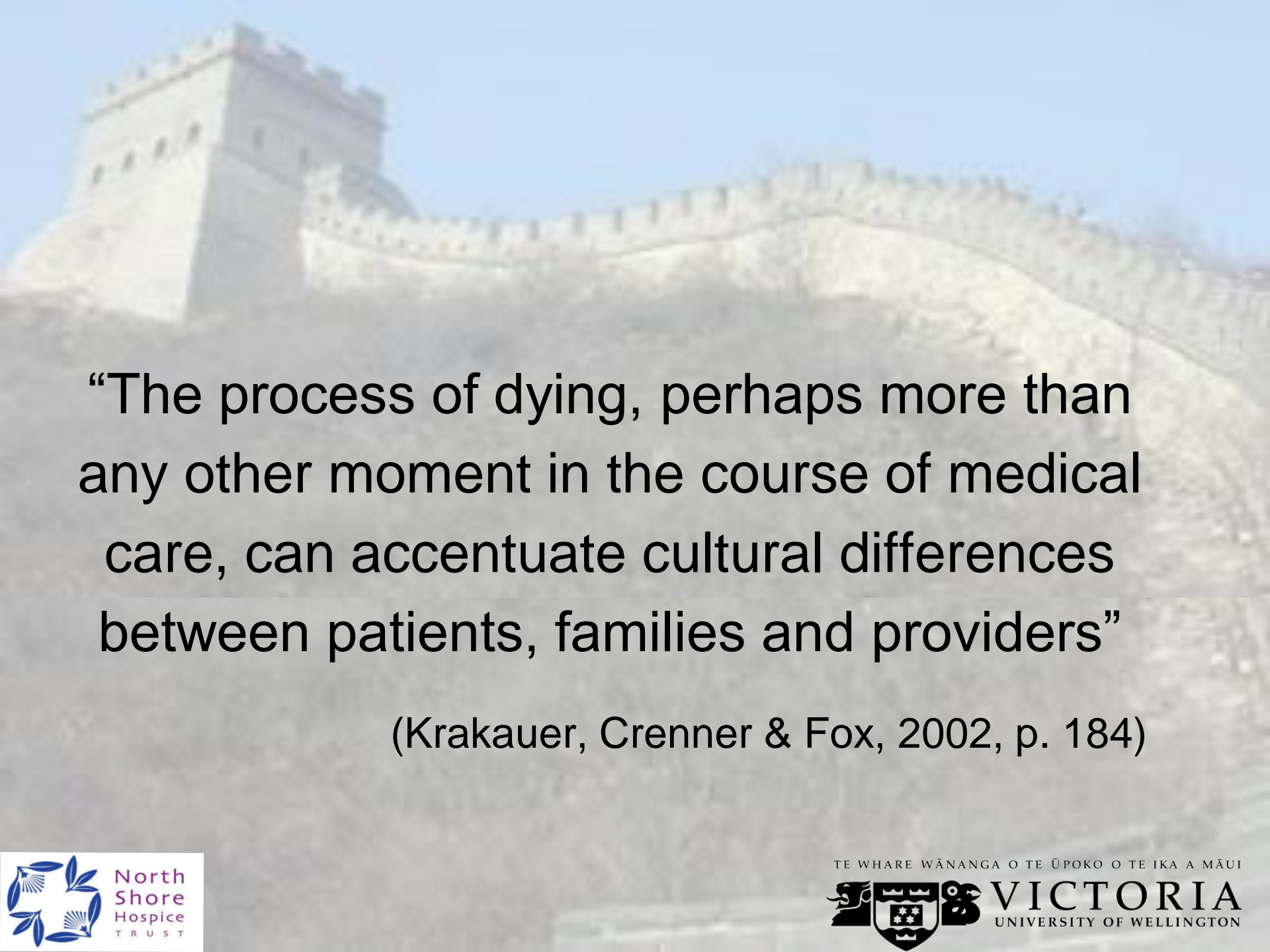




***Over The Great Wall;
Understanding the hospice experiences
and preferences of Chinese immigrant
families in New Zealand***

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“The process of dying, perhaps more than any other moment in the course of medical care, can accentuate cultural differences between patients, families and providers”

(Krakauer, Crenner & Fox, 2002, p. 184)

Why study this topic?

- Concerns from clinical practice:
 - Distressed Chinese patients/families
 - Distressed clinical teams
- Growing Chinese population in NZ
- Chinese community under-represented in hospice referrals
- Service wishes largely unknown

Research Objectives

1. To interview bereaved Chinese immigrants
2. To explore and describe their experiences of using hospice services in NZ
3. To explore and describe their preferences for care at the end of life
4. To identify possible areas for hospice service development

Qualitative Description Methodology

- **Participants:**

- Born in Mainland China, Hong Kong or Taiwan
- Strongly identified with traditional Chinese culture
- Immediate family members and primary caregivers for the patient

- **Cultural Advisor and Interpreters**

- **Semi-structured in-depth interviews**

Family support / Referral / Services / Medical treatments /
Communication / Last days of life / Care comparisons / Improvements

- **Interview summaries returned for checking**

Participants

- 8 interviews conducted during Sept/Oct 2008
 - 7 face-to-face (1 hour on average)
 - 1 over the phone (20 minutes)
- Interpreters present during 6 interviews
- Living in NZ for 5 - 20 years
- 7 cared for a parent, 1 cared for a spouse
- Bereaved for 8 - 26 months (Mean: 18 months)
- Involved with hospice for 1 week – 2 years (Mean: 9 weeks)

Provisional findings

Key themes:

- Unfamiliar territory
- Service experiences and expectations
- Support to cope with terminal illness
- Uncovering sensitive information

Implications for hospice services

All had little or no understanding of hospice services on referral

My family doctor... mentioned [referral to the hospice]. That's the first time we hear 'hospice', we got no idea what's hospice about.

Many wanted more information on referral

I wish next time... they can provide all the information both in Chinese and English to the family, so that they can understand about the service more and they can know what kind [of] services that the hospice can provide. If we knew about hospice service more at the beginning... we have more choices.

Unfamiliar territory:

Misunderstandings were reflected in care decisions

Our understanding is hospice won't allow the family members stay there with the patient. We don't know if he stayed in hospice, can we stay with him?.... So what I do is just not send him here because we think about maybe... some moment he passed away [and] we don't know.

Staff's lack of knowledge of Chinese customs lead to distressing situations

When the nurse came, she didn't take her shoes off... Chinese like to take their shoes off when they come into the house. This is different with local people, we understand.... Why I felt so angry, it's because, step on the carpet is fine, but my father had a blanket under him and she even step on the blanket!

Unfamiliar territory:

4 declined in-patient unit admission due to the inappropriateness of the hospice setting

Because hospice is a hospice, you see people dying maybe every day. This makes your emotion not good.... Because hospice means the life there will be very short... this makes things difficult... instead of get these patients to the hospice... I think rest home is better.

Patients and families had expected hospice to provide more medical treatments

Before he die, probably feel [hospice] can do more... My father cant breath at the end... and I feel have [hospice] got any oxygen things for him?... But they say they haven't... and we always confused on that... my father really feel that he should have something happening.... not meaning that he getting better, probably he expecting getting much more easier for his life.

Service experiences and expectations:

Service
experiences
and
expectations:

Deaths at home were unexpected and families were concerned about symptom management

To be honestly, he is expecting he dying in a hospital. He never expecting he die at home... we never talk about it, die at home, before.... no one will tell you how far away he got.... we vulnerable on that night... his whole body just like everywhere is not comfortable... he feel he wants some more [morphine]... and I said "no don't overdose"... and I am so confused at the end.

Most preferred admission to an in-patient setting for the patient's last days

Only maybe last three or four days... [if] nobody can handle this, then the hospice seems the best place.... But no matter passed [away] at hospital, rest home or hospice, there's no difference.... Home is different... At home, you might face this [bad memory] every day... and you need to think of your future and if you keep thinking the bad things... makes your life unhappy... That's nothing helpful.

Most did not access hospice support services

Probably because of the language barrier, [hospice] didn't provide [emotional support] service to the patient.

All had wanted more psychological support from hospice

No one in this world can deal with this kind of illness.... so that's why they should help the patient to build up their mind.

Support
to
cope:

Maintaining the patient's hope was a key component of a 'good death'

For my father, the hope is the only thing makes him, you know, happy every day. He hope he can recover, he hope next year he might come back to China to visit some friend, why don't we keep this hope? These are happy hope. Then, he go to another world with this hope.

Clinician's interactions with patients can greatly influence hopefulness

I think the only thing the hospice can do is that they have a nurse to visit... this makes my father happy because he build up some confidence... said "look some doctors come every day to look after me and talked with me and say oh you are good, today is very good, and you know this is pretty normal, today I'm good" That makes today happy and next day they come again "oh look, you are still very good".

Support
to
cope:

Most preferred that patient's were not told of their terminal illness directly at the time of diagnosis, to minimise further harm

Since doctor wants to tell patient the truth and on the other hand they didn't provide this kind of service like counselling or other kind of services to support their emotional change, so what is the point to tell them the truth?... Because there is no solution for treat it, it's better don't let patient know... because my mum is very sensitive and if she's crying, it will be worse.

Significant consequences of direct disclosure

After he got this news from doctor, he took sleeping pills, large amount of sleeping pills twice.... because he thought there is no hope left for him.

Uncovering sensitive information:

No intention to withhold information permanently

Family... will find the right moment to talk about this to the patient... we always find the right time... and talk about where you want to bury... and in our culture what kind of clothes you need to put on the day you die and you wear the Chinese old fashioned kind of clothes on your body or the European way, the suit and tie and like that, we got a lot of things to talk about but we know what's the best moment to talk about it.

Most important message for health professionals:

Talk with their family first, to find more information, then get the right answer how we discuss with the patient, which way is better.... Very important things is, get best communication, understand what you can say, what you best not to say, this is first priority.

Uncovering sensitive information:

Take-home messages...

- There is a need for more emphasis on psychological support and maintaining hope by hospice services
- It is important to involve family in all aspects of communication and where possible speak to the family first

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The two hospices accessed for recruitment