Issues for cancer survivors of non-English speaking backgrounds

Professor Afaf Girgis

Centre for Oncology Education and Research Translation (CONCERT)
Ingham Institute for Applied Medical Research
South Western Sydney Clinical School
University of NSW, Australia
@Afaf_Girgis
Overview of presentation

• Australian context

• Evidence from some of our local research:
  - Butow et al - Cross-sectional population-based, case-control study of cancer survivors (Chinese, Arabic, Greek vs Anglo) (n=596)
  - Gerges et al - Qualitative study of Chinese women with breast cancer and their partners (n=26)
  - Meiser et al – Oncology HPs’ challenges communicating with minority patients (n=38)
Australia is multicultural

• Australia is one of the most culturally and linguistically diverse (CALD) countries in the world
• 28% of Australians were born overseas
• 43% had at least one parent born overseas
• In 2011, 18% spoke a language other than English at home; 2% didn't speak English at all

ABS, 2014-2015
Australian research confirms disparities

CALD cancer pts, compared to English-speaking pts:

- Lower screening and survival rates; report more side effects
- Less satisfied with their cancer care
- Lower quality of life
- Higher incidence of clinical depression
- Greater emotional support and information unmet needs
- Significant communication challenges with health care team
- Lack of culturally sensitive resources
- Lower clinical trial participation

Unmet needs of CALD survivors
Differences in types of needs that were most unmet:

• Asian women - information and health system needs

• Caucasian women - psychological needs
Unmet needs of Chinese, Arabic & Greek vs Anglo cancer survivors

Cross-sectional population-based, case-control study of cancer survivors of 1st generation immigrants (Chinese, Arabic and Greek speaking backgrounds) and Anglo, Australian-born controls (n=596) – unmet needs, anxiety, depression

Investigators: Phyllis Butow, David Goldstein, Michael Jefford, Penelope Schofield, Madeleine King, Maurice Eisenbruch, Afaf Girgis, Melanie Bell, Priya Duggal-Beri, Josh McGrane, Ming Sze, Lynley Aldridge

Cancer Registries: NSW, Victoria, Queensland

Funding: NHMRC, Beyondblue, The Victorian Community Foundation
## Top 10 unmet needs of Anglos

<table>
<thead>
<tr>
<th>Needs</th>
<th>% of Anglos endorsing</th>
</tr>
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<tbody>
<tr>
<td>Unable to do usual things</td>
<td>19</td>
</tr>
<tr>
<td>Managing FCR</td>
<td>17</td>
</tr>
<tr>
<td>Changes in sexual relationships</td>
<td>17</td>
</tr>
<tr>
<td>Lack of energy</td>
<td>16</td>
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<tr>
<td>Not sleeping well</td>
<td>15</td>
</tr>
<tr>
<td>Changes in sexual feelings</td>
<td>15</td>
</tr>
<tr>
<td>Information about sexual relationships</td>
<td>14</td>
</tr>
<tr>
<td>Support services</td>
<td>11</td>
</tr>
<tr>
<td>Unable to work</td>
<td>11</td>
</tr>
<tr>
<td>Moving on in life</td>
<td>10</td>
</tr>
</tbody>
</table>
## Top 10 unmet needs of immigrants

<table>
<thead>
<tr>
<th>Needs</th>
<th>% of Immigrants endorsing</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Managing FCR</td>
<td>30</td>
</tr>
<tr>
<td>• Written information in own language</td>
<td>27</td>
</tr>
<tr>
<td>• Information about cancer and its treatment</td>
<td>27</td>
</tr>
<tr>
<td>• Unable to do usual things</td>
<td>24</td>
</tr>
<tr>
<td>• Not sleeping well</td>
<td>24</td>
</tr>
<tr>
<td>• Medical Guidance</td>
<td>24</td>
</tr>
<tr>
<td>• Specialist who speaks my language</td>
<td>24</td>
</tr>
<tr>
<td>• Information about CAM</td>
<td>24</td>
</tr>
<tr>
<td>• Help asking questions</td>
<td>23</td>
</tr>
<tr>
<td>• Other health professionals who speak my language</td>
<td>22</td>
</tr>
</tbody>
</table>
Prevalence and predictors of unmet needs

