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**Publication details:**

Commissioning Body: Cancer Council NSW

**Publication Date:**

2016-12-31

**DOI:**

<https://doi.org/10.4225/53/58d35be5859f2>

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# Cantonese-speaking and Mandarin-speaking people with liver cancer in Australia

A report of two focus group discussions

December 2016

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## Summary

- Participants were generally familiar with the practice of scanning and seeking cancer-related information.
- Unfamiliarity with the English language was a major barrier to participants' negotiating health services and understanding the implications of a cancer diagnosis.
- Participants' main sources of cancer-related information were doctors and specialists.
- They wanted information about living with cancer made available in Cantonese and Mandarin dialects, via booklets and websites.
- Family was the main source of support for cancer patients.
- Mandarin-speakers reported a level of discontent with Australian doctors' and specialists' communication styles regarding a cancer diagnosis.
- Participants strongly recommended that a directory of interpretation services be available through hospitals and at doctors' and specialists' clinics.
- Participants recommended the widespread advertising of the 131 450 telephone interpreting service number for newly diagnosed patients.
- Can Revive was highly recommended as a place for liver cancer patients to access information and to obtain social support and counselling, especially after treatment.

## Recommendations

On the basis of two focus group discussions with Cantonese-speaking and Mandarin-speaking Australians with liver cancer, the following strategies might be considered:

- Liaising with Chinese community medical practitioners to discuss ways of supporting family doctors and liver specialists to ensure patients receive adequate levels of information about living with liver cancer and the treatment options.
- Cantonese and Mandarin language booklets and websites containing information about: liver cancer, cancer medications, methods of cancer treatment and treatment time-frames, treatment side-effects, dietary guidelines, medicine delivery services, private health insurance, Medicare and psychological support services for Chinese-speaking people with cancer and their Carers.
- A directory of Chinese-speaking medical practices, and Chinese language interpretation services.
- Information about and contact numbers for Can Revive.
- Booklets and websites should remind people about the importance of early detection of cancer and include information about screening (why, where and how).

## Overview

The research literature about Chinese immigration to the US (and a small amount of literature about Chinese immigration to Australia) has reported that, generally, Chinese immigrant communities are more acculturated to Western systems and the values enshrined within these systems than are some other immigrant populations. This is partly because Chinese immigration to the West has a long history compared to other Asian ethnicities; Chinese communities are often visible and well integrated into major Australian cities. While these data are limited, the findings of the two focus group discussions with Cantonese speakers and Mandarin speakers reinforce the observation that, for the most part, Chinese–Australians are acculturated to mainstream Australian health beliefs and practices, and have similar understandings to those of the majority of the Australian population regarding cancer.

The Chinese-Australians with liver cancer indicated that they would like to have as much information as possible about their condition and its treatment. They also requested information about new clinical trials of cancer drugs, information about side effects and referrals to organisations that can provide patients with emotional counselling. These findings suggest that this sample of Chinese-Australians were largely comfortable with the tenets of Western neo-liberal ideals of personal responsibility for health; they had attitudes to health seeking and scanning for cancer-related information which were aligned with those of Australians from European backgrounds.

The greatest difficulties faced by Chinese-speaking participants, particularly around diagnosis, was the language barrier. They said they often experienced a sense of helplessness as a result of little or no English language skills. The need to overcome this barrier was one of the main themes of the focus group discussion. Family was very important for a range of reasons, not the least because having younger people in the family who were able to speak English bridged a significant informational-chasm for Chinese-speaking cancer patients.

Participants described a range of experiences regarding information they received at diagnosis; some received enough information while others said they received very little. If a participant had been diagnosed by a Cantonese-speaking doctor they tended to report receiving information. However, one participant blamed short consultation times with a Cantonese-speaking doctor on why he/she did not receive adequate answers to his/her questions, or detailed information about liver cancer in general.

The Mandarin-speaking participants - mostly - held similar views to the Cantonese-speaking participants. However, there were some notable differences. The Mandarin-speaking participants included several people who regularly travelled to China to have treatment for liver cancer (and lung cancer). These participants seemed to be well-resourced. One participant in particular, a doctor who cared for his wife who had cancer, was disappointed with Australian doctors' communication skills, and his criticism was also levelled at Chinese-speaking Australian doctors. The Mandarin speakers reported significant cultural differences that they had observed between Chinese-Australians and Australians from European backgrounds in relation to how a cancer diagnosis is conveyed to a patient. Several participants believed that doctors in Australia, including the Chinese-speaking doctors, are too blunt when it comes to giving a cancer diagnosis. It was reported that Chinese doctors and families preferred not to tell a cancer patient that they have cancer, but instead used euphemisms, like 'liver disease'. This practice of concealing a cancer diagnosis from a patient was described by Mandarin-speakers as a wide-spread cultural and medical norm throughout China.

