Can you really 'Conquer' Fear of Cancer Recurrence?

Phyllis N Butow, Belinda Thewes, Jane Turner, Jemma Gilchrist, Louise Sharpe, Afaf Girgis, Allan B Smith, Joanna E Fardell, Stephanie Tesson, Jane Beith, and members of the Conquer Fear Authorship Group

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beyondblue

NATIONAL BREAST CANCER FOUNDATION

Australian Government

Cancer Australia

Definition

- **Fear of cancer recurrence** is the **fear** or **worry** that **cancer** could **return** or **progress** in the same place or another part of the body

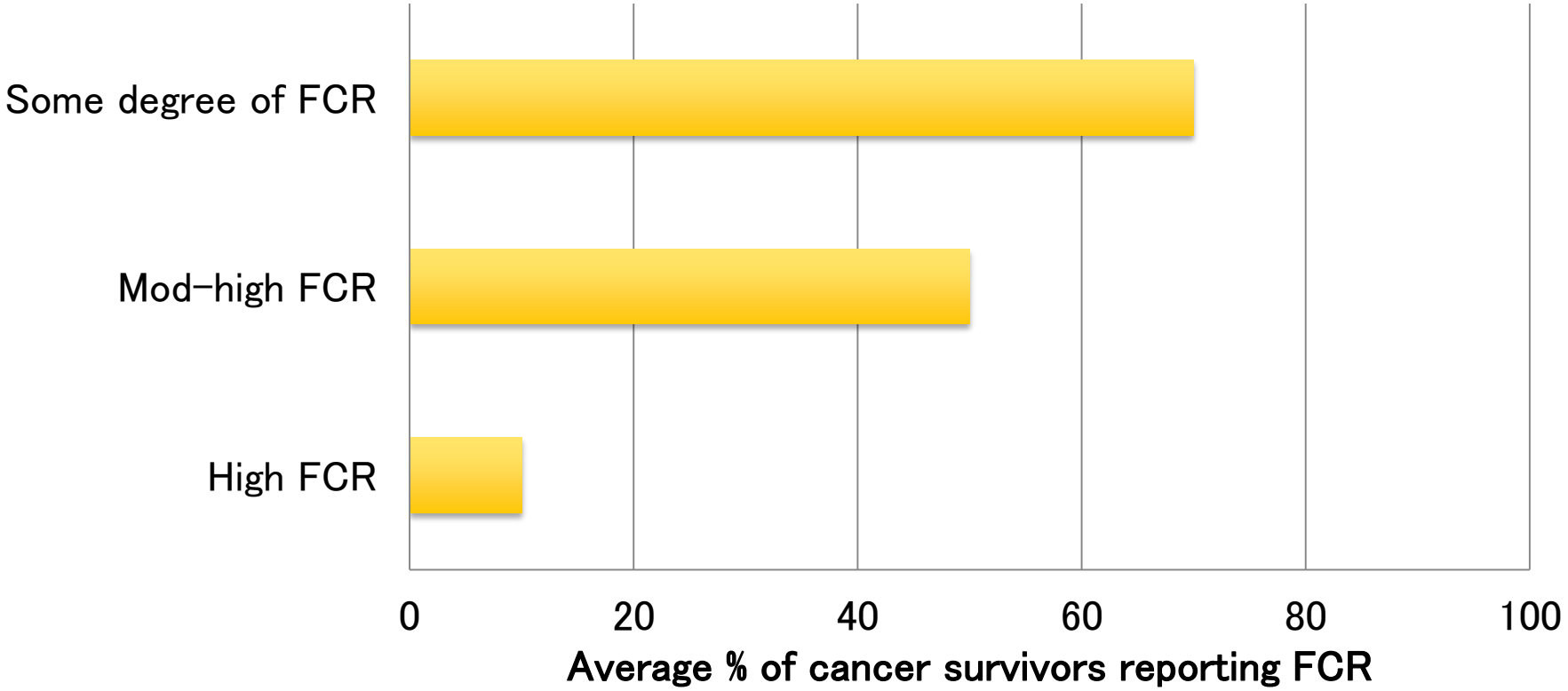
  – Lebel et al, 2016

- Relevant to both early stage and late stage disease

- But mostly studied in the context of early stage disease

Fear of cancer recurrence prevalence

– Patients, survivors *and* carers experience fear of cancer recurrence (FCR)



Does not resolve over time

How does FCR manifest?