• Immigrant survivors had significantly higher unmet needs than Anglo-Australian cancer survivors matched on cancer diagnosis (even when controlling for potential confounders)

• Unmet needs were associated with increased anxiety and depression and poorer QOL

• Main predictors of unmet needs were:
  – Not understanding the health system
  – Having language barriers

Butow et al. Supportive Care in Cancer, 2013
Challenges experienced by CALD survivors
Challenges for Australian immigrants

• Feeling misunderstood, isolated, overwhelmed

• Difficulty understanding the Australian health system (27% vs 11% in Anglo, p<0.0001)

• Difficulty accessing information in their native language (only 21% reported receiving information in own language)

• Difficulty communicating with their treating team (24%), even with the help of interpreters

  ➢ “I just sit there and say yes, yes, but I left his consultation and I didn’t understand most things.” (Arabic patient)

  ➢ “You know it is like the chicken talking to the duck. It’s different voices.” (Cantonese patient)

Challenges, supportive care needs and coping strategies of Chinese women with breast cancer (n=26)

Use of traditional Chinese medicine: “It’s the problem of lymphoedema because we had breast cancer. Practising Tai Chi will improve the movement of the arms and prevent oedema.”

Experience with cancer: “a malicious sickness” “very unsettling, very unhappy, very scared,” “a sad cloud all over my sky,” and “a great stress inside my heart.”

Unreliability of interpreter services: “my son had to say to the interpreter, ‘sorry, can you stop interpreting please? We’ll speak for ourselves.’ He immediately heard that the interpretations were incorrect.”

Protecting others from diagnosis: “I know my mother’s character. She would just cry non-stop for a few months ... I just don’t want her to be sad and it would be harmful to her health.”

English resources vs Chinese resources: “I finished reading the Chinese ones quickly because after all, it was in our own language. After reading the explanations, we understood more about our illness.”

Level of involvement in treatment decisions: “then he just cut and what, all decided by the doctor. The way he talked was not a discussion. It was his decision.”

Challenges experienced by health professionals
Oncology HPs’ challenges communicating with CALD patients

- Oncology health professionals need to be ‘culturally competent’ to address the needs of CALD patients (~ 21% of cancer cases)
- Currently no formal training in cultural competency in communication for HPs working with cancer patients

- Bettina Meiser et al - ARC Linkage Grant (2012-2015), CINSW
  - **Study 1**: Experiences of oncology health professionals (n=38 interviews) working with CALD patients
  - **Study 2**: Design and evaluate the first interactive (online) and culturally sensitive communication skills training module in oncology
• 82% reported degrees of **uncertainty and discomfort** working with minority patients
• **Language barrier** is most significant challenge – affects rapport building, giving and receiving subtle verbal and nonverbal cues
• **Lack of resources** in different languages (eg take-home printed material to reinforce information)
• **Interpreter service issues:**
  – Shortage of interpreter services
  – No, or inadequate, processes for identifying a CALD patient prior to their appointment
  – Only 8/38 participants had received any formalised training for working with interpreters
Addressing the challenges
Study 2: Trial of communication skills training focused on cultural competence (Meiser et al, ARC, CINSW)

Effective Cultural Communication in Oncology

A training program for Oncology Health Professionals

Click to Begin

Now that you have completed the Cultural Competence section, let’s explore some issues oncology health professionals encounter during their consultations with cancer patients from CALD backgrounds.

We recommend that you begin with Maha’s story, followed by Li’s story and then Helen’s story.
Other strategies

• Accessible resources in different languages (Australian Cancer Survivorship Centre)

• Decision aids:

• Patient navigators:
  – increased screening rates, patient satisfaction, adherence to diagnostic testing and more timely diagnostic testing in comparison to women engaging in usual care
  – reduced anxiety, time between testing and diagnostic resolution
Summary

• CALD survivors’ unmet needs significantly greater
• Communication barriers - challenging for survivors and oncology professionals
• Information is a major gap – need for more culturally appropriate resources
• Interpreter services – much room for improvement in both access and quality
• More research is needed
  – Exploring health literacy of Arabic and Vietnamese patients
  – Testing strategies to enhance trial participation
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Thank you
afaf.girgis@unsw.edu.au
@Afaf_Girgis