

**SUPPORTING SELF MANAGEMENT OF PEOPLE AFFECTED
BY CANCER: A REVIEW OF THE EVIDENCE**

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June 2005

**PLEASE NOTE: This report presents a review of published research studies
and is not a comment on the activities of Macmillan Cancer Relief.**



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Acknowledgements

This literature review was commissioned by Macmillan Cancer Relief and conducted by Drs Claire Foster, Heidi Hill, Jane Hopkinson and David Wright at the Macmillan Research Unit, School of Nursing and Midwifery, University of Southampton.

SUPPORTING SELF MANAGEMENT OF PEOPLE AFFECTED BY CANCER: A REVIEW OF THE EVIDENCE

Executive summary

Purpose

In 2003 Macmillan Cancer Relief coordinated workshops with Macmillan stakeholders including people affected by cancer to prioritise research areas. One of the topics identified in these workshops was *supporting self management of people affected by cancer*. The remit of the Southampton Macmillan Research Unit in 2004 was to review published primary research to establish the evidence base for supporting self management of people affected by cancer. Macmillan's purpose in supporting research is to ensure that research underpins and supports its core strategy to improve the lives of people affected by cancer.

There is clear interest in and emphasis on patient self management in the UK. Recent policy from the Department of Health is encouraging a move towards partnership between health professionals and patients evidenced by the National Service Framework for Long-term Conditions¹, NICE guidance for supportive and palliative care², and the piloting of the Expert Patient Programme for patients living with chronic conditions³ as examples. Macmillan is piloting living with cancer self management programmes and these are currently being evaluated. The potential for translating chronic illness self-management programmes to cancer will be explored in the evaluation. Macmillan's policy priority areas include improving the user's experience, improving supportive and palliative care, self management and user involvement.

The purpose of this literature review is to explore how to support self management of people affected by cancer by systematically examining published research evidence exploring what people do to help themselves when living with cancer (from the point of diagnosis, through treatment and beyond). This is a review of research studies that have been published in peer review journals and not a comment on the activities of Macmillan Cancer Relief. The research studies included in this review investigate elements of self management, collect evidence to address specific research questions and present an analysis of the evidence. Such a review is timely. This is

the first review of the research evidence in relation to self management by people affected by cancer. By gaining a better understanding of what people do to help themselves based on research evidence, health and social care professionals will be in a position to support choices made by people affected by cancer to enhance physical and psychosocial well-being beyond decisions about treatment options. Findings from this review will also inform further research both within and beyond Macmillan Cancer Relief.

Definitions and scope

This review is limited to literature relating to self-initiated actions of people affected by cancer over the age of 18 years. The volume of literature generated (over 30,000 hits) in the initial scoping exercises prompted the decision to focus on patient-initiated actions and exclude actions initiated by health care professionals. Whilst self management by people affected by cancer is the focus of this literature review, in research terms it is a poorly defined concept. Several terms are used inconsistently in the literature included in this review to describe different elements of what people do to help themselves when living with cancer. For the purposes of this report we will use the following definitions to distinguish types of self initiated actions:

- ❖ *Self care*: This term will be used to describe usual, everyday self care behaviour such as eating, washing and dressing typically associated with nursing. These behaviours may be modified according to symptoms experienced or efforts to prevent future difficulties and can therefore be proactive or reactive.
- ❖ *Self management*: This term will be used to describe medical management of the cancer, symptoms or disease process by the patient. Examples would be administration of chemotherapy, self medication for pain, vomiting or other symptoms. These actions could be initiated to avoid or control disease symptoms and treatment side effects and may be proactive (to prevent) or reactive (to control or treat).
- ❖ *Self help*: This term will be used to describe activities additional to everyday self care and self management. These are additional activities that people may engage in which are non-medical to enhance physical and/or psychological well-being. Examples include attending support groups, use of complementary and alternative therapies (hereafter referred to as CAM), and information seeking. Self help can be proactive (to prevent problems or maintain current state) or reactive (in response to a particular need or difficulty).

Methods

A literature scoping exercise was conducted to estimate the size of the research literature from a range of key databases which hold published research studies [BIDS, BNI, Cancer.gov, CINAHL, Medline, Psychinfo, Web of Science]. This process enabled identification of search terms needed to capture relevant articles. Secondary questions were refined at this stage. A detailed account of the search process can be found in the full report. Several sources of literature were searched for the years 1960–2004 including bibliographic databases and internet sites. 19,960 articles were retrieved and reduced to 8,044 after removal of duplicate papers. Titles and abstracts of each of these 8,044 papers were examined to determine whether they were relevant for the review. 453 abstracts appeared relevant for the review and were then independently assessed by 3 researchers. 97 published papers were selected for review according to strict criteria. The full text articles were retrieved for more detailed evaluation. 37 of these met the inclusion criteria. Most of the studies in this review were observational studies without control groups. As a consequence no formal hierarchy of evidence to distinguish randomised controlled trials from other types of studies was applied. The studies were both quantitative (surveys, questionnaires) and qualitative (interviews, focus groups). The quality of both quantitative and qualitative studies was assessed with the use of structured checklists. Descriptive synthesis of data was undertaken and summarised in tables which appear in the appendices of the full report.

Findings

The articles included in this review do not represent a cohesive body of work relating to self initiated action to support living with cancer and there is no theoretical framework i.e. no core principles inform the work. The lack of a theoretical framework limits the usefulness of the evidence. Without relevant theory underpinning the work it is difficult to explain what self initiated action means for people affected by cancer and how it can best be supported in practice. In fact, the papers included in this review encompass an unconnected collection of research papers that have something to say about self initiated actions to support living with cancer. Studies explore particular aspects of what people do e.g. self care behaviour by people on treatment and use of CAM. These are largely descriptive reports rather than explanations of why particular actions are viewed as helpful and how they can be supported. Consequently none of the studies reviewed help build a general picture of what people living with cancer do to help themselves and how this can be supported.

Most studies included in this review focus on CAM use and other self help actions. There was no evidence to suggest how people manage symptoms and side effects beyond their treatment in terms of self care and none of the studies explored medical self management by people affected by cancer. The studies raise numerous methodological concerns. The populations included in these studies are very mixed (heterogeneous) which greatly limits the usefulness of the data collected. In particular, there is little or no consideration of age, gender, or ethnicity in relation to self initiated actions taken by people affected by cancer. This matters because in order to support people in ways most appropriate to their needs or circumstances it is necessary to know if people have different needs at different times in their life, if there are gender differences, differences according to ethnicity, socio-economic status and so on. The current evidence does not allow us to answer these questions. Neither are self initiated actions to support living with cancer considered according to cancer site or stage of the disease. The studies included in the review involve a mixture of patients on and off treatment, patients in remission, patients with early stage disease, patients with advanced disease and long term survivors. These studies do not explicitly explore self initiated action by people who have a recurrence. In order to support people we need to know what they are doing to help themselves from the point of diagnosis, through treatment and beyond and how this can be supported. At present it is difficult to ascertain this from the current evidence.

Most studies provide cross-sectional data including retrospective accounts. Asking people about past experiences on one occasion is likely to blur changes over time. Only four studies provide longitudinal data and these focus on self care behaviour during treatment. Various recruitment strategies were employed including self selected individuals responding to advertisements, attending support groups, patients receiving CAM and clinical populations. Findings should be considered in relation to the recruitment strategies used as individuals engaged in support groups or CAM may not be typical of clinical populations. In order to have a broad picture of what people do to help themselves when living with cancer it is important to go beyond those who are already engaged in self help groups or related activities and include individuals that are engaging in self initiated action in their own homes and those who would like to engage in self initiated actions but need support to do so. These people would not be included in studies that recruit participants from self help groups or complementary therapy clinics.

Conclusions

Macmillan's purpose in supporting research is to ensure that research underpins and supports its core strategy to improve the lives of people affected by cancer. There is currently insufficient research evidence to determine how best to support self initiated action by people affected by cancer. That is not to say that we can not learn from these research papers. On the one hand they do not enable an understanding of what people do to help themselves over time or whether gender, age, cultural differences, type of cancer diagnosis or stage along the cancer journey influence what people do to help themselves. On the other hand, they do identify gaps and methodological problems that will need to be carefully considered in future research to establish a strong and theoretically sound evidence base to support the choices made by people affected by cancer to enhance their physical and psychosocial well-being when living with cancer. We suggest the term self action rather than self management to encapsulate all actions that people affected by cancer might engage in to help them live with their cancer. Further research will have both practice and policy implications as it can identify need and provide evidence for how best to support self action by people affected by cancer. Evaluation of the translation of self management programmes designed for people with chronic illness to people living with cancer is underway and will contribute to the developing evidence base. This is clearly an undeveloped area with much potential.

Recommendations

In order to establish a useful evidence base it will be necessary to explore these issues so that an understanding of self action to support living with cancer can be built across the cancer journey from the point of a cancer diagnosis, through treatment and beyond. This is an undeveloped area and the potential for further work is great. General areas that could be addressed include:

- Development of a theoretical framework to conceptualise and explain self action by people affected by cancer is needed so that people affected by cancer can be supported. Within the research literature self management/action when living with cancer is a poorly defined concept. We will develop this work by starting with an exploratory study in the Southampton Macmillan Research Unit. This will be a carefully designed and sufficiently focused programme of work to provide a strong evidence base on which to build practice and support people affected by cancer.

- There is a need to understand how self action changes over time - from the point of diagnosis, through treatment and beyond (including recurrence) and how people manage symptoms and other effects associated with a cancer diagnosis
- There is a need to explore social inequalities and self action
- The focus of this review has been on self action by people who have received a cancer diagnosis however there is a need to explore self action within the family context and consider the role of carers
- There is a need to consider the experiences of people who are often marginalised, for example children and young people, people with rarer cancers, those living in rurally isolated areas and people from black and minority ethnic groups

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1. Introduction

In 2003 Macmillan Cancer Relief coordinated workshops with Macmillan stakeholders including people affected by cancer to prioritise research areas. One of the topics identified in these workshops was *supporting self management of people affected by cancer*. The remit of the Southampton Macmillan Research Unit in 2004 was to review the existing research literature and establish the evidence base for supporting self management by people affected by cancer. Macmillan's purpose in supporting research is to ensure that research underpins and supports its core strategy to improve the lives of people affected by cancer.

There is clear interest in and emphasis on patient self management in the UK. Recent policy from the Department of Health is encouraging a move towards partnership between health professionals and patients evidenced by the National Service Framework for Long-term Conditions¹, NICE guidance for supportive and palliative care², and the piloting of the Expert Patient Programme for patients living with chronic conditions³ as examples. Macmillan is piloting living with cancer self management programmes and these are currently being evaluated. The potential for translating chronic illness self management programmes to cancer will be explored in the evaluation. Macmillan's policy priority areas include improving the user's experience, improving supportive and palliative care, self management and user involvement.

The literature review was based on the broad question *How do people with cancer self manage?* This review is limited to published primary research studies relating to self-initiated actions of people affected by cancer diagnosed over the age of 18 years. The volume of literature generated in the initial scoping exercises prompted the decision to focus on patient-initiated actions and exclude those initiated by health care professionals. Secondary questions were refined following the initial scoping exercises:

- What are patients' initiated actions?
- What enables patients to initiate these actions?
- How effective are the actions?

1.1 Aim

The purpose of this literature review is to explore how to support self management by systematically reviewing published primary research evidence of what people affected by cancer do to help themselves when living with cancer (from the point of diagnosis, through treatment and beyond). By gaining a better understanding of what people do to help themselves, health and social care professionals will be in a position to support choices made by people affected by cancer to enhance physical and psychosocial well-being beyond decisions about treatment options based on research evidence. Findings from this review will also inform further research both within and beyond Macmillan.

1.2 Why a systematic review?

Systematic reviews are increasingly recommended as a rigorous tool to review research evidence on which to build practice. Conducting a systematic review enables assessment of evidence on a specific topic of interest of relevance to health care planners, professionals and more recently patients.

Robust systematic literature reviews are a valuable source of information because by locating, appraising and synthesising evidence from primary studies, they provide empirical answers to focused questions about health care and related issues. In addition, by identifying both what we know and do not yet know, they help in planning new research. Systematic reviews differ from traditional reviews and commentaries produced by 'content experts' in that they adhere to a scientific methodology which seeks to minimise bias and errors. Hence, rather than reflecting the views of 'experts', they generate balanced inferences based on the collation of the best available evidence. (p.iii)⁴

1.3 Background

Advances in diagnostic techniques and the treatment of cancer have resulted in more people being diagnosed and living with cancer for longer⁵. Cancer is a term used to describe a large range of diseases with different causes, prognoses, diagnostic techniques, symptoms, treatment options and long term effects. Treatment and its effects are often complex and patients may need long term care which is frequently provided by informal carers in the home or community. Patients often undergo physically and emotionally demanding treatment regimens and the literature review *Long term living with cancer* has revealed the challenges that people may face more than five years beyond the diagnosis of their cancer⁶. Mortality associated with

cancer remains high in many instances however cancer has recently been conceptualised as a chronic or long-term condition³. Whilst there may be communalities in the experiences of people with a chronic illness such as long term effects including disability, pain and stigma, there are also important differences such as intensive, acute treatment, fear and high mortality. As such it has been argued that cancer should not be defined as a chronic condition although potential similarities are recognised⁷. Clearly many people live with cancer and the consequences of a cancer diagnosis for long periods and there is a necessary shift in emphasis towards 'living with cancer' and how people affected by cancer can be supported to do this.

Expectations of health care are changing as a result of rising educational standards, wider public access to health information, and less faith in the health profession⁸. Interpersonal aspects of health care appear key to patient satisfaction⁹. The NICE guidance for improving supportive and palliative care for adults with cancer highlights needs of adults with cancer which include: being treated as individuals, having their voice heard, receiving high quality information, and good face-to-face communication². Inclusion of patients' perspectives is necessary for defining and understanding a problem, identifying possible solutions and managing illness. Unfortunately, patient experiences and beliefs are often ignored or dismissed by health care professionals.

*A gap exists between health care and ourselves, a gap designed to be occupied by things, not designed to be about me the person who is ill or in need of care, but about health care and health functions. The 'system', the processes and procedures that seem to dominate, the physical structures of health care – buildings, machines, equipment, the people engaged in administering the system, the way matters relating to health care are communicated – are all about 'you' – the person in charge of my care or treatment, or about the administration of a vast bureaucracy. They are not about 'me' – the person for whom the processes and procedures are designed. Nowhere does there appear to be effort directed at examining and enhancing the experience of health care by those who receive it.*¹⁰ (p.1-2)

Poor communication and disregard for patients' experiences are the cause of many formal complaints⁸.

