

**National Cancer Survivorship Initiative
Supported Self-Management Workstream**

**SELF-MANAGEMENT SUPPORT FOR
CANCER SURVIVORS: GUIDANCE FOR
DEVELOPING INTERVENTIONS**

AN UPDATE OF THE EVIDENCE

Macmillan Cancer Support,
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Nicola J Davies
and
Lynn Batehup

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Any comments or enquiries regarding this review are welcome:

Lynn Batehup, Project Manager, Self-Management Workstream, NCSI, Macmillan Cancer Support; LBatehup@macmillan.org.uk.

Nicola Davies, Evaluation and Research, Self-Management Workstream, NCSI, Macmillan Cancer Support Coordinator; NDavies@macmillan.org.uk.

Self-Management Support for Cancer Survivors – Helping People Help Themselves

Summary of Findings

- Patient engagement in healthcare via self-management is widely recognised as crucial to improved outcomes for people with long-term chronic conditions (DH, 2010). With increased cancer survivorship, cancer in its chronic form, or with late consequences of treatment and co-morbidities, it is equally or even more crucial to cancer survivors.
- This shift starts at the point of diagnosis, with a collaborative and interactive relationship between patients and healthcare professionals, which empowers patients to take on responsibility for their condition with the appropriate clinical support. There remain major challenges to this change, for example, from moving from the position of seeing the healthcare professional just as an expert giving advice, to an enabler who supports the person they are caring for to achieve their goals; and the challenge of patients seeing themselves as passive recipients of care, to becoming ‘activated’ and taking responsibility for their own contribution to improving their health and well-being outcomes, and being empowered to do so.
- Where people are assessed as lacking confidence for self-management, it is fundamental to provide access to tailored education, training, and support for the development of self-management skills and strategies, based on personalised assessment and care planning.
- Supported self-management education and skills training for cancer survivors can be viewed at three levels (Figure 11; pg. 43):

Level	Example
Type	<i>Adjustment-focused</i> (e.g. facilitating transition to survivorship) or <i>problem-focused</i> (e.g. enhancing coping skills for specific problems or symptoms, such as fatigue or relationship difficulties), and a mix of both.
Delivery	Groups; one-to-one; technology-assisted (e.g. web-based, telephone); home visits; professionally-led; peer led; co-tutor approach.
Techniques	Goal setting; action plans; problem solving; self-monitoring; stress management; information provision; sharing experiences; counselling; coaching; motivational interviewing; positive feedback; peer modelling.

- Tailored information alone can increase knowledge and prepare patients for change, and should be provided for all survivors, but additional tailored support and ongoing input from healthcare professionals is required to help some survivors to use this information (Coulter and Ellins, 2006).
- A key component of effective self-management is the enhancement of self-efficacy (i.e. the confidence to use self-management skills successfully), based on Bandura’s social cognitive theory. Methods for enhancing self-efficacy include:
 - Mastery: success with self-management skills raises self-efficacy.
 - Vicarious experience: seeing others succeeding in self-management increases personal self-efficacy.
 - Verbal persuasion: positive feedback increases self-efficacy.
 - Physiological feedback: subjective perceptions of physiological responses can alter self-efficacy.

- Different types of supported self-management can be provided based on need, for example:
 - Peer modelling videotapes for people who are unprepared for transition to survivorship.
 - Psycho-educational counselling for people prepared for transition to survivorship.
 - One-to-one or telephone-delivered support for older cancer survivors with comorbidities, low self-esteem, or physical and practical limitations.
 - Group and peer discussions for prostate cancer survivors with relatively low levels of social support, low self-esteem, and higher depressive symptoms.
 - Problem-focused support for prostate cancer survivors with sexual functioning difficulties.
 - Telephone-delivered support for issues of a sensitive nature such as sexual functioning.
 - Telephone-delivered support for male ethnic minorities who might be uncomfortable in groups of mainly white participants.

- To effectively support cancer survivors in self-management, cancer healthcare professionals require patient in partnership *communication skills training*, incorporating *motivational interviewing skills*.

- To be effective and cost-efficient, there needs to be a shift away from 'one size fits all' to providing support based on individual needs and priorities. Risk assessment methods offer a viable way of achieving this through stratification according to individual needs.

- Risk stratification measures requiring further testing for feasibility as screening instruments within supported self-management for cancer survivors include:

Need	Instrument	Stratification
'Readiness'/ Motivation	Contemplation Ladder	Level of preparedness.
Patient activation	Patient Activation Measure (PAM)	States of change for levels of 'activation': starting to take a role; building knowledge and confidence; taking action; maintaining behaviours.
Anxiety and depression	The Hospital Anxiety and Depression Scale (HADS)	Levels of anxiety and depression: not clinical; borderline clinical; clinical.
Social needs	The Social Difficulties Inventory (SDI)	Levels of isolation, social support, relationship difficulties.
Symptom distress (prostate cancer)	The Expanded Prostate Cancer Composite Score – Short-Form (EPIC-26)	Prostate-specific symptom severity.
Physical activity	The General Practice Physical Activity Questionnaire (GPPAQ)	Physical activity levels: inactive; moderately inactive; moderately active; active.

- There are four key stakeholder outcomes important when measuring the effectiveness of supported self-management for cancer survivors:
 - Patient outcomes - health literacy (i.e. to navigate the healthcare system, understand information, and access support when needed); self-efficacy to self-manage; self-management skills development; reduced symptom burden; improved quality of life; adjustment to survivorship; satisfaction with service.
 - Clinician outcomes – patient in partnership communication skills for the provision of self-management support; appropriate healthcare utilisation; more clinic time; multidisciplinary team work.
 - Commissioner outcomes – quality; innovation; service improvement; cost-effectiveness.
 - Policy outcomes – establishment of patient-centred care and the patient/provider partnership approach; effective healthcare utilisation; reduced costs of treatment; secondary prevention; earlier diagnosis; increased survival; improvements in cancer care.

- Figure 13 (pg. 47) illustrates key recommendations for designing supported self-management interventions for cancer survivors, comprising seven steps:

Level	Example
Needs assessment	Identify high risk groups and specific problems.
Intervention type	<i>Adjustment-focused or problem-focused.</i>
Theoretical framework	Selecting the most appropriate theoretical framework for measuring the effects of the intervention.
Intervention delivery	Deciding the method of delivery for the needs of the population taking part in the intervention.
Intervention techniques	As illustrated in Figure11, utilising the evidence-base for what works.
Implementation plan	Devising a detailed protocol with evaluation timing.
Evaluation	Utilising robust instruments to measure expected outcomes.

- Significant limitations can be found in the evidence available for supported self-management for cancer survivors, including:
 - Long-term outcomes and sustainability of support programmes
 - Predicting who will benefit from a self-management programme
 - Difficulties in recruitment to intensive programmes, and attrition from programmes
 - Cost-effectiveness and external validity
 - Comparative efficacy of different strategies within and between tumour groups
 - Equality across tumour groups
 - Cultural adaptation of support programmes
 - The most appropriate outcomes to assess effectiveness
 - The most robust instruments for measuring outcomes.

SUPPORTED SELF-MANAGEMENT FOR CANCER SURVIVORS: INTRODUCTION

Defining ‘Self-Management’ and ‘Supported Self-Management’

‘Self-management’ has become a widely-used term within the literature on chronic conditions, with the advent of the Expert Patient Programme (DH, 2001) highlighting the skills and abilities of patients to be actively involved in their healthcare. The term self-management has become generally well defined as *“learning and practicing skills necessary to carry on an active and emotionally satisfying life in the face of a chronic condition”* (Lorig, 1993; p. 11). ‘Supported self-management,’ on the other hand, has been defined as *“any formalised patient education programme aimed at providing the patient with the information and skills necessary to manage their condition within the parameters of the medical regime”* (DH, 2001; p. 22). This is a narrow definition implying that self-management support is only provided through formalised training programmes. The Co-Creating Health Project (2008) defined supported self-management as *“what health services do in order to aid and encourage people living with a long-term condition to make daily decisions that improve health-related behaviours and clinical and other outcome,”* which is broader and adopted as relevant to cancer self-management support. In the context of cancer care, self-management has been described by Foster et al. (2007) as *“Approaches used by the individual affected by cancer and its effects to optimise living with the illness and its effects,”* which relates to self-management rather than self-management support for cancer survivors. The Macmillan Cancer Support self-management workstream of the National Cancer Survivorship Initiative (NCSI, 2009) has described cancer self-management as:

“awareness and active participation by the person in their recovery, recuperation, and rehabilitation, to minimise the consequences of treatment, promote survival, health and well-being.”

The workstream distinguishes self-management support as:

“What health and social care professionals, and service delivery organisations to do support self-management.”

In February 2009, the self-management workstream who developed this definition commissioned the Macmillan Survivorship Research Group at the University of Southampton to conduct *‘Self-Management Support: A Review of the Evidence’* (Fenlon and Foster, 2009). The review was commissioned in recognition of the growing number of people living with or beyond cancer and, indeed, living with chronic symptoms and the long-term effects of treatment (Kings College London, 2008). The review addressed evidence for self-management support in cancer, whilst drawing on evidence from self-management support for people with long-term conditions. This was necessary due to the paucity of evidence specific to cancer self-management. However, since the commissioning of this review, self-management support for cancer survivors has achieved more prominence, now being one of the ‘five key shifts’ highlighted in the NCSI Vision Document (Figure 1; DH, Macmillan Cancer Support, and NHS Improvement, 2010).

Figure 1: Five Shifts in Care and Support for People Living with and Beyond Cancer (DH, Macmillan Cancer Support, and NHS Improvement, 2010)

- 1) A cultural shift in the approach to care and support for people affected by cancer – to a greater focus on recovery, health and well-being after treatment.
- 2) A shift towards assessment, information provision and personalised care planning - a shift away from a one-size fits all approach to follow-up to personalised care planning based on assessment of individual risks, needs and preferences.
- 3) A shift towards support for self-management - a shift away from clinically-led follow-up care to supported self-management, based on individual needs and preferences and with the appropriate clinical assessment, support, and treatment.
- 4) A shift away from a single model of clinical follow-up to tailored support that enables early recognition of and preparation for the consequences of treatment as well as early recognition of signs and symptoms of further disease.
- 5) A shift from an emphasis on measuring clinical activity to a new emphasis on measuring experience and outcomes for cancer survivors through the routine use of patient-reported outcome measures.

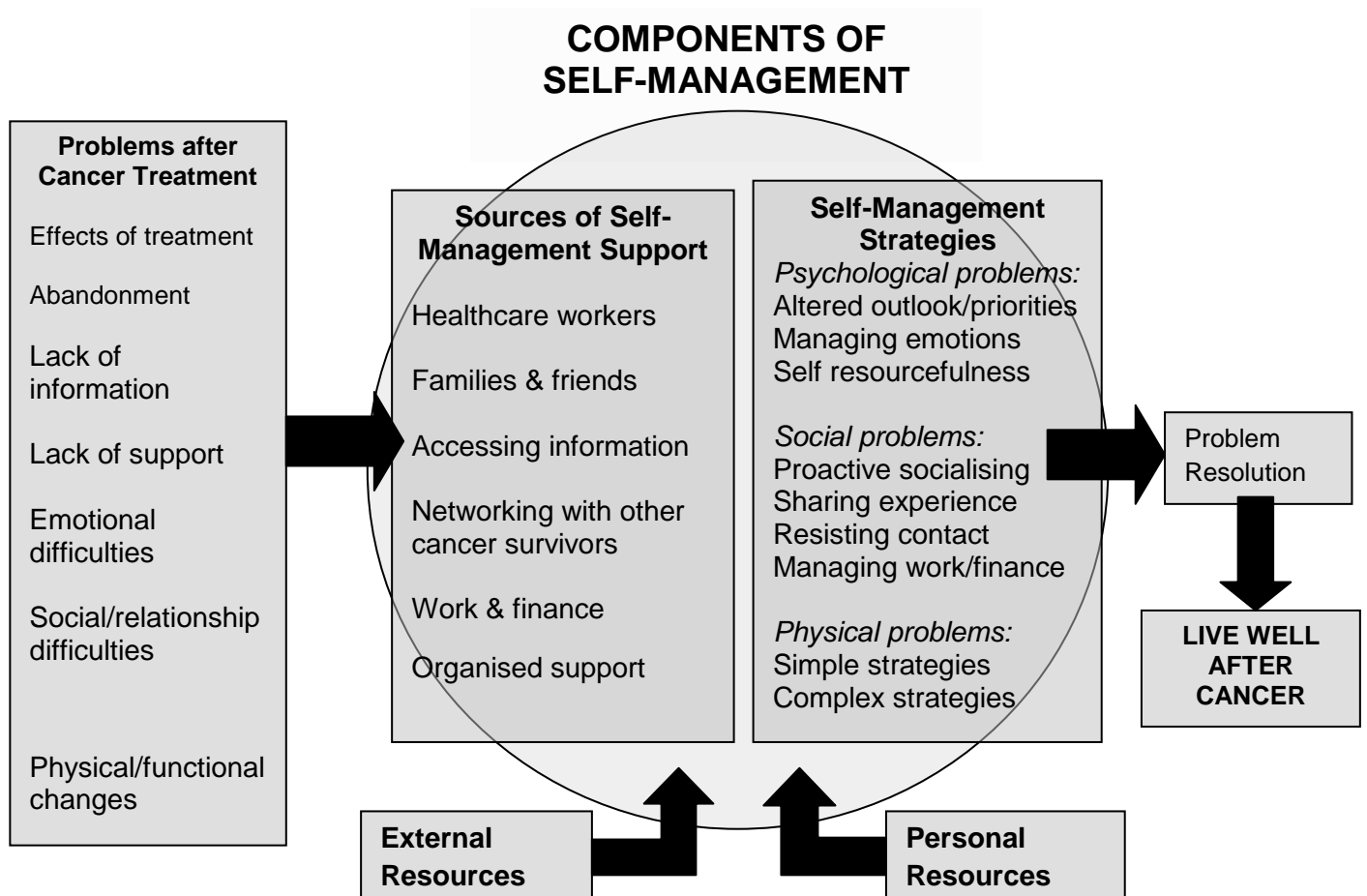
Updating the Evidence: The Rationale

The review by Fenlon and Foster (2009) requires updating in-line with the key shifts outlined in the Vision Document, as is the primary aim of the current document. The evidence base for self-management support for the wider range of long-term conditions (diabetes, heart disease, etc.) remains entirely relevant to cancer self-management support, whilst the current review attempts to refine knowledge on cancer-specific components of such support. There is also a need for the evidence to be graded in order to establish where the strength of support lies in providing a feasible and efficacious patient-centred service to survivors (Coulter and Ellins, 2006). It is anticipated that this will facilitate the accumulation of evidence for and against various strategies and frameworks, thus providing guidance for present and future self-management initiatives. Furthermore, cost-effectiveness has become of greater importance given the present economic climate, and thus this needs to be addressed in more detail (Richardson et al., 2005).

Further research conducted by the Macmillan Survivorship Research Group at the University of Southampton, as part of the strategic research plan, strengthens the evidence for this review update. In a qualitative study, using semi-structured interviews to examine the self-management strategies adopted by cancer survivors of various tumour sites 6-12 months post-treatment (n=31; 30 survivors and one partner of a man unable to participate himself; 24 women and 7 men), Foster et al. (2009) have enhanced understanding of the strategies cancer survivors describe in the management of problems associated with their condition/s. They have also provided exploratory data on perceived benefits and barriers encountered while self-managing, enhancing insight into how people can be supported. The findings from these interviews were used to develop a model illustrating the components of self-management for problems associated with cancer survivorship, whereby sources of self-management support (i.e. healthcare workers; family and friends; accessing information; networking with other cancer survivors) and personal self-management strategies for

problems that are psychological, physical, and social facilitate problem resolutions and enhance well-being (Figure 2). These components will be considered within this update of the self-management literature.

Figure 2: Components of cancer survival self-management (Foster et al., 2009)



The advancement in the prioritisation of self-management support for cancer survivors not only builds on the evidence that patients want to be involved in healthcare decisions (Coulter, 2005; Hibbard and Cunningham, 2008), but also complements a recent review of the current follow-up services available to cancer survivors (Davies and Batehup, 2009). This review evidenced a growing shift towards a more personalised and tailored approach to care following cancer treatment with examples of patients being offered some form of patient-initiated contact or self-referral process. This indicates a greater need for planned supported self-management, so that patients are confident and informed in terms of self-management and the support available to them. In addition, the 'chronicity' of some forms of cancer lends itself to an approach which incorporates self-management support. The current drivers for change would indicate the need for self-management to be incorporated into an integrated model of aftercare (Davies and Batehup, 2009).

The Current Review

There is a clear need to identify evidence that will inform commissioning and provide a framework for the self-management support available to patients living with or beyond cancer. This review updates current knowledge of cancer-specific self-management support, as well as provides insight into selective self-management support initiatives currently being tested within practice. By updating '*Self-Management Support: A Review of the Evidence*' (Fenlon and Foster, 2009), followed by an evaluation of the literature and selected current oncology practice, it is anticipated that this review will enable a tailored approach to self-management support.

The definition of supported self-management developed by the NCSI self-management workstream will be adopted to establish evidence pertaining to the self-management support available for cancer survivors. Furthermore, emphasis will remain on the firmly established belief that self-management is likely to be enhanced by a whole systems approach, where both patients and healthcare providers are considered as experts within a partnership (Grazin, 2009; Davies, 2010).

There remains a challenge to bring about change in practice, as the role of the patient as an active partner in their healthcare is not yet sufficiently recognised or supported. For example, a US review reports that 85% of doctors considered they shared decisions with their patients, whereas just 50% of patients considered that this was the case (Hibbard and Tusler, 2007). The situation of the consultation/interaction between a patient and their healthcare professional is the widest and most ubiquitous context in which patients can be advised and supported to self-manage. The development of this aspect of the clinician/patient relationship has received attention and development for health professional teams dealing with people with long-term conditions (Powell et al., 2009; Health Foundation, 2010), but has yet to receive attention for the majority of cancer clinicians. There is one notable exception; facilitating self-management within the medical consultation is addressed in the cancer communication framework of the National Cancer Institute (Epstein and Street, 2006). Whilst the development of healthcare professionals to support self-management in their interactions with patients is important, equally important is the focus on transforming patients to be activated and empowered partners with their healthcare professional. This review has not covered this important aspect of self-management support and will be the subject of a future separate in-depth review and analysis.

METHOD

Evidence for this review commenced with a more detailed evaluation of those cancer-specific self-management programmes referenced in the review being updated (Fenlon and Foster, 2009). This was followed by a number of literature searches, utilising the following databases: The Cochrane Database of Systematic Reviews (CDSR), DARE and NHS EED, MEDLINE, and EMBASE. Searches were restricted to using the search terms “cancer” OR “neoplasm” AND “self-management” OR “self-care” OR “support” in title and abstract fields. Reference lists from identified studies were handsearched.

The evidence was further informed by networking with experts in the field of oncology and self-management, as well as talking to service providers offering self-management support to cancer survivors.

Inclusion Criteria

Studies assessing cancer-specific self-management support services for survivors of the four most common tumour sites were included: breast; colorectal; lung; prostate. Primarily, those studies aimed at survivors who had completed active treatment were sought in order to fill a gap in the literature. Nevertheless, studies including cancer patients undergoing treatment were included if the rationale and findings might add to the knowledge base of self-management support for survivors, such as interventions aimed at symptom management. In addition, any studies looking at multiple sites, or generic self-management (i.e. not site-specific) were considered.

For clinical effectiveness, systematic reviews and randomised control trials (RCTs) were included. Prospective cohort studies were included due to their relevance in examining the etiology of cancer outcomes. Pilot and feasibility studies, or those of a non-randomised design, were also included due to this being a novel area of cancer service redesign where pilot testing will be expected and can be learnt from. Proposed studies pertaining to self-management support for survivors were presented on the basis of illustrating evidence in practice as well as the future of self-management support for cancer survivors. Studies comprising newly diagnosed cancer patients or palliative patients were excluded.

Included reviews were not restricted by outcome, but clinical outcomes considered being of interest included quality of life (QoL), symptom management, behaviour change, self-efficacy, patterns of healthcare utilisation, and cost-effectiveness.

All titles and abstracts of studies identified by the searches were scanned for relevance in terms of topic and participant group. For any titles or abstracts that were potentially relevant, full paper manuscripts were obtained and the relevance of each study assessed according to the pre-specified inclusion criteria.

Data Extraction

Data from all published studies were extracted using a standardised data extraction template (appendix 1), extracting the following details: author; title; aims; participants; outcomes; methods; randomisation; response rates; results; conclusions; and, strengths and limitations.

A summary of all studies providing results are also presented in a table comprising author, intervention, sample, follow-up period, attrition, outcomes assessed, and findings (appendix 2).

Data Synthesis

Data were combined in a narrative synthesis, categorised by tumour site (i.e. breast; colorectal; prostate; non site-specific) and again by type of self-management support (i.e. adjustment-focused or problem-focused). This was followed by a discussion of the intervention features (i.e. theoretical framework; intervention timing; follow-up length) in order to identify patterns and elicit evidence for the most successful strategies.

RESULTS: WHAT IS THE EVIDENCE FOR SUPPORTED SELF-MANAGEMENT FOR CANCER SURVIVORS?

After assessing all generated records against the pre-defined inclusion criteria, a total of 34 studies and initiatives were identified. These have been categorised according to the primary focus of the self-management support within the study or initiative, all of which were either focused on **adjustment** to living with or beyond cancer (n=18) or on specific long-term physical or psychological **problems** experienced during survivorship (n=16).

Adjustment to Survivorship:

The period between the completion of primary cancer treatment and returning to a 'new normal' is most often referred to in the literature as a 'transition' – a transition from patient to survivor. This period is also referred to as the 're-entry' or reintegration' stage, as well as a period of 'adjustment' and 'adaptation.'

Specific Problems in Survivorship:

There are a number of long-term and late effects of treatment that a survivor might be confronted with, including fatigue (Bower et al., 2006), psychological problems (Thewes et al., 2004), lymphoedema (Deo et al., 2004), and osteoporosis (Brown et al., 2006). There might also be difficulties related to return to work or withdrawal from social activities due to disability (Taskila et al., 2007).

BREAST CANCER

Six adjustment-focused and two problem-focused self-management support programmes and initiatives were identified for breast cancer survivors.

Adjustment-Focused Self-Management Support

In addressing transition to survivorship for stage I or II breast cancer survivors (n=558), Stanton et al. (2004) conducted the '*Moving Beyond Cancer*' (MBC) four-year multisite RCT. This was developed from stress and coping, self-regulation, and social learning theories with the aim of measuring the effect of two psycho-educational interventions and a control group on 6 and 12-month fatigue and cancer-specific distress. The authors also sought to test the level of baseline *preparedness* for transition with the effectiveness of these interventions. The first intervention comprised **psycho-educational counselling** (n=184) with trained cancer educators (e.g. social worker, psychologist), combining one 80-minute face-to-face session, one 30-minute telephone session two-weeks later, and a '*Moving Beyond Cancer*' videotape designed to promote peer modelling. The second intervention comprised the same **videotape** (n=187) whilst the control group (n=187) received a standard printed booklet: the 1994 National Cancer Institute publication '*Facing Forward*,' 43-pages containing general information on post-treatment issues.

Of 1,314 eligible women, 558 (42%) participated whilst 756 (58%) declined, could not be contacted, or did not return baseline measures. QoL scores did not differ between participants and non-participants, but participants were:

- younger
- white
- married

Also, participants completing 6 (n=418) and 12-month (n=399) assessments were:

- older
- more likely to be employed
- more likely to be taking tamoxifen
- less likely to report cancer-specific distress or depressive symptoms at baseline

This suggests that whilst younger women might be more inclined to take part in an intervention of this kind, older women are more likely to complete the intervention once started. On the other hand, if those with depressive symptoms or symptom distress at baseline are more likely to drop out of a self-management programme such as this, this may be an indication that this type of intervention is failing to address these needs, and there needs to be some kind of alternative support in place for this 'in-need' group.

