FEAR OF CANCER RECURRENCE

Jane Turner

Discipline of Psychiatry

School of Medicine

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"The fear, concern or worry that cancer could return or progress"

Lebel et al. Psycho-Oncology 2016 **Feb 18.**
doi: 10.1002/pon.4103

EXTENT OF THE PROBLEM

Population-based sample recruited from 2 state-based cancer registries

Data from 1323 survivors 6 months after diagnosis:

- Prostate, lung, colorectal, breast, melanoma, NHL, leukaemia and H&N

Unmet needs assessed with 34-item Supportive Care Needs Survey

37% of survivors reported moderate or high level of unmet need in relation to one or more items

Table 2 Ten most prevalent 'moderate' or 'high' level unmet supportive care needs

Rank	SCNS-SF34 item	Number (%) moderate or high needs	Domain
1	Concerns about the worries of those close to you	192 (15)	Psychological
2	Fears about the cancer spreading	185 (14)	Psychological
3	Not being able to do the things you used to do	169 (13)	Physical/ daily living
4	Uncertainty about the future	168 (13)	Psychological
5	Lack of energy/tiredness	157 (12)	Physical/ daily living
6	Changes in your sexual relationships	140 (11)	Sexuality
7	Changes in sexual feelings	139 (11)	Sexuality
8	Work around the home	137 (11)	Physical/ daily living
9.	Worry that the results of treatment are beyond your control	128 (10)	Psychological
10	Feeling down or depressed	120 (9)	Psychological

Total number of observations for each item ranges from 1292–1302 due to missing values.

Boyes et al BMC Cancer 2012;12:150

FCR IN CAREGIVERS

Partners have similar (or higher) FCR to patients

One study found 50% of carers had high FCR

Factors associated with high FCR in carers:

- **High FCR in person affected by cancer**
- **Low satisfaction with communication**
- **Poor communication about FCR (blocking discussions, minimizing concerns, avoiding the person, being critical, or expressing discomfort)**
- **Family stressors and illness**
- **Recurrent or metastatic disease**

Zimmerman et al (2011) Behav Med 37:95–104.
Mellon et al (2007 Psychooncology 16:214–223.
Hodges & Humphris (2009). Psychooncology 18: 841-848.
Cohee et al (2015) Psychooncology, doi: 10.1002/pon.4008.

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CONSEQUENCES OF FCR

FCR has been found to be associated with:

- Worse QOL
- Greater distress and general anxiety
- Intrusive preoccupation with cancer
- Inability to establish future goals and plans

FCR also associated with both:

- Over-checking and monitoring for cancer
  - Higher frequency of breast self-examination
- Avoidance of screening and monitoring
  - Not having mammograms or ultrasounds or other forms of screening in the past year

Thewes et al Supportive Care in Cancer 2012;20:2651-2659

FCR appears to persist over time

TRADITIONAL APPROACHES TO DISTRESS

Cognitive behaviour therapy:

- **Aims to:**
  - Help identify unhelpful thoughts and behaviours
  - Develop skills to challenge cognitive distortions, selective abstraction etc.

- **Fails to:**
  - Acknowledge the clinical reality and uncertainty about prognosis
  - Help the person understand the origins of maladaptive patterns of thinking and behaving
  - Help the person respond to existential challenges

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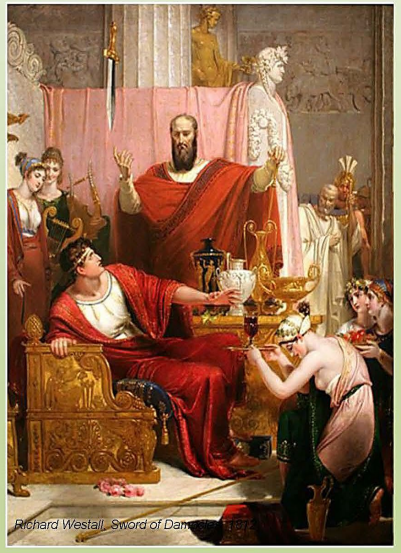
CONQUER FEAR: STUDY AIM

