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Self management support: a review of the evidence

Working document to support the National Cancer Survivorship Self management work stream

Macmillan Research Unit
University of Southampton
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Deborah Fenlon
Claire Foster

UNIVERSITY OF
Southampton
School of Health Sciences

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Collaborative

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Document outline

This report is presented in three sections:

Section 1.

A two page introduction and summary of recommendations is provided with an overview of the brief for the work and the main findings and seven broad recommendations for further work.

Section 2.

The second section details the seven recommendations and gives supporting evidence. This section also includes the background and definitions of self management and self management support and describes the way that the evidence was gathered to inform this report.

Section 3.

The appendix includes a broader range of evidence that was gathered and upon which the recommendations for further work were based. This is organised according to the initial search strategy covering a wide range of symptoms at different times of cancer survivorship. The two broad headings are: 1) techniques and tools for specific symptoms and side effects following cancer 2) evidence for the ways in which patients and caregivers can work together.

Section 1. Introduction and summary of recommendations

Introduction and overview

Cancer for some is a chronic condition with more people surviving many years beyond diagnosis. Research commissioned by Macmillan estimates that the number of people living with or beyond cancer in the UK currently stands at two million and is rising by more than 3% a year^[1]. There is significant impact on the lives of people who have had cancer e.g. as a consequence of the treatments they have had. There is evidence that people want to know how to manage these consequences for themselves and that there could be considerable health benefits for them if they were supported in doing this. Currently there is very little support for people who have completed treatment for cancer. Most have no long term follow up and for those that have it, follow up is based on assessing recurrence rather than on the health and support needs of the individual. There is increasing evidence to suggest that people who are engaged and informed about how to manage their own health needs may achieve the best health and quality of life.

A review of research evidence for self management support in cancer was commissioned to assist the National Cancer Survivorship Initiative self management work stream. This is a working document and this first phase addresses evidence of self management support in cancer, some of which is informed by self management support for long-term conditions which is more established in research terms. This report provides an overview of the research evidence for self management interventions and strategies used in cancer care, and identifies gaps in the research with specific recommendations for areas where further work needs to be undertaken. The report focuses specifically on supported self management, which is the interaction between health professionals and people with cancer to help people to manage problems associated with cancer and its treatment for themselves. A broad definition of supported self management is used which covers a wide range of activities. In order to take a wide ranging look at the available research, this report was not a systematic review of the research literature and any research based on this report should undertake a comprehensive review of the literature in the area under investigation.

The recommendations from this evidence review are that the following areas be researched to enhance self management in cancer care:

1. Survivorship care plans
2. Topic specific programmes
3. Programmes for socially disadvantaged groups
4. Support materials
5. Key worker role
6. Health professional training
7. Ways of evaluating efficacy of self management interventions

Recommendations

Recommendation 1. Survivorship care plans

It is suggested that people who have come to the end of active treatment, or newly diagnosed with recurrent disease, should have one to one assessment by a health care professional and a survivorship care plan drawn up, in conjunction with goals as expressed by the cancer survivor. There is evidence that this might be beneficial but this strategy has not been tested in cancer survivors.

Recommendation 2. Topic specific programmes of care

Cancer survivors have many, varied needs and they have expressed the need for programmes of care to be more targeted towards their specific needs. It is therefore suggested that a variety of programmes of care should be made available covering specific topics, such as: management of lymphoedema; management of chronic pain; fatigue management; healthy eating programmes; carers programmes; cognitive behavioural therapy; skills for communicating with health professionals. There is some evidence that individual topic specific programmes are effective in cancer survivors, but they have not been tested as part of an overall strategy for care.

Recommendation 3. Programmes for socially disadvantaged groups

There is evidence that some groups are disadvantaged when delivering care in programmes. Where programmes have been developed to address the specific needs of minority ethnic and socially disadvantaged groups there is evidence that these have been welcomed and effective use made of them. There is the potential to have greater benefit amongst these groups when programmes are appropriately targeted.

Recommendation 4. Support materials

Self management programmes may not be appropriate for all individuals and written or computer based packages may even be more effective for some. There is a continuing need for a wide variety of support materials to be developed and tested as an adjunct to other forms of support. These may be written, web-based, CDs or other, as appropriate to the survivorship group.

Recommendation 5. Key worker role

There is evidence that long term interventions bring about more long lasting behaviour change. Furthermore, cancer survivors needs change over time and so long term support is required for cancer survivors. Therefore, it is suggested that each cancer survivor be assigned a key worker (either community or clinic based) who will provide regular, long term follow up. Due consideration should be given to the title, role and training of this individual and whether they are based in primary or secondary care.

Recommendation 6. Health professional training

Working towards improving self management involves a change in approach from health care professionals. Therefore it will be necessary to implement appropriate training to health care professionals and, in particular, to the key worker role in collaborative working and theories of change management.

Recommendation 7. Evaluation

The potential benefits of self management are many and varied, therefore careful consideration needs to be given to the measurement of outcomes. There is also a wide range of issues and problems faced by cancer survivors for which there are, as yet, no self management strategies identified. It is therefore important that any changes in practice should be fully evaluated and further unmet needs identified and researched.

Section 2. Supporting evidence

The evidence that supports the recommendations outlined in the executive summary is presented below. However, before these issues can be addressed it is important to be clear about what is meant by self management and self management support. Self management, self care and self management support are often used interchangeably in the literature. The report will therefore give working definitions for self management, self management support and what the goals of supported self management might be. We briefly consider the need for enquiry into self management support. The focus of the report is on available evidence for self management support in the context of cancer, drawing on literature from long term conditions.

Self management and self management support

The effective management of chronic illness entails an active partnership between healthcare professionals and patients, combining professional expertise and lay experiential knowledge^[2]. In this collaborative approach, the health professionals principal role is to encourage, facilitate and support the patient in their self management activities^[3]. Bandura's self efficacy model is most widely used^[4]. This refers to an individual's belief in their capacity to successfully learn and perform a specific behaviour. A strong sense of self efficacy leads to a feeling of control and willingness to take on and continue with new and difficult tasks. When applied to health, this theory suggests that patients are empowered and motivated to manage their health problems when they feel confident in their ability to achieve this goal. Interventions for improving self management should therefore focus on confidence building, and equipping patients with the tools (knowledge and skills) to set personal goals and develop effective strategies for achieving them^[3].

Self management is a relatively well defined concept within the literature for people living with long term, chronic conditions such as arthritis and diabetes. In this context self management:

“involves (the person with the chronic disease) engaging in activities that protect and promote health, monitoring and managing the symptoms and signs of illness, managing the impact of illness on functioning, emotions and interpersonal relationships and adhering to treatment” (p1)^[5]

This enables the person with the condition:

“to make informed choices, to adapt new perspectives and generic skills that can be applied to new problems as they arise, to practise new health behaviours, and to maintain or regain emotional stability.” (p11)^[6].

Having an active role in managing a long term health condition can empower patients to act for themselves, increase confidence in their ability to manage problems associated with the disease and its treatment and enhance quality of life^[7, 8]. Self management also includes communicating effectively with health care professionals^[5, 8, 9] *by helping the participant become an active, not adversarial, partner with health care providers. Chronic disease is best treated by a balance of traditional medical care and the*

day-to-day practice of self management skills (p11)^[6]. Self management and health care are likely to be enhanced by a collaborative approach where both patients and health care providers are considered as experts of the condition from different perspectives^[10].

Cancer is increasingly being thought of as a long term condition with an increasing emphasis on the ability of the person to manage for themselves the long term effects that cancer and its treatment can cause. The remit of this report is to consider how the health care system and health care professionals can support patients in their self management. We therefore propose a definition of self management support which is adapted from Natalie Grazin's definition (Health Foundation, presentation to the NCSI self management work stream):

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

Lorig and Holman^[9] have suggested that the goals of self management support are to enable patients to perform three sets of tasks:

- medical management of their illness (e.g. taking medication, adhering to a special diet).
- carrying out normal roles and activities
- managing the emotional impact of their illness

In the case of cancer the goals may be different as the problems for cancer survivors may be more about managing the long term effects of disease and treatment and health promotion, rather than management of active disease, although this may be the case for people with metastatic disease.

Evidence for self management support needs

There is a growing literature which suggests that cancer survivors are at greater risk of future health problems compared to people without cancer^[11, 12]. Furthermore, 20-30% of people are likely to experience psychosocial problems in the long term following a cancer diagnosis^[13] and people want help with managing every day problems associated with cancer and its treatment^[14]. A 2005 survey of the population in England indicates that there is interest in both practising self management and leading healthy lifestyles^[15]. Of those with long term health conditions 87% were interested in more actively managing their chronic condition. A review of the literature by Lev^[16] found that where self-efficacy is increased in cancer (i.e. their confidence in their ability to successfully self care/self manage) there are a number of improved health care outcomes, including increased adherence to treatment, increased self-care behaviours and decreased physical and psychological symptoms. As well as improving quality of life and reducing symptom distress Lev and Owen^[17] provide evidence that aspects of patients' self efficacy in relation to self management may mediate caregiver stress. Furthermore, Lev et al ^[18] showed that without intervention, cancer patients' measures of self-efficacy in relation to self management and adjustment, including quality of life, deteriorate over time. Lev et al ^[19] found that a nurse administered self efficacy intervention given on 5 monthly

occasions enhanced patients ability and confidence to self manage (measured by SUPPH Strategies Used by Patients to Promote Health), increased quality of life and decreased symptom distress.

A report from the Health Foundation concludes that there is evidence for the effectiveness of interventions to improve self management in chronic illness^[3]. They suggest that efforts should be focused on providing opportunities for patients to develop practical skills and the confidence for self managing their health problems. Patients can be empowered to set their own self management goals and to devise appropriate strategies for meeting these.

There is, however, a substantial problem in providing evidence of the effectiveness of self management interventions due to their wide variation, in objectives, content, method of delivery, duration and target population. It is often assumed that providing information to patients will lead to behaviour change and that behaviour change will produce improved health outcomes. This may not be the case. Self management interventions may be effective according to other measures, such as patient satisfaction, but not bring about measurable health outcome changes. Outcomes that have been used to measure effectiveness in self management interventions include: disease status, symptom management, pain control, quality of life, self efficacy and self management behaviours, knowledge of condition and its treatment, functional status and disability, medication use, psychological wellbeing, coping skills, health service utilisation, school/work absenteeism, patient satisfaction and long term complications. Lorig and Holman^[9] suggest that the beneficial effects of self management education arise not from its impact on self management behaviour but from its enhancement of patients' sense of self efficacy. Very few studies measure self efficacy as an outcome and therefore evidence must be sought in a variety of ways. Furthermore, as health care providers, publicly funded by a national health care system, it may be that other outcomes are more pertinent. The outcomes of self management support in cancer care still need to be agreed.

