A peaceful mind: Vietnamese-Australians with liver cancer

Interview report

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Summary:

- Participants indicated little desire for detailed information about liver cancer.
- Family doctors and liver specialists were the primary sources of information about liver cancer.
- The internet was another source of liver cancer-related information.
- DVDs, print resources and Australian/Vietnamese media were not considered to be good sources of liver cancer-related information.
- Participants relied upon interpreters for understanding the information and advice given by doctors and specialists.
- Culture and family had a large influence over dietary decisions.
- Unemployment and under-employment as a result of illness created financial stress for participants.
- Participants borrowed money from friends and family when necessary.
- Coping with liver cancer was facilitated by a focus on keeping a peaceful mind.

Strategies to consider:

On the basis of interview findings derived from this small sample of Vietnamese-Australian liver cancer patients, the following strategies might be considered:

- Liaising with Vietnamese 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 treatment options.
- A review of Vietnamese language websites for people with liver cancer, and a compilation of URL addresses of the best site(s) for dissemination via Vietnamese media, community family doctors and liver cancer specialists.
- A review of interpretation services for Vietnamese people with an aim to publish an online directory and printed directory in the Vietnamese media.
- Interventions that could facilitate ‘a peaceful mind’, this might include: resources on transcendental meditation, yoga and tai chi (available online, and as a CD and DVD); a collection of traditional Vietnamese music (classical and folk); a resource on managing stress and relaxation techniques.
‘Keep sweeping your house and you end up finding rubbish everywhere’.

(ID 8, quoting a Vietnamese proverb)

Information seeking and scanning does not appear to have the same currency, or function, for the Vietnamese-Australian people interviewed for this project as it does for people who have been socialised within a Western neo-liberal framework of personal responsibility for health (see discussion).

The findings of this project, if replicable, have important implications for health promotion and the dissemination of liver cancer-related information to people from Vietnamese backgrounds living in Australia.

**Introduction**

These data are not generalizable to all Vietnamese-speaking people in Australia with liver cancer. Therefore the interview findings and the suggested strategies for consideration must be viewed with the methodological limitations in mind.

The views and practices of Vietnamese participants in this project challenge common assumptions about the needs of individuals following a cancer diagnosis. For the most part, these participants believed that if there is anything they needed to know about liver cancer then their doctors would tell them. Looking for information was deemed unnecessary; most participants saw little point seeking and scanning for information about their condition unless it was to clarify information they had received from a family doctor or liver specialist. Participants were at most curious about their condition while others seemed disengaged; some said they ‘did not care’ or they ‘did not need’ information about liver cancer. For these Vietnamese-Australian people with liver cancer, it was more important to stay calm about their diagnosis and to keep a peaceful mind, than filling it with facts about cancer, its treatment and lifestyle change.

**Main findings: Information about liver cancer**

The findings presented below provide insight into some of the issues, concerns, barriers and facilitators reported by participants with regard to accessing information about liver cancer for people from Vietnamese backgrounds living in Australia.
1. Primary source of liver cancer-related information: family doctors and specialists

All eight participants reported that family doctors and specialists were their preferred primary sources of information about liver cancer. This was because the information they received from their doctors and specialists was tailored to each individual patients’ condition, unlike information accessed via other avenues which, reportedly, is often too generalised.

Q: When you went to your doctor, did he explain clearly to you about liver cancer?

A: There are two types of doctors. One type of doctors who understood but explained briefly, that’s the family doctor. The ones who explained in very detail are the specialists. The family doctors often are very busy so kept the explanation short. The specialists explain very thoroughly.

Q: Overall, are you satisfied with the information given by your doctor?

A: I noticed that the family doctor is sometimes not very thoughtful. But the specialists, particularly at the hospital, are very thoughtful and they have lots of information. (ID 8)

Participants reported that their primary source of information about suitable diet and lifestyle changes was also their family doctors and specialists. However, relying upon a doctor or specialist for information about liver cancer, diet and lifestyle had its shortcomings as these health professionals did not always have enough time to answer patients’ questions. While most participants were satisfied with the information their doctors and specialists provided, some wanted more detail about their individual condition.