A Psychological and Educational Intervention for Fear of Cancer Recurrence

THERAPIST TREATMENT MANUAL



RCT evaluating the efficacy and cost-efficacy of a theoretically-based therapist-delivered intervention to reduce clinical FCR in cancer survivors vs. relaxation control arm

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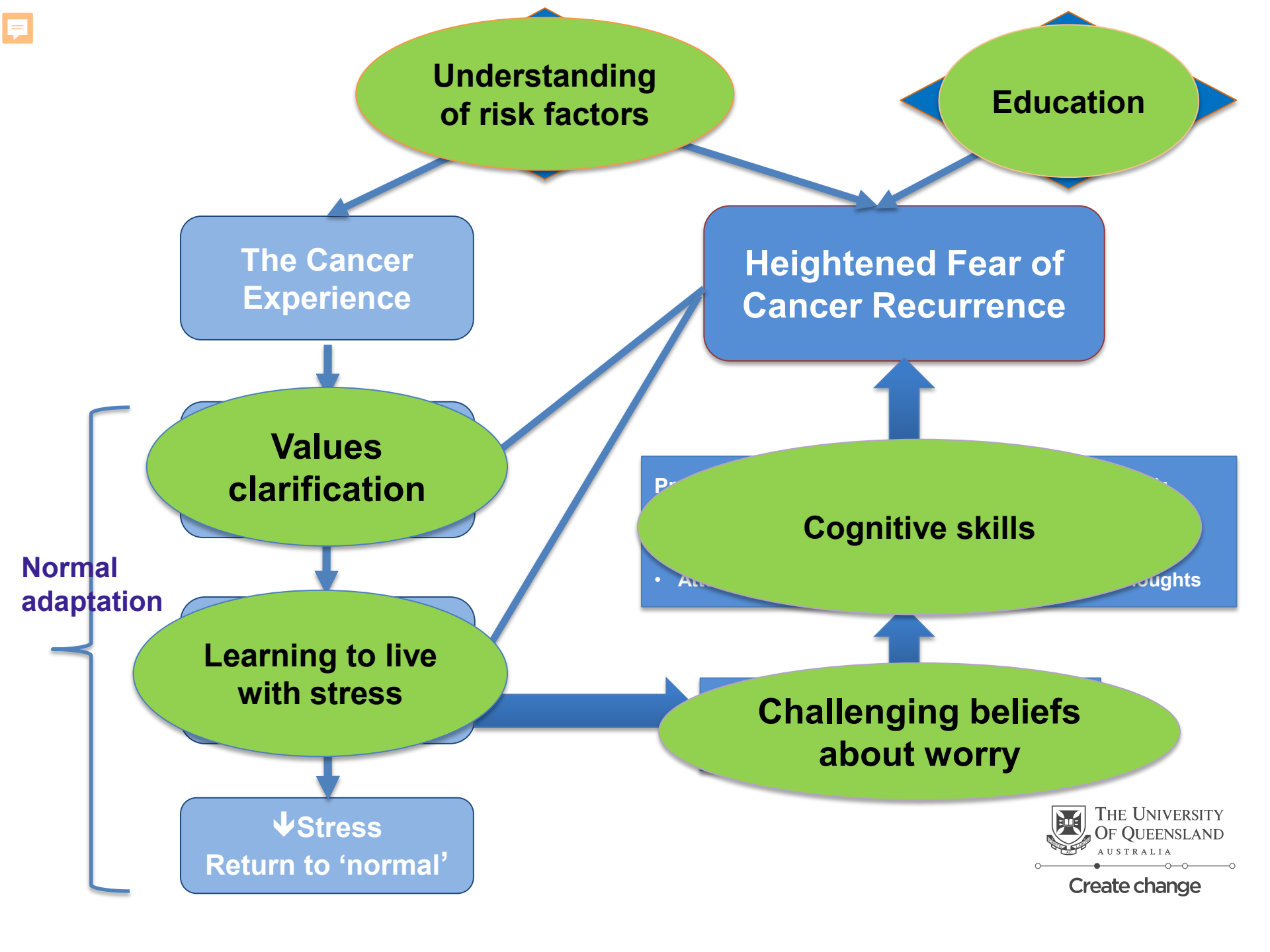