Methods

This is a brief overview of the literature and aims to give an indication of the breadth of the literature and some of the gaps. It is not a systematic review as this would define a narrow search question and take a number of months, but rather a broad scoping of the research evidence to inform the development of self management support in cancer care and to outline the gaps and questions that need to be addressed by further research in this area. Furthermore, the studies in this report have not been evaluated in terms of the strength of evidence as the aim of the scope is to identify areas of research conducted and what the gaps are. As such any further work based on the recommendations of this report would need to conduct a thorough literature search in the area under investigation.

A framework was suggested by the commissioning group to address three main stages of survivorship after cancer: assessment, planning and immediate post treatment approaches to care; managing active, progressive and recurrent disease; and late effects of treatment. The group also indicated that specific symptoms and side effects following cancer should be addressed. These included: cognitive impairment; fatigue; pain; diet/nutrition; mobility; peripheral neuropathy; joint and

bone problems; feeling low/coping and self image; symptom management (other symptoms); urinary/faecal incontinence; lymphoedema; erectile dysfunction and post menopausal symptoms. The evidence found was organised into two broad categories using the definition of self management given above and presented under the headings:

- a) techniques and tools for specific symptoms and side effects following cancer
- b) evidence for the ways in which patients and caregivers can work together.

The details of these findings are presented in the appendix. Evidence for this review was gathered from a number of sources including published reports and reviews. A number of literature searches were conducted. The databases CINAHL, Medline, BNI and AMED were searched using the search terms: 'cancer' or 'neoplasms' and combined with 'self care' or 'self management'. All abstracts were reviewed for relevance. Further searches combined 'self care' or 'self management' with specific symptoms, such as fatigue, pain or lymphoedema. There were relatively few articles which were filed under the heading of 'self care' or 'self management' so searches were conducted for each topic area. The topic heading or symptom under investigation was combined 'cancer' or 'neoplasms' with 'disease management' or 'patient care management'. These papers were assessed for relevance to this review, using the definitions of self management provided. The literature was searched to explore evidence for self management techniques for symptom management at any of three time points: immediately post-treatment, active or recurrent disease and late effects of cancer. Where available, systematic literature reviews were accessed, backed up by a search of the primary research literature published since the review. Hand searches were conducted in all the volumes of the *Journal of Cancer Survivorship* and the *Journal of Supportive Oncology* and references sought from experts in the field.

Evidence for self management interventions and programmes from other chronic conditions, such as arthritis and diabetes has been drawn on, largely using published reviews and reports, such as The Health Foundation report on supported self management in chronic conditions in the UK: 'Patient focused interventions: A review of the evidence'^[3] and the Department of Health report: 'Research evidence on the effectiveness of self care support'^[20]

Complementary and alternative therapies (CAM) have not been considered within this report. The use of CAM could be considered a self management activity, however, there is insufficient space within this report to consider the breadth of CAM strategies and if they are to be incorporated into any programmes or interventions evidence should be sought independently.

Findings

The primary research literature clearly demonstrates that the needs of cancer survivors are great as their active treatment comes to an end, but there is little specific research on self care or self management activities at this time. Most symptom research, including self management, has been conducted during the active phase of treatment, with very little research found for any other period of

survivorship. Research which focuses on self management support activities such as information giving, counselling, support groups or symptom management is also largely associated with active treatment, although there is some blurring into the post treatment phase, and many of the findings may be applicable to post treatment as well as to active treatment. Very little evidence was found on any self management techniques or interventions for problems in long term survivorship, living with the long term consequences of treatment or recurrent disease.

There is a great deal of literature which describes the late effects of cancer treatment, such as cardiac dysfunction, neuropathy and second tumours^[21, 22], but virtually none on how patients might manage these themselves. There is literature on symptom management with some symptoms becoming a part of chronic survivorship, such as fatigue and pain. There is a limited amount of evidence available for symptom interventions, some of which could be described as, or could become, self management interventions. There is also literature on health promotion after cancer which largely focuses on reducing obesity through diet and exercise and in smoking cessation^[23]. Health promotion activities may be seen as part of a cancer survivorship programme.

A systematic literature review of self management strategies used to manage problems associated with cancer and its treatment revealed little research evidence detailing strategies used, benefits of these or how self management strategies might be supported in practice^[24]. A small number of studies assessed strategies used by people on treatment and there was almost no evidence to suggest how people manage problems themselves beyond treatment. Very little research has explored the benefits to individuals affected by cancer in acting for themselves in relation to their health although benefits are often assumed or inferred. The authors suggest that some people might be more motivated to manage problems themselves than others and careful consideration of recruitment strategies is needed to ensure that individuals typically underrepresented in research, and those who might benefit most from receiving support to self manage are included. This work has been taken forward to reflect the priority of the Macmillan Listening Study^[14] where patients wanted more research to support everyday management of problems i.e. what problems do people experience and what helps/hinders self management.

A summary of the literature found in this review can be seen in the appendix. These findings were then drawn upon to identify gaps in knowledge around self management in cancer care and the following recommendations made for further research.

Recommendation 1. Survivorship care plans

For people who have come to the end of active treatment, or newly diagnosed with recurrent disease, to have one to one assessment by a health care professional and a survivorship care plan drawn up, in conjunction with goals as expressed by the cancer survivor.

People who have come to the end of active treatment for cancer report feeling abandoned by health professionals, yet there is evidence to suggest that they may have multiple, ongoing problems that are inadequately met^[25] which affects their health to the same extent as people with other chronic illnesses. These could be addressed by assessment, provision of appropriate information and signposting towards sources of help and support which will enable cancer survivors to self manage any consequences or long term effects of their cancer or its treatment. Diagnosis of recurrent cancer is another key time point when patients could both benefit from, and be open to, interventions that are aimed at increasing their ability to self manage their health problems.

Although there is much information available, it is not always accessed by patients in need and they continue to report a lack of information^[26]. The timing of information delivery has been shown to be important^[26] and, in cancer care, the end of treatment has been identified as a 'teachable moment'^[27, 28], where people are keen to learn more about how to manage their own health, yet require the skills and knowledge to do this. It is also clear that each patient has a different set of needs which therefore requires individualised planning^[26, 29, 30]. As well as a need for personalised information there is evidence that some people are more likely than others to benefit from programmes of support^[31].

Health care providers are regarded as a trusted source of information and patients are more likely to take up an intervention that is supported or recommended by their health care providers^[32]. There is evidence that self management strategies built on improving confidence can be effective for people with cancer and that without intervention cancer patients self-confidence and quality of life decrease over time^[18, 19]. With the transition from active treatment to survivorship post treatment it is inevitable that patients will have less access to health professionals, nevertheless people with cancer identify that health care professionals provide an important source of support to increase their ability to self manage, by providing information, support and signposting or referral to other avenues of support^[24]. It is also suggested that aspects of care which are traditionally outside of the remit of health care providers may need to be considered, such as help with financial and work considerations^[24].

One way to address the wide range of personal needs would be to draw up individualised survivorship care plans^[33]. Cancer survivors identify that a major source of support to increase their ability to self manage is from health care professionals providing, information, support and signposting or referral to other sources of support^[24]. A one to one health care professional assessment of each individual would help to identify information needs and whether there are any available resources or programmes that would help increase a range of self management skills.

Recommendation 2. Topic specific programmes of care

For programmes of care to be available covering specific topics, such as: management of lymphoedema; management of chronic pain; fatigue management; healthy eating programmes; carers programmes; cognitive behavioural therapy; skills for communicating with health professionals.

One of the elements of the survivorship care plan, as discussed above, might be the inclusion of specific programmes, targeted at particular problems that have been identified for the individual. Self management programmes have been developed for people with long term conditions and conducted in the US, Australia and the UK^[7, 34, 35]. Some cancer specific programmes have also been developed, largely in the US^[36-40] and Australia^[41], with some programmes in the UK led by charitable bodies, such as Macmillan and Breast Cancer Care.

The Expert Patient Programme (EPP) in the UK has been beneficial for many people with chronic conditions, such as asthma, diabetes and arthritis^[42]. It is based on the principle that people need a generic set of skills to self-manage successfully. The programme is highly structured and led by volunteer patients guided by manuals. There is little engagement by health professionals and this could be a weakness for cancer patients^[43]. Patients themselves view the EPP as a reinforcement of their existing self management behaviour rather than as an opportunity to learn anything new. Furthermore, the use of volunteers may be problematic due to problems of availability of sufficient and suitable tutors and difficulty with quality control^[43]. Alternatively, there is evidence that self management programmes may be more effectively facilitated by health professionals and that patients have more confidence in professional led programmes^[44]. There have been some similar programmes for cancer patients and their carers in the United States^[36, 38, 39, 45, 46] and Australia^[41]. Findings from these studies suggest that patients benefit from an increased sense of control^[41], improved confidence in their ability to effect change^[36] and an increase in health information seeking behaviour^[38].

Many supported self management strategies use psychological techniques, such as counselling and CBT. There is evidence to support the use of these strategies for cancer patients. Cancer support groups have been shown to be effective for a wide range of coping abilities and psychological benefits^[3, 31, 47-54]. Educational programmes have also been successful in increasing self management^[55]; with a variety of beneficial health outcomes, such as improved symptom management^[56-59] an increase in knowledge^[45] and associated healthy behaviours^[60-63]. Elements of support groups and education programmes may be incorporated into self management programmes as appropriate.

Cancer patients identify that they would prefer programmes that are more specific to their needs^[41] or are condition specific courses. There is evidence that targeted programmes are more effective at bringing about long term behaviour change than broad, non specific programmes^[45]. Studies are available to support the use of supported self management programmes to reduce fatigue^[64-66], pain^[57, 67, 68], hot flushes^[69, 70] to improve bone health^[71], to increase exercise^[72-74] and long term change to healthy diet^[60], with evidence that increased confidence is related to behaviour change^[75]. Some patients have specific needs that can only be dealt with by

highly targeted programmes, such as post surgical changes and lymphoedema prevention and management^[76-82]. There is little evidence for programmes to address the needs of people with metastatic disease, however, two studies found psychological support and education to be effective for pain relief in patients with advanced, metastatic cancer^[68, 83]. One highly effective programme has brought about significant long term change to women's diet after breast cancer. The Women's Healthy Eating and Living (WHEL) programme was successful in supporting women to maintain a change to a healthy diet over four years^[60].

As well as condition specific courses there may be a place for more general health promotion after cancer, covering diet, healthy living and early detection of new malignancy. There is much evidence that people who have had cancer alter their diet with the aim of improving their health or preventing cancer recurrence^[84-88]. The belief is that if diet is a factor in cancer causation then diet should influence the risk of recurrence^[89]. There is evidence to suggest that unhealthy diet is a factor in cancer development^[90, 91], but very few specific foods that have been shown to affect the risk of cancer^[92]. A large multinational study (EPIC) has shown that increasing fibre, fish, fruit and vegetables reduces the risk of certain cancers and a large intake of red or processed meat, high levels of fat (particularly saturated fats), can increase cancer risk^[93]. Other protective mechanisms are keeping physically active, reducing weight and reducing waist to hip ratio^[93]. However, this evidence relates to risk of developing cancer and there is little evidence to help understand the role of healthy diet after cancer has occurred^[11]. It appears that obesity is associated with increased mortality in breast cancer^[94] and there is some evidence to suggest that a low fat diet can reduce the risk of breast cancer recurrence^[95, 96], although the large Women's Healthy Eating and Living study which studied the effect of a diet high in vegetables, fruit and fibre and low in fat has not been able to identify any effect on breast cancer recurrence or survival^[97]. These changes in diet were achieved by supported self action. While it is not clear what the benefits are of changing diet after cancer, it is clear that both many cancer patients wish to do this and that they can be supported to make appropriate changes at different stages in the cancer experience.

