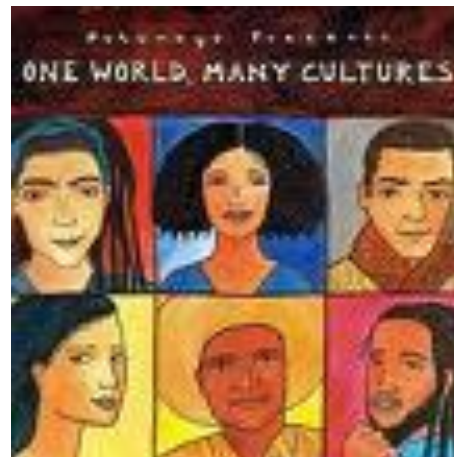




Psycho-oncology Co-operative Research Group

# Immigrants with cancer: What are their unmet needs?



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# Australia is multicultural

- 24% of Australians were born overseas
- 44% had at least one parent born overseas
- Over 560,000 people (2.8% of the total population) spoke English poorly or not at all

**2006 census**

## Ethnic disparities in outcomes

- Minorities diagnosed with cancer have poorer outcomes than majority groups:
  - lower screening rates
  - lower survival rates
  - poorer quality of life
  - higher anxiety and depression

Du XL, et al. *Cancer* 109(11):2161-70, 2007

Chu KC, et al. *J Natl Med Assoc* 99(10):1092-100, 2007

Krupski TL. Et al. *Ethnicity & Disease* 15(3):461-8, 2005

Gotay CC. et al. *Psycho-Oncology* 11(2):103-13, 2002

Butow et al, *European J of Cancer*, In Press.

**How is the system  
failing them???**

## Unmet needs: Definition

- *“Problems for which people express a requirement for assistance, out of recognition of existing resource deficits, to enable problem resolution and attainment of goals”.*
- Foot G. *Needs assessment in tertiary and secondary oncology practice: A conceptual and methodological exposition.* Newcastle, University of Newcastle; 1996.
-

# Previous studies of unmet needs

- None comparing **immigrant** and native-born populations
- Some have compared **minorities** and native-born populations

## Ngui et al, J Health Care 18:931-49

- One study explored unmet needs in 1040 cancer survivors recruited through cancer registries
- Non-White ethnicity predicted higher information needs

## Moadel et al, Cancer 2007; 15:446-54

- 248 oncology outpatients
  - 48% non-Hispanic whites
  - 25% African Americans
  - 19% Hispanic
- Ethnicity the sole predictor of needs ( $P < .02$ )
- Even after controlling for SES confounders



# Percent endorsing needs

Needs	African Americans	Hispanics	Non-Hispanic Whites
Informational	81%	85%	70%
Practical	63%	68%	36%
Supportive	69%	73%	48%
Spiritual	49%	60%	31%



# Conclusion

- Minority groups (who may have been in the country for many generations) have increased needs
- But do new immigrants experience the same or worse?

# Study aims

- **In cancer survivors**, to compare quality of life, depression, anxiety **and unmet needs** of 1<sup>st</sup> generation immigrants (**Chinese, Arabic and Greek speaking backgrounds**) and Anglo, Australian-born controls
- To determine if there are between-culture differences

# Design

- Cross-sectional population-based, case-control study
- Registry recruitment in NSW, Victoria and Queensland

- **Community advisory board members:**

<b>Greek Advisory Board</b>	Nicole Komninou, Fr. Sophronios Konidaris, Maria Petrohilos, Bill Gonopoulos, Dr. Peter Calligeros, Elfa Moraitakis, Dr Nick Pavlakis, Effie Conomos
<b>Chinese Advisory Board</b>	Wendy Wang, Theresa Chow, Daniel Chan, Viola Yeung, Dr. Agnes Li, Hudson Chen, Dr. Ven Tan, Nancy Tam, Soo See Yeo, Prof. Richard Chye
<b>Arabic Advisory Board</b>	Fr. Antonios Kaldas, Mona Saleh, Seham Gerges, Katya Nicholl, Shei Khalil El-Chami, Dr Mustafa Alameddin, Hancey Ibrahim, Dr Adel Soliman

## Case ascertainment: Registry

- Born in a country where Arabic, Chinese, or Greek spoken
- Have surname indicative of this background
  - names data-base developed by PoCOG
- Aged > 18
- Diagnosed less than 6 years previously with one of 12 most prevalent cancers
- Random sample: English-speaking, Australian-born patients matched on cancer type
- (Mostly survivors with early stage disease)

# Recruitment

- Registry
  - asked nominating doctor to confirm eligibility and consent
  - mailed patient to request permission for researcher contact
- Researcher
  - phoned patients and mailed them questionnaire in language of choice and 1800 number
- Non-returnees phoned 5 times, sent replacement questionnaire

# Measures

- **Demographics**
- **Anxiety and Depression - HADS**
- **QoL – FACT-G**
- **Unmet Needs**
  - **SCNS** (Supportive Care Needs Survey)
    - *Physical and Daily Living & Sexuality domains*
  - **CaSUN** (Cancer Survivors Unmet Needs Scale – *future items*)
  - **Culturally specific support / information** (study specific (from qualitative phase))
- **Translated versions used, or rigorous translation undertaken**



The image displays three translated versions of a survey form, each with the PoCoG logo at the top. The forms are:

- Arabic:** "احتياجات مرضى السرطان الذين من خلفيات ثقافية متنوعة - دراسة قومية" (Needs of Cancer Patients from Different Cultural Backgrounds - National Study). It includes a title, purpose, and instructions in Arabic.
- Traditional Chinese:** "來自不同文化背景的癌病患者之需求 全國性調查" (Needs of Cancer Patients from Different Cultural Backgrounds - National Survey). It includes a title, purpose, and instructions in Traditional Chinese.
- Greek:** "Οι ανάγκες των καρκινοπαθών από διαφορετικές πολιτιστικές προελεύσεις - Μια εθνική μελέτη" (Needs of Cancer Patients from Different Cultural Backgrounds - A National Study). It includes a title, purpose, and instructions in Greek.