- Constant and intrusive thoughts about cancer
- A conviction that cancer WILL return
- Inability to plan for the future (in case cancer interferes)

- Avoidance of, or excessive screening
- Interpretation of symptoms as signs of cancer recurrence
- Excessive visits to the doctor

- Anxiety, distress, feeling trapped
- Poorer quality of life

WHAT IS FCR?

Patient Perspectives

"I hope it is not going to be soon, but one day I think it is going to come back. For most people, once you have cancer then later you die from cancer" (L aged 52 yrs)

"I'm trying to live for the moment, but there are always thoughts lurking" (C aged 40)

FCR: Not irrational

› FCR – not irrational

› Inextricably linked with existential issues

› Goal of therapy NOT to remove FCR,

› but to help people live better with FCR, to give less importance and attention to it, and to develop goals for the future which give their lives purpose, meaning and direction

What factors contribute to FCR?

Treatment and prognosis seem un-related to FCR

- Prognosis
  - 11 studies +
  - 16 studies −
- Recurrence or metastatic diagnosis
  - 5 studies +
  - 4 studies −
- Treatment type
  - Also weak evidence

Simard et al, 2013

Risk perception IS related to FCR

- Risk perception / optimism
  - 8 studies report strong + association with FCR
  - Suggests that assessment and review of **unrealistically high subjective risk** may be a strategy for combating excessive FCR

Simard et al, 2013

Symptoms ARE related to FCR

- Symptom experience
  - 22 studies report strong + association with FCR
  - Global symptom burden, pain, fatigue, body image
  - Suggests that **education about the meaning of symptoms** and those likely related to recurrence may be helpful

Simard et al, 2013

General anxiety IS related to FCR

- Global anxiety disorder, other psychiatric conditions, related to FCR in some studies
- 1/3 to ½ of young women with breast cancer and FCR also met criteria for GAD or hypochondriasis
  - (Thewes et al, Psycho-Oncology, 2013; 22: 2797-806)

- Possibly related to severe FCR
- Probably bi-directional

- **General interventions to reduce anxiety** may help FCR

NEED FOR INTERVENTIONS

- 123 Australian Oncology health professionals surveyed
  - 31% spent > 25% of their time in f/u consultations discussing FCR
  - 46% found discussing FCR challenging
  - 71% interested in more training

UNMET NEED FOR HELP WITH FCR

- Survivors want help for FCR
  - Highest unmet need in survivorship studies
    (Hodgkinson et al 2007, Sanson-Fisher et al, 2000)
  - 2nd most important survivorship research priority in consumer (BCNA) survey (2009) (n=835)
    - (after physical risks for recurrent BrCa)

FCR

So, what helps?

ConquerFear: DEVELOPMENT

- PoCoG established FCR interest group
  - = Team of experienced clinicians & researchers

Preliminary work

- Surveyed psycho-oncology health professionals
- Conducted literature reviews
- Developed a model, synthesising theoretical approaches
- Developed a theoretically grounded treatment and manual
- Obtained feedback on content from Australian psychologists
- Conducted a pilot study to establish acceptability and likely efficacy

Treatment Approaches circa 2012/13

Psycho-Oncology
Journal of the Psychological, Social and Behavioral Dimensions of Cancer
APOS BPOS IPOS

Psycho-Oncology
Psycho-Oncology **23**: 390–396 (2014)
Published online 1 November 2013 in Wiley Online Library (wileyonlinelibrary.com). **DOI**: 10.1002/pon.3423

Current approaches to managing fear of cancer recurrence; a descriptive survey of psychosocial and clinical health professionals

B. Thewes[1]*, R. Brebach[3], M. Dzidowska[1], P. Rhodes[3], L. Sharpe[3] and P. Butow[1,2]

- 141 Oncology HPs (64 psychosocial) surveyed
  - Current treatment approaches vary widely
  - Lack of evidence-based interventions

