



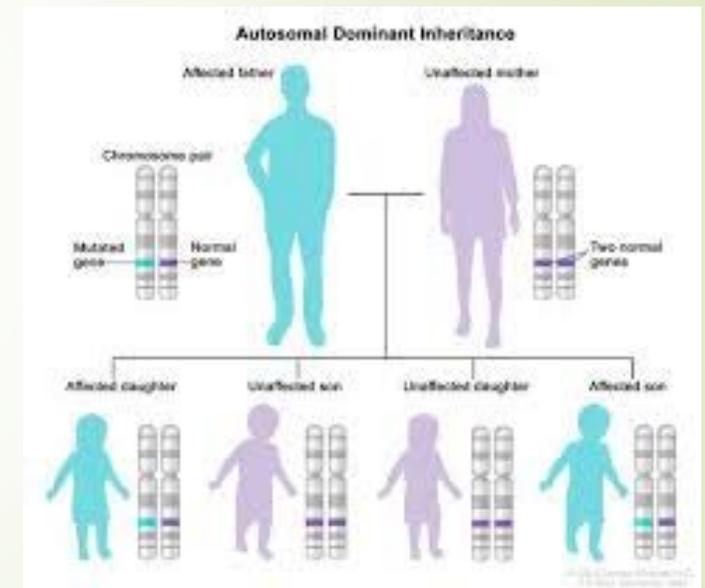
The experience of hereditary diffuse gastric cancer: Desiree's story

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Hereditary Diffuse Gastric Cancer

- ▶ Autosomal dominant
- ▶ 56% risk of stomach cancer by 80 years of age for women if gene positive
- ▶ Average age of onset = 38 years
- ▶ Women also predisposed to breast cancer (42% risk)





Just watching her die, it's really hard watching someone die, wasting away. She used to get the hymn book and rub it all over her, because she thought that would save her. I remember her arms and legs were so skinny....



Vulnerability



The Cloud

“He then explained it was because the Huntington’s Disease ‘cloud’ that was hovering over him had consumed so much of this thinking in the last few years. The idea that he could lift the cloud one way or the other was then what eventually brought him to having the test.”

(Cox, 2003, p. 265).

Hamilton & Bowers, 2007

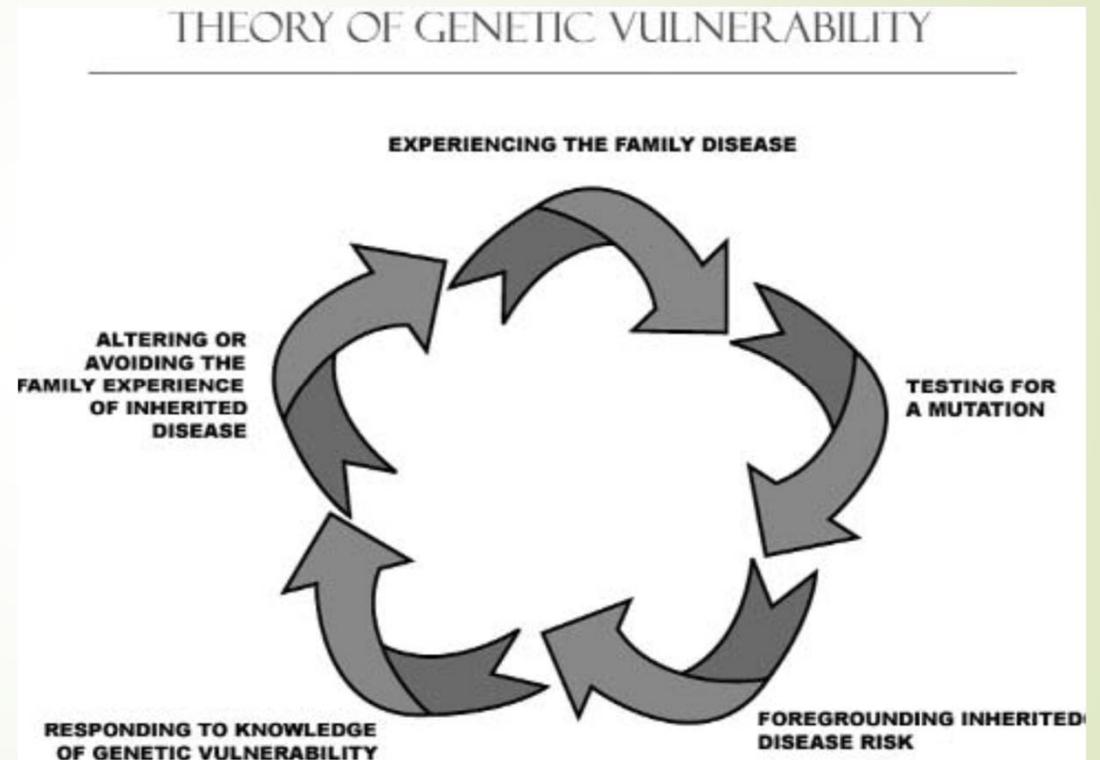
Hereditary non-polyposis colorectal cancer

- ▶ “bad blood in the family”
- ▶ “like an assassin hiding in the attic with a dozen different ways to kill you”

(Grierson, 2011)

Hereditary breast and ovarian cancer

(Norris et al., 2009)





Factors that affect risk perception

Family resemblance

I thought I was going to be positive. I guess mainly because I look like my dad, I act like my dad, you know like everything about me is from my dad

(Hamilton & Bowers 2007)

Family experience

I watched as one by one, all my remaining brothers were diagnosed, trying to stifle the growing fear from my realising my own at risk status for this disease and knowing I was the last male in our family that had not been officially diagnosed

(Hamilton & Bowers 2007)



I remember when Pauline came to visit me and told me that I could have a blood test to see if I would get the cancer. At the time our family was doing all this research about what was causing the cancer. I thought the discovery was ground breaking. I said to Pauline, "yes, I want to do it". I couldn't wait to have the test. At last I could have some peace of mind knowing one way or another if I had it.