Despite such reported differences, there appeared to be more similarities between these two language groups of Chinese participants.

Participants strongly recommended that a directory of interpretation services be available through hospitals and at doctors' and specialists' clinics as a way of overcoming the language problem and better managing the diagnosis experience. Participants recommended the widespread advertising of the 131 450 telephone interpreting service number for newly diagnosed patients. Interpreters were important in participants' quest to acquire the right information after diagnosis. 'Social work nurses' were said to be helpful because they provided home-visits and were accompanied by an interpreter. However, these visits usually occurred after the diagnosis period when, according to participants, information became less urgent.

Another main theme was the need for emotional support to help people adjust to a cancer diagnosis and to help people cope with cancer in general. The organisation Can Revive

was very highly regarded, as an information service but also as a social service because it supported people by bringing cancer patients together for day-trips and other social events. Participants recommended referring newly diagnosed patients to Can Revive to assist with their adjustment to living with cancer. Family was said to be the best source of support but it was reported that family members of cancer patients also experience a difficult time and need supporting as well as the patient.

The preferred medium for receiving information about liver cancer was a Cantonese or Mandarin-speaking doctor or specialist, but participants were also keen to access information via a booklet and via the internet. There were some quite specific recommendations regarding the types of information desired and the best formats for its dissemination, and these are reported below.

Finally, these data are not generalizable to all Cantonese-speaking and Mandarin-speaking people in Australia with liver cancer, and therefore the findings of the focus group discussions and the suggested strategies for consideration must be viewed with the methodological limitations in mind.

## 1. Cantonese-speaking participants

### Description of focus group discussion content

#### Diagnosis and information provision

- Little information was provided to some participants at diagnosis.
- It is unclear, but some participants seem to be saying that they received little information at diagnosis because their doctors and specialists were often English-speakers and participants were not able to understand enough English medical terms to know the details of their diagnosis and prognosis.
- One participant said Australia needs more Cantonese-speaking oncologists.
- However, another participant indicated through his account of diagnosis that he received no information from a Cantonese-speaking doctor because of the short appointment times.
- Another participant with a Cantonese speaking doctor reported receiving very little information about cancer (the stage it was at, treatment options, side effects of treatment etc.), even though there was no language barrier.
- One woman provided an emotional account of the difficulty faced by Cantonese people when diagnosed with cancer in a context where English is the only language spoken. She was confused, emotional, felt 'helpless' and had to ask her daughter to look up the meaning of words the doctor used when she got home.
- This woman sought information from the Cancer Council but was not satisfied (unclear, but I think the one and only booklet she received was in English). She was then able to access information in Cantonese from Hong Kong and this helped her.

- Nonetheless, participants who were diagnosed by Cantonese-speaking doctors and specialists were usually able to converse with their doctors.
- Some participants had family members with them at appointments to interpret English-speaking doctors' and specialists' advice.
- One participant spoke about 'falling into a very dark cave' after his diagnosis, i.e., he says he became very depressed.
- One participant said that, if people are unfamiliar with the health system and hospitals, the cancer diagnosis experience is even more daunting, and in order to avoid this turmoil he **strongly recommended that new patients must be informed of the interpreter services at hospitals**. This is for translating and clarifying the information given to patients at diagnosis by a doctor or specialist.
- Participants said that the **131 450** phone number for the interpreting services line should be widely publicised.
- It was reported that doctors do not tell their patients about interpreter services, so somehow newly diagnosed patients need to be informed of these services.
- When asked about what information to recommend for people who were newly diagnosed, participants said that a directory of Chinese-speaking doctors and specialists would be a great help to them.
- Participants wanted to know their cancer stage and as much information as they needed to help them to make decisions about their treatment options etc.

