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DRAFT **CONFIDENTIAL**

Improving supportive and palliative care for adults with cancer

Research Evidence Manual

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Contents

1. Introduction

This manual comprises the research evidence identified, generated and appraised in the review to date. The methods of review followed those of standard systematic reviews, and were based on those used in the generation of evidence for the Clinical Outcomes Guidance in Cancer, married with those of the National Institute of Clinical Excellence and the Cochrane Collaboration.

The sections below outline first the methods of the review, including literature searching, inclusion and exclusion criteria, data extraction and synthesis. Then there is a short section discussing the general nature of the evidence and highlighting some of the limitations of the review to date. Finally, the evidence has been grouped for each topic area and the evidence is presented, to appraise the recommendations provided by the Editorial Board.

Purpose of Review

The purpose of this review is to determine the current state of the evidence on interventions to improve service configurations for the supportive and palliative care for those affected by cancer. An underlying assumption of the review is that interventions that improve health professionals' practice and health care provision should have a beneficial effect on patient outcomes.

Objectives

The objectives of this review are to determine the effectiveness of different interventions, targeted at health care professionals or the structure in which health care professionals deliver their care, to improve the supportive and palliative care for those affected by cancer.

Secondary questions are:

1) Which intervention strategy or parts of intervention strategies are the most effective?
2) What do the most effective strategies have in common?

Review Methods

Search strategy for identification of studies

Relevant studies for meeting the inclusion criteria were identified by:

a) Searching MEDLINE, EMBASE, CINAHL, CancerLit, CDSR, the Cochrane Effective Practice and Organisation of Care Group (EPOC) specialised register and the Cochrane Central Register of Controlled Trials (CENTRAL).

b) The reference list of identified studies were searched for further relevant studies.

The methodological terms from the existing EPOC search strategy were combined with:

1) exp Palliative care/
2) Terminal care/
3) Terminally ill/
4) Attitude to death/
5) Bereavement/
6) Right to die/
7) Hospices/
8) Respite care/
9) Palliat$.tw.
10) Terminal$.tw.
11) Terminal$.mp. and (care or caring or ill$).tw. [mp=title, registry number word, mesh subject heading]
12) Hospice$.tw
13) Bereav$.tw.
14) Grief.mp. or griev$.tw. [mp=title, abstract, registry number word, mesh subject heading]
15) (Attitude$ adj5 (care or caring)).tw.
16) (Respite adj5 (care or caring)).tw.
17) (Attitude$ adj5 (death$ or dying)).tw.
18) (support$ adj5 (care or caring)).tw.
19) Social support/
20) (Spiritual$ adj5 support$).tw.
21) Alternative Medicine/
22) Complementary therap$.tw.
23) Consumer Participation/
24) Patient Participation/
25) User involvement.tw.
26) Information.tw.
27) Communication.tw.
28) 132 or 133 or 134 or 135 or 136 or 137 or 138 or 139 or 140 or 141 or 142 or 143 or 144 or 145 or 146 or 147 or 148 or 149 or 150 or 151 or 152 or 153 or 154 or 155 or 156 or 157 or 158

29) Neoplasms/
30) Cancer$.mp or neoplasms.tw. [mp=title, abstract, registry number word, mesh subject heading]
31) 160 or 161

Literature search process

Palliative care search strategy

MEDLINE (1966 to March 2003): Search was not limited to the cancer field only. The palliative care search terms were used without AND with cancer search terms. The reason for this was the concern that relevant studies with pallcare organisational or professional interventions would be missed if the words neoplasm or cancer did not appear anywhere in the abstract. This was piloted to make sure that the HITS were specific enough and did not retrieve lots of completely irrelevant studies. The results were good so a broader search was run. The HITS were directly exported to REFMAN and the abstracts assessed.

EMBASE (1980 to March 2003): Search was limited to the cancer field. The search retrieved many completely irrelevant studies and it was decided to AND with cancer search terms. The HITS were directly exported to REFMAN, any duplicates removed and the abstracts assessed.

CINAHL (1982 to March 2003): Search was limited to the cancer field. The search retrieved many completely irrelevant studies and it was decided to AND with cancer search terms. The HITS were directly exported to REFMAN, any duplicates removed and the abstracts assessed.

CENTRAL (2001, Issue 4): The search terms ((Palliat* or Terminal*) and Cancer) were used. The abstracts were assessed in the library and any potentially relevant studies were printed and then cross-checked for duplicates in REFMAN. Any studies not found in REFMAN were manually entered.

CDSR (2003, Issue 2): The search terms ((Palliat* or Terminal*) and Cancer) were used. The reviews were assessed in the library and any potentially relevant reviews were printed and filed.

EPOC specialist register: These can be located in 2 separate databases sent by the information specialist.

Supportive care search strategy

MEDLINE (1966 to March 2003): Search was limited to the cancer field only. The HITS were directly exported to REFMAN and the abstracts assessed.

EMBASE (1980 to March 2003): Search was limited to the cancer field. The HITS were directly exported to REFMAN, any duplicates removed and the abstracts assessed.

CINAHL (1982 to March 2003): Search was limited to the cancer field. The HITS were directly exported to REFMAN, any duplicates removed and the abstracts assessed.

Inclusion Criteria

Types of Studies

1) Randomised or quasi-randomised controlled trials (RCTs)
2) Controlled clinical trials (CCTs)
3) Controlled before and after studies (CBAs)
4) Interrupted time series and observational studies (ITSs)
5) Systematic literature reviews

At the initial stage qualitative studies were included only when higher grade evidence is not available.

Types of Participants

Any person involved in the delivery of supportive and palliative care for those affected by cancer in a hospital, home or community setting.

Types of Intervention

Any intervention strategies to improve the supportive and palliative care for those affected by cancer, specifically

1) Professional interventions

   This category includes strategies to provide professionals with information or training on appropriate practice.

2) Organisational interventions

   This category includes interventions that are predominantly about changes in organisational systems, such as the introduction of multi-disciplinary teams, changes in skill mix, or in the setting or site of service delivery. It also includes interventions for families and carers of patients with cancer that provide support to enable them to fulfil the crucial role of carer, and interventions that test mechanisms to ensure that users are involved in service planning and delivery.

Types of Outcome Measures

Objectively measured health professional performance or patient outcomes in a clinical setting and self report measures with known validity and reliability.

1) Any objective measure of health professional performance (according to the EPOC categories for behaviours – see METHODS USED IN REVIEWS under GROUP DETAILS), or patient outcomes to be included.
2) Patient and carer outcome measures:

- Pain
- Symptom control (nausea/vomiting, constipation, breathlessness, mouth discomfort, insomnia)
- Psychological morbidity (anxiety, self-esteem, stress, depression)
- Well-being
- Perceived death
- Quality of life
- Functional status
- Patient satisfaction
- Carer satisfaction
- Provider satisfaction
- Knowledge
- Referral to other services
- Place of care
- Use of other services
- Place of death

Exclusion criteria

Studies were excluded if they evaluated screening programmes. Case reports and descriptive studies, discussion papers, needs assessments, studies primarily concerned with children, and studies on preferences or developing measurement tools were excluded, as were those which did not measure outcomes or professional performance.

Data Extraction and Analysis

Data were extracted in to tables which defined the study setting, objectives, population, outcome measures, and main results. If available quantitative meta-analyses were extracted from existing systematic literature reviews. Because of the degree of heterogeneity between studies and outcome measures it is not possible to conduct meta-analyses in many of the areas for review. However, we would wish to explore the possibility of conducting meta-analyses in the future in some of these areas, but this will require considerably more time than is available to the evidence review team at present. The studies were linked to the appropriate topic area and reviewed and appraised in these sections.

Grading the evidence

Individual studies were graded, using a standard system, as in the Clinical Outcomes Group as in the table below. Systematic reviews were not graded.

Grading system for individual studies	
Grade I (RCT)	IA – calculation of sample size and accurate, standard definition of outcome variables IB – accurate and standard definition of outcome variables IC – neither of the above
Grade II Prospective study with a comparison group (non-randomised controlled trial, good observational study) or retrospective study with controls effectively for confounding variables	IIA – calculation of sample size and accurate, standard definition of outcome variables and adjustment for the effects of important confounding variables. IIB – one or more of the above
Grade III	IIIA – comparison group, calculation of sample size and accurate, standard definition of outcome variables IIIB – two or more of the above IIIC – none of these

The quality of combined research were graded using the NICE hierarchy of evidence:

Level	**Type of evidence**
Ia	Evidence obtained from systematic review of meta-analysis of randomised controlled trials
Ib	Evidence obtained from at least one randomised controlled trial
IIa	Evidence obtained from at least one well-designed controlled study without randomisation
IIb	Evidence obtained from at least one other type of well-designed quasi-experimental study
III	Evidence obtained from well-designed non-experimental descriptive studies, such as comparative studies, correlation studies and case studies
IV	Evidence obtained from expert committee reports or opinions and/or clinical experience of respected authorities

This NICE hierarchy maps on to the evidence grading for individual studies, but incorporates a level for systematic reviews and allows the evidence from different studies to be combined.

Results: The Research Evidence

Nature of the evidence and emergent issues and limitations

Several issues arose in the process of the review.

A. A large amount of high quality evidence (grade Ia, Ib and II) is apparent in these reviews. This was much greater than was anticipated by the proposal generating team, the project team and the funders. This has meant that the task of reviewing the evidence has been onerous. However, this finding shows that supportive and palliative care is an area where there is evidence available to support the use of many of the interventions. In some instances the evidence is not addressing the exact questions of the proposal generating team. Instead the evidence considers whether an intervention is or is not effective, rather than the detail of how it actually works, or how the components parts should be configured. These more detailed areas will clearly need to be aspects for research in the future.

B. Because of the size of evidence generated we anticipate that we will have not identified every single relevant study to date. We concentrated on attempting to identify the highest levels of evidence in the core areas of the recommendations.

C. The process of matching the evidence to the recommendations was complicated by the fact that the proposal generating team and editorial board made a number of changes to the conceptual framework for the manual. This was because their own thinking evolved and new elements of evidence emerged which affected the guidance. This further complicated the process of organising and matching the evidence appropriately: the guidance requiring evidence appraisal changed while the evidence was being compiled.

D. During the process of the review we also noted limitations in the electronic search methodology. The methodological filter screen was used following advice from the Effective Practice and Organisation of Care (EPOC) group of the Cochrane Collaboration. This was linked, as the protocol shows, with terms relevant to palliative and supportive care. However, it seems that this methodological filter screened out some relevant studies, including relevant randomised controlled trials that were then identified by the Editorial Board and the evidence review team. This aspect of the methodology of effective systematic literature reviewing requires further exploration in the future. Because of the time constraints of these reviews it has not been possible to undertake hand searching in the large number of areas that needed to be covered. We propose that future research should develop and test robust methods of conducting systematic reviews in this field, to aid future reviewers. Our findings to date could inform this work.

E. Many of the interventions, particularly new services or changes in organisation, are complex. They comprise multiple components, which are difficult to separate. Often services are structured in different ways. However, the theoretical research basis and details of the structure and process of the interventions are sometimes not well described, particularly of services. This is a widely acknowledged problem in all areas of health services research, partly because funding for service modelling and description is not well supported, and partly because journals will not publish this information. Ideally, we would like to go back to some of the studies and explore whether the outcomes from different subcategories of intervention can be compared, but this has not been possible within the time constraints of this review. Within each topic area, the types of intervention tested often varied considerably between studies. We recommend future investment in research to compare the effects of some of these different models or interventions so far considered only against controls.

Results of searches:

A total of 5263 were identified by the electronic search strategies. After abstract assessment, 443 potentially eligible studies were identified. This was augmented by studies identified by the editorial board and an earlier meeting to generate proposals for supportive and palliative care held in Tewkesbury. After further assessment of the papers, the data of 302 studies were extracted and reviewed. There was considerable overlap, 18 studies were relevant for more than one topic area.

The search engine for CCTR is very limited and is a particular problem with supportive care because the terms are quite exhaustive. The information specialist at EPOC has only searched the register using palliative care search terms. The same problem as with CCTR arises.

Duplicate studies were identified and removed (as far as possible) in the order of MEDLINE, EMBASE, CINAHL, CCTR, CDSR, EPOC.

The results of the research evidence are presented according to the topic areas as in the guidance manual on supportive and palliative care for cancer patients.

3. CO-ORDINATION OF CARE

Nature of the evidence

We have extracted the data into tables from eleven individual studies that implemented interventions to improve the co-ordination of services. These studies are all good quality grade I evaluations (five grade Ia and five grade Ib), except one IIIc study[1]. Four studies were carried out in the UK, one in Scotland, two in North America, one in Canada, two in Norway and one in the Netherlands.

Types of interventions

With the exception of one trial, all the studies in the area of the co-ordination and integration of care experimented with organisational changes in the usual available care[2-8]. Finlay et al. 1998[9] was an educational intervention for medical students which was designed to stimulate active learning by placing the student in a one-to-one relationship with a patient with cancer undergoing active therapy or palliative care. An educational programme was offered as a part of the intervention to the community professionals in Jordhoy et al. [6].

Three of the studies focused on home care. Jordhoy et al.[6] implemented a palliative care intervention providing services to enable patients to spend more time at home and die there if they preferred. Zimmer et al[8] evaluated a new home care approach for homebound patients, including a cost-effectiveness component to the intervention. Smeenk et al[4] investigated the effects of transmural home care which provided a hospital back up for community health care. Two of the studies focused on the co-ordination of different existing services. Addington-Hall et al.[2] assessed the effects of the co-ordination of services available within the National Health Service, from local authorities and from the voluntary sector. Raftery et al[5] assessed the cost-effectiveness of this co-ordination service. Latimer et al[7] used the Patient Care Travelling Record to attune the different services that a palliative patient with complex life-threatening illness usually needs. The interventions were compared with the available standard care.

Different types of intervention were evaluated to realise the co-ordination of services. In the studies by Addington-Hall et al[2] and Smeenk et al.[4] a nurse co-ordinator provided the link between services, a community-based and a specialist nurse co-ordinator respectively. Jordhoy et al[3;6] and Zimmer et al.[8] experimented with teams with different compositions. Jordhoy et al.[3;6] established close co-operation between the community health care professionals who acted as the principal formal caregivers and a multidisciplinary consultant team that co-ordinated the care. Zimmer et al.[8] experimented with a palliative care team consisting of a physician, a nurse practitioner and a social worker delivering primary health care in the patient's home. These nurse co-ordinators or teams were combined with several other measures to link services. Additional mechanisms included the provision of a 24-hour telephone service[4;8], the use of a collaborative home dossier, protocols for specific care[4], and predefined guidelines to keep the interaction between services optimal[3;6].

Several interventions were meant to test packages that document and pool the care the patient received previously from different services, such as the shared-care record[1] containing appointments, a diary of significant events, medications, carers' addresses and contact numbers[1]. Latimer et al.[7] experimented with the Patient Care Travelling Record (PCTR) which is a passport-like health care summary meant to convey important clinical information in a complex health care system in which patients move between home, hospital, emergency room, and outpatient clinic, and see a number of different health care professionals. A patient-held record was evaluated in the management of patients with advanced cancer and palliative care needs in Cornbleet et al.[10]. Sarna[11]tested the efficacy of a structured symptom assessment protocol in patients with advanced lung cancer.

The interventions were mostly directed towards patients who were terminally ill[3;6;7;10;11]. Smeenk et al.[4] focused on the direct caregivers of palliative patients and Addington-Hall et al.[2] looked at the effect of the intervention on both patient and family. Finlay et al.[9] targeted medical students to improve their future practice and attitude towards patients with cancer.

Outcome measures

The studies of the home care interventions reported different results. Jordhoy et al.[6] reported that the palliative care intervention enabled more patients to die at home. However, they concluded that more resources for care in the home –palliative care training and staff– and an increased focus on the use of nursing homes would be necessary to increase time at home and reduce hospital admissions. In the same study, no significant differences on any of the quality of life scores were found. The authors suggest that for the programme to be effective and to achieve improvements of the various dimensions of quality of life on a group level, interventions directed toward specific symptoms or problems may have to be defined, evaluated, and included in the programme. Zimmer et al.[8] reported fewer hospitalisations, nursing admissions, and outpatient visits than in the controls. The patients were often able to die at home, if this was their wish. This study found that home care could be both cost-effective and desirable for those who prefer it. With the transmural care intervention programme, Smeenk et al.[4] achieved positive effects on the quality of life of direct caregivers of terminal cancer patients, both one week after discharge and three months after death. This finding can be explained by the enhanced co-ordination and co-operation between professional care givers working in intramural and extramural care, leading to improved supportive care for these patients and their direct caregivers.

Addington-Hall et al.[2] found few differences in symptoms and symptom control, service provision and satisfaction, and psychological or social support between groups. They conclude that co-ordinating services is not useful. Raftery et al.[5] demonstrated the limited cost-effectiveness of the service with some transfer of costs between settings.

The results in Sarna et al.[11] showed that systematic use of structured symptom assessment forestalled increased symptom distress over time. Chemotherapy lessened symptom distress, but the impact diminished with time. Subjects with more depression and greater functional limitations had greater symptom distress.

Interventions which experimented with packages that document and pool the care the patient received previously, such as the shared-care record[1]; patient could contribute to the co-ordination of care provided by different services. Latimer et al.[7] found that the PCTR is effective in enhancing certainty which is of great value to people who are seriously ill and dying. The PCTR appeared to be more effective for younger adults who may be more receptive to the model of health care represented by the PCTR, i.e. the sharing of information and decision making and participation in care delivery. However, the study undertaken by Cornbleet et al.[10], which evaluated the introduction of a patient-held record provided no evidence on which to base the widespread promotion of patient-held records, although local projects with committed clinicians and patients may well prove popular and effective.

The educational programme, which placed the medical student in a one-to-one relationship with a patient with cancer, was beneficial to the student’s personal experience with the disease. By following an individual patient, students observed the natural history of cancer and could evaluate the outcome of different interventions[9].

Implications of the evidence for recommendations

The evidence shows that the good co-ordination of services opens up the possibility of home care for patients at the end of life. Enhanced co-ordination and co-operation between organisations enables them to complement each other and provide better quality services. In home care, which is often the patient’s wish, the informal caretaker is a crucial part of the health care team. The needs and education of the informal caregiver are important areas to take into account. Lack of emotional support or the inability to adequately alleviate symptoms in certain circumstances can lead eventually to the patient’s re-admittance to the hospital in their terminal phase[4]. Zimmer et al.[8] showed that patient and caretaker satisfaction are directly related to health care utilisation and cost reduction. However, this service was a multiprofessional palliative care team. It may be that the effect on satisfaction was related to several components, not just that of co-ordination, although co-ordination may have been an important component. Optimal co-ordination, and communication between the various professional caregivers provides better supportive care at home for patients for whom this is the preferred option, and for their immediate caregivers.

The evidence also suggests that active learning for medical students, involving direct one-to-one access to patients, has an important influence on their knowledge, skills and attitudes. This is a way to provide health professionals, early in their careers, with an understanding of both the impact of the disease and its treatment on patients and their families, and the natural history of malignant disease.

Tables of Evidence: Co-ordination of Care

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Addington-Hall et al. 1992[2] & Raftery et al. [5] UK Ib	To measure the effects of terminally ill cancer patients and their families of co-ordinating the services available within the National Health Service, from local authorities and from the voluntary sector. To compare cost effectiveness of a co-ordination service with standard services, for terminally ill cancer patients, with a prognosis of < 1 year.	A total of 203 cancer patients expected to live less than one year and who had at least one follow-up interview: I=54% female, 82% 65 years or older, 46% married. C=54% female, 76% 65 years or older, 56% married. 118 carers: Carers characteristics did not differ significantly between groups.	*Design* –RCT, stratified random sampling of patients attending a district hospital or oncology, radiotherapy, general surgery, or urology outpatient clinics. Interviewers blind. *Intervention* – I=104 received routine services plus community based nurse co-ordinators who provided a link between services. C=99 patients received routinely available services. Follow-up at intervals of between two weeks and six months, until death; plus carers at same time and eight weeks post-bereavement.	• Symptoms and control ADL. • Shortened Family Apgar Scale. • Satisfaction. • HADS. • Spitzer QoL Index. • Service use. • Sources of income. • Carers experience and satisfaction. • Leeds depression and anxiety scale for carers. Cost effectiveness of service.	Intervention group improvements in: Fewer days spent in hospital (particularly acute) or hospice. Fewer home visits. Less likely to feel angry when they thought of the patient's death. No difference in: Satisfaction with services. Mean number of inpatient days in specialist cancer hospital. The proportion having unmet needs for help or aids and appliances at home. The numbers receiving advice on benefit entitlements or savings.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Cornbleet et al. 2002[10] Ia Scotland	To evaluate prospectively the introduction of a patient-held record (PHR) in the management of patients with advanced cancer and palliative care needs.	A total of 244 patients with advanced cancer were recruited. 80 patients with the PHR and 97 without were interviewed. Patients from an oncology outpatient clinic in a cancer centre in Glasgow or Edinburgh, or who received home-care or day care services from one of six hospice/specialist palliative care services.	*Design* – A prospective parallel group RCT. *Intervention* –The Newcastle Record. The record was designed as loose-leaf, soft covered booklet that would roll up to fit into pocket or handbag. It contained separate sections for personal details, 'what I have been told', personal diary, shared care notes, blood test results, useful telephone numbers and special treatments.	The subjective views of patient satisfaction with communication and perception of communication between patient and health-care professionals, as determined by structured interview at baseline and 4-6 months. A postal opinion survey of 83 health professionals known to have received the PHR 14 months after the PHR was first introduced and received 63 replies.	No improvement in the provision of information to patients, or in the satisfaction of patients with information provided by out-patient doctors, primary care teams or hospice staff. Overall, patients' perception of communication between all staff involved in their care with and without PHR was excellent in 24% and 21% respectively, or very good in 56% and 58% (p=0.89). The patient-held record made no difference to information passing between health professionals, or to the degree of family involvement. However, most of those who had a record found it of some use and benefit.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Drury et al. 1996[1] UK IIIc	To assess the acceptability of patients with cancer holding their own shared-care record	34 patients with progressive cancer and a prognosis of three months or more. 38% female; mean age 65; *Types of cancers:* not reported	Observational study of out-patients recruited over 13 week period in 1992 from a hospice and three general practices. All patients were given a shared care record detailing appointments, medication, carers' addresses and contact telephone numbers, the contact address of support organisations, and a diary of significant events to be completed by patients and carers. Two patient interviews were carried out after entry, at 4-6 weeks and 10-12 weeks; carers were interviewed at 10-12 weeks	In-depth, semi-structured interviews, developed by the working group	*Record use and value:* After 4-6 weeks 41% patients were writing in it, 65% were reading it and 76% took it to appointments (after 10-12 weeks: 37%, 67% and 80%, respectively) Professional carers use was similar after 10 to 12 weeks. Community nurses used it the least frequently. Patients found the diary pages, medication pages, page of contact addresses for carers and appointments page helpful. After 10-12 weeks the majority of patients, professionals and relatives found the record helped them a lot.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Finlay et al. 1998[9] UK Ib	To assess the effect of portfolio learning in the teaching of oncology to medical students.	A total of 195 students were randomly allocated into the study group (n=80), and the control group (79).	*Design* –RCT *Intervention* – I= Following a patient with cancer for 9 months, supported by bi-monthly small-group tutorials, plus continuing the standard curriculum. C= continuing the standard curriculum. *Data*– I= Students recorded triggers to learning and key items in a personal learning portfolio. Tutors were either general practitioners or hospital consultants.	• Analysis of the students' performance in clinical examinations during the course. • Portfolios were assessed at the end of the first clinical year using a standard mark sheet. • Final assessment was by hidden questions in the final degree examination in the form of 3 stations in the Pharmacology and Therapeutics objective structured clinical examination.	Intervention group improvements in: Students in the study group showed higher marks in factual knowledge of oncology, particularly amongst the weaker students (P=0.01). Those submitting portfolio's for formative assessment had higher overall marks than those in the study group who did not (P=0.04), representing the more motivated students. The whole study group showed a beneficial trend in their knowledge of oncology.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Jordhoy et al. 2000[6] Norway Ia	To assess the effectiveness of an intervention programme that aims to enable patients to spend more time at home and die there if they prefer.	A total number of 434 patients who had incurable malignant disease and an expected survival of 2-9 months. I=235 patients. C=199 patients. In the clusters, the intervention and control groups consisted of 134 and 116, 77 and 65, and 24 and 18 patients, respectively, with the smallest number of patients in the rural pair.	*Design* – A cluster RCT. *Intervention* – 1. All inpatient and outpatient hospital services were provided at the Palliative Medicine Unit unless care elsewhere was required for medical reasons. 2. To strengthen Cupertino with the community service, the team at the Palliative Medicine Unit served as a link to the community. 3. Third, predefined guidelines were used to keep the interaction at an optimum between services. *4.* The community professionals were offered an educational programme.	Main outcomes: • Place of death (home or in hospital). • Days spent as an inpatient in the last month of life.	395 patients died. Of these, more intervention patients than controls died at home (54 [25%] vs 26 [15%], p<0.05). The time spent at home was not significantly increased, although intervention patients spent a smaller proportion of time in nursing homes in the last month of life than did controls (7.2 vs 14.6%, p<0.05). Hospital use was similar in the two groups.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Jordhoy et al. 2001[3] Norway Ia	To assess the impact of comprehensive palliative care on patients' quality of life. The intervention was based on co-operation between a palliative medicine unit and the community service and was compared with conventional care.	A total number of 434 patients who had incurable malignant disease and an expected survival of 2-9 months. I=235 patients. C=199 patients. In the clusters, the intervention and control groups consisted of 134 and 116, 77 and 65, and 24 and 18 patients, respectively, with the smallest number of patients in the rural pair.	*Design* – A cluster RCT. *Intervention* – 1. All inpatient and outpatient hospital services were provided at the Palliative Medicine Unit unless care elsewhere was required for medical reasons. 2. To strengthen co-operation with the community service, the team at the Palliative Medicine Unit served as a link to the community. *3.* Predefined guidelines were used to keep the interaction at an optimum between services. *4.* The community professionals were offered an educational programme.	Main quality of life end points: Physical and emotional functioning, pain, and psychological distress. This was assessed monthly by using the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire-30 (EORTC QLQ-C30) questionnaire and Impact of Event Scale (IES).	No significant differences on any of the quality of life scores were found. At later assessments and for scores that were made within 3 months before death, there was also no consistent tendency in favour of any treatment group on the main outcomes or other EORTC QLQ-C30 scales/items.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Latimer et al. 1998[7] Canada Ia	To determine the effectiveness and efficiency of the Patient Care Travelling Record (PCTR) in improving patient mood, decreasing uncertainty, improving satisfaction with health care, reducing use of health-care services, and maximising pain control.	A total of 21 palliative patients. I=12 patients, C=9 patients at 1-2 month follow-up. High dropout rate: • Due to the seriousness of the illness, resulting in death (N=18). • Feeling too overwhelmed (N=7). • Some dropped out before baseline data were collected.	*Design* – RCT. *Intervention –* I=Received PCTR. C=Did not receive PCTR. Patients completed questionnaires at baseline and at 1 and 2 months. *Data–* The PCTR is a tool to convey important clinical information about the palliative care patient. It is a six-sided document that provides the names of health care team members involved in ongoing care, patient's next of kin and contact person, power of attorney for personal care, most responsible physician and pharmacy, patient's diagnosis, health care problems, hospital admissions, and medications being taken. It includes the patient's and family's understanding of the illness and care plans, and a chart of suggested therapies for symptom control.	At baseline: Measures of sociodemographic variables, pain control, mood, certainty of illness, health care and social service utilisation, and satisfaction with care. A pain severity scale developed by the Hamilton Civic Hospitals Pain Study Group. The Mishel Uncertainty of Illness Scale (MUIS). Profile of Mood States (POMS). Inventory to measure health service utilisation, developed by Browne et al. (1990).	Intervention group improvements in: Uncertainty was reduced by 0.32 (11%). There was no change in the control group [P=0.09 9two tail) or P=0.045 (one tail)]. The PCTR was not as effective in reducing uncertainty in the elderly as it was in persons under 65 years (F=5.98, P=026). There was no additional use of health care services, no differences in mood states, pain relief, or satisfaction with health care.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Sarna et al. 1998[11] Ia USA	To test the efficacy of structured symptom assessment on level and rate of change in symptom distress over time.	A total of 48 patients newly diagnosed with advanced lung cancer, predominately non-small cell. Most patients received chemotherapy, 50% were women. Average age: 62. 190 observations were analysed.	*Design* – A prospective 6 month RCT. *Intervention* – structured assessment C: usual care, using routine assessment to identify problems.	Symptom distress was measured by: • Symptom Distress Scale(SDS) • Hospital Anxiety and Depression Scale (HADS) Physical functional status: • Karnofsky Performance Status (KPS) • Physical functioning Scale (PFS) Demographic questionnaire.	Fatigue was the most common severely distressing symptom. In a multivariate model, chemotherapy and systematic assessment were associated with less symptom distress over time. Higher scores in depression and more functional limitations were related to higher levels of overall distress. Weight loss had a small impact.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Siegel et al. 1992[12] USA Ia	To assess and subsequently reduce the prevalence of unmet needs for concrete services of patients with cancer.	Outpatients with advanced cancer who were receiving chemotherapy. Stage 1 involved 200 outpatients. The stage 2 evaluation used an independent sample of a total number of 109 patients.	*Design* –A two-stage study with RCT. Stage 1: cross-sectional survey. Stage 2: the intervention of an automated telephone outreach system coupled with timely social worker assistance, aimed at reducing the prevalence of unmet needs. Subsequent stage 2: The experimental trial, consisting of three automated surveys to evaluate the efficacy of the intervention.	• Comparability of the control and experimental groups. • Patient-reported needs.	Patients in the experimental group who received three automated surveys reported fewer unmet needs in the subsequent assessment than those in the control group. In each of the surveys, the three most frequently reported unmet needs were: 10understanding or paying medical bills, 2) the cost of transportation to the hospital, 3) heavy housekeeping.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Smeenk et al. 1998[4] Holland Ib	To investigate the effects of a transmural home care intervention program for terminal cancer patients on the direct caregivers' quality of life, compared with standard care programs.	A total of 45 direct caregivers of patients having a diagnosis of cancer; having an estimated prognosis of less than 6 months; who are at least 18 years, who are fully informed of the diagnosis; and are admitted to the hospital's multidisciplinary oncology unit.	*Design* – A quasi-RCT. *Intervention* –The transmural home care intervention program consisted of four main elements: a. A specialist nurse co-ordinator, who is the key person. b. A 24-hour telephone service in the hospital with access to a transmural home team, c. A collaborative home care dossier (case file), d. Protocols designed for specific care.	Primary Outcome Measures: Daily functioning by the Sickness Impact Profile. Fear by the State Trait Anxiety Inventory. Loneliness. General well being. Quality of Life of the direct caregivers was measured one week before (T1), 1 week after (T2), and 4 weeks (T3) after the patient's discharge from the hospital, as well as 3 months after the patient had died (T4).	Multiple regression analyses showed that the intervention contributed significantly positively to the direct caregivers' Overall Quality of Life Index at T2 (β= .30; p $\leq$.05) and T4 (β=.28; p $\leq$ .05), compared with standard care.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Zimmer et al. 1985[8] USA Ib	To evaluate a new team approach to home care for homebound chronically or terminally ill elderly.	A total of 146 patients. Eligibility criteria: Patient being home-bound, wishing to remain at home, having significant illness (not primarily psychiatric) requiring medical care, not having a physician who would make home visits, living within the county, having a family member ore friend ("caretaker") who could assist in their care at home, and being willing to participate in a research study.	*Design* – RCT. *Intervention* – The team includes a physician, nurse practitioner, and social worker delivering primary health care in the patient's home, including physician house calls. Weekly team conferences assure co-ordination of patient care. The team is available for emergency consultation through a 24-hour telephone service. The team physician attends to the patient during necessary hospitalisations.	Initial Baseline Questionnaire. Health Service Utilisation Diary. The Sickness Impact Profile (SIP). Philadelphia Geriatric Centre (PGC) Morale Scale. Patient and Caretaker Satisfaction Questionnaire. Death (date and place).	The team patients had fewer hospitalisations, nursing admissions, and outpatient visits than controls. They were often able to die at home, if this was their wish. As expected they used more in-home services, measured in weighted cost figures; their overall cost was lower than their controls, but the difference was not statistically significant. Their functional abilities did not change differently from the controls, but they, and especially their informal caretakers expressed significantly higher satisfaction with care.

4. USER INVOLVEMENT IN PLANNING, DELIVERING AND EVALUATING SERVICES

The nature of the evidence

There are two systematic reviews on user involvement in health care[13;14], both carried out in the UK. We found four grade I studies (one grade Ia and two Ib)[15]. The other papers are grade III (one grade IIIa and five grade IIIc). Among the grade III papers there were two unpublished reports and one editorial. Eight studies were carried out in the UK, two in Australia, one in Canada, and two in the USA.

Types of interventions

Recently a systematic review by Crawford et al.[13]examined the effects of involving patients in the planning and development of health care. Papers for possible inclusion were identified by combining searches of electronic databases, hand searches of reference lists of papers, contact with experts in the field and patients belonging to the national Patients Forum, and a purposive hand search of grey literature. Another systematic review aimed to identify evidence from comparative studies on the effects of involving users in the delivery and evaluation of mental health services[14]. Five RCTs and seven other comparative studies were included.

Two studies focused on training for consumers of health care. A study evaluated an advocacy training programme for breast cancer consumers in Australia[16], as it was by no means clear that skills in consumer advocacy can be learned and effectively applied after a short course. The study by Brotchie & Wann[17] was undertaken to find out about the needs of lay people involved in health and whether training meets their needs. Its findings relied on a questionnaire specifically constructed for this purpose, on interviews and on a review of recently published literature referring to lay involvement in health.

We identified four studies which were concerned with the promotion of consumer involvement in decisions about individual health care. Entwistle et al.[18] focused on information-giving. The paper explored the question of what constitutes quality, given that there is as yet no gold standard for assessing the quality of information intended to support consumer involvement in health care decision making. The paper was concerned with information for consumers about health care interventions and how they compare.

Two randomised controlled trials experimented with methods to encourage patients to take an active role in medical decision making. One trial, Street et al.[19], aimed to find out whether the effectiveness of patient education is influenced by its format of delivery. They tested two methods for preconsultation education: a brochure and an interactive multimedia programme. Similarly, Brown et al.[20] investigated two means of promoting cancer patient question asking, comparing the provision of a question prompt sheet to patients prior to the consultation with their oncologist, with the active endorsement and systematic review of the question prompt sheet by their oncologist against a control condition.

Grunfeld et al[21] evaluated two methods of health service delivery: routine follow-up of breast cancer patients in specialist clinics or by their own GP. These two methods showed no important difference in primary clinical outcomes, so patient satisfaction became more important as an outcome to evaluate the two services.

There was one randomised controlled trial evaluating different methods of providing support for women with gynaecologic cancer[15]. This study compared the long-term benefits of a thematic counselling model used both as a structure for group support and for counselling patients individually. An exploratory pilot study was found which evaluated the current role of cancer support groups and identified strategies which would improve communication between these groups and the staff of the regional and district general hospitals[22]. A report was written documenting the development of an Advocacy Project by the Liverpool Cancer Support Centre[23], and a questionnaire evaluated its activities. One paper[24]provided a description of and commentary on the important historical trend of the growth of a patient/survivor movement in Canada.

We found an editorial on the rights of patients in research settings which started out by critically looking back at past malpractice relating to participants in certain trials. The editorial argued that greater lay involvement in health research would help to promote reliable, relevant research of importance to patients and those caring for them.

Outcome measures

The systematic review undertaken by Crawford et al.[13]provided evidence to support the notion that involving patients has contributed to changes in the provision of services across a range of different settings, but the effects of this process on the quality and effectiveness of services is unknown. However, this absence of evidence should not be mistaken for an absence of effect. Simpson et al.[14] examined the few comparative studies of users' involvement that have been published and concluded that involving users as employees, trainers, or researchers has no negative effect on services and may be of benefit.

Findings from the Davis & Redman[16] study showed a significant increase in participants' involvement in boards or committees, clinical trials recruitment issues, patient resources and breast cancer advocacy groups after completing the training programme. However, no change was found in other key advocacy areas, such as, lobbying for change, serving on research review or ethics committees, serving on government advisory committees, involvement in breast cancer awareness, development of new strategies for current breast cancer groups/programmes, writing letters to newspapers, or involvement in key breast cancer organisations. One possible reason for the lack of change in many key advocacy areas may have to do with the recent introduction of the advocacy movement in Australia. The areas of significant change may reflect those areas which were easier and more accessible for consumers. Results also highlighted that participants were still having difficulty in knowing where to look for advocacy opportunities or how to approach organisations in which they wanted to be involved even after the training programme. Future training programmes may be more effective if various levels of courses are offered for beginning and more experienced advocates.

The main finding from the report which focused on training for lay people was that training should take place in multidisciplinary committees and teams, through joint training of professionals and lay representatives, which would eventually lead to closer collaboration between the groups and through team building[17].

Entwistle et al.[18] concluded that quality of information for consumers is highly dependent on theoretical perspectives adopted and practical contexts in which it will be given. Existing checklists appear to be derived from a variety of unstated perspectives and there are some discrepancies between their criteria.

Street et al.[19] investigating whether the effectiveness of preconsultation is influenced by its format of delivery came to different conclusions. First, although some patients (specifically those younger than 65 years and college educated) were more expressive in discussing treatment, patients generally were more involved in these consultations when their physicians encouraged and facilitated patient participation. Second, providing preconsultation education about treatment options appeared to be an effective strategy for increasing patient understanding of treatment issues prior to their visits with physicians. Third, although patient involvement was not affected by method of education, patients tended to learn more about breast cancer treatment after using a multimedia programme than after reading a brochure. Finally, patients who were more knowledgeable about treatment options were also more optimistic about the future. Brown et al.[20] found that the provision of a question prompt sheet prolonged consultations and increased patient anxiety; however when oncologists specifically addressed the prompt sheet, anxiety levels were significantly reduced, consultation duration was decreased and recall was significantly improved. The authors concluded that a patient question prompt sheet, used proactively by the doctor, is a powerful addition to the oncology consultation.

The results which were obtained in Grunfeld et al.[21] showed that patients were more satisfied with follow-up in general practice than in hospital outpatient departments. The matter of patient preferences must be considered. When discussing follow-up with breast cancer patients, they should be provided with complete and accurate information about the goals, expectations, and limitations of the follow-up programme so that they can make an informed choice. This is consistent with findings that patients want more information, would like to be involved in the decision making process, and experience better psychosocial adjustment if good communication is a part of their cancer care.

The data from the randomised controlled trial Cain et al[15] conducted confirmed the thematic counselling model to be equally helpful whether it was used as a structure for individual counselling or more cost-effective group counselling. They added that this model is easily adaptable to the needs of persons with other forms of cancer. The results of the study by Bradburn et al.[22] indicated that local support groups were a considerable resource for cancer patients in the catchment area, offering mutual support together with a wide range of other services which were not provided elsewhere. Hospital staff were not well informed about support groups and were inclined to be cautious in referring patients to these groups. There was a need to improve communication between hospitals and groups in the area in order that patients, their families and staff were made more aware of the support available to them. There was also a need for hospital staff to face the challenge presented to them by this form of non-professional care.

The Advocacy Project showed regular high attendance of the meetings and positive feedback from participants, health professionals and the Health Authority[23] .

Gray's paper on the development of a patient/survivor movement in Canada argued for the value of increased patient participation to provide a needed balance to the traditional medical perspective, to address patients needs free from other vested interests, to provide insights available only to cancer survivors and to facilitate empowerment. The move beyond token patient representation was found to be the greatest challenge to substantive participation.

The editorial on the rights of patients in research[25] developed guidelines which can be summarised as: patients should (a) help to set the research agenda, and advise on the outcomes to be studied, (b) be involved by commenting on the design of the study, thereby possibly reducing the prevalence of unnecessary research, (c) assess the quality of consent as they are in a much better position than researchers to do this, (d) help with publicity to encourage recruitment, (e) insist on publication of research and (f) counter the tendency of research results not being put into practice.

Implications of the evidence for recommendations

The systematic reviews identified for this topic area[13;14] provided evidence that user involvement in health care did bring about changes in the provision of services. Simpson et al.[14] added to this conclusion that these changes did not have a negative effect on services and may even be of benefit. More research is needed that focuses on how the quality and effectiveness of services are affected by users' participation. One of the important findings in Crawford et al.[13] was that the involvement of patients had led to a change in the culture of organisations that made them more open to involving patients.

Two grade III studies supported the recommendations made regarding training and education for users who wish to be involved in health care[16;17]. The findings in Brotchie & Wann[17] on users' needs in relation to training concur with the needs mentioned in the recommendations. Currently most lay people obtain their training 'on the job', which shows that training programmes should be developed particularly attuned to lay people's needs and experience[16;17]. Training appeared to be most effective when it was provided together with information and support and jointly with medical professionals as this offers opportunities for closer collaboration between the groups. As yet we have not found studies that evaluate training programmes for health professionals.

The evidence on consumers' participation in decision making about individual health care is disproportionately represented in the recommendations and this issue deserves to be considered as a more important area of patient participation.

Grunfeld et al.[21] addressed the issue of patient relevant outcomes which can have important consequences for policy and practice. When the evaluation of two methods of health service delivery showed no difference in primary clinical outcomes, patient satisfaction was measured. This is the lowest level of patient involvement but it can have important consequences.

Tables of Evidence: User Involvement in planning, delivering and evaluating services

Systematic Reviews

Author, country	Aims of the review	Inclusion criteria	Exclusion criteria	Outcome measures	Results
Crawford et al. 2002[13] UK	To examine the effects of involving patients in the planning and development of health care.	Papers describing the involvement of patients, defined as "the active participation in the planning, monitoring, and development of health services of patients, patient representatives, and wider public as potential patients."	Papers describing patient involvement in other activities such as research, community development, health promotion, self management and self help and the role of doctors and patients in determining individual treatment choices. Papers that described the measurement of patient satisfaction or patient preferences without describing how this information was used to help development of the service.	The overall impact of the involvement of patients has been made by conducting surveys of participants and retrospectively examining records of meetings.	Effects on users involved: • Increased self-esteem. • Some describe dissatisfaction with the process. • Staff found the initiatives rewarding, but some report on difficult relationships. Changes to services: • New or improved information for patients. • Greater accessibility of services. • New services commissioned as a result of patients' requests. Other effects: • On organisational attitudes, i.e. staff more favourable and change in culture occurred. • The concern of the involvement of patients as legitimisation of decisions.

Author, country	Aims of the review	Inclusion criteria	Exclusion criteria	Outcome measures	Results
Simpson & House 2002[14] UK	To identify evidence from comparative studies on the effects of involving users in the delivery and evaluation of mental health services.	Evaluations of the impact of research on services if users had an active role in the design or in collecting data. Studies about users training mental health professionals. Studies about delivery involving users in partnership with others if services were integrated by health professionals and users working together.	Studies dealing with only: Learning disabilities. Decisions about a user's own treatment. Providing information to users. User satisfaction surveys researched by the provider. General health services. Forensic services Services not health related. Services operating outside the health system.	Five RCTs and seven other comparative studies.	Nature of involvement: Case managers (8 studies) Trainers (2 studies) Interviewers (2 studies) Effect of user involvement: The process of service delivery of employees who were or had been users differed from that of employees who had not. Employing users in, or alongside case management services did not have any detrimental effect on clients. Most of the studies identified involved few users and have substantial methodological weaknesses.

Individual studies

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Bradburn et al. 1992[22] UK IIIc	To evaluate the current role of cancer support groups and identify strategies which would improve communication.	Members and leaders of cancer support groups and consultant clinical oncologists and members of their team from 11 district general hospitals.	*Design*–Cross sectional study.	Profiles of groups. Links with hospitals and other agencies. These data were obtained by conducting a questionnaire, interviews, and participant observations during meetings.	There were 18 support groups, 13 provided general support and 5 were groups for specific cancer sites. The groups included cancer patients from all the stages in the cancer pathway. The groups varied in size and format, numbers could fluctuate widely. A wide range of services was provided by some groups to respond to the needs of patients, highlighting the gaps in services. Links with hospitals and primary care teams were poor. The exceptions were: 3 groups started by a GP, and one by a district nurse. Hospital staff were among the regular membership of five of the groups. Hospital staff were inclined to be cautious in giving information about local support groups to patients rather than making information freely available to all.

Author, country, grade	**Aims of the study**	**Patient population**	**Study design**	**Outcome measures**	**Results**
Brown et al. 2001[20] Australia Ia	To investigate two means of promoting cancer patient question asking.	A total of 318 patients with heterogeneous cancers, seeing one of 5 medical and 4 radiation oncologists for the first time.	*Design*– RCT *Intervention*– a) a question prompt sheet provided 15-20 minutes prior to the initial consultation with the oncologist (25%). b) active endorsement and systematic review of the question prompt sheet by the physician (25%). c) control group (50%)	Anxiety: Spielberger State Anxiety Scale. *Involvement and information preferences*: Cassileth Information Styles Questionnaire. *Satisfaction:* Scale adapted from Roter ('77) and Korsch ('68). *Recall:* Structured telephone interview. Consultations were audiotaped and content analysed. Anxiety was assessed immediately after the consultation. The questionnaires and the interview were completed within 10 days of the consultation.	Patients with a prompt sheet asked significantly more questions regarding prognosis than those without. Significant differences were detected in the consultation length as a result of the interventions. Relatively high unmet information needs were reported, especially on prognosis. The prompt sheet and pro-active doctor had a significant effect on patients' recall compared to the prompt sheet alone. The prompt sheet alone group was significantly more anxious than either patients with a prompt sheet and pro-active doctor or control group.

Author, country, grade	**Aims of the study**	**Patient population**	**Study design**	**Outcome measures**	**Results**
Cain et al. 1986[15] USA Ib	To report on a controlled randomised study of different methods of providing support for women with gynaecologic cancer.	A total of 80 women participated. They were selected from consecutive admissions to Yale-New Haven Medical Centre. Criteria: diagnosis of gynaecologic cancer; no previous cancer history; age between 18 and 75 years; no previous history of psychiatric problems. 15% of the women who met the criteria declined to participate.	Design– RCT Intervention–Three counselling modes were compared. I1: Thematic individual counselling. I2: Thematic group counselling. C: Standard counselling. Data–The thematic individual counselling comprised 8 weekly sessions. The social workers conducted them at the hospital or in the home. Thematic group counselling included 8 weekly sessions. 4-6b women participated in each session.	Psychosocial status was assessed before counselling, immediately after and again six months later. Instruments: The Hamilton Anxiety Scale. The Hamilton Depression Scale. PAIS Scale. Mood and social adjustment questionnaires.	The women who participated in thematic counselling were significantly less depressed and less anxious and had more knowledge of their illness, better relationships with caregivers, fewer sexual difficulties, and more participation in leisure activities.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Davis & Redman 2001[16] Australia IIIa	To assess the effectiveness of an advocacy training programme for breast cancer consumers in Australia.	A total of 51 women who attended a 3-day advocacy and science training programme in three different states across Australia. The majority of participants were breast cancer survivors. Most were either health professionals or other professionals.	*Design* – Pre- posttest design. Intervention–The women were trained by the consumer advocacy and science training programme. The three day course was to empower women to participate at all levels where breast cancer decisions are made. Data– The programme was developed to provide advocates with the skills to participate in a range of activities: research, decision making within government, the scientific community and industry, raising awareness, serving on committees, lobbying for changes in legislation, public speaking, writing for the media, networking.	The participants completed: (a) a pre questionnaire on their current involvement in breast cancer advocacy activities; (b) a follow-up questionnaire six months after training to assess changes in their advocacy activities.	Significant improvement in involvement in: Serving as a member of a board or committee, working on clinical trial recruitment issues, working on patient resources, and involvement in breast cancer advocacy groups. No change found in: Lobbying for change, serving on research review or ethics committees, serving on government advisory committees, involvement in awareness, development of new strategies for current breast cancer groups/programmes, writing letters to the editor of newspapers, or involvement in key breast cancer organisations.

Author, country, grade	**Aims of the study**	**Study design**	**Outcome measures**	**Results**
Entwistle et al. 1996[18] UK IIIc	To debate the quality of information to support consumer involvement, considering the theoretical perspectives which relate to the nature and purpose of consumer involvement in health care decision making, and the contexts in which information is used.	*Method*–The critical review of four quality checklists for people developing information for patients. The list produced by the NHS Executive. The list produced by Kings Fund Centre. The list produced by Patients Forum. The list produced by Hope.	Dimensions of quality: Relevance Accuracy Accessibility, comprehensibility and usability Acceptability Cost and resource implications.	Quality of information for consumers is highly dependent on the theoretical perspectives adopted and practical contexts in which it will be given. Existing checklists appear to be derived from a variety of unstated perspectives and there are some discrepancies between their criteria.

Author, country, grade	**Aims of the study**	**Patient population**	**Study design**	**Results**
Goodare & Smith 1995[25] UK Editorial	To reflect on how patients who participate in research can contribute to more patient-centred research.	Patients having participated in health research in the past.	*Method*–previous research experiences.	*Guidelines to patient contribution in research*: Patients should help set the research agenda. Patients should advice on the outcomes to be studied. Patients can comment on the design of the study. Patients are in a better position to assess the quality of consent. Patients can help with publicity to encourage recruitment. They can insist on the publication of research. They are able to counter problems of the results of research not being put into practice.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Grunfeld et al. 1999[21] UK Ib	To assess the effect on patient satisfaction of transferring primary responsibility for follow-up of women with breast cancer in remission from hospital outpatient clinics to general practice.	A total of 296 women with breast cancer in remission and receiving regular follow-up care at two district general hospitals in England.	*Design*– RCT Intervention– Patients received continued routine follow-up in outpatient clinics according to usual practice (hospital group), or routine follow-up from their own GP (general practice group).	An instrument measuring patient satisfaction developed by the College of Health in the UK. Patient satisfaction was assessed at three points in time during the three month study period: baseline, mid-trial, and at the end of the trial.	The general practice group selected responses indicating greater satisfaction than did the hospital group on virtually every question. In the general practice group there was a significant increase in satisfaction over baseline. A similar increase in satisfaction was not found in the hospital group.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Street et al. 1995[19] USA Ib	To examine factors affecting patient involvement in consultations to decide local treatment for early breast cancer and the effectiveness of two methods of preconsultation education aimed at increasing patient participation in these discussions.	Sixty patients with Stage I and Stage II breast cancer. *Brochure group: N=30* Mean age: 60.8 *Multimedia group:* N=30 Mean age:57.4 No significant differences between the multimedia or brochure group with respect to the patient's age, education, disease stage, or ethnicity.	*Design* –Randomised trial. *Intervention –* The patients were pretested on their knowledge about breast cancer treatment and optimism for the future. They were randomly assigned to one of two methods for preconsultation education: interactive multimedia program or brochure. They completed knowledge and optimism measures. They consulted with a medical oncologist, radiation oncologist, and general surgeon. They completed self-report measures assessing their involvement in the consultations and control over decision-making.	Patients: Assessment of breast cancer treatment with an 11-item, multiple choice test. Patients' optimism was assessed with an 8-item instrument developed by Scheier and Carver. Patient involvement was assessed by behavioural measures and perceptual measures. The latter was assessed with a scale derived from Lerman et al.'s Perceived Involvement in Care Scale (PICS). The patients' perceived control over the decision was measured with five items derived from England and Evan's Perceived Decision Control (PDC) instrument. *Physicians:* Behavioural measures: physician's use of patient-centred responses. Perceptual measures: Physician facilitation of patient involvement, with the five item doctor facilitation subscale of Lerman's et al.'s PICS measure.	College-educated patients younger than 65 years of age were more active participants in these consultations than were older, less educated patients. Patients showed more involvement when they interacted with physicians who encouraged and facilitated patient participation. The method of education did not affect patient involvement although patients tended to learn more about breast cancer treatment after using the multimedia program than after reading the brochure.

Reports

Author, country, grade	**Aims of the study**	**Patient population**	**Study design**	**Outcome measures**	**Results**
Brotchie & Wann 1993[17] UK IIIc	To find out about the needs of lay people involved in health and whether training meets their needs. To present arguments about the provision of training support and information. To explore what it involves being a lay member, and what they need to be effective.	Different groups of lay people involved in health (not a particular group of lay representatives such as members of research ethics committees).	*Design*–Observational study. *Intervention*–No new intervention was provided. The existing training possibilities were evaluated and other needs were identified.	Interviews (some in depth) about experiences, knowledge and opinions of the provision of training. A questionnaire constructed specifically for this purpose. 190 were completed. Review of the literature of recently published books, reports and articles referring to lay involvement in health.	Training is most effective when it is provided together with information and support. Training medical professionals and lay representatives jointly offers opportunities for closer collaboration between the groups. Networks and contacts are useful ways to provide support for lay people working in isolation. Most lay people obtain their training 'on the job'. Training should include: Communication skills training (plus community development and representation skills). Information on the NHS and the voluntary sector. The best way to train: In multidisciplinary committees and teams, through joint training and team building.

Author, country, grade	**Aims of the study**	**Patient population**	**Study design**	**Outcome measures**	**Results**
Keatley & Berry 2003[23] UK IIIc	To report on the development of an Advocacy Project and the resources and skills which are used to empower its members.	Patients with cancer or palliative care needs, carers and families, and groups from pre-diagnosis to post-bereavement.	*Method*–Questionnaires. 62 surveys sent out, 49 returned, approximately 78%. *Intervention*–A patient-centred advocacy service, including: 1. Advice and information. 2. Self Advocacy. 3.Crisis Support (single issue) 4.Crisis Support (short term). 5.Long term advocacy support. 6. Peer Advocacy. 7.Collective or group Advocacy. 8. Professional Advocacy.	1. Referral to Centre. 2. Participant status. 3. Kind of support sought. 4. Previous support sought. 5.Emotional state at first contact. 6. Kind of support taken up. 7. Period of contact with Centre. 8. Improvement of coping skills and needs met. 9. Usefulness of self-help support. 10. ideas for the development of resources	Focus group statistics: Group sessions: 48. Individual members: 40. Individual attendances: 528. Average number per week: 15. Lowest number: 8. Highest number: 19. 18 regular members. 22 new referrals specifically for the group. Due to the regular high attendance at group sessions, the possibility is considered of offering further groups, e.g. a separate group for carers, bereaved people, young families and men.

5. FACE-TO-FACE COMMUNICATION

Nature of the evidence

A grade Ia systematic review has been undertaken for the topic area of communication skills, including 21 randomised controlled trials and analytic studies. This systematic review comes from Canada[26]. Twenty-seven studies were identified and extracted into tables. Eleven were grade I (range a-c) randomised controlled trials. Of these five were carried out in the UK, three in the USA, one in Australia and two in Canada. We extracted the data of one critical review.

Types of interventions

The systematic review was undertaken to ascertain whether the quality of physician-patient communication makes a significant difference to patient health outcomes[26].

One prospective cohort study assessed satisfaction with medical care expressed as two scores, one of which measured satisfaction with communication and decision making[27].

Fourteen studies have undertaken interventions to improve communication with cancer patients through educational sessions. Two studies are grade I randomised controlled trials[28;29], one is grade IIa[30], three are grade IIb[30;31;31;32], two grade IIIa[33], and five grade IIIc[34-38].

The studies varied in content, design, length and outcomes. A combination of didactic and experiential methods, such as teaching, role play, feedback, group work and discussion, formed a major part of the interventions carried out by Maguire and Faulkner[35], Faulkner et al.[36], Maguire et al.[37;38], Klein[29], Fallowfield et al.[39]. Maguire and Faulkner[35] evaluated workshops in communication and counselling skills run jointly for doctors and nurses working in hospital and community settings. Maguire et al.[37;38] assessed the impact of communication skills workshops on interviewing skills of health professionals. Faulkner et al.[36] implemented an intervention to improve the communication skills of doctors when giving distressing information. Klein et al.[29] experimented with the use of real-life patients to teach medical students. Fallowfield et al.[39] aimed to change key communication skills of senior doctors by an intensive 3-day training course. There is also the study of Jenkins et al.[28], who focused on the psychosocial attitudes and beliefs of physicians and whether these would change after communication skills training.

Experiential methods were used where the emphasis was on participant’s feelings and attitudes. Anderson[32] adopted this approach in teaching medical students communication skills when dealing with terminally ill cancer patients. Students were encouraged to challenge their beliefs and opinions about giving bad news to a patient in a case study. This was achieved by group work with open discussion and modelling of the desired behaviour using a video with the case study acted out.

In the context of studies which have demonstrated that patient education before consultations can increase patient involvement in medical encounters, Street et al.[19] have undertaken a trial to find out whether the effectiveness of the education is influenced by its format of delivery. They experimented with two methods for preconsultation education: a brochure and an interactive multimedia program.

The study which Razavi et al.[40] undertook assessed the impact of differently emotion-loaded role-playing on interviewers' behaviours, as well as the impact of training workshops in communication skills on interviewers' behaviours in these three differently emotion-loaded role-playing.

Bucher's[33] intervention training was aimed at problem solving. It was provided to cancer patients and their families by a trained social worker.

Four studies examined the effects of training on clinical practice[31;34;39]. Heaven & Maguire[34] conducted assessments of hospice nurses' communication skills before and up to nine months after training. Wilkinson et al.[31] evaluated a programme aimed at nurses' performance of patient assessment. A subset of these nurses was a follow-up at one year post-training[30].

Two studies experimented with organisational interventions to facilitate communication between patients and health professionals[41;42]. Glimelius et al.[41] examined the effects of a care package in which communication played a central role. The intervention included written materials, interaction with medical personnel, staff meetings and education. Sepucha et al.[42] tested an intervention with researcher-mediated consultations. Lilly et al.[43] introduced a proactive, multidisciplinary method of communicating with critically ill patients and their families that identified the criteria that would determine whether a care plan was effective at meeting the goals of the patient. The other interventions focused on the provision of material to facilitate communication. Tierney et al.[44] used computers to remind primary care physicians to discuss advance directives with their elderly patients. A critical review of 9 studies was undertaken to examine whether taping consultations improves communication with patients[45]. Deutsch[46] and Hogbin et al.[47] carried out a study on the same topic, while Tattersall et al.[48] looked at the efficacy of providing a tape of the first consultation with an oncologist and compared this with other options. In the case of Bruera et al.[49], although improvement of communication was not the initial purpose of the intervention, which provided the patient with an audiotape of the consultation with the physician, communication was an important outcome. Three studies[50;51] experimented with routine telephone contact for patients to improve the adequacy of support.

The SUPPORT study[27] in the USA recruited family members and other surrogate respondents for seriously ill, hospitalised adults who died, to assess appropriately the need for communication in end-of-life care.