Between the three groups, women who received the video experienced greater improvement in energy at 6-months; this was a significant difference between the video and booklet, but not significant between the video and counselling. Women in all groups experienced a decrease in cancer-related distress, with no significant differences between groups. The effect of the interventions was mediated by level of preparedness for transition into survivorship:

- ✓ Less prepared for transition → Video → Moderate improvement in energy
- * Less prepared for transition → Booklet → Moderate decline in energy
- * Less prepared for transition → Counselling → Moderate increase in cancer-related distress
- ✓ More prepared for transition → Counselling → Small decline in cancer-related distress

No significant effects were found at 12-months. This may be related to the design of the measurement instruments, but also may relate to the natural progression of time on recovery, recuperation, and resumption of social relationships. More insight into the natural history of recovery is required before we can say that longer-term effects of self-management support interventions are significant.

The authors conclude that a peer-modelling videotape can accelerate the recovery of energy during transition to 'normal' life in women who feel unprepared for that transition. However, it is well-documented that information alone is unlikely to result in long-term effects (Coulter and Ellins, 2006), so whilst a video might be useful in enhancing perceived preparedness, further support is likely to be necessary for this preparedness to be acted upon. Since fatigue has been identified as one of the most prevalent issues arising across all stages of the survivorship pathway from diagnosis through to end of life care (NCSI Mapping Project, 2009), a video that can reduce these symptoms via peer modelling would be useful if these effects were sustained over the long-term, which was not the case in this study. **The concept of *preparedness* may be a useful factor in the development of a risk**

stratification approach to identifying the type of self-management support suitable for individual patients, and could be measured via a validated instrument such as the Contemplation Ladder (Biener and Abrams, 1991), which draw on the Transtheoretical Model (Prochaska et al., 1992).

The data reported by Stanton et al. (2004) in the above study were utilised by Mandelblatt et al. (2008), who conducted an economic analysis of the three interventions (n=389). Intervention delivery costs per participant are presented in Table 1. At 6-months, the incremental costs for psycho-educational counselling were fairly high, even though this arm was not more effective in increasing energy or decreasing distress than the other arms. One-to-one consultation is understandably more expensive than providing educational material (videos or printed booklets), however, the limited benefits of this approach in this particular study is somewhat surprising and suggests issues around the design of the counselling as opposed to the efficacy of it. Indeed, there was one exception where the counselling arm was more effective, resulting in an incremental cost of £28,860.43 for each unit decrease in distress: in decreasing distress among women who perceived themselves to be more prepared for transition to survivorship. This suggests that a combination of personal preparedness and professional support can be effective in facilitating adjustment to survivorship. It is likely that being prepared empowered participants to use the information and support provided to them, whilst those who were unprepared lacked in self-efficacy, a concept well-documented to play a role in successful self-management.

The video improved energy levels of participants at low cost (£1.37 per unit improvement in energy) and was also effective in improving energy among women who felt less prepared for the transition to survivorship. This intervention was even less costly per unit benefit in the less prepared compared with the more prepared group. The effective element within the video intervention, using Bandura's theory of self-efficacy (Bandura, 1986), is likely to be vicarious experience and verbal persuasion, provided through the video using peer facilitators and models of effective performance by peer cancer survivors. By 12-months, there were no significant differences in healthcare costs post-intervention by intervention, although there was a trend for women receiving counselling to have higher costs for all categories of service. It might be that more information and insight lead to a higher use of healthcare services. In the short-term this might increase costs, however, in the long-term it is likely to lead to earlier detection of recurrence or morbidity and thus reduced costs. As highlighted in a recent analysis of the cost of cancer in England, huge savings could be made if, among other changes within oncology, England were as effective as other countries in the earlier diagnosis of cancer (Featherstone and Whitham, 2010). **Regardless, these results suggest that the most cost-efficient approach to improving adjustment to survivorship is to match self-management support to individual needs and factors, such as level of preparedness for transition.**

Table 1: Intervention Delivery Costs per Participant

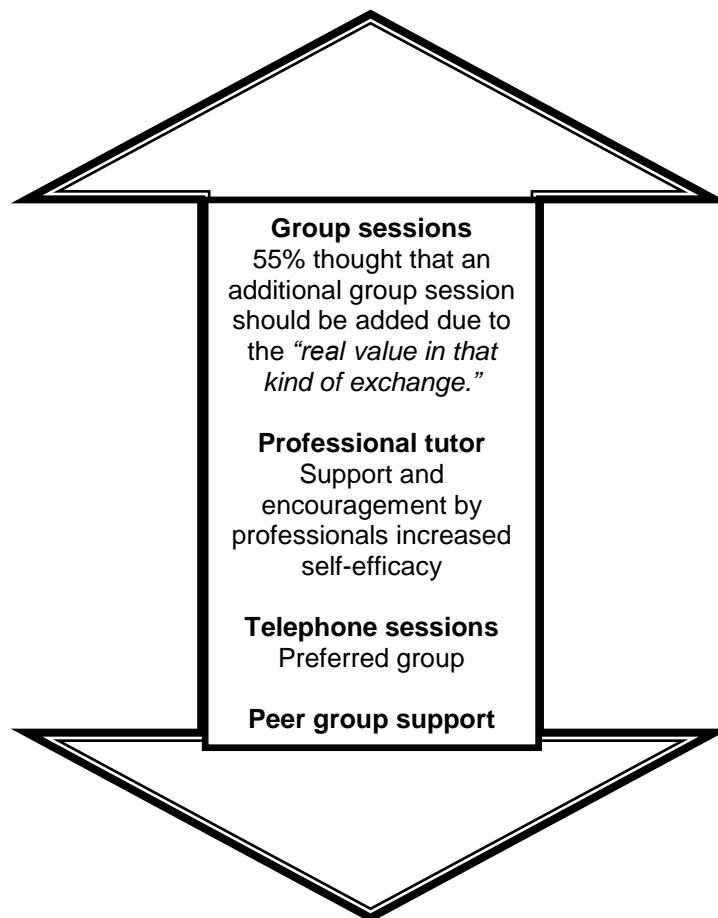
Component	Control Booklet	Video	Counselling
Materials (e.g. booklet, video)	£0.65	£3.86	£10.03
Mailing (e.g. booklet, video)	£1.14	£3.12	£1.14
Patient Time (e.g. read booklet, watch video, attend counselling)	£0.32	£0.58	£2.69
Staff/Counsellor Time (e.g. face-to-face counselling, telephone follow-up)	—	—	£1.14
Total Costs	£7.33	£16.78	£87.28

Another intervention designed to assist breast cancer survivors (n=25) in their transition to survivorship is the 7-week *'Taking CHARGE'* programme, based on Bandura's (1986) social cognitive theory: **C**hoose a concern; **H**ave the information; **A**ssess the situation; **R**ecord the plan; **G**ain confidence and insight; and **E**valuate progress (Cimprich et al., 2005). *'Taking CHARGE'* represents a combination of 'core' generic self-management skills development (goal setting; action planning) with a topic focus (nutrition; physical activity; and fatigue), which reflects one of the main established self-management programmes – the Stanford University Chronic Disease Self-Management programme (Lorig et al., 2003). The delivery approach is, however, different. It comprised four sessions at two-week intervals, combining two professionally-led (oncology nurse practitioner and health educator) face-to-face group sessions with two one-to-one telephone sessions made at two-week intervals. Group sessions were designed to foster a sense of self-efficacy and improve skills in coping with fear over recurrence, one of the biggest fears expressed by cancer survivors (Vickberg, 2003). Telephone sessions included a symptom specific component, aiming to develop self-management skills for physical symptoms such as fatigue, lymphoedema, cognitive problems, etc., as well as to promote strategies that involve exercise and changes in diet.

Attrition was low, with three withdrawals, only one of which was related to the programme. All four sessions were ranked as being 'useful,' but the session on psychological well-being was ranked the highest. The most frequently selected area of concern was physical activity (50%) and the most frequently requested additional topic was nutrition (95%), supporting the identified need for more lifestyle-related support for cancer survivors (Thomas, Davies, and Batehup, ongoing).

On a scale of 1-5, 5 being 'most useful,' group sessions and nurse/health educator support achieved a mean rating of 4.4, telephone sessions 4.2, and peer group support 4.1 (Figure 3).

Figure 3: Participant Preferences for Intervention Delivery



In terms of programme length, 81% felt it was ‘just right,’ whilst 14% would have preferred longer. The majority (89%) preferred mornings or afternoons. Daytime and weekend options received greatest endorsement, which has been found in a number of self-management support programmes.

This intervention did not measure participant outcomes, nor did it have a comparative group. It does, however, represent an increasingly popular approach to providing self-management support. More evidence is required as to whether this type of intervention, using expensive professional resources, is necessary for the majority of breast cancer patients, or whether less intensive interventions are suitable for survivors, with this type of intervention being tailored for patients who have a higher level of risk. For example, a recent study by Armes et al. (2009) found that nearly two thirds of cancer survivors reported few or no unmet needs at the end of treatment and the number without unmet needs increased 6-months after the completion of treatment. A key issue is to ensure that there is some form of assessment of needs post-treatment

More recently, Chung et al. (2009) conducted two focus groups to determine the utility and cultural relevance of ‘*Taking CHARGE*’ for African American post-treatment breast cancer survivors (n=26), a group of survivors currently under-represented within the oncology self-management literature (Aziz and Rowland, 2007). Although findings indicated that the

program's content was relevant to participants' experiences, African American women identified a need for cultural enhancements in a number of areas (Figure 4).

Figure 4: Suggested Cultural Enhancements

- Spirituality
- Self-preservation
- Positive valuations of body image
- More emphasis on competing demands
- More emphasis on anticipatory guidance
- More emphasis on disclosure
- More emphasis on persistent fatigue
- Photographs of younger African American women
- The use of images depicting strength
- The use of vivid colours
- Age-specific concerns about body image/sexuality
- Inclusion of portable observation logs

The feedback provided by participants is consistent with the positive psychology movement, with a focus on self-preservation, positive valuations, and images of fighting spirit. This suggests that testing self-management support that is based on positive psychology might be a useful step towards identifying and meeting the needs of African American breast cancer survivors. One such example is the HOPE (Helping Overcome Problems Effectively) programme, currently being piloted by Macmillan Cancer Support and Coventry University (DH, 2010).

Although this feedback is from a small sample, considering the under-representation of ethnically diverse groups (Aziz and Rowland, 2007; Fenlon and Foster, 2009), these findings at the very least provide preliminary insight into the potential for culturally adapting self-management support for cancer survivors of ethnic minority.

Another period of 'transition' or 'adjustment' encountered by breast cancer survivors is the 5-year milestone, which is widely acknowledged as a time when risk of recurrence is reduced. Whilst this can be a time of relief, it can also be a time when family and friends are eager to move on from the disruptions of the cancer experience, leaving women to work through unresolved questions and feelings alone (Lewis and Field, 1995). Bloom et al. (2008) report on a pre-post test RCT of three 6-hour educational sessions designed for women (n=404) approaching this milestone, a period when survivors reflect on their experience and make future decisions. The sessions took place at monthly intervals on a Saturday (n=201); the control group attended a one-day educational session (n=203). The three sessions focused on resources generated through supportive relationships with family, friends, acquaintances, co-workers, and other people within a survivor's social network. These were reported as key supports for self-management by the survivors in the study by Foster et al. (2009). Through a variety of activities and presentations, each session addressed four themes: addressing unmet informational needs; promoting exercise and nutrition; improving communication

skills; and providing and receiving emotional support. Whilst similar to the content of the self-management programmes already discussed, some novel additions include a comical sketch addressing communication problems with physicians and a session led by two legal experts presenting information about the rights of breast cancer survivors.

The participation rate was a low 54% and, on analysing the reasons why women declined to participate, two explanations were found. Eighteen percent indicated that they wanted to put the experience behind them, emphasising the importance of individual assessments prior to being contacted to participate in a supportive programme; a perceived need is required for the programme to be of any efficacy to the patient and the provider. The remainder indicated that they were willing to participate but were unable to commit to the sessions.

There was a 96% retention rate at 3-months post-test, with women in the intervention group compared to the control group demonstrating significantly greater knowledge regarding breast cancer and its treatment. Women in the intervention group were also significantly more likely than controls to report increased physical activity. However, no dietary changes or evidence of improved communication with family members or physicians was found, providing further support that increased knowledge does not reflect changes in behaviour or health outcomes, or that their baseline support and dietary habits were perceived as effective (Coulter and Ellins, 2006). This was an interesting intervention and rare in studying survivors at this point in time. However, it does reinforce the contention that for the majority of breast cancer survivors, they are managing well in a 'new normal' life. There will be, however, others who may benefit from an intervention which meets their unmet needs. Predictably, this may be related to late consequences of treatment, the change of behaviours which would improve health, make an impact on survival and mortality, and serve psychological factors. The key is in detection of these needs, which may be achieved through the regular collection of patient experience and symptom data, as proposed by the National Cancer Survivorship Initiative (DH, Macmillan Cancer Support, and NHS Improvements, 2010).

The sheer importance of self-management support for cancer survivors has led to a shift from a clinically-led approach to aftercare to supported self-management based on individual needs and preferences (DH, Macmillan Cancer Support, and NHS Improvement, 2010). The aim is to empower survivors to take on the responsibility for their condition, facilitated by the appropriate clinical assessment, support, and treatment. In Canada, Nyhof-Young et al. (2006) have developed an evidence-informed patient empowerment course: '*Managing Your Cancer Journey*' (MYCJ). Initially, a 45-60 minute assessment with a breast cancer nurse is provided in order to create a personalised self-management care plan to ensure the program best suits the patients' needs since a number of support options are offered, including: educational courses; peer support (e.g. 'buddies' who are cancer survivors); '*Cancer Voices*' web-based forum; and a resource library. This reflects a 'continuum' of intensity of intervention support options, and avoids a 'one approach fits all' approach.

Correspondence with the program manager has provided some unpublished findings from a pilot evaluation conducted in 2009 demonstrating that attendance at an MYCJ session was associated with both an increase in self-efficacy and a decrease in anxiety post-session. Data collected three weeks after attendance at MYCJ were inconclusive due to loss of

several participants to follow-up, which requires further investigation and leaves only limited evidence of effectiveness.

Qualitative data suggests that three general elements of the programme were valued most by the participants:

- learning coping skills
- time spent with a medical oncologist
- information sharing between patients

These three components encapsulate the key aspects of self-management support – information provision, sharing with peers, the support of significant healthcare professionals, and the development of self-management skills.

This preliminary data provides some limited evidence of the feasibility of integrating self-management support into standard aftercare, which is fundamental if this service is to be available to all and tailored to need. It has been suggested that it is imperative that models of self-management support facilitate or augment current practice rather than attempting to replace services (Jordon et al., 2008), and models such as this support the feasibility of such integration. However, there remains a requirement for longer-term follow-up as well as an analysis of cost-effectiveness.

The integration of self-management patient education into breast cancer (n=100) aftercare is also being trialled in the UK. For example, Breast Cancer Care (BCC) is conducting an ongoing single-centre open, pilot RCT at Calderdale and Huddersfield NHS Foundation Trust called '*Living with Breast Cancer*' (Dent et al., ongoing). **This is a professionally-led 4-week course provided over four half-days designed to replace hospital-based aftercare with patient-initiated aftercare supported by a self-management programme.** This pilot does not at this point include a co-facilitator who has cancer experience. The model of shared delivery between a health professional and a peer facilitator is potentially more effective on participant outcomes, than either a lay tutor alone (as in the expert patient programme) or with a professional tutor alone (Griffiths and Foster et al., 2007; Foster and Taylor et al., 2009).

It will be important to explore whether all patients need this intensity of intervention for self-triggered follow-up. Outcomes of interest will be any reductions in unscheduled care, or increases in scheduled care such as GP attendance. This approach also has the potential to correct erroneous health beliefs. The alternative is to target the programme at higher risk individuals who may experience greater morbidity related to treatment consequences and co-morbid conditions.

Positive feedback about the course itself has been gained from participants, with QoL data expected to be ready by mid-2010. Feedback demonstrated that self-management support groups can provide a sense of 'normalisation' to the symptoms and experiences confronted during survivorship, as well as increase health literacy and motivation to carry out health-enhancing behaviours:

"Made me feel that the symptoms I am experiencing are quite normal."

"I am thinking more positively about exercise and will get started."

"Supplements and diet and the effects of menopausal symptoms helped a lot."

Problem-Focused Self-Management Support

Poor Levels of Physical Activity

In the UK and England, 62.8% of people living with or beyond cancer are 65 years of age or older (Office of National Statistic, 2009), making older cancer survivors a high risk group for age and disease-related functional decline. There is evidence for the benefits of exercise in older cancer survivors as well as in other older populations and yet the adherence of this population to physical activity support can be problematic for a number of reasons, including lack of confidence, co-morbidities, and travel difficulties (Courneya et al., 2004). More research is needed to guide clinical decisions about exercise in older cancer survivors, and indeed, to identify the very unique support needs of this group of survivors (Addington-Hall et al., 2010).

In a single-group, pre- and post-test study among older (mean age = 59.6 years) stage I or II breast cancer survivors (n=34) of up to 5-years, Damush, Perkins, and Miller (2006) examined the efficacy of a 3-weekly one-hour oncologist-referred exercise programme designed to promote moderate intensity activity. The programme, based on social cognitive theory, focused on increasing exercise self-efficacy and enjoyment of physical activity, whilst also improving QoL and reducing perceived barriers. The programme was delivered by the researchers at a primary care centre, and participants also received three 15-minute follow-up telephone calls during weeks 4, 6, and 10 to discuss behavioural contracts and facilitate problem-solving.

Despite the belief that cancer survivors are more receptive (than non-cancer survivors) to messages and advice regarding lifestyle behaviours and change, there was a very low uptake of this intervention. Of 101 eligible participants, only 43% chose to participate. Those who did not participate were either uninterested (58%) or unreachable by mail or phone. Of the 34 participants enrolled on the programme, 13 attended the sessions, 11 requested individual sessions, 4 received session materials by mail, and 6 received no intervention. Information pertaining to participants who requested individual support is not provided, but would have been beneficial in further evaluating the needs of different survivors. Nevertheless, it can be hypothesised that those requesting individual support might have felt embarrassed or lacked confidence. **Research on the needs of older breast cancer survivors suggests that poor body image, disability due to co-morbidities, or lack of**

transport might have also played a role in requests for individualised support or for declining to participate (Addington-Hall, 2010).

Thirty participants (88%) provided information at 6-months, which demonstrated improvements in self-efficacy, enjoyment of physical activity, uptake of physical activity, improved QoL, and a reduction in perceived barriers. The increase in QoL and physical activity, as well as the reduction in perceived barriers approached statistical significance, but the other variables did not. It is unknown whether improvements were due to the exercise component of the intervention or the social support component. Furthermore, this was a very short intervention that, offering little evidence for the sustainability of increased exercise among this group of women. **Nevertheless, some evidence that can be concluded is that there is a low uptake of exercise interventions among older cancer survivors and thus there is a need to further examine the reasons for this and how this might be overcome.** There is also a need to consider the best mode of delivery, be that group support or one-to-one support; given that 32% of this small cohort requested individual support indicates that this might be a potential barrier for older cancer survivors wishing to access support with physical activity.

Figure 5 describes a physical activity programme for cancer survivors, which meets many of the key criteria of patient-centred care, including partnership in care, holistic individual needs assessment, tailored support, and informed choice.

An exemplary physical activity programme available to survivors of breast, colorectal, and melanoma cancers is the BACSUP (Bournemouth After Cancer Survivorship Project) 'Active Wellness Programme,' developed in partnership with Royal Bournemouth Hospital, NHS Bournemouth and Poole, Bournemouth University and MacMillan Cancer Support (Milne et al., 2010). The programme involves two initial one-to-one consultations with a specially trained member of staff where an holistic assessment is carried out, including a discussion of barriers to exercise, in order to tailor the programme to individual needs, as well as to provide a personalised information pack to help get the most from the programme. **A readiness check is done prior to referral, an approach recommended based on the Stanton et al. (2004) study of preparedness; a readiness to be physically active score of >70 is required for participation.**

Participants receive a telephone call at three-weeks for the provision of support and encouragement, followed by a one-to-one review at six-weeks to assess progress, maintain motivation levels and modify the programme if necessary. A one-to-one review and reassessment is also provided at twelve-weeks to measure improvements and discuss and agree ongoing activity options in a collaborative way. Additional support options are available, such as the BACSUP Active Wellness Group, which provides an opportunity to meet others survivors and listen to life improvement guest speakers.

In a pilot study of the programme, survivors who had completed primary treatment within the previous 5-years (n=180) were referred to the service: 58 completed the programme; 65 are currently on the programme; 30 started but are on hold due to circumstances; 21 were not yet ready to join the scheme.

QoL outcomes at 12-weeks included:

100% reported improved body/self-image	97% showed improved flexibility
95% reported improved feelings of well-being	95% showed improved cardiovascular fitness
92% reported reduced fatigue	84% showed improved blood pressure
91% reported improved shoulder function	58% lost >1kg in weight
	34% lost >3kg in weight

100% would recommend the programme:

*"I feel there are so many doors open and I shall certainly go through a few."
"I feel a real sense of achievement, more energy and generally fitter."*

Improving Health Information-Seeking Activity

With the changing nature of the needs of breast cancer survivors and considering that little is known about what long-term breast cancer survivors require to maintain their disease-free status, to make informed health decisions and to reduce potential co-morbidities, Becker et al. (unpublished) aimed to: a) understand the knowledge and attitudes of breast cancer survivors about their health status, and b) test if a self-management program can assist in increasing health information-seeking and influence health behaviours that decrease chances for other cancers or health conditions. This prospective exploratory pilot study of a self-management programme, *'More than just Cancer,'* comprised survivors (n=20) who were at least five or more years disease-free. The programme was designed around the Stanford Chronic Disease Self-Management program, as well as a combination of Bandura's social learning and Beck's cognitive behaviour theories. The aim of the study was to test if a self-management program can assist in increasing health information-seeking behaviours and influence health behaviours that decrease chances for other cancers or health conditions, where evidence is growing that 'normal' body weight, regular physical activity, and healthy diet, can affect cancer recurrence, survival, and mortality (Demark-Wahnefried, and Jones, 2008; Kellen et al., 2009). The programme addressed five key areas commonly adopted in self-management programmes: problem-solving; decision-making; resource utilisation; patient/healthcare provider partnership; and direct action. Despite the low sample size, there was a significant improvement in information-seeking, demonstrating that a self-management program tailored to the needs of long-term breast cancer survivors can increase desire to access information that might increase health literacy and subsequently increase the uptake of self-management behaviours. **Self-management support aimed at increasing health literacy is fundamental for the sustainability of self-management behaviours (Jordon et al., 2008) as well as to the provision of patient-centred care (IOM, 2001).**

Health literacy:

The capacity to seek, understand and utilise health information to participate in decisions about one's own health. It is central to a person's participation in their healthcare – knowing when to seek medical advice; communicating effectively with healthcare professionals; and adhering to treatment (Jordon et al., 2008).

Patient-centred care:

Patient-centred care has been defined by the Institute of Medicine (IOM, 2001) as: *"providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions."* It is about putting the patient and their experience at the heart of quality improvement.

According to the lead investigator, four years post-implementation, members of this long-term cancer support group still talk and meet annually, illustrating the strength of the social aspect of such programmes. Nevertheless, further evaluation via statistical testing, as well as the exploration of health outcomes that might improve as a result of increased information-seeking, is warranted.

COLORECTAL CANCER

One adjustment-focused and one problem-focused self-management support initiatives were identified for colorectal cancer survivors.