2. Other key sources of information

The internet

The internet was the next most commonly used medium for accessing information about liver cancer and lifestyle, after family doctors and specialists. To supplement information from a doctor or specialist, participants would refer to the internet if they knew how to use a computer. For example, information they gleaned from a website helped their understanding of medical terminology:
I often played with computer and went on the Internet to visit liver cancer websites in Vietnamese ... There are more than enough information ... When I was in the hospital, I heard the doctors used those new words. For example the words “anaesthetic”, “chemotherapy”, I kept them in my memory. When I came home, I checked the meanings in the [online] dictionary. (ID 7)

Information from a doctor or specialist was sometimes described as detailed, and difficult to understand, so participants turned to the internet to seek clarification. Conversely, when participants came across information they could not understand on an internet site or from another source, they would seek further explanation from their family doctor or specialist.

Most participants indicated that they saw little point in knowing a lot of detail about their condition. Some accepted information from their family doctor or specialist however they rarely actively scanned or sought information about liver cancer:

Q: What information do you think is useful for you to understand liver cancer?

A: I don’t care. As long as people send to me the information, I will read it. I still don’t know what information I can find to facilitate my understanding of the disease. (ID 6)

The search engines Google and Yahoo were used to access mostly Vietnamese sites, which used participants’ native language. However English-language websites were accessed by those who understood some English.

Finally, the internet was described as a good source of information because it gave a wider set of perspectives on things such as cancer treatments than print media does, and it is available anytime. On the other hand, information obtained from the internet was also described as not specific to the needs of an individual patient and the reliability of some information was questioned by several participants. One participant disseminated some of the information he found on the internet to his friends.
**Australian and Vietnamese media**

The mainstream Australian media was reportedly not a site for accessing liver cancer related information. However five out of eight participants did discuss the Vietnamese ethnic media, and their reports reflected diverse practices and mixed opinions regarding its value: two participants said they occasionally accessed Vietnamese ethnic newspapers, radio and television to find information; another participant has ‘listened’ to ethnic media and ‘doubts’ the information about liver cancer he has heard; a fourth participant said he ‘rarely listens’ to ethnic Vietnamese media; and a fifth participant said he ‘never’ accesses ethnic Vietnamese media for cancer-related information.

**Digital and printed resources**

Among this sample of Vietnamese people with liver cancer, the option of receiving health and cancer-related information via digital video discs (DVD), pamphlets or another form of printed media was not coveted. Some said they might pick up a DVD or pamphlets and booklets if they came across them. There were concerns about privacy and confidentiality when accessing media containing cancer-related information. Generally, these resources were viewed as incidental to information and advice received directly from a doctor or specialist. A participant below described his response to these other options for receiving information, as such:

**Q**: What do you think is the best way(s) to receive information about treatment, its side effects and ways to improve your quality of life? For example DVD, Internet or Health professional or pamphlet? Which one(s) is the best way for you to receive information?

**A**: I think that it depends on what my attitude is, if I want to find the information or not. If all the information are there, DVD, Internet or newspaper, and I don’t seek it, it’s as if there is nothing. That’s why all the means are good, depending who you talk to. (ID 5)

This participant believes that all the published information in the world is not going to help someone who has no wish to read it. He concludes by acknowledging that indeed it is good to have a variety of ‘means’, but their value will always be measured in direct proportion to demand, and if there is no demand: ‘... it's as if there is nothing’.
The second extract is more literal; he is also saying that, perhaps because of his age, education and background, DVDs and the internet are not an option however they may help others. He does not give an opinion regarding ‘leaflets’.

