

Conceptualisation of post-treatment survivorship: experiences from different cultural groups

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Australian Cancer Survivorship Centre
The Australian Cancer Survivorship Centre is a national research centre for cancer survivorship, established in 2012. It is a collaboration between Cancer Australia, Cancer Council Australia, Peter MacCallum Cancer Centre, and the University of Melbourne.

Background

- Australia has one of the most culturally diverse populations in the world with approximately 28% born overseas
- Recent Australian research shows that
 - CALD migrants have a poorer cancer experience
 - CALD migrants with cancer report inferior quality of life, higher levels of unmet needs and depression
 - Survivors from Chinese and Greek-speaking backgrounds report unmet need for culturally appropriate information

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Background

Anglo-English speaking Australian groups

- The period after finishing treatment (the survivorship phase) can be distressing
- Consumers are often fearful of the cancer coming back
- Consumers can have financial, family, physical and/or emotional concerns
- Consumers are at risk of recurrence, long-term and late effects from cancer and its treatment

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Background

- Little is known as to whether issues for CALD survivors are the same as for Anglo-Australian cancer survivors
- It is not adequate to simply translate existing information materials
- Consideration of cultural differences (attitudes and beliefs) and language (the meaning of 'cancer survivor') are important

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Project Aim

To develop culturally-appropriate information about cancer survivorship for people with Chinese and Greek-speaking backgrounds

1. **Understand conceptualisation of survivorship post treatment & the unique information needs**
2. Develop/adapt written information material tailored to specific CALD groups
3. Disseminate written information materials widely

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Method

Focus groups (Victoria and New South Wales)

- Recruitment from community groups and hospitals
- Two focus groups for each three languages
- Semi-structured interviews, with language speaking researchers
- Participants were asked how they define survivorship, about life after cancer treatment, and what their information needs were
- Recorded, transcribed and translated by NAATI accredited translators

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Results

Participants

- 39 CALD survivors (30 female): from Greek (11), Cantonese (14) and Mandarin (14) backgrounds.
- Primary diagnostic groups included: breast (20), colon (7), nasopharyngeal (3), anal, prostate, kidney, lung, thyroid (1 each), and unknown (4).
- Age (years) groupings were: 30-44 (5); 45-60 (12); 61+ (18); and unknown (4).

Results

Themes

- Ongoing cancer related stressors
- Misunderstandings about cancer
- Coping strategies
- "Survivor" seldom reflects self-appraisals
- Varied information content and access modes needed

Results

Ongoing cancer related stressors

- *Of course we are worried about recurrence. But the doctor will say you have recovered and that you are a normal person now. It is impossible!*
- *Everybody around you, friends, relatives, family members, will treat us differently, ... are afraid to talk about your sickness. They will take it as I am already fully recovered from cancer. ... it is not a comfortable feeling.*

Results

Misunderstandings about cancer

- *I saw on the TV they can extend life 10 years. I think, I've had six-and-a-half, so I have only three-and-a-half left*



Photo source: CanReview, NSW

Results

Coping strategies

- *It helped me to seek out other people who had been sick. I found more understanding than if I had kept it hidden.*
- *(We) forget our pains, forget our diseases. This is our greatest happiness when coming here to join the activities.*



Results

"Survivor" seldom reflects self-appraisals

- *It's over, if it happens again then I'll go through it again.*
- *I do not care, this name (survivor) is nothing*
- *According to Chinese tradition, 'survivor' implies that the survival rate is very low*

Results

Varied information content and access modes needed



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Conclusions

- This study provides new insight into the experiences and information requirements of CALD cancer survivors from Chinese and Greek backgrounds
- Many information preferences are consistent between CALD communities and native Australians
- CALD communities preferred the term 'recovery' or 'aftercare'
- CALD survivors needed greater understanding about accessing healthcare, welfare and community-based services in their language
- First of their kind information resources for Chinese and Greek communities were produced

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Cancer Survivorship Resources CALD Communities



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Project Team - acknowledgement

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