There are also a number of studies exploring the benefit of exercise programmes after cancer^[72, 73]. Karvinen et al^[98] identified that the majority (81%) of survivors of bladder cancer were interested in participating in an exercise programme. They preferred home based, walking, moderate intensity and unsupervised sessions. A study delivering an 8 week full body aerobic programme found that both physical fitness and quality of life improved, with no evidence of injury or lymphoedema^[74]. This suggests that this level of activity is safe after breast cancer, although the numbers were small and there was no control group.

After cancer people experience a wide range of difficulties as a consequence of their illness and its treatment. There is evidence to suggest that health professional led programmes aimed at improving self management through an increase of knowledge and skills, targeted at specific problems, will bring about a wide range of benefits. However, Bury et al^[44] caution that, while self management programmes represent one potentially useful approach to care, they are not suitable to all and should be used as part of a range of formal and informal resources. This reinforces the need for individual assessment as discussed in recommendation 1.

Recommendation 3. Programmes for socially disadvantaged groups

For targeted programmes to be developed to address the specific needs of ethnic minority and socially disadvantaged groups.

A criticism of current sources of support and programmes such as the Expert Patient Programme is that they may have more appeal to articulate middle class patients who may not have the greatest need^[50, 99-101]. People who have greater need may be more likely to benefit from programmes of education and skills development. Target groups might include ethnic minority groups, low literacy groups, different social classes, older people and rural communities^[102]. For example, older patients experience a higher level of pain than other age groups and they receive poorer pain management^[103]. Another study showed that while 74% of older cancer survivors were taking dietary supplements^[88], those who were eating healthy diets, were older, female or with higher levels of education were more likely to be using supplements. This suggests that those most at risk of nutrient inadequacies were less likely to be taking supplements. It has also been suggested that older people are less likely to benefit from psychoeducational support groups^[52]. There is evidence to suggest that lack of engagement is not due to choice, but rather by accessibility or educational ability^[104]. With sufficient support disadvantaged groups still want all available information and to participate in decision making and personal interactive learning^[104].

While there are disparities in care, there is evidence to suggest that targeted programmes can be effective for underserved groups. For example, it appears that some minority ethnic patients may experience worse pain than white patients^[67], with one possible explanation due to poor communication between minority ethnic patients and their doctors. Kalauokalani et al^[67] found that disparities in pain are significantly reduced when ethnic minority patients are given increased education and coaching on pain. Targeted ethnically sensitive telephone counselling intervention has been shown to improve physical well-being and quality of life^[105] and a targeted intervention in a low literacy group of men found an increase in patient initiated discussions on health and uptake of relevant health testing^[29].

There is very little research available which addresses self management in disadvantaged groups. Targeting programmes at socially disadvantaged groups, either due to ethnicity, social class or other disparity, has the potential to result in large benefits.

Recommendation 4. Support materials

For self management programmes to be fully integrated with a variety of support materials, which may be written, web-based, CDs or other, as appropriate to the survivorship group.

While there is evidence that some skills are best transferred by face to face contact^[106-108] especially where attitude change^[57] is required, there is also evidence that some knowledge and skills may equally effectively be gained from information in written, web based and a variety of other sources as long as patients are provided with direction and support to find these sources^[45, 60]. Indeed, an internet version of the Chronic Disease Self management Program has been found to be equally

effective to the small group version^[109]. One of the skills to be taught in the programmes might be about finding appropriate information and support resources to self manage on a long term. There is a great deal of written information available to people with cancer and much evidence to support its use^[26], although some groups do not access written materials that are available, highlighting the need for written material to be a supplement to oral information^[26] and for health professionals to signpost these materials^[110]. Audio-recorded consultations, summary letters and videos may also improve satisfaction and decrease anxiety in cancer patients^[30], although caution may be necessary as one study showed that these audio recordings improved anxiety in those with a good prognosis but increased anxiety in those with a poor prognosis^[26].

Computer based support may be particularly effective for children and young people, where CD-ROMs have been shown to be more effective than written information and video games have been used to improve self management in young cancer patients^[111]. Use of interactive technologies for patient education in cancer care has been used in cancer survivorship^[112] and shown to have benefits including a shift in doctor patient interaction to a shared decision making model, increased levels of social support and greater benefits for disadvantaged groups^[113]. The cost of a personalised information system is no more than general computer information and may be less than written information. However, evidence suggests that technological devices should be used as an aid to and not as a substitute for interaction with a health professional^[113].

Remote support such as telephone and web based interventions can be useful for peer support and education and even cognitive behavioural therapies^[114]. There is evidence that cancer patients use the Internet to access a wide range of information and support^[115-118]. This may result in increased social support, decreased loneliness, and can improve patient confidence in the clinical consultation^[108, 117]. There is also evidence of improved knowledge, social support, health behaviours and clinical outcomes, such as a decrease in depression^[119, 120]. It has been suggested that internet support groups are better for people who want to remain anonymous, those with rare cancers and those who are geographically isolated^[119, 121]. There is currently little information available for cancer patients on the financial implications of cancer. Internet packages could be a useful source for assessing the financial impact of cancer and pointing patients in the direction of appropriate resources^[122]. However, Doolittle and Spaulding^[123] caution that online health information can be confusing for patients to interpret, and it can sometimes be conflicting or incorrect. Therefore appropriate sources of information need to be developed and careful signposting provided health professionals. A useful research framework for developing internet resources for cancer patients is provided by Whitten et al^[124], based on the development and design of online cancer services, online consumer behaviour/communication, behaviour change, and living with cancer.

Telephone interventions have been effectively used in many ways in a variety of chronic conditions^[3]. Overall modest benefits are seen in general chronic disease management with the potential to reduce social isolation, improve self-efficacy, quality of life, patient empowerment and psychological outcomes. In cancer care telephone support has also been used in a variety of ways, most frequently during active cancer treatment, for example in home monitoring for chemotherapy

symptoms^[125], to replace traditional medical follow up^[126], for ongoing support and counselling^[60] and often in conjunction with other modes of care delivery^[36, 127, 128]. Benefits include accessibility of care, as patients do not have to wait for face to face visits^[37], and higher satisfaction^[129, 130], with some studies showing improvement in health outcomes, such as decreased pain, and improvements in physical, emotional and social aspects of life^[128]. Long term behaviour change has been maintained through telephone support^[60]. Overall costs appear to be similar to traditional models^[37]. Campbell et al^[121] found that telephone support, in the same way as internet support, may be better for people who want to remain anonymous, those with rare cancers and those who are geographically isolated.

Recommendation 5. Key worker role

For each cancer survivor to be assigned a key worker (either community or clinic based) who will provide regular, long term follow up.

Many studies introducing self management strategies showed short term benefits^[44, 69], but for long term behaviour change to be sustained long term follow up and support is required^[3, 51, 60]. A criticism of the EPP has been about sustaining the effect of the programme and what reinforcement might be necessary^[131]. Cancer patients report that they would prefer longer programmes to those currently available^[41]. Long term behaviour change has been successfully demonstrated by programmes such as the Women's Healthy Eating and Living (WHEL) study which enabled women to change and maintain a healthy diet for over four years^[60].

There is also evidence that people's needs change over time and that issues which were considered unimportant during active treatment, such as menopause, fertility and sexuality, increase in importance once treatment is complete. Currently this means that these needs go unmet as there is no mechanism for detecting and supporting patients with the chronic consequences of cancer treatment. There is evidence that health needs, such as bone health and erectile dysfunction, are not discussed by health professionals and so patients are not directed towards available support resources^[110]. Coward and Wilkie^[132] This has been shown to be a problem in people with pain due to metastatic bone pain where less than half took adequate pain medication due to misconceptions about pain and cancer recurrence. Coward and Wilkie^[132]. The suggestion is that ongoing, personalised assessment and signposting to appropriate education might aid understanding of metastatic pain and better use of medication might lead to better self management of pain. There is also some evidence to suggest that people with metastatic cancer have improved length of survival if they have ongoing support for psychological self help work^[133], although this is controversial^[134].

Programmes to care for people with chronic illnesses, such as diabetes and arthritis, have been under development for many years. Integrated care programmes are an effective intervention which combine self management support and patient education, with structured clinical follow up and case management, often by specialist nurses^[135]. Important elements of these programmes are self management support, professionally directed interventions and organisational change^[135]. Although the objective of self management support is to give patients greater autonomy and control over their health, many studies point to the importance of regular contact between patients and those supporting them^[3]. With changing needs over time and a

continuing need for support and advice about how to self manage new or long term problems it is clear that a single assessment will be insufficient for long term survivors of cancer. It is therefore recommended that regular, long term assessment is offered.

Recommendation 6. Health professional training

Appropriate training to be provided to health care professionals and key workers in collaborative working and theories of change management.

A key element of self management support is the delivery of information to enhance knowledge and skills. Nevertheless the delivery of information is not a simple matter and inappropriately delivered information can be detrimental^[26]. Furthermore, in order to enable people to change behaviour and take up strategies to improve their lives other skills are required by health professionals^[136]. Education for health care professionals has been shown to be important in delivering effective integrated care programmes^[135].

Recommendations from the Health Foundation suggest that for self management to be truly effective a new approach needs to be taken^[3]. This is referred to as 'co-creating health'. The difference between this principle and those used in the Expert Patient Programme is that co-creating health is an active and collaborative partnership between patients and their health professionals. Key points are:

- The agenda is set by patient and clinician collaboratively
- Decisions about what skills and knowledge are needed are decided together
- Clinicians and patients understand that health behaviour change is brought about by the belief in the ability to change (self-efficacy) and not by knowledge alone
- The patient believes they have an active role in bringing about their own health improvement
- Goals are set by patients and supported by clinicians
- Decisions are made as a patient-clinician partnership

This new way of working would require development of health professionals to improve their communication skills and teach them how to provide theory based self management support^[35]. If programmes are co-facilitated by patients alongside health care professionals then the training needs of the patients will need to be considered^[137] and health professionals benefit from extra training to work alongside patients^[138].

Recommendation 7. Evaluation

For any changes in practice to be fully evaluated and further unmet needs identified and researched.