## Support

- A 'social work nurse' who was aided by an interpreter helped one participant by coming around to his house and checking on him. This nurse provided counselling and gave a lot of information about the patient's condition through the interpreter.
- **Can Revive was highly recommended** for patients, especially after having treatment. It was recommended highly because of the support and activities, such as day-excursions, the service provided cancer patients. This helped patients cope emotionally.
- Emotional support was very important; Can Revive was seen as very good at providing emotional support.
- However family support was best (when participants had a family), but for people with no family or who had carer responsibilities themselves (one woman with liver cancer looked after her son who was confined to a wheelchair), the experience of having liver cancer was reportedly so much harder. Can Revive had helped this woman.
- Participants said that more social gatherings were needed where people can give each other emotional support, especially for the carers of people with liver cancer because the whole family is affected by liver cancer.



- Participants indicated they would not be offended if a doctor referred them to a psychologist. They said that a psychologist can help some people, and at least one participant said that they had already been to see a psychologist.
- To have information about psychological support and counselling in a booklet was described as 'great'.

### **Information resources: content and format**

- Participants wanted a Chinese language booklet with information about liver cancer.
- Specialists reportedly did not talk about the side effects of chemotherapy. Some people were surprised by the side effects of their treatment. A booklet or another resource needed to address side-effects.
- The internet was recommended as a good source of information. A participant used the internet to find information about diet, new treatments, side effects, and which drugs are subsidised by the Australian Government.
- Participants mentioned foods they found they could not eat, or they had heard they should not eat, including prawns and crabs.
- One participant said that Western doctors do not care about giving information regarding diets for people with liver cancer.
- Some participants used Chinese medicine (CHM) but didn't tell their Western doctors because they thought their Western doctor would not approve. Reportedly however, CHM could assist in reducing some of the side effects of treatment.
- Transport was a problem for participants who had no family to drive them to appointments.
- Financial difficulties occurred when 'the pillar of the family' became sick.
- The social work nurse offered to hand in forms to Centrelink for one participant who needed help with this. A social work nurse that could help with negotiating the social security and health systems for patients was desired.
- Participants preferred a 'small booklet' with cancer information than a CD or DVD because people get tired listening to a CD or watching a screen. A booklet was said to be something that people can pick up and put down as they please. Also, CDs and DVDs require a certain level of technological proficiency and usually that means a young person has to be around for a cancer patient to listen to a CD or watch a DVD.
- Copies of booklets should be left at hospitals and with specialists because that is where people are diagnosed and is often when people need information the most.
- A monthly magazine or internet site with information about drug trials, new medications and their side effects was also seen to be useful for people.

- Participants had experienced problems with appointments being cancelled because doctors went on holiday and they then had difficulty re-booking appointments.
- Some suggested it would be good to have a nurse (a social work nurse?) who could be a 'middle-man' to help with problems caused by language, to reassure patients, to get repeat scripts and to rebook appointments.
- Apparently there are services, such as medicine delivery to patients, but many people do not know about these services because they are only discussed and advertised in English.
- People need to be reminded to keep their medical records handy in case they are taken away in an ambulance. This information could be part of a booklet.

### **General**

- Participants said that they were 'shown respect' when they attended hospital in Australia.
- Participants knew that Asian people had a high population prevalence of hepatitis B and that this virus was a cause of liver cancer.
- Participants spoke about other people's fears around cancer, for example of it being contagious, but they were generally positive about their own experiences with people.

## **2. Mandarin-speaking participants**

### **Description of focus group discussion content**

This was a significantly shorter focus group discussion than the Cantonese-speakers' focus group. As such, the description of the content is not categorised.

### **General**

- Once again, the 'language barrier' was said to be the biggest problem faced by participants when they seek healthcare.
- One participant was unhappy with the way she was treated by an Australian oncologist because she felt he/she did not take her symptoms seriously (?), although this is unclear; she was eventually diagnosed with lung cancer. It might be that the liver cancer had spread to the lungs, but this is not articulated.
- Another participant talks about her decision to go against her doctor's wishes and not have chemotherapy for liver cancer because of information she found on the internet which described the treatment as having significant side effects. She preferred to live her last years in comfort rather than be constantly sick (the information from the internet said that on average patients only live an extra two years by taking these specific chemotherapy drugs).