The interventions which implemented training targeted either the patient and the family[33], medical students[29;32], or health professionals[31;34-39] in order to improve communication skills. Maguire & Faulkner[35] also focused on both doctors and nurses. Wilkinson et al.[30] carried out an intervention aimed at nurses, while Heaven & Maguire's[34] intervention was aimed at hospice nurses. Maguire & Faulkner[35], Faulkner et al.[36], Maguire et al.[37;38], and Heaven & Maguire[34] and Jenkins et al.[28] and Razavi[40] worked with health professionals. Fallowfield et al.[39] focused on senior oncologists.

The interventions working with material were also directed toward patients as well as health professionals[44]. The telephone call interventions were provided for patients who were undergoing radiotherapy[50], patients during the potentially stressful period between completing radiotherapy and the first follow-up visit[51]. The provision of audiotapes were interventions targeting patients and the public[45], and breast cancer patients and their carers[46-48].

In the organisational interventions all those involved in the care of the cancer patient, as well as the patient himself were targeted[41;42].

The interventions were aimed at reducing communication impediments such as time constraints and physician language, and a lack of confidence on the part of the patient. These interventions were implemented to contribute to patients' autonomy and their active involvement in clinical decisions.

Outcome measures

Most of the studies reviewed in the systematic review demonstrated a correlation between effective physician-patient communication and improved patient health outcomes[26]. The outcomes affected were, in descending order of frequency, emotional health, symptom resolution, function, physiological measures (i.e. blood pressure and blood sugar level) and pain control. The components of effective communication identified by these studies can be used as the basis both for curriculum development in medical education and for patient education programs.

The SUPPORT study[27] showed the need for improvement in communication and decision making as an important part of satisfaction with end-of-life care.

The interventions that experimented with contact by telephone resulted in different outcomes. Hagopian & Rubinstein[50] and Munro et al.[51] found that no significant differences had been brought about by the intervention. However, based on these same data, they reach conflicting conclusions. According to Munro et al.[51] a routine policy of such intervention for all patients cannot, given the present limitations on resources, be justified. While Hagopian & Rubinstein[50] find that the telephone calls were clinically significant and provided a mechanism for demonstrating that the health care professionals cared about their patients and provided an opportunity to talk about their concerns.

The organisational interventions to facilitate communication between patients and health professionals were also demonstrated to be of benefit to patients' relatives and carers, as well as possibly contributing to the continuity of care[41;42]. The intensive communication intervention, which Lilly et al.[43] implemented allowed caregivers to be informed of patient preferences about continued advanced supportive technology when its continuation would result in a compromised functional outcome or death.

The review by McClement & Hack[45] found varying outcomes with respect to the effect of the provision of audiotapes on psychological distress, from a reduction in distress in three studies through no effect in two studies to negative outcomes for people with poor prognoses. Uncontrolled studies reported enhanced memory recall, but RCTs produced mixed results.

Generally audiotapes contributed to patient satisfaction. Deutsch et al.[46] evaluated the taping of consultations as positive based on a questionnaire on tape use and value of content. Tattersall et al.[48] showed that audiotapes were preferred above other options such as a phone call, a summary letter or a talk with an oncology nurse. However, audiotapes were found to be unsatisfactory for those wanting minimal news. Hogbin concludes that audiotapes remain one of the best means of communication with partners and extended family. From their study it became clear that patients often listen with their support groups both in the family and outside. The same finding came out of the intervention which Bruera et al.[49] implemented.

The studies focusing on training show that the interventions had positive effects on patients and families, and on physicians' outcomes although the results also include caveats. In Maguire & Faulkner[35] and Maguire et al.[37;38] the training method adopted improved health professionals' skills in effective interaction, and in Faulkner et al.[36] it helped to find the right strategies for giving distressing information. However, inhibitory behaviours, such as blocking patients' responses, were still present in three of the studies[36-38]. In two studies, follow-up evaluations at six months showed that inhibitory behaviours had reverted to pre-training levels[37;38]. An informal evaluation of the reasons why the initial achievements were not maintained showed that the participants were anxious about emotional situations. This suggests that participants' concerns need to be addressed for the interventions to be successful.

The assessments of hospice nurses' communication skills before and after nine months of training resulted in improvements in micro-skills. However, there was little change in the nurses' ability to elicit patients' concerns[34]. Wilkinson et al.[31], on the other hand, had positive outcomes for communication. The training showed better structured patient assessments, which covered a wider range of areas and improvements in the psychological aspects of the assessments. These gains were maintained at nine months. A longitudinal follow up of a sub-set of nurses at one year post-training showed that these gains were maintained. A possible explanation for the differences in findings could be that the training provided in Wilkinson et al.[31] was more comprehensive and included both micro- and macro-skills training. A large component of the training involved experiential learning over an extensive period of time. This enabled nurses to put their knowledge into practice and to obtain personal feedback. They were also encouraged to be critical towards their own performance. As such they could become more aware of the importance of communication in general.

Anderson et al.[32] reported positive outcomes for the experiential approach that they applied. Following the training session there was an increase in the numbers of students willing to take the responsibility of informing a patient about their diagnosis. The greatest changes were seen in those who initially stated they would not tell the patient they had cancer. The results of this study should be treated with caution, however, as evaluation was based on self-report, which may have biased the findings. The effects of the communication skills training in the other studies were increased confidence in taking informed decisions[33], and increased patient satisfaction with the assistance of physicians [29;44]. Medical students were more aware of the importance of good communication between doctors and patients and recognised that a relationship based on trust is essential to provide good care in accordance with patients' wishes[29]. Fallowfield et al.[39] provides objective evidence for the effectiveness of training courses for senior doctors working in the vital area of cancer medicine. Jenkins et al.[28] showed that a communication skills training intervention using behavioural, cognitive, and affective components not only increases potentially beneficial and more effective interviewing styles but can also alter attitudes and beliefs, thus increasing the likelihood that such skills will be used in the clinical setting. The successful transfer of communication skills to clinical practice was one of the difficulties that was emphasised by the results of studies reviewed by Libert et al.[52]. The other difficulty was the maintenance and consolidation of these communication skills.

Street et al.[19], investigating whether the effectiveness of preconsultation is influenced by its format of delivery came to different conclusions: first, although some patients (specifically those younger than 65 years and college educated) were more expressive in discussing treatment, patients generally were more involved in these consultations when their physicians encouraged and facilitated patient participation. Second, providing preconsultation education about treatment options appeared to be an effective strategy for increasing patient understanding of treatment issues prior to their visits with physicians. Third, although patient involvement was not affected by method of education, patients tended to learn more about breast cancer treatment after using a multimedia program than after reading a brochure. Finally, patients more knowledgeable about treatment options also were more optimistic about the future.

Razavi et al.[40] shows that different emotional contents in interviews with patients produce different communication behaviours. Different emotional contents of role-playing or *in-vivo* sessions certainly require different communication skills. The results of this study show that appropriate changes are only noticeable in highly emotional role-playing. This may be a result of the fact that HE-SRPS-induced behaviours are more sensitive to training effects than WE- and ME-SRPS-induced behaviours. The results of this study may underline the importance of creating and generating a full range of emotional tones during training workshops, in order to ensure the appropriate changes in the trainees.

Implications of the evidence for recommendations

The recommendations from the proposal generating group focus on communication skills training for professionals. There is grade Ia evidence which provides a successful example of the training for senior doctors. Grade Ia evidence also supports the positive effect of educational courses for health professionals, although additional training may be needed to preserve newly acquired skills.

There is also evidence ranging from grade Ic to IIIa and c that communication skills training for patients has a beneficial effect on patient outcomes, but more work is needed to find the best way of doing this.

Besides training, the provision of material to facilitate communication has been shown to improve the supportive and palliative care for patients (range: grade Ia to IIIc).

Tables of Evidence: Face-to-face Communication

Systematic Reviews

Author, country	Aims of the review	Inclusion criteria	Outcome measures	Results
Stewart 1995[26] Canada Ia	To ascertain whether the quality of physician-patient communication makes a significant difference to patient health outcomes.	Randomised controlled trials and analytic studies of physician-patient communication in which patient health was an outcome variable. Methods: The Medline database was searched for articles published from 1983 to 1993 using "physician-patient relations" as the primary medical subject heading. Several bibliographies and conference proceedings were also reviewed.	Of the 21 studies that met the final criteria for review, 16 reported positive results, 4 reported negative (i.e. nonsignificant) results, and 1 was inconclusive. The quality of communication both in the history-taking segment of the visit and during discussion of the management plan was found to influence patient health outcomes. The outcomes affected were, in descending order of frequency, emotional health, symptom resolution, function, physiological measures and pain control.	Most of the studies reviewed demonstrated a correlation between effective physician-patient communication and improved patient health outcomes.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures
Anderson JL 1982[32] Hong Kong IIIc	To evaluate a practical approach to teaching communication with terminally ill cancer patients	61 medical students undertaking a second year pre-clinical Behavioural Sciences Course	Pre/post comparison study; teaching formed part of their medical training. P*re-session:* given a case scenario of a terminally ill lung cancer patient and 3 questions relating to what, how and who should inform him of his diagnosis and prognosis; solutions documented *Practical session*: students encouraged to discuss their solutions in small groups and to reach an agreed solution; watched a video where the scenario was acted out where the doctor was shown as sympathetic and "patient-centred; discussion with course tutor and presentation of solutions. Students completed an evaluation sheet and these were compared against their original solutions.	*Pre-solutions:* • 84% would tell the patient they has cancer • 54% would tell the patient he was going to die • 77% stated that it was the doctor's responsibility to give the diagnosis and prognosis *Post-evaluation:* • 38% had a change of opinion on at least 1 of the 3 questions; those against telling the patient he had cancer were more likely to change their opinion. • 79% felt that they had learned from the practical session.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Baker et al. 2000[27] USA Ia	To examine factors associated with family satisfaction with end-of-life care in the study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT)	Family members and other surrogate respondents for 767 seriously ill hospitalised adults who died.	*Design* –RCT. Embedded within the RCT a prospective cohort study of all the enrolled patients. *Intervention* –The delivery of prognostic estimates for survival and functional status and reports of patient's pain and treatment preferences to attending physicians. The intervention was delivered by nurses specially trained to facilitate communication among medical staff, patients, and their surrogates regarding treatment preferences, advance planning, and pain.	Eight questionnaire items regarding satisfaction with the patient's medical care expressed as two scores, one measuring satisfaction with patient comfort and the other measuring satisfaction with communication and decision-making.	16% of respondents reported dissatisfaction with patient comfort and 30% reported dissatisfaction with communication and decision making. Factors significantly associated with satisfaction with communication and decision making: • hospital site • whether death occurred during the index hospitalisation (AOR 2.2,95% CI 1.3-3.9), • patients who died following discharge, • whether the patient received the intervention (AOR 2.0, 1.2-3.2)

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Bruera et al. 1999[49] Canada Ia	To assess the impact on patients' recall of and overall satisfaction with their consultation by the addition of an audiocassette recording of a consultation to written recommendations.	A total of 60 patients 36 males, 35 females)with advanced cancer. The mean (SD) age was 62 (10) years.	*Design* –RCT Prospective, randomised, double-blind trial. Randomisation by computer-generated code. *Intervention* –Patients receive a tape recording of a consultation to written recommendations.	• Patients gave their global ratings of the clinic. • They were tested for their recall of information given. • They responded to questions about the utilisation and role of the cassette in influencing family communication.	The addition of the audiocassette to written communications significantly increased patient satisfaction with the clinic (8.7 +/- 1.7 vs. 7.7 +/- 2.0 on a scale of 0-10; P=0.04) and significantly improved recall of the information given during the consultation (88% +/- 8.7% vs. 80% +/- 15.5%; P= 0.02). Patients expressed a high level of satisfaction with the audiocassette. Patients listened to the tape a median of 2 (range 1-4) times, family members and friends a median of 2 (range 1-3) times.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Bucher et al. 2001[33] USA IIIa	A program evaluation was conducted to explore the potential effects of a 90 minute problem-solving education session for persons with advanced cancer and their families.	A total of 89 participants who were visiting a tertiary-care outpatient setting, 49 caregivers and 40 patients were selected using a convenience sampling method. *Eligibility criteria:* patients in advanced stages of disease, >19 years, English speaking and able to identify a primary family caregiver.	*Design* – CBA. Non-randomised intervention in an observational study. *Intervention* –A 90-minute individualised educational session that taught basic problem-solving principles using a cognitive-behavioural framework. This was led by a trained social worker. *Data:* • COPE problem-solving principles. • The Home Care Guide for Cancer. • Chapters from the Home Care Guide for Advanced Cancer.	• Social Problem-Solving Inventory-Revised Survey (SPSI-R) completed before and after the course. • Karnofsky Performance Index. • Brief Symptom Inventory Scale (BSI).	At baseline: Most participants reported low confidence about their ability to provide cancer care and felt uninformed about community resources. At follow-up: Participants reported feeling more informed about community resources and achieved higher posteducation scores for problem-solving ability. Especially caregivers reported that reading The Home Care Guide for Cancer made a great deal of difference in their approach to home care.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Deutsch 1992[46] UK IIIc	To examine whether taping consultations improves communication with patients	100 adult cancer patients 78% responded to questionnaire; *Types of cancers:* not reported	Cross-sectional survey of patients attending a general clinical oncology practice for a consultation where it was anticipated that difficult issues would need to be discussed; patient given tape of consultation to keep; follow up not stated	Questionnaire on tape use and value of content	• tapes played a range of 1-12 times, to relatives, friends, neighbours and to GPs. • all thought it was worthwhile. • the content was judged to be correct by all respondents in terms of the amount of information.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**
Heaven C & Maguire P 1996[34] UK IIIc	To investigate the effect of skills training in communication for hospice nurses	Nursing staff from 2 hospices: 44 nurses recruited 87 patients recruited 33 nurses completed pre- and post-intervention assessments, 22 assessed by follow-up	Repeated measures design 10 week teaching programme including 2 large group sessions on skills and the assessment interview, followed by 4 small-group sessions providing individual feedback on practice tapes made with either patients, relatives, actors or colleagues. Participants were evaluated pre-, post- and 9-month follow-up intervention by carrying out an audio-tape recorded assessment interview with the patient	*Improvement from pre to post and to 9 month follow-up assessment in:* • proportion of open questions used, number of behaviours with a psychological focus and the level of clear expression used with patients. • levels of blocking behaviours increased, but this was initially lower than reported in previous studies; • little improvement seen in ability to identify the patient's main concern and by 9 months this had decreased to below pre-intervention levels.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Fallowfield et al. 2002[39] UK Ia	To assess the efficacy of an intensive 3-day training course on communication skills for oncologists.	A total of 160 oncologists of specialist-registrar status or above from 34 UK cancer centres. A heterogeneous sample of 2407 patients with a confirmed or suspected diagnosis of cancer took part.	*Design* – A prospective RCT *Intervention*– Oncologists randomly allocated to four groups: - Written feedback followed by course. - Course alone. - Written feedback alone. - Control. Data– course content included structured feedback, videotape review of consultations, role-play with simulated patients, interactive group demonstrations, and discussion led by a trained facilitator.	Primary outcomes: Objective improvements after the intervention in key communication skills. Other outcomes: Subjective ratings made by researchers, doctors, and patients. Two videotapes of the median length from each doctor were analysed by use of the medical interaction process system (MIPS).	In Poisson regression analysis of counts of communication behaviours, course attendance significantly improved key outcomes. The estimated effect sizes corresponded to: Higher rates of use of focused questions (difference between course attenders and non-attenders 34%, p=0.003). Expressions of empathy (69%, p=0.003). Focused and open questions (27%, 0.005). Appropriate responses to patients' cues (38%, p=0.026). A 24% lower rate of use of leading questions (p=0.11) Little evidence for the effectiveness of written feedback.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures
Faulkner A et al. 1995[36] UK IIIc	To improve the communication skills of doctors in giving distressing information	78 staff having to give distressing information. The final group included: consultants, senior registrars, senior house officers, nurses and other health professionals' self-selection or nominated as requiring training.	Pre/post comparison study Weekend residential workshop: Identifying areas of concern for the participants (these were: how to; where to; collusion and cost); teaching and discussion on strategies for giving distressing information; discussion of problems in health care and in palliative care; video-tape recording of a role play of giving distressing information to a simulated patient. Feedback by letter to participants occurred after analysis of the interview	*After training:* • 91% of the doctors used a warning shot to prepare the patient psychologically for the distressing information. • 85% gave the information in stages. • 5% picked up the pieces and attempted to find out how the patient was feeling. • 57% questioned patients' feelings, but immediately blocked the response. • 38% blocked responses immediately after the bad news by giving information about treatment or changing the subject.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Glimelius B et al. 1995[41] Sweden IIb	To examine the effects of a care package in which communication played a central part	I group consisted of 177 cancer patients 120 of their relatives. *Types of cancers:* 46 breast; 28 Hodgkin's disease; 26 Non-Hodgkin's; 49 lung; 23 leukaemia. C group; not significantly different from I group (n=54); at different stages in the treatment process; 24 relatives	Comparison observational study; *I* group consisted of patients from one university hospital undergoing chemotherapy with curative intention on 3 wards; non-randomised; *C* group of patients with similar characteristics and treatments as I group, treated one month before the intervention was initiated *C*: pre-project 4 week evaluation *I* : a care package with several interventions to improve communication; document sheet of information given; written materials; assessment and mapping of problems by interview including interaction with medical personnel; increased relative participation; a key nurse identified on each ward involved in incidental teaching; staff meetings; staff education Interviewed at diagnosis, regular intervals over 2-3 months, and 6 months (at the last treatment course); times varied depending on cancer type ; relatives interviewed at the same times.	Cancer Inventory of Problems Situations (CIPS) a scale with 131 problem orientated statements, rated on a 4-point scale; high scores indicate more problems; 'Significant others" version of CIPS for relatives	*Comparison of C and I groups;* "medical interaction" problems were low for C; more problems communicating with physicians than nurses. I reported less problems with "medical interaction" and on all sub-scales *Relationship between patient-staff interaction and CIPS;* in both groups at all time periods there was a relationship between medical interaction and psychosocial and marital problems a relationship between physical problems and medical interaction was found in the C group communication with and control of the medical team were strongly related to psychosocial problems Comparison of patients and relatives; overall relatives tended to rate problems higher; less problems reported by relatives of the I group

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Hagopian & Rubenstein 1990[50] USA Ia	To investigate the effects that a weekly telephone call intervention had on patients' well-being.	A total of 55 patients undergoing radiation therapy for cure and who were able to communicate by telephone. No significant differences between the intervention and the control group in anxiety, age, gender, diagnosis (breast cancer most prevalent in both groups).	*Design* –RCT *Intervention–* I= 27 patients receive usual care plus weekly telephone calls. C= 28 patients receive usual care currently practised in the Radiation Therapy Department by the physician-nurse team. This care consisted of weekly on-treatment visits with both the physician and nurse during the course of treatment, usually 6 weeks.	Three self-administered tools: • The State-Trait Anxiety Inventory. • The Side Effects Profile • The Coping Strategies Profile • Telephone survey.	No significant differences between groups in anxiety, severity of side effects, helpfulness of self-care strategies, and coping strategies.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Hogbin et al. 1992[47] UK Ib	To examine whether audiotapes of "bad news" consultations improved patients' retention of information given during the interview and whether the provision of tapes has any bearing on psychological morbidity and other post-consultation events.	A total of 67 women diagnosed with breast cancer. This group was identified as showing particular dissatisfaction with information given to them about their disease and treatment. *Mean age*: I=57.54 years. C=57.88 years.	*Design* –RCT *Intervention* –The women were given a tape with the interview regarding the diagnosis and treatment by a consultant surgeon to take away and make reference to it during the preoperative period.	*Three questionnaires were administered*: • the Understanding Questionnaire: devised specifically for this study, measuring how well the subject had understood different aspects of the treatment information. • The HADS scale: to measure the subjects' current degree of anxiety and depression. • The RSCL: to measure the subjects' psychological and physical distress as experienced by cancer patients. *Repeated measures:* • Following the consultation (all three of the questionnaires) • Two to three days preoperatively (partners: Understanding questionnaire plus HADS scale). • Patients: HADS plus RSCL; partners: HADS.	*Understanding questionnaire*: the tape recording produced a better level of understanding of treatment in the immediate preoperative period (Wilcoxon T=75, d.f.=30, p<0.01). *HADS*: measures were on average at sub-clinical levels in both groups. A considerable proportion of each sample did exceed the threshold. *Seeking further information:* patients in the "no-tape" group made significantly more visits to their GP. *Tape usage:* patients made good use of the tapes and responded positively to the tapes. Partners experience comparable degrees of psychological morbidity. Women who undergo wide local excisions remain significantly more anxious postoperatively than women who have mastectomies.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Jenkins et al. 2002[28] UK Ib	To measure the psychosocial attitudes and beliefs of physicians working within oncology in the United Kingdom and to examine whether beliefs alter after communication training. Additionally, to investigate whether physicians' attitudes are reflected in communication behaviours with patients during interviews.	A total of 93 physicians. Inclusion criteria: Senior and junior physicians working in oncology, who participated in a 5-year prospective randomised controlled study that implemented an intensive residential communication programme. This program had shown more positive attitudes towards psychosocial attitudes. That RCT was to provide objective evidence that the changes in attitude resulted in the desired changes of communication behaviour.	*Design* –RCT *Intervention*– A three-day residential communication skills course. I=48 C=45	Baseline: Before randomisation the physicians completed a 32-item Physician Psychosocial Belief (PPSB) questionnaire. Follow-up: Three months later the participants completed another PPSB and a self-assessment questionnaire recording perceived changes in communication with patients. At both time points, physicians' consultations with two consenting patients were videotaped. Communication behaviors were measured using the Medical Interaction Processing System.	Significantly improved attitudes and beliefs towards psychosocial issues compared with controls (P=.002). This was reflected in the analysis of the videotapes: expressions of empathy in course group at T2 (P=.001)). open questions (P=.02). appropriate responses to patient cues (P=.005) psychosocial probing (P=.041) These objective findings were supported by physicians' self-report of changes in communication style.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Klein 1999[29] UK Ia	To evaluate the immediate effects of the participation of patients with cancer on the attitudes of undergraduate medical students receiving an interview skills training programme, and to assess the effects of the participation of patients with cancer on the attitudes and interview performance of students 2 years later.	A total of 249, randomised in 2 cohorts of third year undergraduate medical students. I=123 students (54 males, 69 females) C=126 students (64 males, 62 females)	*Design* –RCT *Intervention* – Took place before a 6 session interview methods course in third year. I=Students were taught with patients with cancer. C=Students were taught with patients with other diagnoses. Before and after the course, 233 students (94% response rate) completed an Attitudes Questionnaire. Again, in their fifth year 54 students completed the questionnaire, and in addition made a video recording of an interview with a patient who had gynaecological cancer.	• The Attitudes Questionnaire (a 32 item self-report questionnaire). • Interview Rating Instrument (a 36 item behavioural assessment of students' interview performance).	Intervention group improvements in: Students were more likely to consider the ability to listen an extremely important characteristic of hospital doctors, and to consider more strongly that trust is an essential part of the doctor-patient relationship. Two years after the course, the ability to communicate with patients, and the need for clinical decisions to reflect patients' wishes, were considered to be more important by the intervention group students. Even 96% of controls felt both these issues were very or extremely important.

Author, country	Aims of the review	Inclusion criteria	Outcome measures	Results
Libert et al. 2001[52] Belgium Review	To discuss the different communication skills training designed to physician interactions with cancer patients.	The literature on objectives and used techniques (theoretical information, case discussion, role-playing, feedback). The review also includes the discussion about training module integrating several techniques.	The efficacy of experiential techniques as well as participative techniques.	The results of the available studies are emphasising two difficulties: the maintenance and the consolidation of the various skills acquired over time and their successful transfer to the clinical practice.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Lilly et al. 2000[43] USA IIa	To determine the effects of a communication process that was designed to encourage the use of advanced supportive technology when it is of benefit, but to limit its burdens when it is ineffective.	A total of 530 adult medical patients who were consecutively admitted to a university tertiary care hospital for intensive care, and their families.	*Design* –Controlled before and after study. A prospective, non-blinded change-of-practice intervention. *Intervention* – A three-month preintervention period including 134 consecutive patients. A nine-month intervention period including 396 consecutive patients. ***Data*** – Multidisciplinary meetings were held within 72 hours of critical care admission. Patients, families, and the critical care team discussed the care plan and the patient's goals and expectations for the outcome of critical care. Clinical "milestones" indicative of recovery were identified with time frames for their occurrence. Follow-up meetings were held to discuss palliative care options when continued advanced supportive technology was not achieving the patient's goals.	• Length of stay. • Mortality. • Provider team and family consensus.	Intensive communication significantly reduced the median length of stay from 4 days (interquartile range, 2to 11 days) to 3 days (2 to 6 days, P=0.01 by survival analysis). This reduction remained significant after adjustment for acute physiology and chronic health evaluation (APACHE) 3 score [risk ratio (RR) =0.81; 95% confidence interval (CI), 0.06to 0.99; P=0.02). The intervention which allowed dying patients' earlier access to palliative care, was not associated with increased mortality.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
McClement SE & Hack TF 1999[45] Canada Review	To review the literature evaluating evaluated the effects of audio-taping the oncology treatment consultation. An intervention designed to improve communication.	Studies which evaluated the effects of audio-taping on patient's psychological well-being, information recall and satisfaction. *Types of cancers:* heterogeneous cancer types in 8 studies; bowel and breast cancers in 1 study	Critical review of 9 studies. 5 randomised control trials (n= 67, 34, 142, 117). I groups- given a copy of the taped consultation. 3 descriptive exploratory studies (n= 46, 29, 76). 2 gave questionnaires, 1 study method not stated. 1 randomised single blind cross-over trial (n=182). Compared audio-tape with summary letter.	Hospital Anxiety & Depression Scale General Health Questionnaire Psychological; Adjustment to Cancer Scale; tape content analysis Roter Interaction Analysis System; satisfaction and recall measures.	*Psychological distress:* 3 studies showed a reduction in psychological distress; 2 found no effect. 1 study found that for patients with poorer prognoses audio-tapes could be detrimental *Information recall:* • uncontrolled studies reported enhanced memory recall; RCTs produced mixed results with either greater recall or no effect *Patient satisfaction:* Overall the audio-tapes were of benefit; satisfaction levels were generally high but there was some evidence for increased satisfaction in I groups

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures
Maguire P & Faulkner A 1988[35] UK IIIc	To evaluate workshops in communication and counselling skills run jointly for doctors and nurses working in hospital and community settings with cancer patients	218 people: 23% doctors, 66% nurses, 7% social workers, 4% other professionals from hospice, Macmillan, Marie Curie and other backgrounds	Pre/post comparison study 3-4 day workshops with participation and feedback; problems are identified by the group and teaching is by video and role play; areas covered: Basic interviewing skills; breaking bad news; patient advocacy; dealing with anger; dealing with a misinformed patient; the withdrawn patient; sudden unexpected death; challenging denial; breaking collusion; participant coping skills.	*Interim results* (51 cases): • Skills of effective interaction improve after a 3 or 5 day workshop, but few participants are encouraging the patient to clearly express their feelings.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures
Maguire P et al. 1996a & 1996b[37;38] UK IIIc	To assess the impact of communication skills workshops on interviewing skills of health professionals.	206 professionals involved in cancer care. 24% doctors 65% nurses 7% social workers 4% psychologists and others. Completed pre- & post-workshop assessments. 169 also completed 6 month follow-up assessment	Pre/post comparison study with follow up 3 or 5 day workshops in communication training including identification of areas of concern for participants, strategies for interviewing patients and role play of interviewing a simulated patient with feedback (as for Maguire et al, 1988); Assessment of role play occurred immediately before and after the workshops and 6 months later	*Pre/post comparisons;* • increase in the use of open directive questions, questions with a psychological focus and clarification of psychological aspects at follow-up assessment with some decline by 6 months. • significant improvements in professionals ability to elicit key patient problems, sustained over time. • reduction in the use of inhibitory actions at immediate follow-ups. • increased inhibitory behaviours towards pre-workshop level at 6 months.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Munro et al. 1994[51] UK Ia	To test the hypothesis that routine contact by telephone might significantly improve the adequacy of support for patients during the potentially stressful period between completing radiotherapy and the first follow-up visit.	A total of 100 consecutive unselected outpatients attending for radiotherapy under the care of one consultant. Exclusion criteria: • Not English-speaking. • No access to telephone. • Patients with HIV related malignancies. • Those treated with < 5 fractions of radiotherapy • Hospital inpatients. 75% completed questionnaires in intervention group 79.6% in control	*Design* –RCT *Intervention* – I= usual care plus telephone contact on days 4, 8, 14, and 18 after completing radiotherapy. C= usual care during and after treatment.	Adequacy of support was assessed by a questionnaire administered at the first follow-up visit.	There were no significant differences in the perceived adequacy of support between the two arms. 76% of the intervention arm versus 61% in the control arm rated their support after radiotherapy as "extremely adequate". The 95% CI for this 15% rate difference was –6-+ 36. Analysis by intention to treat showed a rate difference of only 4% (95% CI –17-+25) in favour of the intervention.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Razavi et al. 2000[40] Belgium IIIa	To assess the impact of different standardised role-playing sessions (SRPS) emotional content on induced communication skills (CS). To test the sensitivity to training workshop-related changes of CS induced by the three emotionally different SPRS contexts.	A total of 25 health care professionals were accepted to take part in the training workshops and research programme. Mean age: 37 years, with a standard deviation of 9 years. There was a majority of nurses (72%). Only two participants did not (8%) have, during the last 2 years, a professional experience with cancer patients.	*Design* –Interrupted time series ITS *Intervention* – Health care professionals participated in training workshops in communication skills. Before and after the training workshop, the health care professionals' communication skills were assessed with three different SRPS, built on the basis of emotionally contrasted scenarios. Data– The training workshops were meant to improve health care professionals' understanding of psychological and psychiatric dimensions related to cancer diagnosis and progression: psychological and psychiatric complications, patients' and relatives' coping mechanisms, loss and bereavement, psychological interventions, and other related issues. Three emotionally different SPRS contexts (weakly emotional (WE), moderately emotional (ME), and highly emotional (HE)) were tested.	Tape-recorded SPRS, scheduled before and after the training workshops, were retranscribed, and assessed according to the Cancer Research Campaign Workshop Evaluation Manual , which provides a rating of form, function and structure for each utterance.	CS are different in WE-, ME-, and HE-SRPS: regarding form (HE-SRPS induced more 'directing', 'leading' or 'multiple' questions; WE:20.7%; ME:19.7%; HE:33.7% (p,0.001)); regarding function (HE-SRPS induced more 'inappropriate' information; WE:6.5%;ME:8.2%; HE;15.6% (0.001)); and blocking (HE-SRPS induced more 'blocking' utterances; WE:7.2%,ME:13.8%,HE:30.2 % (0.001)). CS changes induced by training workshops are the highest in HE-SRPS (14.8%increase of 'open' questions for the HE- versus 1.0% for the WE-SRPS; 11.6% decrease of 'inappropriate' information for the HE- versus 3.3% for the WE-SRPS ; and 17.5% decrease of 'blocking' for the HE- versus 2.6% for the WE-SRPS.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Sepucha et al. 2000[42] USA IIb	To test an intervention designed to improve the quality of consultations between cancer patients and their physicians	24 patients, all early stage breast cancer who were facing local or systemic treatment decisions	Sequential controlled trial. 12 patients in intervention arm. All patients received a consultation planning session with trained researcher prior to appointment with physician. In the intervention group the researcher was also present in this appointment, and led the parties through the five step intervention, 'consultation recording': contracting, agenda, mapping, commitments and debriefing. In the control group the researcher was present but did not participate in the consultation	Decision Quality Scale MD Decision Scale Satisfaction with Consultation Scale	*I group achieved* • 'higher quality decisions' (p<0.008) • higher patient – physician agreement (p<0.0001) • no statistically significant difference in satisfaction with the consultation compared to control group

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Street et al. 1995[19] USA IIa	To examine factors affecting patient involvement in consultations to decide local treatment for early breast cancer and the effectiveness of two methods of preconsultation education aimed at increasing patient participation in these discussions.	Sixty patients with Stage I and Stage II breast cancer. *Brochure group: N=30* Mean age: 60.8 *Multimedia group:* N=30 Mean age:57.4 No significant differences between the multimedia or brochure group with respect to the patient's age, education, disease stage, or ethnicity.	*Design* –Randomised trial without control group. *Intervention –* 1. The patients were pretested on their knowledge about breast cancer treatment and optimism for the future. 2. They were randomly assigned to one of two methods for preconsultation education: interactive multimedia program or brochure. 3. They completed knowledge and optimism measures. 4. They consulted with a medical oncologist, radiation oncologist, and general surgeon. 5. They completed self-report measures assessing their involvement in the consultations and control over decision-making.	*Patients:* Assessment of breast cancer treatment with an 11-item, multiple choice test. Patients' optimism was assessed with an 8-item instrument developed by Scheier and Carver. Patient involvement was assessed by behavioural measures and perceptual measures. The latter was assessed with a scale derived from Lerman et al.'s Perceived Involvement in Care Scale (PICS). The patients' perceived control over the decision was measured with five items derived from England and Evan's Perceived Decision Control (PDC) instrument. *Physicians:* Behavioural measures: physician's use of patient-centred responses. Perceptual measures: Physician facilitation of patient involvement, with the five item doctor facilitation subscale of Lerman's et al.'s PICS measure.	College-educated patients younger than 65 years of age were more active participants in these consultations than were older, less educated patients. Patients showed more involvement when they interacted with physicians who encouraged and facilitated patient participation. The method of education did not affect patient involvement although patients tended to learn more about breast cancer treatment after using the multimedia program than after reading the brochure.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Tattersall et al. 1994[48] Australia Ic	To compare the efficacy of providing a tape of the first consultation with an oncologist	182 adult cancer patients without advanced incapacity I Group 1 (*I1*): 76% female; mean age 51 I Group 2 (I2): 81% female; mean age 51 *Types of cancers;* Breast (I1:48%, I2:42%); gynaecological (I1:18%, I2:17%); other (I1:32%, I2:38%); none (I1:2%, I2:3%)	RCT crossover trial, single blind; new referrals between 3/1992 to 1/1993 for consultation with one medical oncologist at a university teaching hospital; consultation audio-taped and the oncologist documented the most salient points covered then prepared a letter summarising the consultation; *I 1* (n=94) received the tape then letter; *I 2* (n=88) received the letter then tape; the second communication aid was received 7-10 days after the first; Follow up then occurred 7-10 days after the tape or letter had been given to the patient	14-item HADS; satisfaction with communication aids; ranking of six possible post-consultation communication aids: recall compared with the salient points nominated by doctor outcomes assessed by telephone interview and postal questionnaire	• anxiety scores decreased for both groups, depression unchanged • patients felt the tape was more effective in reminding them • the tape was the preferred post-consultation communication option above a letter, a phone call with oncologist, a letter from the oncologist to their doctor, a talk with the oncology nurse, or phone call with the oncology nurse • recall similar for both groups • > 80% of both groups satisfied • those who wanted minimal news were less satisfied with the letter than those wanting good/all news.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Tierney et al. 2001[44] USA Ia	To assess the impact of discussions of advance directives on patients' satisfaction with their primary care physicians and outpatient visits.	*Patients:* A total of 686 patients who were at least 75 years old, or at least 50 years old with serious underlying disease. The trial was conducted in a hospital-based academic primary care general internal medicine practice that mainly serves inner-city indigent patients. Health provider: 87 of the patients' primary care physicians (57 residents, 30 faculty general internists).	*Design* –RCT. Embedded within the RCT a prospective cohort study of all the enrolled patients. *Intervention* –A computer system generated reminders to the primary care physicians to discuss advance directives with their elderly, chronically ill patients. I= Randomly assigned to 1 of 4 groups: 1. Computer reminders to discuss instruction directives (a list of care interventions which the patients wanted or not, in the case of terminal illness and cognitive impairment). 2. Reminders to discuss proxy directives (a form of naming a health care representative). 3. Reminders to discuss both types of advance directives. 4. Control group: no reminders were generated.	Interviews with patients in the waiting room after completed visits with their physicians (baseline and follow-up). Two satisfaction measurements were used: • ABIM (American Board of Internal Medicine) measures patients' satisfaction with the primary care physician. • MOS-VSQ (Questionnaire developed for the Medical Outcomes Study) assesses patients' satisfaction with a particular visit.	Discussion of advance directives was associated with greater satisfaction with the physician (P=.052). At follow-up, the strongest predictor of satisfaction with the visit was having previously discussed advanced directives with that physician (P=.004), with a trend toward greater visit satisfaction when discussions were held during that visit (P=.069). An increase of 34% of patients scoring visits prior without advance directive discussions as "excellent" to 51% for visits with discussions (P=.003).

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures
Wilkinson S et al. 1998[31] UK IIb	To evaluation a palliative care nurse- patient communication programme.	110 Registered Nurses undergoing further training. Diploma in Nursing (n=30); Diploma in Palliative Care (n=60); Marie Curie Advanced Award in Palliative Care (n=20) 90 female; mean number of years since qualification 11.5	Repeated measures design 26 hour training program over 6 months formed part of their course and evaluation; training focused on knowledge, attitudes and skills with personal feedback on performance and self-critique Pre/mid/post course audio-tape of patient assessment; 2 separate raters assessed the tapes in terms of blocking and facilitating behaviours and the depth in which 9 key areas were covered; 3 raters randomly rated 13 tapes (88% agreement) Pre-course 17 -item questionnaire the Fear of Death Scale; overall the sample showed moderate levels of death anxiety	*Pre-course:* • assessment coverage was low, especially for psychological areas; with little structure *Mid-course (at 3months in to the course):* • improvement in assessment structure and coverage, 58% assessed patients' awareness of diagnosis or prognosis; more attempts were made to elicit feelings *Post-course (3 months after course completion):* • improvement in coverage maintained; no further improvement in psychological and social assessments • compared to pre-course the training significantly improved nurses' communication skills in 6 out of 9 key areas, especially for psychological aspects, handling difficult questions and illness awareness • 90% of nurses' scores improved, 4% remained the same and 6% decreased

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures
Wilkinson S et al. 1999[30] UK IIb	To perform a longitudinal evaluation of a communication skills programme evaluated previously by Wilkinson et al. (1998). *(presented in the table above)*	Of the 110 nurses who completed the original study 45% (n=50) agreed to take part; only 33 returned usable data; no significant differences between those who took part and those in the original study *Sample characteristics;* mean length of time since the original study was 2.9 years; 94% female; 46% employed in a hospice; 30% in hospitals; 6% in the community; 18% specialist nurses	Longitudinal follow up study Respondents were sent a letter and audio-tape cassette asking them to record a patient assessment; feedback on the tape was given to each nurse; their original pre/ post course scores were examined; *Pre-course* coverage scores were low especially for psychological assessment in 88% of cases; 49% gave an adequate or good physical assessment, whereas 61% cases did so for coverage of present illness; Post-course there were improvements in all areas; these were statistically significant for: introduction; patient's awareness of diagnosis; history of illness; physical assessment; psychological assessment; closure of assessment.	*Comparison of pre/post course and follow up:* • overall mean score at follow up was 15.2 compared to 10.7 (pre) and 16.3 (post) this was significant between the pre-course and post-course, and between pre-course and follow up • no significant differences between post-course and follow up scores were found, except in the area of psychological assessment where there was an improvement • the evaluation indicated that the course can improve levels of competency in communication skills which can be maintained

6. INFORMATION

Nature of the evidence

Two systematic reviews have been written on the topic area of information. One was a Cochrane Review including both randomised and non-randomised controlled trials[53]. The other systematic review included ten randomised controlled trials[54]. There were 33 studies identified for the topic. Seventeen studies were grade I randomised controlled trials (range a-c). Of these six were carried out in the USA, four in Canada, three in the UK, one in Scotland, one in Sweden, one in Australia, and one in the Netherlands. There were 6 grade II studies; one grade IIa and five grade IIb. There were six grade IIIc studies. Two articles were not graded as these were not intervention studies[55;56]. Two critical reviews were found[45;57] .

Types of interventions

A Cochrane Review[53] evaluated the effects of providing audiotapes or summaries of consultations to people with cancer and their families. The systematic review by McPherson et al.[54] evaluated methods of information provision to cancer patients and their families. Interventions ranged from written information to audiotapes, audiovisual aids and interactive medium.

The studies implemented a variety of interventions:

- Written materials such as leaflets or booklets, both general and specific[33;58-62], or letters summarising the consultations, either in combination with tape recordings of the consultation or by themselves[48;53].
- The provision of an audiocassette recording of the consultation[45;53;63-67].
- A preparatory slide tape to educate patients prior to procedures[68].
- Video and booklet interventions about cancer pain and its management[69].
- An educational video to take home following the first consultation[70].
- Telephone help-lines supplying information and support to cancer patients, their significant others and the general public[71;72].
- Documentation of information and/or care: shared-care record containing appointments, a diary of significant events, medications, carers' addresses and contact numbers[1]; patient information folders holding records of written materials given to the patient, according to the patient's informational needs[62;73]. A directory of information materials including a selection of websites produced by UK organisations with expertise in cancer information[55]. A computer based information system that is personalised using each patient's medical record[74].
- A structured patient-centred group educational programme [75;76].
- An educational session that taught basic problem-solving principles[33].
- A group psycho-educational program[77-79].
- An interdisciplinary team providing information[80].
- Structured nurse interventions[81;82].

Most of the studies applied their interventions to patients[45;48;57-60;62;63;65-68;70;74;78-82]. We also found studies which applied their interventions to both patients and their families[33;53;54;72]; to both patients, their families and the public[71]; and to both patients and their families and to health professionals[1;56;64].

In four of the studies the interventions were carried out with patients in the early stages of the disease. This was to prepare them before surgery and to gain control over the illness experience, especially directed towards moments of crisis[57-60;62;68;78;80;82].

The emphasis of the interventions was on coping with the disease. The interventions were aimed at promoting understanding and psychological adjustment[45;48;53;54;61-63;65;66;70-72;78-80;82], symptom management[33;67;77;81], the continuity of care [1;33;74], and behaviour change[77].

Outcome measures

The two systematic reviews[53;54] concurred with the results of the individual studies on giving information to cancer patients. Scott et al.[53] concluded that although their systematic review was based on small and heterogeneous studies it is possible that the provision of recordings or summaries may benefit patients with cancer. The participants in the studies found recordings or summaries of their consultations valuable, with a better recall of information, but no effect on anxiety or depression. Also in McPherson et al.[54], the studies included in the systematic review indicated that the interventions had positive effects on a number of patient outcomes, such as knowledge and recall, symptom management, satisfaction, preferences, health care utilisation and affective states. In the majority of studies the interventions had no effect on psychological indices.

Most individual studies have concluded that patients find audiotapes or written summaries useful[45;57;64-66]. Some studies found a better recall of the information given[65] but other studies contradicted this result[48]. Also in Tattersall et al.[48] it was found that audiotapes were preferred above a summary letter, a talk with the oncology nurse or a telephone call with the oncologist.

None of the studies were able to demonstrate that audiotapes had an effect on psychological conditions. Tattersall et al.[48], Hogbin et al.[47] and Ream & Richardson[57] reported that the levels of anxiety and depression remained unchanged with their intervention. Hogbin et al.[47] provided the first objective evidence that tape-recorded consultations can be a useful memory aid to patients. These also resulted in fewer visits to general practitioners. Ong et al.[66] show that the patients who received an audiotape in their study were able to reproduce what was said during the consultation in more detail and that they were more satisfied with the consultation, or with the care given in general[67]. However, audiotapes may be detrimental to patients with a poor prognosis[63]. A minority of patients found that the use of audiotapes can increase patients' distress[65], also a minority found that the procedure interfered with the consultation[64;65] and those wanting minimal news found it unsatisfactory[48]. This suggests that it is necessary to take patient's views into account so that the appropriate channels can be used and adapted to their needs. Hogbin et al.[47] also documented the psychological morbidity of the partners in that they experienced levels of anxiety and depression comparable to the patients. Partners provided with tapes also made considerable use of them, thus suggesting that provision of information for this group may be as important as it is for the patients themselves. Studies in this area are heterogeneous and use different outcome measures.

Written materials in the form of leaflets or booklets are the mainstay of supplementary patient education. Huchcroft et al.[59], Eardley et al.[61] and Mohide et al.[58] provide evidence to support the use of written information. Preparatory written information prior to a clinic appointment, whether by mail or at the clinic before the consultation, resulted in patients being better informed and less confused about the reasons for the appointment[59]. This was strengthened by Mohide et al.[58] where new patient information packages received before the first appointment were useful in meeting the informational needs of patients. The timing of the provision of information appears to be important in preparing patients for an event. Eardley et al.[61]found that patients receiving a booklet about radiotherapy were significantly less concerned about side effects and more satisfied with information. The type (general, specific), presentation, comprehension, and provision of five commonly used cancer information booklets were examined by Butow et al.[60]. The results of this study showed that patients preferred booklets written at the level of grade eight English (13 year-olds) because of the simpler language. Also, booklets containing specific information to prepare patients for chemotherapy were preferred by patients and their families. Most patients favoured receiving general cancer information at the treatment decision stage, which would assist them in reaching a well informed decision. Berner et al.[83] found that patients appreciate receiving written cancer information, although it may not increase their cancer knowledge. The majority of the patients in their study were lacking basic knowledge about their disease.

Slide shows are another medium for conveying information about cancer, its treatment and options for care. Rainey[68] found that a slide presentation to prepare patients for radiotherapy helped alleviate anxiety and mood disturbance at follow up. Anticipating needs and possible side effects of treatment can prepare patients better and help them cope with adverse events. A videotape intervention and accompanying booklet helped patients prevent and control their pain[69]. An educational video to take home following the first consultation during which either chemotherapy or radiotherapy was recommended led to a significant decrease in anxiety and depression levels among these patients[70]. Almost all of them found that the video was very helpful and only a slight minority felt that this extra information was worrying[70].

Lechner and De Vries[71] and Venn et al.[72]concluded that the availability of a cancer information helpline was a good resource for patients, the people close to them and for the general public. Evaluations of these services showed that the majority of the callers were satisfied with the quality and the amount of information they received.

Structured patient-centred interventions with elements of counselling and support, provided to groups[79], Derdiarian[76], Johnson[75;77], or individually[33;81] had beneficial outcomes for patients. The effects of the interventions on the breast cancer patients undergoing chemo-, radio- or hormone therapy in Braden et al.[79], for example, were a higher level of confidence in cancer knowledge sufficient for self-management and self-help, regardless of whether they had high or low resourcefulness at baseline. Similarly, the importance of information and support appeared in the nursing intervention evaluated by Benor et al.[81], where empowering the patient with the relevant knowledge and skills improved symptom awareness, decreased symptoms and increased perceived support. Bucher et al.[33] reported more confidence in providing care and the feeling of being better informed about community resources. In the case of Robinson's intervention[77] compliance with medical recommendations increased. Information was found to be a necessary condition for behavioural change to occur[77].

Packages with the aim of disseminating, documenting, mapping relevant information about the patient may be useful not only to the patient and his relatives but also to carers and health providers. Interventions such as the shared-care record[1] or patient information folders[62] can contribute to the co-ordination of care provided by different services. Jones et al.[74] also showed that patients preferred computer systems that provided information from their medical records to systems that just provided general information. The Directory of Information Materials for People with Cancer has brought together key internet resources produced by UK organisations with expertise in cancer information, which were assessed against specific quality criteria, in particular C-H-I-Q's health information appraisal guideline[55].

There are three studies that show only partial effectiveness of the interventions applied. Helgeson & Cohen[78] report on a psycho-educational intervention where only the educational component focusing on the provision of information was successful. The results remained, even after a three years period, although effects dissipated with time. Yet, the peer discussion intervention, which was another condition of the trial, showed no effects with hints of adverse effects on the patients, whether implemented alone or in combination with the provision of information. In Lilja et al.[82] the patients operated on for breast cancer or for total hip replacement (THR) showed a differential outcome. Breast cancer patients in the intervention group were significantly more anxious than THR patients. Also, the women who underwent wide local excisions in Hogbin et al.[47], remained significantly more anxious postoperatively than women who had mastectomies. Bloom et al.[80] only had a delayed positive response to the counselling and information sessions given by an interdisciplinary team before, during, and after hospitalisation. Immediately after surgery the results indicated that the affective responses of the intervention patients were more labile than the responses of the control patients. Two months later, however, the women in the intervention group scored significantly higher on the measure of self-efficacy.

The diversity in results can be explained from a psychological point of view. Cancer patients with different diagnoses may have very different needs and use different coping mechanisms accordingly, as is evident in the study Lilja et al.[82] conducted with breast cancer patients and THR patients. This also applies to the different stages of illness, which require different kinds of support. People who have a more controllable illness might benefit from a problem-focused intervention that focuses on providing information and enhancing control. People who have a less controllable illness or people at later stages of a disease might benefit from an emotion-focused intervention that focuses on accommodating to the disease[78]. This indicates a need for individualised modes of information.

Implications of the evidence for recommendations

The recommendations comprise the most important issues relating to the effective use of information exchange in helping patients with cancer to deal with the challenges they face. Different types and forms of information are proposed to inform patients as well as carers. There is also grade IIIc evidence where health professionals are targeted to assist them in improving the co-ordination and the continuity of care. Evidence of grade Ia indicates that the information should be targeted to the individual. The recommendations take this into account at several levels by assessing patients' views on the appropriateness of information, and ensuring that mechanisms for listening to, recording and responding to patients' needs, views and priorities are in place.

Tables of Evidence: Information

Systematic reviews

Author, country	Aims of the review	Inclusion criteria	Exclusion criteria	Outcome measures	Results
McPherson et al. 2001[54] UK	To systematically review randomised controlled trials that have evaluated methods of information giving to cancer patients and their families.	RCTs that evaluated methods of information giving to patients, families and carers and in which the intervention was aimed primarily at educating rather than counselling. E.g. written information, audiotapes, audiovisual aids and interactive media. Also individually tailored methods such as patient care records and patient educational programmes.	• Studies of medical procedures such as surgery, chemotherapy or radiotherapy. • Studies on psychoeducational methods (e.g. comparisons of different therapies or between educational and counselling therapies). • Studies on communication skills. • Studies that focused on one type of cancer.	The majority of the studies assessed outcomes thought to be both directly and indirectly related to the intervention. *Directly related outcomes:* • objective measures e.g. knowledge acquisition, recall and understanding and the use of educational resources. • Subjective measures: preferences for information, attitude toward the intervention, uncertainty, satisfaction. *Indirectly related outcomes:* affective states, symptom management, expectations, health service utilisation, and coping.	All the interventions reviewed were shown to improve at least one of the outcomes evaluated. The greatest improvements were seen in measures of knowledge and understanding. In the majority of studies the interventions had no effect on psychological indices.

Author, country	Aims of the review	Inclusion criteria	Results	Discussion
Scott et al. 2001[53] UK	To examine the effects of providing recordings or summaries of their consultations to people with cancer and their families.	*Inclusion criteria* Randomised or non-randomised controlled trials which evaluate the effects of providing audio-tapes or summaries of consultations. *Data collection and assessments of studies* Two reviewers independently assessed the relevance of titles and abstracts reviewed from literature searches. Each accepted study was assessed for methodological quality based on eight criteria. Three effect types were looked for: • Information recall / understanding • Experience of health care • Health and wellbeing	• 8 studies satisfied the inclusion criteria. • *Benefits of receiving recordings or summaries:* • In 7 studies 83 – 96% of participants found recordings or summaries of their consultations valuable. • 4 out of 6 studies reported better recall of information • 2 out of 4 studies found that participants were more satisfied with the information received • no studies (of 6) found any effect on anxiety or depression • no study evaluated effect on quality of life or survival	• The studies did not measure similar outcomes • Possible Hawthorne effect affecting results of studies: that is that there might be a positive impact on the content of consultations if practitioners are aware they are being recorded. • Recording of consultations may also affect patients' consultation behaviour: participants in control groups were aware that their consultation were not being recorded, and this may have affected their responses to the research instruments. • Overall: studies were small and heterogeneous. Therefore evidence is not strong, but it is possible that the provision of recordings or summaries may benefit patients with cancer.

Individual studies

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures
Benor et al. 1998[81] Israel IIb	To measure the effect of a structured nursing intervention aimed at empowering the patient by giving them the relevant specific knowledge, support and skills to deal with their own care and symptoms.	94 ambulatory patients between 20-70 years; no metastatic spread; treated with chemotherapy and/or radiotherapy 22 males *Types of cancers:* 56 breast; 19 intestine; 7 genitals; 12 lymphomas 40 nurses self-selected who took part in a 6 month course and passed an oncologic knowledge test	Quasi-experimental design with patients attending an oncology day centre between 1992-1994; partially randomised; matched I and C then randomised; *I:* visited at home by a nurse for 1-2 hours for 3 successive months; patient and nurse rated SCA at visit and other complaints; patients given relevant knowledge, support and guidance; encouraged to generate their own solutions to problems C: given usual information and treatment at the day centre; completed SCA at the same time periods as I I and C group pre-intervention differences; I: anxiety higher; more dependent on all 16 symptoms. C: greater perceived family support	Symptom Control assessment (SCA) designed for the study; evaluates; 16 symptoms and complaints specific to cancer patients; 8 basic, universal needs subdivided in to 13 elements; pain; anxiety, self-image and sexuality; rates the level of intensity, independence, perception of help from others and knowledge

Author, country, grade	Aims of the study	Patient population, study design	Outcome measures	Results
Berner et al. 1997[83] USA Ib	To evaluate providing a copy of the Physician Data Query (PDQ) Patient Information File (PIF) to cervical, endometrial, and ovarian cancer patients.	106 new patients with cervical, endometrial or ovarian cancer. Setting: US University clinic and one private practice. 7 month study period. All new patients (n=120) with cervical, endometrial, and ovarian cancers were randomised by site to two groups: 1) verbal communication only and 2) verbal communication plus PIF. 106 were available for follow-up interview. Age of patients not reported. *Intervention*: PIF downloaded from National Centre for Cancer Information CancerNet web site and reformatted for readability. PIF included information on description of each cancer, explanation of staging, overview of treatment options and sources of additional information.	Extent of patient's cancer knowledge assessed by telephone interview two weeks after treatment. Patients asked about the primary site of their cancer, the stage and whether it had spread. Scored as 1 for correct answer, 0 for wrong or do not know. Scores summed to give total knowledge score. What sources of information did patient use, satisfaction with information received, did she remember receiving the PIF? How helpful was PIF?	*Patient's knowledge about their cancer.* No significant difference between PIF patients (n=56) and no PIF patients (n=50) in their cancer knowledge (χ^2=1.67). Majority of patients from both groups lacked basic knowledge about their disease. *Patient's satisfaction with information given.* No significant difference between patients groups in satisfaction with information they received from their physicians (χ^2=4.69). *Patient's use of other information sources* Majority of patients (74%) did not use any source of information other than their physicians and/or nurses. *Satisfaction with PIF* Overall reaction to PIF was good or excellent for 92% of 36 patients surveyed. 13/56 could not remember receiving PIF. 4/56 could not remember anything about PIF apart from receiving it. 3/56 did not want to read it. Patients appreciate receiving written cancer information, although it may not increase their cancer knowledge.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Bloom et al. 1978[80] USA IIb	To examine the effectiveness of the counselling-education intervention program.	A total of 39 women with initial breast cancer having undergone breast surgery. I=21 women. Average age: 49. C=18 women. Average age: 53.	*Design* –Prospective non-randomised controlled trial. *Intervention* – I=Counselling and information are offered to patients with a mastectomy by an interdisciplinary team. An oncology counsellor (nurse) provides support and information during hospitalisation; and a social worker provides co-ordination and continuity of service between the hospital and the community.	*Demographic variables.* Psychosocial variables: - the Health Locus of Control (HLC). - Profile of Mood States (POMS)	*Immediately after surgery:* The affective responses of the group in the intervention program were more labile than those of the control group. These differences diminished over time. Both groups were equivalent on the measure of self-efficacy (t= -0.53, df=32, n.s.). *Measure after two months:* patients in the intervention group score significantly higher (t= -2.16, df=32, p<0.05).

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Braden et al. 1998[79] USA Ia	To determine the efficacy of self-care/self-help promotion and uncertainty management interventions offered by the Self-Help Intervention Project (SHIP) for women receiving chemotherapy, radiation therapy, or hormone therapy for breast cancer.	A total of 193 women receiving treatment for breast cancer. *Inclusion criteria:* 18 years and older, and literate in English.	*Design* –RCT *Intervention –* - Self-help course. - Uncertainty management. - Self-help course plus uncertainty management. - Control group. Data were analysed by a repeated measures multivariate analysis of variance procedure. A two-level blocking factor was used: high and low resourcefulness.	Outcome variables measured: - Self-care by the Inventory of Adult Self-Care Behaviours (IASC), and the Self-Care Inventory Wellness Promotion (SCIWPR). - Self-Help by the Inventory of Adult Role Behaviour. - Psychological Adjustment by the Negative Affect Scale. - Confidence in Cancer Knowledge by a visual analogue formatted single item. Data were collected: - At baseline (T1) after initiation of adjuvant therapy - (T2) 6-8 weeks after T1. - (T3) 2 months after T2.	Participation in SHIP interventions resulted in higher levels of self-care, self-help, psychological adjustment, and confidence in cancer knowledge by time effect in a significant number of women regardless of their baseline resourcefulness. Women with low baseline resourcefulness demonstrated the greatest change over time in outcome variables. The effect was primarily the result of changes in psychological adjustment, confidence in cancer knowledge and self-care.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Bruera et al. 1990[67] Canada Ia	To assess the impact on patients' recall of and overall satisfaction with their consultation by the addition of an audiocassette recording of a consultation to written recommendations.	A total of 60 patients 36 males, 35 females)with advanced cancer. The mean (SD) age was 62 (10) years.	*Design* –RCT Prospective, randomised, double-blind trial. Randomisation by computer-generated code. *Intervention* –Patients receive a tape recording of a consultation to written recommendations.	• Patients gave their global ratings of the clinic. • They were tested for their recall of information given. • They responded to questions about the utilisation and role of the cassette in influencing family communication.	The addition of the audiocassette to written communications significantly increased patient satisfaction with the clinic (8.7 +/- 1.7 vs. 7.7 +/- 2.0 on a scale of 0-10; P=0.04) and significantly improved recall of the information given during the consultation (88% +/- 8.7% vs. 80% +/- 15.5%; P= 0.02). Patients expressed a high level of satisfaction with the audiocassette. Patients listened to the tape a median of 2 (range 1-4) times, family members and friends a median of 2 (range 1-3) times.

