



UNIVERSITY OF
Southampton
School of Health Sciences

Understanding recovery & self management following primary cancer treatment & developing supportive interventions

Claire Foster, PhD

Head of Macmillan Survivorship Research Group

Faculty of Health Sciences

University of Southampton

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Survivorship

‘Anyone living with or beyond cancer’

Corner (2009)

Cancer survivorship – ongoing problems

- 40% said life was affected ‘more than a little’ by cancer
- 53% harder dealing with emotional than physical needs
- 60% experienced problems in a close relationship
- 32% reported job disruptions or loss
- 72% reported depression at some point in their recovery
- 70% felt their physician had been unable to help with their non medical needs

‘It’s no life’: Living with the long term effects of cancer.

(Macmillan Cancer Support 2009)

- As many as 78% cancer survivors said they had at least one physical condition occurring as a result of cancer and 62% at least one psychological condition.
- 20% those with physical ailments and 40% with emotional difficulties had not sought or been offered medical help or support
- Of those that visited their primary health physician only about half of the doctors mentioned cancer as a possible cause.

What do we know about cancer survivors?

- Very little
- In the UK limited data on:
 - Numbers
 - Hospital activity
 - Primary care use
 - Needs
 - Health and well being
 - Self management of problems

Life after primary treatment

At the end of it you just feel kind of left out at sea. You are a bit kind of 'OK what happens now?' And it's like a security blanket has been taken away in some ways. You kind of miss it! It's the worst thing you'd ever go through, you miss having it there and the routine of it there. (Lyn)

You don't want to upset people around you so much, you still hide a lot of it, because I think if you had somebody else to talk to at that time, you would have opened up a lot more and maybe it would have been a lot easier, I don't know. But that's how I feel about it myself really. (Charlotte)

I'm not terrified of...I am a bit scared, just occasionally...you know that sort of thing 'oh what if I'm not here' and I think the thing that really bothers me, and I get upset when I talk about this, but is what is going to happen to the children. (Chloe)

Self management

- Engaging in activities that protect and promote health,
- Monitoring and managing the symptoms and signs of illness,
- Managing the impact of illness on functioning, emotions and interpersonal relationships,
- Adhering to treatment (Von Korff et al,1997).
- Making informed choices
- Communicating effectively with health care professionals,

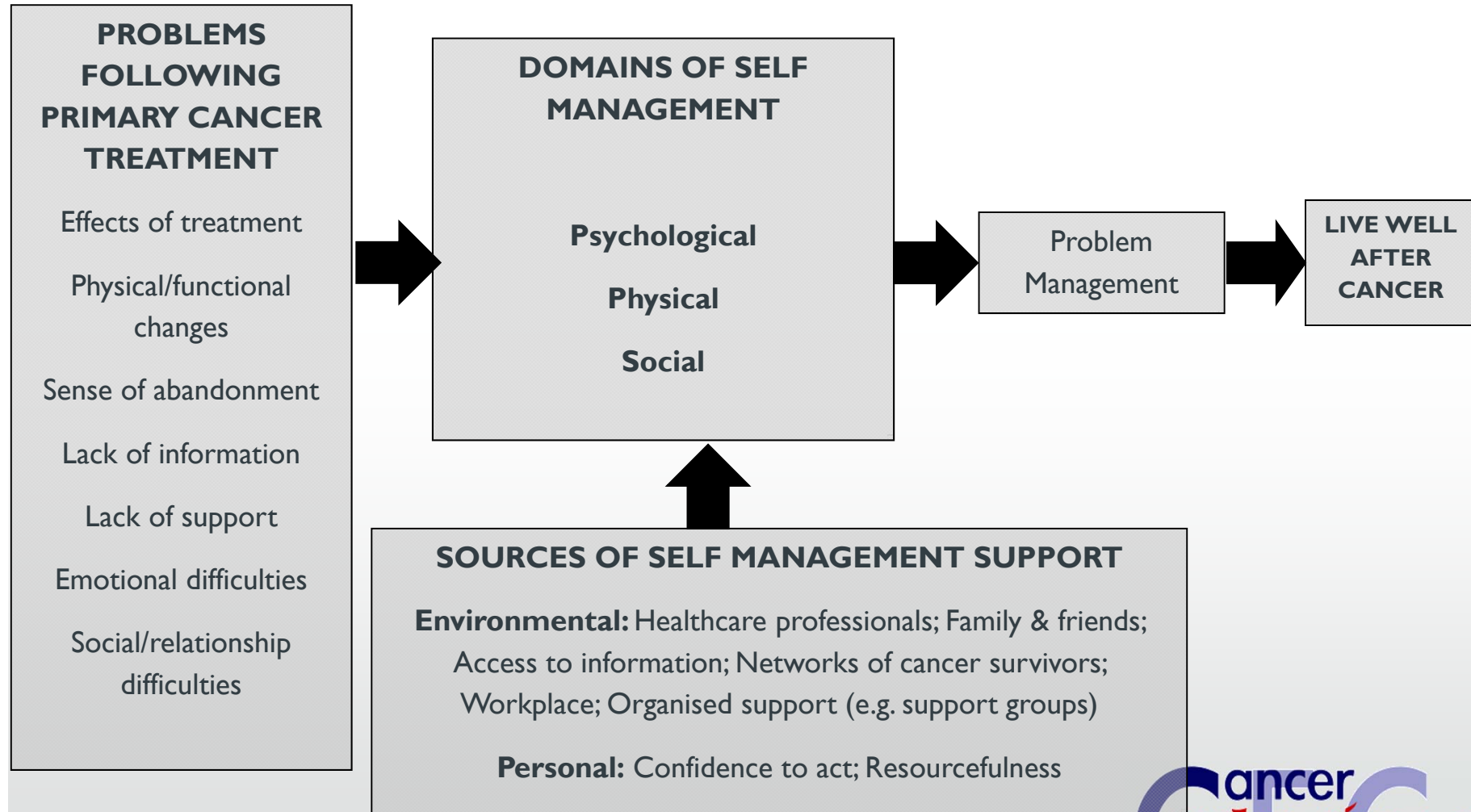
“To adapt new perspectives and generic skills that can be applied to new problems as they arise.. AND ...to practise new health behaviours, and to maintain or regain emotional stability.”