Understanding of risk factors
Education
The Cancer Experience
Heightened Fear of Cancer Recurrence
Values clarification
Cognitive skills
Normal adaptation
Learning to live with stress
Challenging beliefs about worry
↓Stress
Return to 'normal'
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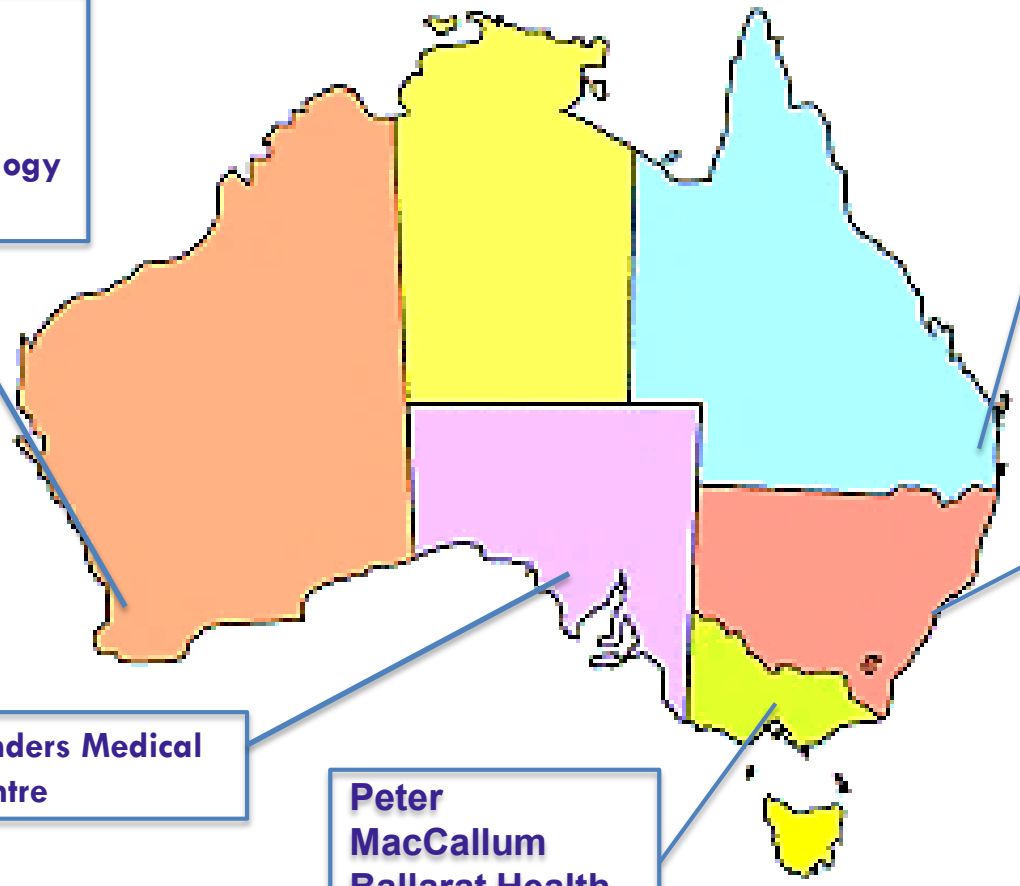
PARTICIPATING CENTRES