Our health care system was initially equipped to tackle acute conditions and as such the role of the health care provider was to diagnose and treat¹¹. With acute conditions the patient is generally inexperienced and relies on the expertise of the health care professional. In recent times chronic conditions have become the focus of the healthcare system. With long-term conditions the role of the health care provider is different as people affected by the condition develop expertise about the condition, manage it and live with the consequences on a daily basis.

*When you leave the clinic, you still have a long term condition. When the visiting nurse leaves your home, you still have a long term condition. In the middle of the night, you fight the pain alone. At the weekend, you manage without your home help. Living with a long term condition is a great deal more than medical or professional assistance.*¹²

Many people affected by cancer adopt an active role in their treatment and living with cancer throughout the cancer journey rather than being passive recipients of medical expertise. Coulter⁸ argues that paternalism in health care has had its day and consequently there is a need to redefine the patient role:

In the 21st Century the patient is a decision-maker, care manager and co-producer of health, an evaluator, a potential change agent, a taxpayer and an active citizen whose voice must be heard by decision-makers. (p.6)⁸

Coulter⁸ emphasises the need for patients to be encouraged to see themselves as active participants in their health and illness (including shaping health policy) and that health care professionals have to change their behaviour to accommodate this new role by becoming facilitators. Active partnerships between patients and health care professionals would call for a 'culture change' in the NHS. Promoting active partnerships with patients (i.e. patient involvement in decision making) should: restore confidence in the system; facilitate appropriate treatment choices; manage care more effectively; ensure patient safety; increase quality standards; and accountability⁸. Failure to address the social nature of illness (the context in which individuals live e.g. socioeconomic, cultural elements) may affect the ability to provide services that are acceptable to service users¹³. The question surrounds how this can be achieved.

Patient-centred care (for a review of definitions see⁹) is the core theme of the NHS Plan¹⁴ and the NICE guidance on improving supportive and palliative care for adults with cancer². The stated aims are to inform, involve, respond quickly and effectively

to patients' needs and wishes, ensure patients are treated with dignity in a supportive manner and provided with an opportunity to have a say in the development of services. The guidance regarding face-to-face communication focuses on good quality information provided **by** health care professionals **to** people affected by cancer in relation to breaking significant news, explaining complex treatments and discussions with individuals approaching the end of their life. The emphasis is on information provision and level of patient knowledge about their cancer and its medical treatment. Whilst patients' information needs are *considered* the guidance does not suggest a dialogue with people affected by cancer regarding how they are living with cancer or what they might be doing to help themselves when living with cancer and how this might be supported. In this respect the guidance does not appear to value the contribution of people with cancer or their carers beyond treatment decisions or how they might react to bad news.

Not all patients want an active role in decision making about their treatment and care. Shared decision making involves sharing information and both clinician and patient deciding together. For shared decision making to happen, the doctor should be well informed and the patient enabled to voice their experience of illness, social circumstances, habits and behaviour, attitudes to risk, values and preferences. Therefore the value of patients' preferences is acknowledged and the patient has to accept some responsibility for decisions made. Encouraging patients to take more responsibility may shift the blame for a 'problem' (e.g. not following treatment recommendations) to the patient. The philosophy of empowerment is grounded in individual responsibility and self-care¹³. Factors that may hinder participation in this process should be explored rather than placing the burden of responsibility with the patient¹³.

Lewin et al¹⁵ demonstrate that interventions to promote patient-centred care can significantly increase quality of communication and patient satisfaction in primary care. However, the evidence for a positive impact on health care behaviour and health status is inconclusive. Whilst the NICE² recommendations suggest ways to enhance face-to-face communication with people affected by cancer so that significant news is conveyed more carefully, people understand their condition, can participate in decision making about treatment and be involved in discussions about approaching the end of life, they do not appear to acknowledge that patients can be actively 'engaged' with managing their condition beyond decision making about treatment and responses to bad news.

Coulter⁸ suggests that patients who are more actively engaged in their health care are more likely to follow treatment recommendations and recent evidence from evaluations of self management programmes in the USA suggests that teaching people to manage aspects of their chronic condition themselves can result in enhanced health status and fewer hospital admissions¹⁶. Training in self management programmes by people with asthma coupled with regular medical reviews appear to improve health outcomes for patients¹⁷.

Self management programmes are well established in the USA and Canada¹⁸. These programmes emphasise the patient's central role in managing their long-term illness. The programmes are based on self efficacy theory (self efficacy: individual's confidence in their ability to achieve a desired outcome¹⁹) and focus on problem solving, decision making and confidence building¹⁶. The programmes aim to help patients with medical management, maintaining life roles, and managing emotional consequences of their condition (e.g. anxiety and depression). The programmes are designed to provide patients with the knowledge, skills and confidence to manage illness related problems themselves. The programmes also prepare patients to collaborate with their health care professionals and the health care system. If a culture change is to take place in the health service it would seem sensible that health care professionals are also a part of this process.

Self management programmes have been shown to be effective in the US for people with arthritis attending an illness-specific programme. Programme participants have reported increased perceptions of control, reduced pain (despite greater disability), less depressed mood, and fewer visits to their physician in the four years following the programme²⁰. Similar benefits have been reported by those attending courses for people with various chronic conditions²¹. Remote care by telephone or electronic means has also been reported as highly effective in reducing hospital visits and increasing confidence²². Self management programmes for asthma have received criticism for focusing on the transfer of information and mastery of skills with little consideration for patients' views and experiences about asthma or the self management programmes²³. Self management programmes should be based on patients perceived concerns and problems and could be different from group to group¹¹. People with cancer have not been included in published research relating to self management programmes to date.

There is clear interest in and emphasis on patient self management in the UK. Recent policy from the Department of Health is encouraging a move towards partnership between health professionals and patients evidenced by the piloting of the Expert Patient Programme for patients living with chronic conditions³. The central message of this Programme is that having an active role in managing one's own chronic condition enhances quality of life. Indeed evidence from UK programmes for chronic conditions (not including cancer) suggests that having an active role in managing one's chronic condition can indeed enhance quality of life. This has been demonstrated in the UK for arthritis^{24;25} and programmes for people with various chronic conditions²⁶. Macmillan is currently piloting models of self management programmes for people affected by cancer, one of which is based on the Expert Patient Programme for people with chronic conditions. Evaluation of these pilot programmes is underway. The potential for translating chronic illness self-management programmes to cancer will be explored in the evaluation.

Exploration of self management by people affected by cancer is timely. The focus of self management programmes on treatment and managing symptoms based on programmes for people with long term conditions may be appropriate for individuals living with a cancer diagnosis. However there are also likely to be important differences. Due to the aggressive nature of many forms of treatment for cancer individuals may live with long term effects (physical, psychological, social) once treatment is over. What people do to help themselves will vary according to individual circumstances and the needs they have. Similarly the illness pathway that an individual faces may vary considerably depending on their diagnosis, treatment and other factors. There is undoubtedly a need to explore what people do to help themselves when living with cancer both within and beyond self management programmes so that they can be supported.

This is the first review of primary research evidence in relation to self management by people affected by cancer. By synthesising evidence from primary research studies this report documents what is known, what is unknown and suggests ways of building the evidence base to support people affected by cancer help themselves when living with cancer.

1.4 Definitions

In this report several terms will be used and require definition:

- ❖ *People affected by cancer*: People who have received a diagnosis of cancer and may be at the point of diagnosis, going through treatment or beyond. This is an intentionally narrow definition used for the purposes of this report only.

Self management is a broad term used in government policy documents and self management programmes and includes medical management, maintenance of life roles and management of emotional consequences of a long term condition (other than cancer). Within the research literature relating to cancer the term self management is poorly defined and inconsistently used. Three key terms are used in the literature included in this review to describe actions that people take to help them live with their cancer: self care, self management and self help. Two of these, self care and self management, are frequently used interchangeably. For the purposes of this review we will use the following definitions to distinguish between the types of activities individuals engage in:

- ❖ *Self care*: This term is used to describe usual, everyday self care behaviour such as eating, washing and dressing typically associated with nursing. These behaviours may be modified according to symptoms experienced or efforts to prevent future difficulties and can therefore be proactive or reactive.
- ❖ *Self management*: This term is used to describe medical management of the cancer, symptoms or disease process by the patient. Examples would be administration of chemotherapy, self medication for pain, vomiting or other symptoms. These actions could be initiated to avoid or control disease symptoms and treatment side effects and may be proactive (to prevent) or reactive (to control or treat).
- ❖ *Self help*: This term is used to describe a vast array of activities additional to everyday self care and self management. They are additional activities that people may engage in which are non-medical to enhance physical and/or psychosocial well-being. Examples include attending support groups, use of complementary and alternative therapies (hereafter referred to as CAM), and information seeking. Self help can also be proactive (to prevent problems or maintain current state) or reactive (in response to particular need or difficulty).

1.5 Summary of key points

- *Supporting self management* was identified as a priority research area in workshops with Macmillan stakeholders coordinated by Macmillan Cancer Relief
 - There is clear interest in and emphasis on patient self management within the UK
 - Self management by people affected by cancer is a poorly defined concept
 - This is the first review of research evidence of self management by people affected by cancer
 - By gaining a better understanding of what people do to help themselves, health and social care professionals will be in a position to support choices made by people affected by cancer to enhance physical and psychosocial well-being based on research evidence
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2. Methods

A full account of the process used for this systematic review can be found in Appendix I. In brief, the following process was completed:

- ❖ **Literature scoping:** The size of the literature was estimated from a range of key databases holding published research papers [BIDS, BNI, Cancer.gov, CINAHL, Medline, Psycinfo, Web of Science]. This process enabled identification of search terms needed to capture relevant articles.
- ❖ **Modification of review protocol:** Due to the volume of literature retrieved in the scoping exercises (over 30,000), the decision was made to concentrate on patient-led actions. Whilst it is difficult to separate self and health care professional initiated actions in reality, for the purposes of this review we excluded papers that referred to actions that patients were taught to help them live with symptoms and other effects associated with their cancer. Secondary questions were refined:
 - What are patients' initiated actions?
 - What enables patients to initiate actions?
 - How effective are the actions?
- ❖ **Conducting the review:** Several sources of published research literature were searched for the years 1960–2004 including bibliographic databases and internet sites.
- ❖ **Search results:** 19,960 articles were retrieved and reduced to 8,044 after removal of duplicate papers. At this stage each title and abstract was assessed for its relevance to the review. This reduced the total number of abstracts deemed relevant to the review to 453. Many of the papers were commentaries rather than research studies (i.e. contained no data) or were unrelated to the review topic.
- ❖ **Selection of studies:** Abstracts of the 453 articles were independently assessed by 3 researchers and selected for review according to the following strict criteria:
 - Relevant to the topic and questions
 - English language
 - 1960–2004
 - All cancers
 - Patients diagnosed ≥ 18 years
 - Primary studies
 - UK theses

- Patient narrative

Excluded articles were considered as background information to ensure the review provided primary research evidence within the context of informed, current debate.

- ❖ **Data extraction:** The 3 researchers agreed that 97 abstracts appeared to meet the inclusion criteria. The full papers for the 97 selected were retrieved for more detailed evaluation. These 97 papers were independently assessed by 2 researchers who completed extraction sheets for each paper (see Appendix II). 37 of these articles met the inclusion criteria.
- ❖ **Study quality assessment:** Most of the papers included in the review are observational studies with no control group. Therefore, no formal hierarchy of evidence to distinguish randomised controlled trials from other types of studies was applied. The quality of quantitative and qualitative studies was assessed with the use of structured checklists (see Appendix III). These were compiled after discussion with several researchers and based on other quality scoring systems such as CASP.
- ❖ **Data synthesis:** Descriptive synthesis of data was undertaken and summarised in three tables (See Appendix IV). Excluded articles were also summarised in a table (See Appendix V).

3. Findings

The 37 research papers included in this review do not represent a cohesive body of work relating to self management in its broader sense and there is no theoretical framework. None of the papers specifically set out to explore what patients do to help themselves when living with cancer. In fact, the included papers encompass an unconnected collection of papers that have something to say about self initiated actions to support living with cancer. These are largely descriptive reports. Few individual studies have been informed by explicit theory and none build a general picture of what people living with cancer do to help themselves and how this can be supported. Studies explore particular aspects of what people do e.g. self care behaviour of people on treatment or use CAM which answers a different question to *what* people do across the cancer journey, what is perceived to be beneficial and how this can be supported.

The majority of included papers described self help (attending support groups, CAM use and information seeking). Few studies reported patient initiated self care behaviours in response to symptoms and progression of cancer, those that did focused on patient actions to alleviate side effects associated with treatment (chemotherapy and radiotherapy) or dietary modification to promote health. No papers explored self management of medical aspects of cancer. Anti-emetic medication was mentioned in 3 papers but not explored in any detail²⁷⁻²⁹. No studies assessed self managed pain relief or the medical management of other symptoms. In terms of self care and self management, the majority of actions described refer to reactive behaviour during treatment (tackling symptoms). In terms of self help both reactive (seeking social support to reduce feelings of isolation, relaxation to alleviate stress) and proactive (keeping healthy, trying to reduce the likelihood of recurrence) actions were reported.

3.1 Methodological considerations

Although this is not a cohesive body of literature which limits the meaning and value of the findings presented, it is important to consider methodological elements of the papers to put findings in methodological context and help identify ways forward for meaningful research in the future.

Theoretical framework

As the included articles do not represent a cohesive body of work there is no theoretical framework i.e. no core principles inform the work. This lack of theoretical framework limits the usefulness of the evidence because without relevant theory underpinning the work it is difficult to explain what self management is and how it can best be supported in practice. These are largely descriptive reports rather than explanations of why particular actions are viewed as helpful and how they can be supported. This is an undeveloped area with much potential.

Populations

The populations included in these studies are very mixed (heterogeneous) which greatly limits the usefulness of the data collected. In particular, there is little or no consideration of age, gender, or ethnicity in relation to self initiated actions taken by people affected by cancer. This matters because in order to support people in ways most appropriate to their needs or circumstances it is necessary to know if people have different needs at different times in their life, if there are gender differences, and differences according to ethnicity, socio-economic status and so on. The current evidence does not allow us to answer these questions. Only three studies (8%) were conducted in the UK. The majority (80%) were conducted in the USA (N=16; including 3 in Hawaii) and Canada (N=14), 1 each in Turkey, Switzerland, India and Australia. 43% of papers reported data for women only and 16% for men only. The remainder (41%) present data for men and women. Most studies reported broad age ranges (from 18 years to over 70 years) and some did not report ages of participants. Consideration of age and gender in relation to self initiated actions of people affected by cancer is generally not addressed. Similarly, most studies involved a majority of white patients and ethnicity was rarely addressed.