Author, country, grade	**Aims of the study**	**Patient population**	**Study design**	**Outcome measures**	**Results**
Bucher et al. 1990[33] USA IIa	A program evaluation was conducted to explore the potential effects of a 90 minute problem-solving education session for persons with advanced cancer and their families.	A total of 89 participants who were visiting a tertiary-care outpatient setting, 49 caregivers and 40 patients were selected using a convenience sampling method. *Eligibility criteria:* patients in advanced stages of disease, >19 years, English speaking and able to identify a primary family caregiver.	*Design* – CBA. Non-randomised intervention. *Intervention* –A 90-minute individualised educational session that taught basic problem-solving principles using a cognitive-behavioural framework. This was led by a trained social worker. *Data:* • COPE problem-solving principles. • The Home Care Guide for Cancer. • Chapters from the Home Care Guide for Advanced Cancer.	• Social Problem-Solving Inventory-Revised Survey (SPSI-R) completed before and after the course. • Karnofsky Performance Index. • Brief Symptom Inventory Scale (BSI).	At baseline: Most participants reported low confidence about their ability to provide cancer care and felt uninformed about community resources. At follow-up: Participants reported feeling more informed about community resources and achieved higher posteducation scores for problem-solving ability. Especially caregivers reported that reading The Home Care Guide for Cancer made a great deal of difference in their approach to home care.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Butow et al. 1998[60] Australia IIIc	An exploratory study to investigate factors which influence patient's satisfaction and utilisation of cancer information booklets. Furthermore, to investigate factors which may influence these outcomes.	*Stage 1:* 36 consecutive patients undergoing chemotherapy for malignancy *Types of cancers:* 50% breast 29% gynaecological 21% other 81% female; mean age 50; 69% response rate *Stage 2:* A second sample of 24 cancer patients (criteria as above) who had been given booklets 1 & 2 as part of the treatment procedure *Types of cancers:* 58% breast 22% gynaecological 19% other 18 females; mean age 49	Cross-sectional survey of patients receiving chemotherapy or who had recently received at least 2 cycles of chemotherapy at one university teaching hospital; previously received literature about chemotherapy *Stage 1:* 5 commonly used cancer information booklets given to cancer patients in New South Wales (NSW) Hospitals were reviewed; each contained information about chemotherapy but their focus differed Booklet; 1- specific to drug therapy 2- practical information about coping with chemotherapy 3- understanding chemotherapy 4- problems that may occur during therapy 5- nature of cancer, treatment and the cancer unit A structured postal questionnaire was sent to patients. *Stage 2:* Examined the relationship between preference for information style, satisfaction and recall from booklets 1 and 2 only. Given to patients prior to the start of chemotherapy; sent a postal questionnaire 2 days later.	*Stage 1:* Patients were asked to rate satisfaction, preference, utilisation (booklet 1 & 2 only) and readability. *Stage 2:* Rating of information preference style; satisfaction; extent to which they had actively sought information and amount they desired. Recall assessed with 20 open ended and multiple choice questions.	*Stage 1:* no differences in satisfaction, this was high • booklets 1 & 2 were well utilised by patients and their families. • the amount of information in booklets 2 & 3 were preferred; particularly booklet 2 which was written at grade level 8 and was ranked highest for understanding • patient's preferred to receive booklets before treatment • most wanted general cancer information at the treatment decision stage; while 11-25% stated would like booklets after diagnosis *Stage 2:* satisfaction was rated highly irrespective of information preference style or the extent to which they sought or desired information no differences in recall between high and low information preference scores • 54.2% (booklet 1) and 55% (booklet 2) preferred to receive them at the time of treatment decision; a third before chemotherapy and 10% at diagnosis.

Author, country, grade	**Aims of the study**	**Patient population**	**Study design**	**Outcome measures**	**Results**
Clotfelter 1999[69] USA Ic	To assess the efficacy of an educational intervention on patient's pain management and pain intensity	36 elderly cancer patients aged between 66-88 years *C*: 61% females; *I*: 67% females *Types of cancers*; breast (C:44% I:62%) lung (C: 17%; I: 0%); bladder (C:0%; *I*:5%) prostate (*C*:17%; I:22%) colon (*C*:5%; *I*:11%) lymphoma (*C*:17%; *I*:0%)	RCT; repeated measures design; patients recruited form one private oncology practice *C*: (n=18) routine pain management from clinic staff *I*: (n=18) given a booklet "Managing Cancer Pain"; patients and their spouses watched a 14 minute video which discussed communicating pain needs; medication addiction, tolerance and side effects; medication types and administration; support groups; non-drug interventions All participants assessed their present pain intensity at the start of the study and 2 weeks later at 2 different times of the same day	Visual analogue Scale (VAS); patients marked their present level of pain along a horizontal line from "no pain" to "worst pain imaginable"; 2 ratings on the same day were used as an average pain intensity rating	*Pre-intervention comparisons;* • *C* group had a higher mean level of pain (17.5) than the *I* group (14.2); controlled for in post-intervention analysis *Post-intervention comparisons;* • patients in the *I* group had significantly mean level of average pain intensity (16.3) than *C* patients (29.4) *Pre/post intervention pain levels;* • both *I* and *C* groups showed a slight increase in pain over the study period; average pain intensity was rated mild to moderate

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Derdiarian 1989[76] USA Ib	To assess the effects of an individualised educational/ counselling intervention on patients and their spouses satisfaction and ability to cope with cancer	60 recently diagnosed male cancer patients with a first-time diagnosis of non-terminal cancer; not yet receiving treatment; mean time since diagnosis 7 days *Types of cancers*; 32 melanoma; 21 sarcoma; 7 colon; 1 testicular age range 25 to 55, mean age 41; *C* and *I* groups not significantly different	*Design* –RCT RCT; repeated measures; patients recruited from a clinic in one cancer centre; blinded. *Intervention* – *C*: (n=30) received routine verbal and written informal information, counselling or follow up care as requested, or if indicated by the informational needs assessment, from the clinic *I*: (n=30)received individualised formal information, counselling, follow up care and referral as indicated by informational needs assessment; literature published by the American Cancer Society; information relating to other agencies and when and how to contact them; 1-2 follow up telephone calls to check the adequacy of the information All participants and spouses completed informational needs and satisfaction instruments independently at baseline and 5-10 days later.	Patient-Informational Needs assessment; Spouse-Informational Needs Assessment both measure disease, personal, family and social informational needs on a 10-point rating scale; Patient-Satisfaction; Spouse-Satisfaction 24 item rating scale; 8 items assessed information received on coping	*Pre-intervention informational needs and satisfaction;* • no significant differences observed between *C* and *I* patients and their spouses *Pre/post comparisons;* • no significant differences for **C** patients and their spouses for informational needs or satisfaction • significant difference between *C* and *I* on satisfaction and informational measures but not for coping post-intervention • *I* patients and their spouses were more satisfied with the information they received and gained more information then *C* patients and their spouses.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Drury et al. 1996[1] UK IIIc	To assess the acceptability of patients with cancer holding their own shared-care record	34 patients with progressive cancer and a prognosis of three months or more. 38% female; mean age 65; *Types of cancers:* not reported	Observational study of out-patients recruited over 13 week period in 1992 from a hospice and three general practices. All patients were given an shared care record detailing appointments, medication, carers' addresses and contact telephone numbers, the contact address of support organisations, and a diary of significant events to be completed by patients and carers. Two patient interviews were carried out after entry, at 4-6 weeks and 10-12 weeks; carers were interviewed at 10-12 weeks	In-depth, semi-structured interviews, developed by the working group	*Record use and value:* • after 4-6 weeks 41% patients were writing in it, 65% were reading it and 76% took it to appointments (after 10-12 weeks: 37%, 67% and 80%, respectively) • professional carers use was similar after 10 to 12 weeks • community nurses used it the least frequently • patients found the diary pages, medication pages, page of contact addresses for carers and appointments page helpful • after 10-12 weeks the majority of patients, professionals and relatives found the record helped them a lot.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Deutsch 1992[64] UK IIIc	To examine whether taping consultations improves communication with patients	100 adult cancer patients 78% responded to questionnaire; *Types of cancers:* not reported	Cross-sectional survey of patients attending a general clinical oncology practice for a consultation where it was anticipated that difficult issues would need to be discussed; patient given tape of consultation to keep; follow up not stated	Questionnaire on tape use and value of content	• tapes played a range of 1-12 times, to relatives, friends, neighbours and to GPs. • all thought it was worthwhile. • the content was judged to be correct by all respondents in terms of the amount of information.
Eardley et al. 1988[61] IIb UK	To assess the impact of a booklet about radiotherapy on patients' worry about treatment and satisfaction with information about radiotherapy	415 new patients scheduled for a course of radiotherapy and waiting for treatment at a tertiary referral centre *Types of cancers:* not reported	I group (n=200) mailed the booklet and questionnaire about worries about radiotherapy. *C* (n=215) mailed questionnaire only	Ad hoc mail questionnaire	Views on booklet: 80% patients thought it a good idea, 66% found it helpful Patients receiving the booklet were significantly less concerned about side effects and more satisfied with information

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Helgeson & Cohen 2001[78] USA Ia	To examine the effects of 8-week support group interventions on the quality of life of women with early stage breast cancer by a 3-year follow-up.	A total of 312 women diagnosed with stage I or stage II breast cancer, treated with surgery followed by adjuvant chemotherapy. Mean age: 48.	*Design* –RCT *Intervention* – • Education: providing expert information and enhancing the women's control over the illness experience. • Peer discussion: an oncology social worker and nurse facilitated group discussions focused on the expression of feelings. • Education plus peer discussion. • Control.	Repeated measures: • (T1) Women were interviewed at baseline. • (T2) 1-2 weeks after the intervention women were interviewed over the phone and completed a mailed questionnaire. • (T3) 6 months later a follow-up took place. • (T4) another 6 months later another follow-up took place. • (T5) and (T6) occurred 1 and 2 years later. SF-36 measured health-related quality of life at all waves.	The benefits of the education intervention were maintained over a 3-year period, although effects dissipated with time. Consistent with the results of 6 months after the interventions no benefits of the peer discussions were found, either alone or in combination with education.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Hogbin et al. 1989[65] UK IIIc	Is the taping of the "bad news" interview practicable and of benefit to the patient?	46 cancer patients: 42 females; mean age 56 years *Types of cancers;* 35 breast; 11 bowel	Prospective study of patients attending for a consultation about their diagnosis and treatment to 3 hospitals' general surgical outpatient departments. Consultation was taped and patients were invited to take it home - 95% listened to it. There were no significant practical difficulties carrying out the recording.	Tape returned to the surgeon when patient had finished listening to it, with a questionnaire. Tape transcripts analysed using Stiles' verbal response modes.	• all patients found it helpful • 38% felt it helped to recall information otherwise forgotten, most frequently about treatments • those who wrote free comments were extremely positive • 21% found the tapes upsetting

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Hogbin et al. 1992[47] UK Ib	To examine whether audiotapes of "bad news" consultations improved patients' retention of information given during the interview and whether the provision of tapes has any bearing on psychological morbidity and other post-consultation events.	A total of 67 women diagnosed with breast cancer. This group was identified as showing particular dissatisfaction with information given to them about their disease and treatment. *Mean age*: I=57.54 years. C=57.88 years.	*Design* –RCT *Intervention* –The women were given a tape with the interview regarding the diagnosis and treatment by a consultant surgeon to take away and make reference to it during the preoperative period.	*Three questionnaires were administered*: • the Understanding Questionnaire: devised specifically for this study, measuring how well the subject had understood different aspects of the treatment information. • The HADS scale: to measure the subjects' current degree of anxiety and depression. • The RSCL: to measure the subjects' psychological and physical distress as experienced by cancer patients. *Repeated measures:* • Following the consultation (all three of the questionnaires) • Two to three days preoperatively (partners: Understanding questionnaire plus HADS scale). • Patients: HADS plus RSCL; partners: HADS.	*Understanding questionnaire*: the tape recording produced a better level of understanding of treatment in the immediate preoperative period (Wilcoxon T=75, d.f.=30, p<0.01). *HADS*: measures were on average at sub-clinical levels in both groups. A considerable proportion of each sample did exceed the threshold. *Seeking further information:* patients in the "no-tape" group made significantly more visits to their GP. *Tape usage:* patients made good use of the tapes and responded positively to the tapes. Partners experience comparable degrees of psychological morbidity. Women who undergo wide local excisions remain significantly more anxious postoperatively than women who have mastectomies.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Hutchcroft et al. 1984[59] Canada Ic	To evaluate the efficacy of a general cancer information booklet in preparing patients for their first visit to a cancer centre.	161 cancer patients due to attend a cancer clinic during an 11 month period; 3 groups comparable on age and sex; *Types of cancers:* not reported	RCT; blind coding of interview schedules; patients recruited from the appointments register 10 days prior to their first clinic visit; randomly assigned to one of 3 groups; *Mail group:* (n=32) received the booklet by mail before the visit *Before group*: (n=50) received the booklet at the first visit before interview *Control group:* (n=79) given booklet after interview on the first visit Booklet included information about; the centre, transportation, care and treatments, resources and services, volunteers, financial matters and the Canadian Cancer Society	Interviewed at the clinic on the first visit using an 18 question precoded interview schedule; open-ended and multiple choice questions assessed: impression of the visit, knowledge of their disease and treatment; knowledge of resources; helpfulness of the booklet	*Comparison between the groups;* • those who received the booklets prior to interview were better informed about specific/non-specific cancer resources • no significant differences between the groups given the booklet prior to interview ;these were combined into *I* group • *I* group were more likely to feel well informed; demonstrated with higher scores on 4 out of 7 items • *I* group more likely to feel well informed about reason for attending the centre • the earlier the booklet was received the less confused patients felt about the visit.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Johnson 1982[75] USA Ic	To measure the effects of a structured patient-centred educational program on chronically ill patient's knowledge of their disease and its ramifications	52 patients randomly selected from a group of cancer patients either newly diagnosed or re-diagnosed; *Types of cancers:* not reported	Prospective RCT, method not stated, not blind, individuals paired before being randomised; private hospital outpatient care settings; follow up after 4 weeks; *I* (n=26) 8 x 90 minute "I can cope" sessions over 4 weeks given by a multidisciplinary team, plus access to a resource centre *C* (n=26) no structured learning instruction or access to resource centre.	State Anxiety Inventory; Purpose in Life Test; a "course inquiry" test for acquisition of factual knowledge; use of learning resources	*I group improvement in:* • mean score for levels of anxiety • mean score for knowledge • mean score for meaning of life *No difference in:* • utilisation of learning resources.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Jones et al. 1999[74] Scotland Ia	To compare the use and effect of a computer based information system for cancer patients that is personalised using each patient's medical record with a system providing only general information and with information provided in booklets.	525 patients started radical radiotherapy; 438 completed follow-up.	*Design* –RCT *Intervention* – I=two groups were offered information via computer (personalised or general or both) with open access to computer thereafter. C= offered a selection of information booklets.	Patients' views and preferences, use of computer and information, and psychological status; doctor's perceptions; cost of interventions.	More patients offered the personalised information said that they had learnt something new, thought that the information was relevant, used the computer again, and showed their computer printouts to others. There were no major differences in doctor's perceptions of patients. More of the general computer group were anxious at three months. With an electronic patient record system, in the long run the personalised information system would cost no more than the general system. Full access to booklets cost twice as much as the general system.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Lechner & De Vries 1996[71] The Netherlands IIIc	To evaluate the impact of a cancer information helpline.	532 callers who contacted the helpline within a 4 week period Included cancer patients (46%), their friends/relatives (37%) and the general public (17%). 74% female; patients significantly older than the other groups (mean age 52); *Types of cancers:* Not reported	Retrospective evaluation of a cancer information helpline by users of the service during October 1989. During the call information was collected on the type of caller, demographics, type of cancer and stage of cancer to enable selective analysis of responses. Postal questionnaire was later sent to 619 callers who agreed to participate. 73% responded.	A structured questionnaire measured; method of communication, quality of information, communicators' skills, degree to which their needs were met, impact of the helpline and overall level of satisfaction	*Method of communication.* majority evaluated this positively but 12% thought that it was not sufficiently accessible *Information.* • 42% wanted general information • of these 78% reported receiving sufficient information • 86% wanted situation specific information. 73% were satisfied with the information provided. *Communicators' skills.* 72% rated this positively; patients and friends/relatives tended to view this more positively *Satisfaction.* • 94% very satisfied or satisfied, 2% no opinion, 4% dissatisfied *Impact.* 42% felt that their tension had decreased; 31% stated that their fear had decreased most callers believed that their expectations had been met.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Lilja et al. 1998[82] Sweden Ia	To evaluate the effects of extended preoperative information given by anaesthetic nurses on perioperative stress, in patients operated on for breast cancer or total hip replacement (THR).	A total of 94 patients. 44 operated on for breast cancer and 55 having a THR operation.	*Design* –RCT Randomised clinical trial with a pre- and post-test. *Intervention* – I=Patients were informed by the anaesthetic nurse about what was going to happen to the patient. C=Patients were given anaesthesia according to standard routines.	To conceptualise stress phenomena and evaluate the effects of preoperative information: A laboratory test (S-Cortisol) The Hospital Anxiety and Depression Scale (HADS) Visual Analogue Scale (VAS)	There were no significant differences between the intervention group and control group for patients with breast cancer or for patients with THR. Breast cancer patients in the intervention group were significantly more anxious than THR patients in the intervention group ($p<0.01$). Breast cancer patients in the intervention group showed the highest anxiety scores on the HADS scale on the day of surgery.

Author, country, grade	**Aims of the study**	**Inclusion criteria**	**Study design**	**Outcome measures**	**Results**
McClement & Hack 1999[45] Canada Review	To review the literature evaluating evaluated the effects of audio-taping the oncology treatment consultation. An intervention designed to improve communication.	Studies which evaluated the effects of audio-taping on patient's psychological well-being, information recall and satisfaction. *Types of cancers:* heterogeneous cancer types in 8 studies; bowel and breast cancers in 1 study.	Critical review of 9 studies. 5 randomised control trials (n= 67, 34, 142, 117). I groups- given a copy of the taped consultation. 3 descriptive exploratory studies (n= 46, 29, 76). 2 gave questionnaires, 1 study method not stated. 1 randomised single blind cross-over trial (n=182). Compared audio-tape with summary letter.	Hospital Anxiety & Depression Scale General Health Questionnaire Psychological; Adjustment to Cancer Scale; tape content analysis Roter Interaction Analysis System; satisfaction and recall measures.	*Psychological distress:* 3 studies showed a reduction in psychological distress; 2 found no effect. 1 study found that for patients with poorer prognoses audio-tapes could be detrimental. *Information recall:* • uncontrolled studies reported enhanced memory recall; RCTs produced mixed results with either greater recall or no effect *Patient satisfaction:* Overall the audio-tapes were of benefit; satisfaction levels were generally high but there was some evidence for increased satisfaction in I groups

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
McHugh et al. 1995[63] UK Ib	To assess the efficacy and acceptability of providing the patient with an audiotape of the "bad news" interview.	117 patients to be given potentially distressing information. *I*: 63.5% female; mean age 45 *C*: 53.7% female; mean age 44.3 *Types of cancers:* breast (*I*:14.3%, *C*:11.1%); gestational trophoblastic disease (I:32%, C:22.2%); testicular (I:11.1%, C:24%); bowel (I:6.3%, C:5.6%); ovary (I:4.8%, C:5.6%); lung (I:3.2%, C:5.6%); other diagnoses (I:28.6%, C:25.8%)	RCT allocated by the CRC Clinical Trials Centre telephone randomisation service, clinician blinded; consecutive new out-patient referrals to a medical oncology department in a teaching hospital; follow up occurred a mean of five months after baseline; *I* (n=63) given copies of the interview tapes and encouraged to listen to them at home *C* (n=54) not given the interview tapes.	30 item GHQ-30; 14 item HADS; an information retention questionnaire; I group received an attitude to tape questionnaire	*I group improvement in:* • recall of information on tests, results, name of treatment, other treatments, side-effects of treatment and specific instructions about self-care ($p<0.05$) • GHQ scores for the *I* group patients with a good prognosis • GHQ scores for *C* group patients with a poor prognosis *Worse outcomes in:* • GHQ scores for poor prognosis patients receiving the tape

Author, country, grade	**Aims of the study**	**Patient population**	**Study design**	**Outcome measures**	**Results**
Mohide et al. 1996[58] Canada Ib	To evaluate the value of an information package or a mini-version in reducing distress and meeting information needs	304 patients newly diagnosed with cancer 59% female; mean age 63 *Types of cancers;* breast (*I1*:25, *I2*:25, *C*: 25); gynaecological (*I1*: 25, *I2*:26, *C*:27); lung (*I1*:25, *I2*:26, *C*:25); prostate (*I1*: 25, *I2*:25, *C*:25)	RCT of patients attending a cancer centre for the first time pre-randomised to one of three interventions: *I* Group 1(*I1*); n=100 received new patient information package (NPIP) one week before their first appointment *I* Group 2 (*I2*); n=102 sent mini version of the NPIP *C* Group (*C*); n=102) no information package Patients followed up 30 minutes before the clinic appointment	Brief Symptom Inventory; Scherer Self-Efficacy Scale; a questionnaire on expectations and fears about the appointment, information preferences, understanding, usefulness of NPIP	• majority of *I* groups found the information packages easy to understand and useful, as did the attending relatives • *I* groups expressed a greater preference for receiving information before they arrived, and receiving it by mail. *No difference in*: • psychological distress, preferences for receiving information (98% overall) or effectiveness between the two packages

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Ong et al. 2000[66] The Netherlands Ib	To assess the effect of access to audiotape of patient's own initial consultation with oncologist in terms of patient satisfaction, recall and quality of life	201 patients, all aware of their diagnosis of cancer, referred to gynaecological or medical oncology clinic. *Types of cancers:* 70% gynaecological, 30% other	Double blind RCT. Immediately after consultation, patients allocated to intervention group were given audiotape. Questionnaire follow up at one and 12 weeks after consultation.	Previously piloted Recall Questionnaire Patient Satisfaction Questionnaire Quality of Life: Rotterdam Symptom Checklist Medical Outcome Studies	*I Improvement in:* • recall of diagnosis, prognosis, operation, radiotherapy, alternative treatment, side effects, consequences ($p<0.001$) • recall of trial procedure and chemotherapy ($p<0.01$) • satisfaction with consultation ($p<0.01$)
Rainey 1985[68] USA IIb	To assess whether preparatory education for patients receiving radiotherapy improves knowledge and reduces anxiety compared to standard information	60 consecutive cancer patients undergoing their first course of radiation therapy Equal numbers of males and females; mean age 60.8 *Types of cancers;* "head and neck most frequently represented group, followed by breast, brain, cervix and prostate".	Prospective comparison study of patients attending a cancer centre; *C* (n=30) standard procedures and a booklet; I (n=30) shown a 12-minute slide-tape program that provided information on equipment, personnel, scope of radiotherapy, procedures; introduced to staff; encouraged patients to be inquisitive Assessments 1-3 days after start of treatment and during the final 5 days of the 4-6 week period of treatment	Radiation therapy questionnaire to assess knowledge; State/Trait Anxiety Inventory; Total Mood Disturbance, (also looked at preferred styles for coping using).	*At the start of treatment:* • *I* group showed greater accuracy of treatment-related knowledge • no significant difference between groups in affective status (anxiety levels or mood) *At follow up:* • I group patients had less state anxiety and lower total mood disturbance, regardless of coping style • no longer a significant difference in knowledge levels

Author, country Grade	**Aims of study**	**Patient population**	**Study design**	**Outcome Measures**	**Results**
Ream & Richardson 1996[57] UK Review	To review the literature on the role of information in patient's adaptation to chemotherapy and radiotherapy	6 studies evaluating the effects of informational interventions for cancer patients; *Types of cancers:* not reported	Review of studies with an intervention and a control group, 5 randomly assigned the groups; Studies used interventions incorporating information about treatment side effects and the management of symptoms. Information was in written format, or as a newsletter, or by tape, or verbally	State-Trait Anxiety Inventory, Multidimensional Health Locus of Control, Profile of Mood States, Sickness Impact Profile, Self-Care Behaviour Questionnaire	• all of the studies reported positive effects of intervention • in all but 1 study, more effective self-care behaviours were being initiated by the patient • inconclusive evidence on whether anxiety was reduced

Author, country, grade	**Aims of the study**	**Patient population**	**Study design**	**Outcome measures**	**Results**
Robinson et al. 1999[77] Canada Ia	To test the effectiveness of a group psychoeducational program based on the "information-motivation-behavioural skills" model of behaviour change in increasing the rate of compliance to regular vaginal dilation.	A total of 32 women with stage I and II cervical or endometrial carcinoma who were being treated with radiotherapy.	*Design* –RCT Randomisation by following a random number table. Participants were assessed prior to intervention and again at 3,6,9 and 12 months postdiagnosis. *Intervention* – I= 2 1.5-h psychoeducational group sessions, which had an informational, motivational and behavioural component. C= Patients met with a counsellor and were given a copy of Sexuality and Cancer.	Primary outcome: Sexual health measured by the Sexual History Form (SHF). Secondary outcomes: 1. Information measured by the sexual knowledge questionnaire. 2. Motivation measured by the fears questionnaire. 3. Behavioural skills measured by compliance with vaginal dilation.	Intervention group improvements: Younger women attending the experimental program (44.4%) were significantly more likely to follow recommendations for vaginal dilation than those who received the control intervention (5.6%). Women, regardless of age, reported less fear about sex after cancer treatment. The older women gained more sexual knowledge. No intervention group improvements: There was no evidence that global sexual health improved.

Author, country, grade	**Aims of the study**	**Patient population**	**Study design**	**Outcome measures**	**Results**
Smith et al 2000[56] UK IIIc	To investigate health professionals' views on imparting information to cancer patients, and to consider the implications of these findings. This is done as part of the Teamwork Project.	A wide range of health professionals across the UK, including policy/decision makers, information providers (general and cancer-specific), medical and nursing personnel.	*Methods:* One-to-one interviews, meetings, discussion meetings, continual networking, a consultation exercise.	Health professionals' views on relevance and value of patient information and education. Their views on the use of a Personal Information File. Their role in the provision of information and education to patients.	There is a growing understanding of the need for patient information to be personalised, appropriate and timely. The response from health professionals to the idea of the Personal Information File was very positive. There appeared to be uncertainty about who should be routinely providing patient information and education.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Tattersall et al. 1994[48] Australia Ic	To compare the efficacy of providing a tape of the first consultation with an oncologist	182 adult cancer patients without advanced incapacity I Group 1 (*I1*): 76% female; mean age 51 I Group 2 (I2): 81% female; mean age 51 *Types of cancers;* Breast (I1:48%, I2:42%); gynaecological (I1:18%, I2:17%); other (I1:32%, I2:38%); none (I1:2%, I2:3%)	*Design* –RCT crossover trial, single blind; new referrals between 3/1992 to 1/1993 for consultation with one medical oncologist at a university teaching hospital; consultation audio-taped and the oncologist documented the most salient points covered then prepared a letter summarising the consultation; *I 1* (n=94) received the tape then letter; *I 2* (n=88) received the letter then tape; the second communication aid was received 7-10 days after the first; Follow up then occurred 7-10 days after the tape or letter had been given to the patient	14-item HADS; satisfaction with communication aids; ranking of six possible post-consultation communication aids: recall compared with the salient points nominated by doctor outcomes assessed by telephone interview and postal questionnaire	• anxiety scores decreased for both groups, depression unchanged • patients felt the tape was more effective in reminding them • the tape was the preferred post-consultation communication option above a letter, a phone call with oncologist, a letter from the oncologist to their doctor, a talk with the oncology nurse, or phone call with the oncology nurse • recall similar for both groups • > 80% of both groups satisfied • those who wanted minimal news were less satisfied with the letter than those wanting good/all news.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Thomas et al. 2000[70] UK Ia	To assess the benefits of receiving a cassette of an educational video to take home following the first consultation, and to assess patients' views with regard to the type and level of information in this carefully prepared film.	A total of 220 patients receiving chemotherapy and radiotherapy over a 6-month period. *Eligibility criteria:* • All patients who were >15 years of age, • Could understand English, • had a diagnosis of cancer . • had completed a consultation with an oncologist during which either chemotherapy or radiotherapy was recommended. I=113 patients, Mean age: 59. Male:40 Female:73 C=107 patients, Mean age: 63. Male:52 Female:55	*Design* –RCT *Intervention* – I=receives the educational video. C=does not receive video.	• Hospital Anxiety and Depression Score (HAD) • An *ad hoc* questionnaire: at the time of randomisation (immediately after the consultation with the oncologist) and 3 weeks into either radiotherapy and chemotherapy. This questionnaire recorded the opinion of the patients on the level and style of information it contained. A separate section measured patients' satisfaction with the information they received.	*Intervention group improvements in:* The mean HAD anxiety score was significantly lower during treatment compared with the control group (4.6 3.7 (range: 0-18) versus 7.4 5.2 (range: 0-20), Chi square test P=0.001). The mean HAD depression scores were also significantly lower in the patients prepared for the side-effects of treatment with the video (2.9 2.9 (range: 0-13) versus 5.3 4.7 (range0-21), Chi square test P=0.001). 81% felt that the video was helpful, only 5% of patients felt this extra information was worrying.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Venn et al. 1996[72] UK IIIc	To review the quality of a cancer information service provided by the British Association of Cancer United Patients (BACUP)	282 (69%) of callers to the information line; excluded those requiring booklets *Callers;* 36% patients; 62% family/friends; 2% others. 80% females *Types of cancers:* 80 breast cancer inquiries; 326 other	Cross-sectional survey of callers during a 10 day period in August 1991; undersampled breast cancer inquiries so as to include other cancer types, otherwise random The cancer information service is a telephone and letter service that provides information and psychosocial support; staffed by trained oncology nurses Postal questionnaire sent to those who agreed to take part one month later	Structured 5-point scales evaluated 7 aspects: access; reason for calling; quality of information and suggestions; nurse's communication skills; impact and satisfaction. Open-ended questions for comment.	*Information & communication skills;* • 87% had received all/almost all the information they required • communication rated positively *Impact & satisfaction;* • callers tended to rate impact as "good" and satisfaction as "very good" • in patient group 18% of impact predicted by quality of information; 14% of satisfaction predicted by communication skills • in friends/relatives group 10% of emotional impact explained by communication skills; 37% of satisfaction explained by communication skills and information quality.

Author, country, grade	**Aims of the study**	**Patient population**	**Study design**	**Outcome measures**	**Results**
Whelan et al. 1998[62] Canada IIb	To evaluate a cancer patient information folder designed to improve the dissemination of written information.	300 consecutive newly diagnosed cancer patients, admitted to a regional cancer centre Time 1 (*T1*): 90 females; mean age 61.4 Time 2 (*T2*)*;* 92 female; mean age 61.8 *Types of cancers:* breast (*T1*:49,*T2*:49); gastrointestinal (*T1*:29, *T2*:23); prostate (*T1*:20, *T2*:21); lung (*T1*:17, *T2*:21); gynaecologic (*T1*:18, *T2*:14); head/neck (*T1*:12, *T2*:19); other (*T1*:5, *T2*:3)	Pre/post intervention design; random selection; equal numbers of patients at T1 and T2; patients contacted within 1-2 weeks of their first appointment *T1*(Pre)- 4 month assessment of existing practice *Intervention*- a personal file folder for each patient with details about written information received, plus pamphlets and information and support materials specific to the patient's needs *T2* (Post)- 6 weeks later over a 4 month period	Structured 15-30 minute telephone interview by a researcher; asked to rate understanding and usefulness of the pamphlets; satisfaction with type and amount of information received; their preferences for information	*Comparison of T1 & T2;* T1-36% of patients with treatment planned received relevant information increase in the number of pamphlets received at T2 • chemotherapy and radiotherapy information increased at T2 • patient satisfaction increased over the study period *Patient preferences for information;* • 27% before the first visit; 29% at the first visit; 34% as needed • treatment related pamphlets read and perceived more useful than support services pamphlets; both rated equally for understanding.

7. PSYCHOLOGICAL SUPPORT SERVICES

Nature of the evidence

Four meta-analyses have been conducted in this area, two from the USA and a more recent one from the UK. Meyer & Mark[84] based their analysis on 45 studies and Devine & Westlake[85] on 116 studies. Sheard & Maguire[86] presented the results of two meta-analyses in their paper based on 39 trials. Recently, a critical and systematic review has been published reviewing all identifiable publications about psychological therapies used by cancer patients. This review was conducted in Australia[87]. In addition, the data of 25 individual studies were extracted and put into tables. There were 21 grade I randomised controlled trials. There are eight grade Ia studies, eleven grade Ib, and two grade Ic. There are four grade II (a and b) studies. The majority of the studies were carried out in the USA (13), six in the UK, two in Scotland, one in Canada, one in Australia, one in Sweden and one in Japan.

Types of interventions

The meta-analyses had the following objectives: to assess published RCTs of psychosocial interventions with adult cancer patients[84], to assess psycho-educational programmes aimed at improving the psychological and physical well-being of cancer patients[85] , and to assess the effect of psychological interventions on anxiety and depression in cancer patients[86]. A recent publication reviewed critically and systematically all identifiable publications about psychological therapies used by cancer patients to provide an objective and scientific evaluation of non-traditional therapies[87].

Psychological interventions for people with cancer made use of different approaches, such as educational based group interventions, carried out in a variety of ways[88-95]. Bloom et al.[80], for example, experimented with an interdisciplinary team, Moynihan et al.[96] used a mental health nurse as therapist, Syrjala et al.[91] used a psychologist, and Bultz two psychologists as facilitator. Bucher et al.[33] evaluated a problem solving education programme, which was designed as a one-to-one educational approach, delivered by a trained social worker. Hosaka et al.[97] tested a structured group intervention program, where the teaching was carried out by health professionals and/or patients themselves. Toseland et al.[98] offered both individual and group sessions given by an oncology social worker.

Mansson et al.[88], Maunsell et al.[99], Spiegel & Bloom[100], Classen et al.[101], Evans[93] reported on group support interventions. Maughan et al.[102] and McArdle et al.[103] delivered a more individually focused intervention where the support was provided by a specialist nurse. In Connor et al.[104] who examined the effects of a psychosocial intervention on denial-related coping ability, the patients were also approached individually. Schwartz[105] evaluated a single two hour problem solving intervention with a health educator, involving discussion about problem definition, generation and evaluation of solutions, decision making and solution implementation. In Barker[106] patients received support from an oncology nurse at home after their treatment was finished. Ambler experimented with an advocacy style of nurse counsellor intervention to find out if this was a more effective and appropriate strategy to approach women with breast cancer at the crucial stage of diagnosis. This study was driven by the need to find a framework for psychological support that could be employed by the growing number of specialist breast care nurses in the UK early in the process of diagnosis and treatment. In Sandgren[107] a telephone administered intervention providing breast cancer patients with cognitive-behavioural therapy was tried out.

A few trials included more than one type of psychosocial intervention, which was offered during the same time frame to patients having the same characteristics, to assess which interventions are the most effective for specific circumstances[78;79;91-93].

The majority of the studies evaluating psychosocial interventions were directed at breast cancer patients. This included newly diagnosed non-metastatic breast cancer patients[99], early stage breast cancer patients[78;95;105], women receiving chemotherapy, radiotherapy, hormone therapy[80], women undergoing breast cancer surgery[103], women after breast surgery for cancer[80;97], women with metastatic breast cancer [89;91;97;100;101] and breast cancer survivors[90].

Other studies focused on patients who had undergone cystectomy for bladder cancer[88], women who had had major pelvic surgery[102], patients with testicular cancer[96] and cancer patients in general and their carers[33]. Evans[93] and Moorey[92] both worked with patients who had different kinds of cancers and focused on those who were depressed and about to undergo radiotherapy[93]. Other studies focused on patients who had abnormal adjustment reactions[92], and who had malignant disease screened for psychological morbidity[94], Bultz et al.[95] and Schwartz[105] targeted relatives of breast cancer patients. The intervention Toseland et al.[98] implemented was primarily for caregivers, but also for the patients they cared for.

The interventions were aimed at assisting with psychological adjustment to the disease by supportive group psychotherapies. These were emotion-focused, aimed at the management of disease-related emotions and the accommodation of the disease[88;90;92;101;103;106]. In some trials this was offered as one arm among other options[78;80;91;92]. The other interventions were mainly problem-focused. These were aimed at providing information and enhancing control[33;94;96;98], or they were carried out as one arm of a trial[79;80;93]. Hosaka et al.[97] and Ambler et al.[108] included both psychological support and problem-focused therapies in his intervention. Two studies were directed at the recognition of patients with needs for psychological support[99;102] or included this as a component[79;96]. Psychological interventions were also implemented for cancer pain relief[90;91;109], and as part of a trial[101].

Outcome measures

The meta-analyses have used different categories of these varied mixes of psychotherapeutic interventions that have been tried out to provide better care for cancer patients. Meyer & Mark[84] concluded with their analyses of 45 studies, that psychosocial interventions have positive effects on functional and emotional adjustment and treatment and disease related symptoms in adult cancer patients. Devine & Westlake[85] concluded with their meta-analysis of 116 studies that psychoeducational care improved anxiety, depression, mood, nausea, vomiting, pain and knowledge among adult patients with cancer. Psychoeducational care covers a plethora of techniques, many of which have been shown to be useful. For example: guided imagery, muscle relaxation, systematic desensitisation and meditation were effective for treating nausea. The meta-analysis was unable to assess the relative effectiveness of these various types of psychoeducational care. The findings of two meta-analyses were presented in Sheard & Maguire[86] using anxiety and depression as a main outcome measure. Their analyses suggest that preventative psychological interventions in cancer patients may have a moderate clinical effect upon anxiety but not depression. There are indications that interventions targeted at those at risk of or suffering significant psychological distress have strong clinical effects.

The recently published review by Newell et al.[87] questions the consistent conclusions reached by previous reviews about the benefits of psychological therapies for cancer patients, which have recommended widespread and routine use of these therapies to improve patients' psychosocial, side effect, survival, and immune outcomes. As these previous reviews of the literature lacked methodological rigor, they suggest that a more cautious approach towards these non-traditional therapies should be adopted. The major finding of the effectiveness review stage was that, despite a body of literature that spans more than 40 years and includes more than 150 randomised controlled trials only relatively few tentative recommendations about the effectiveness of psychological intervention strategies at improving cancer patients' outcomes could be made. However, they could suggest, by exploring the relative effectiveness of the different intervention strategies for each outcome and follow-up period, the most worthwhile strategies for future investigation in relation to each type of outcome.

The individual studies reviewed show mixed outcomes of the psychosocial interventions for patients with cancer. The interventions which were aimed at self-help and self-care promotion generally show positive effects of the treatment, at least initially. Bucher et al.[33]achieved a positive result with a problem solving education program designed to bolster the ability of patients and families to help themselves. Family caregivers are especially likely to benefit from this programme. Barker[106] found that anxiety and depression scores in patients who received social support from an oncology nurse were lower than those in the control group, but that these differences were not sustained longer than the intervention period. Edelman's study[89] showed mood, depression and self esteem were beneficially effected by cognitive-behavioural therapy among breast cancer patients but these effects were no longer present at three months, and at ten months the intervention group faired more poorly than the control group. Hosaka et al.[97] found that the clinical effectiveness of a structured group intervention was persistent for Japanese breast cancer patients without psychiatric comorbidity at entry. However, this program was insufficient for those with adjustment disorders concomitantly, and additional group meetings and individual psychotherapy is needed for them. Bloom et al.[80] concluded that the patient counselling/information programme had a long-term positive value. Sandgren's study[107] achieved an improvement in mental functioning and distress levels with cognitive-behavioural therapy .The problem-focused intervention implemented by Helgeson et al.[78] as one arm of the trial was successful for early stage breast cancer patients, and Braden et al.[79] show that both more and less resourceful women benefited from the interventions. The advocacy style of nurse counsellor intervention which Ambler compared with a more conventional approach, which was aimed at both enhancing control and providing support did not provide different outcomes when assessed by the standardised scales[108]. The qualitative data however showed the superiority of the advocacy method over a conventional approach. Two randomised controlled trials which implemented interventions with adjuvant psychological therapy (APT) reach similar results. Moorey et al.[92] demonstrated that APT, a type of cognitive therapy designed specifically for use in cancer patients, compared to unstructured supportive counselling, resulted in greater changes in patients adaptations to cancer and coping and that these effects lasted longer. Greer et al.[94] achieves improvement in mental adjustment to cancer with APT, also with longer effects. Moynihan et al.[96], however, reported no benefit of adjuvant cognitive and behavioural treatment for patients with testicular cancer. This group of patients seemed already to have considerable coping abilities.

The supportive interventions aimed at improving the patient's ability to adjust to the changed life situation show both positive and negative results. The one arm of the trial in Helgeson et al.[78] in which emotion-focused therapy was given was not effective. The psychosocial intervention in Mansson et al.[88] was beneficial only to patients who had undergone one particular kind of surgery (cutaneous urinary diversion). Classen et al.[101] report on the positive effect on metastatic breast cancer patients of supportive-expressive group psychotherapy, developed to help patients with cancer face and adjust to their existential concerns. Evans'[93] study experimented with both cognitive-behavioural and socially supportive therapy and finds that both types of interventions were effective, but that social support resulted in longer lasting benefits.

Three randomised controlled trials showed beneficial effects of psychosocial interventions in relatives of cancer patients. Toseland et al.[98] achieved positive results with the short counselling programme they provided to improve problem solving and coping abilities, although these results were not maintained over time. Schwartz [105] found that a problem solving technique, when regularly practised by first degree relatives of breast cancer patients, reduced their cancer-specific distress. Bultz[95] found that partners of breast cancer patients who attended psychoeducational training had improved mood, and maintained scores of marital satisfaction, whereas the control group scores of marital satisfaction deteriorated over time. Moreover, the majority of patients felt they had benefited from their partner's attendance on the program.

The interventions with the aim of identifying patients with needs for psychological support also show different outcomes. Braden et al.[79] showed that women who evidenced high resourcefulness at baseline reported the same level of need for confidence in cancer knowledge and self-help as the women with low resourcefulness. Maunsell et al.[99] report that the monthly screening of distress levels does not improve quality of life for newly diagnosed women with breast cancer. This was due to the availability of a minimal psychosocial intervention at initial treatment. Moynihan et al.[96] showed that patients who agreed to participate in the therapy differed from those who declined and that the former may comprise the clinical group who perceive a need for psychological support.

The three studies examining the effects of psychosocial therapy on medical conditions such as pain management[90;91]and time of survival[100] reported positive results.

We have identified a study on burnout and more generalised psychiatric morbidity among gastroenterologists, surgeons, radiologists, and oncologists in the UK[110]. Doctors are thought to be susceptible to burnout, a description for work-related distress that combines emotional exhaustion, depersonalisation, and a sense of low personal accomplishment. Burnout and more generalised psychiatric morbidity warrant careful consideration, not only because they reflect the personal suffering of doctors, but also because they risk impairing the quality of care doctors are expected to deliver. Burnout was particularly associated with job stress, low satisfaction and poor communication and management skills.

Implications of the evidence for recommendations

Grade IA evidence suggests that psychosocial interventions with cancer patients are important for enhancing coping and life quality for patients with cancer. However, there is a need for caution. Psychotherapeutic interventions are not beneficial per se. Different patient groups with different types or stages of diseases have different needs. Mainly grade Ib studies show that individually tailored interventions such as the specialist nursing interventions or an interdisciplinary team seem to have a positive impact on psychological and physical functioning. The assessment of patient's needs deserves to be stressed in the recommendations.

Tables of Evidence: Psychological Support Services

Meta-analyses

Author, date, country, grade	Aims of study	Inclusion/exclusion criteria	Study design and outcome measures	Results
Meyer & Mark[84] 1995 USA Meta-analysis	To perform a meta-analysis of published RCTs of psychosocial interventions with adult cancer patients.	45 studies, 62 treatment control comparisons 5 GB; 36 USA; 2 Canada; 1 Columbia; 1 Egypt Assessing five categories of dependent measure: Emotional adjustment; Functional adjustment; Treatment or disease related symptoms; Medical measures Sample characteristics: Where mean age was reported, the values clustered around 50yrs. 55% of studies reporting gender had more than 60% female. 14 / 45 were single location / type of cancer (of these 4 breast cancer) total sample size (n) not given.	Inclusion criteria: published randomised trials of groups of adult cancer patients receiving psychosocial, behavioural or psychoeducational intervention compared with another group of cancer patients either receiving no psychosocial intervention or an extremely minimal sham procedure, and the outcome variables included the patient's behavioural, emotional physiological or medical state. (Hospice and terminal home care studies excluded because of few RCTs and preliminary work indicates that these are quite distinct from other psychosocial interventions) Interventions: Cognitive-behavioural Informational and educational treatments Non-behavioural counselling or psychotherapy interventions Social support Other e.g. music therapy (numbers of each type of study not given).	Effect sizes were homogenous for all five categories of dependent measure (when one study removed: Egyptian, and only study where patients are not told their diagnosis) Average effect sizes: psychosocial interventions have positive effects on emotional adjustment, functional adjustment and treatment and disease related symptoms in adult cancer patients. No significant effect seen for medical outcomes (but these studies involved the smallest numbers of subjects) Emotional adjustment d=.24 (CI .17 - .32) Functional adjustment d=.19 (CI.06-.32) Treatment- and disease related symptoms d=.26 (CI .16-.37) Medical d=.28 (CI-.10-.44) Interventions: no difference between intervention type and outcome (by dependent measure) Analysis Unit free effect size g = difference between mean outcome scores in treatment and control group divided by pooled standard deviation d= g x small sample size correction factor (thus obtaining an unbiased value of d).

Author, date, country, grade	**Aims of study**	**Inclusion/exclusion criteria**	**Study design and outcome measures**	**Results**
Devine & Westlake 1995[85] USA Meta-analysis Review IIb	To perform a meta-analysis and review of psycho-education programmes aimed at improving the psychological and physical well-being of cancer patients.	116 studies. Assessing 7 outcomes: Anxiety, Depression, Mood, Nausea, Vomiting, Pain, and Knowledge. *Sample characteristics:* age range 27-69; 70% had more females; 18% only females; 55% involved various malignancies. Meta-analysis performed on 98 of the 116 studies. (n=5326 patients)	*Inclusion criteria:* Experimental, quasi-experimental and pre/post single group designs with > 5 in each treatment group; 87% had control groups; 68% random allocation to groups. *Interventions;* ▪ 38 cognitive therapies (CT) or behavioural therapies (BT) or cognitive behaviour therapies (CBT) (e.g. muscle relaxation, guided imagery) ▪ 19 combinations CBT with relaxation/non-relaxation interventions. ▪ non-relaxation interventions (e.g. problem solving) ▪ 20 education (e.g. general cancer information) ▪ 20 education with counselling (various types) ▪ counselling not CBT(e.g. psychodynamic) ▪ 3 BT combined with non-CT or non-CBT.	Medium heterogeneous effect size in all outcome measures except knowledge, where effect size was hetereogenesis and large Anxiety; positive effect in 95% of studies Depression; positive effect in 92% of studies; Mood; plus? • *Nausea;* BT such as systematic desensitisation, meditation, guided imagery or muscle relaxation were found to be effective in 11 out of 27 studies • *Pain;* relaxation strategies such as muscle relaxation, guided imagery or music therapy were particularly effective. • *Knowledge;* education/teaching increased knowledge, especially when written material was included.

Author, date, country, grade	**Aims of study**	**Inclusion/exclusion criteria**	**Outcome measures**	**Results**
Sheard & Maguire 1999[86] Two meta-analyses UK	To assess the effect of psychological interventions on anxiety and depression in cancer patients.	*For anxiety:* 25 trials were identified and six were excluded because of missing data. *For depression:* 30 trials were identified, but ten were excluded because of missing data.	*For anxiety:* *19 trials (including five unpublished).* A subset of trials which were randomised, scored well on a rating of study quality, had a sample size of >40 and in which the effect of trials with very large effects were cancelled out. *For depression:* *20 trials (including six unpublished).*	For anxiety: The trials had a combined effect size of 0.42 standard deviations in favour of treatment against no-treatment controls (95% confidence interval 0.08-0.74, total sample size 1023). A most robust estimate is 0.36 which is based on the subset of trials. For depression: The trials had a combined effect size of 0.36 standard deviations in favour of treatment against no-treatment controls (95% CI 0.06-0.66, sample size 1101). This estimate was robust for publication bias, but not study quality, and was inflated by three trials with very large effects. A more robust estimate of mean effect is the clinically weak to negligible value of 0.19. Group therapy is at least as effective as individual. Only four trials targeted interventions at those identified as at risk of, or suffering significant psychological distress, these were associated with clinically powerful effects (trend) relative to unscreened subjects.

Author, date, country, grade	Aims of study	Inclusion/exclusion criteria	Outcome measures	Results
Newell et al. 2002[87] Australia	To conduct a critical review of the literature to identify areas where consistent evidence exists regarding the effectiveness of psychological therapies at reducing cancer patients' morbidity and mortality. By identifying methodologic shortfalls in the existing literature, to make recommendations to improve the design of future studies in this area.	This review describes a two-stage review process. In the first 'literature overview' stage, we reviewed all types of papers about psychological therapies for cancer patients. In the second 'effectiveness review' stage, we reviewed the outcome results from only the randomised, controlled trials categorised as having either fair or good methodologic quality.	Despite increased use of randomised controlled trial designs over time, the methodologic quality of the intervention trials , on 10 internal validity indicators, was generally suboptimal, with only one trial achieving a quality rating of 'good' for its methodology. Effectiveness results were used from 34 trials with psychosocial outcomes, 28 trials with side effect outcomes, 10 trials with conditioned side-effect outcomes, and 10 trials with survival and immune outcomes.	Only tentative recommendations for or against most intervention strategies overall or within the different follow-periods could be offered. Group therapy, education, structured and unstructured counselling, and cognitive behavioural therapy offered the most promise for their medium- and long-term benefits for many of the psychosocial outcomes explored. Some intervention strategies could be tentatively recommended for reducing patients' conditioned side effects, but very few could be recommended for reducing patients' physical side effects. Relaxation training and guided imagery appeared to provide benefits for most of the side-effect outcomes explored. Although no intervention strategies could be recommended for improving patients' lengths of survival, some tentative recommendations were possible in relation to immune outcomes, with all the strategies for which trials were performed indicating medium-or long term immune benefits.

Individual studies

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Ambler et al. 1999[108] UK IIa	To assess an 'advocacy style' of nurse counsellor intervention which aims to support patients at the highly stressful stage of receiving a diagnosis. To identify the most effective and appropriate method of intervening at the stage of diagnosis.	A total of 103 women undergoing surgery following diagnosis of breast cancer (n=76) or a benign breast lump (n=36).	*Design* –Controlled before and after study. *Intervention* – The women were supported using either the advocacy intervention or a more conventional model of care. A protocol was set out which aimed to reduce the stress of the diagnostic consultation by directing it more towards the patient's own agenda of needs at this time. The 'advocacy' style of intervention begins prior to diagnosis in contrast to the more conventional approach in which the patient meets the breast care nurse only after the diagnostic consultation has taken place. The main aims are: • to promote better understanding of treatment options, process and outcomes; • to increase patients' sense of personal composure and involvement, both in the consultation and in any decisions that are made; and • to provide emotional support at the time of diagnosis.	Visual analogue scales (VAS), used to explore the extent to which women felt fully informed about their diagnosis, involvement in the decision to have surgery, satisfaction with treatment, psycho-social functioning, perceived levels of social support and feelings about meetings with the breast care nurse. The Hospital Anxiety and Depression Scale (HADS). The Rotterdam Symptom Checklist (RSCL), to measure anxiety, depression, and psychological distress. A semi-structured interview administered by an independent researcher 2 weeks post-surgery and at 6 months follow-up.	No systematic differences emerged from the analysis of data from the standardised scales. Responses to several of the visual analogue scales employed in the semi-structured interview were more favourable in the advocacy condition. Patients in this group rated themselves as better informed, having a greater understanding of the treatment options and feeling more involved in decision-making concerning their treatment. Advocacy was also rated more favourably by those women with a benign diagnosis.

Author, date, country, grade	Aims of study	Patient population	Study design and outcome measures	Results
Barker et al. 1997[106] UK Ib	To investigate whether oncology home support improves psychological morbidity during or after treatment is completed	58 patients recruited from one hospital oncology outpatients department *Group A*: Mean age 60; 30 females *Group B*: Mean age 58; 43 females *Types of cancers:* Not reported	Cross-over, within and between subjects design; randomised in to groups based on odd/even date of birth Group A (n=20) ▪ first 4 months- received usual care during their treatment; hospital appointments only ▪ second 4 months- weekly visits by an oncology nurse following treatment *Group B (n=38) the procedure was the opposite to that above* All visited at baseline (day 1) and at 2 months; *Assessments* performed monthly from baseline with the Hospital Anxiety and Depression Scale (HADS) and Rotterdam Symptom Checklist (RSCL)	*Group A;* • 30% were classified as "at risk" (HADS scores $\geq$ 11) at 4 months; this steadily declined with weekly support but at 8 months this increased sharply to 35%; RSCL scores showed a similar pattern. *Group B;* • during weekly support there was a decline in levels of anxiety from 22% of patients "at risk" at baseline, to 5% at 4 months; this increased slightly to 12% at 12 months; similar trend for RSCL scores. *Comparing groups A and B;* • the supportive intervention was more effective during rather than following treatment.

Author, country, grade	**Aims of the study**	**Patient population**	**Study design**	**Outcome measures**	**Results**
Bloom et al. 1978[80] USA IIb	To examine the effectiveness of the counselling-education intervention program.	A total of 39 women with initial breast cancer having undergone breast surgery. I=21 women. Average age: 49. C=18 women. Average age: 53.	*Design* –Prospective non-randomised controlled trial. *Intervention* – I=Counselling and information are offered to patients with a mastectomy by an interdisciplinary team. An oncology counsellor (nurse) provides support and information during hospitalisation; and a social worker provides co-ordination and continuity of service between the hospital and the community.	*Demographic variables.* Psychosocial variables: • the Health Locus of Control (HLC). • Profile of Mood States (POMS)	*Immediately after surgery:* The affective responses of the group in the intervention program were more labile than those of the control group. These differences diminished over time. Both groups were equivalent on the measure of self-efficacy (t= -0.53, df=32, n.s.). *Measure after two months:* patients in the intervention group score significantly higher (t= -2.16, df=32, p<0.05).

Author, country, grade	**Aims of the study**	**Patient population**	**Study design**	**Outcome measures**	**Results**
Braden et al. 1998[79] USA Ia	To determine the efficacy of self-care/self-help promotion and uncertainty management interventions offered by the Self-Help Intervention Project (SHIP) for women receiving chemotherapy, radiation therapy, or hormone therapy for breast cancer.	A total of 193 women receiving treatment for breast cancer. *Inclusion criteria:* 18 years and older, and literate in English.	*Design* –RCT *Intervention* – • Self-help course. • Uncertainty management. • Self-help course plus uncertainty management. • Control group. Data were analysed by a repeated measures multivariate analysis of variance procedure. A two-level blocking factor was used: high and low resourcefulness.	Outcome variables measured: • Self-care by the Inventory of Adult Self-Care Behaviours (IASC), and the Self-Care Inventory Wellness Promotion (SCIWPR). • Self-Help by the Inventory of Adult Role Behaviour. • Psychological Adjustment by the Negative Affect Scale. • Confidence in Cancer Knowledge by a visual analogue formatted single item. Data were collected: • At baseline (T1) after initiation of adjuvant therapy • (T2) 6-8 weeks after T1. • (T3) 2 months after T2.	Participation in SHIP interventions resulted in higher levels of self-care, self-help, psychological adjustment, and confidence in cancer knowledge by time effect in a significant number of women regardless of their baseline resourcefulness. Women with low baseline resourcefulness demonstrated the greatest change over time in outcome variables. The effect was primarily the result of changes in psychological adjustment, confidence in cancer knowledge and self-care.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Bucher et al. 2001[33] USA IIa	A program evaluation was conducted to explore the potential effects of a 90 minute problem-solving education session for persons with advanced cancer and their families.	A total of 89 participants who were visiting a tertiary-care outpatient setting, 49 caregivers and 40 patients were selected using a convenience sampling method. *Eligibility criteria:* patients in advanced stages of disease, >19 years, English speaking and able to identify a primary family caregiver.	*Design* – CBA. Non-randomised intervention. *Intervention* –A 90-minute individualised educational session that taught basic problem-solving principles using a cognitive-behavioural framework. This was led by a trained social worker. *Data:* • COPE problem-solving principles. • The Home Care Guide for Cancer. • Chaters from the Home Care Guide for Advanced Cancer.	• Social Problem-Solving Inventory-Revised Survey (SPSI-R) completed before and after the course. • Karnofsky Performance Index. • Brief Symptom Inventory Scale (BSI).	At baseline: Most participants reported low confidence about their ability to provide cancer care and felt uninformed about community resources. At follow-up: Participants reported feeling more informed about community resources and achieved higher posteducation scores for problem-solving ability. Especially caregivers reported that reading The Home Care Guide for Cancer made a great deal of difference in their approach to home care.

Author, date, country, grade	**Aims of study**	**Patient population**	**Study design and outcome measures**	**Results**
Bultz BD et al. 2000[95] UK Ib	To assess the effect of a brief psychoeducational group programme for partners of cancer patients.	36 patients (all with early stage breast cancer) and their partners recruited from clinic lists at a tertiary cancer care centre. Mean age of patients: 50 yrs Mean age of partners: 51yrs	RCT I: n=15 Partners met for a psychoeducational group one evening per week for 1.5 – 2 h over 6 weeks, co-facilitated by two psychologists. Intervention had two components: • education (video presentation, question and answer session with medical oncologist) • support (group discussions) *C group n= 21* No intervention Assessments: At baseline, at end of programme, and three months after programme's end: Mental Adjustment to Cancer Scale (MAC); Profile of Moods States (POMS); Index of Marital Satisfaction (IMS); DUKE-UNC Functional Social Support Scale (FSSS).	*I group:* • Reduction in POMS scores at 6 weeks and three months. • Reduction in mood disturbance at three months. • No change in marital satisfaction and social support. • Greater confident support at six weeks and three months. *C group* • No change in POMS scores • Deterioration of marital satisfaction and social support at six weeks and three months. Psychoeducational group was popular: 86% of patients felt it helped partners to be to 'better caregivers'.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Classen et al. 2001[101] USA Ia	To evaluate the effectiveness of 1 year of supportive-expressive group psychotherapy for reducing mood disturbance and traumatic stress symptoms in women with metastatic breast cancer.	A total of 102 women. Eligibility criteria: Confirmed metastatic or locally recurrent breast cancer. Karnofsky score of at least 70% English speaking. Living in Greater San Francisco Bay Area. I=64 women. C=61 women.	*Design* –RCT. Use of the adaptive randomisation biased coin-design method to ensure comparability of medical status in treatment and control conditions. *Intervention* – I= Weekly 90 minutes supportive-expressive group therapy and educational materials. C= educational materials only. Data – The intervention was unstructured with therapists trained to facilitate discussion as the material emerged and in an emotionally expressive rather than a didactic format.	Baseline assessments, and post-baseline assessments were conducted every 4 months during the first year and every 6 months thereafter. The Profile of Mood States (POMS) was used to assess mood disturbance over time. The Impact of Event Scale (IES) was used to assess change over time in trauma symptoms.	Primary analyses based on all available data indicated that participants in the treatment condition showed a significantly greater decline in traumatic stress symptoms (effect size, 0.25). There was no difference in Profile of Mood States total mood disturbance. When the final assessment occurring within a year of death was removed, a secondary analysis showed a significantly greater decline in total mood disturbance (effect size 0.25), and traumatic stress symptoms (effect size 0.33).