Little evidence is available to support the use of self management strategies in cancer, therefore any self management interventions introduced should be adequately assessed for effectiveness prior to implementation. In chronic illness there are a wide variety of measures that have been used to measure the effectiveness of self management interventions. Lorig and Holman^[9] suggest that the beneficial effects of self management are about increasing patients' sense of control and confidence in managing their own health problems. Preferred outcome measures could include self-efficacy, locus of control, fear of recurrence, patient satisfaction and specific symptom measures. It is important to ensure that studies are conducted with baseline measures or valid comparisons, to ensure that any benefits are due to the intervention. Most programmes currently give short term support and do not measure long term objectives. If the aim of self management support is to bring about long term health benefits, then long term outcome measurements will be required. Furthermore, as health care providers, publicly funded by a national health care system, it may be that other outcomes are more pertinent, such as health services utilisation. Consideration should also be given to measurement of resources to ensure not only efficacy for specific interventions but also that they are effective when offered as part of an overall health service^[44]. It is suggested that before commencing any work in supported self management in cancer care that investigators are clear about the expected benefits and how they should be measured.

There is currently little research in self management interventions and programmes for people with cancer. There are many areas of survivorship where there are unmet needs and no self management interventions have been identified, such as chronic, treatment or cancer related pain^[139] Redd et al and goudas et al , cognitive impairment^[140-143] peripheral neuropathy and joint pain^[144-146]. There is very little in the field of advanced or metastatic cancer and virtually no research into self management interventions for the problems faced by people with chronic effects from cancer and cancer treatment. While spirituality and religion are frequently mentioned by patients and may be the most commonly used self management strategy after cancer,^[147, 148] spirituality is rarely a feature of health professional led self-care or self management activities. This may represent an important part of self management programmes.

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Section 3. Appendix

This section of the report contains the broader range of evidence that was gathered for the review and on which the recommendations for further work were based. It is organised according to the initial search strategy and covers a wide range of symptoms at different times of cancer survivorship. The two broad headings are: 1) techniques and tools for specific symptoms and side effects following cancer 2) evidence for the ways in which patients and caregivers can work together. It concludes with some discussion around the limitations of the currently available evidence and how self management research needs to be taken forward in the context of cancer.

A) Techniques and tools for specific symptoms and side effects following cancer

The literature clearly demonstrates that the needs of cancer survivors are great as their active treatment comes to an end, but there is little specific research on self care or self management activities at this time. Most symptom research, including self management, has been conducted during the active phase of treatment, with very little research found for any other period of survivorship. Research which focuses on self management support activities such as information giving, counselling, support groups or symptom management is also largely associated with active treatment, although there is some blurring into the post treatment phase, and many of the findings may be applicable to post treatment as well as to active treatment. Very little evidence was found on any self management techniques or interventions for problems in long term survivorship, living with the long term consequences of treatment or recurrent disease.

Late effects complications

Treatments used in cancer, such as chemotherapy and radiotherapy, can have long term effects on health, particularly if given early in life. Late effects of chemotherapy include cardiac dysfunction, neuropathy, ovarian failure and skeletal problems following bone loss. Long term survivors of central nervous system tumours, retinoblastoma and bone tumours may experience impairment in vision, ambulation, dexterity, cognition and pain^[21]. Second malignancies, such as thyroid cancer, lymphoma and leukaemia may also occur^[22]. There is a great deal of literature which describes the late effects of cancer treatment, but virtually none on how patients might manage these themselves. Some symptoms are addressed, such as pain and fatigue, which may be long lasting effects of treatment, but they have not been addressed specifically as late effects of treatment. Lymphoedema is defined as a late effect and the limited amount of research evidence on the management of lymphoedema is discussed below. There is literature on health promotion after cancer which largely focuses on reducing obesity through diet and exercise and in smoking cessation^[23]. Health promotion activities may be seen as part of a cancer survivorship programme.

Self management activity

A systematic literature review of self management strategies used to manage problems associated with cancer and its treatment revealed little research evidence detailing strategies used, benefits of these or how self management strategies might be supported in practice^[24]. A small number of studies assessed strategies used by people on treatment and there was almost no evidence to suggest how people manage problems themselves beyond treatment. Very little research has explored the benefits to individuals affected by cancer in acting for themselves in relation to their health although benefits are often assumed or inferred. The authors suggest that some people might be more motivated to manage problems themselves than others and careful consideration of recruitment strategies is needed to ensure that individuals typically under represented in research, and those who might benefit most from receiving support to self manage are included. This work has been taken forward to reflect the priority of the Macmillan Listening Study^[14] where patients wanted more research to support everyday management of problems i.e. what problems do people experience and what helps/hinders self management.

In Southampton we have conducted a qualitative study of people 6-18 months post active treatment for cancer, with a focus on problems (associated with cancer/treatment) that they have experienced and barriers/supports to managing these problems themselves i.e. barriers/supports to self management^[149]. This study will inform a large scale survey to assess whether self managing problems has positive benefits using standard measures in a number of domains and what inhibits/supports self management.

One Canadian study found that religion (in the form of prayer) and music were stated as the most commonly used self-care coping strategies after cancer diagnosis^[147]. They also found that other strategies asked about, including breathing exercises, meditation, relaxation, visualisation, hypnosis, counselling, support groups or religious support were all used by less than 30% participants. These kinds of self management activity are likely to be highly culturally specific, for example, one study in Chinese patients found that 20% Chinese patients use Chinese medicines as a self management activity^[150].

Cognitive impairment

The central nervous system is susceptible to chemotherapy and complaints of short term memory loss and generalised cognitive declines are common among cancer patients. A growing body of research supports the hypothesis that chemotherapy can produce long-term changes in some cancer survivors^[140, 141]. Studies of this phenomenon have, to date, been of variable quality and no standard measures for this problem have been identified or agreed^[142, 143]. Good quality, prospective, longitudinal studies need to be conducted with comprehensive neuropsychological assessment and underlying mechanisms elucidated, before treatments can be developed and tested to optimize cognitive function and improve patient quality of life. No research was found which explored any self management techniques for this problem.

Fatigue

Cancer related fatigue is present in 20% to 30% of long-term cancer survivors and 80% to 90% towards the end of life^[151]. There is some evidence for the use of supported self management of fatigue during cancer treatment. For example, Ream et al^[64] found that a supportive intervention of nurses assessing fatigue, providing psychological care and coaching in self management significantly reduced fatigue and associated distress in patients undergoing chemotherapy, while Borthwick et al^[65] conducted a similar study in patients undergoing radiotherapy for lung cancer.

In the phase immediately post treatment there is an emerging body of research into potential self management strategies for cancer treatments. Two literature reviews found that exercise does not help to relieve fatigue post cancer treatment^[152, 153], while the review by Jacobson et al^[152] found some evidence to support the use of psychological interventions to improve fatigue. Jereczek-Fossa et al^[66] suggest that there are benefits to cancer related fatigue with the use of relaxation therapy, group psychotherapy, physical exercise and sleep, but further evidence is required.

Pain

Systematic reviews by Redd et al^[154] and Goudas et al^[155] found very little evidence of self management approaches, but that approaches such as relaxation and hypnosis are beneficial in reducing pain in people with cancer. Currently the evidence relates to professional led hypnosis, although this technique can be taught to use for self management. The best evidence relates to acute pain, such as in diagnostic and treatment procedures where the anxiety and distress due to the procedure is also reduced. There is also evidence that hypnosis helps mucositis related pain^[155].

Yates et al^[57] conducted a randomised controlled trial of 189 cancer patients examining the effectiveness of an educational intervention that aimed to optimise the patients' ability to manage pain. One week post intervention the patients undergoing the education programme had significant increase in pain knowledge and pain treatments. They also had significant increased perceived control and a greater reduction in willingness to tolerate pain, concerns about addiction and side effects and being a 'good' patient. This suggests that an educational programme may alter attitudes that can act as barriers to effective pain management.

It has been suggested that some minority ethnic patients appear to experience worse pain than white patients^[67]. One explanation for this might be due to poor communication between minority ethnic patients and their doctors. This has been addressed by Kalauokalani et al^[67] who found that disparities in pain are significantly reduced when patients were given increased education and coaching on pain. Older patients also experience a higher level of pain than other age groups and they receive poorer pain management^[103]. Specific interventions are needed to target older people.

A systematic review of pain control in cancer^[139, 155] found very few studies on self management methods for pain in metastatic disease and those available had very small numbers. These included studies which suggested that relaxation might be beneficial to reduce pain, but that live training was needed rather than using an audiotape^[106, 107]. Coward and Wilkie^[132] conducted interviews with cancer patients

experiencing metastatic bone pain. They equated pain with cancer recurrence and preferred not to tell others, even their health care professionals. More than half did not take pain medication on schedules recommended by physicians. These findings support the use of education programmes to aid understanding of metastatic pain and better use of medication might lead to better self management of pain. Two studies found psychological support and education to be effective for pain relief in patients with advanced, metastatic cancer^[68, 83].

There was no information reported on the self management of pain as a late effect of cancer treatment in the systematic reviews by Goudas et al^[155] and Carr et al^[139]. Jose Closs^[156] interviewed people with chronic neuropathic pain to explore how people manage their pain. Conventional medicine was often ineffective and had side effects. CAM was also seen to be ineffective but resting or retreating were helpful. Some people tried to accept the pain, but there was insufficient psychological, social, emotional, and practical support to help them do this successfully. The indications were that research is needed on CBT and similar forms of support.

Diet/nutrition

There is much evidence that people who have had cancer alter their diet with the aim of improving their health or preventing cancer recurrence^[84-88]. The belief is that if diet is factor in cancer causation then diet should influence the risk of recurrence^[89]. There is evidence to suggest that unhealthy diet is a factor in cancer development^[90, 91], but very few specific foods that have been shown to affect the risk of cancer^[92]. A large multinational study (EPIC) has shown that increasing fibre, fish, fruit and vegetables reduces the risk of certain cancers and a large intake of red or processed meat, high levels of fat (particularly saturated fats), can increase cancer risk^[93]. Other protective mechanisms are keeping physically active, reducing weight and reducing waist to hip ratio^[93]. However, this evidence relates to risk of developing cancer and there is little evidence to help understand the role of healthy diet after cancer has occurred^[11]. It appears that obesity is associated with increased mortality in breast cancer^[94] and there is some evidence to suggest that a low fat diet can reduce the risk of breast cancer recurrence^[95, 96], although the large Women's Healthy Eating and Living study which studied the effect of a diet high in vegetables, fruit and fibre and low in fat has not been able to identify any effect on breast cancer recurrence or survival^[97]. These changes in diet were achieved by supported self action. The details of the programme will be discussed in section B.

One study showed that 74% of older cancer survivors were taking dietary supplements^[88]. The most common supplements were multivitamins (60%), calcium/vitamin D (37%) and antioxidants (30%). Those who were eating healthy diets, were older, female or with higher levels of education were more likely to be using supplements. This suggests that those most at risk of nutrient inadequacies were less likely to be taking supplements. Miller et al^[88] also discussed the concern that some supplement use is not beneficial.

A variety of self management approaches have been reported by patients for dietary and nutritional problems in patients undergoing chemotherapy by Williams et al^[157] but these have not yet been tested. In people with advanced cancer Hopkinson^[158] suggests that patients find their own solutions to eating problems and that health care professionals can support this self-action. 141 self management actions were

described that fell into four categories: 'taking control', 'promoting self worth', 'relationship work', and 'distraction.' Employing these changes led to changes in thinking and behaviour that were motivated by a desire to enhance wellbeing.