(Lorig et al 1993:11)

Self management support

Self management support is what health services can do to aid and encourage people living with long term conditions to improve or maintain their health and well-being. It can be viewed in two ways: as a portfolio of techniques and tools; and as a fundamental transformation of the patient-caregiver relationship into a collaborative partnership.

(Adapted from Health Foundation, 2008)



Foster, C., Roffe, L., Scott, I. & Cotterell, P. (2010) Self management of problems experienced following primary cancer treatment: An exploratory study. Report for Macmillan Cancer Support

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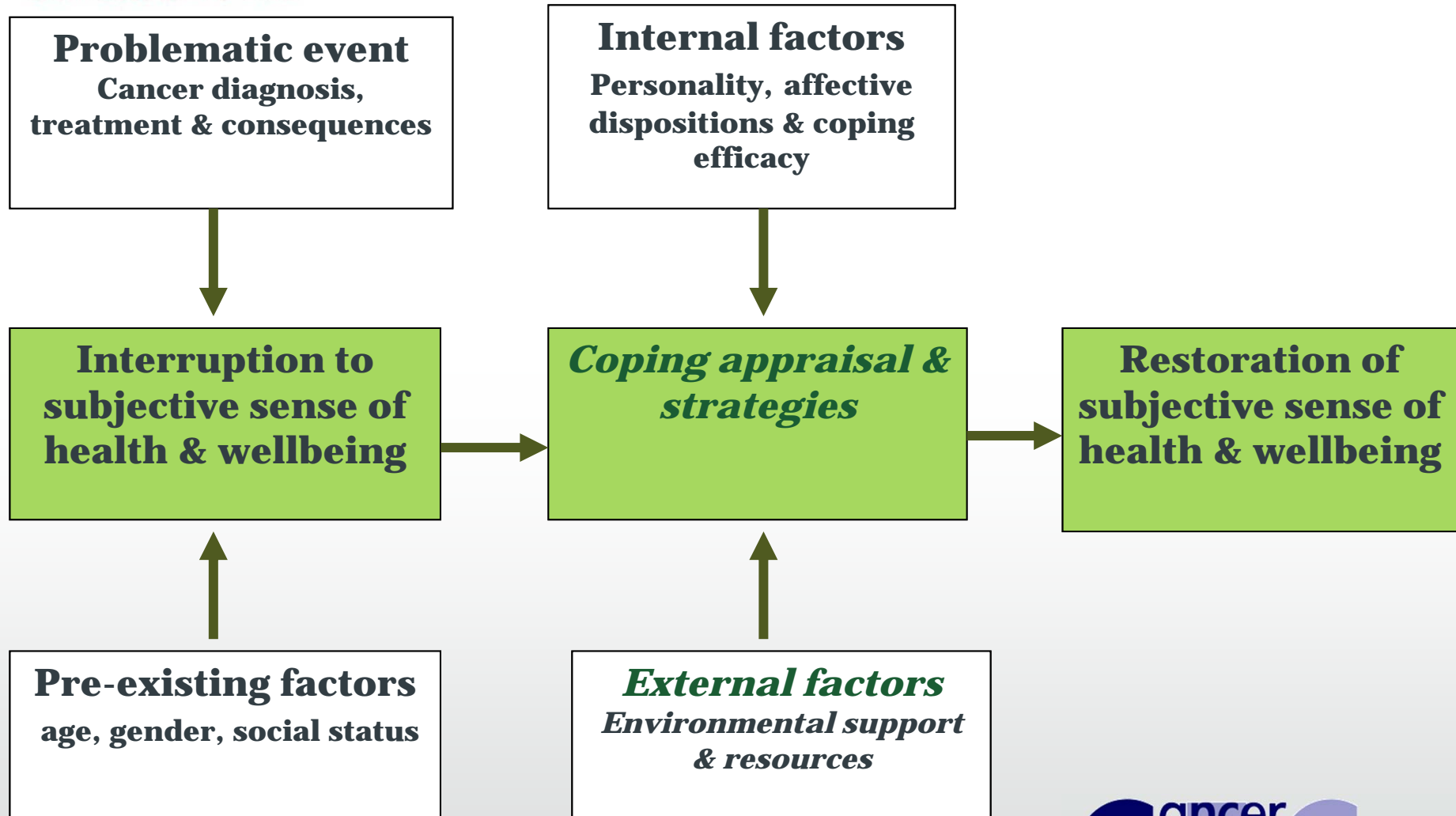
- Understanding recovery and self management following primary treatment
- Co-creating and testing interventions to support self management
- Working with research partners; including those typically underrepresented

