Vivian
The impact of gender on palliative care

Vivian’s origins stems from a plenary I gave at the European Association of Palliative Care Conference in Berlin in 2019. I was asked to speak to the topic: ‘Is palliative care biased?’ It was hard to know where to start. But I decided upon an issue that affects us all. Sex and gender are key determinants of end of life experience, but have been largely ignored within palliative care research, practice and policy to the detriment of both women and men. This bias is all the more powerful in being largely unconscious and almost wholly invisible.

The result of constructing research participants, and research concerns, as gender neutral is that a male worldview has been uncritically normalised and perpetuated. I was unaware of quite how pervasive this trend was until I started to scope the literature where I found evidence of male bias throughout the whole continuum of research from ‘bench to bedside’ with negative implications for us all, whatever our gender identity.

In my presentation I wanted to initiate a paradigm shift in how palliative care as a discipline thinks about gender. In particular I wanted to ensure greater critical attention to how societal expectations of femininity and masculinity determine end of life expectations and experiences. I wanted people who pick up a research paper to critique it for a gender perspective.

Ultimately I wanted us to talk about the fact that most family carers are women, it is less known that women carers experience greater physical and psychological impacts from caring than men and are more likely to be living in poverty. These are all conversations we need to be having if the goal of palliative care – to improve quality of life for all – is to ever be realised.

Inspired by Māori purākau

Yet how to persuade an audience of 3,000 comprised predominantly of clinicians that gender matters? We found our answer in Māori purākau. Purākau are a traditional form of Māori narrative that serve as a vehicle for teaching and learning. More than mere myths or legends, they were (and are) vital for the transfer of knowledge, values and wisdom. In a similar vein, we created Vivian as a story that is imbued with knowledge gained from our research and the broader body of palliative care literature. While Vivian is no woman’s particular story, she represents how gender can affect every woman. Vivian also foregrounds the values of the Te Ārai Palliative Care and End of Life research group – that individuals and their families/whānau are the true experts regarding palliative care and clinicians would do well to listen to them.

Thank you

It was Victoria Egli’s brilliant idea to refashion Vivian as a graphic novel (for the EAPC conference the story was presented as a recorded monologue). Her creative insights, enthusiasm and remarkable op-shopping abilities for sourcing costumes fuelled the project. Lisa Williams provided editorial guidance and served as the project coordinator; as always, her ability to help turn our research findings into creative outputs was vital.
I'm not one to complain but those last four years with my husband Jack were hard.
One year before...

Is that appointment today?

Did I remember to give him his tablets?

This is taking too long...

Vivian!

He has to go into a home

You can't cope anymore...

I'm fine.

I'm so exhausted. I can't do this anymore.

I promised him he'd die in his own bed. I failed him there. A wife looks after her husband.
Tending Jack, I neglected my own health, and so I guess that’s what got me into this mess.

Your GP, Dr Wilson, retired. You’ll have to see someone new, dear.

Don’t call me dear.
Maybe I downplayed the pain too much because the GP wouldn't refer me to a specialist.

er...uhh... I'm having a bit of trouble passing water.

What? Urinating?

It'll just be your age. There is no point referring you. They won't do anything about it.
You alright, lass? Is there anyone I can ring?

No, there's nobody... I'm fine.

Old people.
I’ve just moved in next door, I had no idea she was so unwell.
You have bladder cancer. There is nothing we can do. We'll send a palliative care nurse to you at home.

Thank you.

What's palliative care?
My sons have busy lives. They live far away. I don’t want to be a burden.

Is there a family member I can ring? They are sending you home today.
I'm sorry the biscuits are not homemade.
Here's everything you need to know about ACP.

Now, let's start with what your main concern is at the moment. Pain?

I'm just tired all the time — even more than usual.

Actually, it's money... with winter coming on, how will I afford the heating bill? Can't say that.
I'd like to die at home. But who is going to look after me?

Where do you want to die?

An Advance Care Plan is very individual. You can write about anything that would make your care more comfortable, such as where you would prefer to be looked after and by whom.

- Appointing someone to make decisions for you (Lasting Power of Attorney)
- Specifying treatment you would or would not want

Least I’ll be warm in the nursing home. No more cooking and my sons won’t have to worry.
At the retirement village...
thank you