

Helping cancer survivors find the resilience to survive and thrive

by Phil Kerslake

1

Overview

- ▶ Resilience and its importance for survivors
- ▶ Survivorship stressors
- ▶ Objectives and focuses of resilience work
- ▶ Examples of resilience builders
- ▶ Beyond resilience – posttraumatic growth
- ▶ Conclusions
- ▶ Questions and comments invited

2

Resilience defined

- ▶ The ability to recover quickly from depression or discouragement
- ▶ The quality or state of being flexible

(Roget's thesaurus)

3

Why is resilience so important for cancer survivors?

- ▶ For many people, survivorship brings with it numerous stressors and much suffering, sometimes for many years
- ▶ Even if they are disease-free, they don't feel free of the disease
- ▶ Just having to live from scan to scan is trauma-inducing
- ▶ Quality of life (QOL) can be significantly compromised and some argue, so too can their survival time and/or their potential to recur
- ▶ Resilience is a key factor that enables people to cope with trauma and bounce back from depression to live productive lives

(Coughlin, 2008)

4

Survivors have varying levels of resilience

- ▶ Some people are naturally more resilient than others
- ▶ Many further honed their resilience during the treatment period, others had their resilience eroded through the compounding stressor events
- ▶ Factors involved in determining cancer's impact on them can include:
 - The patient's life stage
 - Individual differences in personality
 - Cultural differences
 - [The patient's prognosis]

(Rowland and Baker, 2005)

5

Re-visiting survivorship's stressors

There is a range of challenges which tend to fall into:

- Physical/physiologic
- Mental/emotional
- Social/economic
- Spiritual/existential

6

I.e. Emeritus Professor Miles Little says:

- Survival can be a downward spiral for maybe a quarter or a third of cancer survivors

'... there are many whose lives contain real unhappiness. It's an unhappiness that doesn't usually fit the pattern of ordinary, clinical depression, nor post-traumatic stress disorder. It's a condition of sadness, isolation and diminished self-respect...'

Survivor research project, The University of Sydney, 2000, in Little & Sayers, 2002.

7

Survivorship's stressors

- ▶ Mixed emotions leaving the hospital that became a safe haven
- ▶ Permanent physical changes
- ▶ Fatigue, brain-fade, infertility, shortness of breath, etc
- ▶ Lost of trust in bodies
- ▶ Disruption of valued order
- ▶ New, acute awareness of mortality
- ▶ Living with the 'cancer' label and the societal prejudices and inconveniences that brings

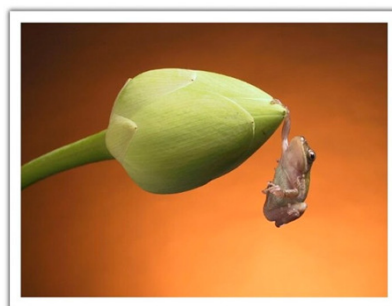
8

Survivorship's stressors

- ▶ Fear of recurrence or new cancers
- ▶ Anticipation trauma: regular medical appointments for year - maybe for life
- ▶ Loneliness, feelings of isolation
- ▶ Communication, relationship &/or sexual difficulties
- ▶ Re-acquainting with old life nigh-on impossible
- ▶ Haunted by hard-to-resolve existential thoughts

9

Objectives & focuses of resilience work



10

Worthy objectives

- ▶ Reduce or eliminate mental, emotional and physical suffering
- ▶ Improve the quality of survivors' lives and those of secondary survivors (their family and whanau)
- ▶ Optimise people's survival time - help them enjoy more birthdays!
- ▶ By helping manage the 'maintenance factor' stressors (i.e. Maslow), enable many to realise the self-actualising potential inherent in responses to trauma (posttraumatic growth)

11

Resilience-work focuses: 1. the mind!

'Modern medicine has focused so intently on fighting disease that it has overlooked a natural ally in the battle - the patient's personal mental management of the stresses associated with cancer.'

- David Spiegel, MD., Stanford University School of Medicine (Spiegel, 2011)

12

Resilience work for the mind

- ▶ Learning stress management and reduction techniques
- ▶ Engendering and reinforcing hope and optimism
- ▶ Paying attention to the spiritual aspects of life
- ▶ Enhancing purposeful living and a sense of meaning

13

Resilience work focuses: Lifestyle factors

- ▶ Physical activity
- ▶ Avoidance of smoking & heavy alcohol consumption
- ▶ Eating a healthy diet
- ▶ Getting adequate rest and sleep

14

Examples of resilience builders



15

Engendering hopefulness & optimism

- Hope and optimism are important mediators of coping and resiliency to illness
- Measures of hopefulness have been found to be positively associated with indices of life satisfaction and well-being
- Among women with breast cancer, optimism is associated with short- longer-term emotional well-being
- People who lack hope are more likely to use negative coping strategies such as alcohol abuse or overeating to alleviate stressful circumstances

(Coughlin, 2008)

16

Resilience-builders

- Information: i.e. early knowledge about survivorship's challenges and specific coping strategies for each
- Avenues to the examination of ways in which the survivor may live more intentionally re: their values, goals, priorities and hopes (i.e. vision and goal setting)
- Guidance on a range of self-management mood and attitude modifiers: e.g.