While it is not clear what the benefits are of changing diet after cancer, it is clear that both many cancer patients wish to do this and that they can be supported to make appropriate changes at different stages in the cancer experience. The goals of supporting this action and the best methods to achieve this need to be clarified.

Mobility

There is little research around the issue of mobility following cancer treatment, although some exercise programmes are available with a variety of health outcomes intended^[72, 73]. Karvinen et al^[98] identified that the majority (81%) of survivors of bladder cancer were interested in participating in an exercise programme. They preferred home based, walking, moderate intensity and unsupervised sessions.

There is a growing body of evidence exploring limitations in the upper limb due to breast cancer treatments, such as surgery and radiotherapy. Ghazinouri et al^[159] describe shoulder impairments, including decreased range of motion, decreased strength, sensory impairments and increased pain. These were seen immediately postoperatively or as long as 10 years after surgery. A cohort study by Karki et al^[160] showed that the most common impairments were breast and axilla scar tightness, axilla oedema and neck-shoulder pain. Scar tightness and axilla oedema decreased significantly by 12 months but limb aches increased. Lifting, carrying and reaching out caused worsening of impairments. These findings have implications for potential self management activities. Forchuk et al^[77] taught limb massage to significant others which resulted in a reduction in postoperative pain and better shoulder function. A study delivering an 8 week full body aerobic programme found that both physical fitness and quality of life improved, with no evidence of injury or lymphoedema^[74]. This suggests that this level of activity is safe after breast cancer, although the numbers were small and there was no control group.

Peripheral neuropathy

A qualitative study by Bakitas^[161] described how chemotherapy induced peripheral neuropathy (CIPN) can cause significant physical limitations, emotional distress and social role impairment. However, there is a need for clinical and research measures to assess the full spectrum of CIPN effects on everyday life. Patients have reported self management activities such as keeping extremities warm and wearing gloves but these have not been tested^[157]. There is some evidence to support the use of some dietary supplements in diabetic neuropathy (alpha-lipoic acid and capsaicin), however, these have not yet been used in cancer related neuropathy.

Joint and bone problems

Joint aches, pains and muscle stiffness are commonly described problems in cancer survivors, particularly after breast cancer where there is evidence to suggest that as many as three quarters of women following treatment for primary breast cancer may experience these symptoms^[162]. These symptoms may be caused by treatments such as chemotherapy used for a wide variety of cancers, or hormone therapy used as adjuvant treatment in cancers such as breast and prostate. There is very little in the

literature on these symptoms. Crew et al^[145] present a series of 51 women taking aromatase inhibitors (AIs: adjuvant hormone therapy), 82% of whom reported joint pain (median severity 7/10) and 73% reported joint stiffness. A paper by Morales et al^[146] describing clinical and radiological examination of twelve women with joint pain taking AIs showed severely limited mobility of the hands in affected women, many of whom had to discontinue treatment. An online patient survey conducted by Breast Cancer Action found that 30% respondents discontinued AI use due to adverse effects; 47% of these due to joint-related problems^[163]. No research has been identified which has explored the impact of this problem or how women choose to manage it.

Low mood, coping, self-image and quality of life

Most self management strategies on mood and self image are based on psychological strategies, such as counselling, support groups and CBT. A systematic review of counselling for women with breast cancer supported its use to reduce anxiety and depression and increase locus of control and general quality of life^[47]. Krischer et al^[31] evaluated the efficacy of a self administered stress management training programme in radiotherapy patients. Only those with high levels of psychological distress at the outset benefited from the programme.

A number of psychosocial outcomes can be improved through the use of support groups. A systematic review of support groups in cancer^[48] showed that they offer benefit for mental health, including an increased sense of personal control, increased coping, improved self-image, increased levels of knowledge, decreased isolation, decreased anxiety and depression. Bottomley^[48] categorised support groups broadly as those which delivered structured interventions, such as CBT or were specifically psycho educational, as opposed to those which were more generally supportive, where patients shared experiences and information. Both of these approaches were seen to be beneficial, although there is some indication that the structured approaches were more beneficial for those patients who were newly diagnosed, and that younger people were more likely to benefit than older ones^[52] although there is some conflicting evidence^[53].

Ashing-Giwa et al^[54] delivered a telephone counselling intervention to Latina-American women with cervical cancer. This small study showed that an ethnically sensitive behaviour based counselling approach can achieve significant short term improvement in physical well-being and quality of life.

A meta-analysis showed that psycho-social interventions could be effective in improving quality of life in cancer patients, including aspects of mood and coping^[51]. These interventions included patient education, social support, coping skills training and psychotherapeutic interventions. The most effective interventions were those of longer duration. There is some evidence to suggest that a group based exercise programme can improve quality of life^[73].

Urinary/faecal incontinence

There are a number of self help approaches suggested to reduce urinary incontinence after prostatectomy including pelvic floor muscle exercises^[164], penile clamps and lifestyle changes. A Cochrane review^[165] concluded that the evidence

shows that pelvic floor exercises do not reduce urinary incontinence and that there is too little evidence to draw conclusions about any of the other approaches.

Lymphoedema

Oliveri et al^[166] reported that 76% women on average over 12 years since breast surgery experienced arm swelling and over half reported constant swelling. Those with severe swelling had significantly worse physical functioning and poorer mental health. Only 37% sought treatment for swelling. Hack et al^[167] report that 72% of women experience arm /shoulder pain, weakness or numbness after breast cancer surgery. Kwan et al^[168] suggest that arm related symptoms are still an issue in women 2 years or more following surgery for breast cancer with 50% reporting symptoms, such as reduced mobility, and 12.5% with lymphoedema, rising to 30% where both axillary surgery and radiotherapy had been given. Lower limb lymphoedema may occur post surgery for gynaecological cancer^[169] but no research was found giving information about prevention or treatment.

There is little research to guide women on self management activities that will prevent the occurrence of lymphoedema following axillary surgery or radiotherapy after breast cancer. However, one study of 45 women followed up for 6 months demonstrated that there was no increase in lymphoedema in those women who undertake weight training in their upper limbs and therefore advice to avoid heavy lifting may be inappropriate^[170]. One small study of 22 women showed that women who undertook an arm exercise programme had smaller arm circumference at the end of the programme than controls^[79]. A study by Fu^[80] found that breast cancer survivors themselves were concerned to ensure that lymphoedema did not get worse, that they needed to keep in mind the consequences of their actions on lymphoedema, that they needed to learn to live with lymphoedema and that they needed to integrate the care of lymphoedema into daily life. Armer et al^[76] suggest that self assessment and early detection, allowing for early treatment, hold the best promise for optimal management of lymphoedema. Armer et al^[76] also suggest that nurses have the opportunity to assist patients in developing these self management activities.

Lymphoedema is generally managed by physiotherapy or compression hosiery. There is very little research evidence on the management of lymphoedema at all and even less on self management. One review of the literature suggests that there is some evidence to support physiotherapy interventions, but that the optimal interventions and regime are not clear^[171]. The use of compression hosiery might be considered self management, but the evidence to support its use is minimal, with one small study providing evidence of its benefit found in a systematic literature and a further study showed that multilayered, low stretch bandaging followed by limb hosiery is more effective than hosiery alone^[78]. A study of self-massage and skin care significantly improved symptom relief and patient wellbeing, but did not significantly reduce arm volume^[81]. This study also showed no additional benefit with the use of aromatherapy oils.

Williams et al^[82] showed that a modified version of manual lymphatic drainage (MLD), known as simple lymphatic drainage (SLD), can be used as a self-help measure. This study provided evidence that MLD reduces arm volume, but that the reduction in volume with SLD was less clear. Williams et al^[82] suggest that clinical

experience shows that SLD is effective over the long term, but that consideration must be given to how well the procedure is taught and monitored over time.

Erectile dysfunction

There is very little about self management support for erectile dysfunction. One study found that men with erectile dysfunction did not use currently available materials and support groups^[110] and that their physicians did not direct them to these resources. There is also no validated measure to collect data or conduct research in this area.

Post menopausal

Early menopause may be induced in a number of women as a consequence of cancer treatment, as a result of chemotherapy or surgery. This includes women with breast and gynaecological cancers, but may be an issue for any woman treated with chemotherapy, such as for leukaemia or lymphoma. Post treatment oestrogen levels may be lower than following a normal menopause, particularly for breast cancer patients. There are a number of long term health issues which arise as a consequence of early menopause and low oestrogen levels as oestrogen affects nearly every major organ in the body. A major potential problem is osteoporosis, for which there are both self management and pharmaceutical treatment options. There is some evidence to support the use of weight bearing exercise, along with increased dietary vitamin D and calcium, to help reduce bone loss^[172]. Those at risk of inadequate intake of calcium include those on restricted dairy diets, low intake of fruits and vegetables and high consumption of carbonated soft drinks. High protein, caffeine and phosphorus and low sodium intake can reduce the intake of vitamin D^[172]. Despite this risk and the knowledge about bone protection one American study showed that only 56% of women had discussed bone health with their health care providers^[173].

Menopausal symptoms can be distressing to women who have been treated for menopause, with the most common being hot flushes and night sweats. There are a number of self help measures which women use, although few of these have been tested. There is evidence that the daily practice of relaxation can reduce the incidence and severity of hot flushes^[69]. There is also evidence that self help measures, such as engaging in cooling activities and drinking cold water can help relieve these symptoms^[174]. Filshie^[70] conducted a retrospective review of breast and prostate patients treated with acupuncture for hot flushes. They were taught self acupuncture which they then carried out at home for up to six years for long term maintenance. This showed a 50% reduction in more than 80% patients. A number of herbal supplements have been purported to be beneficial in treating hot flushes, but the evidence for this is conflicting and there is limited evidence on their safety^[172]. One study shows a small reduction in flushes with the use of vitamin E^[175].

Symptom management for other symptoms

Most self management interventions have been used and tested in cancer patients undergoing active cancer treatment, but results from these might be used to inform research in the later stages of survivorship. Self management interventions such as distraction, hypnosis and relaxation have been used to effect in reducing anxiety and vomiting related to chemotherapy, with the strongest evidence relating to reducing

anticipatory nausea and vomiting^[154]. The management of nausea and vomiting has not been explored in this review as this is more usually associated with acute cancer treatment. Other self management interventions studies include a self management skin care intervention in head and neck patients while receiving chemo-radiation^[176] and a mouth awareness programme to help reduce chemotherapy induced mucositis^[177].

B) Evidence for the ways in which patients and caregivers can work together

The Macmillan self management study mentioned earlier involved interviews with people who had finished their active treatment for cancer 6-12 months previously to identify problems they were living with and ways in which they managed these for themselves^[149]. Patients described a variety of ways that they accessed support to increase their ability to self manage, which included:

Health care professionals providing information, support, signposting/referral to other sources of support

- Social support network prior to cancer: family, friends, work colleagues
- Social support network since cancer: people with similar experiences
- Practical support: work place; help from others; financial support

Not all of these can be directly supported by health professionals, however, it may be possible for health professionals to facilitate some of these suggestions, for example, including the experiences of others in self management programmes. Other aspects of care which may traditionally be outside the remit of health care providers may need to be considered. These include help with financial and work considerations or signposting to appropriate support.