Author, date, country, grade	**Aims of study**	**Patient population**	**Study design and outcome measures**	**Results**
Connor 1992[104] USA Ic	To examine the effects of psychosocial intervention on denial-related coping ability	24 terminally ill cancer patients referred by a medical oncologist with intrapersonal denial. 79% female; mean age 61 *Types of cancer:* Not reported	*Design* –RCT *Intervention –* I group (n=13) talking openly with the Hospice Director about: ▪ their illness ▪ its impact on them and their family ▪ hopes and fears *C group (n=11* no intervention *Assessment:* At 2 – 3 weeks	*Post-intervention:* • *I* group reduction in denial • *C* group increase in denial.

Author, date, country, grade	**Aims of study**	**Patient population**	**Study design and outcome measures**	**Results**
Edelman et al. 1999[89] Australia Ic	To assess the effect of a group cognitive behavioural therapy (CBT) programme on mood and self esteem of metastatic breast cancer patients.	N=124 Metastatic breast cancer patients recruited from Oncology centre. Mean age 50 years.	*Design* –RCT *Intervention – n=62* 8 weekly session of CBT + family night + 3 further monthly sessions. Sessions facilitated by two therapists. *C group n=62* No intervention Assessment: baseline, 1 week, 3 months, 6 months. Profile of Mood States (POMS); Coopersmith Self-Esteem Inventory-Adult Form.	• In the immediate post therapy follow up, patients in the *I* group had better mood, depression and self esteem scores than those in the *C* group. • There was no difference in outcome between the two groups at the 3-month 6-month follow up assessments.

Author, date, country, grade	**Aims of study**	**Patient population**	**Study design and outcome measures**	**Results**
Evans 1995[93] USA Ib	To evaluate the effects of cognitive-behavioural and socially supportive group therapy.	72 depressed stage 2 cancer patients planned to undergo external radiotherapy at a teaching hospital. 62% male; mean age 54 years. *Types of cancers:* Lung 42%; bladder 30%; prostate 22%; head and neck cancer 6%.	*Design* –RCT All patients' scores on Centre for Epidemiological Studies Depression Scale (CES-D) indicated depression. *Intervention –* Social worker – led one hour group sessions weekly for 8 weeks. • *Group 1: (n=29)* Cognitive behavioural treatment: various skills training to reduce anxiety. • *Group 2: (n=23)* Social support: encouraging participants to adopt mutually supportive roles in the group • *Control group: (n=26)* No treatment (but offered crisis intervention) Assessment at baseline, eight weeks (post intervention) and six months using CES-D. Social Provisions Scale; SCL-90-R; Multidimensional Health Locus of Control Scale (MHLC).	*Post-intervention:* Both *I* groups experienced less depression (p<0.01), hostility and somatisation post intervention than control group. *At six months follow up* Social support group participants had less somatisation (<0.01) less depression (p<0.01) and less anxiety (p<0.05) than *C* group.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Ganz et al. 2000[90] USA Ia	To test the efficacy of a comprehensive menopausal assessment (CMA) intervention program in achieving pain relief of symptoms, the improvement of quality of life, and sexual functioning in breast cancer survivors.	A total of 72 postmenopausal breast cancer survivors. Eligibility criteria: • A disease free, female breast cancer patient. • Perimenopausal or postmenopausal. • All chemotherapy or radiotherapy completed at least 4 months prior to enrolment, but could be taking tamoxifen. • Presence of at least one severe target symptom. I=33 patients. C=39 patients.	*Design* –RCT. *Intervention* – I=A structured comprehensive assessment of the three target symptoms (hot flashes, vaginal dryness, and stress urinary incontinence) followed by an individualised plan of education, counselling, pharmacologic and/or behavioural interventions, psychosocial support, referrals, and follow-up tailored to each woman's needs and preferences. The CMA was delivered by a nurse practitioner. C=Received usual care.	Menopausal Symptom Scale Score adapted from the Breast Cancer Prevention Trial Symptom Checklist. Vitality Scale from the RAND 36-Item Health Survey 1.0 (alternatively known as Medical Outcomes Study SF-36) Sexual Summary Scale from the Cancer Rehabilitation Evaluation System.	Intervention group improvements in: Menopausal symptom management (P=.0004). Sexual functioning (P=.04) No statistically significant improvement in: Vitality (P=.77).

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Greer S et al 1992[94] UK Ia	To determine the effect of adjuvant psychological therapy on the quality of life of cancer patients	156 patients with malignant disease screened for those with psychological morbidity and with a life expectancy greater than 12 months I: no colo-rectal cancer, 72% female, mean age 51, 69% married/cohabiting C: 5% colorectal ca, 86% female, 68% married/cohabiting	RCT using telephone randomisation organised by an independent statistician; patients cared for in a hospital dedicated to the care of cancer patients; I (n=72) adjuvant psychological therapy focusing on the personal meaning of cancer to the patient and his or her coping strategies, weekly one hour sessions over eight weeks (median number of sessions received up to four months was 5) C (n=84) not stated whether they were offered any other help; eight weeks & four months follow up.	HADS, Mental Adjustment to Cancer, Psychosocial Adjustment to Illness Scale, RSCL.	*Improvement in:* • at 8 weeks: helplessness, anxious preoccupation, fatalism, anxiety, and health care orientation • at 4 months: anxiety, psychological symptoms and psychological distress. *No difference in:* • all the remaining mean scores except for a slight but significant decrease in fighting spirit seen at 8 weeks that is no longer significant at 4 months.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Helgeson & Cohen 2001[78] USA Ia	To examine the effects of 8-week support group interventions on the quality of life of women with early stage breast cancer by a 3-year follow-up.	A total of 312 women diagnosed with stage I or stage II breast cancer, treated with surgery followed by adjuvant chemotherapy. Mean age: 48.	*Design* –RCT *Intervention* – • Education: providing expert information and enhancing the women's control over the illness experience. • Peer discussion: an oncology social worker and nurse facilitated group discussions focused on the expression of feelings. • Education plus peer discussion. • Control.	Repeated measures: • (T1) Women were interviewed at baseline. • (T2) 1-2 weeks after the intervention women were interviewed over the phone and completed a mailed questionnaire. • (T3) 6 months later a follow-up took place. • (T4) another 6 months later another follow-up took place. • (T5) and (T6) occurred 1 and 2 years later. SF-36 measured health-related quality of life at all waves.	The benefits of the education intervention were maintained over a 3-year period, although effects dissipated with time. Consistent with the results of 6 months after the interventions no benefits of the peer discussions were found, either alone or in combination with education.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Hosaka et al. 2000[97] IIa Japan	To investigate persistence of the clinical effectiveness of a 5-weekly structured group intervention program for Japanese breast cancer patients	A total of 57 patients with breast cancer participated in the program and the 47 who completed were analysed. The mean age +/- standard deviation was 51.3+/-8.8 (Range 29-76). Type of operation: 29 received only mastectomy, eight had breast reconstruction as well, and 10 had lumpectomy and radiation therapy.	*Design* –Controlled Before and After Study. *Intervention* –A series of five 90-minutes sessions to groups of four to eight patients, which included psychoeducation, problem solving, psychological support, relaxation training, and guided imagery. The scores were compared before, just after, and 6 months after the intervention.	At entry of the study: A semi-structured interview for psychiatric evaluation. At entry, at the end and six months after: The Profile of Mood States (POMS) and Dealing-with-Illness (DWI) inventory.	The psychiatric interview at entry revealed that 12 patients (25.5%) were diagnosed as having adjustment disorders according to the Diagnostic and Statistical Manual of Mental Disorders 4th ed. (DSM-IV0. Patients who had no psychiatric diagnosis at entry: There were significant differences in the scores of depression (p=0.019), lack of vigor (p=0.002), tension-anxiety (p=0.027) and total mood disturbances (p=0.042) before and six months after the intervention. The effectiveness of this program persisted for six months. *Patients with adjustment disorders:* The POMS scores slightly decreased after the intervention. Those scores returned to almost the pre-intervention levels 6 months after the completion of the program.

Author, country, grade	**Aims of the study**	**Patient population**	**Study design**	**Outcome measures**	**Results**
Mansson et al[88]. 1997[88] Sweden Ia	To investigate: (1) if early psychosocial intervention after cystectomy for bladder cancer can assist psychosocial rehabilitation; (2) if the outcome of such intervention correlates with the patient's psychological defensive strategies as revealed with the meta-contrast technique (MCT); and (3) if the patient's general philosophical outlook is important in this context.	A total number of 57 patients. The main study population comprised 40 men and 10 women (mean age 66 years, range 46-84). 17 had received an ileal urinary conduit, 17 a continent reservoir with abdominal stoma and 16 an orthopaedic neobladder. The seven patients given post-operative chemotherapy were evaluated separately because of the long treatment period (26-156 days). I=24 patients.	*Design* –RCT. *Intervention* – I= Weekly counselling, in the patient's home, for 4 weeks and thereafter by telephone for 2 weeks. The discussion concerned consequences of the operation, practical and emotional problems, influences on mood and relations to partner and friends.	Patients were evaluated with the Sickness-Impact Profile (SIP) standard questionnaire, and the meta-contrast technique (MCT).	There was no significant difference in the results of the SIP between the intervention and the non-intervention group, as a whole or in its psychosocial dimension. Intervention benefited patients with continent cutaneous diversion, whose scores on the psychosocial SIP dimension were lower than in the groups with ileal conduit diversion or orthopaedic bladder replacement ($P<0.05$). The MCT analysis of defensive strategies identified three clusters of patients.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Maughan & Clarke 2001[102] UK Ib	1. To measure psychological, social, and sexual adaptation following major pelvic surgery; 2. To examine the influence of specialist nursing intervention on psychological, social and sexual recovery following gynaecological cancer. 3. To explore the lived experience of illness following gynaecological cancer from the women's perspective.	A total number of 36 women with a diagnosis of gynaecological cancer who were scheduled to receive major pelvic surgery. I=19. Mean age: 52 years. C=17. Mean age: 48 years.	*Design* –A mixed methodology approach, combining an RCT with an inductive qualitative study. *Intervention* –A clinical specialist nurse specialist (including psychosexual) intervention. *Data* –Provide emotional support at the time of diagnosis to the woman and her partner. Offer information regarding diagnosis and planned surgery/treatment. Support individual coping strategies, and promote social support network. Introduce discussion about effect of surgery on sexual functioning. Provide information and advice on resumption of sexual activity. Facilitate communication between partners, social network and health professionals.	Quantitative outcomes The EORTC QLQ-C30. The Lasry Sexual Functioning Scale Data. Qualitative outcomes: Extensive open-ended interviews with 20 women.	The EORTC QLQ-C30 demonstrated that for the women seen by the specialist nurse there was a trend towards more positive emotional, cognitive, social functioning, and higher sexual functioning scores. Although the differences were not statistically significant. The active group were found to have a better health status, improving significantly over time (P=0.04). They reported less sleep disturbance (P=0.02). The Lasry Sexual Functioning scores show that, sexual functioning in both groups improved over time. Although the differences were not statistically significant, they suggest that the active group did better in the immediate post-operative period and resumed intercourse sooner than the control group.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Maunsell et al. 1996[99] Canada Ia	To assess, 3 and 12 months after surgical treatment, the effect on psychologic distress of a monthly, telephone psychologic distress screening program, with additional individually tailored psychosocial follow-up offered only to high-distress women identified through screening.	A total number of 250 women with newly diagnosed nonmetastatic breast cancer. I=123 patients. C= 127 patients.	*Design* –RCT. *Intervention* – I=Monthly telephone screening of distress levels using a brief, validated instrument (the General Health Questionnaire GHQ), with additional psychosocial intervention offered only to those with high distress at screening. C=Had access to a universal but minimal psychosocial follow-up care program which was already in place for newly diagnosed patients.	Main outcome: Psychologic distress measured by the Psychiatric Symptom Index (PSI). Other outcomes: Performance of usual home, social, leisure, and physical activities. A baseline interview and follow-up telephone interviews were conducted 3 and 12 months later to assess the nature and timing of any screening program effects. These interviews were conducted by the same, specially trained research nurse.	Participants' psychologic distress levels decreased over the study period (P=.0001). However, no between-group differences were observed. Mean distress scores among control and experimental women at 0-, 3-, and 12 month interviews were 20.7 and 20.4, 15.5 and 15.0, a 14.6 and 13.5, respectively. No between-group differences were observed with respect to physical health, functional status, social and leisure activities, return to work, or marital satisfaction.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
McArdle et al. 2002[103] Scotland Ib	To evaluate the effect of support from a nurse specialising in breast care and a voluntary support organisation on prevalence of psychological morbidity after surgery for breast cancer.	A total number of 272 women aged less than 70 years undergoing surgery for breast cancer.	*Design* –RCT. *Intervention* – Comparison of four different types of support for patients undergoing surgery for breast cancer: • Routine care from ward staff. • Routine care plus support from specialist breast care nurse. • Routine care plus support from voluntary organisation. • Routine care plus support from nurse and organisation.	Main outcome measures: Prevalence of psychological morbidity as assessed by self rating scales: 28 item general health questionnaire (GHQ) and its subscales. Hospital anxiety and depression scale. Measurements were made at first postoperative clinic visit and at three, six and 12 months after surgery.	On each self-rating scale, psychological morbidity tended to fall over the 12 month period. For each scale, scores were consistently lower in patients offered support from breast care nurse alone compared with other groups, which were similar to each other. Differences were significant or nearly so: P values were 0.015 GHQ, 0.027 (anxiety and insomnia), 0.027 (severe depression), 0.053 (somatic symptoms), 0.031 (social dysfunction), 0.039 (hospital anxiety), and 0.003 (hospital depression).

Author, date, country, grade	Aims of study	Patient population	Study design and outcome measures	Results
Moorey et al. 1998[92] UK Ib	To compare adjuvant psychological therapy and supportive counselling in patients with cancer.	57 consecutive patients referred for psychiatric assessment to a Psychological Medicine Group, all met the criteria for an abnormal adjustment reaction. mean age 51; 35 females; median time since diagnosis 10 months (APT) and 14.2 months (counselling); *Types of cancers:* Breast 40%; lymphoma 11%; prostate 4%; other cancer 45%	*Design* –RCT Intervention – Therapies included 8 weekly sessions (including spouse where appropriate) • adjuvant psychological therapy (APT)- cognitive-behavioural therapy specifically for cancer patients; teaches coping strategies; ▪ supportive counselling; designed to control for therapist's time and attention, excluding elements from APT; non-directive ventilation of feelings *C group:* No intervention *Assessments*: baseline, 8 weeks, 4 months, 1 year: Hospital Anxiety and Depression Scale (HADS); Spielberger Stait Trait Anxiety Inventory (STAI); Beck Depression Inventory (BDI); Mental Adjustment to Cancer Scale (MACS); Cancer Coping Questionnaire	*Change over time;* • APT significant change on 9 of 10 variables at 2 months, 4 months, and on 7 of 10 variables at 1 year • counselling significant change on 4 of 10 variables (2 months), 6 of 10 variables (4 months), 5 of 10 variables (1 year) *Comparison of therapies;* • APT greater change from baseline to 2 months than counselling on HADS, 2 MACS sub-scales, cancer coping questionnaire, mean self-defined problems, persisted at 4 months *Clinical significant comparisons;* • 100% APT, 82% counselling scored > 8 HADS anxiety at baseline; declined to 29% APT and 71% counselling at 4 months depression was halved in APT at 2 and 4 months; depression declined from 59% to 43% at 4 months in the counselling group

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Moynihan et al. 1998[96] UK Ib	To determine the efficacy of adjuvant psychological therapy in patients with testicular cancer and to compare the characteristics and psychosocial outcomes of men who agreed to participate with those who declined to participate in a randomised trial of psychological intervention.	A total number of 184 newly diagnosed patients with testicular cancer. Eligibility criteria: Aged between 18 and 65 years. Patients having had a unilateral orchidectomy. Patients who had been advised of, and agreed to, a treatment plan.	*Design* –RCT. *Intervention* – I=Six sessions of psychological therapy, each lasting one hour, scheduled between baseline assessment and evaluation at 8 weeks. The therapy was provided by a specially trained nurse. C=standard medical care.	Self report assessments were performed at baseline (before randomisation for patients participating in the trial) and at 2,4, and 12 months. Patients completed the following validated self report questionnaires: • The hospital Anxiety and Depression Scale. • The Mental Adjustment to Cancer scale. • The Psychosocial Adjustment to Illness Scale. • The Rotterdam Symptom Checklist. • The Emotional Concealment Subscale of the Brannon Masculinity Scale. • The Rieker Sexual Adjustment Scale. Patients who declined to participate were asked to complete psychosocial assessments using the same procedures as patients in the randomised trial.	111 of 184 (60%) eligible men declined to participate in the trial. Patients with early stage of disease ($P<0.001$) and fewer physical symptoms ($P<0.001$) were less likely to participate. Psychosocial factors associated with participation included anxious preoccupation regarding disease ($P=0.01$). There were no differences in outcome between participants and non-participants during follow up. Patients seemed to gain little benefit from adjuvant psychological therapy.

Author, date, country, grade	**Aims of study**	**Patient population**	**Study design and outcome measures**	**Results**
Sandgren 2000[107] USA Ib	To test the value of telephone administered cognitive-behavioural therapy in patients with breast cancer.	62 women with Stage I or stage II breast cancer recruited from a tertiary cancer treatment centre. Mean age 51 years, 51% Stage I breast cancer.	*Design* –RCT. *Intervention –* *n= 24.* Received 9 – 10 telephone calls lasting 20 – 25 mins over 14 weeks, carried out by clinical psychology master's candidates. Therapy included providing support, teaching coping skills managing anxiety and stress, and helping solve patient generated problems. *C group: (n=29)* No intervention. Assessments: At 4 and 10 months after therapy initiation therapy. Coping Response Indices- Revised scale; Profile of Mood States (POMS); Medical Outcome Scale.	• *I* group had better physical functioning than *C* group (p=0.03) • Therapy group reported less stress than control group at 4 months, but more at ten months (p=0.04) • *I* group had better mental health at 4 months, but worse at 10 months compared to control group (p=0.05).

Author, date, country, grade	**Aims of study**	**Patient population**	**Study design and outcome measures**	**Results**
Schwartz et al. 1998[105] USA Ib	To assess the effectiveness of brief Problem-Solving Training in reducing stress among women with a first degree relative recently diagnosed with breast cancer.	341 women with a firs-degree relative with a recent diagnosis of primary breast cancer were identifies a multi-cancer centre organisation: the High Risk Breast Cancer Consortium. Mean age 42 years. 83% of relatives were diagnosed with Stage 0 –2 breast cancer.	RCT Both groups received breast cancer risk factor education *I group:* (N= 144) Problem Solving Intervention: a single two hour individual session with a health educator, involving discussion about (I) problem definition (ii) generation of solutions (iii) solution evaluation (iv) decision making (v) solution implementation *C group:* (N=197) General Health Counselling: a single two hour individual session with a health educator, involving assessment of current health practices and advice on possible improvements in these practices. Assessments: baseline and 3 months: Profile of Mood States (POMS) and Impact of Event Scale (IES)	*At three months:* • cancer-specific and general distress decreased in both I and C groups; magnitude of decrease did not differ. • I group: subgroup that regularly practices the PST technique had greater decrease in cancer specific distress.

Author, country, grade	**Aims of the study**	**Patient population**	**Study design**	**Outcome measures**	**Results**
Spiegel & Bloom 1989[100] USA Ib	To assess whether group therapy in patients with metastatic breast cancer had any effect on survival.	A total of Patients with documented metastatic carcinoma of the breast. I=50 patients. C=36 patients.	*Design* –RCT. *Intervention* – I=Received routine oncological care, and they participated in a weekly therapy group led by a psychiatrist or social worker with a therapist who had breast cancer in remission. C=Received routine oncological care.	Cox's proportional hazards model. The log-rank test. Kaplan-Meier plots. Unpaired t tests. Wilcoxon's rank sum. X2 tests.	Intervention group improvements in: Survival from time of randomisation and onset of intervention was a mean 36.6 (SD 37.6) months in the intervention group compared with 18.9 (10.8) months in the control group. Survival plots indicated that divergence in survival began at 20 months after entry, or 8 months after intervention ended.

Author, country, grade	**Aims of the study**	**Patient population**	**Study design**	**Outcome measures**	**Results**
Syrjala et al. 1995[91] US Ia	To examine the effectiveness of cognitive-behavioural techniques and relaxation and imagery (or hypnosis) training in reducing cancer- related pain.	A total of 94 patients who underwent their first bone marrow transplantation (BMT) completed the study. Mean age: 36 years.	*Design* –RCT. The researchers and data collectors were blind to the randomisations of the patients. *Intervention* – Comparing oral mucositis pain levels in 4 groups of cancer patients receiving (BMT): I= 1. Therapist support. 2. Relaxation and imagery training. 3. Training in a package of cognitive-behavioural coping skills which included relaxation and imagery. C= Treatment as usual control.	Oral Pain Visual analogue scale (VAS). Nausea VAS. Oral Mucositis Index. SCL-90-R. Post-Treatment evaluation. Background. Risk.	Intervention group improvements in: Patients receiving either relaxation and imagery alone or the package of cognitive-behavioural coping skills reported less pain than the patients in the 2 other groups. It was not confirmed that the cognitive-behavioural skills package has an additional effect beyond relaxation and imagery. Average VAS report of pain within the therapist support group was not significantly lower than the control group (P=0.103) nor significantly higher than the training groups.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Toseland et al. 1995[98] USA Ib	To assess the impact of a short-term counselling program for cancer care-givers on the caregiver and the patient.	78 spouses of cancer patients I: 50% female, mean age 56, married mean of 28.6 years; patient diagnoses:- 7% colon cancer, 0% large bowel cancer, 3% rectal cancer; C: 49% female, mean age 51, married mean of 24.5 years; patient diagnoses:- 8% colon cancer, 5% large bowel cancer, 3% rectal cancer	*Design* –RCT method not stated; regional oncology centre; interviewer blind; length of follow-up not stated *Intervention*– (n=40), protocol for "coping with cancer" included: support; problem solving; and coping skills; 4-6 1-hour sessions provided by an oncology social worker C (n=38), free to use individual and group counselling services offered by the centre.	Centre for Epidemiologic Studies Depression Scale, State-Trait Anxiety Inventory, Dyadic Adjustment Scale (DAS) for marital satisfaction, a scale adapted from the Social Functioning Subscale of the Health and Daily Living Form for support, Medical Outcomes Study SF20 for health status, Zarit Burden Inventory (ZBI), Caregiving Mastery and Satisfaction subscales of Lawton Caregiving Appraisal Composite Scale, Montgomery and Borgatta Burden Scale, Help Seeking Coping Index from the Health and Daily Living Form, Index of Coping Responsiveness, pressing problems, Personal Change Scale for change in caregiver knowledge	*Improvement in:* physical, role and social functioning as measured by the MOS (F(1,23)=5.14, p=0.03) on secondary analysis of distressed caregivers (n=24: I=11, C=13 who scored <96 on the DAS); ability to cope with pressing problems (F (1,28)=5.25, p=0.03) on secondary analysis of moderately burdened caregivers (n=29: I=11, C=18 who scored >20 on ZBI)) ; patients' depression measured by CES-D (F(1,28)=10.69, p=0.004) *No difference in:* mean scores between caregiver or patient groups on any of the measures over time.

8. SOCIAL SUPPORT SERVICES

The nature of the evidence

Two systematic reviews were identified which were concerned with questions relevant for social support. Both were conducted in the UK. Higginson et al.[111] was a comprehensive review including: (i) an evaluation of systematic reviews, (ii) a description of different models of service, (iii) a meta-regression of studies (quantitative analysis), (iv) a qualitative analysis, and (v) health economic analysis. Payne et al.[112]focused on qualitative, quantitative, published and unpublished studies.

We found fifteen individual studies. Six of these were grade one randomised controlled trials (five grade Ia and one grade Ic). Two studies were grade II (one grade IIa and one grade IIb). Seven studies were grade III (five grade IIIc and two grade IIIb). Seven studies were conducted in the UK, five in USA and the remaining studies came from Canada, Australia and Sweden.

Types of interventions

The systematic review by Higginson et al.[111] had the objective to determine how the palliative care team model differs from conventional care. It aimed to assess the extent to which teams have been shown to be effective and cost-effective.

The paper by Payne et al.[112] reported the main findings of a systematic review of the research literature on communication of information about older people between health and social care practitioners.

Four studies evaluated home care programmes, three in the UK and one in the USA. The study that Higginson & Wilkinson[113] undertook was designed to describe and evaluate the care provided by Marie Curie nurses, and in particular to determine whether patients in their care remained and died at home. This evaluation chose to analyse existing data sets because of the difficulties of undertaking comparative evaluations and randomised controlled trials among patients with a terminal illness.

Clark et al.[114] reported on an evaluation of seven pilot Macmillan Carers Schemes in England which were designed to provide practical and emotional help to both cancer patients and families. The views of informal carers were obtained by retrospective postal questionnaires and the perspectives of Macmillan carers themselves were retrieved by interviews using semi-structured ‘aides-memoires’. A major evaluation of the Macmillan nursing services was undertaken when the services had become sufficiently established[115]. The aims of the study were to investigate its service delivery, costs and outcomes in hospital and community settings. A separate part of this same study focused on the remit and boundaries of the Macmillan Nursing role as this has been called into question recently by a number of policy-driven changes[116].

A cohort study was carried out by Hinton[117]to investigate what a competent home care service provided for people with terminal cancer, how far it met their requirements, and what else might be done. In the study carried out in the USA by Hughes et al.[118] a prior trial of Veterans Affairs (VA) Team-managed Home-Based Primary Care (TM/HBPC) which found favourable outcomes was evaluated to assess the replicability of the model and the generalisability of the findings.

Against the background of the relatively recent interest which has been taken in the potential of palliative medicine in Sweden by politicians and health care officials, Axelsson and Christensen[119] undertook a financial assessment of a hospital-based palliative support programme. They compared a study population with a matched historical control group and a group of contemporary reference patients from a separate geographical area. The staff consisted of one full-time nurse supported by a surgeon one half-day per week.

Allison et al.[120] experimented with a social work service to critically ill non-hospitalised cancer patients based upon Heimler's theory and method of Human Social Functioning. They saw the social worker's role in palliative care in the following activities: identification of problem areas in the patient's present life situation; sharing relevant information concerning the patient with his family within the limits of confidentiality; liaison with community resources to provide necessary supplies and equipment for home care; assisting the patient in purposeful planning for living; helping the family to deal with disrupted relationships; and helping the patient with dysfunctional emotional reactions to illness.

Two studies implemented assessment tools to detect existing needs so that support could be offered soon after these problems arise. Siegel et al.[12] developed an intervention consisting of an automated telephone outreach system coupled with timely social worker assistance, and aimed at reducing the prevalence of unmet concrete needs. Because of the growing number of individuals treated as outpatients and the limited social work staff available to serve them, it was recognised that social workers could not be expected to personally assess all outpatients. Rathbone et al.[121] devised a simple measure of quality of life, made up of a composite of traditional nurse/doctor assessments and a patient-centred self-assessment. The usual quality of life measures are suitable in the earlier stages of terminal illness but become inappropriate or impossible for the patient to complete as the disease advances.

Another effort to contribute to the traditional history and physical examination obtained by the doctor which may not be sufficient for assessing the full range of health-related problems of patients with cancer is the intervention carried out by McLachlan et al.[122] (2001). Their specific aim was to determine whether making patient-reported cancer needs, quality of life, and psychosocial interventions available to the health care team, resulted in reduced cancer needs, improved quality of life and increased satisfaction with care received.

Bloom et al.[80] implemented a change in the health care delivery system for the treatment of breast cancer for patients in the initial stages of the illness. Instead of offering only isolated support interventions remote from standard medical care, this programme routinely involved psychosocial support services with medical treatment. The medical team included a Reach to Recovery visitor who provided a successful role model; an oncology counsellor who provided support and information during hospitalisation and a social worker who provided co-ordination and continuity of service between the hospital and the community.

Simpson et al.[123]carried out a randomised controlled trial to determine whether participation in a group psychosocial intervention by patients with breast cancer would result in an improvement in psychological measures and in reduced billings in medical expenses.

Corner et al.[124] evaluated the effect of non-pharmacological intervention for breathlessness in lung cancer on breathlessness ratings and patient functioning. Treatment for breathlessness in advanced cancer has focused on active procedures such as drainage of pleural effusions and also on pharmacological interventions. However, there is some evidence to suggest that such strategies may not be effective in alleviating the symptom. This study aimed to investigate whether a nursing approach to intervention would be possible, including counselling, breathing re-training, relaxation and teaching coping and adaptation strategies. These could be used earlier in the course of disease and would focus on maximising quality of life and functional ability.

We identified one paper[125] which reported on a randomised controlled evaluation of a computer-based patient support system on quality of life in younger women with breast cancer, with particular emphasis on assisting the underserved. Medical underservice (often associated with minority status and with less health insurance, income and formal education) leads to fewer opportunities to participate in care or obtain needed information and social support. An improvement in these areas might improve psychosocial aspects of quality of life.

Outcome measures

The systematic review by Higginson et al.[111] provided evidence of some small positive benefit of palliative care services on patient outcomes and carer outcomes. This is across a range of services, although the data is most strong for home care services. There was insufficient information to judge whether there were differences between intermediate and specialist palliative care. Thirdly, there appeared to be some substitution of hospital for home costs in the economics of palliative care.

The research literature on the communication of information about older people between health and social care practitioners showed that there is a lack of large-scale empirical research in this area[112]. Current mechanisms for information transfer are inadequate, and have largely depended upon informal means of communication between professionals. The most effective strategy for transferring information is the appointment of a ‘key worker’, who can provide a point of contact between workers from hospital and community. But even in situations where this role has been developed, problems have arisen because both settings are under pressure and pursuing different goals.

The study which evaluated Marie Curie Cancer Care[113] concluded that the results lend support to the theory that the care given to patients in their homes by this nursing service facilitates home death for many patients. Usually the hours of input were relatively small, but a small number of patients required very high nursing hours. This has important service implications. There is the danger that patients who need high or long-term home support will fall outside the resources allocated and be at a severe disadvantage.

Clark et al.[114] who reported on the Macmillan Carer Schemes found that respite for carers was the most common reason for referral (42%). Eighty-six per cent of respondents felt able to go out and leave the sitter with the patient, and 70% found the service to be ‘very important’ to them. The Schemes were accessed quickly by those referred to them, who comprised an elderly and sick population. Informal carers reported high levels of satisfaction with the service received, which was timely, appropriate, friendly and safe. However, the high costs and their borderline position between health and social care may pose problems regarding future funding possibilities. The later evaluation of Macmillan nursing services when these were well-established[115] showed a wide variation across several dimensions: location and context of the services, activity levels, management patterns, work organisation and content, links with other colleagues, and resource use. The authors suggested that such variation is likely to indicate the existence of both excellent practice and suboptimal practice. Initially, these groups of Macmillan Nurses have put considerable energy into establishing a sense of identity, creating a role, and securing a foothold within hospital and community health care organisations. Now, other challenges are occurring which might mean a move towards transdisciplinary working. Seymour et al.[116]found that the appointment of tumour site-specific nurses and the development of posts for palliative medicine, stemming originally from the Calman-Hine recommendations for reorganising cancer services, have created unparalleled challenges of adaptation to new working practices and procedures for the Macmillan Nurse. They concluded that there is a need to clarify the nature and scope of the Macmillan Nurse role, to attend to issues of team working and to improve the skills of nonspecialist staff.

Hinton[117] provided evidence on the effectiveness of a home care service working with a team, day care facilities and 24-hour on call service. The service was improved by allocating nurses to area teams, increasing staff numbers and linking area teams with a social worker to improve liaison. Also a new day care centre was opened. The service modifications were associated with modest rises from the original 27% to 34 % dying at home. The rise came step-by-step and it was unclear how much was contributed by strengthening individual links between nurses and patients, the greater participation by social workers, the additional services from the new day centre, or other factors. The author concluded that interpretation is never simple and that admission may be caused by many contributing factors. Hughes[118] reported on the multisite randomised controlled trial which experimented with a Team-Managed Home-Based Primary Care intervention. This trial found an improvement for most HR-quality of life measures among terminally ill patients and satisfaction among non-terminally ill patients. It is one of the first home-based care studies to demonstrate a significant benefit of treatment on objective caregiver burden among caregivers of non-terminal patients. It reduced hospital readmissions at 6 months, but it did not substitute for other forms of care. The higher costs of TM/HBPC should be weighed against these benefits.

The financial effects of the palliative support service used in the study carried out by Axelsson and Christensen[119] were: savings in hospital care utilisation that more than equalled the cost of running the service; no substantial overuse of the home care service by the study group, compared with conventional care; a cost of approximately six hospital days per patient to cover expenses of this low budget palliative support service. Nevertheless, it must be borne in mind that conclusions from this type of study must be drawn with caution, since it was not a randomised trial.

Allison et al.[120]found that the Heimler method was effective in helping patients overcome their sense of helplessness and distressing emotional reactions to terminal illness. This method was also applicable to the needs of terminal cancer patients across a variety of disease conditions and life situations. A quality assurance programme and a multidisciplinary health care team were proposed as the means of establishing palliative care for terminally ill patients that incorporates social work services.

The two interventions which tested the use of assessment tools as a strategy for the early identification of patients with unmet needs showed positive results. The automated system provided systemic outreach and monitoring of patients' needs in a highly cost-effective manner that allowed the efficient deployment of limited social work resources, focusing staff time on problem resolution[12]. The patient evaluated problem score[121] has proved very useful in the management of patients, enabling the identification of previously unrecognised or underrated problems, particularly of a psychosocial nature, and also as a means of evaluating progress. It is readily acceptable by patients, even those close to death.

The RCT conducted by McLachlan et al.[122] where quantitative self-reported quality of life and psychosocial information was made available in everyday clinical practice was not translated into better outcomes for patients. There were no significant differences between the two arms in cancer needs, quality of life, psychosocial functioning or satisfaction with care. However, there was a significant reduction in depression for the intervention arm for those who were depressed at baseline.

Bloom et al.[80] found that women who participated in the intervention initially expressed significantly more negative affect than those who received standard care but these negative affective states decreased over time and the women scored better in self-efficacy as the time after surgery passed by. The women who received supportive care after breast surgery were more likely to ventilate uncomfortable emotions and were less likely to deny their feelings. Helplessness and feeling overwhelmed were reduced by preparatory information and provision of supportive counselling which increased a sense of control.

The randomised controlled trial carried out by Simpson et al.[123] is the first study to demonstrate the cost efficiency of a group psychosocial intervention over a self-help approach in a population of breast cancer patients. They claimed that the generalisation of this finding to other samples of patients with a wide range of distress levels is reasonable due to the close resemblance of this sample to early-stage breast cancer in other reports. They concluded by recommending the routine availability of such programmes in cancer treatment facilities worldwide.

The results of Corner's study[124] which set out to pilot new ways of managing breathlessness in lung cancer indicate that patients do benefit from the approach that combines breathing retraining, psychosocial support and help to develop adaptive strategies. The intervention enabled patients to reduce levels of disability and to function with greater independence. This has the potential to become an important part of outpatient care and could be integrated with the service provided by Macmillan nurses and palliative care teams.

Gustafson et al.[125] achieved positive results with their intervention. The authors concluded that computer-based patient support systems may benefit patients by providing information and social support, and increasing their participation in health care. These benefits may be largest for currently underserved populations.

Implications of the evidence for recommendations

One pervading problem that the evidence for this topic area reveals is the divide between health and social care staff in hospital and community. Neither setting is fully aware of the needs, limitations and pressures of the other[112]. Therefore, studies on social care services frequently focus on issues such as co-ordination and integration of care of different professional and organisational services[112;114;117;118;120;122]. An interprofessional approach has shown positive results as it lessens divisions[111;117;118;120;126]. The most effective strategy for transferring information is the appointment of a 'key worker' who can provide a point of contact between workers from hospital and community[112].

Gustafson showed that computer-based patient support systems could successfully contribute to providing information and access to social support, bypassing time and resource constraints. A similar effect may have been triggered by the co-ordination intervention with touch-screen intervention[122] if a cluster-type randomisation process would have been used, which would have protected against contamination between the intervention and control group. The no-difference results between the groups could also have been caused by an intervention effect due to the completion of the touch-screen questionnaires, a process that may have served as a prompt for patients to raise their concerns during consultations.

Several studies have included or focused on psychosocial problems in order to improve quality of life and functional ability[80;120-124]. The recommendations could make this broader idea of social support more explicit.

Tables of Evidence: Social Support Services

Systematic Review

Author, date, country, grade	Aims of study	Inclusion/exclusion criteria	Study design and outcome measures	Results
Higginson et al. 2001[111] UK	To determine how the palliative care team model differs from conventional care. To assess the extent to which teams have been shown to be effective and cost-effective. To identify areas for future research.	Exclusion criteria: Reports of individual case histories, evaluations of any of the following not usually considered to be part of palliative care: chemotherapy, radiotherapy, or anaesthetic procedure. Reviews or needs assessment without intervention, description but no evaluation of an intervention, qualitative study without a comparative element, developing countries, an intervention deemed not to be palliative care.	The review has a broad scope: A variety of outcomes which are reported in the studies ranging from he management or control of specific symptoms to improved quality of life and quality of death. The analysis produced: (i) an evaluation of systematic reviews. (ii) a description of different models of service. (iii) a meta-regression of studies (quantitative analysis). (iv) a qualitative analysis. (v) health economic analysis.	A total of 67 publications were included. These represented a total of 43 unique studies, of which 14 were studies containing some economic data. In addition to the 67 papers there were 5 previous reviews. 1. There is evidence to show some small positive benefit of palliative care services on patient outcomes and carer outcomes. This is across a range of services, although the data is most strong for home care services. 2. There was insufficient information to judge whether there were differences between intermediate and specialist palliative care. 3. There appears to be some substitution of hospital for home costs in the economics of palliative care.

Author, date, country, grade	Aims of study	Inclusion/exclusion criteria	Study design and outcome measures	Results
Payne et al. 2002[112] UK	To provide an evidence base for strategies, and effectiveness of the transfer of patient information between hospital and community for older people with physical illness.	Literature relating to similar healthcare systems published between January 1994 and June 2000 on hospital discharge planning. Empirical studies from peer reviewed sources; theoretical papers from non-peer reviewed sources; research papers from non-peer reviewed sources and professional documents.	The literature was evaluated in relation to three research questions: 1. How effective are the existing methods of transferring information across boundaries (professional, organisational and geographical)? 2. Is appropriate information about the patient (and informal carer) provided on discharge to community nurses and social services? 3. What factors are associated with the breakdown of communication between and within professional boundaries?	A database of 373 potentially relevant studies was compiled. Fifty-three were accepted for further analysis. Thirty-one were empirical studies, most of which were qualitative or a combination of qualitative and quantitative design. The most effective strategy for transferring information is the appointment of a ‘key worker’ who can provide a point of contact for workers from hospital and community. Nevertheless, problems have arisen because both settings are under pressure and pursuing different goals. Neither setting is fully aware of the needs, limitations and pressures of the other.

Individual studies

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Allison et al. 1983[120] Canada IIIc	To validate the effectiveness of a social work service to critically ill non-hospitalised cancer patients.	A total of 8 participants. Patients were referred for social work services by medical specialists of the Southern Alberta Cancer Clinic and the nurses of the Victorian Order of Nurses, a community nursing service.	*Design* – Observational study. *Intervention* – Provision of social work intervention based on the model of Heimler's Human Social Functioning Approach (1975).	Heimler Scale of Social Functioning (1967). The Profile of Moods Scale (1971). Self report scales.	The Heimler method was effective in helping patients overcome their sense of helplessness and distressing emotional reactions to terminal illness. A quality assurance program and a multidisciplinary health care team are proposed as the means of establishing palliative care for terminally ill patients that incorporates social work services.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Axelsson & Christensen 1998[119] Sweden IIb	To make a financial assessment of a hospital-based palliative support service.	A total of 97 patients participated in the study. Inclusion criteria: a) a symptomatic, incurable cancer disease. b) a cancer within the realm of general surgery. c) living within 40km of the County Hospital. d) a wish to stay at home; and e) have a principal care-giver prepared to support the patient at home.	*Design* –observational study. *Intervention* –The palliative support service (PSS) consisted of one full-time nurse and a surgeon. The nurse's task was to act as a link between the patient's home and the hospital, to give support to the patient, the caretaker and the district nurse, to instruct the district nurse in the management of technical devices. Within the area the PSS involved nine primary health care centres. The consecutive study patients were compared with matched historical controls and a contemporary group from another area.	Utilisation of institutional days. Days at home to total inclusion days. Days at home during the last two months of life.	The patients in the study group utilised fewer institutional days than the control group, according to such parameters as duration of terminal hospitalisation (P,0.05), ratio of days at home to total inclusion days ($P<0.01$), and days at home during last two months of life ($P<0.01$). The service defrayed its own costs and in excess of that saved another SK17000 per patient. (US$2500).

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Bloom et al. 1978[80] USA IIa	To assess the effectiveness of an intervention program which provides supportive care to breast cancer patients after surgery.	A total of 39 women who had undergone mastectomy. Average age: 53 in the intervention group, 49 in the control group. All patients seen after the intervention program began became part of the intervention group because it was considered impossible to keep the groups apart. C=patients just before the treatment system was changed.	*Design* –CBA *Intervention* – Information and both individual and group counselling is provided. A team approach is used: • A Reach to Recovery visitor provides a successful role model. • An oncology counsellor (nurse) provides support and information during hospitalisation. • A social worker provides co-ordination and continuity of service between the hospital and the community.	Health Locus of Control (HLC) for measuring self-efficacy. Profile of Mood States (POMS) for measuring affective reactions.	After surgery there was no difference between groups (t=-0.53, df=32, n.s) in self-efficacy. Two months later the intervention group scores significantly higher (t=-2.16, df=32, p<0.05). After surgery the intervention group had greater affective reactions. Two months later the difference is no longer significant.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Clark et al. 2000[114] UK IIIc	To describe how the schemes are operated and managed, how and what type of care is delivered, as well as how this is viewed by those who make use of the schemes or are involved in the work of cognate services.	A total of 121carers of a person who had received assistance from the Macmillan Carers Schemes. Response rate: 56%.	*Design* –Retrospective evaluation using postal questionnaires. *Intervention* – Seven MacMillan sitting services. These comprise a team of health care assistants which aims to provide assistance in three ways: (a)Supporting patients, their families and other carers at critical stages of their disease. (b)Supporting those family members and friends who are providing the practical care necessary to enable people with cancer to remain at home during the terminal period of illness. (c) Supporting carers in order to avoid unnecessary and unwanted admission to hospital in the final days of life.	Structure and organisation of the schemes. Views of service providers. Service activities. User satisfaction. Impact on other services.	Respite for carers was the most common reason for referral (42%). 86% of respondents felt able to go out and leave the sitter with the patient. 70% found the service to be very important to them. Cost per referral varied between £75.67 and £550.57; and cost per hour of service ranged between £7.29 and £32.24. The lowest costs associated with a service located within a bureau handling referrals for various forms of care in the community. The highest costs related to a scheme closely integrated with a specialist palliative care and inpatient hospice service.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Clark et al. Seymour et al. 2002[114;116] UK IIIc	To analyse the structure and organisation of the services in which Macmillan Nurses are operating as well as the range of health care resources that are required to support them. To examine the understandings and experiences of postholders in relation to the Macmillan Nurse role.	A total of 12 selected services participated from the Thames region and the Trent region.	*Methods:* semi-structured interviews, clinical records, cost analysis.	Locations and context Activity levels Management patterns Work organisation and content Wider links Resource use Education Co-working and care pathway development	There was wide variation across several dimensions. This is likely to indicate the existence of both excellent practice and suboptimal practice. Differences of expectation between Macmillan Nurses and their managers about the appropriate focus of their work lead to problems of role ambiguity and role conflict. Macmillan Nurses lack resources with which to develop an educative and consultative role and yet substitute for inadequacies in skills and knowledge of other health care staff. Problems are associated in co-working with newly appointed cancer site-specific nurses and palliative medicine colleagues.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Corner et al.[124] 1996 UK Ic	To evaluate the effect of non-pharmacological intervention for breathlessness in lung cancer on breathlessness ratings and patient functioning.	A total of 34 patients had consented to take part in the study. I=19. C=15. 14 patients (8 from the intervention group and 6 from the control group) had to withdraw from the study due to deterioration.	*Design* –RCT *Intervention* – Weekly sessions with a nurse research practitioner over 3-6 weeks using counselling, breathing retraining, relaxation and teaching coping and adaptation strategies.	Outcomes were assessed by three ten-point visual analogue scales to rate breathlessness over the previous week (breathlessness at best, breathlessness at worst and distress caused by breathlessness). The Functional Capacity Scale was used to assess ability to walk distances and climb stairs and an activities of daily living checklist identifies difficulties in performing activities. Hospital Anxiety and depression Scale. Indepth interviews to explore the experience of breathlessness.	Improvements in median scores on all measures except for depression for the intervention group. For the control group median scores were static or worsened. Distress from breathlessness was improved by a median of 53%, breathlessness at worst by 35% and functional capacity by 21%. In contrast, distress in the control group worsened by a median of 10%. Significant improvements compared to the controls: Breathlessness at best ($p<0.02$), breathlessness at worst ($p<0.05$), distress ($p<0.01$), functional capacity ($p<0.02$) and ability to perform activities of daily living ($p<0.03$) but not for anxiety and depression.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Gustafson et al. 2001[125] USA Ia	To assess the impact of a computer-based patient support system on quality of life in younger women with breast cancer, with particular emphasis on assisting the underserved.	A total of 246 newly diagnosed breast cancer patients. Age: under 60 years of age.	*Design* –RCT. *Intervention* –The experimental group received Comprehensive Health Enhancement Support System (CHESS), a home based computer system providing information, decision making, and emotional support (133). C: usual care plus a copy of Dr Susan Love's Breast Book (132).	Fact-B instrument measured Quality of life. A 6-item social support scale measured social support. A 3-item scale measured unmet information scale. A 5-item scale measured information competence scale. Participation in care. Chess use over time was tracked automatically by the system. Pretest and two posttest surveys (at two- and five-month follow-up).	Significant improvements in: Competence at seeking information, Comfort in participating in care, confidence in doctors, at two- month follow-up. Better social support and greater information competence at five-month follow-up. Experimental assignment interacted with several indicators of medical underservice.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Higginson & Wilkinson. 2002[113] UK IIIb	To describe and evaluate care provided by Marie Curie nurses, and in particular to evaluate whether patients in their care remained and died at home.	All the patients who were referred to the services between 1 January 1997 and 28 February 1999 (26 months). N=26632 patients.	*Design* –A retrospective evaluation by the analysis of existing data sets. *Intervention* –The service provides a day-and-night nursing service for patients with advanced and progressive cancer, particularly in the period leading up to death.	• Data on demographic characteristics (gender, age, ethnic origin). • Data on main diagnosis, residential status and place of death.	*Request for Marie Curie service:* 26632 patients. 97% cancer patients. 11% lived alone. The amount of care provided varied enormously (<1 hour-2862 hours), although the majority used less than 300 hours of nursing care. *Place of death:* Recorded for only half these patients. 94% died at home, 2.5% died in a hospice. 2.3% died in a hospital, 0.2% died in a nursing home, and 0.6 % other. Home death most often associated with: Patients receiving medication via a syringe driver, patients living with other people, patients with cancer other than prostate cancer, shorter time between referral and death and younger age.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Hinton 1996[117] UK IIIc	To investigate what a competent home care service provided for people with terminal cancer, how far it met their problems, and what else might be done.	Randomised sample of 77 patients came from 428 patients referred. Excluded: 89 who died or became in-patients in the first week, 69 without a competent caring adult at home, 28 unable to converse and 10 others.	*Design* –A cohort study. *Intervention* – Original intervention consisted of a home care service provided by a home care team, some day care facilities and a 24-hour on-call service. Three separate changes were made in the service: 1988: Nurses were allocated to area teams. 1989: staff numbers were increased and each area team linked with a social worker to improve liaison. 1990: a new hospice day centre was opened.	a) Contacts between professional carers and patients. b) Types of care given. c) Pattern of care in relation to nature of problem. d) Other comments on care. The weekly assessments used in the main study could not be repeated. Instead a comparison of the proportion able to remain at home gave an indication of effectiveness.	Nurses made most contacts (3.0 visits and 2.4phone calls weekly, rising sharply in the last week). GPs averaged 0.4 visits/week but their variation evoked either praise or criticism. Maintaining contact, giving explanations and support were reported to help as often as physical treatments and practical nursing, although staff and recipients' account differed slightly. Weakness led to more admissions than pain. Difficulties in relieving fatigue and strain in relatives curtailed home care. Home care team reorganisation and improvement of day care services were associated with modest rises from the original 27% to 34% of patients dying at home.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Hughes et al. 2000[118] USA Ia	To assess the impact of Team-Managed Home-Based Primary Care. (TM/HBPC)	A total of 1966 patients. Mean age: 70 years. Patients having 2 or more activities of daily living impairments or a terminal illness, congestive heart failure (CHF), or chronic obstructive pulmonary disease (COPD).	*Design* –A multisite randomised controlled trial. *Intervention* – I: Home-based primary care (n=981), including a primary care manager, 24-hour contact for patients, prior approval of hospital readmissions, and HBPC team participation in discharge planning. C: customary Veterans Affairs (VA) care and private sector care (n=985).	Patient Functional Status assessed by the Barthel Index, patient and caregiver HR-QoL and satisfaction, caregiver burden, hospital readmissions, and costs over 12 months.	*Significant improvements in:* emotional role function, social function, bodily pain, mental health, vitality, and general health. Non-terminal patients had increases of 5 to 10 points in 5 of 6 satisfaction with care scales. The caregivers of terminal patients improved in HR-QoL except for vitality and general health. Caregivers of non-terminal patients improved in QoL and reported reduced caregiver burden. Patients with severe disability experienced a 22% relative decrease (0.7 readmissions/patient for TM/HBPC group vs. 0.9readmissions/patient for control group) in hospital readmissions (P=03) at 6 months that was not sustained at 12 months. Total mean per person costs were 6.8% higher in the TM/HBPC group at 6 months ($19190 vs $17971) and 12.1% higher at 12 months ($31401 vs $28008).

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
McLachlan et al. 2001[122] Australia Ia	To determine whether making patient-reported cancer needs, quality of life (QoL), and psychosocial information available to the health care team, allowing co-ordinated specifically targeted psychosocial interventions, resulted in reduced cancer needs, improved QoL, and increased satisfaction with care received.	A total of 450 patients. Patient demographics were well balanced in the two arms. Median age: 61 yrs. (range: 18-92 yrs) 59% were male, 73% Australian born. Fully independent in their functioning, only minor symptoms.	*Design* –A randomised controlled trial. *Intervention* –Self-reported cancer needs, QoL, and psychosocial information was collected using standardised questionnaires via a touch-screen computer. For 2/3 of the patients this information was made available to the health care team who co-ordinated targeted psychosocial interventions. C= Information from the remaining 1/3 was not seen. Assessments: at 2 and 6 months.	The Cancer Needs Questionnaire-Short Form (CNQ), The European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire C30 (EORTC QLQ-C30), The Beck Depression Inventory (BDI) Short Form. These were completed by using a touch-screen computer.	There were no significant differences between the two arms with respect to changes in cancer needs, QoL, or psychosocial functioning between baseline and follow-up assessments, nor with respect to satisfaction with care. For the subgroup of patients who were moderately or severely depressed at baseline, there was a significant reduction in depression for the intervention arm relative to the control arm at the 6-month assessment (P=.001). The acceptability of the touch-screen process as a means of self-reporting and satisfaction with care were highly endorsed in both study groups.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Rathbone et al. 1994[121] UK IIIb	To devise a simple measure of quality of life, made up of a composite of traditional nurse/doctor assessments and a patient-centred self-assessment, which can be applied at intervals until the last few weeks of life and is not a burden to the patient.	Of 70 patients admitted to the unit over a seven-month period, 44 patients completed questionnaires, 38 in full. 55 out of the 70 admissions were for terminal care.	*Design* –An observational study. *Intervention* –QoL was measured with a simple assessment: the patient evaluated problem score (PEPS). The assessment was repeated at intervals, usually weekly, where possible.	The patients were asked to identify and grade major problems as they perceived them and also to grade problems previously identified by the medical and nursing staff. A global QoL score and a self-administered WHO score completed the assessment.	A mean of 5.6 problems per patient were identified, of which 14% were psychosocial. Of those patients who completed questionnaires , 58% identified problems not picked up by the nursing and medical staff, 52% of these were psychosocial problems. Of 28 patients who died having previously completed questionnaires 22 had done so in the previous three weeks including eight in the previous seven days.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Siegel et al. 1992[12] USA Ia	To assess and subsequently reduce the prevalence of unmet needs for concrete services of patients with cancer.	A total of 398 patients, 68% of the 582 patients invited, participated in the Stage 2 experimental trial. Equal participation was attained in the control group (70%) and the experimental group (67%).	*Design* –A two stage study. Stage 1: Needs assessment conducted by a cross sectional survey and in-depth interviews. Stage 2: randomised controlled trial. *Intervention* –An automated telephone needs assessment coupled with social worker follow-up. I= Received three automated surveys.	From the automated surveys: • Needs reported in response to the automated surveys. • Services delivered in response to the surveys. *From the final comprehensive needs assessment*: This was done through an interview held with a social worker 6 weeks after the patient's completion of the automated surveys. • Comparability of the groups. • Patient-reported needs • Patient-reported unmet needs.	Patients in the experimental group reported fewer unmet needs than in the control group. The telephone outreach system proved to be a cost-effective and reliable method for the early identification of unmet patient needs soon after they emerge.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Simpson et al. 2001 USA Ia	To determine whether participation in a group psychosocial intervention by patients with breast cancer would result in an improvement in psychological measures and in reduced billings in general medical expenses.	A total number of 89 patients with breast cancer who had completed treatment for stage 0,1,2 primary breast cancer. Exclusion criteria: Older than 70 years of age; main residence closer than 40 kms from the Centre.	*Design* –RCT *Intervention* –Six weekly cognitive/behavioural psychosocial meetings plus usual psychosocial care. The program had six weekly themes: 1)progressive muscle relaxation, 2) inner relaxation (self hypnosis), 3)stress-management techniques, 4) mental imagery, 5) goal setting, and 6) planning and achieving change.	Psychiatric symptoms Mood Depression Coping Strategies Healthcare billing records. Instruments: Symptom checklist (SCL)-90-R. Beck Depression Inventory (BDI). Mental Adjustment to Cancer Scale (MAC). Profile of Mood States (POMS). QoL index. Dealing with Illness Inventory (DWII). Structured Clinical Interview for DSM-III-R (SCID). Assessments: pre-intervention, post-intervention, 1 year follow-up, 2 year follow-up.	*Significant improvements in:* Depression, overall mood disturbance, overall QoL, fewer psychiatric symptoms than those in the control group, beginning immediately post-intervention and remaining so at 2 years post-intervention. Billing in the intervention group was an average of $147 less than in the control group, a 23.5% reduction.

9. SPIRITUAL SUPPORT SERVICES

The nature of the evidence

One systematic Cochrane review was found for the topic area of spiritual support, which was based on the analysis of four randomised controlled trials. This systematic review was carried out in the UK.

We reviewed 17 individual studies. Among these, there were three literature reviews. The remaining studies were all of grade III (seven grade IIIb and seven IIIc). Nine studies were carried out in the UK and five in the USA. One study was from Canada, one from Australia and one from Scotland.

Types of interventions

The Cochrane systematic review had the specific objective to review the effectiveness of prayer as an additional intervention for those with health problems, who were already receiving standard medical care[127].

Walter[128]undertook a literature review and conducted interviews with hospice personnel and hospice chaplains in the early nineties to understand the evolution of theories and practices of spiritual care. He placed these in a context and considered the implications of each of these options for the organisation of palliative medicine and the roles of chaplains, nurses and other practitioners.

Two studies focused on the provision of spiritual care in different care settings. Wright[129] used a postal questionnaire to identify and compare key features of spiritual care provision in hospices and acute hospitals in England and Wales. The importance of this survey lies in the insight it provides in chaplains' perceptions of the changing spiritual care infrastructure and spiritual care requirements of patients in hospitals and hospices within the largely secular context of the health services. Orchard and Clark[130] mapped out some of the terrain with regard to the care home sector about which otherwise little is known. They looked at the range and type of practices adopted by care homes in the area of spiritual care and the frequency of input from external providers.

We identified five studies which focused on the effects of religion or spirituality on health. Dein & Stygall[131] reviewed a number of studies relating to religion and coping with chronic illness, emphasising those aspects relevant to palliative care. Recommendations were made as to how religious issues can be dealt with in clinical practice. A prospective cohort study[132] was undertaken to explore the impact of spiritual beliefs on the resolution of bereavement. Relatives and close friends of patients admitted to a specialist palliative care centre were followed for 14 months after the death and the strength of their spiritual belief and bereavement outcome were assessed by standardised measures. In a recent exploratory study undertaken by Coleman et al.[133] the implications of spiritual belief for adjustment to spousal bereavement have been studied in a sample of 28 older bereaved spouses. The case study methodology allowed the participants to be followed from the first to the second anniversary.

Kune et al.[134] investigated the association of perceived religiousness to colorectal cancer risk and survival. King et al.[135]undertook a study to assess the role of spiritual belief in clinical outcome of patients nine months after hospital admission.

A subset of the studies on religion and health were concerned with methodological questions towards conducting empirical religion-health research. Mytko & Knight[136] present an overview of the literature relating religiosity and spirituality to physical and emotional health and quality of life especially directed to cancer patients. They discuss standardised measurement scales which assess the religiosity and spirituality of cancer patients in relation to their quality of life. Similarly a study validating the FACIT-Sp measurement scale[137] addressed the question whether spirituality demonstrates a positive association with quality of life, whether this association is unique and whether there is clinical utility in including spirituality in quality of life measurement. Levin et al.[138] explored the relation between religion and health by analysing the literature which addressed the effects of religion on morbidity and mortality, those studies which point to a consistent salutary effect for frequent attendance. This paper reflects on the development of an epidemiology of religion. Another literature review[139] looked at religion and its effects on morbidity and mortality and at special issues which in the past have made the study of religion and death difficult. King et al.[135] presented the development and standardisation of a measure of spiritual, religious and philosophical beliefs. This was the Royal Free Interview which was constructed on the basis of on-going studies by the authors of the nature and strength of belief held by people hospitalised with an acute illness. A later study[140] developed this instrument further into a self-report questionnaire and it was made more comprehensive by including measurement of spiritual experiences in addition to faith or intellectual assent. The RCOPE is a new theoretically based measure to assess the full range of religious coping methods, which is developed and validated by Pargament et al.[141].