Adjustment-Focused Self-Management Support

A USA-based pilot of the Macmillan Cancer Support 'New Perspectives' self-management course programme is 'Self-Management for Cancer Survivors: Taking an Established Intervention to a New Frontier.' The pilot has been designed for colorectal cancer survivors and their family as a free course that recognises the impact that cancer can have on family relationships and activities. This peer-led course, which is based on the Stanford CDSMP, is a post-treatment intervention available at different locations around the Roanoke Valley. Six peer leaders have been trained thus far, and 90 survivors are being sought for the pilot evaluation, with the expectation of gaining data from 60. However, the research lead has commented that despite enthusiasm from survivors and healthcare professionals, there has been some difficulty with recruitment, which is likely due to initiative being self-referral. As such, action is being taken to try and resolve this, including attempts to engage the religious community and utilising the media. Recruitment was most successful following a local television news story, but the difficulty has been in keeping the momentum going. The programme began in October 2009 and February 2010 saw the commencement of the second course, which comprises 12 participants (9 survivors and 3 family members). Outcome measures, which are firmly based on those recommended by the Stanford CDSMP (e.g. self-efficacy, health behaviours, healthcare utilisation), will be taken pre-course and 6-months post-course (Agnew et al., ongoing).

Problem-Focused Self-Management Support

Ostomy Self-Management

Colorectal cancer survivors with ostomies are confronted with a number of short- and long-term complications. In one study of long-term survivors (n= 284) who were 5+ years post-treatment, clinical records indicated that within 30-days of surgery, 19% experienced complications (Liu et al., 2010). From 31-days on, 69% experienced complications. Bleeding and postoperative infection were common early complications, whilst the most frequent long-term complications included hernia, urinary retention, haemorrhage, skin conditions, and intestinal obstruction. Compared to survivors without an ostomy, those with one have been found significantly more likely to report appearance concerns and pain and discomfort (Schneider et al., 2007), indicating these survivors to be a high risk group requiring support with ostomy-related self-management.

The USA Chronic Care Ostomy Self-Management (CCOSM) Program for colorectal cancer survivors is a 9-session programme based on the well-established chronic care model (CCM) as well as designed around the concept of peer support (Krouse et al., ongoing). The program is facilitated by a certified ostomy care nurse and trained peer-ostomate 'buddies,' thus incorporating peer support along with patient and family education and support. The programme is aimed at developing an effective, acceptable, and exportable system of care

for patients with new intestinal stomas, so that they can maintain their maximum QoL and functioning. **Patient activation** will be an important component of this intervention, with secondary aims and outcomes being to evaluate the patient- and caregiver-rated effectiveness and satisfaction of each session and evaluate relationships and correlations between ostomy-specific QoL scores and scores and patient activation. Cost-effectiveness will also be examined, and an infrastructure and strategy for a larger intervention study.

Patient activation (Hibbard et al., 2004)

involves:

- 1) Believing the patient role is important.
- 2) Having the confidence and knowledge necessary to take action.
- 3) Taking action to maintain and improve one's health.
- 4) Sustaining health action, even under stress.

PROSTATE CANCER

Treatment for prostate cancer leaves survivors with an array of long-term physical and psychological needs, all of which can be dependent on the type of treatment received. For example, Mols et al. (2009) showed that out of 780 prostate cancer survivors, 40-74% reported sexual problems, 23-48% urinary problems, and 5-10% bowel problems. Urinary problems were most common after prostatectomy, whilst bowel problems were most common after radiotherapy. Psychological consequences of treatment include reduced feelings of masculinity, anxiety, depression, stress, and problems coping (Lev et al., 2004; Pirl and Mello, 2002; Visser et al., 2003), which have been found to have QoL implications for partner's as well as survivors (Sanders et al., 2006). The National Cancer Intelligence Network (NCIN) will be examining the prevalence of cardiac and bone complications in patients with prostate cancer, and reporting on this in 2010.

A number of needs were also identified as part of the NCSI Mapping Project (2009), in collaboration with the Prostate Cancer Charity, in particular the need for more personal control over their condition and any treatment side-effects. There was particular emphasis on further research into the role of exercise and diet in helping men manage their condition. Furthermore, as with all cancers, the support need of minority ethnic groups has also been highlighted as an area where more support is needed. For example, African American survivors encounter socio-cultural barriers in seeking information and support, leaving many of their needs unmet (Rivers et al., 2010). This needs to be addressed as ethnic minorities living with or beyond prostate cancer have been found to report lower QoL than their Caucasian counterparts (Penedo et al., 2006). Some researchers have also found higher rates of mortality among ethnic minority survivors, along with more extensive disease at diagnosis and worse prognosis (Thompson et al., 2001; Eton et al., 2001).

One literature review addressing self-management support for men surviving prostate cancer was identified, which evaluated RCTs published between 1997 and April 2009 in order to examine the best approaches for developing programmes to meet the needs of these survivors (Cockle-Hearne and Faithful, 2010). The reviewers identified seven RCTs designed to help men *adjust* to diagnosis and lifestyle changes associated with cancer (Table 2) and ten designed to help men with specific *problems* associated with survivorship (Table 3). These RCTs are summarised in the following tables, before the reviewers conclusions are presented.

Table 2: Adjustment-Focused Self-Management Support

Study/Intervention	Sample	Findings
1.7-weekly physical training sessions, with and without additional information (Berglund et al., 2007).	Prostate cancer survivors (n=194) within 6-months of diagnosis.	No improvements in QoL.
2.6-weekly education and skills training group sessions, as well as facilitated peer discussion (Lepore et al., 1999).	Survivors (n=24) post-surgery or radiotherapy.	Improved psychological well-being and some changes in mediating variables showing more favourable outcomes for the intervention group on social conflict, personal control, distress caused by intrusive thoughts and prostate cancer knowledge. The intervention was found to be beneficial to men with relatively inadequate social support.
3.10-weekly group sessions of cognitive-behavioural stress management (Penedo et al., 2004).	Survivors (n=92) within 18-months of radical Prostatectomy or radiotherapy.	Significant improvements in QoL.
4.10-weekly group sessions of cognitive-behavioural stress management (Penedo et al., 2006).	Survivors (n=191) within 10-months of radical prostatectomy or radiotherapy.	Significant improvements in perceived stress management skills, QoL and benefit-finding. Participation in the intervention predicted all three outcomes.
5.12-months phased telephone social support sessions, commencing with weekly calls before moving to fortnightly and then monthly calls (Scura, Buding and Garfing, 2004).	Survivors diagnosed with the last 4-months.	No improvements in QoL.
6. Information booklet mailed 2-weeks post-treatment, outlining coping strategies and encouraging social comparisons (Stiegelis et al., 2004).	Survivors (n=228) 2-weeks post-radiotherapy.	Men who were low in control and high in illness uncertainty prior to their first treatment reported less tension, anger and depression when they received information than when they did not.
7.6-months of 21 cognitive-behavioural group sessions designed to increase physical activity (Taylor et al., 2006).	Survivors (n=134) receiving continuous hormone therapy).	No significant differences in QoL. Both groups were more beneficial in those with greater distress or more limited social support.

Table 3: Problem-Focused Self-Management Support

Study/Intervention	Sample	Findings
1.8-weekly telephone sessions, plus mailed support material, delivering problem assessment, problem solving, cognitive reframing, information, and patient provider communication (Mishel et al., 2002).	African American and Caucasian survivors (n=239) within 2-weeks of catheter removal post-surgery or within first 3-weeks of radiation therapy.	Uncertainty management significantly improved cognitive reframing and problem-solving, control of urine, and satisfaction with sexual function; none of these were sustained over time. Decrease in symptoms across all groups but only sustained over time for African-American participants. Level of education, quantity of information and extrinsic religiosity influenced efficacy of the intervention.
2.6-weekly one hour educational information lectures, with and without an additional 45-minute for peer discussion (Lepore et al., 2003).	Survivors (n=25) within 1-month post-treatment.	Education plus peer group more effective than education alone. Peer group discussion associated with improved sexual bother. Both interventions raised prostate cancer knowledge and neither showed an effect on mental functioning, depressive symptoms or urinary, bowel or sexual functioning. Men with lower self esteem, low prostate-specific self-efficacy and higher depressive symptoms gained the most benefit.
3.8-weeks of once weekly one-to-one face-to-face informal meetings with a peer prostate cancer survivor (Weber et al., 2004).	Survivors (n=30) post-radiotherapy.	Significant effect on depression at 4-weeks into the intervention but not sustained to the end. A smaller effect for self-efficacy by the end of the intervention. Support group showed significantly less sexual bother at the end but there were no significant effects on sexual function or urinary function or bother.
4. Four counselling sessions with homework, with survivor or with survivor and their partner (Canada et al., 2005).	Survivors (n=84) 3-60 months post-radiotherapy or surgery, and their partners.	Partner attendance did not affect outcomes. Men improved on emotional distress, sexual function and satisfaction, which maintained to 3-months follow-up but then declined. Only overall sexual satisfaction continued to improve at 6-months.
5.6-monthly sessions (two face-to-face and four via telephone) of a nurse-led computer-assisted identification of problems related to sexual, urinary, and bowel dysfunction, cancer worry, partner dysfunction, and depression, and tailoring physical, behavioural and emotional strategies to deal with problems (Giesler et al., 2005).	Survivors and partner (n=85) 6-weeks post-treatment.	Significant long-term improvements in sexual functioning, sexual limitation, and cancer worry. No effects for sexual bother, urinary or bowel outcomes. Baseline depression moderated the impact of the intervention. Participants with low depression improved on urinary bother but significance not sustained at follow-up. Weak, outcomes for health-related QoL overall but evidence that high depression associated with some gain in emotional and physical functioning.

6.6-fortnightly support sessions over 3-months, offering information, education, behavioural and psychosocial support, and continued practice of exercises (Zhang et al., 2006; 2007).	Survivors (n=29) with urinary incontinence 6-months post-surgery.	An effect for practicing exercise daily and continence but only weak effects on QoL. Improved continence associated with reduced depression and symptom distress over time.
7.10-weekly group sessions of cognitive-behavioural stress management with an ethnic minority group of men (Penedo et al., 2007).	Monolingual Spanish speaking survivors (n=93) within 18-months post-radiotherapy.	Small effects for QoL. The experimental group increased in physical and emotional well-being. More significant effect for sexual functioning in the intervention group.
8.6-weekly one-hour telephone sessions with patients and their intimate partners, delivering information and coping skills training based on cognitive behavioural techniques (Campbell et al., 2007).	African American survivors and their partners (n=30).	Men in the intervention group reported higher disease-related QoL. No effects found for health-related QoL or for self-efficacy.
9. Three home visits and two telephone sessions, all two weeks apart and consisting of five core areas: family involvement; optimistic attitude; coping effectiveness; uncertainty reduction; and symptom management (Northouse and Mood, 2007).	Survivors and their partner (n=263).	The intervention group reported less uncertainty about their illness and more communication with their spouse immediately post-intervention, but there were no significant effects at four or eight months.
10.10-weekly cognitive-behavioural stress management sessions of 90-minutes didactic instruction and discussion and 30-minutes relaxation training (Molton et al., 2008).	Survivors (n=121) within 18-months post-treatment.	Significant effect on sexual functioning. Men with higher interpersonal sensitivity were particularly responsive to the intervention.

Some further relevant information pertaining to the studies reported by Giesler et al. (2005) and Campbell et al. (2007) have been included within the current report. The addition of this information is anticipated to assist in the final evaluation of those self-management support strategies that are most effective and thus facilitate the formation of a set of recommendations and guidelines that can be used in the development and commissioning of self-management support initiatives.

The implications of prostate cancer for both the patient and their intimate partner is well-documented, with increases in men's problems relating to subsequent decreases in spouse QoL (Kornblith et al., 2001; Eton, Lepore, and Helgeson, 2005; Ko et al., 2005). Hence, recognition of the need for self-management support designed for prostate cancer survivors and their partners.

Giesler et al. (2005) report on a prospective, multi-site, RCT designed to assess the 4, 7, and 12-month efficacy of a 6-month nurse-led intervention (n=48) for improving QoL in prostate cancer survivors and their intimate partner during the first year post-treatment. Comparing QoL outcomes with a control group receiving standard care (n=51), the intervention aimed to facilitate the identification of QoL problems (primarily sexual, urinary, and bowel dysfunction, anxiety over recurrence, partner adjustment, and depression) and provide psycho-educational symptom management advice.

The couples met once each month with a nurse, twice in person and four times by telephone. QoL problems were identified with a computer-assisted assessment program, which presented problem-specific evidence-based strategies from the literature that could be used to develop a mutually agreed upon care plan. Strategies included Kegal exercises for urinary dysfunction and communication skills training for sexual dysfunction and partner adjustment problems.

The demographics of couples who were approached but declined participation (n=207) were similar to consenting couples. By 12-months follow-up, 85 (86%) of consenting couples remained in the study; the primary reason for drop-out was inconvenience. Attrition rates between the intervention and control group were nearly identical and those who dropped out of the study did not differ on demographic or medical factors from those who remained, although those who dropped out did have marginally worse role-emotional functioning, a component of QoL; worse role-emotional functioning indicates that emotional distress interferes with day-to-day functioning.

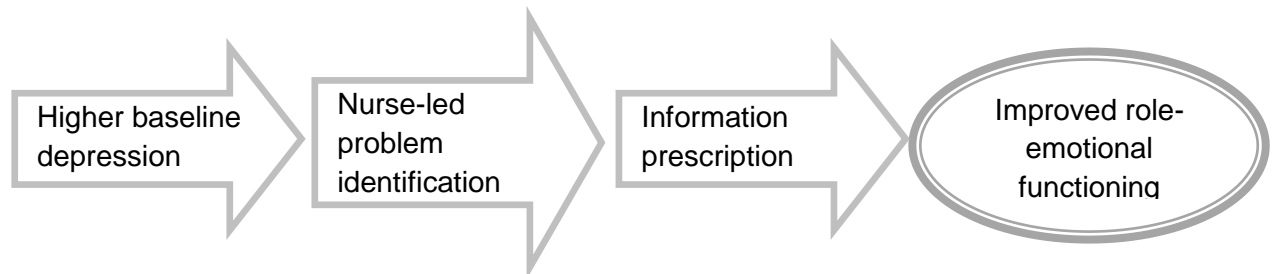
The problems most often assessed as requiring self-management support were sexual dysfunction (23%), urinary dysfunction (19%), and partner adjustment concerns (18%). At 4-months post-intervention, patients who received the intervention reported significantly better gains in sexual functioning, which was a difference that remained marginally significant at 7 and 12-months. Greater reductions in the extent to which sexual dysfunction interfered with role activities were also reported, but by 7 and 12-months this difference was no longer statistically significant. At 12-months follow-up, men in the intervention expressed significant reductions in their anxiety about recurrence and treatment effectiveness. Bowel and urinary-related outcomes, as well as partner functioning, did not differ significantly between groups, yet the severity of bowel and urinary problems at end of treatment could lead to the speculation that most of these effects will resolve over time and some will not.

Nurse-led problem identification →

- ✓Improved sexual functioning
- ✓Reduced anxiety
- ✗No effect on bowel problems
- ✗No effect on urinary problems
- ✗No effect on partner adjustment

One outcome was mediated by baseline depression, with higher baseline depression experiencing marginally greater gains in role-emotional functioning when in the intervention group. This indicates that depression might be a need particularly receptive to nurse-led problem identification support in prostate cancer survivors. Risk stratification via

the **Hospital Anxiety and Depression Scale (HADS)** might offer a feasible method of identifying prostate cancer survivors who might be amenable to this type of support. Furthermore, role-emotional functioning was more likely in those who dropped out of the study, raising questions as to why this might be and also whether they were, in fact, the most in need of this intervention.



Overall, this study demonstrates that nurse-led computer-assisted, combined face-to-face and telephone-delivered interventions for survivors and their partners are capable of improving some areas of well-being in prostate cancer survivors. **The model was particularly effective with sexual functioning, anxiety reduction, and in patients with higher baseline depression, improving role-emotional functioning.** Thus, it could be implied that this intervention was more effective for the patient as opposed to their partner, although the literature does show an association between improved patient well-being and improved partner well-being in this group (Kornblith et al., 2000). Nevertheless, this study might have offered greater utility if partner outcomes had been explored. The context of assessment and delivery of this type of intervention in the UK is increasingly being provided by cancer specialist psychology services, but currently the coverage for all patients remains limited. In the main, this type of provision is delivered in a one-to-one consultation.

As with breast cancer, some researchers are attempting to close the gap in cultural inequalities within prostate cancer healthcare provision. In a small pilot telephone-delivered 6-week partner-assisted coping skills training (CST) programme for African American prostate cancer survivors and their intimate partners, Campbell et al. (2007) compared the feasibility and efficacy (effects on QoL, symptoms, self-efficacy, and carer strain) of coping skills training (n=12) compared to usual care (n=18). **The coping skills' training was delivered to survivors and their partners via six one-hour telephone sessions, focusing on problem-solving and action planning. Communication skills' training was also taught for interpersonal situations.**

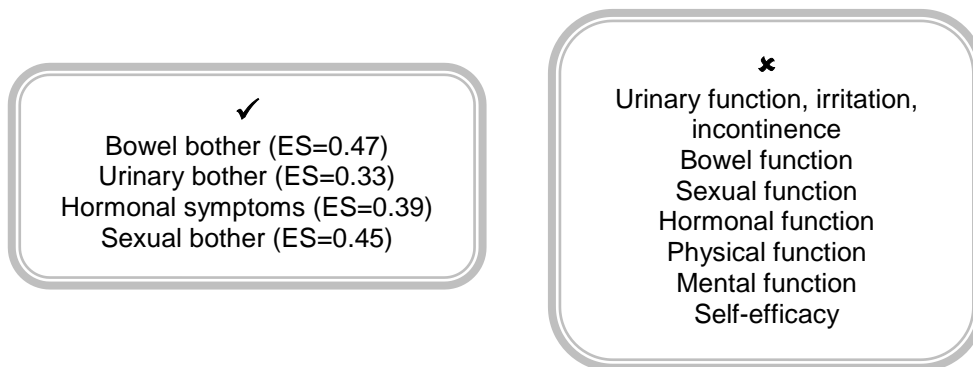
Nine couples did not complete the intervention or did not provide post-intervention data, demonstrating a high drop-out rate. The most common reason for drop-out was difficulty scheduling a time when both the survivor and partner were available. Those couples who completed the training provided the following feedback:

- ➔ 87% described the training as beneficial
- ➔ 60% found communication skills training to be especially valuable
- ➔ 27% found telephone-delivery convenient
 - made it easier to be vocal about sensitive topics
- ➔ 33% would prefer some degree of face-to-face contact

- 27% recommended adding videos to demonstrate skills
 - as well as more time on communication and problem-solving skills.

Notably, videos have been cited as being effective in providing role models for adaptive coping and the delivery of health information in people with cancer (Burish, Snyder, Jenkins, 1991; Mykityshyn, Fisk, and Rogers, 2002). Also, communication skills are an integral component of health literacy (Kickbusch et al., 2005) and particularly important in patient-centred care (Coulter and Ellins, 2006).

Compared to the control group, the coping skills group demonstrated moderate improvements in four QoL domains:



In partners, moderate improvements were found for some areas of QoL and no effect was seen in others:



There were some clear improvements in outcomes for both cancer survivors and their partners, although the sustainability of these improvements has not been tested over time.

Cocklehearn and Faithful (2010) concluded that supported self-management is a viable and appropriate way of providing healthcare solutions to ameliorate men's post-treatment functional and emotional problems. Integration into clinical practice will require training, resources and commitment, but the psychosocial and behavioural studies reviewed provide convincing evidence that can be used to design, implement and evaluate future self-management programmes for men surviving prostate cancer.

These findings, along with the identified needs of prostate cancer survivors, demonstrate the importance of risk stratifying the development of interventions based on the range of different treatment and aftercare modalities (Figure 6). **There are different needs according to treatment group, marital status, and ethnicity.** Interventions for all of these groups appear to require a symptom-specific component that stratifies according to the most

common side-effects of treatment, be that urinary incontinence after prostatectomy or bowel problems after radiotherapy. This clearly needs to be accompanied by further individual needs assessment, for example, interventions designed for the survivor and their partner, or ethnic minorities. Both of these appear to benefit from telephone-delivered interventions, which is likely to be due to the sensitivity of marital issues and socioeconomic barriers.

Figure 6: Risk Stratification Measures for Prostate Cancer Survivors

Risk Stratification:

There are a number of psychometrically robust patient-reported measures that might facilitate such risk stratification, such as the **Prostate Cancer Index Composite – Short-Form** (EPIC-SF; Wei et al., 2000) or the **Social Difficulties Inventory** (SDI; Wright et al., 2007). The former instrument can be used to stratify survivors according to specific physical problems (i.e. urinary, bowel, sexual) or symptoms of depression, whilst the latter might be more useful for identifying socially isolated survivors or those experiencing relationship problems. As an example of risk stratifying according to intervention: survivors identified as having sexual and urinary problems might be stratified to receive one-to-one telephone support; on the other hand, if they are identified as also having relational difficulties due to these problems, telephone support for both the survivor and partner might be more appropriate. Similarly, if the survivor is identified as being socially isolated, group support might be provided.

INTERVENTIONS FOR PATIENTS WITH A RANGE OF CANCERS

Five adjustment-focused and two problem-focused self-management support programmes and initiatives were identified for non site-specific cancers.

Adjustment-Focused Self-Management Support

With the rapid growth of technology, especially the Internet, more opportunities are available for the delivery of self-management support, which can be interactive, convenient, and cost-effective (Foster and Roffe, 2009). Lorig et al. (ongoing, a) are conducting a pilot 6-week self-efficacy enhancing interactive web-based '*Cancer Survivors Online Workshop*' for breast, prostate, colorectal, gynaecologic, and hematologic cancer survivors (n=400) who have not received surgery, chemotherapy, or radiation within the past 5-years. Utilising a longitudinal pre- and post-test design to measure outcomes at baseline, and four and eight-months post-intervention, the programme is looking to improve QoL, psychological well-being, healthcare utilisation, and self-management skills via increased self-efficacy. Four methods are used for enhancing self-efficacy (Figure 7):

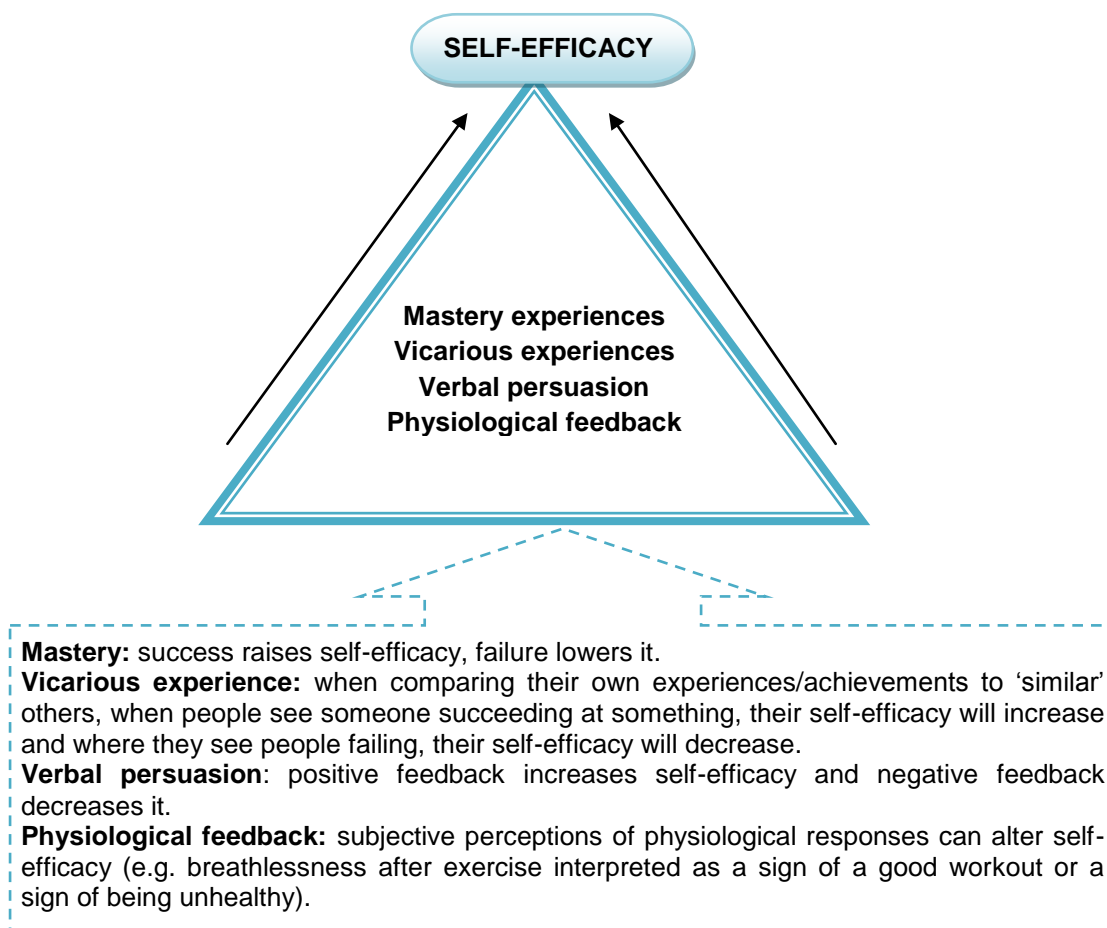


Figure 7: Methods of Enhancing Self-Efficacy

Four online workshops, based on an existing Internet Chronic Disease Self-Management Program for people with chronic conditions, will be offered to cancer survivors, who are asked to log on at least three times weekly for a total of about 2-hours and to take part in the activities for that session. Each workshop, comprising 25-30 participants, includes information, learning opportunities, and peer interaction. Each program is moderated by a pair of trained peer moderators, at least one of whom is a cancer survivor. **This co-tutor approach has been evidenced as offering the greatest benefits to patients (Coulter and Ellins, 2006).** There has been debate over the effectiveness of lay-led education programmes (Griffiths et al., 2007; Foster et al., 2009), hence greater emphasis on a dual delivery model comprising 'expert healthcare professionals' as well as 'expert patients.'