The forms of self management support identified in this review have been grouped into four overall headings: i) information giving, ii) enhancing skills, iii) use of technologies and iv) groups and programmes. There are large numbers of studies in the literature, for example Bloom et al^[45] identified that there are over 100 intervention studies reported solely for breast cancer survivors. We have focused mainly on literature reviews and meta-analyses in order to take key points for this review. It is worth noting that the majority of these interventions were delivered during treatment or immediately post-treatment. Those interventions that were for longer term survivors consisted of CBT for psychological symptoms or efforts to improve specific aspects of survivorship including nutrition, exercise, reproductive health or communication skills with health care providers.

i) Information giving

There is a large literature on the benefits of information giving in cancer care. There are numerous ways in which information is provided, for example, orally, in written form or via the Internet. Many people, including health care professionals and cancer support charities are involved in the provision of information, yet many patients still report lacking information^[26, 178]. Therefore, there remains a question as to how people should best be enabled to access the information they require. Beckjord et

al^[178] identified that cancer survivors need more information about tests, treatments, health promotion, side effects and symptoms, and interpersonal and emotional issues than they receive currently. In 2001 McPherson et al^[26] conducted a systematic review of research into information giving where they selected 10 out of a possible 1120 studies. Findings from this review were that written material is a good supplement to oral information due to difficulties with recall and that documentation of information given is helpful to carers and other healthcare professionals. Gaston and Mitchell^[30] confirm the benefit of written materials in people with advanced cancer. In one study written materials provided to breast cancer survivors appeared to be as effective as a workshop intervention in increasing levels of knowledge and improving quality of life^[45]. Timing is seen as important, so that, for example, preparatory written information prior to clinic attendance is helpful, and specific facts about procedures and services are particularly useful^[26]. The main benefits are increased knowledge and decreased confusion, while psychological indices are not normally affected. One study showed that giving patients an audio recording of the doctor's interview improved anxiety in those with a good prognosis but increased anxiety in those with a poor prognosis. However, a systematic review by Gaston and Mitchell^[30] found that audio-recorded consultations, summary letters and videos improved satisfaction and decreased anxiety in patients with advanced cancer. One study also reported that sharing material with the family facilitated practical and emotional support^[30]. Although inappropriately delivered information can be detrimental, overall patient information interventions have a positive effect on knowledge and recall, symptom management, patient satisfaction and preferences and health care utilisation. The main conclusion of this review was that the diversity of the population means that people's needs for information are very different and that the best results are gained when each r information is assessed^[26]. Beckjord et al^[178] also identified that people with more information needs tended to be younger, non White and with more co-morbid health conditions, and that individual survivorship care plans could be useful in addressing information needs as well as helping to improve quality of life. Certain groups may require specifically targeted information. Kripalani et al^[29] found that a targeted intervention to increase the uptake of PSA (prostate specific antigen) testing in men with low literacy levels was effective in increasing patient initiated discussions around testing and a six fold increase in PSA test orders.

ii) Enhancing skills

Self management education

Self management education is most often interpreted as education that is aimed at assisting the patient to learn how to self-manage. This is usually towards predefined health outcomes and knowledge as defined by health professionals. Programmes of education have been developed to assist patients to self manage specific symptoms, with varying success.

In non cancer chronic conditions, self management education has been associated with improvements in knowledge, coping behaviour, adherence, self-efficacy and symptom management^[3]. However, many of these improvements are short term and these effects tend to diminish over time. There is also some evidence of a reduction

in health service utilisation and cost, and enhanced patient quality of life. Quality of life effects are more likely to be sustained beyond the intervention period.

Information gathered on reviewing the evidence in other fields of chronic illness suggests that self management education can improve patients' knowledge (diabetes, arthritis), increase self efficacy, self management and coping behaviour (arthritis), with some areas suggesting that this results in improved health status, perhaps as a consequence of better adherence to medication protocols and attention to diet and exercise. Combined with regular practitioner review and patient actions plans, asthma self management education can lead to improvements in health services utilisation, quality of life, and self-efficacy. In patients with arthritis self management education has only a small and short term impact on key outcomes, such as pain and functional disability. Self management education has been associated with greater blood glucose control and reduction in diabetic complications in diabetes. In other illnesses, such as chronic obstructive pulmonary disease, no benefits were found with this approach.

The Health Foundation report^[3] found little on self management education for cancer patients. One meta-analysis was found of psychosocial interventions in adult cancer patients, specifically analysing impact on quality of life^[51]. Patient education programmes had a moderate but positive impact on quality of life. Effect sizes were greater for interventions of longer than 12 weeks. No information was found on whether these interventions had any impact on health services utilisation and cost, health behaviour and health status or patients' knowledge and information recall.

Our scoping of the literature revealed a number of programmes that provided education to increase self management. Studies of self management interventions in cancer patients have usually been about professional led programmes aimed at supporting or educating self management. The aims have been to increase coping, general quality of life and to reduce symptom burden and psychological distress. Methods include education to increase perceived control^[55]; to improve coping skills^[125]; to improve symptom management^[59, 179] or psychological interventions, such as stress management^[56], CBT^[59]; psychological support^[133]; to increase knowledge^[45]; to improve healthy behaviours, such as diet^[60], exercise and smoking cessation^[61-63] simple educative advice given to families with regard to symptom reporting^[58] or to improve skin care after stem cell transplant^[180].

Most of the research is during the active phase of cancer treatment, particularly with respect to self-monitoring, where hand held devices have been used to monitor and report symptoms during chemotherapy. However, in advanced cancer, nurse delivered educational programmes for patients, with self monitoring of pain, showed improved pain management^[59, 179], demonstrating increased perceived control, with a greater reduction in willingness to tolerate pain, concerns about addiction and side effects^[57]. A programme to teach patients self massage and skin care for lymphoedema brought symptom relief but did not reduce arm volume^[81].

Larger effect sizes for self management education in non cancer programmes have been with: longer interventions (12 weeks or more), higher intensity programmes, regular review by health professionals, focus on specific topics, participative rather than didactic teaching methods, multicomponent approaches and involvement of

family or other informal carers^[3]. One study compared education groups with peer discussion or combined education and peer discussion and found that education alone was the most effective^[181], even suggesting that for women with good peer support prior to the group, a peer discussion group could be harmful. Furthermore, Bloom et al^[45] found that women who were sent educational materials showed the same outcomes as women who attended educational workshops. Three wide ranging workshops for women five years after diagnosis increased knowledge levels, but failed to bring about change in exercise, diet or communication skills. They suggest that knowledge may be increased by short term interventions, but that to bring about lifestyle changes then more focussed and longer interventions are required.

iii) Use of technologies

Computer based support and education

Computer based learning may be in the form of specific training programmes or as information gathering from the Internet. There is evidence that cancer patients use the Internet to access information and support^[115, 116]. Eysenbach^[182] evaluated 24 surveys of cancer patients use of the internet and found that they used it for email communication, virtual support groups, health information and e-commerce. They found that some support groups can increase social support and decrease loneliness. They also found that internet information increases self-efficacy and can improve patient confidence in the clinical consultation^[182]. It has been suggested that internet support groups are better for people who want to remain anonymous, those with rare cancers and those who are geographically isolated^[183]. However, there may be groups who are underrepresented in use of online cancer support groups, such as African Americans^[100].

Computer based support may be particularly effective for children and young people, where CD-roms have been shown to be more effective than written information^[184] and video games have been used to improve self management in young cancer patients^[111]. Evidence for non cancer uses of computer education include a systematic review of interactive health communication applications (usually web-based packages for patients), which found that this improved knowledge, social support, health behaviours and clinical outcomes^[120] and a systematic review of cognitive behavioural therapy (CBT) found four studies which showed computer based CBT to be as effective as therapist led CBT in reducing anxiety and depression^[114]. A systematic review and meta-analysis of interactive technologies and videotapes for patient education in cancer care by Gysels and Higginson^[113] showed mixed results for both patient satisfaction and knowledge improvement, although there was some evidence of reduction in depression and anxiety. Benefits included a shift in doctor patient interaction to a shared decision making model, increased levels of social support and greater benefits for disadvantaged groups. The cost of a personalised information system was shown to be no more costly than general computer information and was half the cost of full patient access to written information. Gysels and Higginson^[113] concluded that technological devices should be used as an aid to and not as a substitute for interaction with a health professional.

Another way of accessing support from the internet is to join cancer related mailing lists. One survey showed that this resource was used to share information, advice

about coping and support with others who had similar cancer experiences. The main users of this source were over 50, white, and college graduates^[99]. Although there is much available for cancer patients on the internet there is very little on the financial implications. This could be a useful resource for assessing the financial impact of cancer and pointing patients in the direction of appropriate resources. Bradley^[122] describes how this might be done. Weiss and Lorenzi^[185] suggest that focusing the design of online cancer communication systems around the interpersonal relationships of patients and families may provide more effective paradigms for online cancer care and support. Doolittle and Spaulding^[123] caution about the disadvantages associated with utilization of online health services among individuals living with cancer. Accessing accurate, reliable health-related information online gives patients the power to enhance their understanding of information they obtain from their health care providers. However, online health information can often be confusing for patients to interpret, and it can sometimes be conflicting or incorrect. A special issue of the Journal of Medical Internet Research was published in 2005^[124] which provides a research framework for those seeking to further research into internet use by cancer patients. This framework includes an expanded focus on the development and design of online cancer services, online consumer behaviour/communication, behaviour change, and living with cancer^[124].

Telephone support

Telephone interventions can be used in a variety of ways, and have been used to empower patients in their own care, in a variety of chronic conditions, including diabetes, hypertension, cardiac failure and AIDS^[3]. The findings showed modest benefits in general chronic disease management and could reduce social isolation, improve self-efficacy, quality of life, patient empowerment and psychological outcomes. There was little evidence of impact on health services use.

In cancer care telephone support has also been used in a variety of ways, most frequently during active cancer treatment, for example in home monitoring for chemotherapy symptoms^[125] and often in conjunction with other modes of care delivery^[36, 127]. Damush et al^[37] compared home nursing visits with a combination of home nursing plus telephone nurse support given to people learning self management for new stomas as a result of cancer treatment. Telenursing patients indicated higher satisfaction and found that care was more accessible as they did not have to wait for face to face visits. The home health group had one more visit per patient, although overall costs were the same.

Ahles et al^[128] developed an efficient, rapid assessment and management approach for pain in busy community environments. Using a combination of the Dartmouth COOP Clinical Improvement System and a telephone based nurse-educator. The nurse provided pain self management strategies and a problem solving approach for psychosocial problems. Patients in the intervention group scored significantly better on pain, physical, emotional and social subscales of the SF-36 scale.

