turn to western health models often in desperation - Distrust
  - Fatalistic belief - Better not to know
  - Ma’I palagi needs to be cared for in the hospital / Needs western medicine
  - Expectation of an immediate cure
    - Can lead to distrust when expectations not fulfilled

- Traditionally
  - Look after our elderly and unwell
  - Tausima’i
Cultural Beliefs and Values

- Importance of understanding history and cultural beliefs and values in indigenous understanding of sickness and health to understand how these beliefs and values guide how we engage with health services and what health services.

- Need to engage indigenous people in these discussions to gain local cultural perspectives when designing strategies to support ones information and support health seeking behaviours.