Cancer site and stage

Self initiated actions to support living with cancer are rarely considered according to cancer site or stage of the disease. The studies included in the review involved a mixture of patients on and off treatment, patients in remission, patients with early stage disease, patients with advanced disease and long term survivors. These studies do not explicitly explore self management by people with a recurrence of their cancer. In order to support people we need to know what they are doing to help themselves from the point of diagnosis, through treatment and beyond, how this may change over time and how it can be supported. At present it is difficult to ascertain this from the evidence. All of the studies that focused on women involved women

with breast cancer and the male only studies, men with prostate cancer. The remainder involved both men and women with various cancers including: breast, prostate, gastrointestinal, lung, ovarian, leukaemia/ lymphoma, testicular, bladder, head and neck, sarcoma and skin cancers. Self initiated actions to support living with cancer were not specifically considered according to cancer site or stage.

Methods

None of the papers specifically set out to explore the general question: what do people do to help themselves when living with cancer? Studies explore particular things people affected by cancer might do, such as use of CAM and who is likely to do this and what might motivate them to do this. Typically, studies involved some form of assessment of self care behaviours, people's experiences with support groups, CAM or the information they sought.

Surveys and self report questionnaires were used in 14 studies and only five of these used well established (validated) questionnaires^{27,30-33}. These questionnaires were designed to assess mood, coping, supportive care needs and stressful life events and not self initiated activities designed to support living with cancer. Face to face or telephone interviews (semi-structured and structured) were used in 13 studies. The nature of these interviews ranged from broad questions to explore experiences of cancer (sometimes including self initiated actions) to structured interviews (e.g. to assess use of CAM and expectations of support groups). Focus groups were used in 7 studies (e.g. to explore support systems used to cope with breast cancer and experiences of CAM) and structured diaries in two (to record self care behaviours). One study used secondary ethnographic analysis of data from two studies to explore beliefs and practices of patients in relation to use of CAM³⁴. Most studies provided cross-sectional data including retrospective accounts. Only four studies provided longitudinal data^{27,29,35,36} and these focused on self care behaviour to manage symptoms and side effects during treatment. All self help behaviour was assessed cross-sectionally. Asking people about past experiences on one occasion is likely to mask changes overtime. Several surveys reported poor response rates which raises the question of representativeness of participants. Various recruitment strategies were employed including self selected individuals responding to advertisements, attending support groups, attending CAM practitioners, CAM pharmacies, patients receiving CAM and clinical populations. Findings should be considered in relation to the recruitment strategies used as individuals engaged in support groups or CAM are not necessarily typical of clinical populations. There is evidence to suggest that

people who attend support groups are also motivated to self act in other ways in response to their cancer^{33;37}. In order to have a broad picture of what people do to help themselves when living with cancer it is important to go beyond those who are already engaged in self help groups or related activities and include individuals that are engaging in self initiated action in their own homes and those who would like to engage in self initiated action but need support to do so. These people would not be included in studies that recruit participants from self help groups or complementary therapy clinics.

Quality assessment

The quality of quantitative and qualitative studies was assessed with the use of structured checklists (see Appendix III). This process yielded scores for each paper on a scale from 0 to 2. The median score for the 37 papers is 1.3 [range 0.6 - 2]. Quality assessment of each paper included in the review indicates that most are of mediocre quality which limits the robustness of the research base within cancer.

3.2 Self care: Responding to symptoms and promoting health

There is very little evidence regarding what enables people to manage symptoms, side effects and other aspects of living with cancer themselves and how this can be supported. Five papers reported self initiated self care actions taken by patients when faced with cancer^{27;29;38-40}. Three of these reported self care behaviour in response to side effects of chemotherapy (adjuvant and palliative). Common side effects included: fatigue, sleeping difficulty, nausea and vomiting, reduced appetite, changes in taste/smell, mouth sores and weakness. Patients reported managing fatigue by changing patterns of activity, resting, using nutritional strategies and altering sleep/waking patterns²⁹. Another group of patients reported managing side effects by sleeping, distraction, reading, watching TV, changing eating patterns and cleaning their mouth more often⁴¹. Patients did not generally delay more than 24 hours in initiating self care behaviours. However, delay occurred more frequently when symptoms were severe or debilitating²⁷ and when patients were experiencing fatigue²⁹. One longitudinal UK study found that patients appeared to make few attempts to control or alleviate their fatigue. Most self care behaviours to tackle specific symptoms were reported to give some degree of relief²⁹ and rated as 'moderately effective'²⁷ or providing 'some relief'⁴².

One prospective study explored the self care behaviours of women with breast cancer (stage I or II) during and post radiotherapy. Proactive and reactive self care

actions included managing feelings (e.g. distraction, verbally expressing feelings), managing stress (e.g. writing in a diary, cognitive restructuring, reading, taking a holiday, visiting friends, shopping), living life to the fullest/having more appreciation of life, resting, taking exercise, diet and communicating effectively with health care professionals⁴³. Reasons for initiating self care behaviours included the view that they are a more natural and sensible course of action²⁹.

In terms of health promotion, two studies emphasised proactive self care behaviours designed to reduce the risk of recurrence or detect early signs of cancer. These included dietary change (reducing meat/dessert intake and increasing fruit/vegetable consumption)⁴⁴ following diagnosis of localised breast cancer treated with surgery and having symptoms checked for early diagnosis⁴⁵. Women reporting changes in diet following diagnosis were more likely to be younger, have positive lymph nodes, be receiving adjuvant therapy, and have been more distressed initially⁴⁶.

3.3 Self management: Taking medication

None of the papers specifically explored self management by patients in terms of medical treatment and related activities. Three papers mentioned taking (unspecified) medication and anti emetic medication in response to nausea and vomiting^{27;29;47} which was rated as moderately effective^{27;48}. There is no evidence regarding what enables patients to medically self manage their cancer treatment and related symptoms.

3.4 Self help: Attending support groups, CAM and information seeking

The majority of studies in this review focus on self help behaviour including: attending support groups and establishing support networks (both formal and informal), use of CAM, and information seeking. Self help was either reactive (in response to particular concerns or difficulties) or proactive (to prevent or ward off problems, including health promotion).

Support groups

Ten studies^{30;49-57} mentioned attendance at formal and informal support groups, self help groups, professional support or support organisations. Studies reported group attendance by women with breast cancer (including recently diagnosed women both on and off treatment and long term survivors)^{30;52;56-58}, men with prostate cancer (both on and off treatment)^{55;59}, and patients with various cancers (recently diagnosed and long term survivors)^{49;53;60}. The studies generally describe support groups attended

rather than giving a picture of the proportion of patients in clinical populations that attend groups, who is likely to attend and why. Ease of access to groups has been related to group attendance⁴⁹ and the expectation that the group will provide a safe environment to express feelings, meet others in a similar situation, make new friends, learn more about cancer and treatment, and share problems⁵³. Women with breast cancer who reported having strong emotional support from their mothers or extended family members were less likely to attend a support group as regularly as women with less strong family support⁵⁶. Women with breast cancer attending a self help group reported enjoying helping others in the group, receiving a high degree of support from the group in return and feeling empowered by offering support to others⁵⁶. Prostate cancer patients reported being more assertive and taking responsibility for their health following support group attendance⁵⁵.

Complementary and alternative medicine

Within the research papers included in this review there is inconsistent use of the terms complementary and alternative therapies and some studies use the terms to encompass any number of actions. Boon and colleagues⁶¹ provide the following definition in one of the research papers:

CAM encompasses both the use of natural health care products (including herbs, homeopathy, and nutritional supplements) and the process of seeking health advice (i.e. regarding treatment, prevention of disease, as well as health maintenance) from individuals who are not generally considered conventional health care professionals (i.e. herbalists, homeopaths, naturopathic practitioners, and acupuncturists). It is important to recognise that this definition is necessarily time and culture dependent. (p. 639-40).

Most studies refer to *complementary* therapies: things people do to enhance physical and psychological well-being alongside conventional treatment (although the term 'alternative' is at times used to describe what appear to be complementary actions). These go beyond Boon and colleagues' definition above. Essentially studies report anything and everything that people do in an attempt to enhance physical and/or psychological well-being when living with cancer and this is generally complementary to conventional healthcare. CAM varied from individual actions (e.g. diet, supplements, herbal medicine, traditional and ethnic medicines, prayer, humour, exercise, acupuncture, homeopathy, mind-body techniques, relaxation, stress reduction techniques, manual healing and massage) to group actions (e.g. going out,

having a conversation). Few studies report use of alternative therapies i.e. those chosen instead of conventional healthcare.

Many participants were recruited from self help groups rather than clinical populations i.e. they were already engaged in self help. Given the diversity of populations described in this review it is difficult to ascertain differences in CAM use according to gender, cancer type and stage or CAM use at different points in time. The studies do not reveal differences in use according to stage of cancer, prior use or changes in use over time as almost all studies reported cross sectional data. As most studies include heterogeneous groups of patients, the findings do not enable a clear understanding of how CAM use may change over time depending on whether patients are newly diagnosed, receiving treatment, long term survivors, or have advanced cancer. One cross-sectional qualitative study explored the processes by which women with breast cancer made decisions to use CAM⁶² and demonstrated changes in the nature of CAM use at diagnosis where familiarity and recommended CAM are most likely to be used. Following surgery, through treatment and beyond women had more time to experiment with different CAM and find a regimen to suit them. Most used CAM and conventional treatments simultaneously reporting that it was their responsibility to pick and choose and should be an individualised process. Where evidence for effectiveness was unavailable choice of CAM appeared based on perceived effectiveness, opinions and beliefs. There is little evaluation of the perceived effectiveness of CAM in the included studies^{63;64}.

Boon et al⁶⁵ have described fixed and flexible factors that influence decision making in relation to CAM use. Fixed factors (e.g. gender, age, cancer type, stage) are not amenable to change where flexible factors (e.g. knowledge, attitudes, beliefs, availability) are. Younger patients appear more likely to use CAM^{33;66}. The availability and accessibility of CAM influences use as can cost^{61;64;67}. One study demonstrated that literature about CAM was perceived to be more available and appealing than biomedical literature⁶⁸. Family and friends have been shown to be major sources of knowledge and information about CAM^{30;37;69} with physicians being less likely to be informed of use^{62;70;71}. Risks associated with a particular CAM may deter use⁶². There is evidence that higher level of education is related to more CAM use^{33;66;70-72}.

Attitudes and beliefs are key to CAM use. CAM use has been associated with holistic views about health rather than dissatisfaction with conventional medicine³³. Although previous negative experiences with conventional medicine have been associated

with more CAM use⁶¹. Where CAM is viewed to have some influence over the cancer it is more likely to be used. Motivations for use include: belief that CAM will enhance chances of survival^{37;61;73}, determination to beat cancer⁷⁴, slow disease progression⁷⁵, boost immune system^{37;66;76}, prevent recurrence^{65;77}, hope for a miracle cure^{37;64}, and enhance efficacy of treatment⁷⁰. Where CAM is viewed as important for psychological well-being motivations for use include: a need to gain/increase/maintain sense/illusion of control^{62;65;66;78;79}, improve QoL^{37;66;73;80}, maintain hope³⁷, reduce stress⁶⁶ and enhance coping⁷⁰. Women with breast cancer (all stages) have described CAM use as a supportive action to enhance beneficial effects and/or manage unwanted side effects of conventional treatment and provide a sense of security that they are doing something for themselves^{37;62}. Breast cancer patients (all stages) adopted a broad range of health related activities as 'a way of being independently proactive against the disease whilst improving physical, mental and spiritual health'⁶⁶.

'Pulls' and 'pushes' to CAM have been described in the literature⁶⁵:

- ❖ **Pulls** relate to the attraction of CAM including: positive attitudes, beliefs and the appeal of the relationship with a CAM practitioner.
- ❖ **Pushes** relate to factors or experiences that make patients dissatisfied with conventional health care⁶⁵ including: adverse effects from conventional treatments or limited conventional treatment options which make patients more likely to seek other options. Some patients may see conventional treatment as incompatible with active patient involvement in disease management⁸¹.

There is evidence to suggest that some people may be more motivated to self act than others. One study found that CAM users were more health conscious and changed their lifestyle (e.g. smoking habits, nutrition) following their diagnosis of cancer compared to non users of CAM³⁷. There is also some evidence to suggest that younger men with higher education levels attending self help groups for prostate cancer were more likely to use complementary therapy³³. Some individuals that use CAM following a diagnosis of cancer also used CAM prior to their cancer diagnosis³⁷.

Information

Most studies which described information used by patients focused on women with breast cancer⁸²⁻⁸⁵. Women with metastatic breast cancer reported seeking information regarding their medical situation, symptoms and how to act on them, treatment options, how to obtain counselling, homecare services, how to access

CAM and how to talk to relatives about cancer⁸⁶. Less than half of a group of women with breast cancer receiving chemotherapy (adjuvant and palliative) were found to use the internet to find cancer related information and non-use was associated with no access, unfamiliarity and distrust of online information⁸⁷.

The type of information used by men with prostate cancer was explored in one study and included brochures and the internet⁸⁸. Sources of information amongst groups of patients with various cancers⁸⁹ included internet, books, community education, friends with cancer, friends who are health care professionals. One study reported ethnic differences in choice of health information sought by cancer patients (Caucasian, Japanese, non Japanese) and highlighted the need to be sensitive to cultural values and beliefs⁹⁰.

Internet use to access cancer related information was reported as potentially empowering among breast cancer patients on chemotherapy although this was not formally assessed⁹¹. Accessibility, familiarity and trust were key factors that influenced internet use. Most of the internet users in this study reported using information they had found in discussions with health care professionals. Women with non-metastatic breast cancer reported seeking information to gain a sense of control, increase their confidence and security and enable active participation in decision making⁹². Information was avoided to bypass subsequent feelings of worry, through fear or because it was negative and/or depressing. Women with metastatic breast cancer reported seeking information and perceived it as helpful in the sense that it helped them with their own situation and personal future planning⁹³.

3.5 Summary of key points

- Lack of coherent body of literature relating to self management by people affected by cancer
- Lack of definition of self management in the literature regarding cancer
- Lack of theoretical base
- Studies are unrelated to one another but address aspects of self initiated activity by people affected by cancer to help them live with their cancer and its treatment
- Methodological concerns include heterogeneous samples drawn from varied populations and cross sectional studies. This makes it impossible to understand

changes in self initiated actions to support living with cancer across the cancer journey (from the point of diagnosis, through treatment and beyond) and how this might relate to age, gender, cancer type, ethnic background and so on

4. Discussion

Macmillan's purpose in supporting research is to ensure that research underpins and supports its core strategy to improve the lives of people affected by cancer. There is currently insufficient research evidence to determine how best to support self initiated action by people affected by cancer. The purpose of this review was to explore the published primary research literature and establish the evidence base for supporting self management of people affected by cancer. The focus of the review was on adults affected by cancer and only explored actions initiated by people themselves rather than those actions prompted by health care professionals. Questions included:

- What are self initiated actions?
- What enables these actions?
- How effective are these actions?

