

Palliative Care, Health Literacy, Maori Communities Health Services Study

Te Puawaitanga, o te hinengaro mo te tangata

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 THE UNIVERSITY
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NEW ZEALAND
Te Whare Wananga o Tamaki Makaurau

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Te Puaawai tanga, o te hinengaro mo te tangata

- Waipuna Hospice, Tauranga
- Hospice Eastern Bay of Plenty, Whakatane
- Hospice West Auckland
- Mercy Hospice, Auckland

- 10 Focus Groups
- 6 Key Informant Interviews
- 15 Patient/Whanau Interviews

Health Literacy

- “When you go to the initial assessment you have a big envelope that has got stuff about the hospice and their rights and everything you can imagine. I don’t think it gets read.”
- Interviewer: “How do you know when she didn’t understand stuff or when did you know you had to explain things?”
- Whanau: “Because she just used to sit there and smile. [laughs] And agree.”

“...we support whānau in terms of navigating their options in a way that maintains their mana.

And in a way that provides an opportunity to whānau to actually look at what are the choices that they make.

And part of the choices, an informed choice, is actually ensuring that they actually have information that's delivered in such a way that they can comprehend that, they can apply those options to their world view, and to their whānau context and what's actually happening, not necessarily to themselves – they'll always think about their whānau.”



“The difference between what we say, between spoken and what is written and what is understood and how people grasp what that actually means for them and their family.

Especially around end of life because it is such a big emotional event that getting past the emotionality of that is having enough head space to think about it.

So health literacy is just what we live and breathe . . . whether we think about as a concept or not.”



“the people from hospice came out and explained [to the whānau] what needed to be done and what I found was the fact that they showed them how to handle the patient, what to do, and how they should be treated and even how to wash them, and they took all that in and that helped my family heaps, it was fantastic.”

What happens when whanau come into palliative care?

- Confusion about the meaning of palliative care, hospice, end of life care
- Fear of the unknown
- Resistance and putting it off
- 'a place to die'
- When is the right time?
- Belief that hospice will hasten death
- A place of respite
- Letting the whanau have a rest
- Prior knowledge creates comfort with the decision

- “I was the odd one out. The Maori. They do look down on you”
- “Well you know, when I was growing up, we had to take a plate, whether it be a bread and a butter . . . And that’s the thing. I think Hospice has got to let them bring what they want to bring, instead of saying ‘Oh no no, it’s alright, they’ve got it all here’. That’s not the issue. The issue is, this is something I brought to share, but . . .”

- “We have a big family, like lots of grandchildren and stuff – like they didn’t mind us all being there . . . You didn’t feel like that, oh, you’re not allowed to go up there”
- “The good thing about it is that they had this whiteboard and it told you who was on . . . We could talk to any of them about if we had a question or anything . . . And the thing about them was that they were quite straight up with you . . . So you can sort of prepare yourself. Even though it was scary, it was still good”

- “...we’re interested in who they are, not just their disease”
- “I saw the same patient yesterday and I spent, it would have been like four hours at their house and getting this rapport and then today I was there for ten minutes. They figured out the driver, most patients I have to do that every week, they were just like managing and because there was just so much whānau, it was full of women, beautiful women and they just all want to know how to work it and it seems that once the trust is there, you are fast and efficient.”

Does the ethnicity of staff and service matter to whanau?

- Respectful and knowledgeable Maori
 - “the richness of connection”
 - “they spoke Maori to him, and that was just major”
- Respectful non-Maori
 - “she was just an angel”
 - “really, really lovely, really informative”
- Disrespectful from any cultural origin
 - Maori not using whanaungatanga, being pushy and over-familiar
 - non-Maori being clinical and judgmental, “sterile”

- “I can’t do that, all those Māori pronunciations and things very well, but I can still love and I can still do that really good and as long as I’m genuine, then that’s all I can work on.”
- “I think, to me, that translates into slowing down and acknowledging to myself that there is going to be more time required to get to know [them]. The things that are already known and don’t need to be spoken when you share a culture . . . you need to have the time to develop some stuff and it is about us getting to know and about standing still quietly and you know, being known.”

What do palliative care providers do that helps and hurts whanau?

- Helping:
 - Providing resources
 - Teaching and affirming whanau care activities
 - Always turning up
 - Being a person, rather than a robot
 - Advocating and explaining
- Hurting:
 - Lack of information
 - Inaccurate information
 - Inconsistent information
 - Not listening to whanau experience and knowledge
 - Being impersonal
 - Inadequate care
 - Lack of informed consent

“He’s going “Help me.” . . . And then we said, . . . “Give him morphine.” And [the nurse] said, “The doctors won’t give him morphine.” And that’s when I realised that [DNR] wasn’t about [not] reviving him; it was about that they wouldn’t assist him if he couldn’t breathe. That’s a whole different scenario.