**Q: What about DVDs about liver cancer or searching for information on the Internet or the leaflets?**

**A:** I don’t use them so I don’t know. I don’t use and don’t know how to use computer.

**Q: Do you think that these things can help you to understand better?**

**A:** It may help but I don’t know how to use it. (ID 2)

These two responses were typical of other participants. Unlike some liver cancer patients from culturally and linguistically diverse communities in Australia, no one in this sample reported frustration because they could not find a DVD, or pamphlet or booklet with cancer-related information. This might be because their information requirements are lower than for some other patients and/or their doctors have provided them with a satisfactory explanation of their disease, what to expect from treatment and their likely prognosis. Finally, in relation to receiving printed resources, one Vietnamese participant remarked:

*I noticed that Vietnamese patients in the hospital didn’t bother to make an effort to read the information. Sometimes, they received the information and threw them in a bin.* (ID 8)

**Note regarding questions about digital and printed resources:** In several interviews, the questions about digital and printed sources of information appeared to perplex some participants; it was as if seeking information had not occurred to them. These questions might have implied that people ‘normally’ actively seek information and that anyone who does not access DVDs and print media is somehow behaving irresponsibly. Indeed, the line of questioning during interviews may have implied that a participant was not satisfactorily engaged with their healthcare if they had not sought out multiple sources of information, but instead relied solely upon the advice of a doctor or specialist.

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3. English Language difficulties

Of a total of eight participants interviewed, a majority were unable to read English. Some said that they were able to identify and understand certain English words and phrases relating to liver cancer however they said that their command of the language was not to a level satisfactory for comprehending meaning.

Often, a family member would accompany participants to appointments and translate a doctor’s information and advice. Interpreter services were a frustration for some participants because they were not always available for medical appointments. Some had booked an interpreter who did not turn up for the appointment, which meant the participant had to rebook an appointment and make new plans to attend the hospital/clinic at a later date (and add the cost of travel and inconvenience). As one man explained:

*It was difficult when I need something and I cannot communicate. Because I didn’t understand and the people didn’t understand me, I had to wait for the interpreter. Booking an appointment with the specialist was also difficult. On the day that I had the operation, my older sister had to come along with me, my wife’s level of English is very low and my children were at work. I also asked for help from friends. With the specialist, there was limited interpretation assistance. Everything had to be planned more than a month ahead in order to access any assistance. (ID 2)*

4. Avenues for information dissemination: Church/temple and community-based events

Among this sample of people, the opportunity to access liver cancer-related information while attending a temple or church was considered both appropriate and inappropriate. Around half of the participants thought temple or church are appropriate contexts for accessing information:

*Q: Do you think the church is a good and suitable place for you to receive information about liver cancer?*

*A: It’s a good idea because there are lots of people there. At any crowded place, there are people with illnesses and they talk and share lots of information. Each person shares the information in a different way. (ID 2)*
A: It may be a good idea. The information leaflets and DVDs about liver cancer can be placed at the front door of church and temple. People go to church and temple every day or every week, it would be easy for them to pick up the information. (ID 5)

On the other hand, some participants did not consider church and temple to be viable outlets for disseminating liver cancer-related information, and they linked these opinions to ‘Asian’ cultural norms around privacy in relation to health and wellbeing:

No one talks about that at the church or temple. One reflects and prays. No one wants to talk about their sickness there. Everyone hides their sickness until it becomes very serious, particularly the Asians, there are many reasons. That’s my thought. I am the same. I share the news with family and close friends. People outside of my family don’t need to know. (ID 4)

People don’t talk about cancer at the temple. They only burn incenses and donate money. (ID 3)

Two participants had no opinion regarding the distribution of information at church and temple. Both these participants were infrequent attendees at church and temple and their ambivalence was perhaps because of the negligible role that church and temple attendance played in their lives.

Community events, like the Lunar New Year, were considered to be more appropriate avenues than churches and temples for disseminating liver cancer-related information. Several participants said they would pick-up resources such as pamphlets and DVDs if they saw them at Lunar New Year, or similar, community-based events.