At present it is difficult to provide useful answers to these questions as this is an undeveloped area. The studies included in this review did not set out to explore what people do to help themselves; rather they set out to describe particular activities that individuals engage in when faced with cancer. Consequently these studies do not relate to one another or build a coherent picture of self initiated action. Clearly this is an under researched area with a great deal of potential.

Few papers explored what people do to help themselves when faced with symptoms, side effects and long term effects following a cancer diagnosis. Those that did describe ways that people deal with side effects during treatment or ways to promote future health (e.g. dietary change). A great deal of work needs to be done to explore how to support people living with symptoms and long term effects of a cancer diagnosis⁹⁴. No included papers explored self management of medical aspects of cancer and its progression. Studies investigating aspects of self help indicated that patients engage in a number of activities for their perceived psychological, social and physical benefits when living with cancer. Attitudes and beliefs are key to CAM use. Some of the work exploring motivation for CAM use amongst people affected by cancer^{61,65} might prove helpful in informing the development of further work to explore self initiated actions.

We have used the term 'self initiated action' in this report to describe the various things that people affected by cancer may do to help support themselves when living

with cancer. We will propose the term *self action* instead of self management to encompass all activities that individuals engage in to help themselves when living with cancer. Self action can be both reactive and proactive and designed to enhance physical health and well-being. This term includes all things people do to manage physical, psychological and social aspects of their cancer. We apply this overarching term to encompass self care, self management and self help. We will develop and refine the concept of self action further in a new study for 2005.

One reason for this new term is that the term 'self management' has not been conceptualised or well defined in relation to cancer. In contrast, self management is a well used term in the general chronic illness literature although it has not been consistently well defined. Lorig and colleagues¹¹ conceptualise self management as three sets of tasks based on work by Corbin and Strauss⁹⁵: i. medical management (e.g. taking medication, adhering to dietary recommendations, using inhaler); ii. maintaining/changing and creating new and meaningful behaviours or life roles (e.g. moderating activity); iii. dealing with the emotional consequences of the chronic condition (e.g. fear, anger, frustration, depression). Many self management programmes centre on the concept of self efficacy and focus on problem solving, decision making and confidence building in order to help patients with medical management, maintaining life roles and managing the emotional consequences of the condition. Self management programmes are designed to provide patients with knowledge, skills and confidence to manage themselves problems associated with the condition. Having an active role in managing one's chronic condition has been shown to enhance quality of life and this is one of the key outcomes used in promoting self management programmes. However, there is no clear emphasis on health promotion in these groups which may be a key driver for people affected by cancer^{61;65;96}. The value of self management programmes has not yet been demonstrated for people affected by cancer in the UK although an evaluation is currently underway within Macmillan.

There is a clear need to develop an appropriate theoretical framework to explore self action by people affected by cancer. The self management literature for chronic conditions is likely to inform the development of new research to explore self action. There may be a lot we can learn from the literature relating to chronic conditions however living with cancer is different in many respects to living with other long term conditions (e.g. diabetes, arthritis, depression) where the function of treatment is often to alleviate or prevent symptoms. Cancer is a term used to describe a set of

diseases with different causes, symptoms, treatment options and prognoses. Many people diagnosed with cancer may have been symptom free. A cancer diagnosis brings great uncertainty and is often followed by immediate, aggressive and intensive treatment which can be visible (e.g. scarring, hair loss, weight loss/gain) and/or impair functions of the body (e.g. digestive problems, erectile dysfunction). Many of the treatments cause symptoms and side effects which are often immediate and may remain following treatment. These side effects can be debilitating. Where an individual may effectively have been cured of their cancer it is clear that many people continue to experience long term effects (such as physical and psycho-social difficulties)⁹⁴. The experience of life following a cancer diagnosis is highly variable for individuals and does not necessarily follow a standard course as may be expected in some chronic conditions. It therefore follows that an approach to self action by people affected by cancer is necessarily different for other conditions although there may be commonalities.

In the literature relating to chronic conditions self efficacy theory underpins many self management programmes¹⁹. This may be useful for developing a theoretical approach for supporting self management by people affected by cancer but other approaches are also likely to inform the theoretical development of future research. Existing self management programmes focus on managing treatment and illness related issues, however promoting future health is a concern to many people affected by cancer who may wish to do all they can to promote their future health and/or help prevent a cancer recurrence (e.g. by modifying diet, smoking, exercise, sun exposure)^{97;37}. Some of the work by Boon and colleagues^{61;65} exploring fixed and flexible factors and pulls and pushes that influence CAM use could be explored further and related to self action. For example, the need to do something to maintain an illusion of control or a sense of security in acting for oneself^{37;62;65}. There may be a particularly powerful push for some patients to do something when little can be offered by conventional treatment (e.g. watchful waiting in prostate cancer), conventional treatment has adverse effects, or people wish to continue to do something after their treatment has ended and they are living long term after a cancer diagnosis.

The methodological limitations of many of the studies included in this review limit the usefulness of the findings but suggest ways forward for new research. Particular problems relate to the largely mixed (heterogeneous) groups of patients included in the research studies. In order to gain a better understanding of self action and how

best to support it, it will be necessary to explore social and demographic factors such as gender, age and culture. Evidence suggests that healthy men and women exhibit different health maintenance behaviour and social network variables influence self care responses to illness⁹⁸. Also, consideration of cancer type, stage and treatment is necessary to explore self action at different points along the cancer journey. Cross sectional studies do not allow for exploration of change over time. Very little work has explored the benefits to individuals affected by cancer in acting for themselves in relation to their health although benefits are assumed or inferred. Some people might be more motivated to self act than others and careful consideration of recruitment strategies is needed to ensure that typically hard to reach groups and those who might benefit most from receiving support to self act are included in research.

To enable partnership between health care professionals and people affected by cancer and to help support individuals to enhance their physical and psychosocial well-being there is a need to build a better understanding of what people do to help themselves. Failure to address the social nature of illness (e.g. socioeconomic, cultural elements and how people manage to support themselves) may affect the ability to provide services that are acceptable to service users. Clearly there is an urgent need to establish a strong evidence base to inform how best to support people affected by cancer to help themselves in living with cancer. In order to explore the social nature of cancer and what people do to help themselves it is necessary to conduct carefully designed research which would enable consideration of these issues. Research is urgently needed to develop the conceptualisation of self action of people affected by cancer and how this can be supported.

4.1 Summary of key points

- At present it is difficult to provide useful answers to the question: *How can we support self management of people affected by cancer?*
- There is an urgent need to build an understanding of what people do to help themselves and how this can be supported
- We will use the term *self action* instead of self management to encompass all activities that individuals engage in to help themselves when living with cancer
- Self management programmes do not appear to incorporate health promotion which may be important for people affected by cancer

- There is a need to develop a theoretical framework which may be informed by the literature relating to self management of chronic conditions
- Some work exploring motivations for CAM use is likely to be useful
- Methodological difficulties will need to be addressed in future work

5. Conclusions

5.1 Practice implications

At this stage the evidence does not provide answers which can influence practice. Clearly research is needed to explore what people are doing to help themselves and what support they may need when living with cancer. This research needs to be informed by relevant theory and must involve rigorous and well-defined research in order to develop a meaningful and useful evidence base with which to inform practice in the future. No primary research to explore self action by individuals with cancer has yet been published to provide useful insight into supporting self action. The current piloting of self management programmes by Macmillan Cancer Relief and their evaluation is likely to make an important contribution to the evidence base. Future research needs to look beyond formal programmes to reach individuals who may need support with self action who are not currently receiving it.

5.2 Research implications

Evidence to support self action amongst people affected by cancer is clearly less well established than for chronic conditions. Cancer is often referred to as a chronic condition as people may experience physical symptoms, side effects and psychosocial effects over long periods⁷. While there may be similarities with chronic conditions cancer is different in many respects⁷ and these need to be carefully explored to ensure that self action is understood and supported. Clearly, there is a need to consider what people affected by cancer do to manage the symptoms and other effects that follow from a diagnosis of cancer, through treatment and beyond. There is an obvious need for work to build a strong evidence base to help people to help themselves when living with cancer. In the first instance a well designed exploratory study is needed to investigate what self action patients engage in, how this is or could be facilitated and what benefits are experienced as a result of self action. The Macmillan Research Unit in Southampton is developing such a study within the current programme of research and will involve service users during the research process.

In order to conduct well focused and meaningful research to build the evidence base it is likely that a programme of work will be most effective i.e. one piece of work will not be able to answer all of the questions raised in this review. This work will need to consider many of the gaps in knowledge that currently exist including: what self

action is, what the theoretical base is, how self action may change over time and across the cancer journey (from the point of a cancer diagnosis, through treatment and beyond), and whether age, gender, cultural factors and co-morbidity influence self action. One key outcome of this research would be to consider the development of a databank of experiences of people affected by cancer as a resource to be used by people affected by cancer in helping themselves to live with cancer.

Key considerations include:

- Development of a strong theoretical base
- Ability to explore factors that may influence self action such as: age, gender, cultural/ethnic background, cancer type, treatment, diagnosis
- Traditionally hard to reach groups should be involved in the research where possible as they may be most in need of support to self act
- There is a need to build a picture of how/whether self action changes over time, what is useful, how it can be supported
- Ensure there is sufficient focus to yield meaningful and useful findings

This is an undeveloped area and the potential for further work is great. General areas that could be addressed include:

- Development of a theoretical framework to conceptualise and explain self action by people affected by cancer so that people affected by cancer can be supported. We will develop this work by starting with an exploratory study in the Southampton Macmillan Research Unit.
- The need to understand how self action changes over time - from the point of diagnosis, through treatment and beyond (including recurrence) and how people manage symptoms and other effects associated with a cancer diagnosis
- The need to explore social inequalities and self action
- The need to explore self action within the family context and consider the role of carers
- The need to consider the experiences of people who are often marginalised, for example children and young people, people with rarer cancers, those living in rural isolated areas and people from black and minority ethnic groups

Further reviews

This review was necessarily limited due to the sheer volume of the literature. In order to make this a manageable piece of work other potentially important bodies of

literature were not included. Examples include the literature relating to children and adolescents with cancer and literature relating to individuals with chronic conditions which is important to explore in order to build a theoretical framework for future work. Further work to explore these areas is warranted.

This review focused on self initiated actions and excluded actions taught by health care professionals. Whilst it is difficult to separate self and health care professional initiated actions in reality, for the purposes of this review we excluded papers that referred to actions that patients were taught to help them live with symptoms and other effects associated with their cancer. There may be value in exploring this literature separately, however, future work is likely to include reference to this body of literature and consequently a separate systematic review may be unnecessary as the story is likely to be similar as for the body of work included in this review. It is likely to be more fruitful to move forward by developing work in the direction recommended in this report.

5.3 Policy implications

New work is timely and better understanding of how people affected by cancer self act to manage living with cancer is likely to have wide reaching implications for how patients engage with health services in the future. There is a real need to develop a strong evidence base involving people affected by cancer and typically marginalised groups to inform policy such as the Expert Patient Programme³ for patients with cancer. The Expert Patient programme is designed to empower patients with long term medical conditions to become decision makers in their own care. These programmes are led by patients with chronic conditions who teach self management. The overall aim of the programme is to give patients more control over their own health by understanding and managing the chronic condition and ultimately improving their quality of life. The expert patient programme is being piloted across the UK. The Department of Health recommends introduction of 'user-led self management' for chronic diseases to all areas of NHS by 2007. It is hypothesised that self-management programmes could reduce severity of symptoms and improve confidence, resourcefulness and self-efficacy. There is some evidence for this following self management programmes for people with arthritis and other chronic conditions²⁴⁻²⁶. The research evidence tells us little about how best to support people affected by cancer.

6. Appendices

Appendix I: Guidelines regarding conduct of the literature review

Appendix II: Data extraction sheet

Appendix III: Quality scoring sheets for quantitative and qualitative studies

Appendix IV: Tables of included articles

Table 1: Self care: Managing symptoms and promoting health

Table 2: Self help: Support groups

Table 3: Self help: CAM

Table 4: Self help: Information

Appendix V: Table of excluded articles

Self-management for people with cancer: review process

Planning the review

Development of review proposal

- In accordance with the Macmillan workshop priority themes, the review was based on the broad question:
 - How do people with cancer self manage?

Literature scoping

- The aim of this part of the review was to estimate the size of literature from a limited range of key databases, and also to identify the search terms needed to capture all relevant articles to the review proposal.
- All scoping exercises used the following databases for the years 2000-2004: BIDS, BNI, Cancer.gov, CINAHL, Medline, Psychinfo, Web of Science.

Modification of review protocol

- Due to the size of the literature retrieved in the scoping exercises, the decision was made to concentrate on patient-led actions.
- The scoping exercises highlighted the areas of particular interest. It was therefore possible to further refine the initial research question into more specific secondary questions:
 - What are the patients' initiated actions?
 - What enables patients to initiate actions?
 - How effective are the actions?

Conducting the review

Search strategy

- The search terms used were:
 - cancer AND
 - self management OR
 - self help OR
 - self care OR
 - self efficacy OR

- empowerment OR
 - information seeking OR
 - help seeking behaviour OR
 - decision making attitudes
- The following sources of literature were searched for the years 1960 – June 2004:
 - Bibliographic databases: BIDS, BNI, Cancer.gov, CINAHL, Cochrane, Medline, Psychinfo, Web of Science
 - Internet sites: Breakthrough Breast Cancer, Cancer Research UK, Department of Health, Help the Hospices, King's Fund, Macmillan Cancer Relief, Marie Curie, NCI, National Cancer Research Institute, National Cancer Research Network

Search results

- The searches retrieved 19 960 articles which reduced to 8044 after duplicate removal.

Selection of studies

- The abstracts of 453 articles were independently assessed by three researchers, and selected for the review according to strict criteria.
- Inclusion/exclusion criteria:
 - Inclusion: relevant to topic and questions, English language, 1960 - June 2004, all cancers, patients diagnosed aged 18 or above, primary studies, UK theses, patient narrative
 - Exclusion: biomedical data, childhood & adolescent cancer, commentaries, editorials, non-UK theses, letters, reviews, studies examining the quality of the tool/information, studies concerned with euthanasia and PAS if not in the context of supporting self-action
- The excluded articles were considered as background information to ensure that the review provided empirical evidence within the context of informed, current debate.

Data extraction

- A total of 97 full text articles were retrieved for more detailed evaluation.
- 37 full text articles met the inclusion criteria and are reviewed in the following document.

Study quality assessment

- Due to the nature of the studies included in the review, no formal hierarchy of evidence was applied. Instead, the quality of like studies was compared with the use of a structured checklist. These were compiled after discussion with several researchers and based on previous quality scoring systems e.g. CASP.