Theoretical approaches: A review

J Cancer Surviv (2016) 10:663–673
DOI 10.1007/s11764-015-0512-5

REVIEW

Fear of cancer recurrence: a theoretical review and novel cognitive processing formulation

Joanna E Fardell[1,2] · Belinda Thewes[1,8] · Jane Turner[3] · Jemma Gilchrist[4] · Louise Sharpe[5] · Allan 'Ben' Smith[1] · Afaf Girgis[6] · Phyllis Butow[1,7]

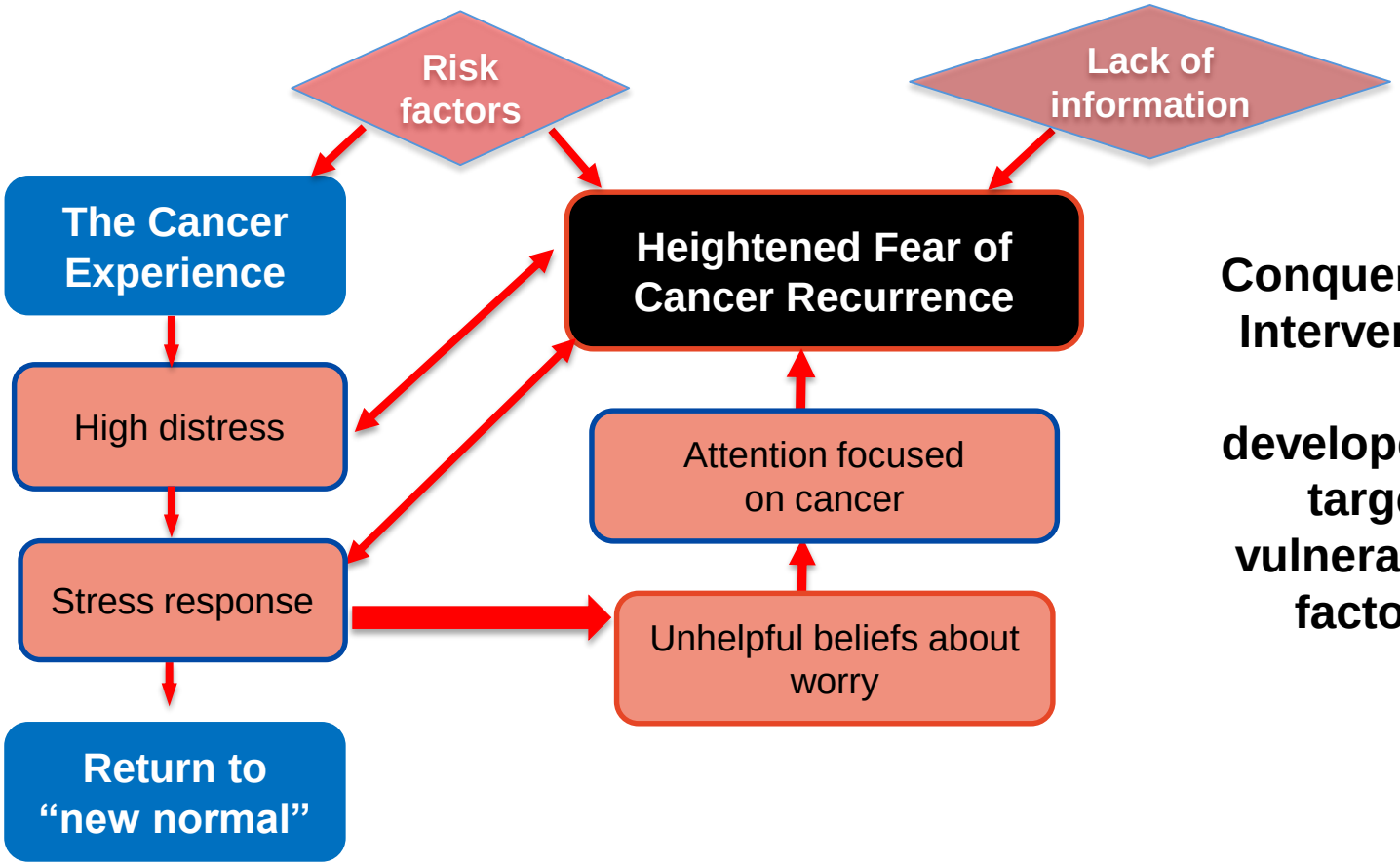
Table 2 Theoretical approaches and their components used to understand FCR