Correspondence with the lead researcher has established that two courses have been offered thus far, which have had satisfactory participation (approximately 1,000 posts over the six-weeks for the 25-30 participants). No outcome data will be available for approximately 8-10 months. The study commenced in July 2009 and the estimated study completion is December 2011.

As well as the preceding study, in partnership with Macmillan Cancer Support in the UK, Lorig (ongoing, b) is testing a 6-week web-based workshop designed for survivors (estimated enrolment = 400) of primary breast, prostate, colorectal, gynaecologic, or hematologic cancers who were diagnosed within the last 5-years and had completed treatment within the last 5-years: *'Thriving and Surviving Online Workshop.'* The overall goal of the study is to determine whether an online cancer survivor education and support workshop can have lasting beneficial effects in helping survivors improve their self-management of health skills as well as improve QoL via better interactions with Oncologists, and the adoption of health behaviours. The workshops comprise 15-25 participants who log on at their convenience 2-3 times each week for a total of 1-2 hours, when they can read the lessons, complete assignments, and share ideas and experiences with 'classmates.' The estimated study completion is December 2011.

One of the NHS Improvement test communities within the NCSI¹ is a programme entitled *'Living well with and beyond Cancer.'* This is an 8-week self-management initiative designed as a potential model of aftercare, which takes a 'whole person' approach to health and well-being and is being piloted with cancer survivors (colorectal, urology, breast, and haematology) at the Penny Brohn Cancer Care centre in Bristol (Stobie et al., ongoing). At present there are 13 participants in one programme and 9 in another. The programme includes ten professionally-led 2-hour sessions covering a range of topics from cancer-specific with the sharing of stories to more general lifestyle advice and information about welfare benefits. The programme has a personalised aspect in that each participant identifies the problems that they would like support with. The researchers will also be running residential weekends as part of this pilot in May and June 2010.

¹ NHS Improvement is leading and supporting the testing of new models/approaches of care for those living with and beyond cancer, as part of the National Cancer Survivorship Initiative (NCSI). There are currently 16 Adult test communities and further Adult test communities will be commissioned.

In Australia, Yates et al. (ongoing) is also evaluating self-management support designed to be integrated into standard aftercare via a pre-post intervention, '*Cancer Survivorship Self-management (CSSM) Care Plan.*' The programme aims to promote sustained improvements in patient self-management abilities following completion of active cancer treatment for breast or colorectal cancer. This project builds on the work developing self-management support for people with long-term conditions in Australia through the National Chronic Disease Strategy and the Sharing Health Care Initiative (Jordan et al., 2008) using the research and development evidence to pilot the approach for cancer survivors. **The intervention includes an education session of around 60-minutes with a registered nurse to develop a personalised care plan followed by additional information and support** (awaiting more info). This reflects some form of risk stratification through individual assessment and needs identification, as well as a tailored approach to assessing self-management needs and then personalising the support required.

This intervention is supported by the evidence for assessment and care planning in facilitating self-management in people with long-term conditions and evidence that for successful self-management, coping, and lifestyle change, for example, there is a need for some patients to have ongoing support (coaching) from professionals (Coulter and Ellins, 2006). The key to success is to identify which patients will benefit from this type of support, and for how long. This might be achieved via risk stratification and the identification of high risk groups, including those that might be at increased risk of cancer recurrence or the development of co-morbidities. Those at high risk are similar to those within the general population, including obese individuals, smokers, elderly people, and ethnic minorities. Whilst lifestyle advice and care tailored for specific groups of people is available for the general population, exercise prescriptions being an example (DH, 2001), this is not yet integrated into the supportive care needs of cancer survivors (Thomas, Davies and Batehup, ongoing; Addington-Hall, 2010). Risk stratifying according to these objective measures is a feasible approach to the allocation of self-management support.

Structured self-directed management plans with priorities and timeframes, developed in accordance with the principles outlined in '*Capabilities for Supporting Prevention and Chronic Condition Self-Management*' (Flinders University, 2009) will form the essence of the transition from completion of treatment to self-management. **Patients in the control group will receive usual care and patients allocated to the intervention group will receive a 30-60 minute education session with a registered nurse, in order to develop an individualised CCSM Care Plan, followed up with additional information and support.** Recruitment is currently underway for the usual care cohort and that the intervention is due to commence in February 2010. Personal communication with the lead researcher has established that the 12-month project is due for completion at the end of May 2011.

A self-management oriented pilot nurse-led telephone model of follow-up, '*Surviving Cancer, Living Life,*' is being evaluated by Guy's and St Thomas' NHS Foundation Trust and Pfizer Health Solutions. Aspects of this service have been evaluated through a qualitative study by Richardson et al. (2009). The nurses aim to utilise specific communication skills based on motivational interviewing, health coaching, and counselling that includes components of self-management support for breast and prostate cancer survivors. **The service has three full-time, experienced and specially trained cancer nurses and each person who signs up for the service is allocated a nurse, who contacts them by telephone at**

pre-arranged times. Elements of the intervention include an in-depth telephone assessment to determine needs and develop a care plan, as well as ongoing coaching to support recovery and behaviour change where agreed. In-depth telephone interviews with a random sample of patients (n=22; both breast and prostate cancer) demonstrated overall patient attitudes being reported as “unequivocally positive” in that the programme filled a need for support at a time period when patients felt it was required.

The age of participants ranged from 41-80 years for females and 51-80 years for males. The majority of both groups were white British. A small number reported co-morbidities, including various levels of depression and anxiety among the men, whilst age-related conditions such as arthritis and high blood pressure were fairly common among men and women. Patients are invited to become ‘members’ of this service and are provided with information to guide their decision.

One breast cancer patient actively dropped out of the programme, whilst three men were withdrawn due to lack of response to phone calls from cancer nurses. The lady who dropped out of the programme after less than 3-weeks, claimed she did not want to take up time which she felt others needed more; she felt in control of her condition and did not feel the need for support. One of the men who was withdrawn had failed to respond due to a major operation, whilst another had gone to the Caribbean to overcome depression related to the prostate cancer. The third man had not responded due to ‘shame’ over not losing weight, as he had told the nurse he would do so. All three men would have liked to have taken part in the programme if circumstances had allowed.

Comments were mainly expressed in terms of attitudes to the relationship experienced with the nurses, as well towards the holistic approach adopted by them; specifically, they viewed the nurses as empathetic ‘friends,’ skilled communicators/counsellors, informed advisors, and valuable contacts. **This provides further support of the fundamental role that patient-centred health professionals can play in supported self-management, as well as provides further emphasis on the importance of communication skills.**

Telephone contact was generally viewed as being advantageous over face-to-face contact, particularly in terms of convenience, confidentiality and continuity. Patients felt they benefited from the programme in various ways, for example:

- it helped them to understand their illness and treatment better
- to improve their morale and face life with renewed confidence
- to adopt necessary changes in lifestyle
- in some cases, to develop better relationships with their families
- an increase in personal confidence when dealing with healthcare professionals.

The programme is very patient-centred and, from the patient perspective, fulfils and unmet need. Whilst some self-management programmes reported in this review have demonstrated a preference for face-to-face or group contact, telephone-delivery seemed acceptable and effective when incorporated into a wider model of aftercare.

Roberts et al. (ongoing) are testing an 8-week (2-hours once weekly) cognitive-behavioural based health and lifestyle coaching programme following cancer treatment at Gateshead Health NHS Foundation NHS Trust in order to assess the acceptability of replacing secondary aftercare with a self-management model. This study is also one of the NHS Improvement/NCSI test communities. The content of the programme, informed by a workshop comprising professionals and cancer service users, includes some novel approaches (e.g. increasing health literacy through information prescriptions) and some important yet often neglected areas of support (e.g. getting back to work).

The sessions within the Gateshead health and lifestyle coaching programme are delivered within the community (i.e. village hall, library or community centre) and adopt a co-tutor approach comprising a professional and peer tutor. **The design of this model reflects both the evidence for promoting the gaining of self-management skills – through the cognitive-behavioural approach, modelling competence and confidence in self-management by a peer cancer survivor, and educational input related to specific topics of interest and relevance (Foster et al., 2009; Griffiths et al., 2009).** The length of the programme should also be sufficient to ensure skills development, confidence building, and knowledge gain. Places are available for a maximum of ten men and women who have completed cancer treatment within the last three to six-months. Recruitment of programme participants will come from a referral from the key worker (clinical nurse specialist or oncologist) supporting the patient and family.

To date, a small pilot of the programme has been completed, comprising four women who had been treated for gynaecological cancer. Individual interviews and a focus group were held with participants, the feedback suggesting that the programme was a positive experience – helpful; supportive; and enhanced emotional coping skills. However, one session pertaining to *uncertainty* was found to be especially emotional and upsetting for some participants. Furthermore, the programme is now moving towards being called '*Mindfulness Coaching following Cancer Treatment*' in recognition of survivors in the pilot finding they were not ready to engage in diet and exercise initiatives due to the emotional distress still being experienced. One study has demonstrated that eight of the top ten most frequently reported needs in women with gynaecological cancer (n=103; 66 were post-treatment) were psychological, such as feelings of uncertainty and fears about recurrence (Steele and Fitch, 2008), making it plausible that some of these emotional issues might need prioritising above health and lifestyle needs. On the other hand, long-term fatigue has been reported as being one of the most prominent physical problems experienced by these women, which might be another reason for not feeling ready to engage in diet and exercise activities (Anderson and Lutgendorf, 1997; Steele and Fitch, 2008). This might suggest a need for greater education on the benefits of physical activity on managing cancer-related fatigue.

The focus of the health and lifestyle programme has moved towards developing skills for people to draw upon when dealing with adversity. Nevertheless, the observations made in terms of readiness to engage in lifestyle changes might be better assessed individually, with those high in psychological needs being stratified to one-to-one counselling and those struggling with fatigue receiving education and lifestyle support. Some women might require a combination of support. Again, the emphasis is on tailoring support according to individual

needs. For example, evidence suggests that women who have received radiotherapy for cervical cancer tend to have lower QoL than those who received surgery or chemotherapy (Vistad, Fossa, and Dahl, 2006); this offers feasible criteria for risk stratification and more effective resource allocation.

Although there were ten places on the initial programme, only four were filled and all by women. The challenges faced in recruitment included difficulties for Clinical Nurse Specialists in being able to identify patients for the programme, which was compounded by the narrow recruitment window initially specified as being between 3-6 months after the end of treatment. Some recruitment difficulties could potentially be resolved via needs assessment and risk stratification protocols. The evidence is that attrition for self-management programmes average around 50% (Coulter and Ellins, 2006), but this is not always the case, especially with programmes that adopt rigorous recruitment procedures. In this study, it was decided that increasing the recruitment window to a period from 3-12 months post-treatment would enhance the potential to meet the recruitment target of ten for the second cohort. An additional 'self-referral' recruitment path has also been added, with posters and leaflets being developed to be distributed to clinics, cancer information centres and day units. It might be useful to compare the outcomes of this programme between those who self-refer and those who do not.

A number of barriers to employment have been identified for people with long-term conditions, including anxiety about the impact of a health condition on ability to work as well as lack of confidence to return to work after having time off for treatment (Green et al., 2000). Through a review of the 1999 to 2008 literature, Munir, Yarker, and McDermot (2009) have shown that most types of cancers result in decreased work ability compared to healthy controls or those with other chronic conditions. Therefore, occupational health is an important component of self-management support and should be included into those programmes designed to take an holistic approach. Figure 8 describes a programme of supported self-management for people with long-term conditions, which comprises many of the key components identified as being important within supported self-management for cancer survivors, including the provision of a key worker, information provision, and one-to-one needs assessment. Currently this is a generic programme for people with a range of long-term conditions, and future plans within the NCSI include exploring the tailoring of the programme for cancer survivors.

Figure 8: The Condition Management Programme

The Condition Management Programme (Barnes and Hudson, 2006) is a cognitive-behavioural education approach to health advice with an emphasis on self-management. As part of the 'Choices Package' provided by Jobcentre Plus in partnership with the NHS, it is a short professional-led programme of up to 16 sessions aimed at helping people on Incapacity Benefit or Income Support to understand and manage their health condition, enabling them to explore the lifestyle and work opportunities available to them. There are one-to-one and group sessions available, with content depending on individual needs that are assessed by a healthcare professional on referral by the Jobcentre. Examples of support include exercise programmes, stress management, positive thinking about health and work, and lifestyle advice and information. Participants are allocated one healthcare professional who works with them throughout the programme, which is similar to the 'key worker' concept that is highly valued by cancer survivors and which the NCSI are attempting to integrate into the care pathway by identifying an effective model for the key worker role (DH, Macmillan Cancer Support, NHS Improvement, 2010).

Poor Levels of Physical Activity

Physical activity can have many benefits for cancer survivors, yet this population often decrease their physical activity at diagnosis and maintain lower levels of activity through treatment and beyond, rarely returning to their pre-diagnosis levels of activity (Doyle et al., 2006). Physical activity measures are available that can be used to identify survivors most in need of intervention (Figure 9).

Figure 9: Physical Activity Risk Stratification Measures

Risk Stratification:

A recommended tool for assessing physical activity in cancer survivors, either at diagnosis or during survivorship, is the **General Practice Physical Activity Questionnaire** (GPPAQ) (DH, 2009), designed as a short measure of physical activity for the routine assessment of whether patients are meeting the National Service Framework (NSF) recommendations for physical activity. Scores are used to determine whether people are sedentary, moderately inactive, moderately active, or active.

In the Netherlands, May et al. (2009) conducted a 3-year prospective, randomised multi-centre trial comparing 3 and 9-month post-intervention effects on cancer survivors' who were 3-months or more post-treatment (n=147; breast, haematological, and gynaecological) QoL and physical activity levels after two self-management rehabilitation programmes: a 12-week group-based programme, combining supervised physical training (twice weekly) and 2-hours cognitive-behavioural training (once weekly) (n=76); or a 12-week group-based physical training (twice weekly) program (n=71). The exercise training in both groups comprised a generic health aspect for improving aerobic capacity and muscle strength, and a cancer-specific component to reduce fatigue and improve role functioning. A number of variables were systematically manipulated during the training in order to enhance self-efficacy, including mastery, vicarious experience, verbal persuasion, and physiological feedback.

Additionally, a variety of evidence-based self-management techniques were incorporated into the programme, such as goal setting, action planning, and self-reflection. The cognitive-behavioural training (CBT) comprised exchanging experiences with cancer, psycho-education about stress, and promoting optimism and self-efficacy for self-management.

QoL and physical activity were significantly improved immediately following the intervention and also at 3- and 9-months post-intervention in both groups, confirming the findings of an identical earlier study testing the same programme (Korstjens et al., 2008). **The findings also add to the evidence suggesting that a more intensive programme of support (i.e. 12-weeks) is required for behavioural change.** This requirement for more intensive support appears to be related to duration rather than breadth of support, as combining physical training with CBT did not add to the beneficial effects. Indeed, the review of cancer self-management education by Rehse and Pukrop (2003) found that interventions of longer than 12-weeks produced greater effect sizes; in fact, when multivariate analysis was

conducted duration of intervention was the only predictor of improved outcomes that remained significant.

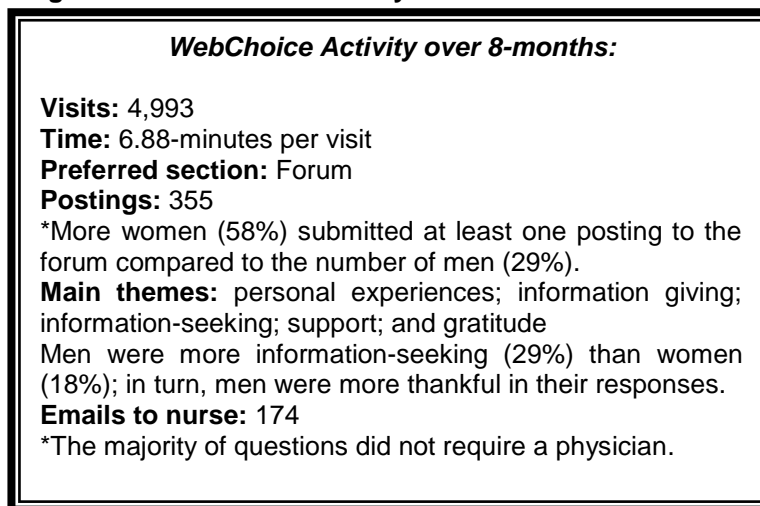
One self-management programme comprising patients undergoing treatment has been included within this review due to its relevance in terms of recent efforts to utilise a web-based means of delivering self-management support to cancer survivors. In Norway, Ruland et al. (2007) are currently conducting an RCT to test a two-way web-based self-management programme, *WebChoice*, with breast and prostate cancer patients (n=320). *WebChoice* provides tailored symptom self-management support where self-reported symptoms trigger the provision of appropriate evidenced-based self-management activities that the patient can choose from. The self-assessment can also be used to monitor improvements or worsening of condition or prepare for medical consultations, with three types of report being available dependent on need:

- a trend report that visualises distress of patients' reported symptoms over time.
- an assessment summary that ranks patients' reported symptoms by their priority for care to facilitate communication with healthcare professionals.
- an individualised self-management plan that summarises those activities patients have selected to alleviate their individual symptoms.

There is also a peer support forum, as well as a communications section for participants to pose questions to a nurse who enters the area daily.

Preliminary usage analysis contains data from 43 breast cancer patients and 31 prostate cancer patients who logged into the system at least once between March-October 2006 (Figure 10).

Figure 10: *WebChoice* Activity



WebChoice is an innovative self-management strategy, allowing convenience and personalised care. The popularity of the forum among cancer patients is likely to be similar with cancer survivors, who require convenient methods of gaining high quality, reliable information and support. **Furthermore, it offers a method of systematically collecting**

patient-reported symptoms and experience, a requirement identified in the NCSI Vision document (DH, Macmillan Cancer Support, and NHS Improvement, 2010).

It can be particularly difficult to engage men in self-management support programmes, as has been found with the Macmillan Cancer Support *'New Perspectives'* programme, although the latter was designed for men post-treatment whilst *WebChoice* is for men in treatment. This might reflect a greater need for support during treatment for men with prostate cancer, or could merely be a difference in the programmes offered. In a 2008 evaluation of *New Perspectives*, only 14% of the respondents (n=186) were men and only 2% were prostate cancer survivors (Surendranath, 2009). Yet, the men utilising *WebChoice* are both receptive and grateful for the provision of supported self-management during the treatment stage. Another possible reason for the difference in involvement is the anonymity presented by a web-based delivery format. Indeed, supported self-management that offers an easier method of discussing personal and sensitive issues, such as telephone-delivered support, has been the most effective with prostate cancer survivors (Cockle-Hearne and Faithful, 2010).

One issue that might require further thought, however, is the potential sustainability due to the need for a technical support line for patients as well as a nurse who will be available to answer questions on a daily basis. The latter is unlikely to be a problem initially, but as the number of user's increases, so will the workload. On the other hand, the need may not be so frequent post-treatment, or questions might be answerable by a volunteer with access to medical advice. Further research would be required to establish the quantity and type of questions most asked by survivors of different cancers.

In the meantime, it has been reported that the researchers behind *Webchoice* are currently working on giving patients more mobile access to the service by developing a version that can be operated by mobile phone (Totland and Lie, 2007). The rationale is for patients to have access to their care plan or communicate with healthcare professionals even when they are travelling

SUMMARY OF STUDIES: WHAT DO WE KNOW ABOUT SUPPORTED SELF-MANAGEMENT FOR CANCER SURVIVORS?

Theoretical Framework

Despite the benefits of integrating evidence-based theory into practice (Lorig and Gonzalez, 1992), supported self-management programmes for cancer survivors have, in the main, lacked validated theoretical frameworks (Foster et al., 2007). Not only does this limit the identification of causal relationships between interventions and outcomes, it also prevents reliable comparisons across models of supported self-management (Linden and Roberts, 2004; Linden, Butterworth, and Roberts, 2006). Furthermore, without a theoretical framework, the precise replicability of successful models of support is often lost, which can in turn lead to 'reinventing the wheel,' something for which the development of 'intervention mapping' was designed to eliminate. The goal of developing intervention mapping is to utilize processes that have already been used to create effective interventions, with theory-based methods being an important component in the design, implementation, and evaluation of health-oriented programmes (Kok et al., 2004).