Although endorsements of the nurse’s duty to give spiritual care have come from some of nursing’s most influential bodies, guidelines for its practice are absent in the nursing literature. Against this background, Ross[142] conducted a survey with the aim to find out how nurses perceived spiritual need and care, how they delivered spiritual care, and to identify possible influencing factors.

Sadler et al.[143]evaluated a cancer education program for clergy and lay church leaders as they are in an excellent position to partner with health educators to increase parishioners awareness of cancer prevention/early detection, pain management and clinical trials. This study gathered baseline data about the involvement of clergy in cancer-related issues and compared two different methods of delivering a cancer education programme.

Outcome measures

The Cochrane review[127] concluded that the data are too inconclusive to guide those wishing to uphold or refute the effect of intercessory prayer on health care outcomes. In the light of best available data, there are no grounds to change current practices. Further study is recommended.

Walter[128] has outlined three ways in which spiritual care has been conceptualised and organised in palliative medicine. ‘The religious community’ embodied in the hospice, and ‘calling in the chaplain’ where patients who raise spiritual issues can be referred to the chaplain, have now been more or less abandoned in the literature. However, 'calling in the chaplain' is still the norm in practice, especially in hospitals. This is a simple approach to providing spiritual care in today's secular institutions. Nevertheless, it implies that only some patients have a spiritual dimension and it is therefore incompatible with the notion of holistic care. The third concept identifies the spiritual as the search for meaning, which has several advantages: it deepens the role of the chaplain; it widens the role of the nurse; both those with and those without faith can offer spiritual care; and holistic care can include the spiritual dimension, even in a secular setting.

Wright's survey[129] yielded an insight in the provisions and organisation of spiritual care in hospitals and hospices in a secular era. The data suggest a changing pattern of spiritual care, for example the role of the chaplain has come to include more than spiritual care and the increasing use of multifaith rooms indicates a trend away from establishing Christian chapels as the spiritual focal point within health care settings. These patterns raise questions for managers and providers relating to the scope and nature of spiritual care and place demands on the adaptability and resourcefulness of spiritual caregivers in health settings. The results from the survey that Orchard and Clark[130] undertook indicated that the increased profile of spiritual support has permeated into the sector of home care. They found a significant level of interest in spiritual care in this environment, with many managers considering it to be an important aspect of the care they provide for residents. Although the views of home managers were not always consistent, the broad, generic understanding of spiritual care as an integrated aspect of holism which is prevalent in the wider NHS was to some extent shared by care home staff. They however concluded that there is much scope for improving the level of understanding among staff about all aspects of spiritual care in care homes of the UK.

Dein & Stygall[131] identified a limited number of studies looking at religion and coping in chronic illness, but these suggest that religion is a common coping mechanism which may have positive effects in relation to adjustment. The recommendations which followed from this investigation mainly point to the pivotal role of the nurse in identifying spiritual need and linking with the clergy. Also, a multidisciplinary palliative care team which involves doctors, nurses, psychologists and chaplains is recommended. The cohort study which looked at the relation between spiritual beliefs and grieving concluded that people who profess stronger spiritual beliefs seem to resolve their grief more rapidly and completely after the death of a close person than do people with no spiritual beliefs[132]. These findings concur with the results obtained from Coleman et al.[133] who found a remarkably strong association between level of belief, personal meaning and well being. Especially among those of moderate belief a clear pattern was found of greater depressive symptomatology and lower perception of personal meaning. In Kune et al.[134]perceived religiousness was found to be statistically significantly protective for colorectal cancer in both men and women and it was associated with a longer survival time. In contrast, King et al.[135] found that a stronger spiritual belief is an independent predictor of poor outcome at nine months in patients admitted to two acute services of a London hospital. Although the results of this study must be regarded as preliminary, the finding that strength of spiritual belief is more predictive of outcome than physical state assessed by clinicians, or self-reported psychological state at admission, suggests that spiritual belief is a factor that cannot continue to be ignored in outcome research.

Mytko & Knight[136] found that religious, spiritual or existential concerns have only just been incorporated into assessments of quality of life or satisfaction with one's life. This is despite the evidence of significant relationships between religiosity, spirituality and physical well being and quality of life. Brady et al.[137] found that spirituality was associated with quality of life to the same degree as physical well-being, a domain unquestioned in its importance to quality of life. Levin et al.[138] argued that an interdisciplinary effort is necessary for empirical religion-and-health research, and discussed the conditions for the development of an epidemiology of religion. The review by Jarvis et al.[139] concluded that studies of religious effects on morbidity and mortality have broadened in focus from the study of specific health practices, or health-related behaviours to include the study of social support, religious participation and health-related attitudes. King et al.[135] tested a measure of spiritual, religious and philosophical beliefs in order to establish population norms, validity and reliability. Their findings demonstrated that people are able to express spiritual and religious aspects of their lives in a way that can be measured with acceptable reliability and validity. In a later study[140] this instrument was developed into a self-report questionnaire, which was brief and simple to complete. The authors recommended that measures of religious and/or spiritual belief like this would be more widely applied in health services research as they evaluate aspects of people's lives that go somewhat further than health status or quality of life. The RCOPE also provided encouraging results suggesting that the instrument may be useful to researchers and practitioners interested in a comprehensive assessment of religious coping and in a more complete integration of religious and spiritual dimensions in the process of counselling[141].

Ross[142] found that the nurses had a propensity to view spiritual need in religious terms, and recognised patients' spiritual needs mainly through non-verbal/indirect verbal cues such as 'distress' and 'helplessness'. The majority of nurses considered it their shared responsibility to respond to patients' spiritual needs, and some did so personally, but still a substantive number preferred to refer these needs to others, mainly the clergy. There is an indication that some nurses may need to be made aware that providing spiritual care is part of their normal duties, while others' concept of spiritual need should be broadened.

In Sadler et al.[143]the clergy to who the intervention was directed, reported opportunities to use their acquired cancer knowledge, a high receptivity to their information, comfort discussing cancer care and clinical trials, and a strong recommendation that the educational program/partnership continue to be offered.

Implications of the evidence for recommendations

There are not many studies on the effectiveness of interventions to improve spiritual support for people experiencing the effects of illness, treatment or who are approaching death. Some studies are now recognising the relation between spiritual belief and adjustment to illness or bereavement. This led to theoretical investigations or reviews of the literature to find out how spirituality can best be understood. Definitions and practices are reconsidered in the changed context of a secular and multicultural society.

The concept of spirituality outlined in the recommendations concurs with recent interpretations of the term, identified as 'the search for meaning' which can include religion but equally can refer to existential concerns in a broader sense.

In the recommendations the assessment of spiritual need is a priority in effective care provision. The literature underscores its importance but indicates that it is not yet clear how this should be done. Recently, attempts have been made to develop measurement scales for spiritual needs, however there is a lot of variation in what is measured and it is not clear whether these instruments are also applicable to other religious populations.

There is discussion of how best to deliver spiritual care and one of the recurrent issues is the unique position of the nurse to pick up spiritual needs and refer patients to chaplains as they generally spend most time with patients. Spiritual care is considered as the nurse' duty and this requires training. Another way of operationalising holistic care, where the patient is treated as a physical, social, emotional and spiritual being is best delivered through a multidisciplinary team.

The literature warns against the danger of medicalising spiritual concerns. Spiritual care can become transformed into rational discourses of measurement, diagnosis or audit while in fact for a person's spiritual beliefs to be respected often more can be achieved by the attitude of "being with" than "doing for" the patient.

We identified a study which reported the success of an educational intervention directed at local faith leaders from the community. The survey which gathered information on the usefulness of the program showed a strong recommendation for the educational partnership to be continued.

As yet we have not found any studies that discuss spiritual support for carers or for staff.

Tables of Evidence: Spiritual Support Services

Systematic Review

Author, date, country, grade	Aims of study	Inclusion/exclusion criteria	Study design and outcome measures	Results
Roberts et al. 2001[127] UK Cochrane review	To review the effectiveness of prayer as an additional intervention for those with health problems already receiving standard medical care.	Inclusion criteria limited to intercessory prayer, thus excluding the majority of prayer studies which also include 'distance healing'. Four studies were included among w3hich three studies focused on people with life threatening conditions: Children with leukaemia (New York 1969) Those admitted to a coronary care unit (San Francisco 1988, San Diego 1999). The participants in the other study were ill with psychological or rheumatic disease.	*Types of studies:* Relevant randomised and quasi-randomised trials. *Types of outcome measures:* • Achievement of desired goals among recipients, care-givers (such as families), and those praying. • Death. • Illness. • Quality of life of recipients and care givers.	There was no evidence that prayer affected the numbers of people dying from leukaemia or heart disease (OR 1.11, CI 079-1.56, n=1424). Intercessory prayer did not clearly decrease the odds of people with heart problems experiencing a bad or intermediate outcome (OR 0.8, CI 0.64-1.00, n=1444) but this finding was moved towards the null inclusion of a negative assumption for those who were dropped from the analysis in one study. Prayer increased the odds of readmission to the Coronary Care Unit (OR 1.54 CI 1.02-2.33, n=1406) but these results are made significantly negative by the inclusion of an assumption of poor outcome for those not accounted for in the final analyses.

Individual studies

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Brady et al.[137] 1999 USA IIIc	To use a large and diverse sample to investigate three questions relevant to the issue of including spirituality in QoL measurement in oncology (1) Is there a positive association between spirituality and QoL in cancer patients? (2) Is this relationship unique? (3) Is spirituality clinically relevant to QoL?	The total sample consisted of 1610 subjects, of whom 52.7% were male. Median age: 55.3 years. Median length of time since diagnosis: 11.8 months. Subjects were recruited from four sites in the mainland US and two sites in Puerto Rico.	*Method* –Large-scale validation of the Functional Assessment of Chronic Illness Therapy (FACIT) measurement scale. This is conducted across languages, cultures and literacy.	Functional Assessment of Cancer Therapy- General (FACT-G). Functional Assessment of Chronic Illness Therapy-Spiritual Well-being (FACIT-Sp) Marlowe-Crowne Social Desirability Scale (MCSDS). Profile of Mood States-Short Form (POMS-SF).	Spirituality, as measured by the Functional Assessment of Chronic Illness Therapy – Spiritual Well-being (FACIT-Sp), was found to be associated with QoL to the same degree as physical well being, a domain unquestioned in its importance to QoL. The significant association between spirituality and QoL was unique, remaining after controlling for core QoL domains as well as other possible confounding variables. Furthermore, spiritual well-being was found to be related to the ability to enjoy life even in the midst of symptoms, making this domain a potentially important clinical target.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Coleman et al.[133] 2002 UK IIIb	To investigate how religious, spiritual and other beliefs and understandings about existential meaning contribute to quality of life in old age.	A total of 28 people who had been bereaved 12-15 months ago. 22 women, 6 men. All but two were interviewed three times over a one-year period. Age range: 61-89 yrs. Mean age: 74 yrs.	*Method* –A case study methodology, following up a limited number of cases over a one-year period, interviewing three times: 1.After the first anniversary of the death. 2. Six months later, 3. After the second anniversary.	• Beliefs • Perceptions of meaning. • Personal meaning and existential transcendence. • Bereavement experience. • Measures of general health. • Depression. • Self-esteem. • Interview data on the person's life since bereavement, sources of adjustment and meaning, nature of beliefs, personal expectations of the church.	All those of strong beliefs: scores above the norm for their age group on personal meaning and existential transcendence. None displayed above criterion depression scores, or gave indications of mental health problems. Depressive symptoms were concentrated among those of moderate to weak belief. A significant number of them indicated below the norm scores on both personal meaning and existential transcendence. However, some people of moderate, weak and no spiritual belief scored high on these scales too. This demonstrates the independence of the measures of personal meaning and spiritual belief.

Author, country, grade	Aims of the study	Inclusion criteria	Outcome measures	Results
Dein & Stygall[131] 1997 UK Critical literature review	To critically examine the studies which purport to demonstrate associations between spiritual beliefs, religious practices and psychological prognosis. To make recommendations as to how religious issues can be dealt with in clinical practice.	Studies relating to religion and coping with chronic illness, emphasising those aspects relevant to palliative care.	The use of religion as a coping mechanism, among people with a chronic disease and among cancer patients.	The studies reviewed suggested that religious concerns and the use of religion as a coping mechanism may occur commonly in patients with a range of chronic physical illnesses. Patients often desire to discuss religious issues. Physicians rarely discuss these topics with their patients. Religions are important resources of social support. Recommendations: The incorporation of clergy into the healing process. Collaboration of chaplains with members of the treatment team. Nurses are in a unique position to pick up spiritual needs and refer to chaplains. Palliative care should be provided by a multidisciplinary team, involving doctors, nurse, psychologists and chaplains.

Author, country, grade	**Aims of the study**	**Inclusion criteria**	**Outcome measures**	**Results**
Jarvis et al.[139] 1987 Canada review	To review studies on religion and its effects on mortality (with particular emphasis on mortality).	Studies on the morbidity and mortality experience of various religious groups, including Protestants, Catholics, Jews, Muslims, the clergy, Seventh-day Adventists, Latter-day Saints, Parses, Jehovah's Witnesses, and Hutterites.	The extent to/ and ways in which the adherents of different religions vary in their mortality patterns	Early studies of religious of religious mortality differentials attempted to explain the differences by specific health-related practices such as smoking. The differentials may not be explained in their entirety by such practices. As well, religious participation, social support and religious attitudes may all contribute to better life expectancy. Gaps in the literature are identified and a preliminary model of religion's effect on morbidity and mortality is discussed.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
King et al.[135] 1999 UK IIIc	To develop and standardise a measure of spiritual, religious and philosophical beliefs	Three reference populations were included: 1. Staff working in the Royal Free Hospital. 2. A consecutive series of attenders to a central London general practice. 3. People who strongly identified with a religious faith were chosen for validation of the spiritual section of the interview.	*Method* –An interview was constructed based on on-going studies by the authors of the nature and strength of belief held by people hospitalised with an acute illness in order to establish population norms, validity and reliability for each question.	Royal Free Hospital and GP attenders compared. Royal Free Hospital and GP attenders combined. Reliability and validity.	The interview performed well with satisfactory validity and internal and test-retest reliability. This interview is not presented as a final product which will meet all needs in this complicated area of study.

Author, country, grade	**Aims of the study**	**Patient population**	**Study design**	**Outcome measures**	**Results**
King et al. 1999[135] UK IIIb	To assess the role of spiritual belief in clinical outcome of patients nine months after hospital admission.	A total of 250 patients participated at baseline and 145 replied to follow-up. These were patients admitted to the cardiology and gynaecology services of an inner London teaching hospital.	*Design* – Observational study.	At admission: Patient characteristics, nature of belief, strength of spiritual beliefs, psychological and social status, impact of illness, relationship between type of belief and health status. At follow-up: Clinical outcome, outcomes in belief and psychological status, prediction of outcome. Instruments: The Royal Free Interview for Religious and Spiritual Beliefs. The General Health Questionnaire. The Nottingham Health Profile. Social Function Questionnaire.	A 197 patients (79%) professed some form of spiritual belief, whether or not they engaged in a religious activity. Strength of belief was lower in patients who were in a more serious clinical state on admission (F=3.099), d.f.=2 and 192, p=0.05). Case note information was available nine months later for 234 patients (94%) and contained useful information for judging clinical outcome in 189 (76%). Patients with stronger spiritual beliefs were 2.3 times more likely (CI=1.1-5.1, p=0.033) to remain the same or deteriorate clinically nine months later. Other predictions of poor outcome were male gender and sleep disturbance at time of admission to hospital.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
King et al.[140] 2001 UK IIIb	To develop the Royal Free Interview for Spiritual and Religious beliefs further as a self-report questionnaire and to make it more comprehensive.	Group 1: staff in the Royal Free Hospital (as a measure of test-retest reliability). Group 2: participants in London and Southampton completed the questionnaire plus the Intrinsic Religious Motivation Scale (as a measure of criterion validity). Group 3: members of a fundamentalist Christian church in London (as a further measure of validity).	*Method:* A self-report format was designed based on discussions with colleagues, advice from users of the interview and comments from respondents. The final format was evaluated.	1. Patterns of response and demographic predictors of belief. 2. Test-retest reliability and internal consistency. 3. Criterion and internal validity. 4. The nature of spiritual experiences and their relationship to beliefs and strength of beliefs.	297 people took part in the validity and reliability tests of the questionnaire. Criterion validity, predictive validity internal consistency and test-retest reliability were acceptably high. The instrument consistently differentiated between people with high and low spiritual beliefs.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Kune et al.[134] 1993 Australia IIIc	To investigate whether perceived religiousness relates to colorectal cancer risk and survival.	The data are based on 715 colorectal cancer cases (388 men and 327 women), 392 colon cancers and 323 rectal cancers. C= 727 community controls (328 men and 329 women). They were frequency matched for age to the cases in 5 year intervals, and sex. Mean age: 65 yrs.	*Method* –Data extracted from the case control and survival substudy arms of a large, comprehensive population based, clinico-pathological and epidemiological investigation of colorectal cancer. Two questionnaires were administered separately by personal interview by two different interviewers.	1. Data on age sex, country of birth, religion, current and past illnesses, operations, medications, bowel habit biopsychosocial factors, number of children and family history. 2. data on diet which included alcohol intake and tobacco use.	Self-reported or perceived 'religiousness' was a statistically significant protective factor [relative risk=0.70,95% CI=0.6-0.9, P=0.002]. This statistically significant protection remained after the previously determined major risk factors found in the study, namely a family history of colorectal cancer, dietary risk factors, beer consumption, number of children and age at birth of the first child, were statistically corrected for (P=0.004). There was no association between Dukes' staging of the cancer and perceived degree of 'religiousness (P=0.42). The perceived high level of 'religiousness' was associated with a longer survival time.

Author, country, grade	Aims of the study	Inclusion criteria	Outcome measures	Results
Levin et al.[138] 1987 USA IIIc	To reflect on the conditions to develop an epidemiology of religion.	27 studies which have addressed the effects of religion on morbidity and mortality and which operationalise religiosity as religious attendance.	Several pervasive epistemological, methodological, and analytical problems with these studies were identified.	There is insufficient evidence to conclude that religious attendance is positively and significantly related to health. The authors present a theoretical basis for expecting such associations. A possible scenario for the development of an epidemiology of religion is discussed.
Mytko & Knight[136] 1999 USA Literature review	To present an overview of the literature relating religiosity and spirituality to physical and emotional health and quality of life.	Studies which assess the religiosity and spirituality of cancer patients in relation to their quality of life. Studies discussing measurement scales of religiosity and spirituality which have been used with a medical population in the past 10 years.	Psychometric qualities of selected religiosity and spiritual measures. Evidence on the connection between religion, spirituality and health. Evidence on the connection between religiosity, spirituality, and quality of life outcomes in cancer care.	Psychosocial research is just beginning to incorporate religiosity and spirituality into studies of emotional and physical illness. To date, studies have found significant relationships between religiosity and spirituality and physical well being and quality of life. This research indicates that religious and spiritual beliefs and practices may provide physiological, affective, behavioural and cognitive mechanisms for coping with illness and distress.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Orchard and Clark[130] 2001 UK IIIb	To provide an overview of the provision of spiritual care in care homes in the Trent region of England.	The study concentrated on homes at a corporate level, by approaching staff who could function as representatives (such as the home manager).	Method – A literature review. Informal interviews with home managers and other staff. Meetings with key stake holders such as registration and inspection officers. A questionnaire.	The home and its residents (e.g. the ethnicity and religious affiliation of the residents and the number of people who died in the last year). The type and frequency of care provided (e.g. whether any regular religious services were held in the home and how many times this happened each month). The views of the home manager about spiritual care (e.g. whether managers thought all dying residents had spiritual needs).	A response rate of 42 % was achieved. Home managers were found to have a broad understanding of spiritual care, according a spiritual dimension to a range of tasks that were social and emotional in nature. Most managers felt that the responsibility for providing spiritual care lay with the home itself, rather than other parties, although concerns were expressed over the ability of some staff to deliver this care. Many homes had input from religious providers via regular services and visiting personnel. There was a perception of a heightened level of spiritual need for dying residents, although it is suggested that physical pain continues to dominate the focus of care at this stage.

Author, country, grade	**Aims of the study**	**Patient population**	**Study design**	**Outcome measures**	**Results**
Pargament et al.[141] 2000 USA IIIb	To develop and validate a new theoretically based measure that assesses the full range of religious coping methods, including potentially helpful and harmful religious expressions.	A total of 540 college students who were coping with a significant negative life event completed the study. Data were also collected from a sample of 551 elderly hospital patients.	*Design* –Cross sectional study.	College sample: Background information. Global religious measures. Religious coping. Measures of adjustment. Hospital sample: Religious coping.	Factor analysis of the RCOPE in the college sample yielded factors largely consistent with the conceptualisation and construction of the subscales. Confirmatory factor analysis of the RCOPE in the hospital sample was moderately supportive of the initial factor structure. Results of regression analyses showed that religious coping accounted for significant unique variance in measures of adjustment after controlling for the effects of demographics and global religious measures

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Ross L.[142] 1994 Scotland IIIc	To report how a sample of nurses perceived and reported how they gave spiritual care, and to identify possible influencing factors.	A total of 685 staff nurses and charge nurses. 1.170 nurses were approached. Response rate of 76.8 per cent. Nurses working in care of elderly people settings in twelve health boards in Scotland.	*Method* –A survey by postal questionnaire. In-depth interviews with a sub-sample of 12 nurses.	The questionnaire sought information on the perception of the concept of spiritual care, the way in which it was delivered and possible factors influencing spiritual care.	76.8%of the nurses said they had identified a spiritual need at some point in their practice. They had a propensity to view spiritual need in religious terms, and recognised patients' spiritual needs mainly through non-verbal/indirect verbal cues such as 'distress' and 'helplessness'. The majority of nurses (n=618) considered it their shared responsibility to respond to patients' spiritual needs, and some did so personally (n=121), 333 preferred to refer these needs to others, mainly the clergy.

Author, country, grade	**Aims of the study**	**Patient population**	**Study design**	**Outcome measures**	**Results**
Sadler et al.[143] 2001 USA IIIb	To evaluate a clergy cancer education program developed in partnership with the region's NCI-designated clinical cancer centre.	Of the 34 invited churches, 19 (55%) participated.	*Design* – Randomised trial without a control group. *Intervention* –Two educational programs: I1: in-person. I2: by telephone. Data–Participants received identical training binders with space to insert the follow-up educational mailings that were sent every eight weeks. These included information about clinical trials, free cancer screenings, educational brochures about specific cancer issues, such as pain management and clinical trials.	*A baseline survey* focusing on the sociodemographics of the participants, their personal experiences with the health care system and their experiences counselling people with cancer. *A follow-up survey (six months later):* gathered information on the acceptability and usefulness of the educational program.	Clergy reported opportunities to use their acquired cancer knowledge, a high receptivity to their information, comfort discussing cancer care and clinical trials, and a strong recommendation that the educational program/partnership continue to be offered.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Walsh et al.[132] 2002 UK IIIb	To explore the relation between spiritual beliefs and resolution of bereavement.	A total of 129 relatives and close friends of patients admitted to the centre with terminal illness. 40% were the spouse or partner of the dying patient, 40% were their adult children.	*Design* – Prospective cohort study.	1. The Royal Free interview for religious and spiritual beliefs assesses the nature and strength of spiritual beliefs and practice. 2. The core bereavement items scale measures the intensity of grief. 3. The hospital anxiety and depression scale measures emotional status. 4. The close persons questionnaire measures social support. 5. The locus of control of behaviour scale is a measure of the extent to which people perceive events as being a consequence of their own behaviour and under personal control. Follow-up: at 1, 9, and 14 months.	People reporting no spiritual belief had not resolved their grief by 14 months after the death. Participants with strong spiritual beliefs resolved their grief progressively over the same period. People with low levels of belief showed little change in the first nine months but thereafter resolved their grief. These differences approached significance in a repeated measures analysis of variance (F=2.42, P=0.058). Strength of spiritual belief remained an important predictor after the explanatory power of relevant confounding variables was controlled for. At 14 months the difference between the group with no beliefs and the combined low and high belief groups was 7.30 (95% CI 0.86 to 13.73) points on the core bereavement items scale. Adjusting for confounders in the final model reduced this difference to 4.64 (1.04 to 10.32) points.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures and results
Walter[128] 1997 UK IIIc	To document the evolution of theories and practices of spiritual care, to place them in context and to note some problems associated with each.	Hospice personnel and hospice chaplains in Britain in the early 1990s.	*Method*– literature review and interviews with hospice personnel and hospice chaplains.	*Three options of understanding spiritual care:* 1. The idea of the hospice as a religious community. 2. Spiritual care as the responsibility of the chaplain. 3. The concept of spiritual care as the search for meaning. Advantages/disadvantages of the 3 options: 1. It enables total care to be given. Conflict can develop as such institutions develop and take on less devout staff. 2. An organisationally less problematic approach fitting a widespread understanding of religion: only some people are religious and they may be referred by staff to the chaplain - but this undermines the goal of holistic care. 3. Recent discussion argues that everyone has a spiritual dimension entailing a search for meaning. All staff can help in this area.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Wright[129] 2001 UK IIIc	To identify and compare key features of spiritual care provision in hospices and acute hospitals within England and Wales.	Senior chaplains in 151 hospices and 194 hospital trusts. The overall response rate was 76%.	*Method* – A survey by postal questionnaire.	The questionnaires sought information about the infrastructure supporting spiritual care, and about the nature of both religious and non-religious humanistic care.	• A trend away from establishing chapels as the spiritual focal point within hospitals and hospitals. • The development of broader roles for chaplains. • A different level of service provision between hospices with funded chaplaincies and hospices with voluntary chaplaincies. • A wide range of non-religious spiritual care requirements on the part of patients. • A more frequent requirement for religious care in hospitals rather than hospices.

10. GENERAL PALLIATIVE CARE SERVICES, INCORPORATING CARE OF DYING PATIENTS

Nature of the evidence

For the topic area of general palliative care we extracted the data of seventeen studies into tables. These were mostly grade I studies (seven grade Ia, four grade Ib, and one Ic). There were two grade II (a and b) studies and three grade III (one IIIb and two IIIc). Eleven studies came from the USA, one from Spain, four from the UK and one from the Netherlands.

Types of interventions

Most of the studies focusing on symptom control experimented with educational interventions[90;91;100;144-150]. Other studies[148;151] experimented with the combination of educational interventions and organisational measures. Elliot et al.[148] implemented their intervention in the clinical community by making use of opinion leaders and developing practice guidelines, and Desbiens et al.[151] through the mediation of nurse clinicians. Four studies, Borras et al.[152], Kane et al.[153] and Ellershaw et al.[73] and Robinson & Stacy[154] were organisational interventions, Borras et al.[152] focusing on home care, Kane et al[153] on the role of the hospice in symptom control and Ellershaw[73] on the implementation of the ICP for care of dying patients into clinical practice in the hospice setting as a method of monitoring best practice regarding symptom control. Robinson & Stacy[154] set out to develop guidelines for primary care teams to follow in the provision of palliative care in the community.

Borras et al.[152], Kane et al.[153] and Ferrel et al.[149], Schuit et al.[155] were concerned with pharmacological interventions and the technical area of pain and symptom control. Borras et al.[152] was a feasibility study of chemotherapy at home compared with hospital treatment. Schuit et al.[155] evaluated whether a single palliative cancer care workshop which included information about drug prescribing, had an effect on the opioid-prescription patterns of general practitioners in daily practice. Kane et al.[153] evaluated the role of the hospice in pain control, and Ferrel et al.[149] experimented with a pain management educational intervention, also adding a non-drug component to the trial. Nash & Hoy[145] evaluated palliative care residential workshops for general practitioner/district nurse pairs from the same practice.

Bredin et al[147], Desbiens et al.[151], Elliott et al.[148], Ganz et al.[90] , Spiegel and Bloom[156] , Syrjala et al.[91] each provided multifaceted interventions, either with the emphasis on pain-related knowledge Ferrel et al.[149], Lasch et al.[146], knowledge and attitude[146], or psychological support[91;147;148;150;156] . The latter two studies provided relaxation and imagery as complementary therapy to the trial.

The aim of the organisational studies was to assess the service of symptom control delivered in different settings, with the exception of Robinson & Stacy[154] who set out to develop standards for primary care teams to use in the delivery of palliative care in the community. The aim of the educational studies was predominantly relief of pain or symptoms. Three studies were specifically concerned with symptoms that cannot be managed with standard medical treatment or with persistent pain[90;91;150]

The interventions were mostly directed towards patients who were critically ill or suffering from severe symptoms like the dyspnoea of lung cancer in Bredin et al.[147] or the dying patient in Ellershaw et al.[73]. One study targeted patients having moderate pain[144;144] and another study breast cancer survivors[90]. Ferrel et al.[149] also included caregivers in his intervention. Desbiens et al.[151] reported an intervention mediating between patients and professionals, and Elliott et al.[148], Schuit et al.[155], Robinson & Stacy[154], and Nash & Hoy[145] were interventions applied in the clinical community. Lasch et al.[146] provided an educational intervention for nurses.

Outcome measures

The outcomes of the organisational interventions focused on a variety of outcomes. Borras et al.[152] found no difference in the quality of life for patients receiving home chemotherapy but showed that it increased patients' compliance with treatment and satisfaction, particularly with regard to nursing care. He concluded that home chemotherapy forms an acceptable and safe alternative to hospital treatment for patients with colorectal cancer. The evaluation of pain control by the hospice, carried out by Kane et al.[153], demonstrated that pain is controlled equally effective by conventional care. Ellershaw et al.[73] found that the ICP for the dying patient is a method of measuring symptom control in the dying patient and providing demonstrable standards, which are integrated into clinical practice. It also facilitates the provision and implementation of symptom control guidelines particularly in anticipatory prescribing for pain, agitation, and respiratory tract secretions. They concluded that the ICP can be used as part of a continuing audit programme to monitor and improve the quality of care and as part of an integrated education programme to empower other health care professionals to care for dying patients. Robinson & Stacy[154] found that the development of multidisciplinary as opposed to medical guidelines for palliative care allows primary health care teams to create standards that are acceptable to them and stimulates individuals within the teams to accept responsibility for initiating the change necessary for more effective care.

The interventions targeting clinical professionals led to different results. In Elliott et al. a significant improvement of both patients' and physicians' knowledge and attitudes with regard to cancer pain management[148] was achieved. The educational intervention for general practitioners Schuit et al.[155] implemented showed only limited efficacy. This corresponds with the findings of other studies that educational interventions only have a limited impact on change in clinical practice and that studies with more innovative teaching methods, involving e.g. feedback concerning prescriptions or face to face interactions between peers should be adopted to effect new behaviours. Moreover, with regard to the use of morphine, it is even more difficult to change prescribing behaviours, partly because cultural beliefs and attitudes associated with this type of drug still have a strong effect on therapeutic choices. Lasch et al.[146] developed a cancer pain education program where a didactic workshop-only approach was compared with an enriched teaching strategy where they could participate in a bedside-precepted visit with an oncology nurse specialist with pain specialisation and a focus group to discuss attitudinal issues. The results showed similar improvements for both educational approaches. The paper has some reservations in accepting these results and considers the possibility that they may be an artefact of the outcome measures. The paper-and-pencil test they used may not have been able to capture the differences in the ability to apply knowledge in the clinical setting. A performance-based assessment might have revealed the hypothesised differences between enriched-model and workshop-only nurses. Desbiens et al.[151] shows no effect with his multifaceted intervention in ameliorating pain in seriously ill patients. This outcome should also be qualified. Several reasons for the failure of the intervention have been given, among which the nurse clinician mediation that could have contributed to the mitigation of the effects of feedback on the physicians and nurses. The authors state that nurse or nurse physicians are necessary agents in the control of hospital pain. They conclude that physicians and nurses must become more involved in pain control. An attempt to address this issue was found in Nash & Hoy[145] who evaluated a residential workshop for general practitioners/district nurse pairs from the same practice. A survey indicated that this workshop had a potential for affecting practice. The findings showed raising confidence in some areas of palliative care, and increasing awareness of the roles of other professionals within the team, based on an understanding of the stress factors involved in caring.

The studies providing pain-related knowledge have positive results. Ferrel et al.[149] show the significant differences in caregiver outcomes in areas such as improved knowledge, reduced fear of addiction, and giving adequate doses of medications. Oliver et al.[144] indicates that the benefit of the intervention was not attained solely by increasing patient knowledge of cancer pain or its management and suggests that the intervention helped patients to interact effectively with their physicians.

The interventions providing psychosocial support through educational strategies show beneficial outcomes in coping and reducing physical and emotional distress[147], in improving quality of life and sexual functioning for breast cancer survivors[90], in survival for patients with metastatic breast cancer[150], and in pain relief for patients with persistent cancer[91].

Implications of the evidence for recommendations

The recommendations take the essential role of physicians, physiotherapists and nurses in pain management into account, which matches the findings of Desbiens et al.[151], and Oliver et al.[144]. The recognition of the importance of dying in the place of choice is a realistic proposal as home care increasingly becomes an option[152], and Kane et al.[153] have demonstrated equally effective care in the hospice and the hospital. The beneficial outcomes of psychosocial support may be also considered as deserving attention, especially in areas where pharmacological treatment modalities do not relieve pain completely.

Training for the family caregivers also becomes apparent from the review of these studies.

Tables of Evidence: General Palliative Care Services, incorporating care of dying patients

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Borras et al. 2001[152] Spain Ia	To compare chemotherapy given at home with outpatient treatment in terms of colorectal cancer patients' safety, compliance, use of health services, quality of life, and satisfaction with treatment.	Patients eligible for study: • Diagnosis of colorectal cancer. • Between 18-75 years. • Suitable for treatment with bolus fluorouracil. I=45 patients. C=42 patients.	*Design* –RCT *Intervention* – I=Treatment with fluorouracil at home. C=Treatment at outpatient clinic.	• Treatment toxicity using the ECOG classification • Withdrawal from trial • Use of healthcare resources • Quality of life measured with EORTC QoL-C30 questionnaire. • Satisfaction with health care.	• Voluntary withdrawals from chemotherapy were significantly higher in the outpatient treatment group (difference 12% (95% C.I. 1% to 24%)). But no differences between groups due to medical reasons. • No significant differences in use of healthcare resource for unplanned visits. • No differences in quality of life. • Global satisfaction with health care was higher in the home group, but the difference was not significant.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Bredin et al. 1999[147] UK Ia	To evaluate the effectiveness of nursing intervention for breathlessness in patients with lung cancer.	Patients (n=119) diagnosed with small cell or non-small cell lung cancer or with mesothelioma who had completed first line treatment for their disease and reported breathlessness. I=51 patients At 4 weeks assessment: n=43. At 8 weeks assessment: n=33. C= (n=52) At 4 weeks assessment: n=40. At 8 weeks assessment: n=27.	*Design* –multicentre RCT *Intervention* – Patients attended a nursing clinic where they received a package of interventions tailored to individual patients to help them to cope with breathlessness and maximise their existing lung function. C: standard management and treatment for breathlessness. *Data* – Detailed assessment of breathlessness, advice and support, exploration of the meaning of breathlessness, training in breathing control techniques, goal setting to complement breathing and relaxation techniques, support coping strategies.	*Primary outcome measure:* distress due to breathlessness. *Other outcomes* • WHO performance status scale. • The hospital anxiety and depression scale. • The Rotterdam symptom checklist.	At 8 weeks, the intervention group showed significant improvement for breathlessness at best, WHO performance status, levels of depression, and physical symptom distress. Levels of anxiety and distress due to breathlessness improved slightly. Groups were similar in breathlessness at worst, psychological distress, and overall global quality of life.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Desbiens et al. 1998[151] USA IIb	To test a nurse clinician-mediated intervention to relieve pain in a group of seriously ill hospitalised adults	A total of 4804 patients with one or more of nine high mortality diagnoses I=2652 patients C=2152 patients	*Design* – quasi-RCT at five tertiary academic centres. *Intervention* –A multifaceted nurse-clinician mediated intervention. Specially trained nurse clinicians assessed patients' pain, educated them and their families. Informed patients' nurses and physicians and suggested or used other pain management resources. *Data:* using information, empowerment, advocacy, counselling and feedback.	Hospital interviews with patients and surrogates to determine patients' pain. *2 and 6 months later or after death:* assessment of pain and satisfaction of its control.	Comparison between I and C: No statistically significant difference in level of pain (OR for higher levels of pain 1.15; CI 1.00-1.32), or satisfaction with control of pain at all time periods (OR for higher levels of pain 1.12; CI 0.91-1.39).

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Ellershaw et al.[73] 2001 UK IIIb	To implement the Integrated Care Pathway (ICP) for care of dying patients into clinical practice in the hospice setting to develop measurable outcomes and set standards regarding symptom control of pain, agitation, and respiratory tract secretions.	A total of 168 inpatients of a hospice participated. Data were collected over a 13-month period. Criteria for entry on the ICP: when the multidisciplinary team agreed that the patient was dying and had at least the following: bed bound, semi-comatose, only able to take sips of fluid.	*Design* – Observational study *Intervention* –The ICPs provide a method of recording and measuring outcomes of care. The ICP document replaces all previous documentation and is a multiprofessional record of patient care.	Symptoms observations: • Pain • Agitation • Respiratory tract secretions.	For each symptom, 80% of patients had one episode or complete control of the symptom, 10% had two episodes, and 10% had three or more recorded. As death neared, there was a statistically significant increase in the number of patients whose pain was controlled.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Elliott et al. 1997[148] USA Ib	To improve the knowledge, attitudes, and clinical behaviours of physicians and nurses; improve the knowledge and attitudes about cancer pain management (CPM) of cancer patients and their family members, and to reduce cancer-related pain experienced in cancer patients.	*Unit of study*: whole Community (all practising physicians and nurses, all cancer patients and their families. I= three communities C=three communities	*Design* –RCT *Intervention* –A multimodal educational intervention. *Data:* community opinion leader clinicians formed CPM task forces, didactic programs and outreach programs.	Patients: • Patients' pain Intensity scores. • Cancer related pain prevalence. • Knowledge and attitudes regarding CPM. Physicians and nurses: • Knowledge and attitude scores regarding CPM.	*Patients and family members:* The prevalence of pain declined and the pain management index improved. The pain intensity score and the total attitude score in patients and caregivers deteriorated. None of the changes were statistically significant. Physicians and nurses: Improvements for all measures. None of them were statistically significant.

Author, country, grade	**Aims of the study**	**Patient population**	**Study design**	**Outcome measures**	**Results**
Ferrel et al. 1993[149] USA Ia	To report on the development and implementation of a pain management educational intervention	*Patients:* (n=40) elderly cancer patients, mean age: 66 years. *Family caregivers:* (n=29), mean age: 60 years.	*Design* –RCT *Intervention* – A three-part structured pain educational intervention. *Data*: Teaching materials, including the verbal instructions for the nurse in the home, a written patient education booklet, two audio-cassette tapes, written instructions for 19 interventions across 5 areas of non-drug techniques. *Evaluation:* Two follow-up home visits at 1 week and 4weeks postinstruction.	QoL Compliance with interventions. Effectiveness of the interventions. Mood.	Patients: Decreasing pain intensity (p=0.05) Decreasing perception of pain severity (p=00.01) Decreasing fear of addiction (p=0.02) Decreasing anxiety (p=0.05) Increasing the use of pain medications (p=0.01) Improved sleep (0.03) Increased knowledge levels of pain principles (p=0.07) Positive about the use of non-drug interventions. Caregivers: Significant differences in caregiver results.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Ganz et al. 2000[90] USA Ia	To test the efficacy of a comprehensive menopausal assessment (CMA) intervention program in achieving pain relief of symptoms, the improvement of quality of life, and sexual functioning in breast cancer survivors.	A total of 72 postmenopausal breast cancer survivors. Eligibility criteria: • A disease free, female breast cancer patient. • Perimenopausal or postmenopausal. • All chemotherapy or radiotherapy completed at least 4 months prior to enrolment, but could be taking tamoxifen. • Presence of at least one severe target symptom. I=33 patients. C=39 patients.	*Design* –RCT. *Intervention* – I=A structured comprehensive assessment of the three target symptoms (hot flashes, vaginal dryness, and stress urinary incontinence) followed by an individualised plan of education, counselling, pharmacologic and/or behavioural interventions, psychosocial support, referrals, and follow-up tailored to each woman's needs and preferences. The CMA was delivered by a nurse practitioner. C=Received usual care.	Menopausal Symptom Scale Score adapted from the Breast Cancer Prevention Trial Symptom Checklist. Vitality Scale from the RAND 36-Item Health Survey 1.0 (alternatively known as Medical Outcomes Study SF-36) Sexual Summary Scale from the Cancer Rehabilitation Evaluation System.	Intervention group improvements in: Menopausal symptom management (P=.0004). Sexual functioning (P=.04) No statistically significant improvement in: Vitality (P=.77).

Author, country, grade	**Aims of the study**	**Patient population**	**Study design**	**Outcome measures**	**Results**
Hainsworth 1996[157] USA IIa	To determine the effect of death education on attitudes and behavioural intentions of experienced nurses who care for hospitalised terminally ill adults and their families and to determine the influence of death education on nurses' self perceptions regarding supervision or peer review of their behaviour toward dying patients and their families.	Self-selected sample (n=28) of registered nurses randomly assigned into experimental (n=14) and control (n=14) groups. Setting: a 612-bed acute care teaching hospital in a large city in central New York.	*Design* –Controlled before and after study (CBA) *Intervention* – An assessment of nurses' stressors related to care of the terminally ill conducted prior to the study identified three major needs: personal death awareness, communication with dying patients and their families, and care for the caregiver. These needs provided the focus for the educational intervention. The educational intervention consisted of three two-hour classes using didactic and experiential learning strategies. *Data* – The classes combined lecture with discussion, videos, music and role-play. Reading homework and exercises were carried over from one class to another. A hospice nurse was invited to the third class to share stress-management ideas with the group.	A 15-item demographic questionnaire. The Attitudes, Subjective Norms and Behavioural Intentions of Nurses Toward Care of Dying Persons and their Families (ASBID) The questionnaires were administered by a researcher two weeks before the educational intervention and one week after its completion.	The researcher detected no significant difference in attitude between the two groups. The educational intervention had a significant positive effect on subjective norms. No significance was detected in overall analysis of behavioural intentions.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Kane et al. 1985[153] USA 1a	To assess the role of the hospice in managing pain associated with terminal cancer.	Patients with a prognosis of two to six months. I=137 patients. C=110 patients.	*Design* –RCT, full method not stated; sampling portion weighted to favour hospice care. *I*=Patients were assigned to receive comprehensive hospice care. C= Patients received traditional medical care.	Tests on baseline data for initial differences between the I and C group. Melzack pain measurement scale. Symptoms scale, adapted from the California Pain Assessment Profile. McGill pain scale. A summary symptoms score. The log-rank test to evaluate differences in survival. The Ware General Well-being Scale for the relation between pain and anxiety. The depression scale.	No significant differences in: The proportion of patients with pain at any time. The intensity of pain. The intensity or frequency of cancer-related symptoms. A significant correlation in: The levels of depression and anxiety and pain scores.

Author, country, grade	**Aims of the study**	**Patient population**	**Study design**	**Outcome measures**	**Results**
Lasch et al. 2000[146] USA Ib	To examine the nurse outcomes of a cancer pain education program for nurses of patients from 11 different ethnic groups.	A total of 496 home, hospital, and hospice nurses. All the groups were similar I terms of sociodemographic and other characteristics.	*Design* –RCT *Intervention* – • The enriched model: bedside-precepted visit with an oncology nurse specialist with pain specialisation and a focus group to discuss attitudinal issues (n=380). • One-day workshop or two half-day workshops on cancer pain assessment and management (n=116). • Control group (n=86)	Attitudes, knowledge and attitude measures. Pretest: before the workshop. Posttest: immediately afterwards and on the day of the workshop. Follow-up test: approximately 12 months after the last enriched-model nurse had participated in a precepted visit and focus group.	*Attitude change*: Those who attended a workshop significantly changed pain management attitudes from pre- to posttest (p=0.01). Attitude changes were maintained at follow-up for both workshop-only and enriched-model groups. The attitudes of the control group nurses did not change except for the ability to take culture into account. Knowledge and application change: The two intervention groups significantly improved their knowledge and application test scores (p=0.0001 and p=0.0001; p=0.0002 and 0.0001 respectively) between the pre- and posttests. The control group did not improve. The improvement at follow-up was maintained for the intervention groups. The control group did not improve on knowledge questions but did on application questions.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Linn et al. 1983[158] USA Ia	To evaluate the effects of training, by changes in staff anxieties about death, attitudes, knowledge, and skill, as well as by changes in quality of life for dying patients assigned to their care.	The nursing home personnel from 10 community nursing homes. I=296 C=290. Ninety-one percent of the nursing staff members participated in the training, with 79% attending all of the sessions. Of those attending, 75% were nursing attendants, 14% were LPNs, 8% were RNs, and 3% were other employees in the homes, such as administrators, social workers etc.	*Design* –RCT Ten homes (five pairs) were randomly selected. Randomisation within pairs by envelope method, based on a table of random numbers. *Intervention* –Training (provided for the five experimental homes) consisted of three two-hour sessions, scheduled three times a day, for groups of about ten on each nursing shift. Sessions were conducted by a Nurse Palliative Care Consultant for the National Forum for Death Education and counseling, who was employed to do the training. The objectives of the course were to decrease personal anxieties about death and dying and to increase empathy and understanding for dying patients and their families, to gently remove the taboo aspects of discussion of death, to gain understanding of the psychological and emotional dynamics of dying, and to learn skills that would be helpful in providing care.	The Collett-Lester Death Anxiety Scale measured fears about death and dying. The semantic differential technique was used to measure attitudes toward caring for the dying patient and dealing with his family. Vignettes were used to test skills. Knowledge was assessed with 12 items focusing on content and objectives of the sessions. Staff members were pretested per pair on anxieties, attitudes, knowledge, and skills before randomisation After the training staff was retested on the same variables.	Intervention group improvements in: Fear of dying of others decreased at the .05 level. Attitudes about caring for the dying patient were significantly improved in the experimental group at the .001, level and attitudes about dealing with the dying patient's family improved at p<.05. The greatest change was seen in knowledge and skill. Anxiety about death of self increased for the experimental group at p,.01.

Author, country, grade	Aims of the study	Population	Study design	Outcome measures	Results
Nash & Hoy[145] 1993 UK IIIc	To describe and develop the content of palliative care residential workshops for general practitioners/district nurse pairs from the same practice.	The general practitioners/district nurse pairs participants of five workshops run between October 1989 and September 1991.	*Method:* Pre-post test study. *Intervention* –Workshops run over a three-day period. Main issues: difficult symptoms, counselling and communication, breaking bad news, grief and loss, coping. Educational strategies: small and large group discussion, video, and case history analysis. Experiential learning, role play.	A retrospective self-rating scale: demographic data, confidence in practice, usefulness of attending together.	GPs who attend these workshops have generally been in practice for a short time, no such pattern is identifiable for district nurses. This workshop has been evaluated very highly. Comments showed high levels of perceived improvement in the understanding of others' roles and more empathy with the difficult issues for other professionals in the practice of palliative care.

Author, country, grade	**Aims of the study**	**Patient population**	**Study design**	**Outcome measures**	**Results**
Oliver et al.[144] USA Ib	To evaluate the effect of an individualised education and coaching intervention on pain outcomes and pain-related knowledge among outpatients with cancer-related pain.	A total of 78 cancer patients (18-75 years old) with moderate pain over the past 2 weeks before enrolment. 64% female, 56% male. Mean age: 55 years. I=34 patients. C=33 patients.	*Design* –RCT. Patients not blinded to the intervention. *Intervention –* I=A 20-minute individualised education and coaching session to increase knowledge of pain self-management, to redress personal misconceptions about pain treatment, and to rehearse an individually scripted patient-physician dialog about pain control. C=Patients received standardised instruction on controlling pain.	Baseline survey Validated single item scale, used for average pain. Six-item pain effects subscale of the Medical Outcomes Study Patient Assessment Questionnaire (MOS-PAQ, for impairment caused by pain. Single item drawn from the MOS-PAQ, for pain frequency. The baseline survey and chart review for additional patient information. MOS standard form (SF)-12 physical and mental health component scores. Medical records and computerised pharmacy logs.	*At baseline*: No significant differences between experimental and control groups. Intervention group improvements in: Average pain severity. *No improvements in:* functional impairment as a result of pain, pain frequency, pain-related knowledge.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Robinson & Stacy[154] 1994 IIIc UK	To develop guidelines for primary care teams to follow in the provision of palliative care in the community using facilitated case discussions with the members of such teams, as a form of internal audit.	A total of 56 cases of patients who required palliative care, or relatives who required bereavement care.	*Method:* Five practices were randomly chosen from the family health services authority medical list. Meetings between facilitators and primary care teams were held over a period of one year. The teams were asked to describe good aspects of care, areas of concern and suggestions to improve these, in recent cases of patient deaths.	Three areas of concern: Communication, clinical care, and Administration.	All practices felt that cohesive teamwork, coordinated management, early involvement of nursing staff and the identification of a key worker were essential for good terminal care. Concerns arose in clinical and administrative areas but the majority were linked to poor communication, either between patient and professionals within the primary care team or between primary and secondary care.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Schuit et al. 2000[155] The Netherlands Ic	To evaluate whether a single palliative cancer care workshop, which included information about drug prescribing, had an effect on the opioid-prescription patterns of general practitioners in daily practice.	A total of 201 general practitioners. I=68. C=133.	*Design* –RCT. *Intervention* –A palliative cancer care workshop, including information about drug prescribing. *Data* –The learning objectives were discussed through case presentations of terminal cancer patients. Guidelines for palliative care were introduced.	The opioid-prescription figures of the general practitioners who had participated in the workshop were aggregated from the computer system of the Regional Sick Fund, and compared a year before and a year after the workshop. A questionnaire before and after the workshops evaluated the participants' achievement of the workshops' learning objectives.	A cancer palliative care workshop had only limited efficacy in altering the morphine-prescribing patterns of general practitioners. This did not accord with the results of the pre- and post-workshop questionnaire evaluating the attitudes of the same practitioners. The questionnaire revealed significant increases in most of the knowledge and behaviour scores.

Author, country, grade	**Aims of the study**	**Patient population**	**Study design**	**Outcome measures**	**Results**
Spiegel & Bloom 1989[150] USA Ib	To assess whether group therapy in patients with metastatic breast cancer had any effect on survival.	A total of patients with documented metastatic carcinoma of the breast. I=50 patients. C=36 patients.	*Design* –RCT. *Intervention* – I=Received routine oncological care, and they participated in a weekly therapy group led by a psychiatrist or social worker with a therapist who had breast cancer in remission. C=Received routine oncological care.	Cox's proportional hazards model. The log-rank test. Kaplan-Meier plots. Unpaired t- tests. Wilcoxon's rank sum. X2 tests.	Intervention group improvements in: Survival from time of randomisation and onset of intervention was a mean 36.6 (SD 37.6) months in the intervention group compared with 18.9 (10.8) months in the control group. Survival plots indicated that divergence in survival began at 20 months after entry, or 8 months after intervention ended.

Author, country, grade	**Aims of the study**	**Patient population**	**Study design**	**Outcome measures**	**Results**
Syrjala et al. 1995[91] USA Ia	To examine the effectiveness of cognitive-behavioural techniques and relaxation and imagery (or hypnosis) training in reducing cancer-related pain.	A total of 94 patients who underwent their first bone marrow transplantation (BMT) completed the study. Mean age: 36 years.	*Design* –RCT. The researchers and data collectors were blind to the randomisations of the patients. *Intervention* – Comparing oral mucositis pain levels in 4 groups of cancer patients receiving (BMT): *I*= 4. Therapist support. 5. Relaxation and imagery training. 6. Training in a package of cognitive-behavioural coping skills which included relaxation and imagery. C= Treatment as usual control.	Oral Pain Visual analogue scale (VAS). Nausea VAS. Oral Mucositis Index. SCL-90-R. Post-Treatment evaluation. Background. Risk.	Intervention group improvements in: Patients receiving either relaxation and imagery alone or the package of cognitive-behavioural coping skills reported less pain than the patients in the 2 other groups. It was not confirmed that the cognitive-behavioural skills package has an additional effect beyond relaxation and imagery. Average VAS report of pain within the therapist support group was not significantly lower than the control group (P=0.103) nor significantly higher than the training groups.

11. SPECIALIST PALLIATIVE CARE SERVICES

Nature of the evidence

There have been seven systematic reviews considering the effect of specialist palliative care teams or hospices or related palliative care services. The most recent of these was the most comprehensive[111;159]. In addition, to finding new literature this 2001/2 review appraised the existing five reviews[160].

The 2001/2 systematic review included 44 original studies, of which seven were grade I (RCT). It combined three methods of data analysis. A meta-analysis, following Cochrane methods assessed specific outcomes, such as pain, symptom control etc, a meta-regression, using all the outcome data, and exploring factors, such as team composition, which may have affected the outcomes, and a qualitative meta-synthesis, combining all studies. Funnel plots indicated slight publication bias.

Of the earlier reviews, five met the criteria for a systematic review[161-165], one defined itself as a 'critical' review[166]. These were of limited quality; using a standardised review appraisal system[167] assessing the way articles were included and combined etc, three scored 10 or more out of a possible total of 14. A total of 42 studies were identified by all the reviews, of these 15 were randomised controlled trials (RCTs – grade I), eight prospective (grade II) studies and 16 retrospective (grade III) studies. The distribution of studies from the US was very high; twelve of the 15 RCTs in total were North American. In comparison, the majority of the UK studies were the retrospective design (grade III) with eight of the 16 studies from the UK.

In addition for the purpose of this review for the guidance, the data from grade I and III individual studies, identified in our search strategy of randomised and quasi-experimental trials, have been extracted into tables, and a further meta-analysis of all the studies in the original Higginson et al[111] review has been undertaken.

Types of interventions

The 2001 review [111;159] specifically included specialist palliative care teams working in home care (22 studies), hospital based (9), combined home/hospital care (4), inpatient units (3), and integrated inpatient hospices/ home care and hospital advisory (6). These highlighted the great variation in type of intervention – ranging from a hospital support team of one full-time nurse and a surgeon (half day per week), to a palliative care ward or hospice, or to a full community team. In the US palliative care services tended to provide all aspects of care, whereas in other countries care was shared between palliative care teams and other professionals. Both small and large units had very varying structures; staff training was often unclear, although the UK tended to report more specialist training. Services were reported from cities, urban and rural areas. The interventions were compared with hospital care, a Foundation home or usual home care. The earlier five reviews assessed an even broader range of services, including communication interventions, chemotherapy support and non-specialist services. The tables extracted here reflect this variation. One problem with the studies evaluating the services is that the randomised controlled trials in the UK[2 168] were not of true specialist palliative care services, but rather of services that worked with specialist palliative care.

Outcome measures

In the 2001 review[111;159], meta-regression found slight positive effect of palliative care teams on patient outcomes, independent of team (or service) make-up or study design. The effect size was 0.1 per outcome, which can be considered as small (see figure) although often multiple outcomes were affected. Thus, a small positive benefit occurred in many areas. Meta-analysis demonstrated small benefit on patients' pain, other symptoms, satisfaction, and therapeutic interventions (combined odds ratio 0.38, 95% CI 0.33–0.44). Home death was largely equivocal. There was support in favour of in-patient palliative care units or hospices, hospital teams[169] and home care teams. The qualitative meta-synthesis supported these data, as did the earlier reviews, although only two of these appraised patient or carer outcomes[161;164]. These found similar or improved outcomes for patient satisfaction, patient pain & symptom control, and family anxiety when compared with conventional care for hospices and home care – hospital teams were little considered in the earlier reviews. This however was not supported in all studies and there was no evidence about the impact of other quality of life measures.

In the studies shown here the palliative care teams also showed more positive than negative outcomes. In Grande's study[168;170], improvements were found in the hospital at home group. These, however, were based on nurses and GP's views which may be biased in favour of home care. Johansson et al[171] shows positive effects of home care nurse contacts on the utilisation of services. McCorckle et al[172] also showed better outcomes in symptom distress and independence than the control group. Zimmer et al[8] showed that home care can be both cost-effective and desirable for those who wish it. It increased patients' and carers' satisfaction with services significantly. In the home support team study for family physicians and nurses no results were found because of early deaths, problems with recruitment and a low compliance rate for completion of questionnaires. Also, the required sample size was not attained. As in the other studies having a cost component McCusker & Stoddard[173] found that cost containment is occurring among home care users due to decreasing hospital days and the reduced mean daily cost of hospitalisation.