# Response rate

- 4,369 potentially eligible
- 45% not confirmed by Dr
  
- 2307 patients contacted by registry
- 596 consented (26%)



# Biased sample?

No significant differences between  
responders and non-responders

on:

gender, age, urban versus rural,  
SES, time since diagnosis,  
cancer type or stage



# SAMPLE (n=596)

Demographics	% Immigrant N=277	% Anglo N=319
<b>Cultural background:</b>		
English-speaking		54
Arabic-speaking	9	
Greek-speaking	13	
Chinese-speaking	24	
<b>Gender:</b>		
Male	54	49
<b>Marital status:</b>		
Married or partnered	80	74
<b>Place of residence: #</b>		
Rural (versus urban)	1	12
<b>Education: #</b>		
<High school	21	5
High school/ tech college	42	71
University	37	23

**p<.0001**

**p<.0001**

Demographics	M (SD) Immigrant	M (SD) Anglo
<b>Years in Australia:</b>	30 (14.6 years)	
Literacy	%	%
<b>Understanding of the Australian Health System:</b>		
Not well:	27%	11% P<0.0001
<b>Confidence speaking English (immigrant only) :</b>		
Not confident	30%	
<b>Difficulty communicating with doctor</b>		
Often	24%	



Disease details	% Immigrant N=277	% Anglo N=319
<b>Diagnosis</b>		
Breast	31	37
Prostate	27	25
Colorectal	19	17
Other	23	21
<b>Stage at diagnosis:</b>		
Localised	57	58
Regional	19	20
Distant	3	3
Unknown or n/a	21	20
<b>Current treatment</b>		
Yes	8	5

# Analysis

- Unadjusted linear regressions
  - Arabic, Chinese, Greek and Anglo
- Adjusted linear regressions
  - Controlled for age, gender, education, understanding of the health system

# Top 10 unmet needs of immigrants

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

# Information

- **Only 21%** of immigrant patients reported receiving information about their cancer and its treatment in their own language



# Distance and Isolation ...

- Communication barriers
  - *“You have no way to communicate you know ... You can’t hear, you can’t speak. It’s very frightening.”*
    - *Mandarin speaker*





# Communication barriers



## Information inaccessible

- *“They gave me some books where I did the chemotherapy, but I couldn’t read them, they were in English.”* Greek patient
- *“The nurse ... spoke English; they gave me a lot of information... I didn’t listen.”* Mandarin patient
- *“He speaks, but what we hear is only 20%, understand 20%.”*
- *“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

# 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

# Prevalence of any unmet need

Needs	Anglos %	Arabic %	Chinese %	Greek %	p
Support	23	35	<b>61</b>	30	.0001
Physical	25	38	<b>42</b>	34	.0001
Sexual*	19	20	21	29	0.3
Future	20	27	36	22	0.2

\* High rate of missing data

## Comparative severity of unmet needs \*

Needs	Anglos (reference)	Arabic	Chinese	Greek	p
Support		1.2	<b>2.1</b>	1.4	.0001
Physical		1.7	1.6	1.4	.0003
Sexual		1.0	1.1	1.2	0.9
Future		1.1	1.5	1.0	0.7

\* Comparative severity (eg an estimate of 2 indicates twice the severity)

# Correlations with anxiety, depression and QOL

- Unmet needs **positively** correlated with anxiety and depression
  - correlations ranged from **0.26 to 0.54**
- Unmet needs **negatively** correlated with QoL,
  - correlations ranged from **-0.34 to -0.57**

## Factors associated with severity of unmet needs (Immigrants only)

- Immigrants **who did not understand the health system** had **2** times higher unmet needs ( $p < 0.0003$ )
- Participants who **needed an interpreter** had **2 to 4** times higher unmet needs ( $p < 0.0001$ )
  - NB, getting an interpreter did not modify this!

## Factors associated with severity of unmet needs (immigrants only)

- **Having accessed a counselor**
  - psychologist, psychiatrist or social workerassociated with having higher unmet **sexual needs** ( $p=0.03$ ) - trends in other domains
- **Longer time since diagnosis** associated with fewer **physical needs** as time passed ( $p=.002$ )

# Summary

- Even when controlling for potential confounders, immigrant survivors had significantly higher unmet needs than Anglo-Australian cancer survivors matched on cancer diagnosis
- Unmet needs is associated with increased anxiety and depression and poorer QOL
- There is an **URGENT NEED** to address these unmet needs



# Summary

- Not understanding the health system and having language barriers;
- ↓
- The main predictors of having unmet needs

# Summary

- Surprisingly, **diagnosis, age, gender, socio-economic status and education level** were *not* related to needs
- Our sample had quite high SES
- SES measure based on postcode
- Needs more exploration

# Summary

- Strategies to overcome language barriers and improve understanding of health system needed (**Interpreters insufficient**)
  - Bilingual cultural advocates
  - Central telephone services
  - Translated materials
  - Audiotaped consultations, QPLs
  - Cross cultural training for health professionals

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