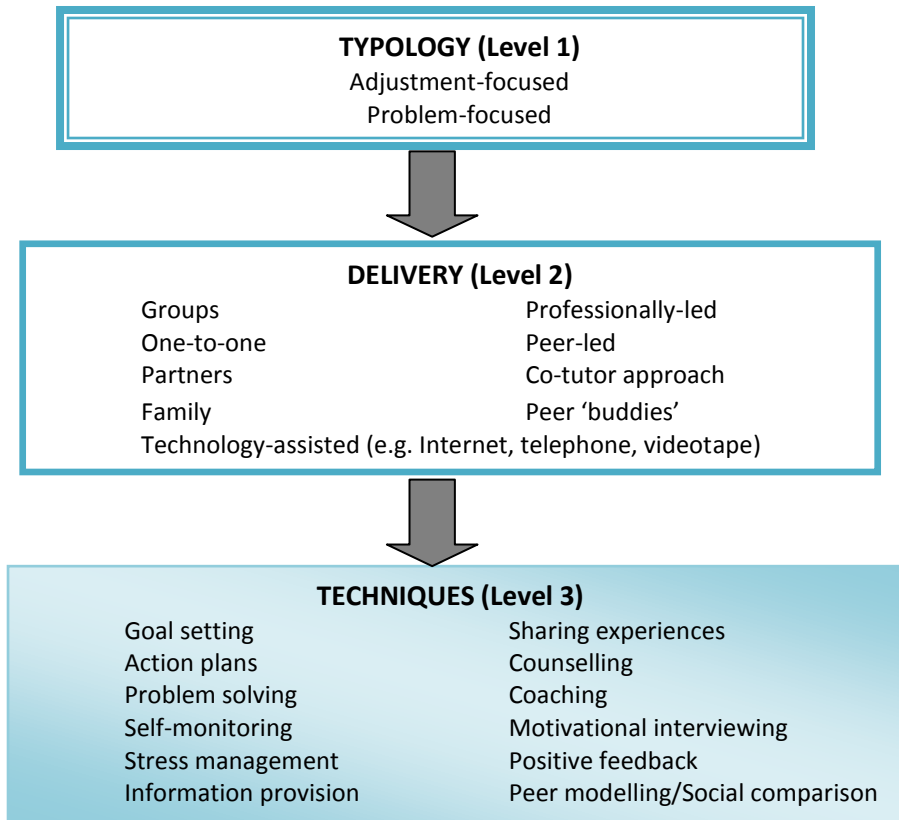
The most frequently adopted theoretical frameworks for self-management support interventions were Beck's (1993) cognitive-behavioural theory and Bandura's (1986) social cognitive theory. Cognitive-behavioural theory provides a psychotherapeutic approach that aims to solve problems concerning dysfunctional emotions, behaviours and cognitions through a goal-oriented, systematic procedure, whilst social cognitive theory posits that portions of an individual's knowledge acquisition can be directly related to social interactions and experiences. Self-efficacy, a person's belief in their own ability to succeed at a specific goal, or in this instance to manage the health implications of cancer and its treatment, is an important component to social cognitive theory and can also enhance the effectiveness of cognitive-behavioural initiatives. Indeed, self-efficacy was a core component of many of these interventions.

Other theoretical perspectives included illness uncertainty, the Chronic Care Model, social comparison theory, Mullan's (1985) stages of cancer survivorship, and Stages of Motivational Readiness.

Structured Programmes of Support (3-Level Process)

When synthesising the evidence presented within this review, a three-level model comprising typology, intervention delivery, and self-management techniques emerged, along with a checklist of evidence pertaining to the types of support that are most effective for specific groups of survivors (Figure 11).

Figure 11: 3-Level Supported Self-Management



PROGRAMME CONSIDERATIONS

- Participants of supported self-management programmes tend to be younger, white, and married. This highlights a potential increased need in these groups, but also emphasises the importance of engaging **'hard-to-reach' groups** (i.e. those who are older, single, or from ethnic minorities).
- Participants completing a programme are more likely to be employed and have less baseline depression, again emphasising the need to engage **vulnerable groups** (e.g. the unemployed) and maintain engagement of survivors struggling with depression, who might be better suited to one-to-one counselling than other modes of delivery.
- Assessment of **preparation** can facilitate intervention (e.g. unprepared → peer modelling videotapes; prepared → psycho-educational counselling).
- Breast cancer survivors may prefer group-delivered self-efficacy enhancing skills training, along with support and encouragement from healthcare professionals, compared to telephone-delivered sessions.
- Use of a theoretical framework such as CBT, or social cognitive theory/self-efficacy will promote acquisition of skills, and adjustment.
- Older cancer survivors may prefer:
 - one-to-one support due to co-morbidity and low self-esteem.
 - telephone-delivered support due to physical and practical limitations.
- Group sessions and peer discussions are often effective for prostate cancer survivors who have relatively **low levels of social support, low self-esteem, and higher depressive symptoms**.
- Nurse-led **problem-focused** support is often effective for prostate cancer survivors (e.g. sexual functioning; urinary incontinence).
- Information alone can be an effective method of reducing negative affect post-treatment in men who are **low in control** and **high in illness uncertainty** pre-treatment.
- Telephone-delivered support is often preferred when support is needed for issues of a sensitive nature such as sexual functioning.
- Male **ethnic minorities** appear receptive to telephone-delivered support (i.e. this can be easier than attending groups primarily comprising survivors of white origin).
- Spirituality can be an important component of supported self-management for some ethnic minorities.

Mode of delivery in studies with post-treatment cancer survivors were primarily group-based, with peer support proving fruitful in terms of enabling coping via the techniques such as social comparisons, the sharing of experiences, and learning from others. This is also often the most cost-effective mode of delivery. A combination of group and telephone consultation or individual face-to-face and telephone consultation were also popular methods of delivery.

Informational interventions were generally delivered via printed material, videotape, or counselling, with videotapes proving positive outcomes in terms of energy levels and cost-effectiveness. Indeed, videos demonstrating skills being learnt were requested by participants. In general, however, information provision was a key component in the self-management support provided, with evidence suggesting that providing information to those who choose not to attend offered workshops gained just as much knowledge as those receiving the social support of the workshops. The benefits of information provision on knowledge might be an effective way of increasing health literacy, although it is evident that information alone will not result in behaviour change, highlighting the importance of designing supported self-management around needs and risk stratifying according to these needs, so that survivors receive tailored support leading to desired outcomes.

More recently, ongoing trials are moving towards the use of technology, especially in terms of web-based self-management support. Efforts are also being made to integrate self-management support into aftercare. Since patient-initiated aftercare is becoming more popular in theory (Davies and Bateup, 2009), integrating self-management support into standard follow-up will be fundamental in providing cancer survivors with the knowledge, skills, and confidence to manage the long-term implications of cancer treatment and initiate their own aftercare when necessary.

Interventions for prostate cancer survivors in particular were designed to be delivered to the survivors and their partner via telephone. In both instances, telephone delivery was found to be the most efficient and convenient form of delivery in terms of communicating with couples about sensitive topics related to sexual matters. However, it is important to note that some face-to-face contact between telephone consultations is often preferred and can also be beneficial, as has been demonstrated with couples comprising breast and gynaecological cancer survivors (Scott et al., 2004). Despite some needs being found to benefit from a number of delivery modes or techniques, very few initiatives offered choice regarding preferred self-management support, although two did find this to be an important component of their success (Nyhof-Young et al., 2006; Ruland et al., 2007). Without the provision of choice, when choice is viable, patient-centeredness is put into question, as it is part of the patient/clinician partnership via *shared decision-making*, as well as being fundamental to improving quality standards (Coulter and Ellins, 2006).

Timing of Intervention

The majority of studies cite being conducted post-active treatment, whilst some provide a clear timeframe of being conducted within 12-months of post-active treatment, with survivors of up to 5-years post-treatment, or with survivors over 5-years post-treatment. There is little coherence reflected in the selection of timing for the interventions. It could be hypothesised that all patients need tailored information close to the end of primary treatment; and, based on need, a percentage will require more intense support for helping themselves around 4-

weeks after treatment in order to help with the management of effects and adjustments in the first 6-12 months.

Duration of Study Follow-Up

As with the review being updated (Fenlon and Foster, 2009) and the review by Cockle-Hearne and Faithful (2010), the long-term follow-up of the evaluated interventions and initiatives was limited. Many studies were pre-test post-test designs, whilst others reported measuring intervention affects for up to 3-months, 4-months, 6-months, 9-months, or 12-months. The paucity of studies comprising long-term follow-up is problematic and many of the ongoing studies propose similar lack of sufficient follow-up, although one will be assessing outcomes at 24-months (Dent et al., ongoing). Whilst there is a call for lengthier follow-up of intervention effects, there appears to be more of a need for greater exploration as to what would be the optimum period in which to follow-up interventions. Much of the research on self-management interventions has been for people living with a long-term condition such as arthritis, cardiac disease and diabetes, where self-management is a way of life and where, in the main, the disease trajectory is increasing chronicity and morbidity. These conditions do not prevail for the majority of cancer survivors and thus more clarity is needed as to the period of time where a self-management intervention would best support the majority of survivors on the road to recovery and back to their 'normal' life, as well as the minority who have a higher risk profile.

Cost-Effectiveness

Despite cost-effectiveness being a key factor in whether evaluated self-management support programmes are feasible in practice, this was rarely an outcome of the evaluated studies. Indeed, only one study reported on cost-effectiveness, demonstrating that the most cost-effective methods of information delivery are those that provide interventions based on individual needs and baseline measures (Mandelblatt et al., 2008). Fortunately, there are a number of ongoing studies planning to assess cost-effectiveness, an endeavour that must continue if feasible evidence-based support is to be provided to cancer survivors.

Ethnic Minorities

Four interventions addressed ethnicity. Mishel et al. (2002) analysed African-American and Caucasian men separately in trying to improve coping with illness uncertainty and treatment side-effects. Penedo et al. (2006) tested cognitive-behavioural skills management with monolingual Spanish speaking men and Campbell et al. (2007) sought to increase research participation and enhance QoL amongst African-American men beyond the acute diagnosis and treatment phase. These studies were based on large samples and showed positive intervention outcomes for the ethnic groups studied. Notably, three of these studies were primarily telephone-delivered, indicating that ethnic minorities might be more comfortable with this mode of interaction. Alternatively, the benefits of telephone delivery might reflect the sensitive nature of some of the issues associated with prostate cancer, with the telephone possibly being an easier way for men to discuss such issues.

Chung et al. (2009) conducted a much smaller study, testing the application of the '*Taking CHARGE*' programme with African American breast cancer survivors. The content of the programme was generally viewed as appropriate to other cultures, but some areas that

lacked cultural sensitivity were identified, particularly in regard to spirituality and the desire to provide more images of African American women in information leaflets – preferably images encapsulating fighting spirit in the face of adversity. Since the review being updated (Fenlon and Foster, 2009), little progress has been made in attempting to meet the self-management support needs of ethnic minorities. Given the high variations in risk for, response to, and recovery from cancer between ethnic groups, these populations are severely underrepresented (Aziz and Rowland, 2007).

Tumour Site

Eight of the reviewed studies comprised survivors of breast cancer, two colorectal cancer, seventeen prostate cancer, and seven a mix of different tumour sites (Figure 12).

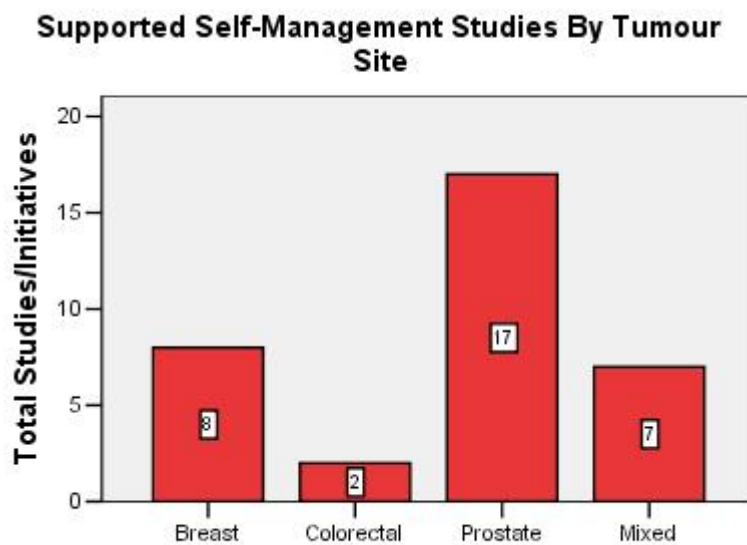


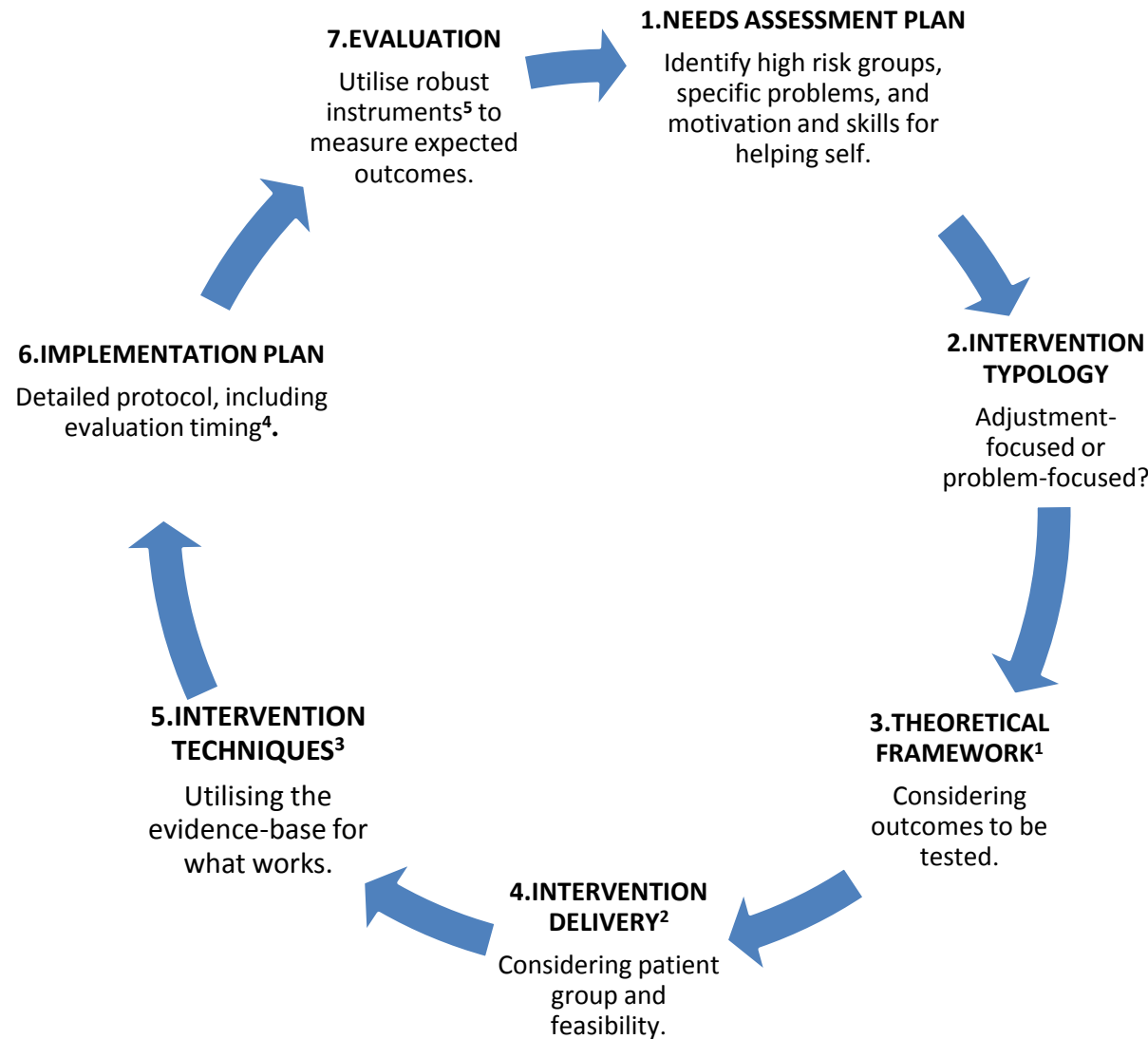
Figure 12: Total Number of Studies by Tumour Site

There was a clear lack of self-management support initiatives designed for lung cancer survivors, with lung cancer being the second and third most common cancer among men and women, respectively, in the UK (Office for National Statistics [ONS], 2009). Furthermore, there is a paucity of self-management support services being implemented for other cancers that might be particularly amenable to self-management support, including testicular and cervical cancer, the former being common among 14-24 year olds and the latter explaining nearly half of all cancer diagnosed in women (ONS, 2009). Prioritisation of which cancers to address is undoubtedly important economically, however, the needs of those living with or beyond the less high profile cancers must not be overlooked.

Designing an Intervention: Key Considerations

Based on the evidence within this report, a model has been devised comprising the key considerations for designing supported self-management interventions for cancer survivors (Figure 13).

Figure 13: Designing Supported Self-Management Interventions



¹Examples: Social cognitive theory; Cognitive-behavioural theory; Illness Uncertainty, etc.

²See Figure 11, Level 2: e.g. One-to-one; group; technology-assisted, etc.

³See Figure 11, Level 3: e.g. goal setting; problem solving; peer modelling; information provision.

⁴Pre and post-test evaluations might be sufficient for adjustment-focused interventions, whereas behaviour change interventions will require longer-term follow-up.

⁵Check the psychometric properties (i.e. Reliability, validity) and operational characteristics (i.e. acceptability, feasibility) (Davies, 2009).

DISCUSSION

The review being updated established the key components of self-management support as being confidence building and equipping patients with the knowledge and skills required to set personal goals and develop effective strategies for achieving them (Fenlon and Foster, 2009). This update provides evidence suggesting that these components are likely to be sufficient for facilitating psychological transition to survivorship. However, for actual behaviour change, which is often a fundamental component of self-management for chronic conditions, and more currently for cancer survivors, a more intensive level of support would be necessary for the maintenance of these new behaviours. The question still remains as to who should be targeted for higher intensity of support. Based on the findings within this review and within previous related reviews (Fenlon and Foster, 2009; Addington-Hall et al., 2010; Thomas, Davies, and Batehup, ongoing), some of the higher risk groups most likely to require intensive support following tailored information provision include:

- Individuals who are *less prepared* for survivorship or self-management support
- Survivors experiencing *depressive symptoms* and greater psychological difficulties, such as survivors of gynaecological cancer, and some breast and prostate cancer survivors.
- Individuals at greater risk of treatment-related *sexual dysfunction*, such as prostate and gynaecological cancer survivors.
- *Ethnic minorities*.
- *Low literacy* groups.
- Individuals who are single, *socially isolated*, or lacking social support.
- *Older* cancer survivors and others with *co-morbidities* or *mobility problems*.
- Individuals requiring *behaviour change* or *lifestyle change* interventions, such as overweight or obese survivors, or those working to increase physical activity.

Confidence in setting and achieving health-related goals as well as being equipped with the required tools have little purpose without willingness or preparedness; that is, the patients motivation to set and achieve goals and to self-manage. Empowerment through information and education provides little efficacy without motivation, and motivation can be enhanced by a number of social cognitive strategies that are also aimed at increasing self-efficacy (e.g. peer modelling techniques; encouragement and positive feedback, etc.). This offers a viable route of offering low intensity interventions, such as one-time information sessions such as the one-day workshop offered by Bloom et al. (2008) or the provision of cost-efficient peer modelling videotapes as described by Stanton et al. (2004) and Mandelblatt et al. (2008). Survivors could be assessed and stratified via short measures of motivation or preparedness, such as a 'readiness-to-change' ruler like the Contemplation Ladder (Biener and Abrams, 1991), which draw on the Transtheoretical Model (Prochaska et al., 1992).

This highlights the need for engaged health professionals who can substantiate information provision via ongoing support and encouragement (Shannon, 2009). The value of the patient/provider partnership in supportive self-management was highlighted by the preference for face-to-face contact as an adjunct to other types of supported self-management delivery (e.g. telephone-delivery) (Campbell et al., 2007). This partnership was

often one of the most important factors in boosting self-efficacy among participants (Cimprich et al., 2005).

Similarly, the literature demonstrates via the Stages of Change model (Prochaska and DiClemente, 1983) that before a person begins to make changes in their life, they first acknowledge that such change is required. In other words, behaviour change occurs through a process of stages of change:



Figure 14: An overweight breast cancer survivor with an increased risk of recurrence acknowledges, after reading an information leaflet, that weight and recurrence are associated. Preparing to achieve a healthier weight, she might decide to attend a supported self-management group designed to educate about exercise and nutrition. Alternatively, she could access information from her GP on obesity management programmes, which are part of national health initiatives such as *Change4Life* (DH, 2008). After attending the first group session or reading the information provided by her GP, she starts to eat more fruit and vegetables and increase physical activity. In order to maintain this change, an action plan is devised for times when she is particularly vulnerable to adopting old behaviours.

Figure 14: Stages of Change (Prochaska and DiClemente, 1983)

For someone in the pre-contemplation stage to be included in a self-management programme is likely to have limited efficacy, indicating the importance of health education sessions or workshops being included in any self-management initiatives; a person requires education about the benefits of self-management before they can contemplate making any changes towards this method of dealing with the consequences of cancer and its treatment. This, again, highlights the importance of health literacy in creating a patient-centred healthcare system (Coulter and Ellins, 2006).

The literature suggests that sustained behaviour change, be this adoption of self-management skills or the uptake of a new health behaviour, requires continued motivation on the part of the patient (Shannon, 2009). Motivation can easily wane once outside of the supported self-management environment, but as demonstrated in some of the studies in this review, motivation can be encouraged and maintained by a number of strategies, including the mailing of motivational postcards or the provision of positive reinforcement (Mishel et al., 2002). These are examples of the strategies encapsulated in motivational interviewing.

Indeed, it has been recognised that shifting aftercare into the realms of self-management support, healthcare professionals will require training and support if this shift is to be successful (a full review of professional training for self-management communication is in development). An evaluation of the studies and initiatives in this review suggests that this training might be best provided in the form of training in adopting a motivational interviewing approach in communication with patients. The leading theory adopted in the design of the evaluated self-management initiatives is that of Bandura's social cognitive theory. This has shown strength in commencing self-management, but further consideration of the stages of change model and motivational interviewing might be important in terms of maintaining self-management skills. Whilst self-efficacy has been a dominant component within many of the evaluated studies and initiatives, it could be argued that levels of self-efficacy and thus levels of motivation can wane without longer-term support from healthcare providers.

Training healthcare professionals in motivational interviewing skills is likely to be fruitful in all areas of cancer care, from diagnosis onwards, and clinician training in these skills has been recommended as part of a strategy to take self-management forward (Glasgow et al., 2008). It has been found that many patients would like to be involved in their care from diagnosis and start to seek information at this time (Rutten et al., 2005). Thus, self-management initiatives could be introduced early on in the cancer journey, providing a longer period to utilise motivational interviewing communication skills and to enhance self-efficacy in their ability to manage their condition and any treatment side-effects. Whilst the end of treatment has been identified as a 'teachable moment,' where patients are keen to learn more about how to manage their own health (Ganz, 2005; Demark-Wahnefried et al., 2005), this is not the case for all and, indeed, a cancer diagnosis could also be perceived as a 'teachable moment' when information and guidance on self-management are likely to be useful (Rutten et al., 2005; Stevinson, 2010). There needs to be a move away from the 'one size fits all' notion towards recognition of the unique and individual experiences of each cancer survivor, all of whom might reach their 'teachable moment' at various points in their own journey.

Recognising the unique experience of each cancer survivor, the more diverse a service can be in the self-management support provided, the more likely they are to meet the needs of their patients. For example, the '*Managing Your Cancer Journey*,' offered in the Breast Cancer Survivorship Program at Princess Margaret Hospital in Canada, provides something for everyone – group-based education; peer support; and a web-based resource. This service is fully integrated into breast cancer treatment, as part of a structured approach whereby survivors begin with a survivorship consultation and personalised care plan produced in partnership with a healthcare professional. The cost-effectiveness of this model is questionable, but evidence supports the usability and feasibility of integrating self-management support into aftercare, which is the approach being taken by some of the ongoing studies currently underway (Dent et al., ongoing; Richardson et al., 2009).

Integration of self-management support into clinical practice will require a number of further considerations beyond the content of these initiatives, including consistent evaluations of cost-effectiveness, rigorous comparisons of different delivery methods, and the longer-term assessment of patient and service outcomes. Furthermore, greater effort needs to be made in the training of professionals to deliver self-management support in a way that activates the patient to take responsibility for their healthcare needs and provides them with the

confidence to navigate the healthcare system in order to have these needs met. This requirement is further supported by Coulter and Ellins' (2006) review of patient-focused interventions, as conducted as part of the Health Foundation's five-year project, Quest for Quality and Improved Performance (QQUIP).

Fenlon and Foster (2009) recommend for any changes in practice to be fully evaluated and further unmet needs identified and researched. This recommendation stands, with this update demonstrating inconsistency in the outcomes assessed. Preferred outcome measures have been reported to be self-efficacy, locus of control, fear of recurrence, patient satisfaction, and specific symptom measures (Lorig and Holman, 2003). Fenlon and Foster (2009) add to this list the importance of measuring healthcare utilisation. A further recommendation made as an outcome of the current review is to assess outcomes at four levels with consideration of patient, clinician, commissioner, and policy outcomes (Table 4).