26 therapists participating from 17 sites around Australia

Treated on average 15 (3-25) patients each



Fiona Stanley
Royal Perth
St John of God
WA Psycho-Oncology

Royal
Brisbane &
Women's
Toowoomba

Concord
Gosford
Macarthur
Nepean
Prince of
Wales
St George
Sydney
University
Westmead

Flinders Medical
Centre

Peter
MacCallum
Ballarat Health
Services

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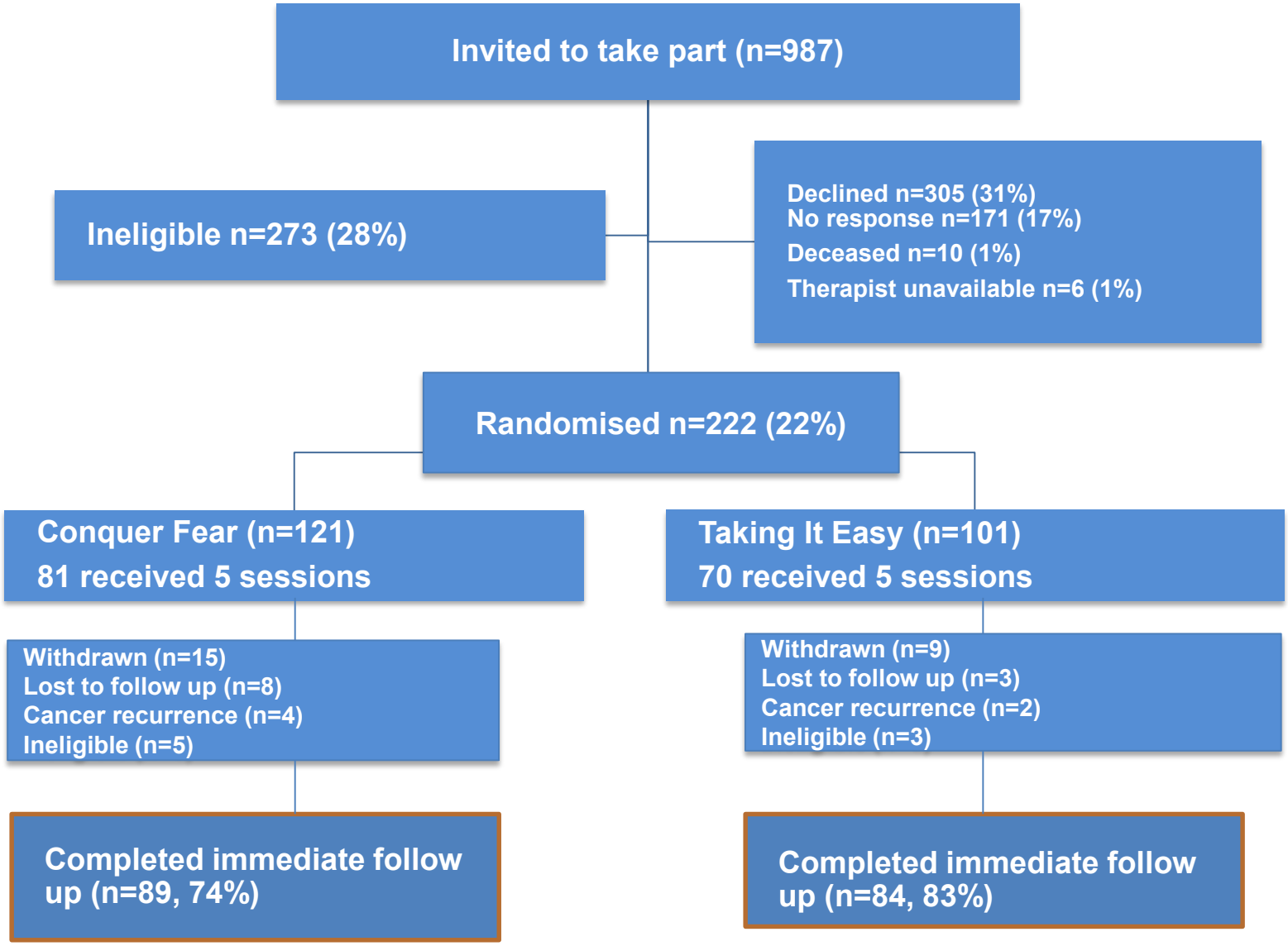
RCT PARTICIPANTS



RESULTS

Participants in both groups improved on all outcomes

Conquer fear > Taking it Easy (relaxation) on primary outcome

- **FCRI total**
  - **FCRI severity**

Conquer Fear > Taking it Easy:

- **Anxiety (DASS-21)**
- **Cancer-related anxiety (IES)**
- **Meta-cognitions (MCQ-30)**

Conquer Fear = Taking it Easy:

- **General distress (DASS)**

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KEY PRACTICE POINTS FOR GPs

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UNDERSTANDING THE CONTEXT

FCR is a rational fear

- **Reassurance does not "make it better"**
- **Additional tests do not provide reassurance**
- **Being urged to be positive (family, community) hinders expression of emotion**
- **It does not dissipate over time**

Developing an understanding of the origins of the concern appears to be helpful

This is the "new normal"

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FCR-SPECIFIC ISSUES

Circumstances of the diagnosis
Experience of treatment
Views about completion of treatment
Understanding of their *objective* risk of recurrence and views of their *perceived* risk of recurrence as a percentage (0-100%)
The exact content and frequency of thoughts about FCR
Degree of bother caused by FCR
Triggers - cognitive, behavioural, emotional, physical
The functional impact of FCR - emotional, physical, financial, inter-personal, on life-goal and future planning

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MEANING AND CONSEQUENCES

Self-examination and surveillance behaviours:

- **Frequency of unplanned or unscheduled medical appointments**
- **Investigations because of concerns about potential recurrence**

What would recurrence mean for this person and those they love?

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“NOT A CLEAN SLATE”

Few people come to a diagnosis of cancer without past experiences of loss or adversity

For many, this has shaped their world view

In response to reassurance or being urged to “be positive”, many people feel guilty or ashamed that they are not “over it”

A formulation allows the person to see the origins of their fears

Not a therapy of itself but can be affirming

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MAKING SENSE OF IT

Francesca 44 years old	Background Issue	Response to cancer diagnosis
	Experienced sexual abuse by an uncle during her late childhood. During her teenage years became "pretty wild" and experimented with drugs and casual sexual relationships. Always felt guilty and ashamed and never told anyone, even her husband Stefan whom she met some years later.	Francesca was terrified that the cancer of the cervix might be "my own fault" because of multiple sexual partners but she felt too guilty to talk about it. Became very protective of her daughters so that they would never be abused. This extended to fear of the cancer coming back which would mean that she couldn't be there to protect them. She did not really think that Stefan would ever abuse her daughters but started thinking that he couldn't protect them the way she could. Because she had never told Stefan about her past, she could not explain her fears to him. Use of "Sleeping Beauty" story.

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LIVING VS. SURVIVING

Cancer challenges our assumptions, thoughts and plans

Can stay "stuck"

Acceptance and commitment:

- **What can be changed and what cannot**
- **Attention to values and goals:**
  - **What matters to me?**
  - **What do I want for my future?**
  - **Where do I currently focus my energy?**
  - **What could I do to achieve my goals?**
  - **Taking an active role in planning and contemplating the future vs. being a "passive recipient of life"**

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THE CARD SORT EXERCISE

Illustrates how we spend time doing things that don't matter and neglect the things that do matter
The person is asked to sort a set of cards into 3 piles

- **These values are not very important to me**
- **These values are of moderate importance to me**
- **These values are of the highest importance to me**

Discuss why they sorted them as they did - surprise at how unimportant some values seem compared to others, and devotion vs. neglect of values

Ciarrochi and Bailey (2008). A CBT practitioner's guide to ACT

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CARD SORT EXERCISE THEMES – EXAMPLES

Engaging in sporting activities	Being curious, discovering new things	Promoting justice and caring for the weak
Engaging in clearly defined work	Having influence over people	Connecting with nature
Striving to be a better person	Being creative	Leading a stress-free life
Feeling good about myself	Experiencing positive mood states	Being sexually active
Enjoying music, art, and/or drama	Teaching others	Managing things
Being self-disciplined and resisting temptation	Having a life filled with novelty and change	Enjoying food and drink

SPECIFIC TECHNIQUES

- Metacognitive approaches
- Attention to threat monitoring
- Information and correction of misperceptions
- Establishing agreed behaviours

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META-COGNITIVE THERAPY (MCT)

Thoughts about thoughts

MCT teaches strategies for controlling worry and dealing with excessive threat monitoring (e.g. frequent self-examination)

- **Challenging value of worry**
  - **Worry is useful, but at set times for set purposes**
- **Attention Training Technique (ATT)**
  - **Turning attention away from cancer-related stimuli**
- **Detached Mindfulness (DM)**
  - **Observing thoughts without reacting to them**

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How do you know that your FCR is harmful?
How long have you been worrying about recurrence?
Have you developed one yet?
What is the mechanism by which FCR can cause cancer recurrence?