When I got my positive results, I cried, because it reminded me of what happened to Mum and I started to wonder what would happen to me. After that, I did adjust, because I had already thought that I would probably have the gene. I needed to start thinking about what I should do because at the time there was nothing that could be done to stop the cancer. I thought about the ones in my family who survived who obviously had the gene because their children had died from the cancer. I wanted to be like my grandfather because somehow he had lived a long life. I remember that he always worked hard, he didn't drink and he lived a healthy life. I made sure I was super fit and tried to keep stress to a minimum. I know drinking didn't help but I still did some of that, you have to have some release somewhere, yeah, but always that fear, that fear, honestly, I just used to look at my kids and think, well my mum's gone, who's going to look after them? (crying).

Relief and Gratitude





Vulnerability Returns





Conclusion

- ▶ Pervasiveness of the cancer within families
- ▶ Social, emotional and physical impact of the illness
- ▶ Patient centred care

(With thanks to Denise Felix (Registered Nurse) who made the voice recordings in this presentation possible)



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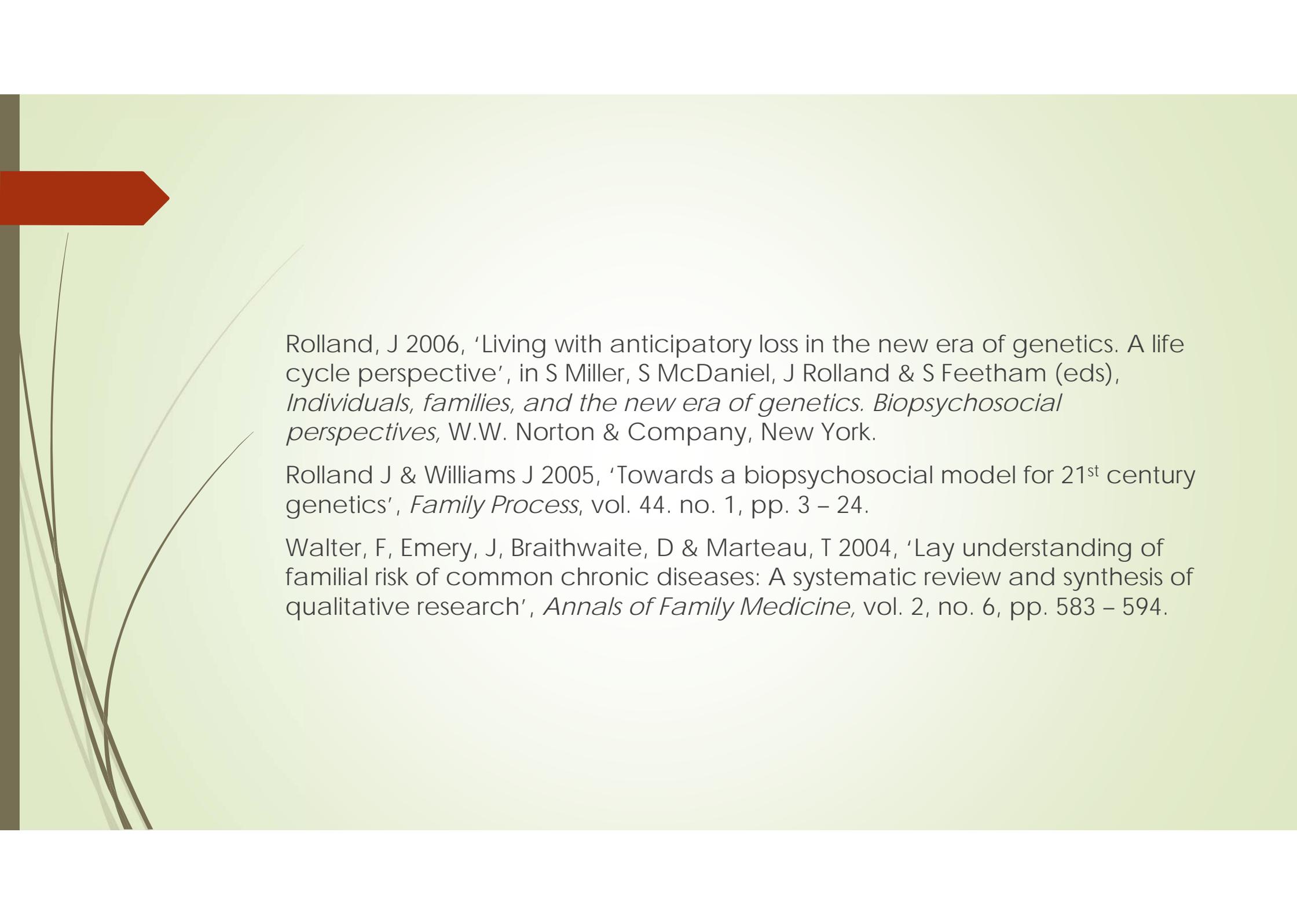
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