5. Advice regarding diet

Participants reported that, for the most part, they were given little advice about diet from their family doctor or specialist. According to participants, this was because the doctors and specialists did not see a need for liver cancer patients to have a special diet. Reportedly, the common medical advice is that a person with liver cancer can ‘eat what you like’. However, one doctor advised his patient against eating salty foods and another doctor gave the following advice to patients:
The doctor said there is no special diet, eat what you like. But for a patient with liver operation like myself, the doctor recommended eating more liver because the liver has a lot of protein and the liver will slowly regenerate so eating more liver will help the liver. Besides that, there is no special diet. (ID 1)

While medical advice regarding diet was laissez-faire, participants were aware of a variety of folk-knowledges about foods to avoid, and some drew upon personal experience to challenge or augment medical advice regarding diet. Advice about diet was the only issue where there was evidence of participants rejecting, or modifying doctors’ or specialists’ recommendations. For example:

I did ask my Specialist about my diet. He said “eat what you like” but there are restrictions at home. I do not eat fatty food and any of the salted fishes. People said the salted fishes have too much bacteria in them. (ID 2)

[A Vietnamese doctor] said “eat what you like and there is no special diet”. I think what he said is not correct. I ate a bowl of beef noodle and it is as if it went into my bloodstream, I felt dizzy and headache and my body were in pain. The T-Bone steak gave me the same problem as if I was drunk. Now I don’t eat chilli, it also gives me problem. (ID 3)

The participant below combined multicultural dietary norms with his own intuition to fashion a diet that worked for him. He did not say from where or whom he had received the dietary advice he quotes, but the advice is consistent with recommendations received, and reported, by other participants:

I mixed the Western and Asian diet practices. I chose the practice that makes sense to me and ignored the one that does not. For instance the advice for a person with liver cancer is to avoid eating fried, fatty, chilli and salty food. For healthy people, these foods are also not good for them. It made sense to me, so I did it. (ID 5)

Finally, there was a variety of what might be described as dietary conventions – or eating ‘the Vietnamese way’ – which were highlighted throughout the interviews. This appeared to comprise mostly eating fish and vegetables, which was considered to be the best diet. One participant said his family wanted him to eat a particular way but he
resisted and it created disharmony in his family. He eventually gave in to their wishes, and changed his diet accordingly, but the specific foods he was being encouraged to eat were not explored during the interview.

6. Financial situation of Vietnamese people with liver cancer

With regard to financial issues for people with liver cancer, some participants mentioned, briefly, the financial hardships they and their families had encountered as a result of cancer and its impact on their ability to work. For example, one participant said he had to reduce the number of hours he worked per week, and another had requested his employer place him on 'light-duties' for a duration. Both these changes had affected their total incomes. Other participants were relying exclusively on Centrelink payments. Financial problems were kept quiet and among this sample, almost always managed within the context of family and close friends; for example, a participant's family had raised funds equivalent to one year's salary so that this man could stop work, receive treatment and rest. Typically, participants remarked:

... [I]f you are sick and are not working then the family finance sometimes has difficulty. The main issue is not because you are buying the medications but because you are not working and in this situation we all meet the same difficulty. (ID 1)

I am borrowing money from friends. Borrowing from friends is difficult and I feel very uncomfortable. I already borrowed some money and have not yet paid it back. It’s embarrassing to borrow money from them again. I have to spend carefully. (ID 3)

The rising cost of living was particularly challenging for participants who were living on Centrelink benefits. Financial problems were also evident for participants who had partners working. One man believed that he could overcome his illness 'easier' if he could live in a financially stable situation. He explained:

Finance is difficult. It's not enough sometimes for example the unemployment benefit allowance received is not enough. It’s difficult. It’s not enough because of the bills. (ID 6)
I went to Centerlink to make an enquiry and was told that my wife’s salary is above the income test. An income of $60K-$70K for a family with 2 children is not enough. I just have to accept the government policy. (ID 5)

Despite financial hardship, participants expressed a sincere appreciation for the Australian healthcare system and contrasted it with their experience of healthcare when living in Vietnam. Many referred to friends and relatives with poor health still living in Vietnam. The gratitude of these participants for the opportunity to obtain gold standard medical care for cancer in a first world nation was palpable:

At first I didn’t know whether I have to pay for the operation. Later, I was told that I do not pay for it; it was paid by the government. I was so happy. I would like to thank the Australian government. (ID 2)

While questions were asked of participants about legal issues and problems they may have encountered, no participant addressed these issues in their interview.