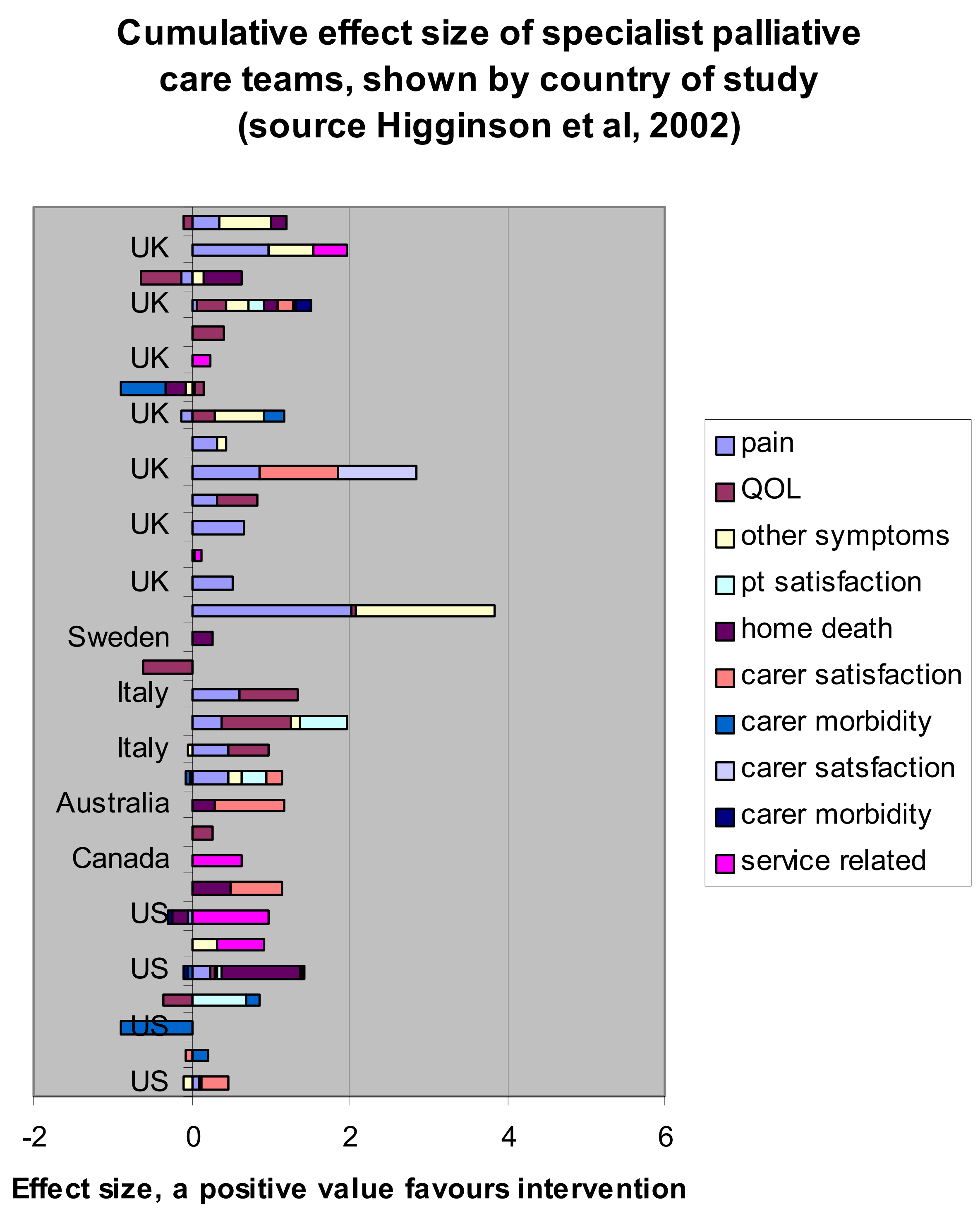
Kane et al[174] shows no substantial differences in cost or effectiveness between the study and the control group, but the patients and their families appreciated the qualitative differences in hospice care. The co-ordinating service study[2] reported that few differences were found in symptoms and symptom control, service provision and satisfaction, and psychological support. A recent study by Jordhoy et al[3] showed no effect of a hospital based team on home care or QoL although this study was carried out in a rural area, where there were many nursing homes, and criticisms have been raised about the outcomes measured.

The analysis of studies where an effect size could be calculated, indicate an overall positive effect of the palliative care team, particularly in the UK based studies (see figure). However, a meta-regression could detect no relationship between team make up, study design, country or other study or team variables which explained the variation in outcome between studies (the heterogeneity in effect)[159]. However the authors observed a tendency for better outcomes in studies where the teams had been categorised as specialist, with multi-professional trained staff, compared to those which were nurse only, and/or had limited training (Finlay I, et al – paper submitted personal communication). There was also in a few studies an effect on service related outcomes, including co-ordination, prescribing practices generally in the hospital where the team was based.

Implications of the evidence for recommendations

The evidence (grade IA, IA, and below) strongly supports specialist palliative care teams working in home, hospitals and in-patient units or hospices as a means to improve outcomes for cancer patients, such in as pain, symptom control and satisfaction, and in improving care more widely. The benefit has been demonstrated quantitatively and qualitatively, in studies and in systematic reviews of these.

Given the variety of interventions within each team, more work is needed to test the specific components of palliative care team activity (for example to compare different types of hospital team or hospice, or to test specific ways of working within their practice), and to discover if a different skill mix or interventions performed by the team, are more effective than each other.



NB Effect size for each reported outcome was calculated by dividing the estimated mean difference, or differences in proportions, by the standard sample deviation. This allows comparisons between outcomes measured in different scales. An effect size of 0.1-0.2 is considered small. The data above shows effects of this magnitude or larger.

Tables of Evidence: Specialist Palliative Care Services

Individual studies

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Addington-Hall et al 1992 & Raftery et al 1996[2;5] UK Ib	To measure the effects of terminally ill cancer patients and their families of co-ordinating the services available within the National Health Service, from local authorities and from the voluntary sector.	A total of 203 cancer patients expected to live less than one year and who had at least one follow-up interview: I=54% female, 82%65 years or older, 46% married. C=54% female, 76% 65 years or older, 56% married. 118 carers: Carers characteristics did not differ significantly between groups.	*Design* –RCT, stratified random sampling of patients attending a district hospital or oncology, radiotherapy, general surgery, or urology outpatient clinics. Interviewers blind. I=104 received routine services plus community based nurse co-ordinators who provided a link between *Intervention* – I=104 received routine services plus community based nurse co-ordinators who provided a link between services. C=99 patients received routinely available services. Follow-up at intervals of between two weeks and six months, until death; plus carers at same time and eight weeks post-bereavement.	• Symptoms and control ADL. • Shortened Family Apgar Scale. • Satisfaction. • HADS. • Spitzer QoL Index. • Service use. • Sources of income. • Carers experience and satisfaction. • Leeds depression and anxiety scale for carers.	Intervention group improvements in: Fewer days spent in hospital (particularly acute) or hospice. Fewer home visits. Less likely to feel angry when they thought of the patient's death. No difference in: Satisfaction with services. Mean number of inpatient days in specialist cancer hospital. The proportion having unmet needs for help or aids and appliances at home. The numbers receiving advice on benefit entitlements or savings.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Axelsson et al 1998[119] Sweden IIb	Financial assessment of hospital-based palliative support service (PSS),	*Characteristics:* study group: median age 72 yrs (range 58-87); control: median age 70 yrs (range 52-86); reference: median age 71 yrs (range 49-88). Total sample: 97; I = male 24, female 17; C = male 19, female 22; reference: male 9, female 6.	Comparing study group – Surgeon half day per week; one full-time specialist nurse; and 6 interested colleagues made occasional home visits. – with matched historical group and contemporary reference group.	Place of care and death, financial needs	The median duration of terminal hospitalisation for the study group was 3 days, which was significantly shorter than for the control group (10 day; p 0.017). the patients in the study group spent 50 days at home from the date of enrolment with the PSS to death, which was significantly more than the control patients, who spent 23 day (median) at home during an identical period. No significant differences in health care utilisation when comparing the study group with the reference group (reduced institutional care at end of life); no significant differences in the utilisation or resources at home outside the PSS (DN, domiciliary service)

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Axelsson & Sjoden 1998[126] Sweden IIIc	Objective was to gather knowledge about the quality of life both of terminally ill cancer patients and their spouses	37 patients receiving support from PSS referred by surgeons or GP. Symptomatic incurable cancer disease. Cancer disease within the realms of general surgery. Patient resident within 40km of hospital. Patients expressed wish to stay at home. Spouse who was ready to support patient at home. Median age: 70 yrs. Range: 31-88 yrs. Total sample: 37 Male: 23 Female: 14	*Interventions* Palliative Support team *Control* No control Patients & carers were asked to complete quality of life questionnaires at monthly intervals.	*Patient / carer* Assessment of quality of life at the end of life (AQEL) 19 questions Spouses: similar instrument comprising 14 questions	Study confirms general downward trend of most patients QoL items when approaching death. 35% of patients were pain free during their terminal month

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Bennett & Corcoran 1994[175] UK IIIc	To examine the influence of a hospital palliative care team on the activity of a local hospice home care team (over a four-year period).	The first 50% of referrals in each of the 4 years, lack of data for 1/5th of the sample; referral to death interval is based on approximately 40% of each years referrals. Almost exclusively cancer patients, 1 chronic neurological.	Retrospective examination of records *Interventions* Referral to death (hospital) impact on the hospice home care *Control* No control	*Patient / carer* Referral to death; impact on hospice home care team; place of death.	The number of new referrals for GHCT rose during 4 years (significant from 1990-92 $p<0.01$). No significant difference in place of death or numbers referred by either JPCT or GPs; the median interval from referral to death was significantly longer for referrals from JPCT than GPs (89 day and 54 days; $p<0.004$). Approximately 80% of patients are still referred within 3 months of their death.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Bloom 1980[176] USA IIIB	To compare the cost of care fore patients who died at home under medical supervision with a control group of patients who died in hospital.	19 matched pairs: median age 68 years, range 35-94; 12 pairs were male, Those who spent the final two weeks of life at home or in the hospital; those who had died at home and had no episodes of hospitalisation during the last two weeks of life	*Method* The billed charges of care during the last two weeks of life for patients dying of malignant disease at home compared to those who died in a hospital. Researchers interviewed the surviving family of home care patient. *Interventions* Home care *Control* Hospital usual care	*Patient / carer* Anecdotal material concerning the family's reaction to the process of caring for their family member. *Economic* Billed charges for home care patients obtained from families, community services, Blue Cross, physicians, pharmacies, and equipment suppliers. Costs for patients who died in a hospital were from daily billing accounts.	There was a 10.5 fold difference between mean total 2-week charges incurred by those who died at home and in the hospital. Mean charges for care of patients dying at home were $586 (range $137 to $1,162); mean charges for care of those who died in hospital was $6,180 (range $3,333 to $11,645). The per diem home care charge was $42 compared with $441 for care in a hospital. All forms of palliative therapy for hospital patients accounted for 28.6% of total charge; for home care patients the charge was $70 (11.9% of total charge).

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Bredin et al. 1999[147] UK Ia	To evaluate the effectiveness of nursing intervention for breathlessness in patients with lung cancer.	Patients (n=119) diagnosed with small cell or non-small cell lung cancer or with mesothelioma who had completed first line treatment for their disease and reported breathlessness. I=51 patients At 4 weeks assessment: n=43. At 8 weeks assessment: n=33. C= (n=52) At 4 weeks assessment: n=40. At 8 weeks assessment: n=27.	*Design* –RCT *Intervention* – Patients attended a nursing clinic where they received a package of interventions tailored to individual patients to help them to cope with breathlessness and maximise their existing lung function. C: standard management and treatment for breathlessness. *Data* – Detailed assessment of breathlessness, advice and support, exploration of the meaning of breathlessness, training in breathing control techniques, goal setting to complement breathing and relaxation techniques, support coping strategies.	*Primary outcome measure:* distress due to breathlessness. *Other outcomes* • WHO performance status scale. • The hospital anxiety and depression scale. • The Rotterdam symptom checklist.	At 8 weeks, the intervention group showed significant improvement for breathlessness at best, WHO performance status, levels of depression, and physical symptom distress. Levels of anxiety and distress due to breathlessness improved slightly. Groups were similar in breathlessness at worst, psychological distress, and overall global quality of life.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Dessloch et al 1992[177] [translated from German] IIIb	To investigate the quality of life in terminally ill cancer patients (hospital versus home-bound care)	Mean age 66 years (range 37-86); Home care: male 4 (20%), female 16 (80%); hospital: male 13 (62%), female 8 (38%) Malignancy, life expectancy of <6 months, Karnofsky score <50 (inability to self care), stay at locality for minimum of 2 weeks, ability to communicate verbally, minimum age of 35 years	Semi-structured interview with patient. Home care (from specialist palliative care team)	Patient / carer Indicators of quality of life: perceived social support and social distress, coping with illness, perceived positive environmental factors, contentedness with medical & nursing care, physical well-being	More home care patients state they receive 'optimal' nursing care. Where there are differences in outcome, they point towards home care. Home care was superior with respect to perceived positive environmental factors, perceived control over daily activities, and caring routines, and contentedness with nursing. No differences between the groups were found for any of the other variables.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Dunt et al 1989[178] Australia IIb	To evaluate the effectiveness and cost-effectiveness of the City mission Hospice Programme	Hospice group: age <60 years 21 (33%), male 32 (49%), care giver: age <60 years 36 (67%), male 19 (31%); Control group: age <60 years 16 (30%), male 29 (53%), care giver: age <60 years 18 (43%), male 13 (25%). Histologically confirmed cancer; life expectancy <6 months.	Quasi-experimental design; monthly interviews of patients &/or care givers until patients death Intervention – *Hospice programme* Control group from specialised cancer home nursing service, large general home nursing service, and oncology department of other hospital.	*Patient/carer* Symptoms and other outcome variables assessed using a 5-point verbal rating scale; measures of QoL based on dissatisfaction with care, Spitzer QLI; Tunstall's social contact score. *Economic* Cost benefit analysis; marginal costs of direct patient care: daily costs and individual patient log of use of services	At first and assessment non-hospice patients had significantly higher usual pain duration. There were no significant differences for all other symptoms. At the first assessment there were no significant differences in levels of QoL, at the last assessment the non-hospice patients had significantly higher dissatisfaction with care scores. The proportion of hospice and non-hospice patients dying at home was identical. Non hospice caregivers had lower levels of difficulty in their roles as care givers (at last assessment). The largest treatment cost is for place of care at first assessment and is statistically significant.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Edmonds et al 1998[179] UK IIIc	To determine symptom prevalence and outcome for inpatients and outpatients referred to a multi-professional hospital palliative care team	*Characteristics* Mean age: 68.5 yrs Range: 26-101 yrs Total sample: 352 Male: 182 Female: 170 *Clinical diagnosis* Cancer: 325 (92%) Non-malignant: 27 (8%) Length of hospital stay approx. 2 weeks. Died during admission: 78	Clinical assessment by doctor / nurse at referral then twice weekly till death or discharge *Interventions* Hospital Palliative care team: X2 part-time doctors X2 full-time CNS	*Patient / carer* E-STAS	Significant improvements (pain, mouth discomfort etc.) Only score not to improve: depression, possibly due to short period of admission
Ellershaw et al[180] UK IIIc	To assess the outcome of interventions made within two weeks of referral with regard to: symptom control, change in patients' and their relatives insight regarding diagnosis and prognosis, and facilitation of patient placement	All patients with malignant disease referred to hospital palliative care team *Mean age: 68 yrs, range: 14-90 yrs* Total sample: 125 Male: 68 Female: 57	Patients were assessed on referral then twice weekly over the subsequent two weeks (unless death or discharge) *Interventions* Hospital based palliative care team *Control* No control	*Patient / carer* Palliative care assessment (PACA) Professionals / services Not evaluated *Economic* Not evaluated	Statistically significant improvements (over day 4, 7) in the symptoms of: pain, nausea, insomnia, anorexia, constipation. Insight significantly changed (at final assessment) and placement appropriate.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Grande et al.[168;170] UK Ib	Evaluation of hospital at home for palliative care.	*Characteristics* Male: 49.8%; female: 50.2%. Age range etc not given: adult and over 75 years. Clinical diagnosis Majority of cancer patients; some HIV and non-cancer. *Prognosis* Time to death: less than 2 weeks and from 2 weeks to 6 months. *Family support* Isolated; alone with family support; family support in own home.	*Design* –RCT, Retrospective proxy assessment. *Intervention–* I=Provide 24 hour nursing care in patients home. C=Usual primary care.	*Patient/carer* Patient's level of pain, nausea and depression; home death rate. Professionals/services Not evaluated. *Economic* Not evaluated.	Can not conclude that hospital at home increased the likelihood of dying at home. Hospital at home appears to decrease the need for out of hours GP visits towards end of life, but did not impact on amount of other nursing care. DN reported hospital at home fared better in terms of night care adequacy and carer support; GPs said they suffered less anxiety and depression and carers said they suffered less pain and nausea.
Higginson et al 1992[181] UK IIIb	To demonstrate the use of STAS in a practical setting and to describe the effect of the palliative care teams in achieving their objectives.	Consecutive patients referred to two teams (over 17 months & 8 months) Mean & median age: 67 yrs range 32-90 years; Total sample: 227 (with 2 assessments) Male: 121 (53%); Female: 106 (47%)	The teams rated the state of each newly accepted patient and family according to the STAS items at first assessment then weekly until death (encouraged to discuss ratings with patients) Interventions Hospice home care support teams, multiprofessional	Patient / carer Pain control; other symptoms; patient anxiety	Unmet needs continued to death: patient / family anxiety; pain control; symptom control. Almost one patient in six either deteriorated or did not improve. One symptom: dyspnoea was not controlled satisfactorily in some patients. Out of the 17 items all but 2 (family anxiety & spiritual) improved significantly during care.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Higginson & McCarthy 1987[182;183] UK IIIc	To describe and evaluate the work of terminal care support teams and to measure the effectiveness of symptom control in patients throughout their period of terminal care.	All newly referred patients (n=124) between December 1984 and December 1985	Prospective assessment of patient symptoms by staff Interventions Palliative care team	Patient / carer STAS (Support Team Assessment Schedule)	In these patients pain was the most common severe symptom on referral. Pain control was improved after one week of support team care and further improvement maintained until death. Towards death 21% of patients developed dyspnoea as their main symptom and this became the most severe symptom at death.
Higginson & Hearn 1997[184] UK IIIc	The prevalence of pain, its effect on advanced cancer patients, and the effectiveness of specialist home-care services in controlling pain (two service evaluations).	Ireland (ICS): mean age 67 years (range 5-95); London (PEP): mean age 67 years (range 32-90). Total sample: 695; Ireland: male 230 (55%); female 188; London: male 150 (54%); female 127. Team management and team members willing to participate; community and hospital based teams could be included; consecutive referrals.	Data was collected prospectively on all referrals using standardised clinical records. Pain was recorded using body charts; its severity was rated at referral then weekly. Interventions Specialist palliative home care services: pain prevalence (six teams in Ireland and five in the UK)	Patient / carer One item of STAS: pain severity	Prevalence of pain in cancer patients receiving specialist palliative care services – mainly in community (70%) is as high as that observed in cancer patients in hospital settings (range 60-79%). Length of survival after referral was not associated with the presence of pain or its severity. No statistical significance was found in levels of pain reported by patients entering the studies from home or hospital. Reduction of severe and overwhelming pain for patients surviving 2 weeks or more (from 14% to 4% after 2 weeks in care).

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Hinton 1979 [185] UK IIIc	To compare patients dying in different circumstances by an assessment of mood and opinions	Mean age 52.8 years (S.D. 10.5); male 30 (38%), female 50 (62%). All were married people expected to die within 3 months from neoplasm; patients were assessed after care had been consistent for at least 2 weeks; willing and able to participate	Comparing four groups of dying people by listening to them and by their words to wife or husband or to the nurses; 20 - 40 minute interviews; matching groups of patients. Interventions Hospice	Patient / carer Descriptive comments on emotional state & feelings; awareness of dying; ratings were made (linear scale) by patient, spouse and nursing staff	In the ratings the hospital came between the modern hospice and the Foundation Home. The hospice (both in-patient and outpatient) shows effectiveness. Patients gave more praise to the outpatient system of care, despite experiencing a little more anxiety or irritability at home. If least distress is consistently found in hospice patients it implies that these units should be encouraged or their significant qualities should be fostered in other units

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Hinton 1994[186] UK IIIc	To assess whether patients with terminal cancer, and their relatives find that competent home care sufficiently maintains comfort and helps adjustment.	Patients: mean age 65 years, (SD 10), carer: mean age 60 years (SD 14). Total sample 77 Patients: male 43 female 34; carers: wife 41, husband 24 daughter/in-law 6, son 3, sister 1, grandson 1, friend 1 'suitable' adults with terminal cancer referred to hospice between 01/08/84 to 31/07/86	One in three sample of suitable adults with terminal cancer. All interviews by author Interventions Home care team	*Patient / carer* Semi-structured (but informal) each week for 8 weeks then, if surviving, fortnightly until 6 months then monthly. Problems were noted with ratings for severity and duration. Spitzer Quality of Life Index scored from relatives' information. *Professionals / services* Not evaluated *Economic* Not evaluated	Subjective aim = subjective criteria. Brief distress was not (could not be) entirely avoided when severe physical symptoms or understandable feelings erupted. Relatives suffered emotionally more than patients in the final month; subjects progress in coping depending on their own resources and support from others.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Hughes et al[187;188] US Ib	To compare the attributes of the Hines model of care (HBHC) with traditional community home care services to which control group patients could be referred. The primary hypothesis of the study was the HBHC would cost less than customary	HBHC: mean age 65.7 yrs (SD 10.9); control: mean age 63.2 yrs (SD 8.0). Total sample: 171 *Male veterans*	Randomised pre-test-multiple post-test experimental design. Baseline then 1 month then 6 month interviews. Patients provided with health care diary to record all home visits. If patient died between baseline and one month, only one month follow-up was conducted with caregiver. I = Hospital-base home care, C= standard community care	Barthels self-care index; Fortinsky, Granger & Seltzer modified scoring system; Short Portable Mental Status Questionnaire; Multidimensional Functional Assessment Questionnaire; short version of Philadelphia Geriatric Centre Morale Scale from Multilevel Assessment Instrument; Satisfaction with Care scale.	HBHC more comprehensive than control care (inter-disciplinary team approach versus nursing services). HBHC more continuous care, Significantly higher levels of satisfaction at one month; no difference in survival rates / functional status; no difference in morale at one month. Increase in costs of home health care was more than offset by reduced VA hospital costs for HBHC patients.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Johansson et al. 1999[171] Sweden Ib	To evaluate the effects of intensified primary care on cancer patients' home care nurse contacts, and to study if patients' use of home care services 6 months after diagnosis can be predicted.	A total of 527 patients newly diagnosed (within 3 months from diagnosis) with breast cancer or under examination for a suspected breast cancer, or diagnosed with colorectal, gastric or prostate cancer. I= 203 patients. C=178 patients.	*Design* –RCT *Intervention* – Intensified primary care (IPC) was implemented. I= • Individual support, i.e. IPC combined with psychological support and, for patients with colorectal and gastric cancer, dietician support. • A combination of individual support and rehabilitation. C= • Rehabilitation. • Standard care.	• Background data were collected on gender, age, marital status, living area, diagnosis and stage of disease at diagnosis. Data were also collected on treatments during the first 6 months after diagnosis. • Hospital Anxiety and Depression Scale (HADS). • An 18-item questionnaire was developed for the assessment of patients' contacts with the home care nurses and perceived benefits of these contacts, 6 months after diagnosis.	Only 27% and 36% of the control patients reported follow-up contacts. Intensified primary care was identified as the strongest predictor for reporting a continuing contact 6 months after diagnosis. Factors associated with a continuing contact were high age, advanced disease and living in a rural district.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Jones & Jones et al[189;190] UK IIIc	To collect information from principal carers of people who had died at home with cancer; to identify areas of support which need improvement.	Patients: <60 yrs (46); 60-80 yrs (132); >80 yrs (29). Carers: <60 yrs (88); 60-80 yrs (110); >80 yrs (9). Total sample: 207 carers; Patients: male 124; female 83	Trained research nurses visited the home 2-4 months after death; semi-structured Interviews with principal carers Interventions Services received by carers and quality of support	Patient / carer The effectiveness of symptom control; and of the extent to which carers had been taught to help themselves. Professionals / services The adequacy of information provided; of the levels of domestic financial and other social support.	Symptom control: most successful type of team: GP, DN, Sp.N; more than 25% of patients had no relief for nausea/ vomiting, dyspnoea, & confusion. Overall outcome during 4 weeks before death: 67/207 carers were unhappy. Improved pain relief provided by primary care teams; augmented in a few cases by Sp.N; control of other symptoms remained poor.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Jordhoy et al, 2000[6] Norway Ia	To assess the effectiveness of an intervention programme that aims to enable patients to spend more time at home and die there if they prefer.	A total number of 434 patients who had incurable malignant disease and an expected survival of 2-9 months. I=235 patients. C=199 patients. In the clusters, the intervention and control groups consisted of 134 and 116, 77 and 65, and 24 and 18 patients, respectively, with the smallest number of patients in the rural pair.	*Design* – A cluster RCT. *Intervention* – 1. All inpatient and outpatient hospital services were provided at the Palliative Medicine Unit unless care elsewhere was required for medical reasons. 2. To strengthen co-operation with the community service, the team at the Palliative Medicine Unit served as a link to the community. 3. Third, predefined guidelines were used to keep the interaction at an optimum between services. 4. The community professionals were offered an educational programme.	Main outcomes: • Place of death (home or in hospital). • Days spent as an inpatient in the last month of life.	395 patients died. Of these, more intervention patients than controls died at home (54 [25%] vs 26 [15%], p<0.05). The time spent at home was not significantly increased, although intervention patients spent a smaller proportion of time in nursing homes in the last month of life than did controls (7.2 vs 14.6%, p<0.05). Hospital use was similar in the two groups.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Kane et al. 1984[174] US Ia	To test the effectiveness of hospices by evaluating comprehensive hospice care and traditional medical care over a two year period.	*Characteristics* Hospice care: mean age 63.3 years, male 97.8%; conventional care: mean age 64.0 years, male 97.2%. Clinical diagnosis All cancer. Prognosis Time to death from 2 weeks to >6 months. *Family support* Alone with family support and family support in own home.	*Design* –RCT, the sampling proportion was deliberately weighted to favour hospice care to ensure full utilisation of the service. *Intervention*– I=Hospital based home care, which includes home care, consultation service. C=Usual hospital care.	Patient/carer McGill-Melzack Pain Scale, Centre for Epidemiological Studies Depression (CES-D scale), anxiety scale, satisfaction scales, functional ability, bereavement – National Health Interview Survey, Chart Audit Protocol. Professionals/service Not evaluated. *Economic* Cost-effectiveness.	There was no significant difference between the two groups in the prevalence of any symptom a month after admission. Among patients who survived at least 3 months, hospice patients were significantly less likely to report symptoms of nausea, diarrhoea and ringing in ears. No significant difference between the groups could be detected in the proportion of patients with pain at any given time or over time or reports of pain. Significant difference in favour of hospice patients for interpersonal care and involvement in care. Caregivers: increased satisfaction with involvement in care and interpersonal care, no difference in health care utilisation.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
McCorkle et al. 1989[172] US Ib	To assess the effects of home nursing care for patients with progressive lung cancer.	*Characteristics* Total sample: 166, 105 men, 61 women; 71 (43%) age 60-69 years. *Clinical diagnosis* Lung cancer *Prognosis* 111 (66%) died or withdrew from the study before completion of five interviews. *Prognosis* *111 (66%) died or withdrew from the study before completion of five interviews.*	*Design* –RCT Longitudinal experimental design *3 treatment groups.* *Interventions*– I= oncology home care program (OHC) - provided by nurses trained to give cancer care & services from other disciplines as needed; standard home care program (SHC) - registered nurses, physio's, home health aides, social worker, OT, speech pathologist. C=OC (control) office care program (OC) provided by patients physicians	*Patient / carer* Symptom Distress Scale (SDS), McGill-Melzack pain questionnaire, Inventory of Current Concerns (ICC), Profile of Mood States (POMS), Enforced Social Dependency Scale, General Health Rating Index, Medical Record Review Instrument. *Professionals / services* Not evaluated. *Economic* Not evaluated.	The 3 groups did not differ significantly with pain questionnaire, ICC, POMS scores; the SDS profiles of the OHC and SHC groups were quite similar; assignment to OC resulted in significantly earlier distress; patients receiving home care remained independent for longer than the OC only group (p=0.02). Total length of stay was lower among OHC patients (258 days) compared with SHC patients (317 days), but not statistically significant; mean length of stay for OHC group 18.43 days (S.D. 19.71) was higher than other 2 groups.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
McCusker & Stoddard 1987[173] US IIIb – but rolled out from Ib randomised controlled trial (see Zimmer et al)	To evaluate an expanded program of home care for the terminally ill (hospital utilisation and costs of care during last months of life).	*Characteristics* Home care: age 55-64 55%, male 51%, female 49%; Non-home care: age 55-64 56%, male 44%, female 56%. *Clinical diagnosis* All cancer. *Prognosis* Average time between first admission to home care & death approximately 2 months; only about 5-6 weeks were spent in home care	*Design* –Retrospective analysis of cancer deaths from claim forms. *Intervention* – I=Home hospice care. C=Non-home care.	*Patient/carer* Not evaluated. *Professionals/services* Not evaluated. *Economic* Claims were divided into 3 service categories: acute hospital, long-term care, and home care. Some claims for services were excluded: outpatient lab, drugs covered by special riders, services received outside Rochester area.	The comparison of trends in costs during the last month suggests that cost containment is occurring among home care users but not among non-home care users. Two mechanisms for cost containment: a reduction both of hospital days and of daily hospital cost. The greatest benefit of home care in terms of cost savings is seen for those individuals who are admitted to home care closer to the time of death. Individuals admitted 5 or more months before death tended to use fewer home care days and greater hospital days during last months of life.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
McIllmurray & Warren 1989[191] UK IIIc	To assess the effectiveness of a new palliative care service	Age not given; 316 admissions in one year; 157 women (49.6%) and 159 men (50.3%) Admitted for terminal care from January to December 1986	All patients assessed on admission by questionnaire (self-rating pain scale) and then at weekly intervals, until discharge or death. The presence of symptoms was recorded retrospectively (after death) with reference to patient records and nursing / medical staff caring for them in last 24 hours. Interventions Evaluation of three common symptoms (pain, nausea, vomiting)	Patient / carer Pain, and other common symptoms (nausea, vomiting).	Pain was present on admission for 53%, majority describing it as mild to moderate (only 2% bad pain). By the time of discharge or death, only 7.5% of patients were still in pain and this was achieved by an increase in the prescription of opiates to 66%. Nausea, vomiting or both was present in 30% on admission, the majority of who were taking opiates; (45% of these not taking anti-emetics). Despite increase in opiates there was a decrease in nausea or vomiting to only 9% by discharge.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
McMillan 1996[192] US IIIc	To evaluate the quality of life of a group of adults, who were serving as primary caregivers for hospice patients, receiving home care.	*Mean age: 65.3-66.4 range 21-90* Total sample: 118 Male: 42 (36%), 27 (37%) Female: 76 (64%) 45 (63%) Patients admitted to home hospice care, family or friends to serve as primary caregivers.	Data collected by trained research assistant who were experienced oncology nurses Interventions Not described.	Patient / carer Caregiver Quality of Life Index (CQLI) Professionals / services Not evaluated Economic Not evaluated (financial sub-scale in CQLI)	Overall CQLI scores in middle of scale. Highest scores for social well-being and lowest scores for physical well-being. Gender differences found in social item (statistically significant $p<0.0003$) with females scoring 15.9 points higher, but by week four the difference is not statistically significant. Support of hospice MDT enabled caregivers to maintain their QoL. Emotional support of hospice team likely to have generalised effect.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
McMillan & Mahon 1994[193] US IIIb	To evaluate the patient's QoL as perceived by the patient and primary caregiver at admission and after hospice services had been implemented	Patients predominantly male (64.4%) mean age 60.7 yrs; caregivers predominantly female (71.2%) mean age 52.2 yrs. Total sample: 80 patients; 67 primary caregivers (13 patients with no primary caregiver deleted from analysis) All patients and caregivers admitted to hospice home care during 7 month period	Data collected by self-administered questionnaire *Interventions* Hospice services	*Patient / carer* Sendra Quality of Life Index (SQLI)	Individual (QoL) scores show increases for some patients and decreases for others. Caregivers reported significant increase in their perceptions of the patients QoL (statistically significant). Only one limited improvement in pain after 3 weeks of hospice care. Hospice services are successful at improving the overall QoL of some but not all patients

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
McMillan & Mahon 1994[193] US IIb	To evaluate the effects of hospice services on the QoL of primary caregivers	Age: caregivers: mean 57.7, range 30-87; Patients: mean 67.0 range 36-90; Non-caregivers: mean 48.9 range 21-94 *Total sample:68 caregivers, 62 non-caregivers* Male: caregivers 10 (14.7%); patients 42 (61.7%); non-caregivers 14 (22.5%). *Female: caregivers 58 (85.3%); patients 26 (38.2%) non-caregivers 48 (77.5%)* Primary caregiver of patient with cancer receiving hospice care. (65% alert & orientated patients; 35% debilitated or comatose). Comparison group: apparently health non-caregiving adults selected from church group, retirement community, and office setting. Not involved in caregiving activities.	Data collected by research assistant and RN experienced in oncology *Interventions* Hospice services	Patient / carer Caregiver Quality of Life Index (CQLI); Hospice Quality of Life Index (HQLI)	Although caregivers mean quality of life did not improve significantly neither did it decrease significantly. The general trend was towards stability. Caregiving appears to have an impact on caregivers regardless of their age. Caregivers QoL appears to be related to the caregivers perception of the patients QoL. During a time of strain and crisis, caregivers of patients with cancer who are terminally ill (receiving hospice services for 3 weeks) are able to maintain their QoL..

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
McQuillan et al 1996[194] Wales, UK IIIb	To evaluate the changes that had been implemented to improve care of cancer and HIV patients at UHW	Year 1: mean age: 60yrs, range 4-90 yrs Total sample: 178 Year 2: mean age: 61 yrs, range 14-91 yrs Total sample: 146 All hospital in-patients with cancer / HIV	Survey of all in-patients with cancer or HIV. Ward pharmacists conducted structured interviews. One year after introduction of the service the survey was repeated *Interventions* Face-to-face discussions about referrals and quarterly lunchtime meetings with doctors, education program for the link nurses Guidelines on pain control for doctors and nurses and information cards for patients	*Patient / carer* Patient: pain assessment and drug chart *Professionals / services* Increased adherence to clinical guidelines Prescribing rationale	Regular teaching required to maintain service Written guidelines are good, but not used by staff Face-to-face discussions are a better method, by more time consuming

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
McWhinney et al.1994 [195] Canada Ic	To evaluate a palliative care home support team based on an in-patient unit	*Characteristics* No data given. *Clinical diagnosis* Symptomatic cancer. *Prognosis* Large attrition rate (death before one month).	*Interventions* Home care support team *Control* Waiting list control (after one month). Patients in study group received the service immediately. *Method* Randomised control trial. Research assistant blind to the assignment, visited the home to leave questionnaires and 3 day diary (for patient and carer). Baseline, then one and two months.	*Patient / carer* McGill pain questionnaire, Melzack nausea questionnaire; patient QoL and carers health. *Professionals / services* Not evaluated. *Economic* Not evaluated.	Because of early deaths, problems with recruitment and a low compliance rate for completion of questionnaires, the required sample size was not attained.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Mor, Greer et al[196-206] USA Iib	To clarify the manner in which hospice is an alternative to the more conventional manner of caring for the terminally ill	Hospice care: adult 74.2%, >75 25.8%; conventional care: adult 88.5%, >75 14.5%. Hospice care: male 48.7%, female 51.3%; Conventional care: male 47.3%, female 52.7%	Quasi-experimental study comparing home hospice, in-patient hospice and conventional care	Spitzer QoL, symptom severity, satisfaction with health care (scale by Wolf), % of analgesic prescribed. Carer: pre-morbidity & post-morbidity - satisfaction with health care, anxiety & depression, emotional distress	Few robust QoL advantages associated with hospice; while hospital based hospice model reduces costs, the hospice home care model may not. Conventional care patients significantly more likely to receive intensive treatments (e.g. surgery) in last weeks before death. Hospice home care is more likely to have analgesic prescribed 2 weeks before death (p<0.05). no significant difference in proportion of pain free patients by setting; Hospice home care significantly less likely to be in persistent pain at the last measure and likely to experience less symptoms. No significant difference was observed in patient reported levels of satisfaction (high in all settings). Primary care person in both hospices was satisfied with place of death and more satisfied than conventional care group.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Mulligan 1989[207] UK (PhD thesis) Iib	???	3 groups of patients: 2 groups received service from Foundation for few months to some years; 1 group no specialist service available. Overall median 67 years, range 25-87 years; male and female patients (no proportions given) Living in two boroughs of Gwent (South Wales)	Patient contact Interventions Specialist home care service	Patient / carer GHQ, pain intensity, mean number of symptoms, Carer: social dysfunction scale, place of death	No clear support that Foundation patients show greater improvement in pain over time (pattern of results provide some suggestive evidence). Foundation involvement may benefit the relatives more than the patient in terms of psychological distress. Foundation led to a much greater proportion of patients dying at home (some indicators that this event in itself facilitated some aspects of grief resolution).

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Parkes 1980[208] UK IIIb	To evaluate the effects of an advisory domiciliary service with the views of spouses of patients who received the care ordinarily provided.	Married men and women under the age of 70 who died in the boroughs adjacent to St Christopher's Hospice	Interviews with surviving spouses about 13 months after the patient's death; SCH home care service was compared with matched groups of spouses who had not been visited by the service	Patient / carer Views on home care service; assessment of symptoms and reactions; hospital admission	SCH patients spent a mean of 2.6 weeks per patient in hospital whereas the comparison group spent 5.6 weeks in hospital. 20 (39%) of comparison patients died at home and only 14 (27%) of SCH group (ns). Caregivers reported a surprising amount of unrelieved physical and emotional distress. Reports included unsatisfactory relief of pain, breathlessness, sleeplessness, nausea &/or vomiting (and others). SCH patient group was said to have been slightly more tense and accepted help reluctantly. In both settings it was unusual for patients to talk about their illness and this was not affected by visits from the home care nurse.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Parkes [209-212] UK IIIc	To measure the effects of the changes by replicating the study carried out 10 years previously	Surviving spouses of patients <65 yrs; male and female. [mean age 55 years] Spouses of patients under 65 years who had died from cancer in London Boroughs of Lewisham & Bromley between 1977-1979	Semi-structured interview - self-assessment of surviving spouses of patients who had died from cancer [replication of 1967-1969 study] Interventions Reactions of patient and surviving spouse to each phase of terminal care	*Patient / carer* Severity and duration of pain, distress and anxiety (max and min intensity of each symptom). Post-bereavement anxiety and grief score.	No significant difference between SCH and other hospitals in the area in terms of the severity of reported pain i.e. pain control in hospitals has been much improved since the 1967 study. No significant difference between SCH and comparison group with regards to overall pain, continuous pain, severe distress or continuous distress. Spouses played a larger part in care of the patient at SCH (1977 study). In both hospices and hospitals patients are generally better in the 1977 study.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Peruselli et al [213] Italy IIIc	To describe the patient's quality of life at the outset and during palliative care at home and to define some potential indicators of palliative care outcomes with the aim of assessing the quality of home care as provided by palliative care unit.	Median age: 65 yrs, range 30-85 yrs Total sample: 73 Male: 38 Female: 35 Consecutive patients who entered the study treated at home for at least 10 days	Initial assessment by nurses, Form completed weekly at staff meeting Weekly evaluation of symptoms etc. *Interventions* (Home care)	*Patient / carer* Patient: Italian version of Symptom Distress Scale (SDS)	Effectively mitigating pain (in part), stimulating appetite, curbing nausea, controlling psychological aspects. Social functional symptoms, steadily worsened independent of support
Seale[214;215] UK IIIa	Evaluative study including in-patient hospice services over more than two sites.	31% of hospice deaths under 65 years, 8% of non-hospice deaths under 65 years All cancer deaths	Random national sample of deaths of people aged 15 or over who died in 10 randomly sampled areas of England. Interviewers visited the home of the person who died to identify and interview the person who knew most about the last 12 months of life Interventions Comparison of hospice and conventional care	*Patient / carer* Care received for pain, carer post bereavement satisfaction, place of death	Process of hospice care in both IPU / home care rather different from conventional care and hospice care seen as valuable. Better pain control in hospices and satisfaction with hospice care reported as high.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Silver 1981 [216] USA IIIC	To identify the life dimensions that hospice addresses and the levels of discomfort or well-being of patients and families achieved in a hospice home care program	No information: for the purpose of the study only patients who had died and who had been evaluated at least twice to be included.	Every patient and family assessed weekly by staff, after several months of service it was anticipated that the progress from distress to well being could be traced; therefore sample 15 patients and their families. *Interventions* Hospice home care program, the number of evaluative observations ranged from 2 to 15 (mean 4.67)	*Patient / carer* Health & medical (physical condition); patient's emotional state; family's emotional state; pain & comfort; social-psychosocial assessment; spiritual need	In general, patients demonstrated greater improvement in all dimensions with al increased length of stay in the hospice program. While the length of contact with the hospice program appeared to affect the amount of change experienced by patients, no particular segment of contact appeared more influential. Pain in particular was substantially controlled and the family's emotional status was improved to the point of sharing problems with the hospice team.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Tramarin[217] Italy Iib	To evaluate the costs and cost-effectiveness of home-care assistance (HCA) as an alternative to hospital-based care only for patients with AIDS (PWA)	Home care: stage 2 median 28 years (S.D. ±7.5) male 2 (50%), stage 3 median 31.3 years (S.D. ±4.8), male 4 (67%); control: stage 2 median 30.6 years (S.D. ±7.9), male 14 (82%), stage 3 median 32.5 years (S.D. ±6.1), male 13 (87%). Stage 2 or 3 (terminal stage of disease); sufficient economic and family support; resident within 10km of hospital; willingness to accept home care.	Prospective study, randomised to home care group *Interventions* Home care	*Patient / carer* Quality of well-being (QWB);	The average cost of hospital treatment was stage 1 $18,071, stage 2 $14,259 and stage 3 $21,854 per patient year. There was an annual estimated saving of 34.8% for the home care group (HCA) compared with the control.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Ventafridda et al[218] Italy IIb	To study whether or not home counselling can improve the emotional and behavioural variations of patients and their families	Two groups of patients: at home with home care program; At home with relatives monitoring Their general physical condition had deteriorated and could not be treated in the out-patients clinic and therefore received home assistance	For any type of check up at hospital or at home the patients were asked to complete a self-rating questionnaire; this study examines data at week zero, two and six. *Interventions* Home care program	*Patient / carer* Integrated pain score; Karnofsky (performance) status; Spitzer QLI; and weakness, mood, anxiety, side effects (LASA).	The integrated pain score on the whole decreased for both groups, however by week two a statistically significant difference was noted in favour of the home care group ($p<0.05$). Quality of life remained virtually unchanged for the home care group, while the family monitored group deteriorated progressively, by the sixth week the difference was statistically significant ($p<0.02$). Mood feelings of weakness and anxiety showed signs of improvement in the home care group while the other did not.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Ventafridda et al[219] Italy IIIb	To assess the quality of life and control of physical and emotional symptoms in a group of terminal cancer patients before and during the treatment by a palliative care team	Mean age: 62 years; Male: 53 (46.1%), female 62 (53.9%); n=115. All patients reviewed during a sample week. Referred to pain therapy and palliative care division because of pain or other symptoms resulting from progression of cancer no longer responsive to anticancer treatment	Weekly self-descriptive record (32items at 4 levels of intensity). Patient contact in out-patient clinic (49%), hospital ward (3%), patients' home (48%). *Interventions* Quality of life assessment, Number of professional sessions: range 1-10 weeks; total duration of patient contact: range 1-214 weeks	*Patient / carer* Pain, other symptoms (vomiting), QoL (felt sad or depressed).	Of the 32 items, statistical improvements seen in nine: pain, feeling weak, drowsiness, not feeling well, difficulties at work, difficulties in visual free time activities, feeling sad or depressed, feeling anxious or scared, feeling nervous or insecure. There are many areas where no improvements were seen. Palliative care can enhance the QoL during the terminal stages of the illness.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Ventafridda et al 1989[220] Italy IIb	To evaluate costs and effectiveness of the program, a comparison between home care and conventional treatment.	Home care: mean age 59.1 years, range 40-70 years; Hospital care: mean age 59.7 years, range 39-70 years. Home care: male 17 (56.7%), female 13 (43.3%); hospital care: male 21 (70%), female 9 (30%) Any type of painful advanced phase neoplasm; patients of both sexes aged between 20 and 70 years; patients no longer subject to oncological procedures; patients treatable analgesically with pharmacological programme (WHO)	Clinical and behavioural data recorded daily on self-judgement form. Data were collected weekly by nurse responsible for patient care. Data collected for entire period of home care. *Interventions* Pain & symptom control, QoL	*Patient / carer* Pain & number of symptoms, Spitzer QLI, judgement of care (satisfaction)	Comparison of two groups significantly favours the home care group, as shown by the performance status after 2 weeks of care, the health scale and the total index of the Spitzer QLI and in general the greater satisfaction of the care received. Home care produces results equivalent to those achieved in hospitals (clinical parameters). The 'approximate' cost quantification of costs shows that home care is cheaper.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Viney et al 1994[221] Australia IIb	A comparison of the quality of life of terminal cancer patients' in two palliative care units with those in a general hospital.	Ω40 yrs: small unit 8%; large unit 3%; hospital 8%; 41-50 yrs: sm.unit 19%; lrg.unit 4%; hospital 14%; 51-60 yrs: sm.unit 19%; lrg.unit 13%; hospital 24%; 61-70 yrs: sm.unit 27%; lrg.unit 25%; hospital 30%; <70 yrs: sm.unit 27%; lrg.unit 55%; hospital 24%. Total sample: 183 Small unit: male 64%; female 36%; large unit: male 48%; female 52%; hospital: male 48%; female 52%. Random selection of patients (83 - 87% of population of units).	Patients were interviewed by trained interviewers at their bedsides Interventions Palliative care units	*Patient / carer* Psychological states representing a different aspect of QoL; Cognitive anxiety scale; total anxiety scale; hostility in scale; sociality scale; Likert scale measure of QoL, and content analysis of free responses.	Cancer patients in the two hospices showed better QoL than patients dying in hospital. They also showed less anxiety related to being isolated / alienated, in general. Indicated that palliative care services were effective at reducing general anxiety. The patents in the small unit expressed significantly more helplessness than those dying in hospital.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Vinciguerra et al[222;223] USA IIb	To compare home (H.O.M.E.) and hospital comprehensive care for advanced non-ambulatory cancer patients	Home care: age (median) 61 yrs; Hospital care: age (median) 63 yrs. Histologically confirmed cancer with evidence of progressive disease; Karnofsky score <50; life expectancy of 2 weeks to 6 months; resident within geographic catchment area of North Shore University hospital, primary care giver required for patients treated at home	Prospective comparative study, patients were assigned to one or the groups based on geographical location: patients within 10 mile radius received home care program *Interventions* Home care: a van transporting the medical staff and equipment visited the patient at home.	*Patient / carer* Major outcome variables: medical - survival, pain medication, place of death; nutritional - weight, changes in dietary intake; psychosocial - social & demographic descriptors, mood profiles.	Patients with low Karnofsky score can be treated at home with no compromised in survival. The average daily morphine equivalent does of analgesics was significantly less for the home patients compared with the hospital group. 47% of home care patients died at home. The calculated total cost for H.O.M.E. visits was $96.30 per day based on 12,082 treatment days during the 2-year study; with review of hospital bills etc. the average hospital charge per day =$394

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Wakefield & Ashby [224] Australia IIb	To provide evidence concerning caregivers' perceptions and experiences of terminal care service delivery in South Australia.	Mean age: 68 yrs (SD 13). Total sample: 100; male 53%, female 47%. Patients aged at least 20 years who died from cancer in the Adelaide area and deaths occurring in institutions	Random sample of case records of patients, letter sent to relative and follow-up phone call 1 week later. Nurses with palliative care experience conducted the interviews. *Interventions* Terminal care services	*Carer:* Awareness of dying; symptom control; use and appraisal of home-care services; satisfaction with institutional care; satisfaction with place of death.	80% indicated that a doctor / nurse had explained terminal condition. Treatment for pain, dyspnoea, and insomnia were relatively effective. However, treatment for loss of appetite, weakness, and weight loss were relatively ineffective. 73% of patients reported to have suffered pain in last month of life, of these 77% rated severe pain (of these 75% received benefit from pain control). 18 patients died at home: 10 had spent all of final month at home. 82 patients died in an institution, of these 34 spent no time at home in final month. Lack of knowledge of services was the frequently stated cause when access to services was a problem (17% of cases). The vast majority rated institutional care as being excellent. Hospices were significantly more likely to be rated excellent. Overall place of death was the right place to die.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Wenk et al[225] Argentina IIIc	To assess the effectiveness of the patient care model	Mean age: 61.5 years (SD 13); total sample: 118; male: 58%; female: 42%. 83 patients cared for by relative; 8 did not have family support Patients with cancer and related symptoms, who were treated by the team between 10/1987 to 12/1988	Retrospective analysis of patients notes; volunteers collect data to study treatment evolution. *Interventions* Pain and symptom control	*Patient / carer* Pain and previous analgesic; treatment evolution; death at home	The median duration of pain that made patients seek pain relief was 90 days (range 4-192); 69% reported 'strong' or 'unbearable' pain, despite treatment they were receiving. Of the 28 patients with complete information (on first treatment days) a statistically significant decrease in pain intensity was noticed, and during follow-up satisfactory control of pain was maintained. 40 (44%) died at home; the remainder in hospital.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Zimmer et al[8] US Ib	To evaluate the home health care team's effectiveness and acceptability.	*Characteristics* Home care team: mean age 73.8 years, n=82, female 61%; control group: mean age 77.4 years, n=76, female 76.3% Clinical diagnosis Home care team: cancer 20.7%, non-cancer 79.3%, control group: cancer 17.1%, non-cancer 82.9% Note: non-cancer diagnosis: stroke, arthritis, dementia, ASHD, COPD, MS. Prognosis: Home care group: terminal prognosis 22%; control group: terminal prognosis 18.4%.	*Design* –RCT *Intervention* – I= Home care team for home bound chronically or terminally ill elderly patients. C= Existing community services. *Method* – Interviews conducted baseline, three and six month follow-up.	*Patient/carer* Sickness Impact Profile (SIP); Philadelphia Geriatric Scale (PGC); Patient and carer satisfaction questionnaires; date and place of death. Professionals/services Not evaluated. *Economic* Health service utilisation diary (daily record).	Team patients had fewer hospitalisations, nursing home admissions and outpatient visits. They were more able to die at home, if this was their wish. As expected they used more in-home services, measured in weighted cost figures; their overall cost was lower than the controls (ns). Home care team patients and their carers expressed significantly higher satisfaction.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Zwahlen et al [226] [translated from French] IIIc	An analysis of two years experience of a palliative care team in a regional hospital	Mean age 67 years (range 34-92), male 52%, female 48% All referrals	Retrospective analysis of all referrals to palliative care team Interventions Hospital palliative care team	Patient / carer Pain, other symptoms, quality of life, satisfaction and carer satisfaction; place of death.	Bed usage of 6 beds went from 25% to 85% occupancy. Irreversible changes in hospital practice of care of patients in last days of life and awareness of pain as an issue. Morphine use in the hospital has increased (no figure given) across all sectors, including post-operative. Many changes in clinical practice across the hospital.

Systematic reviews

Author, country	Aims of the review	Inclusion criteria	Exclusion criteria	Outcome measures	Results
Fordham et al.[227] 1999 UK	To identify and synthesise evidence from studies examining the quality of care of dying patients in both specialist and general practitioner care.	Published research about the developments in the care of the dying during the past 30 years to the end of 1998, identified by online and manual searches.	Not mentioned.	• Three large, population-based surveys. • Five randomised controlled trials of specialist palliative care programmes. • A small number of comparative studies. • A large volume of descriptive, qualitative material.	• Some studies identified major methodological problems. • The overall quality was poor. • Most research concerned selected patients with neoplasms, particularly in settings where specialist palliative care teams are available. • There was minimal information about the care of patients dying from non-neoplastic conditions.

Author, country	Aims of the review	Inclusion criteria	Exclusion criteria	Outcome measures	Results
Hearn and Higginson[164] 1998 UK	To determine whether teams providing specialist palliative care improve the health outcomes of patients with advanced cancer and their families or carers when compared to conventional services.	Studies which considered the use of specialist teams caring for advanced cancer patients and their families. Publications in all languages were considered.	Those studies focusing on one cancer site as the results of such specific studies would not necessarily be generalisable to patients with other types of cancer.	• Aspects of symptom control. • Patient and family or carer satisfaction. • Health care utilisation and cost. • Place of death. • Psychosocial indices. • Quality of life.	Strong evidence from the few RCT's and good observational studies that conventional care alone is inadequate for patients with advanced cancer. Indicates that a multi-professional approach with specialist input is beneficial. Results support the use of specialist MPT in PC to improve satisfaction of patients with advanced cancer and their family. Evidence suggests that MPTs were more able to identify and deal with patient / family needs, and provided access to other services. Also evidence of improved pain control and symptom management as a result of specialist approach. Not all studies show an improvement, although none showed adverse outcomes. The limitations and difficulties associated with research in the PC is discussed (Rink et al & McWhinney). The differences in the systems of health care provision for advanced cancer patients between the UK and USA are

Author, country	**Aims of the review**	**Inclusion criteria**	**Exclusion criteria**	**Outcome measures**	**Results**
Salisbury et al[161] 1999 UK	To identify and review all experimental and descriptive studies which evaluated a model of specialist palliative care, and used quality of life as an outcome measure.	General inclusion criteria: Europe, North America, Australasia or Israel, since 1978, English, French, German, Italian or Swedish. Approaches to the assessment of QoL, which included reviews of assessment tools.	*Exclusion criteria:* Personal opinion, individual case histories or discussion of ethical, legal or educational issues / the impact of chemotherapy /radiotherapy /surgery on QoL. Description of development scales / research instruments to assess QoL (unless included assessment of model *of care).* The impact of palliative care on the QoL of relatives / carers. QoL of cancer patients who were not necessarily terminally ill not included unless specific reference to terminally ill patients.	• In-patient and multi-site services. • Hospital palliative care support teams. • Home care.	*In-patient and multi site services:* In-patient specialist PC results in better pain control compared with home care or conventional care. Based on methodologically weak research not supported in all studies. Parkes follow-up studies show pain control has improved in hospice & general hospitals, greater improvement in latter reducing previous differences. *Hospital palliative care support teams*: Limited evidence that support teams can improve pain control for patients dying in hospital, but no evidence about impact on other QoL measures. *Home care:* Not demonstrated that palliative home care teams, or co-ordinating nurses or advisory teams have an impact on the QoL of patients dying at home. Recent study (IJH) provides evidence that community based specialist PC is beneficial in terms of pain control.

Author, country	**Aims of the review**	**Inclusion criteria**	**Exclusion criteria**	**Outcome measures**	**Results**
Smeenk et al[228] 1998 Holland	To investigate whether for patients with incurable cancer comprehensive home care programmes are more effective than standard care in maintaining the patients' quality of life and reducing their 'readmission time' (percentage days spent in hospital from start of care till death).	*Inclusion criteria:* Patients with incurable cancer and a control group; Prospective study design; Intervention aimed at different aspects of care and its main goal had to be better support of patients at home; The control group had to have received standard available (home) care; The dependent variables to include at least one dimension of QoL or readmission rate of patients.	*Exclusion criteria:* Specific home care interventions aimed just at one aspect of care – such as home parenteral nutrition / pain treatment; Control group received only hospital care.	*Methodological quality of studies:* The median score was 62, showing moderate methodological quality. The most common shortcomings were in the areas of study population homogeneity; comparability of intervention and control groups; handling of dropouts; and blinding procedure for those who collected the outcome measures. The 5 RCTs were compared with the non-RCTs and outcome patterns turned out to be similar. Home care programmes did not have a negative influence on QoL or time spent in hospital; some studies observed positive effects on these outcomes.	The 5 RCTs were compared with the non-RCTs and outcome patterns turned out to be similar. Home care programmes did not have a negative influence on QoL or time spent in hospital; some studies observed positive effects on these outcomes.

Specialist palliative day therapy services

Specialist palliative day care is defined as “a service, which enhances the independence and quality of life of patients through rehabilitation, occupational therapy, physiotherapy, the management and monitoring of symptoms and provision of psychosocial support. It is set in the context of social interaction, mutual support and friendship and may provide some physical care and respite to carers”[229]. The first day care unit in the UK opened in 1975. The numbers of units increased during the 1980s and 1990s and there are now over 250[230].

Nature of the evidence

There are no systematic reviews of the effectiveness of specialist palliative day care and no randomised controlled trials comparing this care with other ways of giving palliative care. However, 15 papers report data from12 observational studies of day care[231-245], 11 from the UK and one from the US[235], and provide some information on the structure, process and outcomes of day care. All are Grade IIIC studies except one prospective study (grade IIIA) comparing 120 patients receiving day care with a matched group of 53 receiving usual palliative care. However, because of illness and death only 49% could be seen for follow up visits[244-246]. Otherwise there are five reports of practice from practitioners within single units[231-236], two surveys of practice across units around the UK[237;238], and four observational studies of practice in between one and 12 different units[239-243]. These studies give some data on the funding, management and policies of the services provided, some needs and outcomes and patients’ views about different aspects of care they receive. Only one study reports the views of relatives or carers[231;232]. There are no studies of referral into day care or the cost of this care. In addition, one expert consensus statement from the US[247], one critical review[248] and one methodological paper[249]from the UK were identified. One study of giving chemotherapy and two reports of offering massage in a day care setting were excluded since they concerned the specific therapy rather than the whole package of day care provided[205;250;251]. Also excluded was one preliminary report of offering some services in an out-patient clinic[252].

Service structure

Funding, attachment and places

Day care units are funded by the independent sector (64%), the NHS (20%) or a combination of both (16%)[237]. Around one third are attached to in-patient units, one third to in-patient units with home care teams, with the remaining third being freestanding or attached to a home care team alone[237]. Units generally open for three to five days each week, providing an estimated 11,000 places[237], or 1.77 places per 10,000 population per year in the UK[238].

Management and staffing

Over 90% of units are led and managed by nurses[237;238]. Although a small number function without nursing or medical input, most commonly staff include nurses, doctors, chaplains, managers, aromatherapists and hairdressers[238]. A wide range of others including social workers, complementary therapists, physiotherapists, occupational therapists, chiropodists and dieticians are also usually available[237]. Most units have the services of volunteers who often organise transport for patients to the day unit as well as some activities[237;238]. The mix of staff, the number of sessions for which they are employed, their level of training, remuneration for those offering complementary therapies and facilities available for creative activities vary[238;239].

Process of care

Standards and models of care

National evidence-based standards or guidelines for care do not yet exist. Initial observations suggested that shared objectives were to provide support, interaction, opportunity for personal growth, carer respite and clinical surveillance[239]. However, in response to surveys units describe themselves are working to deliver palliative care using either a predominantly "social" model of care, a combination of "social" and "medical" models or a "medical" model alone[237].

Referral criteria

Most commonly day care units identify their referral criteria as patient need for social interaction, psychological support, respite for a carer, monitoring, symptom control and assessment[238]. Many do not have a waiting list and most patients are referred directly from home care teams or in-patient units[231;235;244]. Patients in day care therefore represent a selected group of those already receiving palliative care.

The needs of the patient population attending

Patients attending day care are most commonly aged over 60 years[231;235;237;244], with nearly equal numbers of men and women[231;244]. Between 75% and 97% have cancer[231;234;237;244]. Only one study has reported ethnicity and employment and found that most of one sample of 120 patients were white and retired[244].