- She says it is impossible for a cancer patient to be happy, but that one's emotional state can make a real difference to how patients cope.
- Participants did not appear to want to consult a psychologist re their emotional wellbeing.
- A participant told a story of how he went back to China several times to have surgery and to receive radiotherapy for liver cancer. He seemed to have good contacts among medical professionals in China. He preferred being treated in China because he believed that his Australian doctors' approach to treatment was too 'conservative' (a 'wait and see what happens' approach).
- Another participant, who reported being a doctor and who had lived in Australia for the past two years, spoke about his wife's experience of being diagnosed with liver cancer, and later lung cancer, in China after returning to China for a CT scan.
- This Chinese doctor/carer/participant said that Australian GPs 'are not very professional', and that there is 'a communication problem' between GPs and patients in Australia. He includes Chinese-speaking doctors and specialists when criticising medical professionals in Australia. He says that in Australia doctors 'just test and examine' but do not communicate with patients. He says that doctors in Australia 'are just like factory workers'.
- This Chinese doctor/carer/participant goes on to criticise Australian doctors for being too blunt; he says he has a traditional Chinese outlook and that this means a doctor should never tell a patient that they have cancer, because it is too hard for the patient. He says the best way is to tell the family and let the patient think they merely have a liver disease. He never uses the word 'cancer' because it is too hard for patients to accept. Others agreed. They think Westerners 'are more accepting' of the reality of cancer, but – curiously - they almost view this as a fault.
- Some participants also mentioned that they had experienced difficulties during consultations with medical professionals because they cannot speak English.
- The Chinese doctor/carer/participant goes on to criticise Australian-trained medical professionals; he says that Australian medicos conceal information from patients (which directly contradicts his earlier criticism about being too honest with regards to giving patients cancer diagnoses). This statement is based on an experience where Australian doctors did not tell his wife about the side effects of chemotherapy. He says they don't tell patients the truth, but instead give them simplistic, superficial information! He again reiterates his belief that Australian doctors' communication skills are bad.
- Participants wanted information about nutrition, transport and finances for people with liver cancer (but these 'needs' were first suggested to participants by the interviewer).
- A participant said there was 'a huge lack of knowledge' about private insurance (I assume he/she meant health insurance), and how Medicare works as he/she had to wait a long time to get things approved.

- From another suggestion by the interviewer, the interviewees agreed that supporting carers, as well as patients, was necessary to build good relationships between carers and patients.
- Information about social gatherings for cancer patients was requested by a participant, and supported by others.
- Information about psychologists and emotional counselling was also needed by some.
- From a suggestion by the interviewer, participants agreed that a booklet with information about issues such as treatment side effects, the different types of doctors and the name of hospitals that treat cancer patients, information about cancer medications and methods of treatment and treatment time-frames, the importance of early detection, information about screening and having regular check-ups, information about coping with cancer, reducing stress, reducing 'acidity' levels in the body (because one's 'acidity' was reportedly associated with cancer and ill health), and keeping positive.
- Participants believed that Western medicine is better for 'urgent' situations like cancer treatment, but that Chinese medicine is best for repairing the body after treatment with Western medicine. One participant said that people should not try both Western and Chinese medicine at the same time.
- Participants complained about the lengthy waiting times to see a doctor for either serious illness or less serious issues.
- One participant said he/she had to ask the doctor about whether or not cancer was contagious!
- They all agreed that 'Anglo-Saxon Australians' and Chinese-Australians are treated equally in relation to receiving cancer treatment.
- Australia and China were said to be different in the way they approach cancer; Australia was said to be much more relaxed about it, whereas Chinese people react strongly when they hear that someone has cancer.
- Westerners are characterised as open-minded and nonchalant about cancer.
- Can Revive was again spoken of very highly for bringing cancer patients together to help support them.
- It was stated that Chinese people don't talk about having cancer, and that Can Revive is good because people there never ask participants 'how their cancer is going'.
- A booklet with information about liver cancer was the participants' preferred method of receiving information.
- Chinese language newspapers were read by participants and they believed these to be another potential avenue for reading about liver cancer.

## Funding support

This work was funded by Cancer Council NSW and by Cancer Australia through the Supporting people with cancer Grant initiative, funded by the Australian Government (Project ID CA-A1112/49).

We also received support from the Sydney West Translational Cancer Research Centre (TCRC), funded by the Cancer Institute NSW.

Jacob George is supported by the Cancer Council NSW, the Robert W. Storr bequest to the Sydney Medical Foundation and grants from the National Health and Medical Research Council (NHMRC).

The Centre for Social Research in Health is supported by a grant from the Australian Government, Department of Health.

## Suggested citation

Hopwood, M., Robotin, M. C., Porwal, M., Nguyen, D., Sze, M., George, J., & Treloar, C. (2016). *Cantonese-speaking and Mandarin-speaking people with liver cancer in Australia: A report of two focus group discussions*. Sydney: Centre for Social Research in Health, UNSW Australia. <http://doi.org/10.4225/53/58d35be5859f2>