Table 4: Key Stakeholder Outcomes for Supported Self-Management

Patient Outcomes	Clinician Outcomes	Commissioner Outcomes	Policy Outcomes
Health literacy - to navigate the healthcare system, understand information, and access support when needed.	Patient in partnership communication skills for self-management support.	Quality and innovation.	Establishment of patient-centred care and the patient/provider partnership approach.
Self-efficacy to self-manage.	Improved healthcare utilisation - reduction in unscheduled episodes; effective use of other services.	Productivity.	Effective healthcare utilisation.
Self-management skills development.	Clinic capacity for high need patients, and new patients.	Service improvement.	Reduced costs of treatment.
Reduced symptom burden.	Multidisciplinary team work.	Cost-effectiveness.	Secondary prevention.
Improved quality of life.			Earlier diagnosis.
Satisfaction with service.			Increased survival.
			Improvements in cancer care to match those established in the best European countries.

In order to achieve consistency and reduce unnecessary patient burden, it is fundamental that organisations continue to collaborate and share examples of best practice. With the many different self-management initiatives currently underway or being planned, there needs to be some consensus on the most appropriate outcome measures to utilise so that comparisons can be made across interventions. The NCSI and Department of Health are setting up a 'metrics group' in order to facilitate this consensus and to support the NCSI in achieving its vision that cancer survivors are supported to live as healthy and active a life as possible for as long as possible (DH, Macmillan Cancer Support, and NHS Improvement, 2010).

Appendix 1: Data Extraction for Published Studies, in Alphabetical Order by Author

Authors: Bloom et al. (2008)

Title: Addressing the needs of young breast cancer survivors at the 5 year milestone: can a short-term, low intensity intervention produce change?

Aims: To test the efficacy of workshops and information provisions in facilitating transition to survivorship.

Participants: Women diagnosed with breast cancer ($n=404$) and who were 5-years cancer-free since diagnosis.

Outcomes: A 21-item breast cancer information survey was developed for this study, which focused on myths and facts about breast cancer and its treatment. Physical activity - women reported the number of days per week they got at least 30mins of physical exercise. The amount of physical activity was also measured by indicating on a scale from 0 (never) to 4 (frequently) how often in the past month, while not on the job, participants had engaged in walking, standing and stretching exercise, weight bearing exercises involving strength training, non-weight bearing exercise (such as yoga or stretching), and active weight bearing and non-weight bearing recreation; a sum of the items, weighted by number of metabolic equivalents (METs), was formed to obtain a total. At post-test, participants reported specific changes in physical activity in the past 6-months, including whether or not they had increased the amount of physical activity and whether or not they had started a physical exercise program. Diet - women reported how many fruits and vegetables they ate each day and how often they tried to eat non-fat or low-fat foods. They also completed Block's Fruits and Vegetables and Fat screeners, which were used to validate the two measures of dietary change. At post-test they reported specific changes in diet in the past 6-months, including whether or not they had started eating more fruits and vegetables and whether or not they had started a low-fat or low-calorie diet. Patient-physician communication - problems in patient-physician communication were measured by four-items from the Breast Cancer Problems Scale developed (Schain). Communication with family - communication of feelings and needs to spouse/partner was measured on a Likert type scale from 1 (frequently) to 4 (never). Communication issues with children were reported using four-items (reaction to illness, need for emotional support, need for information, and what to tell about illness), which were summed to form a scale. Social support was measured using the Berkman-Syme Social Network Index to assess the number and frequency of social contacts.

Method: An RCT using a pre-post test design. Women ($n=201$) randomised to the intervention group participated in a series of three one-day workshops that took place at monthly intervals. Women ($n=203$) in the control (delayed intervention) group were invited to attend a one-day educational workshop following the end of the post-test assessment. Randomisation: Women were randomly assigned to the intervention or control (a delayed intervention) group.

To reduce the number of women who did not participate actively in the intervention, three different strategies were used: 1) at the time of informed consent and prior to randomisation, women were asked to commit to attending at least two sessions; 2) women who missed a session were advised of the dates and location of the other sessions and invited to come to an alternate location; and, 3) handouts and hard copies of overheads were mailed to each participant who did not attend a session. Thus, all women received information presented at the workshops albeit those who missed a session did not participate in the interactive aspects of the workshops.

Data from a survey of a separate sample of young 5-year cancer-free survivors ($n=185$) were used to inform the design of the intervention and to develop a survey instrument to be used to

test the effectiveness of the intervention. In addition to being interviewed, some participated in focus groups. Empirical generalisations from the survey are as follows: the women stressed the need for education about breast cancer treatment and the need for second opinions; they reported using complementary and alternative treatments; many reported regrets about the type of treatment they had received; concerns reported about their sexuality included lack of desire (56%) and difficulty with arousal (46%), enjoyment (35%), or orgasm (38%); reporting of hormonal symptoms of menopause was common (hot flashes (63%), sleep problems (56%), sweats (51%), and vaginal dryness (49%); diet and exercise were important tools to cope with cancer after treatment; women reported having less emotional support and a smaller social network than in the first months after diagnosis; for many, their family and friends were their greatest source of support; women reported communication problems with their physicians (e.g. physicians didn't listen to them or were insensitive to the psychological aspects of having breast cancer); and, five years later, a vast majority of these women thought they were in excellent physical and psychological health.

Using the information from the survey and focus groups, the research team designed a series of three 6-hour long workshops to be conducted on Saturdays at one-month intervals. All participants were invited to a one-day workshop where most of the talks and activities were piloted. In many cases participants selected between two activities (e.g., yoga or Qi Gong). Based on their input, changes were made in both content and format.

The final intervention was conceptualised through the lens of social support, a theoretical construct which refers to the resources generated through mutual obligations and reciprocal relationships with family members, friends, and acquaintances, including co-workers, who comprise one's social network. The resources supplied by a social network may include, but are not limited to: 1) informational support - the provision of new and helpful information; 2) instrumental support - practical assistance; and 3) emotional support - showing that one is loved, esteemed, valued, and cared for.

To commemorate the 5-year milestone, the three workshops were organised to honour the young survivor's past, present, and future. Through a variety of activities and presentations, each workshop also addressed four cross-cutting themes, addressing unmet informational needs, promoting exercise and nutrition, improving communication skills, and providing and receiving emotional support.

Making the workshops a pleasurable experience was paramount and accomplished by providing music, decorations, food, and making opportunities to socialise. Women were encouraged to share their breast cancer stories and insights gained, and initiate changes to protect and improve their health and QoL. At the end of each workshop, the women were given information and gifts (e.g. a pink baseball cap). All of the topics covered focused on improvement in the women's QoL. Activities and exercises in each workshop focused on inner peace in order to improve emotional well-being (e.g. the use of restorative yoga to enhance flexibility as well as a relaxation exercise; Qi Gong, which also enhances flexibility and an individual's sense of control). A closing exercise was included in all workshops to enhance the integration of the workshops into the women's everyday lives.

Response Rate: Participation rate was 54% and on analysing the reasons why women refused to participate, two explanations were found: 18% indicated that they wanted to put the experience behind them, did not want to think about it, etc, whilst the remainder indicated that they were willing to participate and wanted to be kept informed regarding findings, but were unable to commit to attending at least two workshops, were unavailable on Saturdays due to general commitments or could not participate on the specific dates the workshops were to be held in their community. Of the women randomly assigned to the intervention group, approximately half attended two or more of the workshops and about one-third did not attend any of the workshops.

Results: Women who at post-test reported having started a physical exercise program were significantly more likely to report having increased their amount of physical activity (77% vs.

38%). Women who at post-test reported having started to eat significantly more fruits and vegetables showed greater increases in consumption of fibre and fruits and vegetables than those who did not. A process evaluation was conducted on the 201 women who were randomised to the intervention group. Even though all of the women randomised to the study had agreed that they would attend one of the four series of monthly workshops, approximately half of the women attended two or three of the workshops. Women who advised project staff of their inability to attend a particular workshop were invited to attend the one they missed in another location, and many did. Knowledge levels of the women were not affected by the number of sessions attended, a fact that is likely attributed to the mailing of information to the non-attendees. Responses to the evaluations of each workshop improved over time. Thus, the last series of workshops received the best evaluations. While this finding was generally true for all aspects of the intervention, it was specifically true for the efforts to improve the communication skills of the women in their relationship with family members, friends, and the medical care system.

The post-test was administered 3-months following the third and final workshop of the series in each location. In total, the post-test was administered to 387 women (96% retention rate). At post-test, women in the intervention group compared to those in the control condition, on average had significantly greater knowledge regarding breast cancer and its treatment and their own future health and retained more knowledge from pre- to post-test. Models including demographic and treatment variables indicated that, given the level of pre-test knowledge, having more education and belonging to the intervention group were associated with greater gains in knowledge. Women in the intervention group were also significantly more likely than those in the control group to indicate that they had increased their physical activity. Multiple logistic regression models indicated that women who had a mastectomy were less likely, while those who exercised more frequently at pre-test (four or more times per week) and those with larger social networks were more likely to report having increased physical activity at post-test. However, no dietary changes were found. In three of the series of workshops no evidence of improved communication with family members or physicians was found. In the fourth of the series of workshops, women in the intervention group reported a greater increase in the number of ways they communicated health needs and had fewer patient-physician communication problems at post-test than did those in the control group. However, they also reported a greater decrease in communication frequency with their partner and greater increases in thinking that their children needed more information and in worrying how their children were reacting.

Interestingly, the outcomes for women in the intervention group who did not attend the workshop, but received materials from the workshop were equivalent to those who did attend the workshop. This suggests that the information was more important than the interaction between the workshop participants and the speakers. Evidence from this study suggests that the information component may be delivered either in person or in print form, the latter undoubtedly being a more cost-efficient strategy. It will be important in the future to determine for whom interactive versus non-interactive approaches work best (i.e. providing information by an expert in a setting that allows for interaction versus sending print materials to keep survivors up to date on information relevant to their health). The internet may be appropriate for the latter group.

Conclusion: Overall, a short-term intervention can improve QoL by increasing knowledge levels and begin efforts toward lifestyle improvements such as exercising. However, we also found that more intensive and longer interventions are needed to augment and sustain lifestyle and interaction style changes.

Authors: Campbell et al. (2007)

Title: Facilitating research participation and improving quality of life for African American prostate cancer survivors and their intimate partners.

Aims: To explore the feasibility and efficacy of coping skills training (CST) an intervention developed to enhance coping with treatment side-effects in a sample of African American prostate cancer survivors and their intimate partners.

Participants: African American prostate cancer survivors and their intimate partners.

Outcomes: After completing the intervention period (6-weeks of CST for the treatment group or 6-weeks of usual care for the control group), participants in both conditions completed post-treatment measures. Both evaluations (pre-treatment and post-treatment) and all CST sessions were completed by telephone. Patients were assessed for self-efficacy using the Self-Efficacy for Symptom Control Inventory (SESCI). Disease-specific QoL was assessed using the Expanded Prostate Cancer Index Composite (EPIC). General health QoL was measured using the Physical Function and Mental Health Scales of the Short Form-36 Health Survey (SF-36). Partners were assessed for self-efficacy using the partner version of the SESCOI. Partner QoL was assessed using the Profile of Mood States-Short Form (POMS-SF) and the Caregiver Strain Index (CSI). Transcripts of each post-treatment interview were analysed using a qualitative data analysis program to search and code the transcript data (i.e. group it by topic). Transcripts were analysed at the level of the couple to capture a more complete description of the couple's experience with telephone-based CST. Data from each transcript was categorised into themes in two separate steps: 1) raw transcript data was reviewed, coded and organised into themes, utilising the indexing and text search functions of the software. The interventionist reviewed the raw data and, where needed, the data was annotated by adding words or phrases for clarity or context. No text was deleted, however, thus preserving the raw data; 2) data coding was reviewed by a psychologist who was not directly involved in the delivery of the CST protocol. This step provided an independent check on the validity of the data coding.

Method: A pilot study exploring the feasibility and efficacy of coping skills training (CST), an intervention developed to enhance coping with treatment side-effects in a sample of African American prostate cancer survivors and their intimate partners. Participants in the study were administered pre-treatment measures before being randomly assigned to one of the two conditions: partner-assisted CST (n=12) or usual care (n=18).

The partner-assisted CST protocol was designed to systematically train survivors and their partners in skills for managing symptoms experienced after treatment for prostate cancer. The protocol focused on three goals: 1) providing information about prostate cancer and possible long-term side-effects; 2) teaching problem-solving skills; and, 3) training in specific cognitive and behavioural coping skills (e.g. communication skills, relaxation training, activity pacing).

Survivors and their partners in the partner-assisted CST condition received six one-hour telephone sessions for training in coping skills. Sessions took place approximately once a week. To facilitate communication between each couple and their interventionist, couples were given a speakerphone for use during the session phone calls. The sessions were conducted by African American, doctoral level medical psychologists knowledgeable about prostate cancer and skilled in CST interventions. The interventionists underwent systematic training on the 6-session protocol, including role-playing to master the delivery of each skill via telephone without non-verbal cues. To ensure consistency in delivering the intervention, the psychologists followed a detailed written outline for each session, and met weekly for supervision. Sessions were audio-taped and reviewed by a senior-level psychologist who evaluated sessions for adherence to the protocol and provided ongoing supervision to maintain treatment integrity. At the conclusion of the final session, the interventionist briefly interviewed each couple about their experience with CST. The following three questions were asked: 1) What was it like for you to participate in the study?; 2) What was it like to undergo

coping skills training by telephone?; and 3) Is there anything you would add or change about the CST program? Interview responses were audio-taped and transcribed for qualitative analysis. Survivors and partners in the usual care condition received the routine care provided through their medical outpatient program. Neither survivors nor their partners received training in the coping skills methods outlined above.

Response Rates: Nine couples did not complete the intervention or did not provide post-treatment data, the most common reason was difficulty scheduling a time when both the survivor and partner were available.

Results: Qualitative analysis of interview data identified themes related to overall perceived benefit, usefulness of specific skills, telephone-based format, initial reservations about the CST intervention, and suggested changes to the CST intervention. 87% described the CST intervention as beneficial, noting both individual and couples benefits. Regarding the usefulness of specific skills, 60% found communication skills training to be especially valuable. With regard to telephone-based participation, 27% remarked upon the convenience of participating from their own homes, while two couples observed that the telephone format made it easier for survivors to be more vocal than usual, even about sensitive topics. 33% expressed a preference for some degree of face-to-face contact in spite of the benefits of telephone-based participation. Interestingly, 27% openly shared their initial scepticism or reservations about the study. Finally, 27% recommended specific changes to the protocol, including adding videos to demonstrate skills such as PMR, and more time spent on communication and problem solving skills.

The strongest treatment effect was observed in the bowel domain of the EPIC. Men who underwent CST reported significantly higher QoL in relation to bowel bother (i.e. less bowel bother; the bowel function and bowel total scales did not differ significantly between the groups. In some component of the urinary, sexual, and hormonal domains (subscale scores or total scores) of the EPIC, marginally significant treatment effects were found between the treatment and control groups. Effect sizes in or approaching the moderate range was observed for in subscale scores in these symptom domains. In the urinary domain, an effect size of 0.33 was observed for urinary bother. In the sexual domain, an effect size of 0.45 was observed for sexual bother. Finally, in the hormonal domain, an effect size of 0.39 observed for hormonal function. No significant differences were found between the treatment and control groups on the physical functioning and mental health subscales of the SF-36 or on the self-efficacy subscales or total self-efficacy scores. No statistically significant differences in anger, confusion, depression, fatigue, anxiety, or vigour were observed between partners who underwent CST versus usual care. Moderate effects were observed for depression, fatigue, and vigour, with partners who received CST reporting less depression and fatigue and more vigour than partners in the usual care condition. There were no significant differences in caregiver strain between intimate partners who participated in CST and intimate partners who were involved in usual care. Both groups of partners reported low levels of caregiver strain at post-treatment. An effect size (0.27) was observed in caregiver strain scores, with intimate partners who participated in CST reporting lower levels of caregiver strain than partners in the usual care condition. There were no significant differences in self-efficacy between partners in the treatment and control groups. A small-to-moderate effect size (0.30) was observed for the symptom management efficacy subscale, with partners in the CST condition reporting higher self-efficacy than partners in the usual care condition. Paired-samples *t* test was conducted to evaluate pre- to post-treatment change among survivors within each of the study conditions. The results indicated that the survivors in the treatment group reported significant overall improvements in QoL related to bowel symptoms, overall improvements in QoL related to hormonal symptoms, and specific improvements in bowel bother, which were not found in the control group. The treatment group also reported improvements in activity self-efficacy, whereas the control group did not. In addition to statistically significant improvement in the treatment group there were several trends in toward improvement.

Authors: Cimprich et al., 2005

Title: Taking CHARGE: A self-management program for women following breast cancer treatment.

Aims: The intervention aims to help breast cancer survivors construct a useful understanding of the illness experience to guide self-care behaviours, develop and rehearse necessary management and coping skills, assess the effectiveness of their plan, and connect the experience and self-care strategies to individual lifestyle.

Participants: Women (n=49) were randomised to intervention (n=25) or control group (n=24).

Outcomes: Questions were posed to evaluate all aspects of the program, including: self-management activities (7-item); program content and materials (e.g. usefulness of self-regulation approach, session contents, workbook; 10-items); program format and delivery (e.g. usefulness of group and telephone sessions; 7-items); and suggestions for additional topics to include in the intervention (10-items). In addition, two open-ended questions probed which aspects of the program were most beneficial and which were least beneficial from the participant's perspective.

Methods: The Taking CHARGE intervention builds on two theoretical frameworks: Mullan's (1985) stages of cancer survivorship (e.g. acute or crisis stage; extended or transitional stage; and permanent survival stage) and Bandura's (1986) social cognitive theory. The Taking CHARGE intervention is directed at the second stage, 'taking charge' being a transitional task. Participants use self-regulation processes to prevent, identify, and resolve problems they confront in living with breast cancer and to gain mastery of necessary coping skills. CHARGE is an acronym for the six stages in the self-regulation process: **C**hoose a concern; **H**ave the information; **A**ssess the situation; **R**ecord the plan; **G**ain confidence and insight; **E**valuate your progress. Accordingly, participants were taught to assess their perceived needs and monitor their own behaviour and reactions to accurately assess concerns (CHA). They then learned to identify a behavioural goal and develop a personalised strategic plan for reaching it (RG). Finally, the programme emphasised the importance of evaluating the benefits of selected self-care activities and personal progress toward the goal (E).

The intervention was developed from QoL researchers, medical and nursing oncology specialists, and breast cancer survivors, all of whom provided expert review and content validation. This was followed by a pilot test of women who had recently completed breast cancer treatment (n=12), confirming the feasibility of delivering the intervention. Then, as a preliminary test of the intervention's effectiveness, a randomised clinical trial was conducted with early stage I and II breast cancer survivors who had just completed primary treatment. The **process evaluation**, completed only by participants randomised to the intervention group, focused on the effectiveness of the program's structure and content, format of group and telephone sessions, and overall delivery.

The intervention comprises four contacts made at two-week intervals over a 7-week period. An oncology nurse practitioner and a health educator trained in the Taking CHARGE process co-facilitated the program. An instructor's manual was developed to ensure that all nurse/health educators used standard instructional content and methods. The intervention consisted of two small group sessions and two individual telephone sessions. Content was the major criteria used to determine the session format, with the content dealing with psychological well-being (Session 1) and transitioning successfully to family, work, and social roles (Session 4) considered especially appropriate for the small group format, which offered opportunities to share experiences and self-management strategies. Content related to managing symptoms (Session 2) and achieving functional wellness (Session 3) was delivered by telephone to tailor the sessions to each woman's unique experiences following treatment. This blended delivery system allowed participants to experience peer support in small group sessions and receive individualised education via telephone. Each participant received a

Taking CHARGE workbook, devised with the assistance of health media consultants, which served as a 'road map' for each session and guided women through the steps in the self-regulation process and the breast cancer specific content areas. The workbook was used to review key content covered in the group discussions and better prepare for the issues to be discussed during the telephone calls. Each session served two purposes: 1) to teach steps in the self-regulation process; 2) to address common concerns in breast cancer survivorship.

Women chose to work on one of the following concerns that were most relevant to their survivorship: stress; fatigue; physical activity; or personal relationships. Sample activities that guided them through the steps of self-regulation included using a pedometer to monitor physical activity, recording behaviour in observation logs, identifying relevant barriers, rating self-confidence in changing specific behaviours, and employing a self-contract. Applying the self-regulation steps to address one area of concern was intended to equip women with an approach that could be used in dealing with the additional concerns over the course of breast cancer survivorship.

Randomisation: Recruitment for the process evaluation took place 1-4 months post-chemotherapy or radiation. Baseline telephone interviews were completed within 30-days of enrolment. Participants were then stratified by chemotherapy treatment (yes/no) and randomly assigned by strata either to the intervention or 'usual care' control group using a balanced block randomisation procedure. Subjects started the programme within 30-days of baseline interviews and completed the anonymous process evaluation questionnaire at the end of the fourth and final session. Women (n=49) were randomised to intervention (n=25) or control group (n=24).

Response Rates: Three of those in the intervention group did not complete the program, one of these being related to the program as opposed to outside circumstances.

Results: 100% of attendees reported working on a personal problem or management concern, using the observation logs to monitor their patterns in relation to the selected concerns (the usefulness of this was ranked as high). The most frequently selected areas of concern were physical activity (50%), stress (27%), and fatigue (18%). Out of the participants, 91% developed a specific plan to reach the goal, 77% of whom completed the workbook exercises and materials for the four sessions, and 91% also felt confident that they could reach their goals (59% stating they were 'very confident').

All four sessions were ranked as being useful, but the session on psychological well-being was ranked the highest, followed closely by achieving functional wellness and dealing with symptoms and side-effects. Promoting functional adjustment in family, work, and social roles was useful, but much less so than the other three sessions. The usefulness of the problem-solving process was ranked as high. The most frequently requested additional topics were nutrition (95%), risk of other cancers (86%), changes in body image (63%), and alternative/complementary therapies (56%); 55% thought another session should be added to the program to accommodate another topic, preferably a group session.

In terms of programme length, 81% felt it was just right, whilst 14% thought it should be longer and 5% thought it should be shorter. The majority (89%) preferred mornings or afternoons. Daytime and weekend options received greatest endorsement, and so both options were provided, which had a positive effect on participation.

Support and encouragement by health professionals increased confidence in ability to meet goals. Furthermore, choice was an important part of the programme, allowing it to be relevant to participants.

Conclusion: The programme does require testing with a larger sample and more diverse population, but if successful could be replicated in various formats, including telephone counselling or web-based modalities.

Authors: Damush, Perkins, and Miller (2006)

Title: The implementation of an oncologist referred, exercise self-management program for older breast cancer survivors.

Aims: To examine the efficacy of a weekly social cognitive theory based exercise self-management programme that promoted moderate intensity activity.

Participants: Older (mean age = 59.6 years) stage I or II breast cancer survivors (n=34) (of up to 5-years).

Outcomes: Mediators of physical activity were measured via level of self-efficacy, perceived barriers and benefits, and enjoyment of physical activity. Process of physical activity was measured using the Community Activities Model Program for Seniors (CHAMPS). QoL was measured using the CARES-SF, fatigue by the FACT-F, and depressive symptoms by the CES-D.

Method: A single-group, pretest-posttest study of a weekly social cognitive theory based exercise self-management programme that promoted moderate intensity activity. The programme comprised three weekly sessions held for one-hour for 3-weeks at a primary care centre. The sessions focused on increasing patient exercise self-efficacy and social support to increase physical activity. Participants also received three follow-up telephone calls during weeks 4,6, and 10 in 15-minute durations from the project coordinator to discuss behavioural contracts and problem solve.