Theory	Number of papers using this theory[a]	Role of cognition and beliefs	Triggers (internal/ external)	Threat appraisal	Coping appraisal	Vulnerability factors	Behavioural consequence
CSM	10	✓	✓	✓	✓	✓	✓
S-REF/MCT	3	✓	✓	✓	✓	✓	✓
RFT/ACT	1	✓					✓
Uncertainty in illness	2	✓	✓	✓			
EPPM	1	✓	✓	✓	✓		✓
PMT	1	✓	✓	✓	✓	✓	✓

Abbreviations: *CSM* Common Sense Model, *S-REF/MCT* Self-Regulatory Executive Function/Metacognitive Therapy, *RFT/ACT* Relational Frame Theory/Acceptance and Commitment Therapy, *EPPM* Extended Parallel Process Model, *PMT* Protection Motivation Theory

[a] Papers do not add up to total sample of papers ($N = 16$) as several referenced more than one theory

Theoretical Model

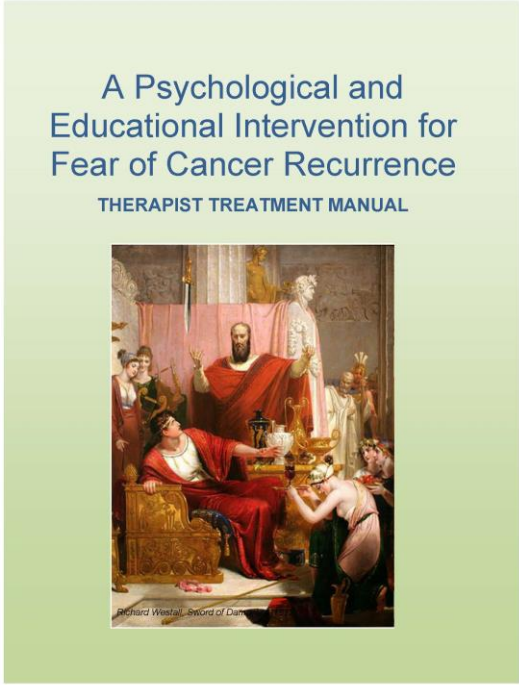


Conquer Fear Intervention