Some groups have used the telephone to provide peer support e.g. for graft versus host disease^[186]. Other services have developed to replace traditional medical follow up at the end of active treatment, with nurse led telephone clinics, either nurse or patient initiated^[126]. A programme to bring about dietary change in women following

breast cancer utilised telephone counselling for support and successfully maintained behaviour change over four years^[60].

Gotay and Bottomley^[129] found that telephone support in cancer patients was feasible and well accepted. Campbell et al^[183] found that telephone support, in the same way as internet support, may be better for people who want to remain anonymous, those with rare cancers and those who are geographically isolated.

Self-monitoring and treatment

Self-monitoring of health status and treatment regimens is now possible as a result of technological developments. These include devices for home self monitoring and diagnostic kits for self testing, for conditions such as high blood pressure and diabetes. The evidence to support these shows cost saving due to decreased utilisation of health services, and appear to be as effective in health outcomes^[3]. There is little evidence available that this approach increases patients' perceived sense of control or wellbeing. Self management diaries have been used during chemotherapy to record side effects and self management actions^[104] and, more recently, cancer patients have used on line, real time report of symptoms when undergoing chemotherapy^[187]. This was well received by patients and clinicians and used by 85% patients. In cancer care, these kind of devices appear only to have been used in the active treatment phase. No studies were identified for technological approaches to self-monitoring in cancer survivorship.

Facilitating patient access to personal medical information

Currently, patients in the UK have little access to personal medical information held by the health care system. Two ways of increasing access to this kind of information are to have patient held records and audiotape recordings of clinical consultations. Evidence found by Coulter and Ellins^[3] showed that audiotape recordings of consultations improve understanding and increase uptake and recall of information, but have no effect on anxiety or quality of life. Patient held records increase sense of control. There is some evidence of increased resource use with patient held records, but also, in maternity patients, they were less likely to be mislaid. There was little evidence of beneficial effect on health status although amongst heart failure patients there was evidence of better adherence to medical advice^[3].

Amongst cancer patients^[184, 188, 189] most studies showed no differences between groups when measuring patient satisfaction, health status, emotional and cognitive functioning, with Lecouturier et al^[188] showing increased satisfaction with information received. There was an impact on helping patients prepare for meetings with healthcare staff and feeling more in control. Pitceathly et al^[190] conducted a systematic review of 16 studies examining the effects of providing recordings of consultation summaries for cancer patients. They found that patient satisfaction, knowledge and recall was improved and that patients found recordings valuable. No studies found any significant difference in anxiety, depression or quality of life, however the reviewers concluded that practitioners should consider offering people recordings or written summaries of their consultations^[190].

iv) Groups and programmes

Support groups

Support groups are run in many different ways and often the distinction between them is not clear. Some are purely led and run as peer support while others have an element of health professional involvement, sometimes as invited speaker and sometimes running the group. The categories described by Bottomley^[48] were those which delivered structured interventions, such as cognitive behavioural therapy, and those which were more generally supportive, with patients sharing experiences and information. The former is more usually led by health professionals and the latter may be peer led.

Large numbers of self help and peer support groups have been set up for a wide range of conditions, including mental health, parents of sick children and cancer. The evidence reviewed by Coulter and Ellins^[3] suggests that their benefits include improved knowledge, increased coping abilities and psychosocial benefits for some, although there are variations. There is little evidence that they have beneficial benefits on health status and make little difference to health utilisation.

Within cancer, there are many self-help and support groups described in the literature; most are delivered during the active phase of cancer treatment (e.g. radiotherapy^[55]; chemotherapy^[56, 191]). A few programmes are reported in the post treatment phase^[37, 38] and a few in metastatic cancer (mostly breast cancer)^[192]. An early report by Spiegel et al.^[193] suggested that participation in these groups not only had psychologic benefits but also resulted in prolonged survival. A review of five randomised trials of support groups for patients with metastatic breast cancer found that this was the only study to report a survival benefit and that the evidence of beneficial survival effects was not convincing^[134]. There was good evidence that support groups in metastatic breast cancer lead to improved psychologic outcomes, although the effects were transient and were not always present for all study outcomes. A more recent Cochrane review by Edwards et al^[194] found that, although there was some short term benefit for women with metastatic breast cancer, this was not sustained over time and the authors conclude that there is insufficient evidence to advocate the use of group psychological therapy for this group. However, this was only a review of 5 studies. It is possible that important effects may be missed with these small numbers and a more targeted programme may be more effective.

The benefits of support groups in cancer appear to be similar to non cancer groups. Systematic reviews of support groups for cancer by Whatley and Milne^[47] and Bottomley^[48] supported the use of support groups to benefit mental health, including an increased sense of personal control, increased coping, improved self-image, increased levels of knowledge, decreased isolation, decreased anxiety and depression and improved quality of life. Nearly all reported supported groups were professional led programmes. One self administered stress management programme for radiotherapy patients showed that only those with high levels of psychological distress at the outset benefited from this^[31]. Ultimately, the magnitude and length of benefit from support groups remains unclear.

Gender has been identified as a potential influence on self help use and coping, as a higher percentage of patients with breast cancer attend support groups than do men with urological diseases, such as prostate cancer^[110] but the study of diseases with equal prevalence amongst males and females have not shown gender to be a predictor of self help use^[195, 196]. It has been suggested that clinicians are at least partly responsible for the lack of self help awareness^[110]. Young and well-educated patients are more likely to use support groups^[101].

Self management programmes

Self management programmes have been developed for people with long term conditions and conducted in the US, Australia and the UK. Some cancer specific programmes have also been developed, largely in the US and Australia, with some programmes in the UK being led by charitable bodies, such as Macmillan and Breast Cancer Care.

The Expert Patient Programme in the UK has been offered to people with chronic conditions, such as asthma, diabetes and arthritis. It is based on the principle that people need a generic set of skills to self-manage successfully. These skills form the basis of the EPP programme, which is highly structured and manual led. Activities include: action planning, relaxation, fitness, decision making, communication and working with the health care team. An evaluation of this programme has shown improvements in self efficacy and health status^[42]. The key findings from this evaluation are discussed. Patients valued the social support generated through sharing experiences with others, however it is not clear that the structured EPP course is the best way to meet this support need. The majority of people on these courses went to share their experiences with others. They viewed the EPP as a reinforcement of their existing self management behaviour rather than as an opportunity to learn anything new. Only a minority practised ad hoc self management, and did not see themselves as 'experts'. They needed opportunities to improve their self management skills and had less access to other resources and support. Recruiting sufficient numbers was not always possible with particular difficulties reaching ethnic minorities, low literacy and other hard to reach groups. This suggests that the programme was not meeting the needs of those with greatest need. Reasons for declining attendance at the course were given as a lack of perceived need, low expectations of course, lack of familiarity with self management principles and a lack of confidence in ability to take part. Patients also stated a preference for condition specific courses. Distinct needs of carers have been identified and led to the development of an Expert Carers Programme. A major problem of the EPP has been the lack of engagement by health care professionals. There was a lack of awareness and resistance to the concept of an 'expert' patient. This meant that clinicians did not refer to the course and many patients are unused to self referral to NHS provided resources, adding to the difficulties in recruitment. Wilson^[43] reviewed the programme to consider its use in cancer patients. She also described the lack of engagement by health professionals, suggesting that this is essential for long term success. She suggests that the use of volunteers gives rise to problems of availability of sufficient and suitable tutors, and difficulty with quality control.

Some have criticised the notion of 'expert patients' and the Expert Patient Programme as a device to transfer the costs and responsibilities for care onto the

patient. Reservations have been expressed by health professionals as to whether there is: sufficient capacity to adequately support all patients in self managing their own care; willingness on the part of health professionals to engage in referral to these programmes; uncertainty as to whether they are appropriate for all patients; and concern about the sustained effect of these programmes and what reinforcement might be necessary^[131]. It is suggested that the evidence for the use of supported self management through programmes such as the Expert Patient Programme is strong and that they are having an impact on many patients, but it is important to recognise the different objectives of interventions for different conditions^[197] and problems may arise when transferring the lessons learnt from programme in 12 000 patients to all those affected by chronic illnesses.

There are a number of programmes that have been initiated for cancer patients following their active treatment. Many have an element of education and overlap with programmes described above. Lewis et al^[198] have described a nurse coaching programme in cancer care as a model that is designed to facilitate the patients and family member's repertoire of behavioural self-care and self management skills. Nurse coaching facilitates cognitive emotional processing of the cancer experience and includes six dimensions: attending to the story; encircling the experience; inviting the work; exploring solutions; anchoring the skill and setting up success.

The Taking CHARGE programme in the United States^[36] for breast cancer patients has been shown to increase self-efficacy when compared with usual care. This was nurse led with 2 group sessions and 2 follow up phone calls. The patients felt that they would like more group sessions to gain additional peer support.

Beckmann et al^[41] in Australia compared a generic vs. cancer specific programme called 'Staying Healthy after Cancer', which included carers and patients. The main findings from this were an increased sense of control for participants, with cancer survivors expressing a strong preference for cancer specific programmes, wanting specific detail relating to cancer, including details on recurrence. They also wanted a longer programme and more time for discussion. Conversely, the carers preferred the generic programme. However, the evaluation was weak, using a small sample and it did not report how many finished the programme.

Some supported self management nurse-led programmes have been identified which are targeted at particular symptoms, such as fatigue. One programme was found to be beneficial in reducing fatigue during chemotherapy^[64] and another in radiotherapy^[65].

Other survivorship programmes found in cancer were: a pilot self management programme for breast cancer patients which showed an increase in health information seeking behaviour^[38]; the PRO-SELF programme which provides information and support to improve skills of cancer patients to carry out effective symptom self management^[39] and a coping skills training programme for cancer patients (Nucare). An interesting finding from this was that those with high self-efficacy and a belief in their ability to change gained most benefit from the programme^[40]. Bloom et al^[45] randomised 404 young breast cancer survivors to 3 x 6 hour workshops over 3 months versus a waiting list control. This covered information and activities to promote physical, social, emotional and spiritual well-

being, including a personalised exercise prescription, diet and cooking based on the WHEL programme and communication skills training. The findings were that the intervention increased quality of life and knowledge, but did not impact on skills or behaviour. A third of the women did not attend the programme but received the written materials. This group had the same outcomes as those who attended, suggesting that the materials were more important than the interactions. Bloom et al^[45] suggest that more focussed programmes would be better able to influence lifestyle changes.

The programme used by the WHEL study to bring about dietary change in women following breast cancer was based on Bandura's social cognitive theory^[4]. The programme used telephone counselling as the principal method using education, increase in self-efficacy, monitoring and motivation^[60]. Monthly cooking classes and monthly newsletters supported the individualised counselling. It is not clear how often the telephone counselling was delivered or for how long it lasted. However, this targeted programme was successful in supporting women to maintain a change to a healthy diet over four years^[60]. Another study successfully used volunteers to deliver and evaluate a low fat dietary intervention^[199]. Although this provides some evidence that volunteers can provide this intervention, most of the volunteers were nurses or dietitians, so it is not clear that untrained volunteers would be as successful.