Questions about travel revealed a central role for family in transporting participants to clinic appointments, participants self-driving to appointments, and sometimes catching public transport. The high cost of parking at hospital parking grounds was mentioned.

7. Keeping a peaceful mind

A theme termed ‘keeping a peaceful mind’ was salient in these data. This theme pertained to the participants’ evident qualities of stoicism, resilience and optimism. The interview transcripts spoke of participants’ capacities for dealing with the realities of ageing, relocation to a foreign culture and of coping with a life-threatening illness. In their individual styles, nearly all participants alluded to a need for maintaining an inner peace (sometimes with reference to their religious beliefs) to meet the psychosocial challenges associated with a cancer diagnosis, the treatment routines and the unknown, unpredictable outcomes.

As mentioned earlier, sometimes the line of questioning during interviews around seeking and scanning information appeared to perplex participants. The idea of searching for information perhaps introduced a level of complexity to their situations that they found irrelevant. These participants did not seek information about their
condition. Instead, they were content to let the doctors do their work, and they preferred to focus on keeping a peaceful mind:

*Everyone listened to what the doctor said and to what other people said but the important thing is to live at ease, to keep your peace of mind, to live and not thinking about your illness: “Do not eat fatty food”! Just live, keep your mind level and whatever come will come. I just focused on the treatment and not to worry. (ID 1)*

*Friends know about my illness, they come and support me mentally. Don’t live with stress. I know I have cancer but I try to live happily. Family and friends help me a lot mentally. (ID 5)*

A sense of fatalism was evident throughout the interview transcripts, but it was a fatalism tempered by participants’ understanding they were living in a wealthy land, where medical science could, at times, turn around the odds of death from cancer:

*I don’t think or worry about [liver cancer]. If we meant to go, we will have to go. If the cancer comes back then I’ll die. As long as it can be treated, let’s treat it … [later] No. I don’t think about it. Others might be scared when hearing about cancer. Not me. It is nothing because I am no longer fearful of it or of death. (ID 6)*

In ways, these participants epitomised the phrase ‘living with cancer’. They weren’t ‘battling cancer’, but instead followed their doctor’s advice to live life normally, and they stayed genuinely upbeat.

*As the doctor advised, I live my life in moderation. I work in moderation. I eat and drink in moderation. I play and have fun in moderation. There is no restriction … [later] Some people go to the extreme of not drinking [alcohol] even one drop. I don’t think that is good either. Moderation is the best way. (ID 8)*

*Instead of being sad, I feel optimistic and keep my mind active … [later] I noticed that after I had liver cancer, my mind doesn’t bother anymore about liver cancer …*
Discussion

In the West, we have seen a gradual divesting of responsibility for health from the State to the individual citizen and the private sector since the 1970s, primarily as a result of globalised capital and the accompanying economic and social changes. Being a responsible Australian citizen today requires an individual to view their health as an asset or resource to be valued and protected. To maintain peak health we are all encouraged to act like individual-entrepreneurs; that is to eschew bad habits and always behave in accordance with health-maximising practices. This means being actively engaged in exercising, eating a balanced diet, giving up smoking, drinking less alcohol, managing stress, screening for disease, and seeking health-related information that will support our individual health-responsibilities. In the academic literature these dynamics have been referred to as health-ism, and health-ism is defined by sociologist Robert Crawford as “a pre-occupation with personal health as ... the primary focus for the definition and achievement of wellbeing; a goal which is to be attained primarily through the modification of lifestyles, with or without therapeutic help” (Crawford, 1980). Health-focused organisations today are founded to reinforce health-ism and personal responsibility for health, by supporting individuals in their endeavours to maintain optimum health and thereby minimise the cost of healthcare to the rest of society.