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- What is the 'normal' pattern of recovery after cancer treatment ends?
- How do people recover health and well-being after cancer treatment?
- What problems do people face?
- What factors facilitate or hinder their recovery?
- What ways do people find to self manage their recovery?
- Can sharing these self-management strategies be of benefit to other cancer survivors?

Self-efficacy

- Lent's (2007) model of restorative well-being for cancer survivors predicts that individual characteristics together with appropriate environmental supports and resources will influence the restoration of health and well-being and that this is a dynamic process
- The model draws on Bandura's (1986) concept of self efficacy
- Confidence to achieve ones goals in living with or managing problems associated with illness is influenced by supports and resources available to the individual as well as their appraisal of the situation. Self efficacy is associated with enhanced well-being



**Model of restorative well-being in cancer survivorship
(informed by Lent, 2007 & Foster et al., 2010)**

ColoREctal Wellbeing [CREW] cohort – 1000 colorectal cancer survivors

Aims

- Explore restoration of health and well-being following primary treatment
- Identify who is at risk of problems
- Explore factors which hinder/enhance restoration of health and well-being
- Recommend where interventions/services can be targeted to support survivors

Online survey of confidence to self manage problems post treatment

- Assess confidence to manage range of problems following completion of primary cancer treatment.
- Identify whether problems are self managed.
- Identify factors associated with self management of problems.
- Identify factors that hinder self management of problems.
- Identify resources required to enhance self management.

Online intervention to enhance confidence to self manage cancer related fatigue following primary treatment

- Develop an online resource, bringing together clinical and lay expertise, offering tailored self management support following primary treatment
- Test the value of the intervention in increasing self efficacy to self-manage cancer related problems following primary treatment

Research Partnerships

- Engage with people affected by cancer
 - Reference Groups
 - Knowledge Café event
 - Development workshops
 - Under represented groups

Macmillan Survivorship Research Group Team

- Dr Deborah Fenlon, Senior Research Fellow
- Dr Phil Cotterell, Senior Research Fellow
- Dr Ikumi Okamoto, Research Fellow
- Matthew Breckons, Research Assistant
- Lisa Bryan, Research Secretary
- Prof Peter Smith, Director of Southampton Social Statistics Research Institute

Advisors....

- Jessica Corner
- Alison Richardson
- Julia Addington Hall
- Jo Armes
- Janis Baird
- Lynn Batehup
- Andrew Bateman
- Nick Beck
- Jane Winter
- Karen Gerard
- Graham Moon
- Rona Moss Morris
- Karen Poole
- Claire Taylor
- Jocelyn Walters
- Mark Weal
- Fran Williams
- Lucy Yardley

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For further information

www.soton.ac.uk/msrg

clf1@soton.ac.uk

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