A standardised written protocol was used for staff leading the sessions. To promote behaviour change, the program included goal setting and behavioural contracting using weekly contracts. Exposure was provided to endurance, flexibility, and resistance training activities. Pedometers were provided to promote brisk walking and Thera-bands for resistance training, and exercise guides and video to promote exercise. Subjects were prescribed walking at a brisk rate for 30-minutes starting at twice per week and gradually increasing to 6-days per week. Strength exercises were recommended at twice per week.

Results: At 6-months, 30 had completed an assessment. This assessment showed improvements in all physical activity mediators, although only perceived exercise barriers approached statistical significance. QoL significantly improved between baseline and 6-months follow-up, depressive symptoms and fatigue decreased. Therefore, this study has demonstrated the implementation efficacy of an oncologist referred exercise SMP on physical activity mediators, processes, and outcomes for older breast cancer survivors. However, it is unknown whether improvements were due to the exercise component of the intervention or the social support component.

Authors Giesler et al. (2005)

Title: Improving the quality of life of patients with prostate carcinoma: a randomized trial testing the efficacy of a nurse- driven intervention.

Aims: To assess the efficacy of a cancer care intervention that was designed to improve the QoL in the patient/spouse dyad during the first year after treatment for clinically localised prostate carcinoma.

Participants: 99 patient/spouse dyads after treatment for clinically localised prostate carcinoma.

Outcomes: Outcomes data were collected using a combination of specific and general self-report measures. Urinary, sexual, bowel, and cancer worry outcomes were assessed using the Prostate Cancer Quality of Life Instrument (PCQoL). The Center for Epidemiologic Studies-Depression Scale was used to measure depressive symptomatology. Two scales from the 32-item Spanier Dyadic Adjustment Scale (DAS) were used to assess relationship functioning: Dyadic Satisfaction and Dyadic Cohesion subscales. The SF-36 was used to measure QoL.

Method: A prospective, multisite, randomised clinical trial. The intervention primarily focused on problems related to sexual, urinary, and bowel dysfunction; cancer worry (i.e. anxiety over recurrence); dyadic adjustment; depression; and other common sequelae of cancer (e.g. fatigue and pain).

After the conclusion of treatment for prostate carcinoma, dyads in the intervention arm met once each month for 6-months with a nurse intervener (twice in person and four times by telephone). The nurse intervener identified and tracked QoL problems using an assessment program developed for the cancer care intervention that was run from a laptop computer. For each problem, evidence-based strategies that had been extracted previously from the medical, nursing, and psychological literature were considered; and a mutually agreed upon, tailored plan of care was then developed and implemented by the nurse and the dyad. The intervention process was facilitated and documented by the computer program. QoL outcome data were collected at enrolment and again at 4-months, 7-months, and 12-months after the conclusion of treatment. After the baseline interview (2-weeks post-treatment), participants were randomised to the intervention arm or the control arm, stratified by recruitment site and treatment modality. After baseline, outcomes data were collected with computer-assisted telephone interviews three more times at 4-months, 7 months, and 12-months post-treatment. Interviewers were blind to the group-assignment of participants. Clinical and demographic data were gathered by research assistants from chart reviews and patient interviews after recruitment.

During each visit, the menu-driven computer program provided standardised questions and response formats that the nurse intervener used to elicit and document information concerning QoL problems. If a participant's score exceeded a pre-specified threshold for a problem, the program prompted the nurse to assess the problem in greater detail and helped identify strategies for that problem.

For each problem, an extensive number of strategies could be called up in menu format from the program. Strategies ranged from those that were specific to a problem (e.g. Kegel exercises for urinary incontinence) to broader strategies that were suitable for a variety of problems (e.g. exercise could be prescribed for fatigue, anxiety, or symptom distress). After the first intervener visit, the program was also used to record whether previously identified problems had resolved or persisted and whether prior strategies should be continued,

adjusted in terms of intensity or frequency, or halted.

During the first visit, which occurred within 6-weeks after the conclusion of active therapy, the nurse intervener primarily focused on assessing and managing bowel and urinary function problems. After the visit, participants were provided with a videotape to view at home (*Living and Loving: Sexuality and the Prostate Cancer Patient*), which showed couples discussing how cancer had affected their sexuality and relationship, and a binder or 'tool kit,' which contained tabbed pages with information related to managing the symptoms and side-effects commonly experienced by patients with prostate carcinoma. The videotape was intended to provide examples that could be modelled of couples discussing potentially sensitive topics (e.g. sexuality) to facilitate discussions of similar topics with the nurse intervener during the next visit. The tool kit was used to enable participants to review the strategies taught by the nurse on an as-needed basis.

During the second visit, which occurred one-month later, the nurse used the computer program to evaluate problems related to sexual functioning, cancer worry, dyadic adjustment, depression, and other cancer-related problems. On subsequent encounters, the patient and spouse were asked to discuss issues and concerns that may not have been addressed effectively during the previous sessions and to identify any new problems that may have arisen. Intervention visits were scheduled to occur once every month during the first 6-months after completion of treatment, with the first two visits in person and the remaining visits over the telephone.

Response Rate: In total, 99 dyads completed the baseline interviews and were randomised. The demographics of potential dyads who were approached but chose not to participate ($n = 207$ dyads) were similar to consenting dyads, although the average age of non-consenting patients was somewhat higher (68 years). By 12-months follow-up, 85 of the original consenting dyads remained in the study, the primary reason for drop-out being inconvenience. Attrition rates across the intervention and standard-care groups were nearly identical, and attriters did not differ from those who completed the study on any demographic, clinical, or baseline QoL variables, with the exception that attriters had marginally worse role-emotional functioning at baseline.

Results: The problems that most often met threshold for intervention attempts included sexual dysfunction (23% of patients), urinary dysfunction (19%), and dyadic adjustment concerns (18%), although fatigue also was experienced by a significant proportion of patients (10%). A variety of other problems also exceeded threshold, but no single other problem occurred in $\geq 10\%$ of the sample. For urinary dysfunction, the most common strategies employed by the nurse interveners were teaching Kegel exercises and scheduled voiding and providing counselling for distress/bother due to urinary dysfunction. For sexual dysfunction, the most common strategies were teaching dyadic communication skills and providing information about Viagra, injections, or other medical methods to overcome erectile dysfunction. For dyadic adjustment problems, the most common strategies were teaching active listening and how to express feelings and perceptions to partners. For fatigue, the use of exercise, priority setting, and energy management were the strategies that were employed most frequently.

The intervention had significant beneficial effects on several of the disease-specific outcomes, with the most consistent effects accruing to the sexual outcomes. At 4-months, patients who received the intervention reported significantly better gains in sexual functioning, which was a difference that remained marginally significant at 7 and 12-months. At 4-months, intervention participants also reported greater reductions in the extent to which sexual dysfunction interfered with (limited) their role activities (e.g. spousal role activities). Although this difference was marginal at 4-months, by Waves 7 and 12-months, this difference had become significant. Intervention participants did not differ from control participants in terms of sexual bother, but there was a clear trend favouring the former group.

In terms of bowel-related and urinary-related outcomes, the intervention and control groups

did not differ statistically. However, by 12-months, the intervention group did differ from the control group in terms of cancer worry. Men who had received the intervention expressed significant reductions in their anxiety about disease recurrence and treatment effectiveness.

Baseline depression appeared to moderate the effects of group assignment on one of the specific QoL outcomes: urinary bother. The intervention had no overall effect on urinary outcomes, as noted above. However, it was observed that baseline depression moderated the effect of the intervention on urinary bother at Waves 4, 7, and 12-months. Across these time points, for patients who had low levels of baseline depression, patients in the intervention group experienced significant improvement on the variable of urinary bother relative to the control group, although this effect became non-significant by 12-months. For participants with high levels of baseline depression, the improvement of patients in the intervention group on this variable was worse relative to the control group, although this effect was marginally significant, and all groups improved over time.

In terms of the more general QoL outcomes, which included dyadic functioning, depression, and the variables assessed by the SF-36, participants who took part in the intervention did not differ significantly from the control participants. Examination of the means reveals clear trends that consistently favour the intervention group (by an effect size of one-fourth to one-third of a standard deviation) on several of the more general QoL variables (e.g. pain and emotional and physical role function), but these differences generally did not attain conventional levels of significance. There was a marginal effect of the intervention on dyadic satisfaction at 12-months, such that intervention participants became more satisfied with the spousal relationship over time, whereas control participants became less satisfied.

For several of the general outcome variables, baseline depression appeared to moderate the effect of group assignment. At 12-months, intervention participants with high baseline levels of depression experienced significantly greater gains in role-physical functioning relative to the control group; participants who had low baseline levels of depression did not differ by group.

Conclusion: This study demonstrates that computer-assisted, nurse-led interventions are capable of improving QoL of patients with prostate carcinoma in a durable manner (i.e. up to 12 months post-treatment). However, the study was underpowered due to low accrual rates.

Authors: Mandelblatt et al. (2008)

Title: Economic Evaluation Alongside a Clinical Trial of Psycho-Educational Interventions to Improve Adjustment to Survivorship Among Patients With Breast Cancer

Aims: To collect data alongside a randomised trial to compare the costs and benefits of three psycho-educational strategies to improve transition to cancer survivorship.

Title: Economic evaluation alongside a clinical trial of psycho-educational interventions to improve adjustment to survivorship among patients with breast cancer.

Aims: To collect data alongside a randomised trial to compare the costs and benefits of three psycho-educational strategies to improve transition to cancer survivorship.

Participants: Women were eligible if they had received surgery for invasive breast cancer of any size or nodal status. Exclusion criteria included use of neoadjuvant chemotherapy, high-dose chemotherapy with bone marrow or stem-cell rescue or protracted reconstructive surgery, and inability to read and write in English. Exactly 418 women completed the original trial; 396 women returned calendar data; 389 women were available for the economic analyses.

Outcomes: The outcomes for this analysis were changes in distress and energy 6 months post-intervention, as measured by the Revised Impact of Events Scale (IES-R) and the SF-36 vitality scale, respectively. The vitality scale captures energy level and fatigue. Because of skewness in the IES-R score distribution, a logarithmic transformation was performed to produce a relatively normal distribution of IES scores; the scores were retransformed for cost-effectiveness analysis. Higher change scores for the SF-36 represent more energy and a higher IES change score represents less distress pre- to post-intervention. There were some baseline imbalances in the study arms, so baseline depression was controlled for in calculating outcomes. Costs stratified by baseline level of preparedness for transition were also calculated. Preparedness was defined by responses to two items ("Overall, I feel very well prepared about what to expect during recovery; Overall, I feel the medical team has done a great deal to prepared me for what to expect during my recovery."). Overall 12-month health care costs were assessed by study arm.

Methods: Women completed a baseline survey 4 to 6 weeks after primary treatment; the survey was repeated at 6 and 12 months after the intervention. The research staff used weekly logs to record the time and resources used to deliver the interventions. Finally, participants were mailed calendars every 3 months to document all health services used; those not returning calendars were provided mail and telephone reminders. Three strategies for improving survivorship transitions were compared. The least expensive approach (a booklet control condition) was compared with the next most expensive (an educational video plus the control booklet); the video was compared incrementally to the most expensive option (counselling plus the video plus the booklet). Women randomly assigned to the control arm were mailed a copy of the 1994 National Cancer Institute publication *Facing Forward*. Women assigned to the educational videotape arm also received the booklet and a videotape entitled, "Moving beyond Cancer." This 23-minute film was designed to address re-entry challenges in physical health, emotional well-being, interpersonal relations, and life perspectives. The video includes peer modelling of active coping approaches to fatigue and other survivorship concerns. The last arm included psycho-educational counselling (one individually conducted in-person session and one telephone session) plus the video and booklet.

Randomisation: Women were randomised to one of three conditions: a booklet control group; educational video plus the control booklet; and counselling plus video plus control booklet.

Response Rates: Exactly 418 women (74.9%) completed the original trial; 396 women (94.7%) returned calendar data. Seven women were missing treatment or other information, leaving 389 women (69.7%) for economic analyses. There were no significant differences between those completing economic data and those not doing so.

Results: The costs of the control, video, and video plus counselling arms were \$11.30, \$25.85, and \$134.47 per person, respectively. The video costs were \$2.22 per unit increase in energy compared with control; among women who were the least prepared for transition, the video was more effective, resulting in even lower costs. The video cost \$7,275 per unit change in distress versus control, but costs were lower in the subgroup least prepared for transition (\$355). The counselling arm was more expensive and less effective than the video for virtually all end points. However, in one group, women more prepared for transition, counselling cost \$1,066 per unit decrease in distress compared with the video. Health care costs tended to increase as intervention intensity increased.

Conclusion: In this trial, the educational video was the most cost-effective way to improve transition to survivorship. It will be important to confirm whether there is an increased use of services after such interventions and if this represents appropriate use of rehabilitative and supportive care or over-use.

Strengths and Limitations: The patients included in this trial had high education and income. It is possible that less advantaged women might be more vulnerable to poor adaptation and might benefit more from intervention or require different or more costly types of interventions. The study was limited to volunteers for a randomised controlled trial in three geographic regions and may not be generalisable to all breast cancer survivors. The study arms were unbalanced for baseline depression and although depression was controlled for, it is possible that there are residual unmeasured differences between the groups. Although the video produced benefits at the lowest costs, this benefit was for a defined, limited period of time: the 6 months after active treatment ended. The video tended to produce continued positive effects at 12 months, but this trend was not statistically significant. The findings are further limited by self-report of health care use. However, the use of randomisation and validated outcome measures adds strength to results.

Authors: May et al. (2008)

Title: Long-term effects on cancer survivors quality of life of physical training versus physical training combined with cognitive-behavioural therapy: results from a randomized trial.

Aims: To compare the effects on cancer survivors' QoL in a 12-week group-based multidisciplinary self-management rehabilitation program, combining physical training (twice weekly) and cognitive-behavioural training (once weekly) with those of a 12-week group-based physical training (twice weekly).

Participants: Cancer survivors' (n=147). Patient inclusion criteria were the following: age ≥ 18 years; last curative cancer treatment completed at least 3-months before study entry; and estimated life expectancy of at least 1-year. The most common cancers represented in this cohort were breast, haematological, and gynaecological.

Outcomes: Quality of life and physical activity levels were measured before and immediately after the intervention and at 3- and 9-month post-intervention using the EORTC QLQ-C30 and the Physical Activity Scale for the Elderly, respectively.

Method: A prospective, randomised multicenter trial over 3-years. Cancer survivors were informed about the study by various methods, including leaflets handed out by oncologists and GPs, information in the local newspapers, and through the internet.

On identifying the four most relevant cancer-related physical problems associated with cancer survivorship (e.g. decreased maximal oxygen uptake; decreased muscle strength; fatigue; and, reduced physical and role functioning), an exercise intervention was developed to improve these four main problems (van Weert et al., 2008). Firstly, the literature was reviewed for evidence regarding the content (e.g. modality and intensity) and delivery of programmes used for each of the problems; only high quality meta-analyses and systematic reviews were sought, but when these were not available, RCTs were used.

The evidence was used along with the intervention mapping technique to develop a supervised exercise programme consisting of four modules tailored to the individual patient's most prominent problem. These modules were formulated in terms of individual goals: 1) improvement of aerobic capacity; 2) improvement of muscle strength; 3) reduction in fatigue; and, 4) improvement in role functioning. The four modules contain two personalised treatment modalities including aerobic exercise training and progressive resistance exercise (PRE), which differ in intensity depending on the problem. The intensity of the programme is moderate to high in the first two modules and low to moderate in modules three and four. A cycling programme was used for aerobic exercise training, whilst PRE included various exercises for the large muscle groups of the lower and upper extremities using machine resistance and/or free weights. Training sessions were 20-30mins in duration for the aerobic cycling programme and 10-20mins in duration for the PRE, with the entire programme lasting 12-weeks. The overall goal of the programme was 'adopting a physically active life.' Delivery was via a group where the individual could work towards their own goals. Thus, the group as a whole perform aerobic exercise and progressive muscle strength training, but the individual exercise modules are tailored to individual problems and are prescribed individually. The delivery of the aerobic and PRE programmes was twice a week with an aerobic home-based walking programme, which allows for an increase in the frequency from once a week to daily, being introduced on week six, starting at 5-10mins and then increasing to 20mins. Mastery experiences, vicarious experiences, verbal persuasion, and physiological feedback, all of which play a role in increasing self-efficacy, were systematically manipulated during the exercise training. For example, the programme starts low intensity so that all participants are able to complete the class and gain a sense of mastery. Verbal persuasion is provided by the therapist strongly encouraging the patient to perform the training activities. Furthermore, the programme is delivered in a group format to enhance vicarious learning and modelling. The

self-management techniques of goal setting, information collection (such as via an exercise log), information processing and evaluation, decision-making, action, and self-reaction were all incorporated into the programme. Goals were required to be **S**pecific, **M**easurable, **A**dequate, **R**ealistic, and **T**ime-related (SMART) in order to maintain motivation.

The programme is preceded by a physical assessment, which defined the patient's problems and needs by assessing exercise capacity (Symptom Limited Bicycle Ergometry; SLBE), testing muscle strength (1-RM test) and anamnesis that include an exploration of the presence of irrational illness perceptions, and the patient's expectations and goals according to the self-management approach.

Before the programme starts, an education session is held to acquaint the patient with peers, therapists and the therapeutic surroundings. Then, in the tailoring phase, the intervention is divided into an Individual Physical Training (IPT) programme and a group-oriented Sports and Games (SGP) programme, both supervised by a clinical therapist. The IPT includes the four models on those physical problems of greatest frequency in survivors, as well as the aerobic bicycle exercise training and PRE. The aerobic training is based on the maximal heart rate reached on the SLBE) and the PRE training is based on the individual 1-RM.

The first four-weeks of the IPT are used to verify the patient's main problem defined at intake and their physiological response to training in order to establish the most optimal training module. The GSP includes twenty-four one-hour sessions over 12-weeks with various sports and games such as indoor hockey, curling, and badminton.

The cognitive-behavioural aspect of the intervention, which was once a week, two hours per session, was based on a cognitive-behavioural problem-solving protocol for individual cancer patients and a group problem-solving protocol. During CBT, the participants learned to apply self-management skills in striving for personal goals (e.g. in physical activity, work, household, hobbies, family relationships, and social contacts). Generalisation to daily life during and after rehabilitation was promoted by practicing activities during sessions and by homework assignments (maximally 30mins weekly). The first 3-weeks focused primarily on exchanging participants' experiences with cancer, psycho-education about stress, relaxation, fatigue, exercise physiology, illness perceptions, and on promoting optimism and self-efficacy for self-management. From week four onward, participants were primarily trained in applying self-management skills to realise personal goals by practicing the following steps in the circular problem-solving process: 1) problem orientation; 2) problem definition and formulation, and goal setting; 3) generation of alternative solutions (brainstorming); 4) decision-making; and, 5) solution implementation and verification.

Randomisation: After written consent, eligible subjects were scheduled for baseline measurements and randomised to physical training (PT; n=71) or physical training plus cognitive behavioural therapy (PT+CBT; n=76). Until the first session, participants were blinded to the rehabilitation group they were allocated to.

Results: Multilevel linear mixed-effects models revealed no differential pattern in change of QoL and physical activity between PT and PT + CBT. In both PT and PT + CBT, QoL and physical activity were significantly and clinically relevantly improved immediately following the intervention and also at 3- and 9-month post-intervention compared to pre-intervention.

Conclusion: Self-management physical training had substantial and durable positive effects on cancer survivors' QoL. Participants maintained physical activity levels once the program was completed. Combining physical training with the cognitive-behavioural intervention did not add to these beneficial effects of physical training neither in the short-term nor in the long-term. Physical training should be implemented within the framework of standard care for cancer survivors.

Authors: Mischel et al. (2002)

Title: Helping patients with localized prostate cancer manage uncertainty and treatment side effects: Nurse delivered psycho-educational intervention via telephone.

Aims: To test a telephone-based uncertainty management intervention.

Participants: African-American (n=105) and Caucasian (n=134) men diagnosed with localised prostate carcinoma.

Outcomes: The Mini-Mental State Examination (MMSE) was used to assess the cognitive status of potential patients during the recruitment process. The following demographic and background information was obtained at baseline from patients: current age, number of years of formal education, marital status, monthly family income, and ethnicity. Medical information, including date of diagnosis (from pathology report), TNM staging, types and amounts of treatment, and names of treating physicians and institutions, was obtained with patient permission from the patient's medical record. Co-morbid health problems were measured by an investigator-developed list of 25 common, age-relevant health problems of men. Uncertainty was measured by a shortened, 26-item version of the Mishel Uncertainty in Illness Scale. Uncertainty management was measured by using four instruments: problem solving and cognitive reframing subscales of the Self-Control Scale and investigator-developed measures of prostate carcinoma knowledge and patient-provider communication. The Cancer Knowledge Scale is an investigator-developed list of 21 statements about prostate carcinoma and its treatment. Patient-provider communication was measured by an investigator-developed scale containing five items that asked the patient about the degree to which he had communicated with his health care provider. The five questions were as follows: How much does the patient participate in planning his care?; How much does the patient tell the doctor?; How much does the patient tell the nurse?; How much information does the doctor tell the patient about his illness and how it will be treated?; How much information does the nurse tell the patient about his illness and how it will be treated? Finally, the management of treatment side-effects was assessed with the Symptom Distress Scale.

Method: The design for the study was a 3 × 2 randomised block, repeated-measures design with three levels of the intervention (uncertainty management direct, uncertainty management supplemented, and control) crossed with two levels of ethnicity (Caucasian and African American). Measurement occurred at three points in time: at entry into the study (baseline), 4-months post-baseline, and 7-months post-baseline. The 4-months measure was timed to occur about 8-weeks after the intervention was completed, allowing time for the patient to manage uncertainties without the aid of the nurse intervener, and served as a test of the efficiency of the intervention. The 7-months data collection point was selected to provide information on the durability of the effect. All study variables were measured at each point except for demographic data, which were collected only at baseline.

Recruiters introduced the study to patients during a clinic visit and then mailed the patient a package that included a recruitment letter, study brochure, and recruitment video. Ten days after mailing the package, a follow-up call was made to determine decisiona about participation and to set a time for the baseline data collection if they agreed to participate. For African-American men, a more elaborate recruitment process. Local community workers, two older African-American men who were well-known in the community, contacted African-American men to arrange a personal visit to further explain the study after the recruitment package had been sent.

Several considerations went into the modification of the intervention, from use with breast cancer to use with prostate cancer. First, education about prostate carcinoma, managing side-effects, and coping were emphasised, because it has been found that lack of knowledge

and misinformation about prostate carcinoma are common among African-American men. Second, preference for an educational format rather than a primarily affective format was selected, because it has been found that male patients with malignant disease prefer problem-solving for managing problems. Third, delivery of the intervention was modified by matching intervention nurses by ethnicity and gender to the patients. Gender matching was designed to assure that the sensitivity of the treatment side-effects would be addressed by having patients talk with men. Matching by ethnicity was intended to address the lingering suspicions of African Americans about research participation based on memories of the Tuskegee trials and other trials that resulted in mistrust of the health care establishment. Fourth, the design of the study included two experimental arms. In one arm, only the patient received the intervention (treatment direct group); in the other arm, both the patient and a family member received the intervention (treatment supplemented group). Patients were asked to select a family member who was involved in helping them with their prostate carcinoma to join the study. Most of the family members selected were spouses.