developed to target vulnerability factors

Model shared with patients

Conquer Fear

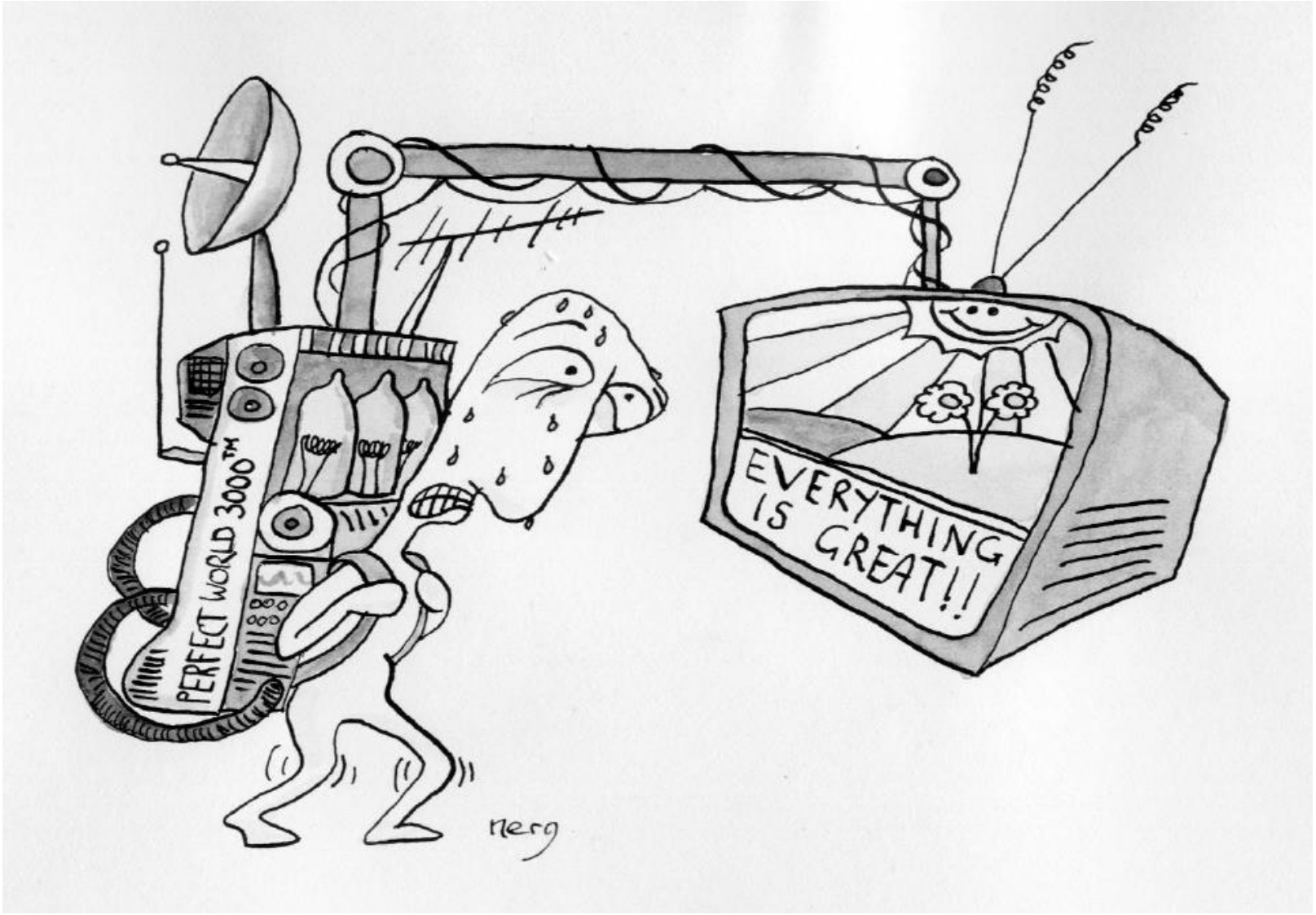


- Individual, face-to-face therapy
- With a clinical psychologist/ psychiatrist
- Focus on “meta-cognitions”

Conquer Fear

Conquer Fear: Intervention

- Assessment: individual profile and risk factors
- Values clarification: planning for future
- Detached mindfulness: focus on moment
- Attention training: control over attention focus
- Meta-cognitive therapy: worry not + or −
- Education: about prognosis and signs of recurrence
- Behavioural contract: non-excessive follow up


PERFECT WORLD 3000™
EVERYTHING IS GREAT!!
Nerg

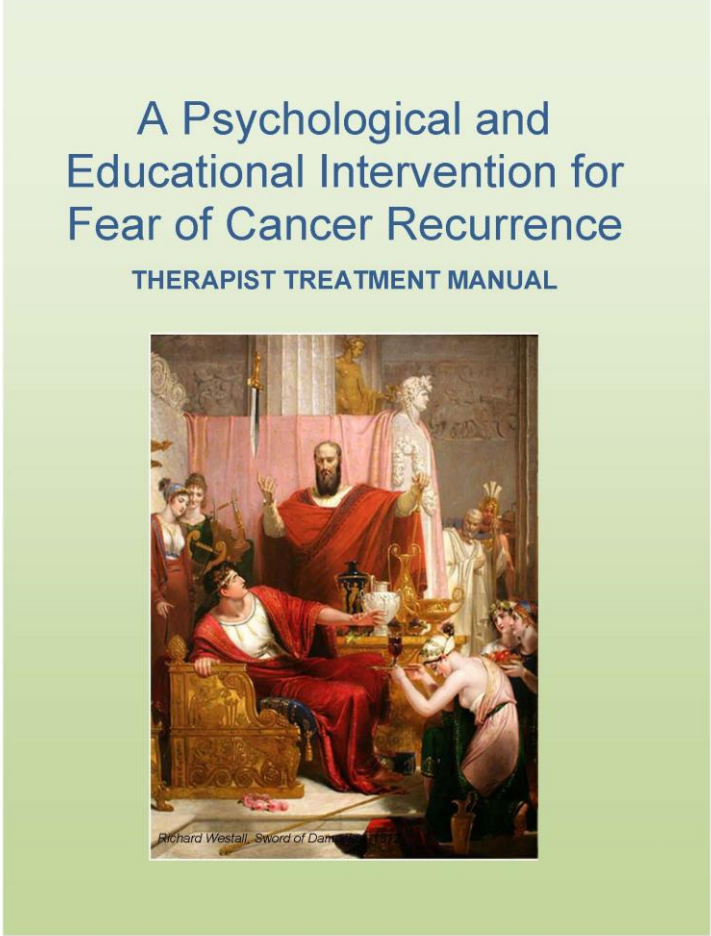
Accept worry, but don't get caught up in it…

- Detached Mindfulness

- Think of your thoughts and feelings as passers by – they come and go
- Accept them – they are there
- Don't judge them, or react to them, or try to get rid of them

- Like leaves passing down a stream
- Or clouds in the sky

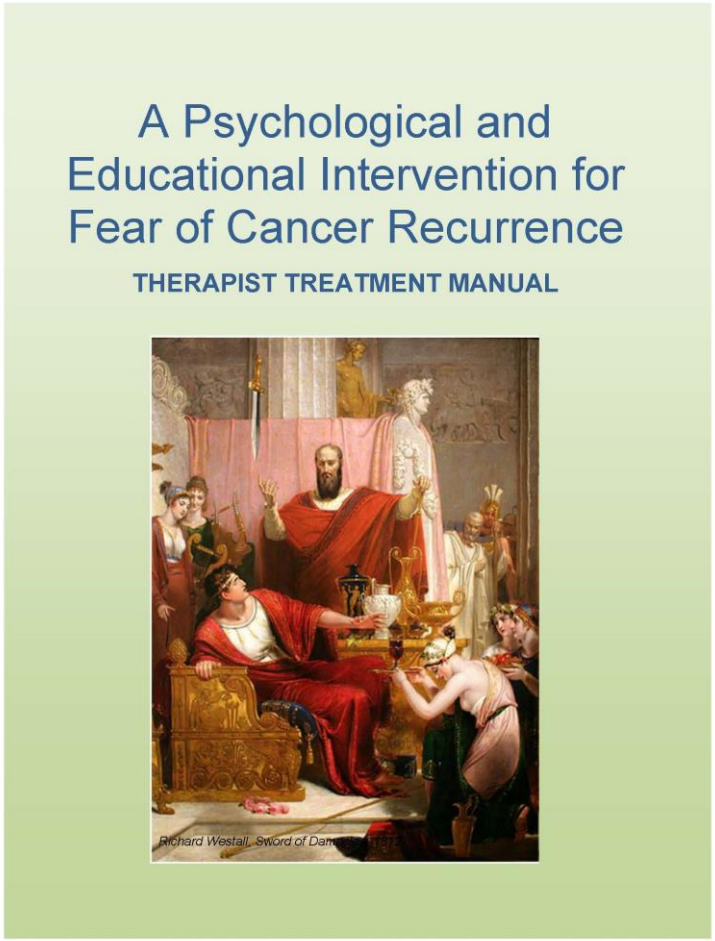
Pilot study



Smith AB, Thewes B, Turner … Butow P. Pilot of a theoretically grounded psychologist-delivered intervention for fear of cancer recurrence (**ConquerFear**). *Psycho-Oncology,* 2015; 24(8): 967-970

Acceptable, feasible, likely effective

Conquer Fear: RCT Study Aim



- To evaluate in a randomised controlled trial the efficacy and cost-efficacy of a theoretically-based therapist-delivered intervention to reduce *clinical* FCR in cancer survivors

Protocol

Butow *et al. BMC Cancer* 2013, **13**:201
http://www.biomedcentral.com/1471-2407/13/201