17

Examples of self-management mood and attitude modifiers

- Meditation and relaxation techniques
- Positive affirmation practices
- Laughter and music as therapeutic aids
- Visualisation practices
- Expressive writing approaches

18

Social support and social connectedness

- Support groups and group therapy have been shown to provide psychological benefits for patients with cancer
- Many cancer survivors encourage each other, teach other cancer patients how to survive and fare well, and help those who are burdened by cancer

19

Networking – the cost-free way to help survivors increase their resilience

- **Why don't we facilitate the establishment of a highly active and visible community of survivors?**
 - This could create a social environment where individual cancer survivors were more apt to think of themselves in a positive light as survivors
 - When people see themselves as part of an energetic, compassionate, and important social movement or community of survivors their relationships, expectations and perspectives are likely positively influenced

20

Two illustrative resilience-building programs



21

Taking CHARGE: a self-management program for women following breast cancer treatment (University of Michigan)

- ▶ Designed to assist women achieve successful transitions to survivorship through developing self-management skills and receiving information on common survivorship topics
- ▶ Consisted of four intervention contacts made over two-week intervals over a seven-week period for 25 women
- ▶ Focused on:
 - Enhancing psychological well-being
 - Managing physical symptoms and side-effects
 - Achieving functional wellness through a healthy lifestyle
 - Promoting functional adjustment in family, work and social roles
- ▶ **Outcomes**
 - Participants found the program to be timely, relevant, and to have high utility in dealing with concerns that exist following breast cancer treatment

(Cimprich et al, 2005)

22

MBSR: University of South Florida Mindfulness-based stress reduction program

- A randomised, controlled trial of 84 breast cancer survivors
- Subjects were assigned to a 6-week MBSR program designed to self-regulate arousal to stressful circumstances or symptoms
- **Outcomes:** Compared with usual care, subjects assigned to MBSR had significantly lower depression and fear of recurrence, along with higher energy and physical functioning

(Lengacher et al, 2009)

23

Common themes from resilience-building interventions in the research

- ▶ Very often relatively brief, resource-light and inexpensive to conduct
- ▶ Often concerned with imparting self-management skills so survivors can independently continue to manage their own circumstances
- ▶ Provide significant positive results for survivors – maximum benefits for minimum inputs (big bang for a few bucks)

24

The rarely acknowledged potential of resilience-building interventions: prolonging life

- ▶ Metastatic breast cancer patients participating in a 1-year intervention involving weekly supportive group therapy with self-hypnosis for pain survived longer than the controls: 36.6 months v 18.9 months (Spiegel et al, 1989)
- ▶ Patients participating in a program that taught strategies to reduce stress, improve mood and alter health behaviours reduced their risk of dying of breast cancer by 56% after an average of 11 years and reduced the risk of breast cancer recurrence by 45% (Andersen et al, 2008)
- ▶ Decreasing depression symptoms over the first year was associated with longer subsequent survival for women with metastasised breast cancer (Giese-Davis et al, 2011)

25

Beyond resilience



26

Posttraumatic growth (PTG)

'It is now a common finding that large proportions of people who have experienced cancer and other life-threatening illnesses appear to find benefit in the experience, reporting such positive outcomes as improved quality of life, better interpersonal relationships, and changes in values and priorities as a result of the experience. Such changes have been reported by 30% - 90% of most samples studied across a wide range of adverse events and have been variously termed cognitive adaptation, personal or posttraumatic growth.'

(Coughlin, 2008)

27

Posttraumatic growth

- ▶ Taxing resilience can lead to positive adaptation and an increased ability to thrive: i.e. posttraumatic growth
- ▶ PTG is more than resilience. Resilience is the ability to bounce back to a previous level of functioning whereas PTG refers to a personal gain of some kind
- ▶ PTG does not occur as a direct result of trauma, rather it's an individual's struggle with the new reality in the aftermath of trauma that's crucial in determining the extent to which PTG occurs
- ▶ Reports of growth experiences in the aftermath of traumatic events far outnumber reports of psychiatric disorders
- ▶ **Important point: continuing personal distress and growth often coexist**
- ▶ (Tedeschi & Calhoun, 1996 & 2004)

28

Conclusions

- ▶ A resilient cancer survivor is better prepared to cope with survivorship's stressors
- ▶ Resilience can be built, taught and facilitated
- ▶ Resilience-focused interventions have been shown to significantly enhance quality of life and survival times
- ▶ Interventions are typically brief and inexpensive to develop and convene
- ▶ For survivors, personal distress and growth often coexist
- ▶ Interventions may be developed to minimise the former and maximise the latter

29

Questions or comments please?



30

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31

About the presenter

Phil Kerslake is a 7-time cancer survivor whose education in the art and practice of coping with cancer and its treatments for best outcomes – including the emotional and spiritual challenges that present during and after cancer – began 32 years ago when he was diagnosed with an incurable lymphoma.

Phil shares what he has learned with patients, health care and support professionals every year – to date to over 10,000 people in NZ, Australia and recently, USA. His goal is to help reduce patient suffering by empowering them with knowledge, inspiration and hope, and he encourages empathetic, patient-centric service delivery from all those professionals who interface with the patients in the system so that the patient experience is continually improved.

Acclaimed by the Cancer Council Australia as *'A book that can make a real difference in the lives of cancer patients from all walks of life...'*, Phil's patient support book *Life, Happiness... & Cancer* (NZ 2006) has sold 13,000 copies in NZ and is now published in Australia (2008), Africa (2010) and Poland (2010) with others editions to follow.

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32