

Issues for cancer survivors of non-English speaking backgrounds



Never Stand Still

Medicine

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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

*Butow et al. European Journal of Cancer, 2013;
Patient Education and Counseling, 2011.
Cancer Institute NSW, 2009.
Goldstein et al. Annals of Oncology, 2014.
Kwok et al. Contemporary Nurse, 2011.
Kwok et al. Journal of Advanced Nursing, 2006
Smith, Girgis et al, in prep 2017*



Unmet needs of CALD survivors

Integrative Review of the Supportive Care Needs of Asian and Caucasian Women with Breast Cancer

Janelle V. Levesque¹ • Afaf Girgis¹ • Bogda Koczwara^{2,3} • Cannas Kwok⁴ • Savitri Singh-Carlson⁵ • Sylvie Lambert⁶

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

Needs	% of Anglos endorsing
• Unable to do usual things	19
• Managing FCR	17
• Changes in sexual relationships	17
• Lack of energy	16
• Not sleeping well	15
• Changes in sexual feelings	15
• Information about sexual relationships	14
• Support services	11
• Unable to work	11
• Moving on in life	10

Top 10 unmet needs of immigrants

Needs	% of Immigrants endorsing
• Managing FCR	30
• Written information in own language	27
• Information about cancer and its treatment	27
• Unable to do usual things	24
• Not sleeping well	24
• Medical Guidance	24
• Specialist who speaks my language	24
• Information about CAM	24
• Help asking questions	23
• Other health professionals who speak my language	22

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

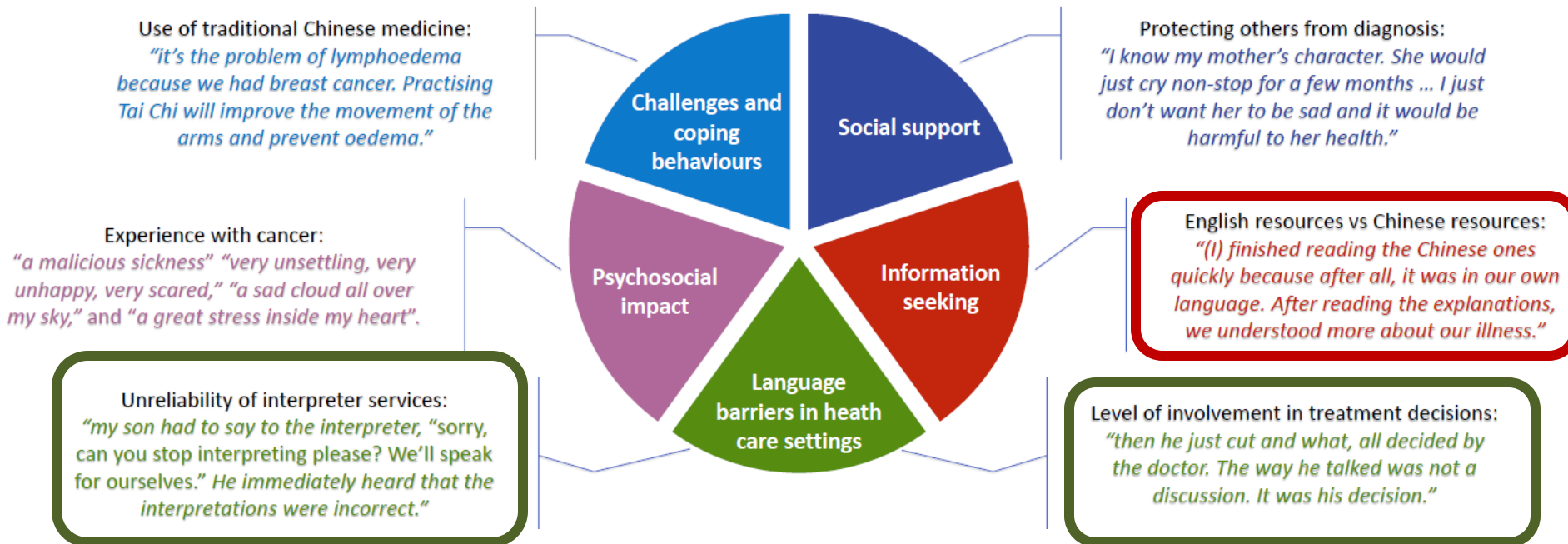
Challenges experienced by CALD survivors

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)*

Butow et al. European J of Cancer, 2013; Supp Care in Cancer, 2013; Patient Education and Counseling, 2011.

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



Gerges, Levesque & Girgis, 2016.

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



Preferences for communication training for working with patients from culturally and linguistically diverse backgrounds: Perspectives of oncology health professionals

Meiser B^{1,2}, Zilliacus E¹, Taouk M¹, Watts K¹, Goldstein D^{1,2}, Kissane D³, Girgis A¹, Butow P⁴, Hale S¹, Perry A⁵, Aranda SK⁶

1. University of New South Wales, Sydney, NSW 2052, Australia; 2. Prince of Wales Hospital, Sydney, NSW 2052, Australia; 3. Monash Medical Centre, Melbourne. 4. University of Sydney Sydney, NSW 2006, Australia; 5. South Eastern Sydney and Illawarra Area Health Service, Sydney, NSW, Australia; 6. Cancer Institute NSW, Sydney

- 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.

Maha



Li



Helen



Other strategies



- Accessible resources in different languages
(*Australian Cancer Survivorship Centre*)

- Decision aids:

- increased shared decision making and patient perceived adherence
(*Pendo et al. Int J Behav Med 2007; 14:164–172*)

- 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
- **lack of evidence related to cancer survivorship** and treatment adherence (*Robinson-White S et al. Cancer Nurs 2010; 33:127–140*)

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

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