On the surface, this focus on individual responsibility for health is intuitive and not an unreasonable expectation. It has an internal logic and appealing qualities. Taking personal responsibility for one’s health sits nicely with contemporary middle-class values (which, arguably, have themselves been constituted by the privileging of hyper-individualism since globalisation). However, the myopia of the ‘personal responsibility for health’ mantra is evident in the assumptions that underpin health-ism. It assumes a level playing field where everyone has roughly equal access to ‘health-giving’ resources. It assumes that everyone has the ability to understand the causes of poor health and has the capacity to apply the strictures needed to overcome ‘bad’ habits (such as using Traditional Medicine). It assumes that Western scientific information and health practices are always superior to any other non-Western health knowledge and practices. Finally, it assumes that people from all ethnicities and cultural backgrounds wish to adopt a Western neo-liberal mind-set that privileges health and wellbeing above everything else, including the pursuit of justice and freedom. Westerners have evolved a pre-occupation with healthy lifestyles and minimising the cost of healthcare, largely as a function of twentieth century globalised capitalism. Despite the growth of Western influence, people from some regions of the world do not perceive or understand health the way Westerners do.
It is important to note that these Vietnamese-Australian participants cared about their health and acted responsibly to improve their health and wellbeing. But one of the precepts of health-ism, that is actively seeking and scanning health-related information, was not a salient exercise among the people interviewed for this project.

Conclusions

Some said to me that they are scared of the doctor. There’s a saying “xem bói ra ma, mà quét nhà ra rác”, meaning roughly “Keep sweeping your house and you end up finding rubbish everywhere”. Similarly, if you go to see a doctor and you will find that you have all sorts of diseases. I think that it’s wrong. One needs to go to see a doctor, if a disease detects early then the treatment can apply quickly. Most of the senior adults arrived from Vietnam have liver diseases. (ID 8)

The above extract suggests that the traditional relationship Vietnamese-Australian participants in this project had with their health was tempered by their immigration from Vietnam to a Western nation where health norms and the availability of world-class medical practitioners and services create new possibilities.

In summary, participants indicated they had a low need for detailed information about liver cancer. Family doctors and medical specialists were the primary sources of information about liver cancer for these participants. The internet was also a commonly referred to source of liver cancer-related information by participants. DVDs, print resources and Australian/Vietnamese media were not highly sought after as sources of liver cancer-related information.

Participants’ limited English proficiency meant that they relied heavily on interpreters for understanding the information and advice given to them by family doctors and specialists. Their reliance on interpreters created problems when these services were unavailable. At times, English-speaking family members could step in to assist participants.

The advice regarding diet that participants reportedly received from their doctors was usually ‘eat whatever you like’. A doctor had warned one participant against eating salty foods and another doctor had suggested a participant eat more liver. Notably, the
dietary advice from doctors - that a patient could eat anything they liked - was not always adhered to. Culture and family had an influence over dietary decisions.

Financial difficulties were evident among this sample of participants. Unemployment and under-employment as a result of illness created stress for some. Participants borrowed money from friends and family when they had to. Several had had problems with Centrelink, or found Centrelink payments inadequate to cover the cost of living.

Finally, participants indicated that a key strategy for coping with illness was a focus on keeping a peaceful mind. This seemed more important to them than seeking information about liver cancer. In relation to living with cancer, participants were optimistic but also philosophical and fatalistic; yes, they wished to get well by following the advice of their doctors, but ultimately their over-riding philosophy might be summarised as _que sera sera_.

**Strategies for considerations**

On the basis of this small sample of Vietnamese liver cancer patients, the following suggestions could be considered:

- Liaising with Vietnamese community medical practitioners to discuss ways of supporting doctors and specialists to ensure patients receive adequate levels of information about living with liver cancer and its treatment.
- A review of Vietnamese language websites for people with liver cancer, and subsequent collection of URL addresses of the best site(s) for dissemination via Vietnamese media, community family doctors and liver cancer specialists.
- A review of translation services for Vietnamese people with an aim of publishing a directory online and in the Vietnamese media.
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Bibliography:


