



# Optimising the Patient Experience

Conferenz Novotel Ellerslie 21<sup>st</sup> May 2014

# My story

2003-2008 PhD Thesis Ethnographic study of patient experiences with limited prognoses; from diagnosis to death

Late 2008 Diagnosed with Invasive ductal carcinoma 25mm Grade 2 tumor

2008-2009 surgery and treatment over Christmas

2011 Shoulder replacement surgery (pyrotitan shoulder)

14 operations in 25 years, so what do I know?

# To be ones own ethnographer is no easy feat

*I'm aware that I feel as if I am moving through silence, the whole world feels like it is shut out from this experience. I feel a sense of vulnerability around people and I notice I avoid eye contact. I feel as if everyone who looks at me knows I have cancer. I feel like I am removed from the world that I am moving in.*

# Breaking bad news

*I do the work I have to do in between thinking about how to tell my family. I think about how I am going to tell them and how they will feel. I feel that I am inflicting this cancer on them, that somehow they will also be inextricably altered by this news. This will now be about them; this will be something that is happening to them, even though the cancer is only in my body.*

## I would have liked...

- ...that I was believed when I said that I knew I had cancer
- ...that my doctor was straight up with me about my diagnosis
- ...that no-one offered to hug me as I was not ready for that
- ...that I had more time to process the news before rushing off for xrays and scans
- ...that people speaking about me, spoke to me, and used terminology that I understood



Anatomy,ectomies, oscopies, otomies...





## Sharing Good and Bad

So much of my care was amazing because

I believed that the health professionals looking after me really cared

I had total faith in my surgical team my oncologist and radiologists

My family and friends wrapped me in a big cocoon of love

No-one ever told me I couldn't do something, like go to work or carry on as if my life was somehow normal, even though it wasn't.

The care I received when I was diagnosed with cancer was the best care I ever received as a patient!

# The not so good

When I say I am in pain and you don't believe me

When I tell you what my experience is and you deny it

25 locals in my face and fifteen in my neck because locals don't work on me

breast biopsies that are so painful because you don't believe that locals don't work on me

waking up in an operation because I could feel what was happening to me and when I tell you, you don't believe me

Telling you I cant walk and you say yes I can and then I pass out in the hallway and bang my head

When you just don't listen because you think you know more about my experience than I do



## Treat me as if

I am your best friend

I am your elderly Grandmother (the grannie test)

I am someone you might need one day

I am the person who will determine if you get a Christmas bonus or pay rise

Treat me with respect & tenderness

Treat me as a spiritual being

Treat me as if I am momentarily fragile, not broken

Treat me as if, in this moment, I am more important than you.



# Resources

**Hughes, C. R.** (2010). *Palliative Care in Context: An Ethnographic Account of the Journey from Diagnosis to the End of Life*. Ph.D. 358 pp. University of Canterbury, Department of Social Work and Human Services.

**Hughes, C.R.**, vanHeugten, K., & Keeling, S. (2014). Cultural meaning making in the journey from diagnosis to end of life (ASW) *The Australian Journal of Social Work*. (In Press).

Cottle, M., **Hughes, C.R.**, & Gremillion, H. (2013). A Community Approach to Palliative Care: Embracing Indigenous Concepts and Practices in a Hospice Setting. *Journal of Systemic Therapies*, 32 (1) .

Dr Catherine Hughes

BSocP Programme Leader and Senior Lecturer

Department of Social Practice

Unitec Institute of Technology

Email [chughes2@unitec.ac.nz](mailto:chughes2@unitec.ac.nz)