Patients who received the uncertainty management intervention, either directly or supplemented, participated in a weekly telephone call for eight consecutive weeks with a nurse who was trained in the intervention. Nurses were matched with the patient and family member (in the treatment supplemented arm) by ethnicity and gender. During each call, which was made at a time convenient for the patient and the nurse, the nurse first used a semi-structured interview to assess the patient's concerns related to prostate carcinoma, uncertainty associated with the concerns, and the degree of threat posed by the uncertainty. Although the nurse followed a standardised list of possible problems (e.g. treatment side-effects) in each encounter, they also encouraged the patient to express his individual specific concerns. Interventions for cognitive reframing included supporting, validating, and reinforcing the views and behaviours of the patient when he already had framed the problem as manageable. This helped to reinforce the existing cognitive orientation. However, when the patient was unable to reframe the situation and saw it as threatening, interventions included providing information about the nature of the problem, how to manage it, or what to expect. The nurse also informed the patient about resources that he could activate or helped him understand the likely trajectory of the problem. Markers or timelines were identified that were meaningful for the individual to personalise the trajectory and to stress that improvement was ahead. Strategies for managing the problem were exemplified by such activities as teaching Kegel exercises to regain urinary continence, potency enhancement methods for impotence, or information on expressing intimacy in ways other than sexual intercourse. The nurses presented all of these strategies in the context that problems were manageable and that the patient had resources and skills for taking action to address the problem.

Problem-solving with the patient was used to generate options, look at alternatives, and consider resources. Nurses taught patients how to monitor a problem themselves so that they could find patterns. They encouraged patients to try out potential solutions and then report on the result at the next phone call. If the solution was successful, then the nurse encouraged the patient to think of other disease-related problems in which the same solution may be applied. If the outcome required revision, then this was explored in the next intervention call.

Strengthening patient-provider communication occurred through providing information so that the patient was knowledgeable about his problems. The nurse also trained the patient in how to ask questions and generate a list of questions for the next physician visit. To promote self-advocacy, the intervention nurse taught the patient assertive communication skills to enhance the patient's participation in planning his care.

These interventions were applied to a variety of concerns, including those about diagnosis, treatment, response to treatment, living with cancer, caring for oneself, and social/lifestyle issues. The intervention protocol designated the range of interventions, but the application of interventions was targeted to the specific concerns and needs of each patient at each phone call. Printed materials, audiotapes, and videotapes for managing specific problems were mailed to patients after each weekly call. Any materials that were sent to the patient were

reviewed with him at the next phone call.

Patients in each of the two treatment groups (direct or supplemented) received the same intervention. In the supplemented arm, the spouse or designated family support person also received a weekly phone call for eight weeks from a nurse who was matched by ethnicity and gender and who conducted a similar assessment of the family members' concerns about the patient using a list similar to that used for the patients.

Men who were assigned randomly to the control group received their usual care. During data collection, printed general health information was given to patients to control for the non-specific effects of the printed information materials sent to intervention patients by the nurse intervener. None of the health information was related to prostate carcinoma or the side-effects from treatment to prevent the information from having the effect of alternative intervention. Men in the control group were offered four intervention calls after completing the final data collection.

Randomisation: Patients were blocked on ethnicity and randomly assigned to one of the treatment groups or to the control group.

Results: It was found that the majority of intervention effects were from baseline to 4-months post-baseline, when treatment side-effects are most intense. Both Caucasian men and African-American men who received either one of the two approaches for delivering the intervention improved in the two uncertainty management methods of cognitive reframing and problem-solving. Similarly, when the intervention groups were combined, men who received the intervention also improved significantly in control of incontinence by 4-months post-baseline. Decreases in the number of treatment side-effects differed by time and treatment/ethnic group interactions as did satisfaction with sexual functioning.

Authors: Stanton et al. (2005)

Title: Outcomes From the Moving Beyond Cancer Psychoeducational, Randomized, Controlled Trial With Breast Cancer Patients

Aims: To address the period of transition into survivorship.

Participants: Women (n=558) recovering from stage I or II breast cancer treatment.

Outcomes: Outcomes were measured at 6 and 12-months via a 39-page survey booklet including standardised questionnaires and instruments developed specifically for the MBC Study. The following domains were included: demographic and medical information, stressful life events, women's health history (including treatments for breast cancer and menstrual changes), psychosocial and health-related adjustment, and additional psychological variables. QOL was assessed with two generic instruments: health-related QOL from the SF-36 and global QOL as measured by the Ladder of Life Scale. Depressive symptoms and affect were measured with two instruments: The Center for Epidemiologic Studies-Depression (CES-D) scale, and the Positive and Negative Affect Schedule (PANAS). The Revised Dyadic Adjustment Scale (RDAS) was used to measure the quality of the woman's partnered relationship. Sexual functioning was measured by the MOS Sexual Problems Scale. Information on symptoms was gained using the Breast Cancer Prevention Trial (BCPT) symptom checklist. The Revised Impact of Events Scale (IES-R) was used to assess cancer-specific distress. The Posttraumatic Growth Inventory (PTGI) to assess reintegration into normal activities, Perceived preparedness for re-entry was assessed at baseline with two author-constructed items: "Overall, I feel very well-prepared for what to expect during my recovery" and "Overall, I feel the medical team has done a great deal to prepare me for what to expect during my recovery from breast cancer treatment."

Method: A multisite, randomised, controlled, behavioural intervention trial comparing two separate psycho-educational strategies. The study comprised three arms: standard print control (CTL; n=187); psycho-educational counselling (EDU; n=184); and VID; n=187). One researcher listened to and rated approximately 25% of the audio taped EDU sessions, and a second researcher listened to 25% of those. Fourteen mixed-response items were constructed to assess fidelity to the intervention (e.g., "Did the educator follow the outline of the session?") and other aspects of competence (e.g., "Educator appeared prepared"). On each item, a criterion for adequate intervention delivery was set. To assess adherence to the intervention, it was assessed whether women attended the two EDU sessions. To assess self-reported adherence to the VID condition, women reported at the 2-month assessment whether they had obtained information from the videotape from this study.

Within 2-weeks after random assignment, the three arms were initiated as follows: women randomly assigned to the standard print control (CTL) condition were mailed a personalised letter thanking them for completion of the baseline survey and reminding them of the upcoming assessment points. The mailing included a copy of the 1994 National Cancer Institute publication *Facing Forward*. This 43-page booklet contains general information for cancer survivors and focuses on health care after cancer treatments, managing emotions, and financial issues. Women assigned to psycho-educational counselling (EDU) participated in one individually conducted in-person session and one telephone session with trained cancer educators (e.g., social worker, psychologist), all of whom had a masters- or PhD-level education and had been trained in a full-day session by the researchers using a detailed manual at each site. In the first session of approximately 80-minutes, women reviewed their cancer-related concerns in the four life domains described previously, identified a primary concern and their associated goals, developed an approach-oriented action plan to address that concern (e.g., getting more information, seeking social support), and addressed barriers to their plan. At this session, they also were given the *Moving Beyond Cancer* videotape and an author-constructed 60-page manual entitled, *Moving Beyond*

Cancer: Your Guide to a Successful Recovery. Developed from an extensive literature review, focus groups with patients who had completed treatment recently, and input from the research team, the manual provided information on what to expect during re-entry, encouraged an active approach, and offered a list of cancer-related resources specific to that study site. The manual was organised to conform to the four life domains. For example, the chapter on the physical domain provides information on and suggestions for managing fatigue, menopausal symptoms, sexual issues, weight gain, vaginal dryness, lymphoedema, symptoms at the surgical site, and pregnancy after breast cancer. Conducted 2-weeks later by the same educator for individual participants and lasting approximately 30-minutes, the second telephone-delivered session was designed to focus on reactions to and questions on the videotape and manual, evaluate progress on and revise the action plan, and address generalisation of strategies to other re-entry challenges. Women assigned to the videotape intervention (VID) received the personalised letter and *Facing Forward*, as well as an author-developed and professionally filmed videotape entitled, *Moving Beyond Cancer* (www.cancer.gov). This 23-minute film addressed re-entry challenges in four life domains: physical health, emotional well-being, interpersonal relations, and life perspectives. Designed to promote adaptive peer modelling, the film observes four breast cancer survivors as they describe their experience in each of the four domains, as well as active coping skills they used to meet associated challenges. The film also depicts an African American breast cancer support group in which the members discuss the experiences of re-entry and model active coping. It includes commentary by an oncologist expert in breast cancer (Susan Love, MD) on the re-entry experience and on active methods for approaching problems during re-entry.

The development of the intervention approaches was guided by research and theory in stress and coping, self-regulation, and social learning. These theories suggest that a breast cancer survivor will recover well if her goal expectancies for re-entry are realisable and she possesses the resources to achieve them. In addition to providing information regarding what to expect during re-entry, the interventions were designed to increase active, approach-oriented coping skills through peer modelling in the videotape intervention and guided practice in the educational sessions.

Randomisation: Potentially eligible patients with stage I or II breast cancer were sent a letter of invitation and a study brochure from their physician. The letter was followed by a telephone call, 2-5 weeks after definitive surgery, from the research staff who explained the nature of the study. Patients were then tracked until the end of therapy, when they were approached about entry into the randomised trial. Limited demographic data (age, race/ethnicity, marital status, and educational level) and responses to standardised measures of physical and emotional functioning were obtained during the registration telephone call. The frequency of subsequent tracking calls was determined on the basis of the woman's projected treatment plan.

Registered participants were tracked by phone until treatment completion, whereupon they were mailed informed consent forms and baseline questionnaire packets. Participants had to return their completed materials within 8-weeks after medical treatment completion to remain eligible for participation in the study. When the baseline packet was returned, each woman was assigned randomly, based on a random number-generated list, to one of three study arms. Intervention assignment was stratified by study site, whether the woman had received chemotherapy, and marital status (married/living as married v other). Random assignment to treatment was revealed to research staff after the participant's baseline questionnaire was received, and personnel performing data checking were unaware of condition assignment.

Response Rates: Of the 1,314 initially eligible women, 756 (58%) refused, either actively or passively and 558 (42%) participated through completion of the enrolment survey and random assignment. SF-36 scores for the women who completed the survey did not differ from those of non-participants; however, study participants tended to be younger than non-participants, white, and married. With regard to participation, 86% of women in VID, 87% in the EDU, and 1.6% of women in CTL reported at 2-months that they had obtained information from the study videotape. Seven of 151 women assigned to EDU did not participate in the

intervention (n = 2, unable to be contacted; n = 3, schedule conflict; n = 2, other) but still completed follow-up assessments.

Results: The arms did not differ with regard to completion rates for the assessments, with 67% (n = 375) of the total sample completing baseline, 6-month, and 12-month assessments; 12% (n = 66) completing the baseline and one follow-up point; and 21% (n = 117) completing only the baseline assessment. Compared with those who did not complete the assessment at 6 months (n = 140), those who completed the 6-month assessment (n = 418) were significantly older, more likely to be employed, more likely to be taking tamoxifen, and less likely to report cancer-specific distress on the log (IES) or depressive symptoms on the CES-D at baseline. Analyses on those who completed (n = 399) versus those who did not complete the assessment (n = 158) at 12 months revealed nearly identical findings.

Analyses performed on SF-36 Vitality change scores at 6-month follow-up, controlling for study site and baseline CES-D, revealed a significant VID versus CTL comparison, indicating that the VID intervention produced a significantly greater improvement in the Vitality subscale score during 6-months than did the CTL condition. Analyses conforming to the original analytic plan to detect main effects of the interactions on the unadjusted mean change scores at 6-months yielded a significant effect for VID versus CTL on SF-36 Vitality, and non-significant differences for EDU versus CTL and VID versus EDU. None of the comparisons was significant for the IES-R. Analyses performed on the log (IES-R + 1) change scores at 6 months, controlling for study site and baseline CES-D scores, revealed no significant main effects. However, the perceived preparedness-EDU interaction was significant. Findings ran counter to hypothesis, in that participants who reported being unprepared for re-entry benefited less from the EDU intervention than did prepared women, who evidenced greater improvement relative to CTLs. Effect sizes for the less-prepared, average-prepared, and well-prepared women were 0.38, 0.12, and -0.15, respectively, suggesting that the EDU intervention was somewhat detrimental for less-prepared women and of some benefit for well-prepared women relative to the CTL condition.

At 12-month follow-up, no significant effects of the intervention, perceived preparedness, or their interaction emerged on the IES-R or SF-36 Vitality scales. After controlling for study site and baseline CES-D, participants in all conditions on average evidenced an increase in the Vitality subscale score and a decrease in log (IES-R + 1) scores from baseline to 12-months.

Limitations: Randomisation failed to equalise the groups on some psychological variables at baseline. Statistical control was instituted to compensate for this limitation, but different effects might have emerged had the randomly assigned groups been equivalent. Furthermore, participation among the 1,314 eligible women was 42%, and more than 20% of randomly assigned women were lost to follow-up. Although multiple attempts were made to contact women, it is possible that the relatively minimal nature of the interventions resulted in participants being less committed to the study. Generalisability of findings is limited to relatively educated women with early-stage breast cancer, and intervention effectiveness for diverse groups requires study. Furthermore, because they received distinct breast cancer treatments, women entered the trial at variable points after diagnosis. However, analyses revealed that diagnosis duration and medical treatment received did not influence findings. Finally, the measure of perceived preparedness was constructed for this trial, and its reliability and validity are not established.

Authors: Taylor et al. (2006)

Title: Active for Life After Cancer: a randomized trial examining a lifestyle physical activity program for prostate cancer patients.

Aims: To explore the impact of aerobic exercise on mood and psychological well-being in patients with cancer.

Participants: Prostate cancer patients (n=134) of any stage receiving continuous androgen- ablation therapy with the expectation to continue therapy for one-year or more.

Outcomes: The primary outcome was QoL (SF-36; CES-D; STAI; BPI). Secondary outcomes were endurance (six-minute walk test), body composition (BMI), social support (Interpersonal Support Evaluation List), and physical activity and mediating variables that might impact physical activity (7-day PARQ; Stages of Motivational Readiness for Physical Activity; Processes of Change for Physical Activity Questionnaire; Decisional Balance for Physical Activity Questionnaire; Physical Activity Self-Efficacy Questionnaire).

Method: *Active for Life* After Cancer is a randomised trial evaluating the efficacy of a 6-month group-based lifestyle physical activity program on QoL, designed for prostate cancer patients. Participants in all conditions completed assessments at baseline, post-intervention (month six), and at 6-month follow-up (month twelve (physical activity interview, tests of physical endurance and body composition, and self-report questionnaires), all of which took approximately one and half hours to complete. Research staff conducting the assessments were blind to the participants assigned condition.

Participants in the Lifestyle (n=46) and the Educational Support Programs (n=51) attended small group meetings of approximately eight men per group for 6-months. Both programs included an orientation session, 16 weekly sessions, and four biweekly sessions, each lasting one and a half hours. In the first hour, the Lifestyle Program implemented a cognitive-behavioural curriculum focused on increasing physical activity. No physical skills training was provided other than occasional brief (5-minutes) periods of walking and one session devoted to injury prevention prior to starting an activity program; during this session, a physical therapist provided a demonstration of some stretching exercises. The first hour of the Educational Support Program provided facilitated discussion. The last half hour of both involved either a facilitated discussion or an expert speaker covering topics such as sexuality, treatment side-effects, or diet. Standard Care participants (n=37) did not attend group support meetings, but received one mailing of the educational material and information about community resources. Throughout the course of the programs, participants received all educational and informational material given to participants in Standard Care. Both group programs were audio-taped, with two investigators reviewing select tapes for intervention quality control.

The Lifestyle Program was adapted from that used with healthy individuals in Project Active (Dunn et al., 1997; Kohl et al., 1998), which targeted building self-efficacy and cognitive-behavioural skills to adopt and maintain regular physical activity. Ultimately, the goal is to help individuals use these cognitive-behavioural skills to integrate activities at least moderate intensity into their daily life. Each session covered specific cognitive-behavioural skills for increasing physical activity including self-monitoring, goal setting, overcoming barriers, cognitive restructuring, and rewarding oneself. Skills were practiced in session, and skills practice was also assigned as homework for return and review during subsequent sessions. Participants also learned ways to monitor their activities including tracking daily minutes of activity, estimating daily calorie expenditure, and using a step counter to track steps taken per day. Each participant was encouraged to use the monitoring techniques of their choice for the duration of the program. In each session, the group leader reviewed the participant's weekly goals, provided feedback regarding the previous week's goal achievement, problem-solved issues preventing goal attainment, and helped participants set new goals based on the previous week's performance.

For the Educational Support Program, interventionists facilitated group discussion based on a series of pre-established questions. Each week, a different prostate cancer-specific topic was covered. Topics included diet, side-effects of androgen-ablation, and sexuality. Though it matched the Lifestyle Program in contact time and group implementation, this program used a discussion format and provided neither skills training nor instruction on behaviours to improve QoL.

Randomisation: Patients (n=134) were randomised to one of three conditions: Two group programmes (Lifestyle Programme or Educational Support Program) or a standard control condition (Standard Care).

Response Rates: The study had high retention rates, with only 6% dropping out by 12-months (five Lifestyle, two Educational Support, and one Standard Care). Six-month data was collected for 83% of participants and 12-month data for 84%. Group attendance was good for both programs, an average of 13.4 and 12.8 sessions out of 21 attended the Lifestyle and Educational Support programs, respectively. Participants were satisfied with the format for both group programmes, with the average ratings being that the program content was 'more than expected' and the duration and session lengths were 'just right.'

Results: There were no significant differences on any QoL outcomes at 6 or 12-months, or measures of body composition, endurance, physical activity, or energy. However, the Lifestyle Program participants reported a higher physical activity state of change at both 6 and 12-months than those in the other two studies. No significant improvements in social support were found in the three conditions.

Conclusion: The lack of improvement in QoL might be due to participants having relatively low levels of problems at baseline, leaving little room for improvement. Nevertheless, the results suggest that a lifestyle program focusing on cognitive-behavioural skills training alone is insufficient for promoting routine physical activity.

Appendix 2

Tables 2 and 3 present the details of published studies for prostate cancer survivors, adapted from Cockle-Hearne and Faithful, 2010)

Table 5: Published Studies for Breast Cancer Survivors

Author	Intervention	Sample	Follow-up Period	Attrition	Outcomes	Results
Stanton et al. (2004)	<p>1) Psycho-educational counselling with trained cancer educators, combining a one 80-minute face-to-face session, one 30-minute telephone session two-weeks later, and a 'Moving Beyond Cancer' peer modelling videotape.</p> <p>2) The same videotape as the counselling group, but no counselling.</p> <p>3) A standard printed booklet: the 1994 National Cancer Institute publication 'Facing Forward' (Control group).</p>	Stage I or II breast cancer survivors (n=558).	6 and 12-months post-intervention.	140 participants at 6-months; 159 at 12-months.	<p><u>Primary:</u> Fatigue and cancer-specific distress.</p> <p><u>Secondary:</u> Preparedness as a moderator of primary outcomes.</p>	Between the three groups, the videotape group experienced greater improvement in energy at 6-months; this was a significant difference between the video and booklet, but not significant between the video and counselling. Women in all groups experienced a decrease in cancer-related distress, with no significant differences between groups. The effect of the interventions was mediated by level of preparedness for transition into survivorship: the less prepared gained a moderate improvement in energy when receiving the video, but a moderate decline with the booklet and a moderate increase in cancer-related distress with counselling. The more prepared had a small decline in cancer-related distress with counselling. No significant effects were found at 12-months.
Cimprich et al. (2005)	Four sessions, combining two professionally-led face-to-face group sessions with two one-to-one telephone sessions made at two-week intervals.	Breast cancer survivors (n=25).	Pre-post evaluation.	Three participants.	The acceptability of the programme.	On a scale of 1-5, 5 being 'most useful,' group sessions and nurse/health educator support achieved a mean rating of 4.4, telephone sessions 4.2, and peer group support 4.1. In terms of programme length, 81% felt it was 'just right,' whilst 14% would have preferred longer. The majority (89%) preferred mornings or afternoons. Daytime and weekend options received greatest endorsement.
Chung et al. (2009)	Four sessions, combining two professionally-led face-to-face group sessions with two one-to-one telephone sessions made at two-week intervals.	African American post-treatment breast cancer survivors (n=26),	None.	None reported.	The utility and cultural relevance of the programme for African American	Although findings indicated that the program's content was relevant to participants' experiences, African American women identified a need for cultural enhancements in a

		who took part in a focus group.			survivors.	number of areas, mainly those related to positive psychology, with a focus on self-preservation, positive valuations, and images of fighting spirit.
Bloom et al. (2008)	1) Three 6-hour educational sessions focusing on resources generated through supportive relationships with family, friends, acquaintances, co-workers, and other people within a survivor's social network. 2) Control group (delayed intervention).	Breast cancer survivors (n=404) approaching the 5-year milestone.	3-months post-intervention.	46%	<u>Primary</u> : Cancer knowledge. <u>Secondary</u> : Physical activity; dietary changes; improved communication with friends, family, and physician.	Women in the intervention group compared to the control group demonstrated significantly greater knowledge regarding breast cancer and its treatment. They were also significantly more likely than controls to report increased physical activity. No dietary changes or evidence of improved communication with family members or physicians was found.
Damush, Perkins, and Miller (2006)	A 3-weekly one-hour oncologist-referred exercise programme designed to promote moderate intensity activity, plus three 15-minute follow-up telephone calls during weeks 4, 6, and 10 to discuss behavioural contracts and facilitate problem-solving.	Older (mean age = 59.6 years) stage I or II breast cancer survivors (n=34) of up to 5-years.	6-months post-intervention.	Six participants.	<u>Primary</u> : Exercise self-efficacy; enjoyment of physical activity. <u>Secondary</u> : QoL and perceived barriers to exercise.	Improvements in self-efficacy, enjoyment of physical activity, uptake of physical activity, improved QoL, and a reduction in perceived barriers. The increase in QoL and physical activity, as well as the reduction in perceived barriers approached statistical significance, but the other variables did not.

Table 6: Published Studies for Non-Specific Tumour Sites

Author	Intervention	Sample	Follow-up Period	Attrition	Outcomes	Results
Richardson et al. (2009)	<i>Surviving Cancer, Living Life:</i> Allocation of a key worker/ nurse, who contacts participants by telephone at pre-arranged times. Elements of the intervention include an in-depth telephone assessment to determine needs and develop a care plan, as well as ongoing coaching to support recovery and behaviour change where agreed.	Breast and prostate cancer survivors (n=22)	Patients with <3-months to 6-months experience of the programme.	None.	Views on the programme.	Comments were mainly expressed in terms of attitudes to the relationship experienced with the nurses, as well towards the holistic approach adopted by them; specifically, participants viewed the nurses as empathetic 'friends,' skilled communicators/counsellors, informed advisors, and valuable contacts. Telephone contact was generally viewed as being advantageous over face-to-face contact, particularly in terms of convenience, confidentiality and continuity. Patients felt they benefited from the programme in various ways, including: it helped them to understand their illness and treatment better; improved their morale and face life with renewed confidence; helped them adopt necessary changes in lifestyle; in some cases, to develop better relationships with their families; an increase in personal confidence when dealing with healthcare professionals.
May et al. (2009)	1) A 12-week group-based programme, combining supervised physical training (twice weekly) and 2-hours cognitive-behavioural training (once weekly). 2) A 12-week group-based physical training (twice weekly) programme.	Cancer survivors' who were 3-months or more post-treatment (n=147; breast, haematological, and gynaecological)	Immediately post-intervention and again 3 and 9-months later.	Not reported.	QoL and physical activity.	QoL and physical activity were significantly improved immediately following the intervention and also at 3- and 9-months post-intervention in both groups
Ruland et al. (2007)	<i>WebChoice:</i> web-based tailored symptom self-management support where self-reported symptoms trigger the provision of appropriate evidenced-based self-management activities. There is also a peer support	Breast (n=43) and prostate (n=31) cancer patients undergoing treatment.	<i>WebChoice</i> activity over 8-months.	Not reported.		Visits: 4,993 Time: 6.88-minutes per visit Preferred section: Forum Postings: 355; More women (58%) submitted at least one posting to the forum compared to the number of men (29%). Main themes: personal experiences; information giving; information-seeking;

	forum, as well as a communications section for participants to pose questions to a nurse who enters the area daily.					support; and gratitude. Men were more information-seeking (29%) than women (18%); in turn, men were more thankful in their responses. Emails to nurse: 174; The majority of questions did not require a clinician.
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