

Head and Neck Support Group, Auckland City Hospital

9.30, June 4, Domain Lodge, Minutes

On a bleak winter's day, there were 18 people at the meeting, three staff and 15 patients/caregivers. The topic of the day was the psychosocial effect of head and neck cancer but before our speaker arrived we introduced ourselves and met two patients who haven't attended for a long time, Peter Smith and another Peter whose surname I didn't get. Noelle is going to follow up some more on the Laura Ferguson exercise classes and will send out some info on this. Alan provided us with name stickers!

Sandy Cavell, health psychologist at the ORL module at the Manukau Superclinic, was our speaker today. Sandy has conducted a lot of research into the psychological effects of this cancer, including into "unmet needs" and "benefit findings". Sandy barely got through her slideshow by 11.45 because there were so many questions and comments. I have a printout of the slides if anyone wants me to send them on. This month I'm going to try to summarise rather than writing down everything said.



There is no dedicated psychologist for head and neck patients at Auckland Hospital. Counties Manukau is fortunate to have Sandy. One bright light is that all hospitals will be audited in future against the new National Standards for Head and Neck Cancer. The Ministry of Health will have to provide funding for more psychologists. We should have one at the Multi-Disciplinary Meeting.

We discussed the tendency of patients to get depressed six months or a year after treatment. The attention is off you and you realise this is how it's going to be. Another factor is social isolation.

If partners are also given attention, patients do better. People can go through the grief cycle after diagnosis but when you get to acceptance, coping is easier. **Acceptance is a powerful position to be in.** Sandy is setting up an Acceptance Commitment Therapy group at the Manukau Superclinic. If anyone is interested, they can contact Sandy at sandy.cavell@middlemore.co.nz.

"Benefit finding" is a concept that drew some gasps of disbelief. How can you get any benefit from having this cancer? However a number of people say it's made them a better person; they've realised the importance of relationships; they're more patient. One of our group said that cancer is "a filter of things that are important and things that are not". Sandy has had one of her articles about this published in a medical journal. Here is a link to the abstract: <http://www.ncbi.nlm.nih.gov/pubmed/25634065>. Once again, I have a copy of this if anyone would like it. (Thesis findings in an Auckland Head and Neck Outpatient Clinic in 2009 showed that 90% experience some benefit and 60% more than three benefits. It is related to active coping and optimism. You can still experience negative effects.)

What about anti-depressants? Sandy said that people need to be monitored from diagnosis and through treatment. Medication is useful.

Why does head and neck cancer have higher distress rates than other cancers? It's more visible. When speaking is a problem it's hard to vocalise your feelings. The social side is also important and as mentioned before, people can become isolated. We are social animals. We need to SCHEDULE social activities. It's very hard to explain what is wrong to a stranger but each individual has to find a way.

Quality of life is an interesting issue. The definition of QoL is "a state of complete physical, mental and social wellbeing not merely the absence of disease or infirmity" so is not directly related to physical health and function. There is often an improvement in QoL one year post-treatment and a decline after 10 years. This could be because of the long term side effects of radiotherapy. QoL twelve months post treatment is associated with survival.

Forty percent of patients show signs of depression/anxiety with anxiety more common before treatment and depression after it.

Then we got into the vexed issue of teeth. Someone wondered why we don't have all teeth removed before radiation. Another patient wanted to acknowledge the work done by Green Lane when he lost seven fillings at once.

High rates of fear of recurrence have been reported in studies. High fear of recurrence causes increased distress and hypervigilance. There is a difference between awareness and checking yourself and this extreme fear. Unfortunately getting to five years is no guarantee of a cure. Statistically five years might indicate that the cancer is unlikely to come back but individuals can experience a recurrence after five years. Belonging to a support group can release some of this stress.

What are the best coping strategies? Most effective is active engagement not avoidance and denial. "Active coping" is related to higher QoL. "Denial coping" is a strong predictor of future health anxiety. **More effective coping is related to lower depression and anxiety, higher benefit finding and better health status.** Active coping means active engagement with the problem. "Dispositional optimism" comes in handy here as well. We didn't have time to discuss this. Something to think about.

Perceptions of the illness can be inaccurate and affect active coping. Self-blame is not helpful either because life is very much random. Denial on the other hand can lead people back to smoking and drinking. "Mindfulness" is a useful idea: being fully in the present.

Patients from some cultures believe they have to be staunch, adding more stress. Pain is also a stressor but can be dealt with. Even a patient who does not have a limited life expectancy can be referred to palliative services for pain relief.

Studies show that patients might need psychological support twenty years after diagnosis.

Summary

- The strong need for psychological support for patients and families is becoming more recognised.
- Functional deficits and long term effects of radiotherapy adversely affect social interaction and lower patients' mood.
- Increased research is being done into the psychosocial effects of head and neck cancer.

We always have interesting presentations at this monthly meeting but this one was very engaging and challenging. Many thanks to Sandy for giving us her time.

Other matters

(Mac found this in the Herald on 15 June)

Researcher's brainchild: Restoring speech

Hamid Sharifzadeh is on the cusp of being able to restore the power of voice.

Using data and technology to restore the power of voice is the kind of problem-solving Hamid Sharifzadeh enjoys.

And after six years' work he is on the cusp of completing a project that will do just that.

The computing lecturer and researcher at Auckland's Unitec has developed technology that will help those who have had their larynx removed speak with full voice again.

Dr Sharifzadeh has created an algorithm capable of reconstructing the natural sound of speech from whispers.

He and his team of researchers are close to finishing a device that can be used by laryngectomees - those who have endured a laryngectomy - giving them the ability to communicate with a natural voice after their operation.

When complete, users will be able to speak into a small microphone and their words will be transmitted through a speaker that can be worn on the shoulder or hip.

When spoken through, the tool will take whispers and transform them to full speech, and could replace the existing electro larynx which sounds monotonous and robotic.

"Your voice is a normal thing that everybody has, but even if you have to rest your voice for just a short time you become aware of how important it is," Dr Sharifzadeh said.

"With laryngectomees the larynx is removed, but they keep everything else - the lung, the mouth, the vocal tract, nose and lips.

"The only thing missing is the vocal folds, so they don't have the 'buzzer' that makes the sound of their voice. Our device will take their whispers and make them audible again."