Assessed by practitioners, patients' most common needs are social and emotional including social support and the "need to get out", nursing needs, carer respite and the control and monitoring of specific symptoms[231;232;234;244]. The most common medical problem reported is pain[232-234;239]. One study of 33 patients initially identified a mean of four problems at first assessment and 11 of 26 patients questioned identified access to a doctor as one reason to attend[233]. In a second 39 patients were reported as "expecting social interaction, carer respite as well as monitoring"[234] and in a third Goodwin and colleagues[244] reported that patients "knew immediately whether they wanted to attend when day care was offered to them". Most attended for one day a week (usually 10am to 3pm) on a day set for them[244].

Nursing, medical, and physiotherapy interventions offered

The nursing activities most commonly undertaken were bathing and wound and bowel care [234;238]. However, units describing themselves as working to a "social" model of care report offering daily wound care and assessment of new symptoms less often despite similar staffing levels[238]. In units with medical staff, doctors carry out assessments, liase with the patient's general practitioner, prescribe drugs and investigations and give advice on a regular or as required basis[237]. Physiotherapy is offered in some but not all units[234;239;242]. In one it was used by 58% and declined by 10% of 263 patients[231].

Activities offered

Occupational therapy, social work, chiropody, dietary advice and art and music therapy are offered less often[238]. One unit reported that occupational therapy was greatly valued by 63% and declined by 6% of 263 patients[231]. Observation of two small groups of seven and 12 patients in two separate units found they spent most time sitting alone, talking or being involved in a range of activities[240;242]. The exact activities developed and offered appear to follow local interest and resources rather than clearly defined local need[238;239].

Inter-professional working

Observations at 12 and 5 different units suggest that together staff they provide an informal warm atmosphere for patients[239;241]. A small in-depth study of a single unit showed that nurses, the social activity co-ordinator and volunteers formed a core team having most contact with patients but tending to work to individual professional rather than shared goals[242].

Social and psychological support

All units see themselves as offering support through relationships with staff and in those that develop with other patients through group work. Just over half of units (53%, 70/131) reported giving carers access for advice[237].

Discharge criteria

Three-quarters (30/43) of units report having a discharge policy, but each unit appears to have experience of a few patients who have attended for many years[238;239].

Outcomes

Symptom control

One early report received replies from 65 of a sample of 140 bereaved relatives, most of whom (71%) reported that the patient had obtained relief from symptoms by their attendance. In the comparative study by Goodwin and colleagues[244-246] the group of patients receiving usual palliative care scored lower on "symptom control" at the second interview (p=0.03) than those in day care, but worse for "practical matters addressed" at the final interview (p=0.03). However, the significance of these findings is limited by baseline differences between the two groups[245;246].

Quality of life

The prospective comparative study found no difference in quality of life scores over time in those patients who could be followed up or between the patients receiving home care[245;246].

Patient satisfaction with care

An early report receiving replies from 37%(23/63) patients found they enjoyed visits and identified themes as "meeting people, feeling useful and having something to look forward to." Only 2% of patients were reported to dislike the day unit[231]. Goodwin and colleagues found most of 120 patients made positive comments about the day unit and three-quarters could identify no "downsides" to attending[244].

Psychological and social support

All reports and studies of patients' views' consistently find they appreciate social contact that the day unit provides[231;234;239;241-244]. Goodwin and colleagues[244] found the most important reasons identified were "meeting people" and "getting out". "Meeting people" became more important over time and was most important whatever model of care the unit was working to. Forty-three percent also reported learning a new skill[244]. One in-depth analysis of 12 patients at one unit suggested they felt accepted and understood, less isolated and motivated to take part in valued activities[243]. An evaluation of one creative project suggested the importance of involvement in creating a sense of self-worth and hope[236]. Another study of 14 patients found that they talked easily between themselves about their illness and about death, though often in a light-hearted and humorous way. This was interpreted as a psychological means by which patients distanced themselves from their own death while at the same time acknowledging their terminal condition[240].

Carer or relative satisfaction and decreased burden

Only one study reported the views of relatives or carers and received replies from 45% (65/140) of bereaved relatives. The majority had found care "excellent" or "good" and were "greatly helped" by their day off. Otherwise attempts to recruit relatives to studies have been unsuccessful[244].

Length of attendance and place of death

Mean length of attendance is reported as 13 weeks[231] or 20 weeks of two visits a week until 15 days before death[235]. One unit found that opening the day care unit did not alter discharge after in-patient admission or length of final stay[231] and another that length of stay of around was not appreciably longer than for those in home care[235]. No studies report the influence of day care on place of death or the overall cost of this care.

Conclusions and outstanding questions

The growth and popularity of day care over the last 20 years suggests that providers perceive it as a successful way of offering a specialist service to meet the complex needs of a proportion of cancer patients already receiving palliative care. All studies that have questioned patients have so far found high levels of satisfaction with the care they receive. In-depth studies find that patients particularly value the social element of contact with staff and other patients that the visit provides, being able to take part in a range of activities and of having symptoms assessed when required. This suggests that in the units studied day care has been successful in achieving a responsive, compassionate and patient-centred service for the patients selected into care. However, many wider questions remain. Studies have been hampered by the difficulty of fully evaluating a service already in operation and of recruiting and studying a vulnerable and deteriorating population of patients. It is therefore difficult to be sure that the right aspects of the service structure, care processes or outcomes have been properly measured. This is especially so since the findings to date suggest that the benefits are more likely to be in the social, psychological and spiritual domains rather than in the more traditionally "medical" and more easily measured areas of quality of life and symptom control. The best models of care and the skill mix needed to achieve the outcomes patients most desire has yet to be formally determined. Issues of access to care including the wider acceptability of day care for patients who are not referred or else decline it, the benefits for relatives and carers and its cost also have still to be tackled.

Tables of Evidence: Descriptions of practice and patients in single day care units

Author, country, Grade of study	Study aims	Patient population and service provided	Study design	Outcome measures	Results
Wilkes et al, 1978[231] UK Grade IIIC	To describe a new day unit set up to reduce patient and relative stress, relatives' burden, provide continuity between out-patient and hospice care, deal with needs that out-patient care could not meet and prolong independence by rehabilitation	263 patients, 75% (197) with cancer and 25% (66) with other chronic illnesses. 70% were aged over 60 years and 60% were female. All referred from the outpatient or hospice unit. The cancer patients' main problems were classed as social problems (14%), emotional needs (16%), lack of social stimulus (10%), inadequate family support (9%), general nursing needs (25%) and specific symptoms (26%). Patients attended around one day a week (10am to 3pm) for a range activities, including support, nursing, exercise, craftwork, hairdressing, beauty and chapel services provided by qualified physiotherapists, occupational therapists, nurses, a social worker and chaplains	Description of patients attending within the first two years of the unit with an evaluation of their views and those of their relatives about the care	Length of attendance, absence, discharge from inpatient admission and length of final inpatient stay. Patients' acceptance of physiotherapy and occupational therapy. Chronically ill patients' questionnaire reports of enjoyment, and for patients who died (140/197), bereaved relatives' judgement of their enjoyment and relief from symptoms. Bereaved relatives were also asked about satisfaction with care and reduced burden	Patients attended on average 13 times, most commonly with breast cancer (38% of all attendances, mean 20 visits). Absenteeism was 12.5%, mostly due to illness, but 2% disliked the unit. Discharge after hospice admission and length of final stay were not altered by starting up the unit. 58% of patients undertook physiotherapy and 10% refused it. 62% were "very keen " on occupational therapy and 6% refused it. 37% (23/63) of the chronically ill patients replied and 22 reported enjoyed visits, feeling they helped morale and symptoms. Meeting people, feeling useful and having something to look forward too seemed important. 45% (65 of 140) of bereaved relatives replied. Of these 78% (51/65) found care "excellent" or "good" care", 68% (44/65) reported the patient's enjoyment and 69% (45/65) their relief from symptoms. 89%(58/65) of relatives reporting having been "greatly helped" by their day off.

Author, country, Grade of study	Study aims	Patient population and service provided	Study design	Outcome measures	Results
Cockburn and Twine 1982[232] Grade IIIC	To describe the second two years of a day unit set up to provide 'a day out for the patient and a day off for the carer'	273 patients, 205 (75%) with cancer and 68 (25%)with chronic diseases including multiple sclerosis, cardiovascular and chronic respiratory disease. Patients were referred by their hospital consultant, a member of the primary health care team or a social worker. The main problems for cancer patients were classed as pain (65%), family or carer stress (14%), nursing needs (17%), social problems (6%) and needing a day out (82%). Patients attended once or twice a week for activities including support, nursing, exercise, craftwork, hairdressing, beauty and chapel services provided by qualified physiotherapists, occupational therapists, nurses, a social worker and visiting chaplain	Descriptive report of the practicalities of running the unit	Not formally assessed	The day care unit was judged to be able to provide a pre-terminal patient with a better quality of life by allowing them a day out in a secure, comfortable and sociable environment where problems could be shared

Author, country, grade of study	Study aims	Patient population and service provided	Study design	Outcome measure	Results
Sharma et al, 1993 UK[233] Grade IIIC	To identify patients' expectations of day care and their need for medical care	33 patients attending an established day unit	Questionnaire survey of patients' views and needs and 12-week study of doctors' work in the unit	Patients' reasons for attending and perceived helpfulness of seeing doctor, time the doctor spent with patients and nurses, and the problems patients presented	11 of 26 patients identified access to a doctor as one reason to attend, 25 found doctors helpful and 20 valued their advice on drugs. The doctor spent 44 minutes a day in the unit, of which 19 was spent in consultations and 13 in meeting patients. Pain (25) and cough (14) were the most common problems
Edwards, 1997[234] UK Grade IIIC	To examine the characteristics, expectations and needs of patients attending day care and to determine the right level of medical care	39 patients, 36 with cancer (12 with lung cancer), and 3 with other illnesses. 18 were male, 21 female ranging 46 to 86 years (median 67). Most (26) were referred to day care from within the hospice. Reasons were for social interaction (21), carer respite (13), monitoring(8), introduction to hospice (7), psychological support (6), doctor's opinion/symptom control (4) Patients used bathing (18), physiotherapy (6), dressings (5), hairdressing (5), complementary therapy (5), bowel care (4), manicure (2) and social worker (1) services	Eight month follow-up study of 39 referred patients. Patients were seen during the first week of attendance, weekly for the first month and then fortnightly afterwards	Frequency and length of attendance. Patient's assessment (on a 4-point scale) of their problems, doctors and patients' assessment of improvement	Most patients attended once or twice a week, for a mean of 11 weeks after first attendance. Patients initially identified between 2 and 8 problems (mean 4). Of the 14 patients reporting pain, there was follow-up data for 10 and 8 reported an improvement. Of 7 identifying social problems, 6 reported these had resolved within one month, of 8 with anxiety five reported an improvement, attributing this to being able to discuss worries in a safe environment. Patients and carers expected mainly social interaction, carer respite and monitoring from day care

Author, country, grade of study	Study aims	Patient population and service provided	Study design	Outcome measure	Results
Thompson 1990[235] USA Grade IIIC	To report what day care can offer	56 patients, average age 63, with cancer or motor neurone disease, 60% using a wheelchair and most of their carers or relatives were working. Most were referred from hospice home care programme. Some were receiving active treatment and had a prognosis of six to 12 months	Descriptive report of a unit open four days a week, run by an occupational therapist, and care assistants, with student and volunteer support	Attendance, length of stay (No data on other outcomes)	Patients typically attended twice a week for four hours. Average length of stay was 45 days until 15 days before death (compared to 42 days for home care). Patients were offered bathing, meals, massage, relaxation, art and craftwork, beautician, chapel and social work services. Attendance said to decrease need for home help and nursing visits.
Kennett, 2000, UK[236] Qualitative grade B	To gain insight into the creative experiences of people with advanced terminal illness, understand how an environment for creativity may be established and to take this into account in developing day care	10 patients, 6 men, 4 women, 8 with cancer, 2 with motor neurone disease and 11 staff taking part in a creative arts project in one established day care unit	Semi-structured interviews with patients and staff following a phenomenological approach undertaken by the day care leader	Positive and negative aspects of being involved in the art project	Positive outcomes included descriptions of enjoyment, enthusiasm, excitement, pride, achievement, sense of purpose, satisfaction and mutual support through involvement. The only negative comments concerned a sense of anti-climax when the project ended. These comments were interpreted as providing patients with self-esteem, autonomy, social integration and thereby hope in their situation

Surveys of practice across different day care units

Author, Country, grade of study	Study aims	Patient population and service provided	Study design	Outcome measure	Results
Copp et al, 1998[237] (9) Grade IIIC	To identify the nature of palliative care provision in the UK	Random sample of 131 of 215 (60%) day care units in 17 UK Heath Regions. (215 of 230 units approached agreed to take part) Units were funded by the independent sector (64%,84/131) the NHS (20%,26/131) or a combination (16%,21/13). Patients "most frequently" between age 61 and 80 and 97% had cancer, 2% HIV and neurological disease	Telephone survey using semi-structured interviews with the day care lead	Funding, staffing, availability of places, and activities offered	Most were headed by a nurse (90%), although 5% (7/131) had no nurse. Most were open 3-5 days a week. One quarter (32/131) had no doctor but in others they undertook assessment, GP liaison, prescribing and investigation and gave advice. Most had volunteers, chaplains, complementary therapists, physiotherapists, social workers, chiropodists, dieticians, occupational therapists, and volunteers. All offered social and psychological support and 53% (70/131) gave carers advice
Higginson et al 2000, UK[239] Grade IIIC	To determine the patterns of day care, its objectives, objectives, structures and processes and whether service characteristics and philosophies could distinguish between more social versus medical models	43 day care units in two UK health regions providing an estimated 1.77 places per 10,000 population and taking 3 new referrals each year. 90% of patients attending had cancer.	Postal questionnaire survey of the leaders of each unit. 40 of 43 units replied	Day care availability and use, management, policies, staffing objectives and; numbers, types and reasons for referral of patients and the services and care provided	34 of 40 were nurse managed, 30 had a discharge policy, and 20 no waiting list. Most had doctors, nurses, chaplains, managers, hairdressers and aromatherapists. Review and monitoring of symptoms and needs, wound care, bathing, physiotherapy, hairdressing and aromatherapy were most common activities. Occupational therapy, social work, chiropody, dieticians and art and music therapy were less commonly offered. Units offering mostly "social" care were less likely to assess new symptoms and wound care daily, despite similar staffing levels

Observational studies of practice and patients in different day care units

Author, country, grade of study	Study aims	Patient population and service provided	Study design	Outcome measure	Results
Faulkner et al, 1993[238] UK (11) Qualitative grade B	To identify good practice and common problems for day care and to review educational objectives for staff	Patients and staff at 12 randomly selected day care units around the UK	Qualitative observational study of practice using a visit proforma, following an initial postal questionnaire	Facilities, opening times, range of staff and activities offered, policy, organisation and staff training and patients' appreciation of support, interaction and carer respite	Facilities varied but most opened 3-4 days a week allowing most patients to attend once a week. Nurses, physiotherapists and doctors were routinely present in 11, 7 and 5 of 12 units. Shared objectives were to provide support, interaction, opportunity for personal growth, carer respite and clinical surveillance, although priorities reflected local interest and resources. Staff provided an informal warm atmosphere and patients appreciated social contact and a day off for their carers. Pain control was their most common clinical problem and for this doctors were contactable. Resources for creative activities and accommodation varied. There was no common policy on the referral, assessment or discharge of patients, organisation or unit management, or the training of staff and volunteers. There was no evidence that units were set up to meet well-defined national standards or local needs

Author, country grade of study	Study aims	Patient population and service provided	Study design	Outcome measure	Results
Langley-Evans and Payne, 1997, UK[240] Qualitative grade B	To examine the way patients talked about cancer, illness and death in a day unit	14 patients, 7 men and 7 women , 13 with cancer aged 36 to 82 attending a day care unit in the South of England which had been set up six months earlier	Participant observation over seven weeks of interaction between patients and between patients and staff. Analysis of field notes, and leaflets and nursing notes using constant comparative method	Descriptive themes identified about the form and style of patients' talk	Patients spent most time sitting and talking with other patients, volunteers, nurses or visitors. Main themes were stories, comments and conversations about illness and death, mostly conducted in a light-hearted manner with humour implicit. Talk about bereavement was more serious and included staff. This allowed patients to distance themselves psychologically from death while acknowledging their terminal condition and so maintain an optimistic outlook
Douglas et al, 2000 UK[241] Qualitative grade A	To understand more about the structure and process of day care and identify which service outcomes could be measured	Five units in one UK Health Region	Qualitative analysis of interviews with staff and patients and observation in each unit over five weeks	Organisational systems analysis approach around the "customers", "actors", "transformation process", "the vision of the world assumed", "ownership" and "environmental constraints"	Despite lack of national standards each unit provided a core set of broadly similar services including medical care, physical therapies, counselling and individual and group social support. Patients had variable needs, and in creating a supportive atmosphere responsive to their needs, staff needed to provide flexible services that could be difficult to plan. This provision depended partly on willing volunteers and this could constrain service development. There were also subtle differences in philosophy making it difficult to measure the benefits of different models of care

Author, country, grade of study	Study aims	Patient population and service provided	Study design	Outcome measure	Results
Lee, 2002, UK[243] Qualitative grade A	To test whether the day care team worked to a common goal, communicated well, that core team had regular contact with patients and others less frequently, that patients were seen as part of the team and experienced care meeting their needs	7 patients attending one unit (4 women, 3 men, aged 66-89) and 12 members of staff	Case study involving semi-structured interviews with patients and staff, observation of the patients, the unit's work and analysis of documents, notes and meeting minutes produced	Patients' reports' of their experience in day care, staff reports of their practice, time patients spent in different activities and observation of communication within the team	The unit worked as a core team of nurse, social activity co-ordinator and volunteers being in regular contact with patients, and others including physiotherapists and doctors and seeing them less often. Staff did not work fully to shared goals but instead to a range of professional goals, with some collaboration and communication problems. Patients spent most time sitting alone, talking or being involved in a range of activities. They saw care as mainly a social experience, provided by many professionals and identified few unmet needs
Hopkinson et al, 2001, UK[242] Qualitative grade A	To discover what was important for patients about day care	12 patients (7 male, 5 female) with cancer attending one day care unit	Qualitative analysis of unstructured interviews with patients	Patients' perceptions' of why care was important for them	All were satisfied with care. The main reasons were 1) welcoming and relaxed atmosphere where they felt accepted and understood 2) promoting self-worth by allowing choice and motivating them to take part in valued activities and 3) reducing feelings of isolation. Each patient described different characteristics as supportive suggesting that the staff were sensitive to and responded to differing needs and values to help individuals cope with their illness in the way they preferred.

Prospective studies comparing patients in day care with those receiving other palliative care

Author, Country Grade of study	Study aims	Population	Study design	Outcome measures	Results
Goodwin et al, 2002[244] Goodwin et al, 2003[245] Higginson et al, 2003, UK[246] Grade IIIA	To evaluate whether day care is effective or cost-effective, what benefits it provides for patients and their families from their perspective	120 consecutive patients attending five day care units in the London Region and 53 receiving other palliative care (home or out-patient care). 95% had cancer, most were white, aged over 65 and retired	Prospective multi-centre study comparing patients attending day care with matched patients receiving home care. 85%(102/120) of day care and 89% (47/53) home care patients were seen within the first 2-3 visits, 49% (59/120) day care patients at 6-8 weeks and only 33% (40/120) day care and 42% (24/53) home care patients could be seen at 12-15 weeks. Relatives generally declined involvement in the study	Patient satisfaction with day care and qualitative themes for their reasoning. Pain, symptom control and quality of life was assessed using the Palliative Outcome Scale and the McGill quality of life questionnaire	Most patients made positive comments about day care with the most important reason given being “meeting people” and “getting out of the home” (60%). Meeting people became most important regardless of whether the unit offered a “social” or “medical” model of care. 43% of patients reported learning a new skill by their attendance. Quality of life scores did not differ between the two groups or over time. The Palliative Care Outcome Scale showed a few differences with the comparison group care scoring lower on “symptom control” at the second interview (p=0.03) but worse for “practical matters addressed at the final interview (p=0.03). However, the significance of these findings is limited by baseline differences between the two groups on these scores

12. REHABILITATION SERVICES

The nature of the evidence

No systematic reviews have been undertaken on cancer rehabilitation. We reviewed 15 individual studies among which the majority were randomised controlled trials (nine grade Ia studies and two Ib and one Ic study). We found one study grade IIb and two grade III studies (IIIa and IIIb). Ten of the studies were carried out in the USA, two in Sweden, two in the UK and one in Canada.

Types of interventions

The studies we found on cancer rehabilitation can not be divided into categories as they often make use of a combination of different interventions: clinical, educational, counselling, informational. These are in response to varying conditions or treatment effects, at different stages in the patient pathway.

Bloom et al.[80] implemented a change in the health care delivery system for the treatment of breast cancer for patients in the initial stages of their illness. Instead of offering only isolated support interventions remote from standard medical care, this programme routinely involved psychosocial support services with medical treatment. The medical team included a Reach to Recovery visitor who provided a successful role model; an oncology counsellor who provided support and information during hospitalisation and a social worker who provided co-ordination and continuity of service between the hospital and the community.

Corner et al.[124] evaluated the effect of non-pharmacological intervention for breathlessness in lung cancer on breathlessness ratings and patient functioning. Treatment for breathlessness in advanced cancer has focused on active procedures such as drainage of pleural effusions and also on pharmacological interventions. However, there is some evidence to suggest that such strategies may not be effective in alleviating the symptom. This study aimed to investigate whether a nursing approach to intervention would be possible, including counselling, breathing re-training, relaxation and teaching coping and adaptation strategies. These could be used earlier in the course of disease and would focus on maximising quality of life and functional ability. A later study[147] replicated this nursing intervention for breathlessness with a multicentre randomised trial design, which is the first study of its kind in the UK.

A randomised prospective study[253] evaluated a brief structured rehabilitation programme ‘Starting Again’ applying a psychosocial group intervention emphasising physical training, information and coping skills over the follow-up of one year.

Holley & Borger[254] reported the preliminary findings of the first 20 participants of an ongoing cancer rehabilitation group intervention project for people with cancer experiencing cancer-related fatigue. This educational intervention focused on topics such as risk factors, effects on daily life, barriers and management strategies for fatigue. Some sessions included exercise instruction by a physical therapist, energy conservation instruction by a occupational therapist, Tai Chi instruction by a Tai Chi master. Each session also included a sharing and support component.

The study by Robinson et al.[77] experimented with a psychoeducational programme to increase the rate of compliance with vaginal dilation for women who had been treated with radiotherapy for gynaecological carcinoma. The intervention consisted of an informational, motivational and behavioural component.

The other studies we identified made use of a more individual format of intervention to reduce the extent to which cancer interferes with a patient's functioning. Ganz et al.[90] provided breast cancer survivors who suffered from menopausal symptoms with the information, skills, medication, and/or support they needed to manage their symptoms more effectively. They developed a comprehensive menopausal assessment intervention which consisted of a structured assessment of three target symptoms, followed by an individualised plan of education, counselling, pharmacologic and/or behavioural interventions, psychosocial support, referrals, and follow-up tailored to each woman's needs and preferences.

An intensified primary care intervention as part of a 'support-care-rehabilitation' project was evaluated with regard to its effects on the frequency of contacts with the home care nurse, and the proportion of patients with a continuing contact 6 months after diagnosis[171]. Individual support included both IPC and psychological support and, for patients with colorectal and gastric cancer, dietician support as well.

Two studies evaluated the effects of a rehabilitation programme which experimented with a walking exercise intervention for breast cancer patients[255;256]. The preliminary study focused on women receiving adjuvant chemotherapy, and looked at the effects of the walking programme in combination with a support group led by an oncology clinical nurse specialist. The later study[256] omitted the support group component of the intervention to concentrate on the exercise alone. Also, this time they involved patients undergoing radiation therapy treatment.

A randomised trial conducted by Loprinzi et al.[257] tested whether prospective dietician counselling could abrogate the unwanted weight gain seen among women receiving adjuvant chemotherapy for resected breast cancer.

A quasi-experimental study sought to determine if a specific nursing intervention programme designed to enhance hope would positively influence levels of hope and QoL in a sample of people with a first recurrence of cancer who were randomly assigned to one of three groups: treatment group (hope), attention control group (informational), or control group (usual treatment)[258].

Jacobsen et al.[259] evaluated two forms of stress management training for cancer patients about to start chemotherapy: a professionally administered form of stress management training and a patient self-administered form of stress management training. These were compared against a usual care condition. This study investigated the efficacy and the costs of the different kinds of training.

We found a study which tested the efficacy of self-care/ self-help promotion and uncertainty management interventions offered by the Self-Help Intervention Project for women receiving chemotherapy, radiation therapy, or hormone therapy for breast cancer[79].

One study was identified evaluating an educational intervention for professionals[260]. The 'Network Project' emphasised a multidimensional concept of cancer pain evaluation and stressed a multidisciplinary model for intervention. This model attempted to address the psychosocial and rehabilitative aspects of cancer and cancer pain in addition to traditional (that is pharmacological) pain management strategies, thereby filling a gap in cancer pain education. The project consisted of four components: an observership programme, a mentorship programme, an educational resource centre and an information-sharing network.

The interventions were aimed at improving the conditions with which people affected by cancer are living. Physical problems and arduous treatment have an effect on psychosocial functioning and lead to spiritual questions. Nurses play an important role in carrying out the rehabilitative interventions[79;90;124;147;171;253;256;258], although the interdisciplinary team is also experimented with[80]. Three studies tested alternative therapies where standard treatments have proved inadequate[90;124;147].

The rehabilitation programmes were aimed at patients. Only one study was found which evaluated an educational intervention designed for health professionals, addressing rehabilitative aspects of cancer. The rehabilitative interventions directed towards patients were especially concerned with crucial stages in the patient pathway, such as the time after surgery[80;255;256], therapy related coping[79;253;255-257;259], recurrence of cancer[258], the end of life[124;147;171], or with symptoms that are particularly challenging[77;90;124;147;254].

Outcome measures

Bloom et al.[80] found that women who participated in the intervention initially expressed significantly more negative affect than those who received standard care but these negative affective states decreased over time and the women scored better in self-efficacy as the time after surgery passed by. The women who received supportive care after breast surgery were more likely to ventilate uncomfortable emotions and were less likely to deny their feelings. Helplessness and the feeling of being overwhelmed were reduced by preparatory information and provision of supportive counselling which increased a sense of control.

The results of Corner's study[124] which set out to pilot new ways of managing breathlessness in lung cancer indicate that patients do benefit from the approach that combines breathing retraining, psychosocial support and help to develop adaptive strategies. The intervention enabled patients to reduce levels of disability and to function with greater independence. This has the potential to become an important part of outpatient care and could be integrated with the service provided by Macmillan nurses and palliative care teams. Bredin et al.[147] who replicated this study confirmed its findings. Two particular elements of the intervention which had not been apparent in the pilot study might be responsible for the improvements: the emphasis on teaching more effective ways of coping with breathlessness and the opportunity to talk about difficult feelings and concerns.

The 'Starting Again' programme[253] was successful with respect to patients' appraisal of having received sufficient information, having developed fighting spirit, physical strength and physical training as late as one year after treatment termination.

The preliminary findings from Holley & Borger's study[254] on the small sample of participants indicated that much could be done to alleviate cancer-related fatigue distress and to improve the QoL for people with cancer. Many patients were quite ill but felt that attending the sessions was important, indicating that this intervention was appropriate and beneficial for patients with cancer experiencing fatigue, even for those who are very debilitated. This programme gives oncology healthcare providers another tool to provide rehabilitation strategies to help people to self-manage the sequelae of their cancer and its treatment.

The sexual rehabilitation programme Robinson et al.[77] set up provided evidence of the effectiveness of an intervention to increase women's vaginal dilation following radiotherapy for gynaecological carcinoma and to reduce their fears about sex after cancer. Most women, particularly younger women, were likely to follow the recommendation to dilate unless they were given assistance in overcoming their fears and taught behavioural skills.

Ganz et al.[90] showed that a clinical assessment and intervention programme for menopausal symptom management in breast cancer survivors is feasible and acceptable to patients, leading to reduction in symptoms and improvement in sexual functioning. Measurable improvement in a general QoL measure was not demonstrated.

The logistic regression analysis did not identify psychological support or diagnosis as predictors of a continuing home care nurse contact 6 months after diagnosis[171]. The authors concluded that it is reasonable to assume that intensified primary care is the main determinant of the patients' home care nurse contacts.

The study results in Mock et al.[255] indicated that patients with breast cancer in the experimental group had improved physical functioning and significantly lower levels of fatigue and emotional distress than the control group. Since the intervention included two components, benefits could not be clearly quantified for exercise versus support group. The later study[256]found that the walking exercise programme can help manage symptoms and improve physical functioning during radiotherapy. The authors concluded that nurse-prescribed and -monitored exercise is an effective, convenient, and low-cost self-care activity that reduces symptoms and facilitates adaptation to breast cancer and treatment.

Loprinzi et al.[257] concluded from the findings of their study that routine prospective dietician counselling aimed at weight maintenance appeared to produce small but statistically insignificant reductions in both calorie consumption and weight gain in this group of patients. It is still unclear what exactly was responsible for the lack of significant differences between the two conditions.

A preliminary attempt to design, implement and evaluate a theory-driven hope intervention programme achieved encouraging findings in the sense that these suggest that it is possible for nurses to increase the feeling of hope and perceived QoL in people with first recurrence of cancer through specifically designed hope interventions. Both the feeling of hope and perceived QoL were higher among the participants in the hope programme therefore suggesting that receiving disease related information and attention and meeting others in a similar situation are not enough. It is also noted that hope may influence the outcome of QoL, as QoL was improved in those individuals receiving the hope interventions.

Jacobsen's study[259]demonstrated the effectiveness of a patient self-administered form of stress management training intervention in improving the QoL of patients undergoing chemotherapy for cancer. Of particular significance is evidence suggesting that the intervention yields improvements in QoL similar to those demonstrated previously for professionally administered form of stress management training interventions but at a more favourable cost. The development of an effective patient self-administered form of stress management training programme that requires minimal professional training and time to deliver, and costs only a modest amount more than usual care, has the potential to greatly improve chemotherapy patients' access to a psychosocial intervention. By improving access, many patients who would otherwise never receive a psychosocial intervention could experience the benefits of improved QoL during chemotherapy treatment.

Braden et al.[79] found that participation in SHIP interventions resulted in higher levels of self-care, self-help, psychological adjustment, and confidence in cancer knowledge by time effect in a significant number of women regardless of their baseline resourcefulness. Women participating in SHIP interventions who had low baseline resourcefulness demonstrated the greatest change over time in the outcome variables.

The Network Project proved to be an effective training and educational programme for a wide range of health care disciplines with diverse speciality areas (for example, oncologists, nurses, mental health professionals). The data from this study showed that participation in the Observership Programme resulted in increased knowledge of pain management and psychosocial issues related to cancer and cancer pain, changes in attitudes toward cancer pain issues, and increased educational activities among observers upon return to their local institution.

Implications of the evidence for recommendations

Interventions in cancer rehabilitation are mostly multifaceted to reduce the often complex adverse physical and psychological effects of cancer and to promote adaptation to its treatment. The study which evaluated the intervention on fatigue for example showed that a variety of different factors may be involved: physical, mental, emotional, environmental, physiologic, and pathologic[254]. The evidence provides a growing body of data on the effectiveness of combinations of interventions. However, to inform decisions about services, more research needs to be done which investigates the relative effectiveness of different interventions. Experiments are needed where several kinds of interventions are compared among patients having the same characteristics, during the same time frame, which allows insight in the effectiveness of interventions under specific circumstances.

The evidence also addressed the issue of access to often expensive and specialised services. Jacobsen et al.[259] suggested modifying the delivery of the interventions instead of relying on professional delivery. This study showed the efficacy and favourable costs of patient self-administered stress management training and suggests the potential of greatly improving patient access to psychosocial intervention during chemotherapy treatment.

Tables of Evidence: Rehabilitation services

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Bloom et al.[80] 1978 USA Iib	To examine the effectiveness of the counselling-education intervention program.	A total of 39 women with initial breast cancer having undergone breast surgery. I=21 women. Average age: 49. C=18 women. Average age: 53.	*Design* –Prospective non-randomised controlled trial. *Intervention* – I=Counselling and information are offered to patients with a mastectomy by an interdisciplinary team. An oncology counsellor (nurse) provides support and information during hospitalisation; and a social worker provides co-ordination and continuity of service between the hospital and the community.	*Demographic variables.* Psychosocial variables: • the Health Locus of Control (HLC). • Profile of Mood States (POMS)	*Immediately after surgery:* The affective responses of the group in the intervention program were more labile than those of the control group. These differences diminished over time. Both groups were equivalent on the measure of self-efficacy (t= -0.53, df=32, n.s.). *Measure after two months:* patients in the intervention group score significantly higher (t= -2.16, df=32, p<0.05).

Author, country, grade	**Aims of the study**	**Patient population**	**Study design**	**Outcome measures**	**Results**
Braden et al.[79] 1998 USA Ia	To determine the efficacy of self-care/self-help promotion and uncertainty management interventions offered by the Self-Help Intervention Project (SHIP) for women receiving chemotherapy, radiation therapy, or hormone therapy for breast cancer.	A total of 193 women receiving treatment for breast cancer. *Inclusion criteria:* 18 years and older, and literate in English.	*Design* –RCT *Intervention* – • Self-help course. • Uncertainty management. • Self-help course plus uncertainty management. • Control group. Data were analysed by a repeated measures multivariate analysis of variance procedure. A two-level blocking factor was used: high and low resourcefulness.	Outcome variables measured: • Self-care by the Inventory of Adult Self-Care Behaviours (IASC), and the Self-Care Inventory Wellness Promotion (SCIWPR). • Self-Help by the Inventory of Adult Role Behaviour. • Psychological Adjustment by the Negative Affect Scale. • Confidence in Cancer Knowledge by a visual analogue formatted single item. Data were collected: • At baseline (T1) after initiation of adjuvant therapy • (T2) 6-8 weeks after T1. • (T3) 2 months after T2.	Participation in SHIP interventions resulted in higher levels of self-care, self-help, psychological adjustment, and confidence in cancer knowledge by time effect in a significant number of women regardless of their baseline resourcefulness. Women with low baseline resourcefulness demonstrated the greatest change over time in outcome variables. The effect was primarily the result of changes in psychological adjustment, confidence in cancer knowledge and self-care.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Bredin et al.[147] U.K. 1a	To evaluate the effectiveness of nursing intervention for breathlessness in patients with lung cancer.	Patients (n=119) diagnosed with small cell or non-small cell lung cancer or with mesothelioma who had completed first line treatment for their disease and reported breathlessness. I=51 patients At 4 weeks assessment: n=43. At 8 weeks assessment: n=33. C= (n=52) At 4 weeks assessment: n=40. At 8 weeks assessment: n=27.	*Design* –RCT *Intervention* – Patients attended a nursing clinic where they received a package of interventions tailored to individual patients to help them to cope with breathlessness and maximise their existing lung function. C: standard management and treatment for breathlessness. *Data* – Detailed assessment of breathlessness, advice and support, exploration of the meaning of breathlessness, training in breathing control techniques, goal setting to complement breathing and relaxation techniques, support coping strategies.	*Primary outcome measure:* distress due to breathlessness. *Other outcomes* • WHO performance status scale. • The hospital anxiety and depression scale. • The Rotterdam symptom checklist.	At 8 weeks, the intervention group showed significant improvement for breathlessness at best, WHO performance status, levels of depression, and physical symptom distress. Levels of anxiety and distress due to breathlessness improved slightly. Groups were similar in breathlessness at worst, psychological distress, and overall global quality of life.

Author, country, grade	**Aims of the study**	**Patient population**	**Study design**	**Outcome measures**	**Results**
Ganz et al.[90] 2000 U.S. 1A	To test the efficacy of a comprehensive menopausal assessment (CMA) intervention program in achieving pain relief of symptoms, the improvement of quality of life, and sexual functioning in breast cancer survivors.	A total of 72 postmenopausal breast cancer survivors. Eligibility criteria: • A disease free, female breast cancer patient. • Perimenopausal or postmenopausal. • All chemotherapy or radiotherapy completed at least 4 months prior to enrolment, but could be taking tamoxifen. • Presence of at least one severe target symptom. I=33 patients. C=39 patients.	*Design* –RCT. *Intervention –* I=A structured comprehensive assessment of the three target symptoms (hot flashes, vaginal dryness, and stress urinary incontinence) followed by an individualised plan of education, counselling, pharmacologic and/or behavioural interventions, psychosocial support, referrals, and follow-up tailored to each woman's needs and preferences. The CMA was delivered by a nurse practitioner. C=Received usual care.	• Menopausal Symptom Scale Score adapted from the Breast Cancer Prevention Trial Symptom Checklist. • Vitality Scale from the RAND 36-Item Health Survey 1.0 (alternatively known as Medical Outcomes Study SF-36) • Sexual Summary Scale from the Cancer Rehabilitation Evaluation System.	Intervention group improvements in: Menopausal symptom management (P=.0004). Sexual functioning (P=.04) No statistically significant improvement in: Vitality (P=.77).

Author, country, grade	**Aims of the study**	**Patient population**	**Study design**	**Outcome measures**	**Results**
Johansson et al.[171] 1999 Sweden Ib	To evaluate the effects of intensified primary care on cancer patients' home care nurse contacts, and to study if patients' use of home care services 6 months after diagnosis can be predicted.	A total of 527 patients newly diagnosed (within 3 months from diagnosis) with breast cancer or under examination for a suspected breast cancer, or diagnosed with colorectal, gastric or prostate cancer. I= 203 patients. C=178 patients.	*Design* –RCT *Intervention* – Intensified primary care (IPC) was implemented. I= • Individual support, i.e. IPC combined with psychological support and, for patients with colorectal and gastric cancer, dietician support. • A combination of individual support and rehabilitation. C= • Rehabilitation. • Standard care.	• Background data were collected on gender, age, marital status, living area, diagnosis and stage of disease at diagnosis. Data were also collected on treatments during the first 6 months after diagnosis. • Hospital Anxiety and Depression Scale (HADS). • An 18-item questionnaire was developed for the assessment of patients' contacts with the home care nurses and perceived benefits of these contacts, 6 months after diagnosis.	• Only 27% and 36% of the control patients reported follow-up contacts. • Intensified primary care was identified as the strongest predictor for reporting a continuing contact 6 months after diagnosis. • Factors associated with a continuing contact were high age, advanced disease and living in a rural district.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Robinson et al.[77] 1999 Canada Ia	To test the effectiveness of a group psychoeducational program based on the "information-motivation-behavioural skills" model of behaviour change in increasing the rate of compliance to regular vaginal dilation.	A total of 32 women with stage I and II cervical or endometrial carcinoma who were being treated with radiotherapy.	*Design* –RCT Randomisation by following a random number table. Participants were assessed prior to intervention and again at 3,6,9 and 12 months postdiagnosis. *Intervention* – I= 2 1.5-h psychoeducational group sessions, which had an informational, motivational and behavioural component. C= Patients met with a counsellor and were given a copy of Sexuality and Cancer.	Primary outcome: Sexual health measured by the Sexual History Form (SHF). Secondary outcomes: 4. Information measured by the sexual knowledge questionnaire. 5. Motivation measured by the fears questionnaire. 6. Behavioural skills measured by compliance with vaginal dilation.	Intervention group improvements: Younger women attending the experimental program (44.4%) were significantly more likely to follow recommendations for vaginal dilation than those who received the control intervention (5.6%). Women, regardless of age, reported less fear about sex after cancer treatment. The older women gained more sexual knowledge. No intervention group improvements: There was no evidence that global sexual health improved.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Berglund et al.[253] 1994 Sweden Ia	To evaluate a brief structured rehabilitation programme, 'starting again', which emphasised physical training, information and coping skills.	A total of 199 patients participated. Inclusion criteria: below75 years, curative treatment for a primary tumour and inclusion within 2 months after post-operative treatment with radio- or chemotherapy.	*Design* –RCT Randomisation by the Efron's method. *Intervention* –Eleven sessions were held in 7 weeks. An oncology nurse, specialised in psychosocial issues conducted the groups during all sessions. She mostly accompanied by a specialist of the theme dealt with at each session. I=98. C=101.	• Work status. • Sick leave. • Patients' appraisal of having received sufficient information. • Physical strength. • Activity.	Patients in the programme improved significantly more than the controls with respect to appraisal of having received sufficient information, physical training, physical strength and fighting spirit.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Breitbart et al.[260] 1998 USA IIIa	To evaluate the efficacy of the Network Project Observership Program	All participants (n=152) who completed a two-week observership through the Network Project at Memorial Sloan-Kettering Cancer Centre between February 1, 1993, and June 15, 1996 were included. Observers were graduate or practising health care professionals who applied for, and were accepted as, Network Observers based on their status as identified local educators or clinical specialists in the area of cancer of AIDS pain.	*Design* –A single group pretest- posttest study. *Intervention* –The Network project has four components: an observership programme, a mentorship programme, an educational resource centre and an information-sharing network.	Knowledge and attitude inventories which contain questions pertaining to cancer pain, psychosocial oncology, and cancer rehabilitation, and follow-up questionnaires completed one year after participation in the programme. The knowledge and attitude inventory was completed one year after the participation both before and after the observership period.	*Significant improvements in:* Knowledge of cancer pain, psychosocial issues, and rehabilitation issues ($P < 0.0001$). In addition, observers reported a significant increase in their local educational and training activities in the year following participation in the Network Project ($P < 0.01$).

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Corner et al.[124] 1996 UK Ic	To evaluate the effect of non-pharmacological intervention for breathlessness in lung cancer on breathlessness ratings and patient functioning.	A total of 34 patients had consented to take part in the study. I=19. C=15. 14 patients (8 from the intervention group and 6 from the control group) had to withdraw from the study due to deterioration.	*Design* –RCT *Intervention* – Weekly sessions with a nurse research practitioner over 3-6 weeks using counselling, breathing retraining, relaxation and teaching coping and adaptation strategies.	Outcomes were assessed by three ten-point visual analogue scales to rate breathlessness over the previous week (breathlessness at best, breathlessness at worst and distress caused by breathlessness). The Functional Capacity Scale was used to assess ability to walk distances and climb stairs and an activities of daily living checklist identifies difficulties in performing activities. Hospital Anxiety and depression Scale. In depth interviews to explore the experience of breathlessness.	Improvements in median scores on all measures except for depression for the intervention group. For the control group median scores were static or worsened. Distress from breathlessness was improved by a median of 53%, breathlessness at worst by 35% and functional capacity by 21% . In contrast, distress in the control group worsened by a median of 10%. Significant improvements compared to the controls: Breathlessness at best ($p<0.02$), breathlessness at worst ($p<0.05$), distress ($p<0.01$), functional capacity ($p<0.02$) and ability to perform activities of daily living ($p<0.03$) but not for anxiety and depression.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Holley & Borger[254] 2001 USA IIIb	To evaluate the acceptability and efficacy of a rehabilitation group intervention for people with cancer experiencing cancer-related fatigue (CRF) and examine the effects of the programme on CRF distress, quality of life (QoL) and depression.	A total of 20 participants have completed the program in four different groups. Mean age: 63.6 (range=38-86). The participants had 6 different types of cancers, and 15 patients were receiving some form of cancer therapy during their participation in the program. Setting: an outpatient area of a 551-bed tertiary-care community hospital.	*Design* –Prospective, pre-post-test intervention. *Intervention* –Eight weekly, 90-minute sessions with educational and sharing components. The educational topics include risk factors, effects on daily life, barriers, and management strategies for CRF. • Reading and journaling, • Exercise instruction, • Energy conservation instruction, • Tai Chi instruction.	Main Research Variables: • CRF distress • Depression • QoL Instruments: The Cancer-Related Fatigue Distress Scale, The Centre for Epidemiological Studies Depression, The Functional Living Index-Cancer, And a demographic information form.	Significant improvements in: CRFDS scores between pre- and post-test (t=20.23, p=0.000). FLIC scores between pre-and post-test (t=-7.68, p=0.000). No difference in: Paired sample CESD scores (t=1.801, p=0.087).

Author, country, grade	**Aims of the study**	**Patient population**	**Study design**	**Outcome measures**	**Results**
Jacobsen et al.[259] 2002 Ia USA	To improve access to psychosocial interventions during chemotherapy treatment by evaluating the efficacy and costs of a patient self-administered form of stress management training that requires limited professional time or experience to deliver.	A total of 411 patients who were diagnosed with cancer; did not have received chemotherapy before; and were scheduled to receive a minimum of 4 cycles with a minimum of 7 days between cycles. 507 patients were approached, 96 (19%) declined. Age: 26-88 yrs.	*Design* – Observational study with a control group. *Intervention* – I1: A Patient self-administered stress management training (distributed by mental health professional) (140). I2: Professionally administered stress management training (a single 60 minute session by a mental health professional) (134). C: A standardised form of psychosocial care (137).	Instruments: The Medical Outcomes Study (SF-36) to measure physical functioning, general health perceptions, role limitations, mental health, vitality and social functioning. Centre for Epidemiologic Studies Depression Scale (STAI-S) to measure the mental component of QoL. Economic aspects of interventions were evaluated by simple cost comparisons. Costs were computed from the two perspectives of payer and society.	Significant improvements: Physical functioning, vitality, role limitations, mental health for patients receiving self-administered intervention. No difference: Between professionally administered intervention and usual care group. Economic aspect: Cost of self administered intervention estimated 66% from a payer perspective, 68% from a societal perspective less than average costs of professionally administered interventions.

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Mock et al.[255] 1994 USA Ia	To examine the effects of a comprehensive rehabilitation program on facilitating physical and psychosocial adaptation of women with breast cancer who are receiving adjuvant chemotherapy.	A total of 14 women (mean age=44 years) receiving adjuvant chemotherapy for breast cancer (86% stage II) following surgical treatment.	*Design* –RCT *Intervention* –A walking exercise program and a support group led by an oncology clinical nurse specialist (OCNS), in addition to usual care. The program was specific to the needs and concerns of women being treated for breast cancer. C=standard care.	Instruments: Karnofsky Performance Status Scale (KPS), and the 12-Minute Walking Test to measure the functional status of the patient. Psychosocial Adjustment to Illness Scale (PAIS) and the Brief Symptom Inventory (BSI)to measure psychosocial adjustment. Tenessee Self-Concept Scale (TSCS). Body Image Visual Analogue Scale (BIVAS) and the Physical Self Subscale of the TSCS. Symptom Assessment Scales (SAS). Qualitative data: Participants kept a diary of exercise periods and subjective data. Interviews to evaluate the program. Support group sessions were tape recorded and assessed by content analysis.	Intervention group improvements in: Higher levels of physical functioning and psychosocial adjustment and lower levels of distressful symptoms. Consistent and progressive increase in physical activity levels over the course of chemotherapy treatment. Support group participants reported higher psychosocial adjustment and lower psychosocial distress. Lower levels of fatigue and nausea.

Author, country, grade	**Aims of the study**	**Patient population**	**Study design**	**Outcome measures**	**Results**
Mock et al. 1997[256] USA Ia	To test the hypothesis that women participating in a walking exercise program during radiation therapy treatment for breast cancer would demonstrate more adaptive responses as evidenced by higher levels of physical functioning ad lower levels of symptom intensity than women who did not participate.	A total of 46 women recruited from two university teaching hospitals. Age: 35-65. Women who were undergoing treatment for newly diagnosed stage I or II breast cancer.	*Design* –RCT *Intervention* –A walking exercise program. The exercise was individualised for each patient. C=usual care. This group was contacted regularly to inquire about their health and general response to treatment to prevent a differential treatment effect. Pretest: before the initiation or during the first days of radiation therapy. Posttest: at the end of radiation therapy. Midtherapy: symptoms were assessed for both groups with the SAS and PFS.	Instruments: 12-minute walking test. Symptom Assessment Scale (SAS) to assess symptom experience. Piper Fatigue Scale (PFS). Diaries were kept with pulse rates and subjective data.	Significant differences between groups on outcome measures (<0.001). The exercise group scored significantly higher than the usual care group on physical functioning (p=0.003) and symptom intensity, particularly fatigue, anxiety, and difficulty sleeping. Fatigue was the most frequent and intense subjective symptom reported.

13. COMPLEMENTARY THERAPY SERVICES

Nature of Evidence

Seven systematic reviews have been found on complementary therapy[261-267]. Two of these looked at prevalence[261;262] and used published surveys. The systematic review on aromatherapy[263] reviewed randomised trials as did the review on acupuncture[268]. The systematic review by Pan et al.[265] looked at randomised, non randomised and case series. The remaining two systematic reviews, which have not been published and in abstract form, looked at aromatherapy and massage for symptom relief in cancer patients[266] and reflexology for symptom relief in patients with cancer[267]. Both reviews examined randomised controlled trials, controlled before and after studies and interrupted time series studies. All the systematic reviews were completed in the UK except the one done by Pan et al.[265].

Four (non systematic) reviews were identified. The review by Cassileth & Brown[269] looked at an updated national survey carried out in the US. The one conducted by Ernst[270] examined all published data and was conducted in the UK. The review by Trijsburg et al.[271] was conducted in the Netherlands and the last review by Vincent & Furnham[272] was done in the UK.

Seven individual studies were identified, five of which used questionnaires[273-277], one was an observation study[278] and the other was a randomised controlled trial[279].

Types of Intervention

Two of the systematic reviews evaluated the prevalence of Complementary and Alternative Medicine (CAM).There was no universal definition of what constituted a CAM therapy in either study. The Ernst and Cassileth[261] paper looked at the prevalence of CAM therapies in patients who were known to have cancer. The systematic review by Harris & Rees[262], however, looked at CAM prevalence in the general population.

The paper by Cooke and Ernst[263] examined the use of aromatherapy in a number of clinical settings. These included cancer, post-operative and ITU (Intensive Therapy Unit) patients within a hospital setting; as well as patients with chronic bronchitis, smokers, post-partum women, healthy adults and patients with alopecia areata. Treatment with aromatherapy was compared with a placebo. Aromatherapy in six studies involved the use of massage with aromatherapy, and in the remaining six studies, two involved inhalation of an aromatic mixture, one involved a daily scalp massage, one involved oral administration of an aromatic liquid and the last involved a dummy cigarette which contained a methanol smell.

The systematic review completed by Vickers[268] on acupuncture evaluated its use in the treatment of vomiting secondary to surgery, chemotherapy or pregnancy. All 33 trials involved the stimulation of the P6 acupuncture point either by needling, manual pressure or electricity.

The systematic review by Pan et al.[265] analysed the role of CAM therapies in the palliation of pain, dyspnoea and nausea. The types of intervention used for the treatment of pain were TENS, acupuncture, and massage, behavioural and relaxation therapies, music therapy and psychological therapies. Dyspnoea was treated with acupuncture, acupressure and behavioural and psychological therapies. The intervention used for nausea and vomiting was acupressure at the P6 acupoint.

The systematic review conducted by Vickers[268] examined the use of acupuncture in a wide variety of clinical settings which included cancer patients receiving chemotherapy, pregnant women and post-operative patients (general, gynaecological, paediatric and orthopaedic surgical procedures).

The systematic review by Pan et al.[265] looked at patients that were nearing the end of their lives. These not only included cancer patients, but also people with HIV (positive) and Chronic Obstructive Airway Disease (COAD).

The systematic review conducted by Fellowes et al.[266] looked at the evidence for the effectiveness of aromatherapy and massage in improving the physical and psychological well-being in patients with cancer. Nine studies were included, seven of which were randomised controlled trials.

The systematic review don by Fellowes, Gambles et al.[267] examined the evidence for the effectiveness of reflexology in improving physical and psychological well-being in patients with cancer. Three studies were included in this review, of which two were randomised controlled trials.

The review conducted by Cassileth & Brown[269] looked at the types of unproven cancer remedies that achieved popularity in America together with their side effects. The paper also gave research based suggestions for the clinician.

The review conducted by Ernst[270] differentiated between alternative cancer treatment (ACT) and complementary supportive care (CSC) and also defined their roles in modern cancer management on the basis of published evidence.

The review conducted by Trijsburg et al[271] looked at the effects of psychological treatment on cancer patients. This study included treatment of patients with hypnotherapy. Different approaches of treatment were used in the studies that were reviewed. There were three main groups; tailored counselling, structured counselling and behavioural interventions or hypnosis. Not all the studies gave an account of exactly what was done in the treatment group (i.e. the results were not reproducible in eleven studies). The treatments were assessed against a control. The duration and number of sessions in the studies examined varied from fifteen minutes to ninety minutes and from a few weeks to over a year. Treatment was assessed using various psychological instruments and variables and also somatic variables. Twenty one out of the twenty two studies used psychological instruments known to be valid and reliable. There was variability as to which psychological and somatic variables were used in the studies.

The review by Vincent & Furnham[272] (1999) gave a broad overview of research on complementary medicine and paid special attention to studies of efficacy of the major therapies and to potential adverse effects. Studies were mainly on general conditions and not confined to cancer patients.

The paper by Clover et al.[273] described the cancer patients attending a complementary therapy service and measured the impact on their quality of life. Whilst the paper by Downer et al.[274] looked at what proportion of cancer patients received conventional as well as complementary treatment. The paper also assessed what treatment was the most popular and what the patients' motivations were for using complementary treatment. The paper by Rees et al.[275]measured the prevalence and costs of complementary therapy use by women diagnosed with breast cancer in the South Thames region. This was done using a questionnaire and from this women that had used complementary therapies were invited to attend a follow up interview (a list of what defined a complementary therapy can be found in the table). The participants were selected from the regional cancer register. The paper by Thomas et al.[276]looked at the scale and scope of access to complementary therapies (acupuncture, chiropractic, homeopathy, hypnotherapy, medical herbalism and osteopathy) via general practices in England.

The paper by White[277] identified the number of oncology/radiotherapy departments in England and Wales offering individual complementary therapies in the management of cancer patients and the types of therapies being offered. It also identified whether the therapies were practised by in-house therapists or by external complementary therapists. Therapeutic radiographer managers were sent a postal questionnaire, which identified the complementary therapies being provided by the department and the different types of practitioners.

The study by Ferrell-Torry & Glick[278] examined the effects of therapeutic massage on pain perception, anxiety and relaxation levels in hospitalised cancer patients who had cancer pain. Nine male patients were recruited with different primaries and stages of disease. Pre massage assessment was done on all the patients. This involved them completing a VAS for pain, State- Trait Anxiety Inventory to assess anxiety and a VAS to assess relaxation together with heart rate, respiratory rate, and blood pressure. These were then repeated after the thirty minute massage (which was carried out by the same person). The physiological measurements were also completed just after the massage (as well as ten minutes after). Seven of the patients had the massage treatment the following day, where the same protocol was adhered to.

The study by Speca et al.[279]assessed the effects of participation in a mindfulness meditation based stress reduction program on mood disturbance and symptoms of stress in cancer outpatients. Any person that had cancer was invited to take part in the study. One hundred and nine patients were recruited, of which ninety completed the study. Patients were randomised to either the treatment group or wait list group. The patients who were in the treatment group had seven weekly ninety minute sessions, which had three components. The first involved theoretical material related to relaxation, meditation and body mind connection. The second involved experimental practise of meditation in the group setting and at home. The third involved group problem solving and supportive interaction between group members. A booklet and audiotape on relaxation and meditation was given to the treatment group as well. Each patient was assessed in regard to their mood (POMS) and symptoms of stress (SOSI) before randomisation and after seven weeks.

Outcome Measures

The systematic review by Harris & Rees[280] showed that a high proportion of the population used CAM in Australia and US (33.8%-50%). The review by Ernst & Cassileth[261] found that the prevalence of the use of CAM therapies varied from 7-64% and that the average prevalence across all adult studies was 31.4%.In the systematic review by Harris & Rees[262], the methodology of all the studies reviewed were flawed. Even the three studies which the authors claimed to be reliable, the response rate ranged from 60-73%, and in the other systematic review, by Ernst & Cassileth[269], five studies had a response rate of 33-66%.(which indicates response bias). The two Esinberg studies, from the Harris paper[262], suggest that that the number of people using CAM more than doubles if the definition included the use of products as well as consultation with therapists. This was also found to be a problem with the other review. In the two studies conducted in the UK[270] the prevalence of using CAM ranged from 16-32%. The authors concluded that the degree of variability was most likely due to different understandings of CAM on the part of investigators and patients.

Both systematic reviews highlight the fact that there needs to be a universal definition of CAM and that surveys and questionnaires need to be clearly thought out and sound in their designs, as all the studies reviewed were flawed. Because of this the results of the reviews cannot be generalised. In the systematic review concerning aromatherapy[263] all studies concluded that aromatherapy was better than the control intervention at reducing anxiety scores immediately after the treatment session. In the six studies that had independent replication five reported statistically significant findings. These results should be viewed with some degree of caution as all the studies were small and had methodological flaws (The highest JADAD score for any of the studies was two out of five). The authors concluded that aromatherapy massage had a mild, transient anxiolytic effect and based on it to be considered for the treatment of anxiety. The conditions that were treated with aromatherapy varied in the studies: COAD, smoking withdrawal, alopecia, and cancer patients. More work needs to carried out on cancer and palliative care patients.

The systematic review by Vickers[268] found that P6 acupuncture point stimulation was an effective antiemetic technique, if it was not administered under anaesthesia, and various plausible reasons are given to account for this. Five of these studies involved the use of cancer patients receiving chemotherapy. Of these, three had a placebo. Blinding did occur in two of the studies. Two of the studies had appropriate statistics. As a result these studies were flawed. These results cannot be generalised to all cancer and palliative care patients, as the trials reviewed focussed on a specific cohort of patients. More research needs to be carried out on palliative care patients before any conclusions can be drawn.

The systematic review by Pan et al[265] found fourteen trials in the treatment of pain, using six different CAM treatments. They found that TENS provided short term pain relief; massage provided immediate pain relief and relaxation with imagery improved pain in patients with oral mucositis. Six studies were found on dyspnoea, three of which showed that the use of acupuncture and acupressure relieved dyspnoea in patients with COAD and one which showed that muscle relaxation and breathing retraining reduced dyspnoea. One study was found on nausea and vomiting and no significant differences were found between control and acupuncture for the relief of nausea and vomiting. All the 21 studies were graded (according to the USPSTF guidelines) and the results suggest a lack of methodologically sound papers.

Most of the studies were small. There was no consensus on what constituted an appropriate control. With these caveats in mind the results should be viewed with caution.

In the systematic review by Fellowes et al.[266] most of the studies compared a massage intervention with a non massage control. The results are still being assimilated, but the authors have stated that both massage and aromatherapy massage confer short term benefits on psychological well-being, particularly anxiety, and on physical symptoms (no significance values have been given). They have concluded that more research needs to be undertaken to "determine the relative benefits of the addition of aromatherapy to massage in developing a consensus on the most appropriate therapy to offer".

In the systematic review by Fellowes, Gambles et al.[267], two trials found positive effects for the use of reflexology and included improvement in breathing, anxiety and an improvement in pain scores (although this also improved with the control). However the authors concluded that the trials were small and that follow up was limited. From this we can deduce that more methodological sound research needs to be done.