Data synthesis

- A qualitative (descriptive) synthesis of data was undertaken and summarised in a research table.

Reporting and dissemination

In addition to the report of the review submitted to Macmillan Cancer Relief, a paper will be submitted for publication in a relevant peer-reviewed journal (to be determined).

Appendix II: Data extraction sheet

Study Details
Refman ID:
Authors:
Title:
Publications Source:
Type of publication:

Study Design	
Experimental: Non-experimental: Qualitative: Opinions:	
Aim:	
Method:	
<u>Criteria for inclusion:</u>	<u>Criteria for exclusion:</u>

Setting & Timing			
UK:	USA:	Europe:	Other:
City/Urban:	Rural:	Affluent:	Deprived:
Participants			
Total number of participants in study:			
Patient:	Family:	HP:	Other:
<u>Intervention group</u>		<u>Control group</u>	
Age:			
Sex:			
Cancer type:			
Time since diagnosis:			

Relevance to Original Questions	
<u>Question 1:</u>	What are patients' initiated actions?
<u>Question 2:</u>	What enables patients to initiate these actions?
<u>Question 3:</u>	How effective are the actions?
Sub-category:	

Quality Scoring

Data analysis

Outcomes	

Conclusions

Limitations

Comments

Appendix III: Quality scoring sheets

Non-experimental studies

<p>1. Is the study based on a representative sample selected from a relevant population?</p> <p>score 2 if:</p> <p>score 1 if:</p> <p>score 0 if:</p>	<p>sample size justified for the study, clear details of participants and recruitment methods, response rates shown and explained</p> <p>sampling mentioned but few descriptive details</p> <p>no details of sample</p>
<p>2. What is the sampling strategy e.g. consecutive?</p> <p>score 2 if:</p> <p>score 1 if:</p> <p>score 0 if:</p>	<p>sample includes complete group or random sample from relevant population</p> <p>convenience sample from population or some attempts at randomisation</p> <p>researchers selected participants for inclusion</p>
<p>3. What is the sample size?</p> <p>score 2 if:</p> <p>score 1 if:</p> <p>score 0 if:</p>	<p>sample size justified for the study</p> <p>small sample size and/or low response rate</p> <p>inadequate sample size in order to address aims</p>
<p>4. Is there a sufficient description of the subjects (age, gender etc.)?</p> <p>score 2 if:</p> <p>score 1 if:</p> <p>score 0 if:</p>	<p>clear demographic details given, and considered in relation to findings</p> <p>brief demographic information and not considered as a confounding variable</p> <p>no background details of participants</p>
<p>5. Do subjects have a similar baseline survival time?</p> <p>score 2 if:</p> <p>score 1 if:</p> <p>score 0 if:</p>	<p>patients at similar time since diagnosis or groups at different stages are clearly defined</p> <p>clear details of time since diagnosis but may be some variation</p> <p>exact time since diagnosis is unclear</p>
<p>6. What were the groups matched on?</p> <p>score 2 if:</p> <p>score 1 if:</p> <p>score 0 if:</p>	<p>groups matched on all possible confounding variables</p> <p>groups matched on some variables</p> <p>no attempt to match groups</p>
<p>7. Are the methods/methodology appropriate and clearly explained e.g. type of data collection/theoretical basis of methods?</p> <p>score 2 if:</p> <p>score 1 if:</p> <p>score 0 if:</p>	<p>methods are appropriate and clearly explained</p> <p>methods may be inappropriate and/or inadequately described</p> <p>methods are inappropriate or there is no mention of them</p>
<p>8. Were researchers blind to exposure status when abstracting the outcomes data?</p>	

	score 2 if: score 1 if: score 0 if:	researcher was blind to exposure status issues of researcher bias were acknowledged no mention of researcher bias
9. Were steps taken to ensure the quality of data collection, e.g. trained researchers, piloted methods such as validated questionnaires, consideration of researcher/participant relationship?	score 2 if: score 1 if: score 0 if:	researchers were trained on the methodology, use of established questionnaires with similar populations, researchers were aware of their influence on the results few details on researcher experience with methodology, established questionnaires used but may not have been validated within this population type, some acknowledgement of researcher influence no details of researcher training on methodology or influence they may have on results, questionnaires not validated or used with similar populations
10. What is the response rate?	score 2 if: score 1 if: score 0 if:	sufficient response rate to minimise response bias and give relevant sample response rate may lead to bias and difficulties with transferability response rate low, meaning that findings cannot be generalised
11. Is response bias explored e.g. how do responders/non-responders differ?	score 2 if: score 1 if: score 0 if:	clear details of responders/non-responders and possible influence on findings acknowledged some appreciation of response bias but few details no attempt to explore response bias
12. Are the drop out rates the same in all groups?	score 2 if: score 1 if: score 0 if:	no drop outs or equal numbers in cases and controls with clear reasons given drop out varies between groups with few details given for reasons drop out rates vary widely between groups with reasons not stated
13. Is the follow-up period sufficient?	score 2 if: score 1 if: score 0 if:	follow-up period is clearly defined and adds to or confirms the findings follow-up period is insufficient no follow-up (if applicable)
14. Is there an adequate description of data analysis?	score 2 if: score 1 if: score 0 if:	clear description of analysis with reasons for tests used, statistical significance discussed minimal details of analysis no mention of analysis
15. Are the findings carefully described		

<p>and do they relate to the aims?</p> <p>score 2 if:</p> <p>score 1 if:</p> <p>score 0 if:</p>	<p>effects are carefully detailed and easy to understand, results directly relate to aims, the data sufficiently supports the conclusions</p> <p>effects are mentioned but data could be more logically presented with more explanation given</p> <p>the effects are not mentioned or do not relate to the aims</p>
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Quality scoring sheet

Qualitative studies

1. Is there a clear description of the study and its aims? score 2 if: score 1 if: score 0 if:	clear abstract, full background to study and justification for the aims some attempt to give background and research questions no background information or aims
2. Is the study based on a clear and justified sampling strategy? score 2 if: score 1 if: score 0 if:	sample size justified for the study, clear details of participants and recruitment methods, response rates shown and explained sampling mentioned but few descriptive details no details of sample
3. Is the sample size appropriate to address the aims of the study? score 2 if: score 1 if: score 0 if:	sample is justified and appropriate for the study questionable whether sample is appropriate inappropriate sample in order to address aims
4. Is there a sufficient description of the subjects (age, gender etc.)? score 2 if: score 1 if: score 0 if:	clear demographic details given, and considered in relation to findings brief demographic information and not considered in relation to findings no background details of participants
5. Do subjects have a similar baseline survival time? score 2 if: score 1 if: score 0 if:	patients at similar time since diagnosis or groups at different stages are clearly defined clear details of time since diagnosis but may be some variation exact time since diagnosis is unclear
6. Are the methods/methodology appropriate and clearly explained e.g. type of data collection/theoretical basis of methods? score 2 if: score 1 if: score 0 if:	methods are appropriate and clearly explained methods may be inappropriate and/or inadequately described methods are inappropriate or no mention of them
7. Were steps taken to ensure the quality of data collection, e.g. trained researchers, piloted methods such as validated questionnaires, consideration of researcher/participant relationship score 2 if:	researchers were experienced with the methodology, use of piloted methods with similar populations, researchers were aware of their influence on the findings

	score 1 if:	few details on researcher experience with methodology, piloted methods used but may not have been validated within this population type, some acknowledgement of researcher influence
	score 0 if:	no details of researcher experience or influence they may have on findings, methods not piloted or used with similar populations
8. Are the drop out rates the same in all groups?	score 2 if:	no drop outs or equal numbers in cases and controls with clear reasons given
	score 1 if:	drop out varies between groups with few details given for reasons
	score 0 if:	drop out rates vary widely between groups with reasons not stated
9. Is there an adequate description of data analysis?	score 2 if:	clear description of analysis with details of coding, how themes were derived
	score 1 if:	minimal details of analysis
	score 0 if:	no mention of analysis
10. Are the findings carefully described and do they relate to the aims?	score 2 if:	effects are carefully detailed and easy to understand, results directly relate to aims, the data sufficiently supports the conclusions
	score 1 if:	effects are mentioned but data could be more logically presented with more explanation given
	score 0 if:	the effects are not mentioned or do not relate to the aims
11. Are the approaches to rigour explained and justified by the study's aims, method and design?	score 2 if:	attempts made to ensure the rigour of the research
	score 1 if:	some acknowledgement of the need for rigour
	score 0 if:	no attempt to ensure the reliability of the findings
12. How important are the findings to a wider population?	score 2 if:	the context and setting of the study is described sufficiently to allow comparisons with other settings
	score 1 if:	some details of context and setting but more needed in order to replicate or compare the study with others
	score 0 if:	no description of context/setting

Appendix IV: Tables of included articles

Table 1: Self care: Responding to symptoms and promoting health

Reference & country	Aim	Design & Methods	Setting & sample	Outcome	Conclusions
<p>Maunsell et al (2002)⁹⁹</p> <p>Dietary change after breast cancer: extent, predictors, and relation with psychological distress.</p> <p>[Canada]</p>	<ul style="list-style-type: none"> Assess extent, predictors and effect on psychological distress of dietary changes in year after diagnosis among women with breast cancer 	<ul style="list-style-type: none"> 3 structured interviews [time of surgery; 3 and 12 months later] Baseline: socio-demographics, distress level (Psychiatric Symptom Index: PSI), stressful life events in past 5 yrs [modified Life Experiences Survey] <p>Quality score: 1.4</p>	<ul style="list-style-type: none"> 250/285 newly diagnosed breast cancer patients with localised/regional disease treated with surgery Age not reported 	<ul style="list-style-type: none"> 41% reported making dietary changes in the 12 months since diagnosis: reduced meat intake (77%); increase in fruit and vegetables (72%); reduction in dessert (66%) Women initiating change: more likely to be younger; higher initial psychological distress; higher number of stressful life events pre diagnosis; previous consultation with mental health professional 	<ul style="list-style-type: none"> Substantial proportion of women report initiating, dietary change after breast cancer
<p>Musci & Dodd (1990)²⁷</p> <p>Predicting self-care with patients and family members' affective states and family functioning.</p> <p>[USA]</p>	<ul style="list-style-type: none"> Describe self care behaviours (SCBs) initiated by patients and relatives to manage side effects of chemotherapy Determine relationship between affective 	<ul style="list-style-type: none"> Longitudinal study over 3 cycles of chemotherapy (12-16 weeks) Tools: POMS (affective states), F-COPES (Family Crises Oriented Personal Scales; family functioning), 	<ul style="list-style-type: none"> Convenience sample 42 patients (67% male) receiving chemotherapy and 40 relatives Ages 18-73 Various cancers Attrition rate 51% 	<ul style="list-style-type: none"> Most common side effects: nausea (90%), fatigue (65%), vomiting (62%), mouth sores (31%), weakness (31%) Most distressing: vomiting and fatigue Patients did not delay >24 hours in initiating 	<ul style="list-style-type: none"> Patients performed modest number of SCBs but rated as moderately effective Patients cited selves as most frequent source of their ideas for SCBs. Side effects become more numerous and

Reference & country	Aim	Design & Methods	Setting & sample	Outcome	Conclusions
	states, family functioning and SCBs <ul style="list-style-type: none"> Predict self care behaviour from affective states, family functioning, demographics and disease variables 	demographic and disease variables. <ul style="list-style-type: none"> Patients reports of SCBs kept in SCB log during study period Quality score: 1.1		SCBs <ul style="list-style-type: none"> Greater delay associated with more severe/debilitating symptoms SCBs seen as moderately effective Patient mood disturbance > than relatives' at all 3 cycles 	severe over the 3 cycles of chemotherapy
Nail et al. (1991) ¹⁰⁰ Use and perceived efficacy of self-care activities in patients receiving chemotherapy. [USA]	<ul style="list-style-type: none"> Describe patient perceptions of the nature and severity of side effects and perceived efficacy of self-care activities 	<ul style="list-style-type: none"> Patients completed self care diary (in house) to obtain information about incidence and severity of side effects and efficacy of specific self care activities. Quality score: 1.1	<ul style="list-style-type: none"> 49/59 patients receiving chemotherapy M=54.9 years [range 21-78] 61% female 31% breast cancer, 22% colorectal, 12% lymphoma, 8% lung, various other Time since diagnosis: < 6 months to > 5 yrs 	<ul style="list-style-type: none"> Fatigue most frequent, sleeping difficulty, nausea and reduced appetite, changes in taste/smell Most severe is hair loss, then fatigue and decreased appetite SCBs: fatigue (sleep), sleeping difficulties (distraction, reading, TV), nausea (anti emetics), reduce appetite (changing eating patterns), change in taste/smell (clean mouth more often) 	<ul style="list-style-type: none"> Majority of activities provided some relief
Richardson & Ream (1997) ²⁹	<ul style="list-style-type: none"> Monitor and describe patients fatigue during 	<ul style="list-style-type: none"> Longitudinal (3-4 wks) Structured diaries: 	<ul style="list-style-type: none"> 109/146 patients receiving different chemotherapy 	<ul style="list-style-type: none"> 89% reported fatigue SCBs initiated on 50% of days when 	<ul style="list-style-type: none"> Patients appear to make few attempts to control or alleviate

Reference & country	Aim	Design & Methods	Setting & sample	Outcome	Conclusions
Self-care behaviours initiated by chemotherapy patients in response to fatigue. [UK]	chemotherapy and SCBs taken by them to ameliorate it. <ul style="list-style-type: none"> Evaluate effectiveness of SCBs. Examine relationship between fatigue and self care 	record actions taken and effectiveness Quality score: 1.9	protocols (continuous, weekly, or 3-4 weekly) <ul style="list-style-type: none"> 72 women, 57 men Mean age 58 years [26-82] 20% ovarian, 15.5% colorectal, 15% small cell lung cancer 42% diagnosed in previous 3 months 57% with metastatic disease 	fatigued <ul style="list-style-type: none"> No association between SCBs and age/gender SCBs: <ul style="list-style-type: none"> Change in patterns of activity/rest Psychological (relaxation tapes, music, reading, TV) Preserve normality (return to work, chores) Reduce symptoms and provide comfort (medication, hot bath) Social interventions (hobbies, going out, conversation) Nutritional strategies (soothing drink, altering meal times) Change in sleep/waking patterns Most usual action is resting, napping during day 	fatigue <ul style="list-style-type: none"> When daily activities sufficiently disrupted patients initiated SCBs to help manage fatigue and continue normal activities. Most SCBs ineffective: 54% partial relief, 9.4% no relief Reasons for SCBs: more natural and sensible course of action
Seegers et al. (1998) ¹⁰¹ Self-care and breast cancer recovery.	<ul style="list-style-type: none"> Identify SCBs described by women during and after radiotherapy for early stage breast cancer 	<ul style="list-style-type: none"> Prospective study Baseline questionnaire: perceptions of support, side effects, mood, 	<ul style="list-style-type: none"> 23 women with stage I or II breast cancer Mean age 58 years [25-79] 	<ul style="list-style-type: none"> Women reported average of 6 SCBs [range 2-11] 95.6% 'establishing good social network' 	<ul style="list-style-type: none"> Interviews not designed to elicit reports of SCBs. Older women (>60 and generally unmarried) reported