ATTENTION TRAINING
(WELLS 1990, WELLS 2008)

In ATT thoughts or inner experiences which intrude into conscious are viewed as 'noise'

ATT aims to give people greater control over directing their attention away from that 'noise' to focus elsewhere

It is important that focusing elsewhere does not mean the person is not aware of their thoughts & inner experiences

ATT is not intended to create a "blank mind"

- In fact, thought suppression has the opposite effect: "Pink elephant"

DETACHED MINDFULNESS

Aim of detached mindfulness is to:

- Teach patients a new way of relating to their thoughts
- Develop a sense of objectivity or detachment from thoughts (self as separate from our thoughts, observer)
- Develop awareness (meta-awareness) of thoughts
- Without being locked-in to thought (suspension of conceptual processing, evaluation, engagement)

Aim of DM is to be able to:

- ✓ Have a thought
- ✓ Be aware of it
- ✓ Do nothing about it (not engage with it)

A *"do-nothing strategy"* (Wells)

Can be used in conjunction with worry postponement skills

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THREAT MONITORING

Threat monitoring (TM) is necessary to identify & manage danger

Key points:

- **Many people who had had cancer become oversensitive to danger cues**
- **This makes some people check more for them (TM) & some people avoid them**
- **Research has shown that neither of these techniques is particularly useful**
- **Uncertainty is a normal part of life – the aim is to live with it**
- **One technique is developing "body awareness"**
  - **This involves checking as often as recommended, knowing changes to be aware of and changing lifestyle factors**

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INFORMATION AND CORRECTION OF MISPERCEPTIONS

- Information about risk may be difficult to interpret
- Goals of follow-up may not be clear to patients
- Importance of moving beyond surveillance to promotion of wellness
- Contribution of lifestyle factors
- Prevention of other health problems
- Stress is part of life!

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ESTABLISHING AGREED BEHAVIOURS

- Clarification of goals of follow-up
- Information about lifestyle issues
- Mutual agreement about surveillance
- Approach to emergence of new symptoms

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CLINICAL ASSESSMENT

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CLINICAL ASSESSMENT

Presence of FCR

- **Do you worry your cancer may come back?**

Frequency of worry

- **How often do you think about recurrence?**

Level of worry

- **How much does this affect your quality of life?**

Level of need for help

- **Would you like help to deal with your concerns about this?**

Cancer Australia. The impact of fear of cancer recurrence (FCR) on wellness: A systematic literature review. Cancer Australia, Surry hills, NSW. 2014.

Thewes et al Psycho-Oncology 2012;21(6):571-587

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FEAR OF CANCER RECURRENCE INVENTORY (SEVERITY SUBSCALE)

0	**1**	**2**	**3**	**4**	
Not at all	A little	Somewhat	A lot	A great deal	
9. I am worried or anxious about the possibility of cancer recurrence ……	0	1	2	3	4
10. I am afraid of cancer recurrence ……	0	1	2	3	4
11. I believe it is normal to be worried or anxious about the possibility of cancer recurrence …..	0	1	2	3	4
12. When I think about the possibility of cancer recurrence, this triggers other unpleasant thoughts or images (such as death, suffering, the consequences for my family) ……..	0	1	2	3	4
13. I believe that I am cured and that the cancer will not come back ……	0	1	2	3	4
14. In your opinion, what is your risk of having cancer recurrence? ……..	0	1	2	3	4

15. How often do you think about the possibility of cancer recurrence?

0	**1**	**2**	**3**	**4**
Never	A few times a month	A few times a week	A few times a day	Several times a day

16. How much time <u>per day</u> do you spend thinking about the possibility of cancer recurrence?

0	**1**	**2**	**3**	**4**
I don't think about it	A few seconds	A few minutes	A few hours	Several hours

17. How long have you been thinking about the possibility of cancer recurrence?

0	**1**	**2**	**3**	**4**
I don't think about it	A few weeks	A few months	A few years	Several years

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