Integrated care programmes

Programmes to care for people with chronic illnesses, such as diabetes and arthritis, have been under development for many years. Integrated care programmes are those which combine self management support and patient education, with structured clinical follow up and case management, often by a specialist nurse. A review of systematic reviews demonstrates that integrated care programs generally have positive outcomes^[135]. Many were supported by multidisciplinary care teams and care pathways. Feedback and education for the health care professionals were seen to be important. The most commonly used outcome was functional health status, with important outcomes being effect on hospitalisation, dependency and mortality. These outcomes were not consistently applied and they might not be the most appropriate outcomes for programmes for people with cancer. Self management support was seen to be an important part of these programmes, but that the programmes were not likely to be most effective without also including professionally directed interventions and organisational change^[135].

Peer led support

Most of the programmes found for cancer patients were clinician driven with a clinician agenda. Exceptions to this were the Macmillan 'Living with Cancer' programme, which is patient driven with no clinician input and the Breast Cancer Care 'Living with Breast Cancer' facilitated by the charity, with invited speakers who may or may not be health professionals. No evaluation was found for either of these UK based programmes.

In a systematic review of 10 randomised controlled trials Hoey et al^[108] identified five models of peer support for cancer patients. A one to one trial of face to face support improved depression at four weeks but not in the long term. Some small

studies of group and one to one telephone support found no effects on emotional distress, or other psychological measures, although participants reported more social support. A study of group internet support found positive effects on depression, perceived stress and symptoms of PTSD (post traumatic stress disorder) and the participants had greater confidence in their own healthcare. Macvean et al^[46] reviewed 28 studies exploring the use of volunteers in support programmes for people with cancer. The outcomes were mixed with the authors concluding that using volunteers in cancer care may have its merits but that further evidences is required to demonstrate effectiveness.

Summary and key points on self management programmes

Some considerations that arise from the review of these programmes include:

- The current evidence suggests that programmes should be part of a range of self management supports
- Targeted programmes are more successful to bring about long term change than generic programmes
- Programmes aiming for behaviour change need to be theory based and driven.
- How should success of programmes be measured: by health care or participant defined outcomes?
- There is more evidence for the success of programmes involving health care professionals, even if only by endorsement, than without.
- Careful consideration of the name of the programme (does 'Expert Patient' antagonise health professionals? What messages are given to participants?)
- Health professional training needs to be guided by philosophy of concordance rather than compliance
- May need to prepare course leaders to be flexible to needs of the participants.
- May need to add in follow up sessions post programme
- Telephone follow up can be effective
- Integrating self management support with structured clinical follow up and case management may be the most effective model.

Factors that affect self management

The Macmillan self management study^[149] has identified that there are a number of barriers to self management experienced by people living with problems following active treatment for their cancer. These include:

- Barriers to health care provision and support: Lack of, or limited, support and help from health care professionals
- Barriers to management of information and support: Lack of information; media coverage can be frightening and unhelpful; conflicting advice; lack of financial information; not wanting information; limited access to others' experiences
- Psychological barriers: emotional barriers; lacking focus; worries and fears (e.g. check-ups); boredom; frustration; concentration
- Social network barriers: unhelpful experiences; limited access to others; others' reactions

This review of the research literature has identified further specific factors that affect the engagement in self management support. Self management programmes are more available to those who are well educated and have higher self-efficacy. This limits their effectiveness for all groups. Information sources are also better utilised by those who are better educated. One study reported a group of African American cancer patients who had an average reading age of 11 to 12 year olds, but who still wanted all available information, to participate in decision making and preferred personal interactive learning^[104]. The authors stated that over half of this group would be unable to read most available patient education materials.

More women use support groups than men and the young and well-educated are also more likely to use support groups^[101]. Breau et al^[110] suggest that some of this bias, particularly for men, is due to clinicians. Napoles-Springer et al^[200] surveyed Latin American breast cancer survivors on their use of support groups. They found that 32% had used support groups. Of the non-users the main reasons for non use were: receiving enough support from elsewhere, not needing a support group, and being unaware of groups in their area. Family members were highly influential in encouraging women to use support groups and spiritual well-being was inversely associated with support group use. Napoles-Springer et al^[200] and Ashing-Giwa et al^[54] identify the need for more culturally and linguistically appropriate support service and increasing the awareness of these services. One Canadian study showed that strategies such as relaxation, visualisation, hypnosis, counselling, support groups and religious support were all used by less than 30% participants^[147]. The question as to why these self help measures are not used by more patients is not yet clear. This could be about availability, but there may also be attitudinal issues that need to be addressed. A further consideration in putting together a programme was that some studies found they needed 'live' trainers, rather than remote learning e.g. for relaxation^[106, 107]. There also seems to be an issue relating to the ways in which support interventions are labelled. Practical sessions on topics such as cooking or coping with hair loss appear to be acceptable to a broader range of people than support groups, counselling or behavioural therapy. Interventions of longer duration were more effective^[51, 60].

A finding from the Health Foundation report on self management in chronic conditions was that although the objective is to give patients greater autonomy and control over their health, many of the studies point to the importance of regular contact between patients and those supporting them^[3].

Limitations of research findings on self management support approaches

There are a number of limitations of the research on self management. There is very little research that focuses on self management approaches in cancer survivorship, on the long term consequences of cancer treatment or in advanced disease. The majority of trials have tended to measure only short term outcomes of up to 6 months. Financial considerations have been largely overlooked. Studies have been conducted in specialist research settings, leaving open the question of whether implementing self management support in routine care is feasible. The WHEL study^[97] has shown that, with ongoing and regular support, people with cancer can be supported to make long lasting change in their lifestyle. Most programmes give

short term support and do not measure long term objectives. It is suggested that programmes for self management might need structured, ongoing support to be most effective. There is little research aimed specifically at ethnic minority groups and available research suggests that they may be less likely to be engaged in self management activities to enhance their health, such as exercise^[201]. A frequent finding is that less well-educated people are less likely to utilise self management activities. Little research is directly focused on this group, yet there is evidence to suggest that they benefit from targeted material.

Recommendations for further research to be undertaken include:

- longer follow-up measurement of outcomes
- more research into self management approaches to symptom control
- more research into advanced and metastatic cancer
- structured self management support interventions over a longer period of time, evaluating frequency and duration
- a combination of approaches with closer links between health care professionals, lay and charitable sources of support
- further examination of the involvement of volunteers
- evaluation of clinical and cost effectiveness
- further evaluation of the relationship between the dimensions of self management and health status outcomes.
- consideration of the use of appropriate outcomes; consider self-efficacy as an outcome measure
- further evaluation of self management support interventions for which evidence is most lacking, including telecare, patient support groups and self monitoring
- consider the needs of minority groups (such as ethnic minorities, low literacy groups)
- more work on the ways of enhancing family support
- consideration of the role of spirituality and how this might be incorporated into interventions
- more use of computer and internet programmes and packages.

Discussion

The example of supporting people to change their diet in the WHEL study^[97] demonstrates that cancer survivors are prepared and able to adopt self management approaches over the long term if they are appropriately supported. Ganz et al^[33] suggest that survivorship care plans are a key component of high-quality cancer care. The Macmillan study showed that patients not only utilised their health care professionals as a source of support but also accessed social and practical support from their social support networks prior to and since cancer and that they also accessed work based and financial support. Programmes designed to support self management might need to consider the incorporation of these sources of support. For example, having informational material to share with family members promotes practical and emotional support^[30].

Lessons from this review include the finding that interventions need to be long term and focussed if change is to be brought about. They need to be personalised but can be facilitated by mailed, written information and by motivating telephone

communication. The endorsement of physicians is important, but interventions can be delivered by other health professionals. Interventions which utilised behavioural theory in their design and implementation were more likely to be successful. When asked, patients raised spiritual issues as key sources of support, yet very few programmes appeared to take this into account. Computer and internet based interventions are effective for some, particularly for some underserved groups. There is also evidence that computer aided information interventions improve shared decision making.

Despite decades of improving information giving, this still does not seem to be adequate. There are also doubts about appropriate handling of information, particularly for those with poor prognosis. More research may be needed into assessing and identifying the needs of individuals. This may also be an issue of communication skills training for health professionals.

Marketing or labelling self management support interventions needs some consideration. It was suggested that the title 'The Expert Patient' may carry negative connotations for health care professionals. From the patient's perspective the content of the intervention may need to be reflected in the title. Many cancer patients identify that they do not need support groups or that they get their support from elsewhere^[200], therefore an intervention labelled as a support group may alienate many patients.

Helping patients to enhance their self management may include moving away from traditional relationships between patients and health care professionals to think more broadly about the social context in which the patient lives. Recommendations from the Health Foundation suggest that for self management to be truly effective a new approach needs to be taken^[3]. This is referred to as 'co-creating health'. The difference between this principle and those used in the Expert Patient Programme is that co-creating health is an active and collaborative partnership between patients and their health professionals. Key points are:

- The agenda is set by patient and clinician collaboratively
- Decisions about what skills and knowledge are needed are decided together
- Clinicians and patients understand that health behaviour change is brought about by the belief in the ability to change (self-efficacy) and not by knowledge alone
- The patient believes they have an active role in bringing about their own health improvement
- Goals are set by patients and supported by clinicians
- Decisions are made as a patient-clinician partnership

In order to achieve this The Health Foundation suggests three strands of work. One is a development programme for clinicians improving their communication skills and teaching them how to provide self management support. The second is the self management programme for patients, which this report has mentioned. Thirdly there is a service improvement programme which aims to change and improve the way that health services are designed and managed to enhance self management support. There may be extensive evidence which relates to service improvement and to communication skills training for health professionals (not covered by this report)

which may be of equal importance for truly effective self management support and may need to be considered in further work. One example of such evidence of training for health care professionals comes from Hopkinson^[158] who has shown that people with advanced cancer practice self action techniques to reduce distress associated with appetite and weight loss. A training programme for health professionals to support patients and carers in this self action brought about significant benefits.

The issue of determining outcomes remains to be resolved. Outcomes that have been reported here vary from specific health outcome measures and range from self-efficacy to health utilisation, which may represent diametrically opposed outcomes in health care provision. However, this remains a fundamental issue relating to the purposes of supporting self management.

Recommendations and further work

Recommendations for further work include considering carefully the implications of the co-creating health model, what this means for training of health care professionals and how else this model could be introduced. Possible pilots to take forward the work presented here include:

1. A range of focussed interventions available for particular problems
2. Interventions targeted towards specific groups
3. Programmes co-hosted by clinicians and patients
4. Generic cancer programmes for carers
5. Generic cancer programmes with some concurrent cancer specific sessions
6. Development of survivorship care plans with regular review
7. Combined group programmes with telephone follow up support

It needs to be remembered that not all people with cancer want intervention programmes and that other methods of delivering self management support need to be developed. Therefore further research should identify groups who do not want to participate in group support and explore alternatives with them. Internet based support may help provide an alternative for some of these groups. The broader picture also needs to be addressed in terms of health care services and training of health professionals into collaborative working and consideration given to the wider social situation and whether support can be provided in areas such as work and finance.