Reference & country	Aim	Design & Methods	Setting & sample	Outcome	Conclusions
[USA]		<p>intrusive thoughts</p> <ul style="list-style-type: none"> 7 months post radiotherapy telephone interview: experiences of breast cancer, experiences since end of treatment. Content analysis <p>Quality score: 0.9</p>		<ul style="list-style-type: none"> Living life to fullest, managing feelings, managing stress Rest, exercise, diet, keeping scheduled medical appointments Communicating effectively with health professionals; taking responsibility for own health 	more SCBs (especially physical and cognitive domains)

Table 2: Self help: Support groups

Reference & country	Aim	Design & Methods	Setting & sample	Outcome	Conclusions
Deans et al. (1988) ⁵³ Cancer support groups- -who joins and why? [UK]	<ul style="list-style-type: none"> Determine characteristics of membership of Tak Tent groups in Scotland 	<p>Cross-sectional survey</p> <p>Quality scoring: 1.2</p>	<ul style="list-style-type: none"> 146/185 Tak Tent members: 53 patients, 50 relatives, 30 HCPs, 13 other Patients 25-83 yrs (mean: 50) 81% patients female Cancer type not recorded 	<p>Patients and relatives expected groups to enable them to:</p> <ul style="list-style-type: none"> meet others in similar situation express feelings openly make new friends learn more about cancer & treatment share problems get support in coping with cancer 	<ul style="list-style-type: none"> Groups appear to be 'safe' environments to openly express feelings Less satisfied with how group participation had enabled them to cope better with cancer
Gray et al. (1997) ¹⁰² A qualitative study of breast cancer self-help groups. [Canada]	<ul style="list-style-type: none"> Explore women's experiences of self help groups 	<ul style="list-style-type: none"> Descriptive study Semi-structured interviews <p>Did not actively seek to reveal how patients help themselves but describe their experience of self help groups</p> <p>Quality score: 1.3</p>	<ul style="list-style-type: none"> 24 Caucasian women with breast cancer attending 4 self-help groups; 10 long term survivors, 11 diagnosed in past 3 years, and 4 diagnosed in past year 33-75 yrs (15 women < 50 yrs) 	<ul style="list-style-type: none"> Participants reported group involvement to be helpful Emotional support benefits (connecting with other breast cancer survivors, feelings understood, sharing experiences, providing hope) Informational and practical support (sharing important information, learning how to get what you want) 	<p>Reasons women sought support from patient-led groups:</p> <ul style="list-style-type: none"> Helping others helps self Unburden away from family/community therefore increasing participation in community/family Learning how to deal with doctors/prostheses etc Avoid panic visits to doctor

Reference & country	Aim	Design & Methods	Setting & sample	Outcome	Conclusions
<p>Gray et al. (1997)⁵⁵</p> <p>Interviews with men with prostate cancer about their self-help group experience.</p> <p>[Canada]</p>	<ul style="list-style-type: none"> Explore men's experience with prostate cancer self-help groups 	<ul style="list-style-type: none"> Semi-structured interviews: experience of benefits and limitations of group Coding of themes <p>Quality score: 1.1</p>	<ul style="list-style-type: none"> 12 men with prostate cancer involved in a local prostate cancer self-help group [4 men from 3 groups in 3 cities] Long term survivors and men with advanced disease 45-80 years 	<p>Key reasons for attending groups:</p> <ul style="list-style-type: none"> Seek and give information Talk and listen Revitalise through work/achievement: (leadership roles within groups) Link with the community Connection/intimacy Self-change (e.g. boost self esteem; more assertive in taking responsibility for own health) 	<ul style="list-style-type: none"> Benefits of self-help group involvement: primary motivation is need for information; emotional support – connecting with others
<p>Henderson & Fogel. (2003)³¹</p> <p>Support networks used by African American breast cancer support group participants.</p> <p>[USA]</p>	<ul style="list-style-type: none"> Explore support networks used by African American breast cancer support group participants 	<ul style="list-style-type: none"> 4 focus groups: Discuss support systems used to cope with breast cancer Ways of Coping Questionnaire <p>Quality score: 0.8</p>	<ul style="list-style-type: none"> 43 women with breast cancer Time since diagnosis: M=4.08 yrs (sd 5.15) Mean age: 53.14yrs (sd 8.23) 	<p>Support networks used:</p> <ul style="list-style-type: none"> God (51.2%) Family (44.2%) Friends (25.6%) Internet (5%) Professional help (51.2%) 	<ul style="list-style-type: none"> Women used a number of support networks Claims made about coping in general e.g. African American women want to focus on resolving their situation, yet they only looked at those attending a support group.

Reference & country	Aim	Design & Methods	Setting & sample	Outcome	Conclusions
<p>Pilisuk et al. (1999)⁵⁶</p> <p>Participant assessment of a non-medical breast cancer support group.</p> <p>[USA]</p>	<ul style="list-style-type: none"> Explore experiences of women with breast cancer attending YWCA group 	<ul style="list-style-type: none"> Interviews Survey: demographics, medical history, global ratings of adequacy of support in general, and specifically in coping with cancer <p>Quality score: 1.4</p>	<ul style="list-style-type: none"> 131/230 patients (60% response rate) Women with breast cancer Aged 30-85 years 	<ul style="list-style-type: none"> Women who reported being able to talk more freely with their families and who considered their own mothers/extended a source of emotional support attended less regularly Frequent attendees enjoyed helping others in group and felt they received high degree of support from group in return Women attended because encouraged by HCP, unhappy with HCP or relatives could not provide necessary support 	<ul style="list-style-type: none"> Drop-in, drop-out format, absence of fees, facilitation by non-HCP and exercise component are factors many women find beneficial and conducive to support group participation Participants felt empowered by offering support to others in group
<p>Stevenson & Coles (1993)⁵⁷</p> <p>A breast cancer support group: activities and value to mastectomy patients.</p>	<ul style="list-style-type: none"> Survey breast cancer patients attending support group to elicit effectiveness of this kind of support 	<ul style="list-style-type: none"> In house questionnaire survey to elicit patient perceptions of the group <p>Quality score: 0.6</p>	<ul style="list-style-type: none"> 34% response rate 36/106 women with breast cancer 31- >61 years 	<p>Reasons for attending:</p> <ul style="list-style-type: none"> 86% emotional support 75% information exchange 72% giving of support 67% speakers 19% social 	<ul style="list-style-type: none"> Support groups provide valuable and needed assistance to patients <p>Conclusions loosely related to findings</p>

Reference & country	Aim	Design & Methods	Setting & sample	Outcome	Conclusions
[USA]				<p>Ways support group helpful</p> <ul style="list-style-type: none"> • Received comfort from those that made it through • Increased knowledge about breast cancer • Provided challenge to become role model • Greater ease in sharing personal feelings 	

Table 3: Self help: CAM

Reference & country	Aim	Design & Methods	Setting & sample	Outcome	Conclusions
<p>Bennett & Lengacher (1999)⁴⁹</p> <p>Use of complementary therapies in a rural cancer population.</p> <p>[USA]</p>	<ul style="list-style-type: none"> Determine current use of and interest in various complementary therapies in a sample of rural patients with cancer 	<ul style="list-style-type: none"> Descriptive, cross-sectional survey Tool developed by authors Complementary Therapy Rating Scale [CTRS]: List of 14 complementary therapies with 5 point likert rating to indicate whether using therapy and how likely to try if not; effectiveness rating of therapies used on 3 point scale Quality score: 1.5 	<ul style="list-style-type: none"> 75 patients at 3 cancer treatment centres and 25 patients at local breast cancer support group 53 respondents (53% response rate) 68% female Mean age 64 years [42-91 years] 92% Caucasian 47% breast; 17% prostate; 8% colon; 6% lymphoma/leukemia; 4% skin Time since diagnosis 0.8-20 yrs 	<ul style="list-style-type: none"> 87% reported using at least 1 of the 14 listed CAM and 77% using more than one Prayer most frequently used (60%), humour (57%), support group (56%) Females more interested in use of CAM than men ($p<0.005$). Younger patients more interested in CAM than older patients Education level and income not associated with interest Support group participants expressed more interest in CAM 	<ul style="list-style-type: none"> Women and younger patients more interested in CAM (all support group attendees were female, younger) Problems with effectiveness rating scale (often ignored)
<p>Boon et al. (1999)⁶¹</p> <p>Breast cancer survivors' perceptions of</p>	<ul style="list-style-type: none"> Explore breast cancer survivors perceptions and experiences of 	<ul style="list-style-type: none"> 6 focus groups: discussion of experiences of CAM 	<ul style="list-style-type: none"> 36 breast cancer patients Mean 54 years [41-73 years] 	<p>Key themes:</p> <ul style="list-style-type: none"> On diagnosis, discovery and investigation of 	<ul style="list-style-type: none"> Dominant reason for using CAM - increasing chance of survival

Reference & country	Aim	Design & Methods	Setting & sample	Outcome	Conclusions
complementary/alternative medicine (CAM): making the decision to use or not to use. [Canada]	decision making about CAM	<ul style="list-style-type: none"> Recruited through advertisements distributed at regional breast cancer support groups, cancer centres, health food stores, CAM pharmacies, naturopathic practitioners. <p>Quality score: 1.5</p>	<ul style="list-style-type: none"> 8 months – 15 yrs post diagnosis 6 women reported more than 1 recurrence 11 women were non-users of CAM; 25 self identified as users prior to attending focus group (5 reported CAM use pre diagnosis of breast cancer) 	<p>CAM</p> <ul style="list-style-type: none"> Decision making process with respect to CAM Barriers to using CAM (cost; limited access; time; fear of harm; lack of information) 	<ul style="list-style-type: none"> Majority used conventional medicine and CAM simultaneously, believing it was their responsibility to pick and choose. In absence of evidence, choice about CAM appears based on perceived effectiveness, opinions and beliefs Those who considered risks of a particular therapy often decided not to use it
Boon et al. (2003) ⁶⁵ Men with prostate cancer: making decisions about complementary/alternative medicine. [Canada]	<ul style="list-style-type: none"> Explore perceptions, experiences, feelings and ideas regarding decisions to (not) use CAM 	<ul style="list-style-type: none"> 5 focus groups: experiences of trying to decide whether to use CAM Thematic content analysis Recruited through flyers placed in support groups and cancer centres. Men invited to 	<ul style="list-style-type: none"> 29/58 respondents Mean age 65 years (49-84 years) Average time since diagnosis: 39 months (3-124 months) 26 with localised prostate cancer 21 had used CAM (6 of these had used CAM prior to cancer) 	<p>Key themes:</p> <ul style="list-style-type: none"> Fear/fear of recurrence Loss of control Fixed factors (disease status, co-morbidity, age) Flexible factors (perceptions of CAM and conventional therapy; experiences of conventional healthcare and 	<ul style="list-style-type: none"> Decision making process ongoing, complex and dynamic A group of patients felt a need to take action and to feel in control of their body and the decision making process around their illness management Lack of conventional treatment options available to some men or the

Reference & country	Aim	Design & Methods	Setting & sample	Outcome	Conclusions
		<p>participate in <i>group discussions about CAM</i></p> <p>Quality score: 1.7</p>	diagnosis)	practitioners; perception of need for control)	<p>experience of ineffective conventional treatments appeared to be important factor in decision to use CAM (a way to be proactive against the cancer and find some hope and comfort)</p> <ul style="list-style-type: none"> Perception that CAM options were without adverse effects helped pull participants towards CAM Men who felt conventional caregivers were not willing to support their need to explore a variety of treatment options were more likely to pursue CAM
<p>Braun et al. 2002¹⁰³</p> <p>Supports and obstacles to cancer survival for Hawaii's native people.</p> <p>[USA/Hawaii]</p>	<ul style="list-style-type: none"> Explore how cultural values of Hawaii's native people impact on health beliefs, attitudes and behaviours of cancer survivors 	<ul style="list-style-type: none"> 8 focus groups: explored survivors' experiences with cancer diagnosis, treatment and recovery <p>Quality score: 1.5</p>	<ul style="list-style-type: none"> 45 patients; 36 female Average age 58 years [36-83 years] 19 breast and range of other cancers 	<p>Perceived supports to survival:</p> <ul style="list-style-type: none"> Proactive health behaviour (getting symptoms checked; seeking information; directing care by participating in 	<ul style="list-style-type: none"> Health providers, when faced with someone from unfamiliar culture, should seek perceptions of cancer and probe for obstacles and supports to survival

Reference & country	Aim	Design & Methods	Setting & sample	Outcome	Conclusions
				decision making) <ul style="list-style-type: none"> • Determination to 'beat it' • Guidance from God, holy spirit or spirits of ancestors • Desire to help others • Humour • Medicinal plants • Support groups 	before taking clinical decisions
Chiu (2001) ⁵² Spiritual resources of Chinese immigrants with breast cancer in the USA. [USA]	<ul style="list-style-type: none"> • Investigate the spiritual resources of 15 Chinese immigrants to the USA 	<ul style="list-style-type: none"> • Semi-structured interviews: explored pattern of spiritual resources used or that were available for Chinese immigrants in everyday situations and relationships • Thematic analysis Quality score: 1.3	<ul style="list-style-type: none"> • 15 breast cancer patients (all stages) • 33-67 years • 1-13.5 yrs post diagnosis 	6 categories of spiritual resources found: <ul style="list-style-type: none"> • Family closeness • Traditional Chinese values • Religion • Alternative therapy • Art/prose/literature • Chinese support group 	<ul style="list-style-type: none"> • New insights into interplay between culture, spirituality and health: religion is important to healing therefore places of prayer etc are important
Edgar et al. (2000) ³⁰ Resource use in women completing treatment for breast cancer.	<ul style="list-style-type: none"> • Explore resources used by women completing treatment for breast cancer, how they learned about 	<ul style="list-style-type: none"> • Part of RCT • Questionnaire on resource use administered to women completing treatment for first 	<ul style="list-style-type: none"> • Consecutive series of 156 women recruited from 3 University teaching hospitals • Most stage I and 	<ul style="list-style-type: none"> • N=113 users of support organisations or CAM (mean age 50 yrs) • N=43 non-users 	<ul style="list-style-type: none"> • Women completing treatment for breast cancer made use of a wide range of resources as they re-entered the world 'in