And he didn’t know that. I didn’t know that either.

All the time we were told that this would be a peaceful passing, and it wasn’t. And it wasn’t. And I watched him and I watched this poor nurse who didn’t know what to do. . . He was mouthing “Help me,” the whole time. . . And I realised then that they knew that this was going to happen.

The next few days at his tangi we just couldn’t get that image out of our mind, the agony”

“I was really quite upset that they had done that to Mum, and what they don’t understand is that like mum and all them, they looked forward to going . . . And it wasn’t just about like what they got, but it was like mixing and mingling. . . I was thinking god mum had more of a social life than me, because she was always bloody darting off here and there sort of thing eh? But like after she finished . . . she went sort of downhill”

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- “Not having enough time, if you are in a rush, I think it does worse than good. It shows you have no respect for that person.”

Navigators

- “I was trying to take notes and then [the navigator] just took my book and she just - so I could listen, she did all the notes for us and I really appreciated that. And by the time I got my book back she had all the phone numbers in it, she had everything I needed, yeah.
- “She was always keeping a step ahead of us. Like she knew what questions we didn’t know to ask, and she knew that soon we would be needing certain services . . . so that they would contact us or she would give us the information and we would contact them. . . She was saying, “Do this now, don’t wait till it gets worse, so that you’ve got a rapport with these people before you need them.”

What do whanau need to know about palliative care, and how do they find out?

A new language and set of skills about

- Illness
- Medications
- Equipment
- Procedures
- Home care
- Staff roles
- Building access
- Transport
- Funding
- Infection control
- Nutrition
- Terminology
- Support services
- Grief
- Loss
- Whanau dynamics
- Wills
- Advance directives
- DNR orders
- Bodily functions
- Sick leave from work
- Respite care
- Hospital schedules
- Referrals
- Bedsores
- Pain assessment

“It has been hell. I didn’t know what palliative care meant - I guessed it meant dying but what does it mean?

No one explains anything, they give you pamphlets. But no one says this is what this one does and this is what this one does - hospital, GP, public health nurses, district nurses, hospice, chemist ...

And most important, what they don’t do - oh we don’t do that. Well who does and how do I find out about that and who do I have to talk to about them and when and where? ...

There is so much information and it is so confusing”



“We had a big folder where if you asked us for any medical records, anything, prescription slips, we got it all organised in tabs. So what do you want?

So we were trying to get [the doctor] to – don’t talk to us like we’re idiots – talk *to* us and explain to us what you’re looking at.”

- So I started writing down and I think I looked at the time and I wrote down the time and he goes, ‘Oh, what are you writing from me? You make people nervous when you write’. And actually I had that said to me by about three people at the hospital. And he goes out and he come back in and he goes, ‘Oh, it’s 2 o’clock now. I’m having my lunch. Do you want to write that down too?’

Self-informed care

- “There are times when I do listen, when a doctor makes sense to me”
- “They used long words and didn’t explain and so I would try and remember what it was and write it down and then look it up on Google on the laptop the older kids gave me every night”
- “I kept a diary every day of what the doctors and nurses said . . . I needed to do that to make sense for me and my family”

What are whanau saying now?

- “I’ll never ever feel below a nurse or a doctor. They don’t know all the answers. They’re not there 24/7 with your family member and they don’t know as much as you do”
- “I would have asked a few more questions . . . I probably would have been a little bit more assertive”

“Our doctor never rang back, and this is one that we have a personal relationship, never rang and followed up to see what we had done. Here’s us saying, “He’s not breathing, he’s not breathing,” and [he] never rang us personally or his nurse and I just kind of - I was disappointed, yeah.

I thought at least he would have rung back to say what have you - did you call an ambulance? What have you decided?”

- “And look at now [if] anything happened now, I go and Google it eh!”
- “When my mum passed away, my mum’s sister ended up getting cancer too, so I passed [my note] book on to my cousin saying, “Take notes from here cousin, so that you know.” Yeah, I gave all those to my cousin.”
- “I’ve been able to do the same now for my brother-in-law and his family, too . . . So it sort of paid off”

What are the service and workforce issues for palliative care staff in relation to health literacy?

- Hospice being a self-identified “white, middle class, female organisation”
- Recruitment and training that doesn’t support cultural diversity and competence
- Poor links to Maori communities
- Focused on cancer and MND
- Inconsistent definitions of palliative care, esp. around life expectancy and associated service provision
- Ambivalence about generating Maori referrals