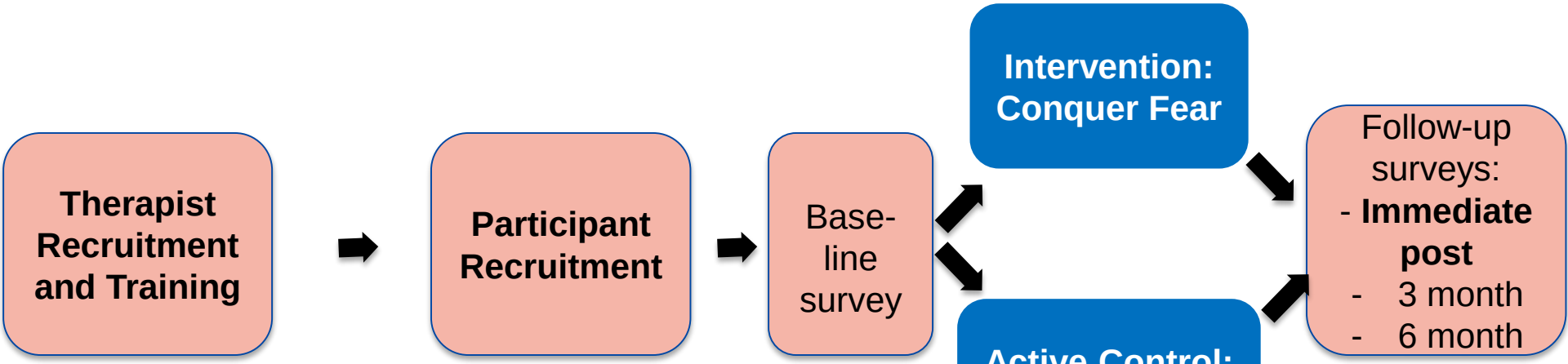
BMC Cancer

STUDY PROTOCOL Open Access

Conquer fear: protocol of a randomised controlled trial of a psychological intervention to reduce fear of cancer recurrence

Phyllis N Butow[1*], Melanie L Bell[1], Allan B Smith[1], Joanna E Fardell[1], Belinda Thewes[1], Jane Turner[2], Jemma Gilchrist[3], Jane Beith[4], Afaf Girgis[5], Louise Sharpe[6], Sophy Shih[7], Cathrine Mihalopoulos[7] and members of the Conquer Fear Authorship Group

Study Design



>2 years experience in psycho-oncology

- Br, CR or Mel
- Early stage
- 2 months to 5 years post tx
- Clinically sig FCR

Intervention arms

Therapists delivered both interventions
5 sessions in 10 weeks (60-90 minutes each)

Conquer Fear: Intervention

- Values clarification: planning for future
- Detached mindfulness: focus on moment
- Attention training: control over attention focus
- Meta-cognitive therapy: worry not + or −
- Behavioural contract: non-excessive follow up

Taking it Easy: Active control

- Introduction to stress
- Progressive & passive muscle relaxation
- Meditative relaxation
- Visualization and quick relaxation

Measures

- Primary outcome
  - **Fear of cancer recurrence**:
    - Fear of Cancer Recurrence Inventory (FCRI) Total
    - FCRI Severity subscale

- Secondary Outcomes
  - **Cancer-specific distress**: Impact of Events Scale (IES)
  - **General distress**: Depression, Anxiety, Stress Scales (DASS-21)
  - **Quality of life**: Assessment of Quality of Life 8D (AQOL8D)
  - **Unmet information needs**: Survivor Unmet Needs Survey (SUNS) Info Scale
  - **Meta-cognitions**: Meta-cognitions Questionnaire (MCQ-30)

Statistical Considerations

- Sample size = 260 (130 each arm)
- To detect a14.5 point difference between groups in FCR
  - 90% power, two-sided alpha of 0.05
  - Allowed for 30% drop-out rate

- T-test, multivariate adjusted analysis
- Repeated measure analysis employing GEE models to test impact over time

Australian Sites

26 therapists participated from 17 sites

Treated on average 15 (3–25) patients each