Reference & country	Aim	Design & Methods	Setting & sample	Outcome	Conclusions
[Canada]	them and psychological factors that predict their use	diagnosis of breast cancer <ul style="list-style-type: none"> Questionnaires completed one month before intervention phase of RCT Tools: Profile of Mood States; Life Orientation Test (measure of optimism); Modified Cantril's ladder (rate of perceived control over events in life on 10 point scale); Ways of Coping Questionnaire (positive problem solving; escape/avoidance; seeking social support); In house Resource Use questionnaire Quality scoring: 1.4	II, 7 stage III <ul style="list-style-type: none"> Mean age 52 yrs Cancer treatment: surgery and radiation and or chemotherapy for almost all women 	(mean age 56 yrs) <ul style="list-style-type: none"> No significant differences between users and non users in sense of personal control, levels of optimism, or use of coping style 'seeking social support' Most cited resources: family, oncologist, books Most women found out about resources for themselves Family and friends were major source of knowledge about CAM but did not generally speak about cancer support groups 	limbo' following treatment <ul style="list-style-type: none"> Recommendation or approval of the oncologist was important [valued oncologist's support]
Eng et al. (2003) ¹⁰⁴ A population-based survey of complementary and alternative medicine	<ul style="list-style-type: none"> Determine prevalence and patterns of use of CAM among men recently diagnosed 	<ul style="list-style-type: none"> Mailed survey to patients recently diagnosed with prostate cancer (<80 years) 	<ul style="list-style-type: none"> 451 men responded (42% response rate) Mean 68 years [47-81 years] 	<ul style="list-style-type: none"> 39% reported using CAM [30% of these started using CAM post diagnosis] Of these, 58% 	<ul style="list-style-type: none"> 39% of men in study reported using CAM to boost immune system and prevent recurrence

Reference & country	Aim	Design & Methods	Setting & sample	Outcome	Conclusions
<p>use in men recently diagnosed with prostate cancer.</p> <p>[Canada]</p>	<p>with prostate cancer</p>	<ul style="list-style-type: none"> In house questions: demographics, diagnosis and conventional treatment received, CAM used, reasons for CAM use, perceived benefit, disclosure to physician, use of CAM information resources <p>Quality score: 1.4</p>	<ul style="list-style-type: none"> 99% received/were receiving conventional treatment (majority radiation or radical prostatectomy, most in combination with hormone treatment) 	<p>reported telling Drs about CAM use; 13% had not; 29% did not respond to question</p> <ul style="list-style-type: none"> Reasons for using CAM (first two are main reasons): to boost immune system; prevent recurrence; improve QoL; slow disease progression; increase sense of control over illness Most common sources of information: friends and relatives Perceived benefit of using CAM reported by 60% of users 	<ul style="list-style-type: none"> Not all CAM users perceived benefit of use
<p>Gupta et al. (2002)⁶⁴</p> <p>Patterns and perceptions of complementary and alternative medicine (CAM) among leukaemia patients visiting haematology clinic of a north Indian tertiary care</p>	<ul style="list-style-type: none"> Discover prevalence of use of CAM cancer therapies in leukaemia patients visiting a haematology clinic of a north Indian tertiary care 	<ul style="list-style-type: none"> Interviews: demographics; CAM use <p>Quality score: 1.0</p>	<ul style="list-style-type: none"> 533 patients with leukaemia: 313 male, 220 female >18 years - >50 years Receiving conventional treatment 	<ul style="list-style-type: none"> 302/533 use CAM CAM used more often by men (60%) than women (40%) amongst all age groups Most users in rural areas, either illiterate or 	<ul style="list-style-type: none"> Some patients seek hope from CAM Important to understand why a significant proportion of population is going beyond conventional medicine to treat serious medical

Reference & country	Aim	Design & Methods	Setting & sample	Outcome	Conclusions
hospital. [India]	hospital			<p>educated to primary level and low annual income</p> <ul style="list-style-type: none"> • Most patients (61%) sought conventional treatment before adding CAM; 28% took CAM first; 11% started both at same time • Most common reason for using CAM: hope for miracle cure (52%) • 33% satisfied with CAM; 51% dissatisfied • Those satisfied with CAM described benefits as mild physical and psychological 	problems
<p>Henderson & Donatelle (2004)⁶⁶</p> <p>Complementary and alternative medicine use by women after completion of allopathic treatment for breast cancer.</p>	<ul style="list-style-type: none"> • Determine post breast cancer treatment health behaviours with regard to use of CAM 	<ul style="list-style-type: none"> • Telephone survey of women following treatment for breast cancer • Assessing use of CAM <p>Quality score: 1.6</p>	<ul style="list-style-type: none"> • 551/757 women with breast cancer (all stages) • Mean 64 yrs (sd 11.68 [31-91 yrs]) • Average 3.5 yrs post diagnosis at time of interview 	<ul style="list-style-type: none"> • 2/3 women had used at least 1 CAM in past 12 months (av 2) • Diet and spiritual healing perceived to be 'quite important' in remaining free of cancer 	<ul style="list-style-type: none"> • Higher education may enable information seeking behaviour • Younger patients may be more inclined to try everything available • CAM use did not reflect negative attitudes towards conventional care

Reference & country	Aim	Design & Methods	Setting & sample	Outcome	Conclusions
[USA]				<ul style="list-style-type: none"> Reasons for CAM use: improve QoL (41%); increase feeling of control (21%); boost immune system (11%); reduce stress (10%); combination (18%) CAM users differed significantly from non users in education insurance and younger age 	<ul style="list-style-type: none"> The women adopted a broad range of health-related activities for self-care, healing and optimisation of health and well-being ("a way of being independently proactive ... whilst improving physical, mental and spiritual health")
Kao & Devine (2000) ⁷⁰ Use of complementary health practices by prostate carcinoma patients undergoing radiation therapy. [USA]	<ul style="list-style-type: none"> To gather information on the use of CAM in a group of men receiving potentially curative radiotherapy treatment 	<ul style="list-style-type: none"> Questionnaire survey Quality score: 1.2	<ul style="list-style-type: none"> 46 men with non metastatic prostate cancer 51-78 yrs 	<ul style="list-style-type: none"> 37% men were using one of the listed CAM Some patients had started pre-diagnosis, other practices were mostly started post diagnosis aiming to cope better or augment efficacy of radiotherapy Patients using CAM had higher levels of education and income Physicians considerably 	<ul style="list-style-type: none"> Unrecognised use of CAM may have undesirable consequences e.g. contraindications with conventional treatment Patients used CAM in addition to conventional treatment

Reference & country	Aim	Design & Methods	Setting & sample	Outcome	Conclusions
				underestimated use by their patients	
<p>Lengacher et al. (2002)⁷¹</p> <p>Frequency of use of complementary and alternative medicine in women with breast cancer.</p> <p>[USA]</p>	<ul style="list-style-type: none"> Estimate the frequency of use and describe specific types of CAM used among women diagnosed with breast cancer and to identify demographic and clinical factors associated with CAM use in these patients 	<ul style="list-style-type: none"> Postal survey assessing Use of Complementary Therapies; usefulness of therapies and whether they had been discussed with a physician <p>Quality score:1.1</p>	<ul style="list-style-type: none"> 105/125 breast cancer patients (probably all stages) Mean age 59 yrs (+-12) 	<p>CAM divided into 3 sub groups:</p> <ul style="list-style-type: none"> Diet and nutritional supplements: vitamins and minerals used regularly by 2/3 patients; antioxidants used regularly by 1/3. The majority had discussed this with their doctor Stress reduction techniques: 2/3 reported using one stress reduction technique: 49% prayer or spiritual healing, 37% support group, 21% humour. Often not discussed with doctor. Often used pre-diagnosis Traditional and ethnic medicines: rarely used. Mostly not discussed with 	<ul style="list-style-type: none"> CAM use is common post diagnosis of breast cancer Stress reducing techniques often not discussed with physicians

Reference & country	Aim	Design & Methods	Setting & sample	Outcome	Conclusions
				doctor <ul style="list-style-type: none"> Higher level of CAM use associated with previous chemo and more high school education 	
Montbriand (1993) ¹⁰⁵ Freedom of choice: an issue concerning alternate therapies chosen by patients with cancer. [Canada]	<ul style="list-style-type: none"> Explore beliefs and practices of patients in relation to the use of CAM 	<ul style="list-style-type: none"> Ethnographic study: secondary analysis of data from 2 studies. The second quantitative study designed in response to the findings of the first qualitative study Quality score: 1.1	<ul style="list-style-type: none"> 300 men and women with all stages of respiratory and GI tract cancers Ages 35-80 yrs 	<ul style="list-style-type: none"> 71% used CAM: Physical: substances (e.g. herbs, vitamins), manipulation (e.g. reflexology, massage), objects (e.g. talismans) Spiritual: to give cosmic force control of healthcare e.g. God Psychological: mind as director of care e.g. visualisation Patients reported difficulties accessing information sources and perceived alternative care literature to often be more accessible understandable 	<ul style="list-style-type: none"> Challenge if people have freedom of choice if they have incomplete information and/or have not interpreted it appropriately

Reference & country	Aim	Design & Methods	Setting & sample	Outcome	Conclusions
				and appealing than biomedical	
Read et al. (1990) ¹⁰⁶ Supplementation practices of a group of patients with cancer. [USA]	<ul style="list-style-type: none"> Examine use of nutritional supplement products by patients with cancer 	<ul style="list-style-type: none"> 32 patients with cancer referred for nutrition consultation and evaluation. Interviewed by dietician about supplement use. Medical records also used to gather information relevant to cancer diagnosis and treatment Quality score: 0.6	<ul style="list-style-type: none"> 32 patients; 19 men, 13 women Women aged 33-72 (mean 54 yrs) Men aged 49-79 (mean 63 yrs) Of the women 7/13 have breast cancer, 5/19 men have lung cancer 	<ul style="list-style-type: none"> 92% women and 63% men vitamin/mineral supplements 46% women and 32% men herbal supplements 38% women and 21% men 'other' supplements Many patients took well over RDA for vitamins 	<ul style="list-style-type: none"> Supplementation may not be innocuous, and may even be counter productive to traditional cancer therapies
Samur et al. (2001) ¹⁰⁷ Factors associated with utilization of non-proven cancer therapies in Turkey. A study of 135 patients from a single center. [Turkey]	<ul style="list-style-type: none"> Evaluate prevalence of and factors associated with usage of non-proven cancer remedies in a teaching hospital in Turkey 	<ul style="list-style-type: none"> Self report questionnaires: demographics, usage of non-proven methods, possible contributing factors Quality score: 1.4	<ul style="list-style-type: none"> 135 patients attending outpatient clinics: 78 female; 57 male Age 23-94 yrs (median 52.42) 49 breast cancer, 28 lung cancer, 15 colorectal cancer, 43 other cancers All patients receiving chemotherapy 	<ul style="list-style-type: none"> All patients had no/primary education 50% used NPT Generally someone other than patient provided NPT and source of information from friends or close relatives About 1/3 of users found the method effective 	<ul style="list-style-type: none"> 3% of patients delayed/interrupted conventional treatment to use CAM Likelihood that patients will use NPT increased with duration of disease

Reference & country	Aim	Design & Methods	Setting & sample	Outcome	Conclusions
			(curative and palliative)	<ul style="list-style-type: none"> Few non-users wanted to try NPT 	
Steginga et al. (2000) ³³ The supportive care needs of men with prostate cancer [Australia]	<ul style="list-style-type: none"> Assess supportive care needs of men with prostate cancer who are members of prostate cancer self help groups 	<ul style="list-style-type: none"> Tool: Supportive Self Care Needs Survey – validated measure assessing perceived need in various domains. Men with prostate cancer recruited from self help groups <p>Quality score: 1.7</p>	<ul style="list-style-type: none"> 206/334 (62%) men with prostate cancer 1 month – 5 yrs post diagnosis Mean 68 yrs [48-85 yrs] 	<ul style="list-style-type: none"> 55% of men had used CAM in past 12 months: vitamins most common (36%), herbal treatment (29%), selenium (26%) 40 men reported using 'other' Younger, higher education level predicted CAM use. 	<ul style="list-style-type: none"> Men who joined support groups are higher users of CAM and main join such groups in part to discuss and find out more about CAM CAM use related to holistic views about health vs dissatisfaction with conventional medicine
Struthers & Eschiti (2004) ¹⁰⁸ The experience of indigenous traditional healing and cancer. [USA]	<ul style="list-style-type: none"> Describe the meaning and essence of the lived experience of 4 indigenous people who have been diagnosed with cancer 	<ul style="list-style-type: none"> Qualitative phenomenological methodology Interviews with 4 indigenous people: <i>As an indigenous person, what is the experience of being healed by an indigenous traditional healer?</i> <p>Quality score: 1.2</p>	<ul style="list-style-type: none"> 4 patients with breast, lung, prostate cancer and sarcoma of the leg 3 female 49-61 yrs 	4 essential themes: <ul style="list-style-type: none"> Receiving diagnosis: knowing something wrong; hearing something wrong Seeking healing Connecting to indigenous culture Contemplating life's future 	<ul style="list-style-type: none"> Study illustrates that culture, belief system, and interpretations of the meaning of illness have an important effect on what approaches to treatment are sought when illness strikes
Tatsumura et al (2003) ⁷³	<ul style="list-style-type: none"> Identify religious 	<ul style="list-style-type: none"> Semi-structured 	<ul style="list-style-type: none"> 143 people with 	<ul style="list-style-type: none"> Patients who use 	<ul style="list-style-type: none"> Use of RSR and CAM

Reference & country	Aim	Design & Methods	Setting & sample	Outcome	Conclusions
<p>Religious and spiritual resources, CAM, and conventional treatment in the lives of cancer patients.</p> <p>[USA]</p>	<p>and spiritual resources (RSR) used by patients with cancer.</p> <ul style="list-style-type: none"> Explore themes and relationships between them 	<p>interviews</p> <ul style="list-style-type: none"> Grounded theory approach to analysis <p>Quality score 1.2</p>	<p>cancer; 2/3 women</p> <ul style="list-style-type: none"> 1/3 with advanced disease Breast, prostate, GI most common sites Age not recorded 	<p>RSR do so in belief that it can: i. cure; ii. enhance QoL</p> <ul style="list-style-type: none"> If these purposes were perceived to be shared with those of CAM and for conventional treatment then the 3 were seen as related RSR was important to decision making and was a source of hope and solace 	<p>is dependent on beliefs about health i.e. role of mind and body/importance of control</p>
<p>Truant & Bottorff (1999)⁶²</p> <p>Decision making related to complementary therapies: a process of regaining control.</p> <p>[Canada]</p>	<ul style="list-style-type: none"> Investigate process by which women with breast cancer make decisions related to using CAM 	<ul style="list-style-type: none"> Purposive sampling: recruited through word of mouth or adverts at breast cancer support groups, cancer treatment centres, and CAM research centre Grounded theory Open ended interviews: <i>Tell me how you came to use CAM for your breast cancer?</i> <p>Quality score: 2</p>	<ul style="list-style-type: none"> 16 women with breast cancer – various stages receiving /had received conventional treatment and who used a wide range of CAM Various cultural backgrounds 39-71 years 	<p>Central theme: regaining control through CAM use</p> <ul style="list-style-type: none"> DECISION PHASE Getting something in place: covering all bases: often at diagnosis when uncertainty highest and ends just after surgery; diagnosis leads to sense of urgency to do something for self; little time to research CAM, go with what's known or recommended 	<ul style="list-style-type: none"> CAM use - means of regaining ('illusion of') control during experiences of uncertainty; leads to maintenance of hope Desire to regain control can facilitate adaptation to illness

Reference & country	Aim	Design & Methods	Setting & sample	Outcome	Conclusions
				<ul style="list-style-type: none"> • Hand picking CAM that fit: getting a personalised regimen in place: Taking back control; usually begins post surgery, through treatment and beyond. Modify CAM to create regimen to suit; supportive action to manage side effects of treatment. • Information rarely sought from HCPs; often withhold information about CAM • Living with the security of CAM: fine tuning a regimen to live with: maintaining illusion of control; sense of security that doing something for self; generally began after orthodox treatment finished 	

Reference & country	Aim	Design & Methods	Setting & sample	Outcome	Conclusions
				and extending indefinitely	
<p>van der Weg & Streuli (2003)³⁷</p> <p>Use of alternative medicine by patients with cancer in a rural area of Switzerland.</p> <p>[Switzerland]</p>	<ul style="list-style-type: none"> Assess prevalence of and motivation for use of CAM in a population in rural Switzerland 	<ul style="list-style-type: none"> Structured questionnaire (multiple choice) administered by a clinician <p>Quality score: 0.8</p>	<ul style="list-style-type: none"> 108 cancer patients (N=42 non users) 49% breast cancer; colorectal; ovarian; other 77% female Age <50 - >70 yrs Time from diagnosis: <1 yr - > 3 yrs 	<ul style="list-style-type: none"> 81% of CAM users had heard about the therapy from friends or family; 45% from other cancer patients; 29% from books Reasons for using therapy (multiple choice options): 'feel more hopeful' (83%); 'do as much as possible for myself' (83%); 'conventional treatment cannot help' (10%); 'boost immune system' (81%); 'improve QoL' (67%); 'prolong life' (29%); 'cure disease' (19%) More users than non-users were health conscious and changed their lifestyle e.g. smoking/nutrition post diagnosis 	<ul style="list-style-type: none"> Maintaining hope and taking an active role in self care are the main stimuli for using CAM

Reference & country	Aim	Design & Methods	Setting & sample	Outcome	Conclusions
Verhoef & White (2002) ⁸¹ Factors in making the decision to forgo conventional cancer treatment. [Canada]	<ul style="list-style-type: none"> Explore reasons why people forgo conventional treatments and factors influencing the decision 	<ul style="list-style-type: none"> Focus groups with cancer patients who have refused at least one conventional treatment Quality score: 1.6	<ul style="list-style-type: none"> 31 patients (13 breast cancer, 8 prostate cancer, 10 other) 30 - > 70 yrs 18 females 	<ul style="list-style-type: none"> Predisposing factors: negative experience of mainstream medicine; significant other died of cancer whilst receiving conventional treatment; use of CAM pre-diagnosis; belief in body-mind healing as opposed to biomedicine Perceived severity of side effects of conventional treatments: 'against everything natural'; breaking down immune system Beliefs: conventional treatment not healing orientated; need to adopt a mind-body approach to deal with cancer Need for control Outcomes of 	<ul style="list-style-type: none"> Patients forgoing conventional treatment have a strong belief that it will not be effective. They are more likely to see it as incompatible with active patient involvement in disease management

Reference & country	Aim	Design & Methods	Setting & sample	Outcome	Conclusions
				decision making: perceptions of improved sense of well-being or cure	

Table 4: Self help: Information

Reference & country	Aim	Design & Methods	Setting & sample	Outcome	Conclusions
<p>Bilodeau & Degner (1996)¹⁰⁹</p> <p>Information needs, sources of information, and decisional roles in women with breast cancer.</p> <p>[Canada]</p>	<ul style="list-style-type: none"> Compare women with breast cancer's expressed preference for participating in treatment decision making with their actual experience 	<ul style="list-style-type: none"> Cross sectional survey Tools: developed for the study - control preferences card sort; Thurstone scaling of information needs; ranking of information resources Quality score: 0.82 	<ul style="list-style-type: none"> 74 women recently diagnosed with breast cancer Mean age: 57.5 yrs [range: 18-83 yrs] 60% stage I, 30% stage II, 5% stage III, 4% stage IV breast cancer 	<ul style="list-style-type: none"> 43% women preferred and 57% actually assumed passive role in treatment decision making Greater proportion of older women (65-83 yrs) assumed passive role in treatment decision making 37% women preferred collaborative approach to treatment decision making but only 19% able to assume role Higher education level more use of medical journal as source of information (p=0.002) 	<ul style="list-style-type: none"> Women who want collaborative roles in decision making may experience difficulty in achieving this
<p>Breau et al. (2003)¹¹⁰</p> <p>Assessing self-help issues for patients with prostate cancer,</p>	<ul style="list-style-type: none"> Determine prevalence of self-help for several urological diseases including prostate 	<ul style="list-style-type: none"> Cross sectional study Structured interview: demographic, 	<ul style="list-style-type: none"> 30 men with prostate cancer; almost ¼ were symptomatic at diagnosis; ¾ had 	<ul style="list-style-type: none"> Compared to other patient groups reported least need for support and information, and 	<ul style="list-style-type: none"> Brochures are form of self help most used by these patients, and can be a first resource for education and a

Reference & country	Aim	Design & Methods	Setting & sample	Outcome	Conclusions
<p>interstitial cystitis, erectile dysfunction and urinary diversion.</p> <p>[Canada]</p>	cancer	<p>illness information, disease-related needs, self help-issues (rated for usefulness; awareness of resources; how might be used in future)</p> <p>Quality score: 1.45</p>	<p>adverse side effects (erectile and/or urinary problems post treatment)</p> <ul style="list-style-type: none"> • Average 3.6 yrs post diagnosis; Average 3.3 yrs post treatment • Mean 67 yrs (sd 9.2) 	<p>reported being most satisfied with support and information received</p> <ul style="list-style-type: none"> • Support groups reported as most useful in providing social support and coping skills, books most useful in providing disease and treatment information • Married patients more satisfied with social support than single patients • Higher education and single men more likely to use internet for self help. 	<p>means for directing patients to other forms of self help</p>
<p>Gray et al. (1998)¹¹¹</p> <p>Information needs of women with metastatic breast cancer.</p> <p>[Canada]</p>	<ul style="list-style-type: none"> • Explore the information needs of women with metastatic breast cancer 	<ul style="list-style-type: none"> • 8 focus groups: current information needs related to breast cancer • Recruitment through nurses in hospitals, regional cancer centres or breast cancer 	<ul style="list-style-type: none"> • 38 women • mean age 54.4 [29 - 75 yrs] • Mean time since diagnosis: 6.5 yrs • 50% had participated in a support group for women with 	<p>Two themes</p> <ul style="list-style-type: none"> • Expressed desire for information in specific context areas (understand medical situation; treatment options; anticipate/act on symptoms; 	<ul style="list-style-type: none"> • Majority of women sought information and saw it helpful to the degree it helped them with their own situation and personal future planning

Reference & country	Aim	Design & Methods	Setting & sample	Outcome	Conclusions
		support group • Thematic analysis Quality score: 1.7	breast cancer	counselling; homecare services; unconventional therapies; how to communicate with family members) • Issues relating to benefit/harm of information (difficult to judge e.g. book/web; potential to be overwhelmed)	
Kakai et al. (2003) ⁹⁰ Ethnic differences in choices of health information by cancer patients using complementary and alternative medicine: An exploratory study with correspondence analysis. [USA/Hawaii]	• Investigate ethnic differences in health information seeking behaviour amongst cancer patients in Hawaii. Also to explore possible association between patients education, ethnicity and health seeking behaviour	• Interviews with stratified sample of patients who had taken part in a survey on CAM Quality score: 1.6	• 140 patients; N=65 Caucasian; N=33 Japanese; N=42 non- Japanese • 40 – 80+ yrs • 61-67% females per group • Breast, GI, prostate and other cancers	• Caucasians likely to seek information from telephone information services, professional references e.g. journals and internet • Non-Japanese sought health information from other cancer patients, physicians and family/friends/ co-workers • Japanese patients sought health information from TV, printed media	• Cultural values and beliefs play a role in health information seeking behaviours which may affect survival and QoL

Reference & country	Aim	Design & Methods	Setting & sample	Outcome	Conclusions
				(e.g. books), and CAM providers	
Pereira et al. (2000) ¹¹² Internet usage among women with breast cancer: an exploratory study. [Canada]	<ul style="list-style-type: none"> Explore internet use amongst breast cancer patients and their families 	<ul style="list-style-type: none"> Survey of women attending breast cancer systemic therapy outpatient clinics (adjuvant and palliative) Family and friends also attending invited to participate Quality score: 0.6	<ul style="list-style-type: none"> 79 patients and 28 relatives 15% response rate Patient internet users (N=34) mean age 43.5 yrs (+/- 6.5) Patient internet non-users (N=45) mean 49.1 yrs (+/- 10.8) 	<ul style="list-style-type: none"> 43% patients said they had used the internet to look for cancer related information, 57% had not Reasons for non-use: no access (53%), unfamiliar with internet (33%), distrust of info (13%) 	<ul style="list-style-type: none"> Patients who used internet were younger than non users (also better educated and less satisfied with amount of treatment related information given to them than non users) Majority discussed internet information with HCPs
Rees & Bath (2001) ¹¹³ Information-seeking behaviours of women with breast cancer. [UK]	<ul style="list-style-type: none"> Explore information seeking behaviours of women with breast cancer 	<ul style="list-style-type: none"> Mailed survey to examine information seeking behaviours of women: Recruited via outpatients breast clinics Recruited via breast cancer support group: 3 focus groups, views of women with breast cancer concerning their information seeking behaviours: Purposive sampling Tools: Miller 	<ul style="list-style-type: none"> Survey: 156/202 women with a diagnosis of breast cancer in past 10 yrs (non metastatic) Median age 59 yrs [range 32-89] Focus groups: 30/208 women Median age 58 [range 38-76] 	<ul style="list-style-type: none"> Survey: no significant associations between monitoring behaviour and demographics or illness characteristics Focus groups: 3 themes Seeking vs avoiding information Why seek information? Gain sense of control; increase confidence and security; active 	<ul style="list-style-type: none"> Monitoring/blunting not associated with demographics or cancer/treatment characteristics Focus groups demonstrate that people vary in their desire for information depending on the circumstances

Reference & country	Aim	Design & Methods	Setting & sample	Outcome	Conclusions
		Behavioural Study Survey Quality score: 1.1		participation in decision making • Why avoid information? To bypass subsequent feelings of worry; fear; negative and depressing	

Appendix V: Table of excluded articles

Reference	Brief reason for exclusion
Making the patient a part of patient care. Mod Hosp 1973; 121:105-110.	Newsletter not a study
Adamsen L, Rasmussen JM, Pedersen LS. 'Brothers in arms': how men with cancer experience a sense of comradeship through group intervention which combines physical activity with information relay. J Clin Nurs 2001; 10:528-537.	Not relevant – evaluation of group
Adamson G. Patient empowerment in cancer management: healing the whole person. Complementary Therapies in Nursing & Midwifery 9(3):109-13.	No data - commentary
Bayuk L. Relaxation techniques: an adjunct therapy for cancer patients. Seminars in Oncology Nursing 1985; 1(2):147-150.	Commentary – no data
Bishop A, Kovtun A, Okromeshko S, Karpilovskaya S, Suprun N. Lives renewed: the emergence of a breast cancer survivor movement in Ukraine. Reprod Health Matters 2001; 9:126-134.	Not relevant
Braden CJ, Mishel MH, Longman AJ. Self-Help Intervention Project. Women receiving breast cancer treatment. Cancer Practice 1998; 6(2):87-98.	Not relevant. HCP initiated intervention
Bryant W. Self care for cancer patients. Nursing RSA 1993; 8(2):19-20.	No data - commentary
Bulsara C, Ward A, Joske D. Haematological cancer patients: achieving a sense of empowerment by use of strategies to control illness. Journal of Clinical Nursing 2004; 13(2):251-258.	Not relevant
Carlsson M. Cancer patients seeking information from sources outside the health care system.[see comment]. Supportive Care in Cancer 2000; 8(6):453-457.	Not relevant
Comartin MA. New directions in care. Self help for the cancer patient... part 1. Canadian Nurse 1983; 79(2):42-44.	No data
Dodd M J. Efficacy of proactive information on self-care in chemotherapy patients. (Study). Patient Education and Counseling 1988; 11(3) 215-225.	Not relevant – HCP initiated

Reference	Brief reason for exclusion
Dodd MJ. Self-care for patients with breast cancer to prevent side effects of chemotherapy: a concern for public health nursing. Public Health Nursing 1984; 1(4):202-209.	Did not report motivation/source for self care activities
Dodd MJ. Patterns of self care in cancer patients receiving radiation therapy. Oncology Nursing Forum 1984; 11(3):23-7.	Not relevant – Frequency of SCBs
Dodd MJ. Patterns of self-care in patients with breast cancer. West J Nurs Res 1988; 10:7-24.	Not relevant – Frequency of SCBs
Dodd MJ, Dibble SL. Predictors of self-care: a test of Orem's model. Oncology Nursing Forum 1993; 20(6):895-901.	Nurse led self care. Not patient initiated.
Fogel J. Use of Internet information by women with breast cancer.[comment]. Health Expectations 2003; 6(4):361-362.	Prevalence of internet use
Foltz AT, Gaines G, Gullatte M. Recalled side effects and self-care actions of patients receiving inpatient chemotherapy. Oncology Nursing Forum 1996; 23(4):679-83.	Not clear whether actions are self initiated.
Gammon J. Coping with cancer: the role of self-care. Nursing Practice 1991; 4(3):11-15.	Self care taught by nurses
Hall JD, Bissonette EA, Boyd JC, Theodorescu D. Motivations and influences on the use of complementary medicine in patients with localized prostate cancer treated with curative intent: results of a pilot study. BJU Int 2003; 91:603-607.	Not relevant
Hellawell GO, Turner KJ, Le Monnier KJ, Brewster SF. Urology and the Internet: an evaluation of internet use by urology patients and of information available on urological topics. BJU International 2000; 86(3):191-194.	Not relevant
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