The review by Cassileth & Brown[269] revealed that of 1000 cancer patients, 45% used metabolic therapy of which the side effects were death from electrolyte imbalance, bowel necrosis and perforation, toxic colitis, hypokalaemia and sepsis. These side effects were all secondary to colonic irrigation. 32% used diet (as a mode of CAM). The main side effect was nutritional deficiencies. 20% used megavitamins and the main side effect was toxicity. 16% used mental imagery. The reasons given as to why patients used unorthodox cancer treatment included fear, previous negative experiences, lack of information, media overplay social and psychological pressures. The authors gave many suggestions for the clinician, but the only one that had a reference was the statement that the initial interaction with the patient was crucial as it established the style and quality of the doctor patient relationship. This paper updated a national survey that was done in 1984. No methodology was given as to how this was done or even how the original survey was done. Not all comments were backed up by references and the studies that were referred to were not graded. For these reasons this paper has to be viewed with caution. The results cannot be generalised.
The review by Ernst[270] found that there was in general, no real convincing evidence to support the use of alternative cancer treatments in reducing tumour burden or in prolonging the life of cancer patients. (See tables). The paper found that complementary treatment had some potential in improving quality of life via the promotion of relaxation. These trials were small. Ernst concludes that more research and money needs to go into complementary medicine.

The review by Trijsburg et al.[271] found that of the twenty two studies reviewed, nineteen reported positive effects of psychological interventions on cancer patients. Tailored counselling was effective in patients that were distressed and was good in self concept. Structured counselling was effective in depression, distress and anxiety. Behavioural interventions and hypnosis was effective in treating anxiety, depression, pain and nausea and vomiting. On somatic effects, tailored counselling yielded positive effects in ten out of the nineteen variables measured; structured counselling was effective in four out of the six variables and behavioural interventions and hypnosis was effective in all the variables that were measured. As the authors have stated, the studies were heterogeneous (experimental conditions, group comparability, patient selection, the intervention -structure, goals and treatment techniques and outcome measures), which makes it difficult to draw general conclusions. However since most of the studies have concluded that psychological treatment is beneficial to cancer patients it would be worth doing more research into this field, using more precise design, psychological intervention and outcome measures, where hopefully one can draw conclusions as to what type of psychological intervention is the most appropriate, the duration and number sessions and what patient group if any would benefit most.

The review by Vincent & Furnham[272] found that a third of people in Europe had used a complementary therapist or remedy in any one year. The patients tended to be female, well educated and from a higher than average social class. The reasons given for people embarking on complementary therapy included that it was more natural, allowed more patient participation and there was a failure for orthodox treatment to relieve a specific complaint. A review on acupuncture looked at fifty one controlled trials for chronic pain. Eleven of these studies had reasonable methodology, when graded. In these higher graded studies there were an equal amount of positive and negative findings. The most positive results were for the treatment of musculoskeletal pain. A review on manipulative therapies found thirty five randomised controlled clinical trials, which were all methodologically flawed. Eighteen of these trials found that manipulation was better than placebo, physiotherapy or drugs. But because these trials were flawed these results would have to be viewed with caution. A review on herbal remedies found forty trials on the use of gingko for cerebral insufficiency, but only eight of these were of good quality. Seven of these trials were beneficial to the disease when compared to placebo. A homeopathy review found one hundred and seven trials which dealt with various conditions. Eighty one had positive results and twenty four had negative results when homeopathy was compared to placebo. However most of the studies were methodologically flawed, with only sixteen trials being of good quality. From this we can say, as the authors have themselves concluded, further research is warranted. Vincent & Furnham[272] have acknowledged that there are problems in conducting clinical trials in the field of complementary medicine and they include the blinding of subjects and clinicians, participation in a study can affect behaviour and outcome, artificially standardised treatments, inadequate attention to individual responses, outcome measures that do not necessarily affect the patients' concern and various ethical issues. They have suggested some pointers for future research which include larger trials and more funding, a definition of what is an appropriate control group, an agreement on a standard methodology, perhaps more flexibility in research design whilst still ensuring standardisation, more longitudinal research, examination of the reliability and validity of some of the diagnostic techniques, elements of the consultation should be monitored and related to satisfaction and other variables and audit.

Fifty patients were recruited for the study conducted by Clover et al.[273]. The age range was from 25 to 78. Thirty one women and eleven men were recruited. Of these twenty one completed the six month follow up.36% had a diagnosis of breast cancer (although there were many different primary sites). 74% had confirmed metastases. The therapy prescribed included homeopathy (100%), Iscador (58%), relaxation (50%), diet (24%) and acupuncture (14%). Analyses of the results were on twenty nine patients who attended the clinic on at least two occasions. There were significant improvements in psychological distress ($p<0.005$ on RSCL) and anxiety ($p<0.01$ on HADS) after three visits. The original sample was biased, as the patients were all attending a complementary therapy clinic voluntarily. The statistics carried out were not analysed on an intention to treat basis. As it turned out, the sample size was small. As the authors conclude themselves, that as the study was uncontrolled, no firm conclusions can be drawn. They suggest that further randomised controlled trials need to be carried out.

The study by Downer et al.[274]found that 16% of patients that responded to the questionnaire used or were using complementary therapies. The most commonly used therapies were healing, relaxation, visualisation, diets, homeopathy, vitamins and herbalism. (This is different to what patients in America opt for. In the study by Cassileth & Brown[269]the most popular form of CAM used were metabolic therapy, diet and mega vitamins). They found that patients using complementary therapy were younger (50 vs. 58, $p<0.005$), from a higher socio-economic background (58% from groups 1, 2,3N compared to 33%), and were women. There was no difference in marital status or ethnicity in patients using conventional or complementary therapies. Patients were attracted to complementary therapy because they felt more hopeful, thought that the remedies were non toxic and holistic, gave them more participation and gave them a more supportive relationship with the practitioner. The authors found that patient's expectation from complementary treatment ranged from a cure to remission or prevention of spread. Other reasons given were to boost the immune system and to improve quality of life. Eighty two percent of the patients were satisfied with the therapies that they had chosen. Dissatisfaction arose from diet therapies and herbalism and also from the doctor -patient relationship and side effects of conventional treatment. The paper had a low response rate, which could in turn bias the results. Not all the patients that used complementary therapy accepted the invitation to have a further interview. (This could also be a source of bias). However the paper does give us some insight as to why patients opt for complementary therapy. This study was included in the systematic review by Ernst[270].

The study conducted by Rees et al.[275]had a response rate of 74%. 38% of the respondents were from social classes I and II (which is slightly higher than the female working population of Great Britain-32%). They were also more highly educated. In the twelve months prior to completing the questionnaire 22.4% (95% CI 19.4-25.6%) had consulted a complementary therapist. 31.5 % (95% CI 28.1-35.1%) had done so since diagnosis and 15.1% (95% CI 12.6-18%) had used complementary therapy prior to their diagnosis. The most commonly used therapies in the twelve months prior to the study were massage/aromatherapy, chiropractic/ osteopathy, relaxation/ yoga/ meditation and spiritual or faith healing. Over the counter products had been used by 33.2 % of women (95% CI 29.8-36.8%). Logistic regression analysis, where $p<0.0.05$ found that these women were slightly younger, more educated and more likely to have used complementary therapies before their diagnosis than non complementary therapy users. In the year prior to the study £17,000 was spent by 111 women on complementary therapies. Most of the healing and relaxation was paid for by donations. Most treatments were paid for directly. Eighty respondents were interviewed and the comparison of postal questionnaire with the interview suggested that the questionnaire responses underestimated the prevalence of complementary therapy use in the twelve months prior to the study and also before the diagnosis of cancer was made. The adjusted figures are 24.2% (95% CI 21.1-27.5%) and 24.8% (95% CI 21.6-28.1%) respectively. However these results should be viewed with caution as only a small proportion of the total number of participants was interviewed. The authors claim that that their findings were representative of all women (between the ages of 18 and 90) that were diagnosed with breast cancer between 1990 and 1996 and who were living in the South Thames region. The authors conclude that the use of complementary therapies following diagnosis is significant and is possibly a growing phenomenon. These results however cannot be generalised, as the study only looked at women with breast cancer. It is interesting to note that the patient profile is similar to the findings of Downer et al.[274] – women, younger age group and from a higher socio economic background. Also these two studies have found some similar results in the most commonly used therapies in complementary medicine (relaxation and healing). It would have been interesting to know if paying for treatment was a factor in deterring people from not having therapy.

The study by Thomas et al.[276] had a 78.6% response rate from GPs. Of those that responded, 39.5% provided access to some form of complementary therapy for their NHS patients. This figure drops to 30.3% if all non-responding GPs were included and were assumed to be non providers. 21.4% offered access by provision of treatment by a member of the primary health care team. 6.1% employed an individual complementary therapist. 24.6% made NHS referrals for complementary therapies. Acupuncture and homeopathy were the most commonly available therapies. Former fund holding practices were significantly more likely to offer complementary therapies than non fund holding practices. It s interesting to note that the patients being referred for complementary therapies did not include cancer or palliative patients.(The patients had various medical conditions including depression, stress, diabetes, back and musculoskeletal pain) One explanation for this could be that these patients were already offered it from the hospital/hospice.

The study by White[277] had a 100% response rate.70% of oncology departments in England and Wales used at least one method of complementary therapy. The most common therapies used were aromatherapy, relaxation, massage, reflexology, visualisation and acupuncture. The study found that the vast majority of therapies were practised within the hospital by employees of the hospital. The author has suggested that in the future perhaps oncology care providers may find themselves having dual roles (professional as well as complementary therapy qualifications). It would have been interesting to see what the uptake rate for the use of the therapies was from the oncology patients.

The study by Ferrell-Torry & Glick[278] found that pain decreased significantly on the two days following massage treatment ($p<0.007$ on day one and $p<0.025$ on day two). Similar results were found with anxiety, in that massage reduced anxiety levels significantly. Patients also felt significantly more relaxed having had massage. The physiological measurements showed that the respiratory rate of patients was significantly less than before treatment with massage. When systolic blood pressure was measured, it was noted that there was a significant reduction in the blood pressure ten minutes after the massage was completed compared to the reading done just prior to the treatment. Seven of the patients had massage the following day (no reasons were given as to why the other two patients did not take part) and five of them reported that they had a better nights sleep. This study was small and the subjects were all men. There was no randomisation or control and there was no mention as to whether the patients needed more or less analgesia during the trial period. (It would have been valuable to see whether the effects of massage lasted more than one day). So these results need to be viewed with caution. But they do look promising. The authors state that more studies need to be carried out.

The study by Speca et al.[279] found that mood scores were significantly reduced in the treatment group compared to the control ($p<0.01$). It also found that stress scores were significantly reduced in the treatment group as well. It is interesting to note that even with no treatment some of the patients in the control group, after seven weeks, had less stress and an improvement in their mood scores. All the patients that dropped out of the study had a higher POM score than the patients that completed the study. The authors conclude that perhaps this treatment should be for people with moderate mood disturbance. The patients were a self selected group, who were probably more motivated than the usual patient. The results of this study are encouraging and as the authors have pointed out future research should pinpoint the most effective aspects of the treatment that was given.

From all the papers reviewed we can conclude that larger controlled trials need to be done on palliative care patients. These trials need to have sound designs, larger sample sizes, reliable blinding and specific and relevant outcome measures. However, in the field of complementary therapy, doing the classical randomised controlled trials does have its problems. For example, blinding a patient to the smell of an aromatherapy treatment will not be possible. Also complementary therapy involves a holistic approach to the patient, and this will not be conveyed to the patient in a randomised control trial, where treatment will be given in a very controlled environment, so as to reduce bias. With these problems in mind we would have to question whether randomised controlled trials are actually the best methodological approach in assessing CAM.

Although the studies in the two prevalence reviews were flawed, they do give an indication that the use of CAM therapies is increasing, although the exact figures are unknown, due to the fact that there is no universal definition of what should constitute a CAM therapy, and perhaps this is what is needed- a universal definition. No firm conclusions can be drawn from any of the reviews as most of the studies included were small and methodologically unsound. Definitive conclusions cannot be made on the effectiveness of complementary therapies. This however does not mean that CAM therapies should be dismissed.

The study by Downer et al.[274] has given some insight as to what type of patients use CAM- women in a younger age group and from a higher socio economic background (compared to patients using orthodox treatment). This was also fond in the study by Rees et al.[275] /id}. Two of the studies, Cassileth & Brown[269] and Downer et al.[274] come to similar findings as to the reason why patients use CAM. These include; previous negative experiences, lack of information, media overplay, social and psychological pressures, gives the patient more participation, treatment is non-toxic and holistic and treatment will improve their quality of life.

Tables of Evidence: Complementary Therapy services

Systematic Reviews

Author, date, country, grade	Aims of study	Inclusion/exclusion criteria	Study design and outcome measures	Results
Ernst & Cassileth[261] 1998 UK	To summarise published data on CAM use in oncology. To detect national differences and trends when possible	Studies were included if they has original data relating to the prevalence of CAM in samples of patients with cancer. No exclusion criteria were stated.	Types of studies: Surveys Types of Outcome measures: No standard definition of CAM was stated Therapies listed: Alternative Treatments/ Healing/ Homeopathy/ Reflexology/ Herbs/ Vitamins/ Diets/ Psychological methods/ Any unconventional cancer treatment/ Chinese medication/ Healing/ Folk remedies/ Counselling/ Meditation/ Relaxation/ Imagery/ Hypnotherapy/ Not specified	26 publications found from 13 countries. 14 concerned paediatric cancer patients. 2 studies were done in the UK. Of the studies done in adult cancer patients 50% reported that up to 27% of respondents used CAM. The use within and between countries varied. Of the 2 studies done in the UK: Burke & Sikora found that 32% of patients used CAM. Downer et al. found 16% used CAM.

Author, date, country, grade	Aims of study	Inclusion/exclusion criteria	Study design and outcome measures	Results
Harris & Rees 2000[262] UK	Systematically examine published surveys addressing the question "What proportion of the General Public uses CAM?" (Complementary and Alternative Medicine)	Studies were included if: 1. Used survey methods (structured interviews or self completed questionnaires) to estimate the extent of CAM use among a target population. 2. CAM use was measured among the general population as opposed to a clinical population or other, more narrowly defined group. 3. The prevalence of CAM estimated by the study was expressed as a % of the population (or it could be calculated from the data) Studies were excluded if: 1. Estimated the prevalence of a single therapy only 2. Did not describe the study methods 3. Was not written in English	Types of studies: Published surveys. No standard definition of CAM was stated. Therapies listed: Acupuncture/ Aromatherapy/ Alexander Technique/ Bio feedback/ Chiropractic/ Herbal therapy/ Homeopathy/ Iridology/ Natural therapy/ Osteopathy/ Reflexology/ Relaxation/ Rolfing/ Self-help groups/ Spiritual Healing/ Massage/ Blood letting/ Folk healers/ Hypnosis/ Diet/ Imagery/ Yoga	12 studies met the inclusion criteria.(from 6 countries) Prevalence rates varied from 2.6 (C.I.2.2-3.0) to 48.5 (C.I.46.7-50.3). 3 of the 12 studies produced reliable data. McLennan et al reported in 1993, half the population of S. Australia had used non medically prescribed alternative medicine and 20% had visited CAM practitioners. 2 Esinberg studies suggested the use of CAM practitioners/ products increased from 33.8% in 1990 to 42.1% in 1997 in the US. A UK study (Thomas et al) found in 1993 8.5% of respondents had visited a CAM practitioner. (An earlier study by Yung in 1996 revealed a figure of 2.6%)

Author, date, country, grade	**Aims of study**	**Inclusion/exclusion criteria**	**Study design and outcome measures**	**Results**
Cooke and Ernst 2000[263] UK	To summarise the randomised intervention studies that have been carried out on the use of aromatic plant extracts (essential oils) for a variety of conditions. To examine systematically the use of aromatherapy massage for anxiety in a health care setting.	Trials were included if : 1. Randomised trials 2. Described as a trial of aromatherapy by the authors. 3. Human patients. No exclusion criteria were stated.	Types of Outcome measures: Anxiety Well being Symptom scores Stress Measuring Instruments used: Spielberger State Trait (Anxiety Inventory) Rotterdam symptom checklist	12 studies were reviewed. 6 had independent replication and involved aromatherapy and massage in cancer patients, post-operative patients and patients in an ITU. All studies concluded that aromatherapy was better than control intervention at reducing anxiety scores immediately after the treatment session. 5 out of 6 studies (those with independent replication) reported statistically significant findings. Symptom scores and reduction in Anxiety were transient.

Author, date, country, grade	Aims of study	Inclusion/exclusion criteria	Study design and outcome measures	Results
Vickers[268] 1996 UK	To examine whether P6 acupuncture point stimulation has specific effects in the control of nausea and vomiting associated with surgery, cancer chemotherapy or pregnancy. A secondary aim was whether acupuncture had any specific effects on health.	Trials were included if: 1. There was stimulation of the P6 acupuncture point by needling, manual pressure or electricity. 2. Patient had nausea and/or vomiting resulting from surgery, cancer chemotherapy or pregnancy. 3. The clinical outcome of a group of patients receiving P6 stimulation was compared with that in patients receiving no intervention, a placebo or a non-acupuncture intervention. No exclusion criteria were stated	Types of studies: Randomised and Controlled trials. Types of Outcome measures: In the Surgical patients: If the patients remained symptom free (no nausea or vomiting) Number of times the patient vomited per day. In the Cancer chemotherapy patients: Subjective preference Symptom free Number of vomiting episodes In the Pregnant patients: Improvement in symptoms Symptoms reduced Symptom free Change in score of nausea	33 trials were analysed. In 4 trials were stimulation was given under anaesthesia, P6 had no effect. Of the remaining 29, 27 were positive for P6 anti emesis ($p<0.005$). 12 trials were analysed further (randomised placebo controlled trials, with no anaesthesia, and the methodology was deemed average, fair or good). 11 revealed statistically significant differences between P6 and placebo. (1 of which was a cancer chemotherapy trial).

Author, date, country, grade	Aims of study	Inclusion/exclusion criteria	Study design and outcome measures	Results
Pan et al[265] 2000 US	The role of CAM (Complementary and Alternative Medicine) therapies in the palliation of Pain, Dyspnoea and Vomiting in terminally Ill patients.	Inclusion criteria were not explicitly stated. Patients were excluded if they had chronic conditions that were not fatal or if they were not characteristic of most dying patients.	Types of studies: Randomised controlled trials, non-randomised controlled trials and case series. Types of Outcome measures: Pain: EORTC QLQ-C30 WHO grading system VAS Pain rating scale Not stated Dyspnoea Modified Borg VAS Subjective improvement in Dyspnoea Nausea and Vomiting Not stated	21 studies were reviewed. Pain: 14 studies using 6 CAM treatments were found. Relaxation with imagery improved pain in patients with oral mucositis ($p<0.001$) TENS provided short term pain relief. Results varied from 22 – 66 % of patients. Massage provided immediate (but not prolonged) pain relief in cancer patients. There was a reduction on days 1&2 ($p<0.025$) Dyspnoea: 6 studies used 5 different CAM treatments. 3 studies found that the use of acupuncture and acupressure relieved Dyspnoea in patients with COAD ($p<0.05$) 1 study showed that the muscle relaxation and breathing retraining reduced Dyspnoea ($p<0.04$) Nausea and Vomiting: 1 study was identified which found no significant difference between acupuncture and no treatment for nausea and vomiting

NON SYSTEMATIC REVIEWS

Author, date, country, grade	Aims of Study	Inclusion/exclusion criteria	Study design and outcome measures	Results
Cassileth & Brown[269] 1988 US	To review the types of unproven cancer remedies that have achieved popularity, as well as their toxicities. Provide research based suggestions for the clinician who must deal with a patient using or considering an alternative treatment.	None stated	Types of studies: Not explicitly stated. Types of Outcome measures: If patient used metabolic therapy, diet, megavitamins or mental imagery.	Updated data from 1000 cancer patients revealed: 45% used metabolic therapy. Side effects stated were death from electrolyte imbalance, bowel necrosis and perforation, toxic colitis, hypokalaemia and sepsis all secondary to colonic irrigation. 32% used diet. Side effects were nutritional deficiencies. 20% used megavitamins. Side effects were toxicity. 16% used mental imagery. Reasons why patients used unorthodox cancer treatment included: Fear, previous negative experiences, lack of information, media overplay, social and psychological pressures. (The authors gave their view which included: despair and discouragement concerning cancer treatment. The discrepancy between conventional medical statements and current cancer statistics shake patients' confidence, and encourage them to seek alternative options. The lure that treatment seems to be natural and non toxic. Suggestions for the clinician: Initial interactions with the patients is crucial as it establishes the style and quality of the doctor patient relationship. There needs to be open communication. Patients should be given a role in their own care.

Author, date, country, grade	**Aims of study**	**Inclusion/exclusion criteria**	**Study design and outcome measures**	**Results**
Ernst[270] 2000 UK	To differentiate between alternative cancer treatments (ACTs) and complementary supportive care (CSC) and to define their roles in modern cancer management on the basis of published evidence.	None stated	Types of Studies: Not stated Types of Outcome measures: If patient had ever had dietary treatments, supplements, hypnotherapy, reflexology, visualisation and music therapy.	ACTs: Dietary treatments- A review fund no evidence to support the claim that alternative diets prolong life. There are no controlled trials on macrobiotic diets. Herbal medicinal products- A systematic review failed to identify any published data on Essiac. Two systematic reviews identified several trials on mistletoe, but none of the evidence was conclusive. Preliminary results on PC-SPEC and an extract of St. John's wort look promising, but controlled trials need to be performed. Supplements- Lots of anecdotal evidence on shark cartilage. In one uncontrolled experiment the authors concluded that as a single agent it did not prolong life or improve quality of life. 13 RCTs have bee done on thymus extract, 5 of which suggested it was of benefit. However all trials were methodologically flawed. CSC: A review that looked at all published clinical trials on hypnotherapy concluded that there was encouraging, but not compelling evidence to suggest that it was helpful in controlling anxiety, pain, nausea and vomiting in cancer patients. There have been few studies conducted on cancer patients to show benefit of relaxation. Trials done on reflexology suggest it may benefit in stress reduction. Several RCTs suggest visualisation and music therapy were effective in reducing stress, pain and increasing QoL in cancer patients.

Author, date, country, grade	Aims of study	Inclusion/exclusion criteria	Study design and outcome measures	Results
Trijsburg et al.[271] 1992 Netherlands	To review the effects of psychological treatment on cancer patients.	Only studies that compared 1 or more experimental conditions with at least 1 control group were included. Studies published between 1976 and September 1990 were reviewed. Studies that looked at the effects of educational programs, information per se or self-help groups were not included.	Types of studies: Not stated. Outcome measures: (These varied between studies) Psychological instrument scales: POMS, PAIS, STAI, BDRI, etc Psychological variables: Anxiety, depression, anger, distress, self-concept, health, locus, of control. Somatic variables: Fatigue, nausea and vomiting, pain, functional status, leisure activities, loss of weight, work, pulse rate, blood pressure	22 studies were reviewed. 12 studies involved tailored counselling, 4 offered structured counselling and 6 gave behavioural intervention or hypnosis. 12 studies concentrated on 1 type of cancer whereas the remaining studies selected patients with different types of cancer. 19 studies reported positive effects of psychological interventions. Tailored counselling was effective in depression, distress, self-concept. Structured counselling was effective in depression, distress and anxiety. Behavioural interventions and hypnosis were effective in anxiety, depression, and nausea and vomiting. Somatic effects: Tailored consiling-10/19 variables measured had positive effects. Structured counselling - 4/6 variables had positive effects. Behavioural and hypnosis-all variables measured had positive effects.

Author, date, country, grade	Aims of study	Inclusion/exclusion criteria	Study design and outcome measures	Results
Vincent & Furnham[272] 1999 UK	To present a broad overview of research on complementary medicine, with special attention to studies of efficacy of the major therapies and to potential adverse effects, so that clinicians can make informed decisions.	None were stated.	Types of studies: not explicitly state	In Europe, surveys have commented that 1/3 of people have seen a complementary therapist or used remedies in 1 year. Reasons for using CAM include it is more natural, patient has a more active role in their treatment, and failure of orthodox medicine to give relief of their symptoms. Patients tend to be female, well educated and of a higher than average social class. Acupuncture: 1 trial identified 51 controlled trials on chronic pain. Treatment for musculoskeletal problems showed most positive results. Manipulative therapies: 1 review of 35 RCTs found that 18 trials showed better results for spinal manipulation than placebo, physiotherapy or drugs. Herbal remedies: 1 review of 40 trials of ginkgo on cerebral insufficiency found positive results compared to placebo in 7 of 8 good quality papers. Homeopathy: 1 review of 107 controlled trials was found. 81 indicated positive results and 24 had negative findings when homeopathy was compared to placebo. A meta analysis found that homeopathy was better than placebo. Side effects: Over a 20 year period world wide there have been 216 cases of serious complications (infection, pneumothorax) with the use of acupuncture. A review on manual therapy revealed 16 cases of vertebral artery injury where the patient died and 55 cases of neurological deficit. There are few adverse reactions to herbal therapy, although toxicity remains a concern

STUDIES

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Clover et al.[273] 1995 IIIC UK	To describe the patients attending a complementary cancer therapy service and to measure the impact on quality of life.	50 consecutive patients with cancer, who were attending a complementary therapy cancer service outpatient for the first time, participated in the study. 21 completed the six month follow up Age: range = 25-78 Sex: 39 female, 11 men	Design: Prospective survey. Intervention: homeopathy (100%), Iscador (58%), relaxation (50%), diet (24%), acupuncture (14%)	Instruments used: Health related quality of life, measured by the Hospital Anxiety and Depression Scale (HADS). Rotterdam Symptom Checklist (RSCL).	36% had breast cancer and 74% had confirmed metastases. There were significant improvements in psychological distress ($p<0.005$ on RSCL) and anxiety ($p<0.01$ on HADS). Physical symptoms remained the same.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Downer et al.[274] 1994 IIIC UK	To determine what proportion of oncology patients receiving conventional medical treatment also use complementary treatments. To assess which complementary treatments are the most popular and to assess patients' motivation for using them. To evaluate associated advantages and risk.	*Criteria for inclusion*: Diagnosis of cancer for 3 months or longer. Patient aware of diagnosis. Ability to speak or understand English. All tumour types and stages of disease. Age of participants were 18 years or older. A total of 415 (69%) of cancer patients returned the questionnaire completed. Sex: 206 male, 209 female Age: Mean 56	*Design*: Postal screening questionnaire followed by a semi structured interview. Intervention: A screening questionnaire was sent out to patients. Those that had used complementary treatments were invited to participate in an interview.	Prevalence and demography of use of complementary therapies. Patients' motivation and expectations of therapy. Areas of satisfaction and dissatisfaction associated with conventional and complementary therapies.	The response rate was 69 %. Of these, 16% used or were using complementary therapies. These patients were younger (50 vs.58, $p<0.005$) and more women than men used the service (one in five women vs. one in eight men, $p<0.05$). There were no significant differences in marital status and ethnic origin. 58% of those using complementary therapies were in socio-economic groups 1, 2,3N in comparison with 33%of patients using conventional treatment. The most commonly used therapies were: Healing, relaxation, visualisation, diets, homeopathy, vitamins and herbalism. Attractions to complementary therapy: Hope, non toxic and holistic nature of remedies, more patient participation, supportive relationship with practitioner. Expectations from treatment: Cure, remission or prevention of spread, physical effect on illness, boost immune system, improvement of quality of life. 82% satisfied with therapies they had chosen. Dissatisfaction focussed on diet therapies and herbalism, doctor patient relationship and side effects of treatment.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Rees et al.[275] 2000 IIIC UK	To measure the prevalence and costs of complementary therapy use by women diagnosed with breast cancer (in the South Thames region)	Criteria for inclusion: Diagnosis of breast cancer between 1 January 1990 and 31 December 1996. Women were aged 18 years and over. Participants lived in the South Thames region. A total of 1023 were sent the questionnaire. Interviews were given to participants who had received therapy and who were interested in being interviewed (80). 38% of responders were from Social Class I or II and relatively highly educated.	Design: Postal questionnaire.	Participants were asked if they had seen, or received treatment from an: acupuncturist, chiropractor/osteopath, spiritual or faith healer, medical herbalist, homeopath, hypnotherapist, massage therapist/aromatherapist Nutritional therapist, reflexologist, relaxation, yoga or meditation class, other specialist in alternative or complementary medicine, counsellor, psychotherapist, support/self help/patient groups.	The response rate was 74%. 22.4% (95% CI 19.4-25.6%) had consulted a complementary therapist in the 12 months prior to completing the questionnaire. 31.5% (95% CI 28.1-35.1%) had done so since diagnosis. 15.1% (95% CI 12.6-18%) had done so prior to the diagnosis. The most common therapies used were massage/aromatherapy, chiropractic/osteopathy, relaxation/yoga/meditation and spiritual or faith healing. The women consulting therapists tended to be slightly younger, more educated and were more likely to have used complementary therapies prior to their diagnosis than non users.(when logistic analysis was carried out). Most treatments were paid for by the patients. (Almost £17000 was spent by 111 women who had used complementary therapies in the previous 12 months.) Most of the healing and relaxation was paid for by donations.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Thomas et al. 2001[276] IIIC UK	To describe the scale and scope of access to complementary therapies (acupuncture, chiropractic, homeopathy, hypnotherapy, medical herbalism and osteopathy) via general practice in England	Criteria for inclusion: A total of 964 (78.6%) of GPs returned the questionnaire.	Design: Postal questionnaire. Multi stage random sampling was used to select practices from all fund holding and non fund holding practices in England.	Whether practices offered or referred patients to the NHS for complementary therapies.	Of the 964 GPs that replied to the questionnaire, 39.5% (95% CI 35-43%) provided access to some form of complementary therapy for their NHS patients. This figure goes down to 30.3% if all non responding GPs were included and assumed to be non providers. 21.4% (95% CI 19-24%) offered treatment by a member of the primary health care team. 6% (95% CI 2-10%) employed an independent therapist. 24.6% (95% CI 21-21%) made NHS referrals to therapists. Acupuncture and homeopathy were the most commonly available therapies. Patients made some contribution for 25% of practised based provision. Former fund holding practices were significantly more likely to offer complementary therapies than non fund holding practices (45% vs. 36%, p=0.02

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
White P[277] 1998 IIIC Hong Kong	Outline the complementary therapies used in the management of cancer patients in England and Wales. Identify whether the complementary therapists were employed within the hospital or contracted externally.	All 55 Oncology/Radiotherapy centres in England and Wales were sent a questionnaire.	Design: Postal questionnaire. A pilot study was used.	Participants were asked if they provided the following complementary therapies: Acupuncture, aromatherapy, Bach flower remedies, Bristol centre approach, healing, herbalism, homeopathy, hypnotherapy, massage, meditation, naturopathy, nutritional therapies, osteopathy, reflexology, relaxation, visualisation, vitamins, others (Alexander technique, art therapy counselling, shiatsu, spiritual care, therapeutic touch) For each therapy respondents were asked to comment on the level of provision.	There was 100% response rate. 70% of Oncology departments I England and Wales used at least 1 method of complementary therapy. Of the remaining 17, 5 indicated that they had plans of introducing it in the future. The most common therapies used were aromatherapy, relaxation, massage, reflexology, visualisation and acupuncture. The vast majority of therapies were practised within the hospital by hospital staff. Less commonly external practitioners came to the hospital.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Ferrell-Torry & Glick[278] 1993 IIIC US	To examine the effects of therapeutic massage on pain perception, anxiety and relaxation levels on hospitalised cancer patients experiencing cancer pain.	Criteria for inclusion: Diagnosis of cancer Patient had cancer pain. No recent (< 6 weeks) surgery. Ability to read and write English. A total of 9 patients participated in the study. Sex: All male Age: range 22-77 (mean 56.6) Cancer: All types and stages.	Design: Not explicitly stated. Intervention: Having completed the pre massage assessment, all patients were given a 30 minute massage (by the same therapist). Those that were able had the same procedure the next day (7 patients).	Pain was assessed using VAS. Anxiety was measured by the State-Trait Anxiety Inventory (STA-I). (Pre massage and post massage scores were taken.) Relaxation was measured using VAS and heart rate, respiratory rate and blood pressure before, immediately after and ten minutes after the massage.	Pain: Pre massage pain score was 48.2(+/-29.1mm) and following massage it reduced to 18.7(+/-22.5mm), where p<0.007. On day 2 the mean pain score prior to massage was 43.3(+/-31.4mm) and it reduced to 20.7(+/-22mm) Anxiety: Pre massage anxiety score was 55.9(+/-10.2) which reduced to 42.6(+/-15.8) after massage, where p<0.02. On day 2 the score was 53.6(+/-4.0) prior to massage and reduced to 40.7(+/-7.2) after massage, where p<0.004. Relaxation: Pre massage score was 64.0(+/-19.7mm). This reduced to 32 (+/-29.9mm) after massage, where p<0.0001. On day 2 the pre massage score was 57.4(+/-21.0mm) and this reduced to 21.7(+/-17mm) pot massage, where p<0.0004). The respiratory rate following massage was significantly less (p<0.05) than before massage. The systolic blood pressure decreased and was only significant, statistically, 10 minutes after the massage finished (p<0.05). There was no statistically significant difference in diastolic blood pressure after massage.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Speca et al.[279] 2000 IB Canada	To assess the effects of participation in a mindfulness meditation based stress reduction program on mood disturbance and symptoms of stress in cancer outpatients.	Criteria for inclusion: Any patient having a diagnosis of cancer. 109 patients entered the trial. 90 completed the study. Age: 27-75 (mean 51) Sex: 86 female, 23 male All types of cancer (most common was breast) All stages of cancer	Design: Randomised wait-list controlled clinical trial Intervention: Patients were randomised to either a wait list control group or the treatment group. Treatment involved 7 weekly 90 minute sessions, which had 3 components: 1. Theoretical material related to relaxation, meditation and body mind connection. 2. Experimental practice of meditation during the group meeting as well as at home. 3. Group process focused on problem solving related to effective practice, day-to-day practicalities and supportive interaction between group members. A booklet was given and an audiotape of relaxation and guided meditation.	Mood – POMS questionnaire Symptoms of stress- SOSI questionnaire	37 patients completed the study in the control group. 53 patients completed the study in the treatment group. 19 patients dropped out and reasons are given for this. These patients had more disturbance in their mood compared to the patients that finished the study. Mood Score: There was no difference in mood scores prior to randomisation. The treatment program resulted in a 65% reduction in total mood disturbance, whereas the reduction in the control group was 12%. When the results were analysed on an intent to treat, there was a significant ($p<0.01$) reduction in total mood disturbance in the treatment group compared to the control group. Stress Score: There was no difference in scores between the 2 groups prior to randomisation. There was a reduction of 30.7% in total stress symptoms in the treatment group compared with 11.1% in the control group. When the results were analysed on intent to treat, total stress symptoms were significantly reduced compared to the control group.

14. CARE FOR FAMILIES AND CARERS, INCLUDING BEREAVEMENT CARE

The nature of the evidence

This review is based on the systematic review conducted by Harding & Higginson[281] which focused on interventions for carers of patients using home cancer and palliative care services. In this review, 22 interventions were identified, comprising home nursing care[282-285] (4), respite services[286-288] (3), social networks and activity enhancement[289;290] (2), problem solving and education[291-293] (3), and groupwork[114;168;192;294-300] (10). Of these, 9 were delivered solely to carers (i.e. were targeted services). Only six of the carers' interventions had been evaluated, two of these had used an RCT (grades IB), three employed a single group methodology (2 prospective grades IIIC and one retrospective grade IIIC) and one was evaluated using facilitator feedback.

There was a lack of outcome evaluation designs, small sample sizes and a reliance on intervention descriptions and formative evaluations. Methodological challenges may mean alternatives to "pure" RCTs should be considered. The current evidence contributes more to understanding feasibility and acceptability than to effectiveness. Practitioners and evaluators must prioritise the further development of intervention studies.

Types of interventions and outcome measures

Home care

Home care services generally include carer support in their aims. Carers report high satisfaction with such services,[168;296], and describe them as useful[192]. However, the high levels of psychological morbidity and unmet need reported in samples of carers of patients using home nursing care services in both cancer[289] and palliative care[287] demonstrate that such generic supportive nursing care does not meet all of carers' needs.

Carers of those using hospice care (n=83) reported a greater reduction in anxiety and higher satisfaction compared to conventional care (n=69) in an RCT (randomised controlled trial)[297]. However, the data does not distinguish between those using inpatient and home hospice care. An RCT of a hospital at home service for the terminally ill, concentrating on the last two weeks of life, importantly found low uptake of the intervention due to the carer feeling unable to cope. No significant difference was reported between intervention (n=152) and standard care (n=33) by carers on perceived support, suggesting that further specific interventions are needed for carers. However, carers in the intervention arm did report having a better perception of the patient care provided[168].

A formative qualitative evaluation of a community palliative care service (incorporating home care, day care and respite, evaluated as a single service) found carers valued specific elements of the service, particularly that the service offered a single point of contact, that it felt like a "home from home", that it helped them overcome reluctance to access services, and that familiarity was achieved between patients carers and staff[298]. A prospective single group evaluation of a home hospice service (service not described, n=118) found that from entering the service to four weeks, carers' quality of life scores remained stable[192]. This stability is attributed to home care provision.

A longitudinal randomised controlled trial examined the effect of a home care nursing intervention on caregivers' psychosocial status for caregivers with and without physical problems of their own[301]. The intervention resulted in an improvement in psychosocial status from baseline to 3 months, and no change at 6 months. Among caregivers with physical problems, the psychosocial status of those in the treatment group declined compared to those in the control groups in the 3 months after discharge; an opposite pattern was observed in the following 3 months. This means that caregivers for cancer patients who have physical problems of their own are at risk for psychological morbidity, which may have a delayed onset. This delay may reflect the replacement of an initial optimism with discouragement as the reality of long-term illness sets in. Home care may create a situation in which caregivers are required to confront the realities of long-term caregiving quickly, cutting short their initial optimism, but also preparing them for what is to come.

A psychoeducation programme for cancer caregivers implemented by nurses and social workers was evaluated, which addressed symptom management, psychosocial support, and resource identification. Findings confirm the chronic and consuming nature of cancer caregiving. Data indicate that perception of burden did not worsen even when caregiving tasks increased in intensity. Caregiver perceptions of their own health actually improved over time. In addition, the number of caregivers who said they were well informed and confident about caregiving after programme attendance increased over time. Further study that randomises caregivers to intervention/control groups is needed to substantiate the role of similar programmes.

Respite care provision

The importance of respite services lies in providing time away from the caring role[283]. Respite can take many forms, and may prove unacceptable to those carers unwilling to leave the patient. Great ambivalence has been identified among this caring population, and respite care may not be accessible to those who wish to remain in the home (57).

A "sitting service" designed to provide practical and emotional help to both cancer patients (624 referrals in one year) and families was evaluated using retrospective postal questionnaires[114]. Respite for carers was the most common reason for referral (42%). 86% of respondents felt able to go out and leave the sitter with the patient, and 70% found the service to be "very important" to them. Descriptive data from carers emphasised the importance of talking and having someone to listen. However, high costs and lack of funding options for mixed health and social care interventions made the service unfeasible. Elsewhere, the costs of such a sitting service were reduced through the use of volunteer sitters[299]. However, issues of boundary maintenance, high stress and early burnout among sitters were experienced. This volunteer sitting service was evaluated using a single group retrospective questionnaire study (n=190). It found over 90% satisfaction among carers, though 33% felt the service had been offered too late.

Massage has been provided as a form of respite, aiming to enhance physical caring abilities and sleep, and reduce physical and emotional stress[300]. The single group prospective evaluation (n=13) reported improvements in single items of emotional stress, physical stress, physical pain and sleep difficulty.

Social networks and activities

An "activation programme" for relatives of cancer patients aimed to promote increased active caring on behalf of carers, with the aim of also increasing social activity patterns[302]. The evaluation comprised a controlled trial, with an age and sex matched comparison group from a control ward. Data were collected monthly and one and two months into bereavement (n=50 for intervention and n=45 control at baseline, n=22 and n=19 respectively 2 months post death). The activity group reported significantly higher proportion of activities involving friends during treatment, and data from the last interview preceding death found the activity group were significantly more involved in their own activities. However, the patients in the study were using both inpatient and home care services, and the data does not distinguish between places of care.

The Well Spouse Foundation promotes the well being of carers of the chronically ill through peer rather than professional support[303]. This national network provides telephone letter and group support, providing information and practical sharing of ideas. The advantage of this organisation is that the "round robin" letters ensure that those who are unable to attend services are still able to access support. No evaluation data is presented.

One-to-one interventions

One to one interventions, where feasible, are proposed as a means to provide both support, education and build problem solving/coping skills. However, these interventions are time consuming and costly, and such psychologically and/or individually based services may prove to be unacceptable to many carers.

An RCT of six one hour sessions focusing on carers' problem solving skills (n=40) versus standard management (n=38) among cancer carers found that the intervention appeared effective only for a distressed sub-sample of the of the cancer carers in the study. This burdened subsample were better at dealing with pressing problems following intervention (n=11) compared to the control (n=18). This may be explained by the fact that the caregiving activities of the sample were low, and that carers of patients with high ECOG (patient physical performance) scores or recent diagnoses were excluded from the study[98].

A family cancer pain education programme consisting three 1-hour sessions on the management of cancer related pain was delivered in the home to patients and carers (n=50)[288]. Data were collected (by the same nurse who had delivered the intervention) at baseline and one week following the intervention's completion. Significant improvements were found on all scores (knowledge/attitudes to pain, pain management, and carer burden).

An RCT of psychotherapy for the spouses of newly diagnosed lung cancer patients evaluated the service aim of assisting the carer in fulfilling their support function: i.e. to maintain patient social support, promote patent autonomy, advocate for patients in the medical system, encourage patient communication, and facilitate mutual expression of feelings[304]. It is noteworthy that only the latter two aims can be seen as providing direct benefits to the carer. Twenty-three percent of the eligible population refused to participate, and 35% were deemed ineligible. Ongoing weekly support counselling was provided for the 27 carers in the intervention arm, and 21 were allocated to the control. The outcome analysis was of those interviewed at the third point of data collection (6 months after diagnosis): 10 carers in group 1 and 13 in group 2. No significant difference was found on the outcomes of emotional, social, or physical function.

Group work

Group work interventions in cancer and palliative care are widely suggested as an appropriate format to deliver the necessary support and information to carers, and have been used successfully in this way for cancer patients[305].

Although carers' groups may not be appropriate for all carers (particularly those psychologically vulnerable carers who may have their needs best met elsewhere[306]), it is postulated that the benefits of information requesting and giving, sharing practical and coping skills, and social comparison processes[307] may be great. The sharing of experiences underpins most groupwork interventions, with other carers being seen as the most natural form of support[308]. Carers groups appear to favour a format of mixed content, combining information on care and group discussion, with an emphasis on promoting self-help[309]. However, research into the effectiveness of these interventions is needed, particularly the format and optimum length of interventions[293].

An RCT of a 6 week stress and activity management group for patients and carers (n=26) versus standard management (n=25) found that spouses who had attended the intervention had significantly higher knowledge scores, achieved activity goals, coped better with medical situations, and were more satisfied with the care provided. However, psychosocial adjustment did not alter between the two groups[310].

A descriptive evaluation of eight weekly combined patients' (n=73) and carers' (n=54) group sessions in cancer care, found that the provision of information and education promoted understanding and facilitated coping, and that familiarity with the facts and feelings involved reinforced confidence[311]. Although anxiety was not reduced it was better recognised, therefore making it easier to deal with.

A retrospective single group questionnaire evaluation of a monthly group (1 hour plus socialising) designed for both cancer patients and families found that opinions were divided on whether bereaved carers should be allowed to return to the group after a patient's death. The evaluative questionnaire explored negative feelings experienced after having attended the intervention. Twenty-six percent reported feeling more anxious worried and 29% more sad, and this is an interesting aspect of the study although it lacks comparison group data. Uptake of the group was low at 18%, and one of the reasons cited for not attending was a fear of finding the experience of listening to others too depressing[312].

An observational study evaluating the impact on quality of life in cancer patients and their families compared a control (n=12), six group sessions plus individual/family counselling (n=12), or ongoing support group having previously attended the group (n=8)[313]. No significant differences were found in quality of life or coping strategies. However, scores of patients and carers were combined, and comparative baseline or post-intervention scores between these groups were not presented, and the number of participating carers is not identified.

The development of a multi-disciplinary group model has been described, aiming to alleviate the carer stress that stems from lack of knowledge in implementing necessary caring skills[314]. Three 2 hour multi-disciplinary sessions are proposed, though no evaluation is presented. A similar description of the development of a group intervention for family cancer carers describes the content focus as being on communication, symptom management, and community resources[315]. The intervention combined lectures, group discussions, case studies, and written materials over a period of six hours of education and interaction, with allowance for regional variation to meet local need. The group was evaluated using a single group prospective design with measures taken at baseline and 6-8 weeks after the intervention. However, neither the outcomes measured or the data are reported, although attendees are reported as being less overwhelmed and more able to cope. Further descriptive evaluation data reported recruitment difficulties. The major issues preventing attendance by potential attendees were being in employment and having family obligations, having concerns about leaving the patient alone, and the carers' own physical restrictions[316].

An ongoing group for spouses of patients with a brain tumour, aiming to enhance physical and emotional capabilities and provide education, met for 90 minutes per week for two years, with an average of 10 spouses attending. Evaluation was undertaken using only data from facilitator feedback, stating that the group provided social support and transition between phases of caring[317].

The feasibility of an education and support group for patients with gynaecological cancer and their family carers was explored in terms of content and projected uptake[318]. Those with formal education were most interested in attending, and topics prioritised were cancer and its treatment, living with cancer, treatment side effects, pain and psychological reactions.

Ongoing family group therapy has been described, although not evaluated[319]. The group (for both patients and carers) aimed to enhance communication, deal with the intrapsychic conflicts of serious illness, and enhance communication with physicians. The group ran for two hours per week, was not closed (therefore membership varies each week) and families of the recently deceased were permitted to attend.

A retreat/workshop approach has been taken in an attempt to meet the needs of all generations of cancer family members[320]. The weekend retreat consists of parallel sessions (separating adults, teenagers and children) using a multidisciplinary approach to education, relaxation, and family/communication, with additional social activities. No evaluation data are presented.

Discussion

Evaluating carers' interventions

Many questions need to be answered in evaluations of carers' interventions, including defining the optimal type of support offered, length of intervention and attendance, and understanding ethnic differences in acceptability and effectiveness[293]. Careful consideration needs to be given to exactly what such interventions can realistically expect to accomplish[321], as short-term interventions are unlikely to produce multi-dimensional change. Rather than seeking global and dramatic change, it might be more useful to try to identify useful elements of interventions, although these may have a rather weak effect on global scores of burden and stress. It seems likely that, over short periods of time, domains such as information are likely to show more real change than, for example, depression. It is also important to consider participant goals, which may not match those of the facilitators. The lack of evidence may well be a result of the use of global rather than specific behavioural measures[322].

One of the aims of carers' interventions is to reduce stress levels. The detection of improvements in scores may be clouded by the baseline scores of those who choose to attend this type of intervention. It has been suggested that carers are not under severe stress when they access interventions, and that they do so to gather information to assist them in advance of the situation worsening[322].

Implications for research and practice

Currently there is a small body of evidence on the effectiveness of interventions for carers in palliative and cancer care. There are a handful of unevaluated descriptions of interventions, which are valuable in terms of providing information about the design and format of interventions. However, evaluations (especially rigorous ones) are rare, with only two (quasi) experimental evaluations identified in the present review.

The provision of supportive interventions may be detrimental to carers[323], and this proposition has as yet not been refuted due to the lack of evaluation data in services for carers. Supportive interventions need to consider acceptability in the early design stages[324]. Despite carers' recognition of unmet need, they report self reliance and independence as important values[325], and the barriers to accepting or making extensive use of services need to be more fully understood[323].

No single service model will be acceptable to the population of carers, or meet all needs for individual carers. A range of models have been identified in the present review, although only nine papers referred to interventions designed specifically for carers. The evidence for home care highlights the satisfaction with patient care on behalf of carers. However, the evidence of unmet need among carers using home palliative care services highlights the limited scope of this type of intervention. The expansion of such services to include multi-professional support for families and carers independently of patient care would offer opportunities to meet unmet carer need.

Respite services aim to provide carers with the time away from caring and rest needed, although the literature has rarely answered questions of acceptability among a population noted for its ambivalence toward leaving the patient (57).

The challenge of supportive provision may be greater in rural areas, and therefore it is important that carers and families are informed of informal peer support (such as the US model of postal networks) (24). Existing social networks should be maximised, and the present evidence from controlled trials is positive for such interventions in both individual and group formats. The evidence for one to one therapeutic interventions for carers is currently unclear. From the two published trials, only one found benefits for the intervention group and this was for a significantly depressed subsample. Although larger trials and evaluations of different styles of interventions may find benefits, at present there is no evidence for the general provision of this high cost intervention.

The only controlled trial of group interventions invited patients to attend the intervention with their carers. However, the outcome data from carers in attendance showed benefits gained in information and social activities. The development and provision of groupwork entails many variables regarding aims, format and content, and is largely chosen as a vehicle for the provision of information and support. However, groupwork interventions usually have fairly low uptake, and tend to be acceptable to carers with particular demographic profiles. It would be worth running outcome evaluations of groups specifically for carers, as the current evidence suggests benefits in several domains, including support, coping and information giving.

Each of the models of provision described offered formats to meet the needs of carers, and there is as yet little proof that they have met their aims. Practitioners planning to develop interventions for carers must 1) ensure that their service is theory based, 2) focus specifically on the needs of carers (i.e. not a generic care service), 3) address issues of access and acceptability in the initial stages, 4) have clear and modest aims (which should not necessarily be multi-dimensional), and 5) ensure that these aims are evaluated using rigorous evaluation methods (using repeated measures from baseline and employ comparison groups).

Tables of Evidence: Carer Support

Reference & grade of evidence	Palliative or cancer care?	Target population: (C=carers P=patients)	Service description	Evaluation design	Findings
Home care					
Grande et al 2000[168] I A	Palliative	C, P	Hospital at home, specialist palliative nursing care up to 24 hours daily for a maximum of 2 weeks. For patients whose prognosis is less than 2 weeks, or for respite.	RCT. Allocation 4:1, intervention (n=152): standard care (n=33). Data collected at referral, and then retrospectively 6 weeks into bereavement, regarding last 2 weeks of life.	Informal carers in intervention group reported better satisfaction with care and better pain control. No increased likelihood of patient remaining at home in last 2 weeks.
Ingleton 1999[298] IV	Palliative	C, P	Community service offering home care, day care, and respite care.	Formative qualitative, investigating satisfaction among carers, n=17.	Carers valued sense of service "being there" (single point of contact), the "atmosphere" (being like a home from home), "didn't need to ask" (service helped overcome reluctance), and that it felt "different from other places" (familiarity).

Kane et al.[297] 1985 I B	Palliative	P, C	Hospice care, multi-disciplinary home and inpatient care.	RCT, hospice care n=83, conventional care n=69. Data collection from baseline until death.	Carers in hospice care reported greater reduction in anxiety and greater satisfaction. Data do not distinguish between home and inpatient care.
McMillan 1996[192] III C	Palliative	C, P	Home hospice service, not described.	Prospective single group study. Data collected from carers on admission to service and at 4 weeks. N=118.	Quality of life scores remain stable over 4 weeks. This stability is attributed to the amelioration of carers' well-being through the provision of home care.
Respite					
Clark et al 2000[114] III C	Cancer	C, P	Seven MacMillan sitting services, offering practical and emotional support.	Retrospective evaluation using postal questionnaires. N=121, data collected 3 months post death. 56% response rate.	Respite for carers was most common reason for referral (42%). 86% of respondents felt able to go out and leave the sitter with the patient, and 70% found the service to be "very important" to them.
MacDonald 1998[300] III C	Palliative	C	Home massage service, aims to reduce stress and improve physical health. Between 3 and 9 75 minute sessions.	Single group prospective study, n=13. 4 items measured at baseline and following last massage.	Improvements in emotional stress, physical stress, physical pain and sleep difficulty. No benefit having had 7 massages compared to 3.

Johnson et al 1988[299] III C	Palliative	C	Marie Curie/St Lukes Relative Support Scheme. Paid and volunteer sitters provided, average of 3.1 hour visits over 6-7 weeks.	Single group retrospective study using postal questionnaire evaluation. Data collected 6 weeks post death/discharge. 77% response rate. N=190.	High rating of satisfaction with service (over 90%). Many (33%) found the service was offered too late.
Social networks & activity enhancement					
Randall 1993[303] N/A	"Chronically ill"	C	National network of spouses who offer emotional support. Support and information groups and also letter writing to maintain contact and support.	None	Currently 2500 members and 100 support groups across the USA .
Haggmark et al 1987[302] I B	Cancer	C	"Activation programme", aimed at increasing opportunities to participate in patient care and improving social patterns.	Controlled trial, using comparison to age and sex matched comparison group from "control" wards. Data collected monthly, and 1 and 2 months into bereavement. **Intervention : control** During intervention n=50:n=45 Last preceding death n=23:n=31 1 month post death n=22:n=19 2 months post death n=22:n=19	Activity group reported significantly higher proportion of activities involving friends during treatment. Data from the last interview preceding death found activity group were significantly more involved in their own activities. Mixed sample of inpatients and home care does no distinguish between place of care.

Problem solving and education					
Toseland et al 1995[98] I B	Cancer	C	6 1-hour individual sessions focused on support, problem-solving and coping skills. .	RCT evaluation. Treatment n=40, control n=38.	Intervention effective only for a distressed subsample. For those carers with poor couple adjustment (control n=13, intervention n=11), physical role and social functioning were significantly better than control following intervention. For burdened subsample (control n=18, intervention n=11) intervention group were significantly better in dealing with pressing problems following intervention.
Ferrell et al 1995[288] III C	Cancer	C, P	3 1-hour pain education sessions delivered in the home.	Single group prospective study. Measures administered by the educator. N=50.	Improvements on all carers' scores reported over time (knowledge/attitudes to pain management, caregiver burden).
Goldberg & Wool 1985[304] I B	Cancer	C, P	Weekly one to one support counselling for 6 months, focused on supporting patient and enhancing communication.	RCT, evaluation on n=10 control n=13 intervention after 3 timepoints of data collection.	No significant difference on emotional, social, or physical function.

Group interventions					
Cawley et al 1988[314] N/A	Cancer	C	Description of development of multi-professional intervention. Course aimed to provide information to meet day-to-day tasks of caring and to enable carers to care for themselves.	None	3x 2hour, multi-disciplinary sessions.
Robinson et al 1998[315] see also Barg et al 1998 III C	Cancer	C	Description of development of 6 week group intervention, focusing on communication, symptom management and resource locations.	Single group prospective design. Questions not reported.	No data presented. Only that carers "more able to cope" and "less overwhelmed".
Horowitz et al 1996[317] IV	Cancer	C	Ongoing group for spouses of patients with a brain tumour, to enhance physical and emotional capabilities and provide education. Average of 10 spouses attended for 90 minutes per week over a 2 year period.	Evaluation via facilitator feedback.	Facilitators conclude that the group provided social support and provided a means of transition between phases of caring.
Carlsson & Strang 1996[318] N/A	Cancer	C, P	Exploratory study to evaluate interest in an education and support group.	Postal questionnaire n=173, 80% response rate.	Younger people, couples and those with higher formal education were interested in participation. Most requested topics for inclusion were cancer and its treatment, living with cancer, treatment side-effects, pain, and psychological reactions.

Grahn 1996[311] IV	Cancer	C, P	Eight 2-hour group sessions. Information given on aspects of disease and treatment, and reactions to change. Multi-professional input including music, art, body awareness, relaxation and visualisation.	Qualitative evaluation. Of 127 attendees, 54 were carers. 37 carers interviewed.	Carers' responses analysed using grounded theory, concluded that supportive education promotes understanding and facilitates coping. Familiarity with facts is stressed as reinforcing confidence.
Plant et al 1987[312] IV	Cancer	C, P	Monthly evening meetings, including those bereaved. 1-hour discussion followed by socialising. Focus on support and clarification.	Postal questionnaire evaluation. 58% response rate, of these 55% of these were carers.	Members equally divided on whether patients and carers should be in the same group. Reported increases in happiness and relaxation. 26% more anxious and 29% more depressed or sad following attendance.
Reele 1994[313] III C	Cancer	C, P	Ongoing support group, or 8 week education group with 2 sessions of individual/family counselling.	Observational study comparing interventions (ongoing group n=8), group + counselling n=12) to control (n=12).	Number of carers not identified. No significant differences on measures of quality of life and coping strategies.
Wellisch et al[319] 1978 N/A	Cancer	C, P	Ongoing patient and carer open ongoing therapy group, focusing on communication, psychological conflict, and physician relationship.	None	Facilitator reports that group was "enhanced" by inviting patients to what had been a carers' group.
Johnson & Norby 1981[320] N/A	Cancer	C (whole family)	Weekend retreat for all family members. Using multi-disciplinary education, skills building and creative arts with social activities.	None	

Heinrich & Coscarelli 1985[310] I B	Cancer	C, P	Stress and activity management 6 week group programme. Intervention included education, information, stress management, activity management and problem solving.	Randomised trial. Treatment n=26, control n=25.	Treatment group (patients and carers) reported significantly greater increase in their fund of information about cancer. Intervention group spouses were more active than controls at post-intervention. Activity group carers were more satisfied than controls with the care that they had received.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Jepson et al.[301] 1999 USA Ib	To examine changes in the psychosocial status of caregivers of post-surgical patients with cancer, and how their status was affected by (a) whether caregivers had physical problems of their own, and (b) whether the patient received a home care intervention.	A total of 161 patients completed all the assessments. Patients were recruited first, after which their caregivers were invited. Eligibility criteria: Sixty years of age or older; diagnosed with a solid tumour cancer within the past 2 months; currently hospitalised for surgical treatment of the cancer; a prognosis of 6 months or greater; living within 50 miles of the study centre; having a complex problem at the time of discharge.	*Design*– RCT. *Intervention*– Patients received a Standardised Nursing Intervention Protocol (SNIP) over a four week period between interviews 1 and 2, consisting of 3 home visits and 6 telephone calls from an oncology clinical nurse specialist. Intervention activities: problem assessment and monitoring, symptom management, teaching self-care behaviours to patients and caregivers, and co-ordination of resources to meet ongoing needs. C= Patients received usual care in outpatient surgical clinics.	*Measures:* Demographic characteristics. Presence of a physical problem. Psychosocial factors, measured by 2 standardised instruments: The Caregiver Reaction Assessment (CRA) and the Centre for Epidemiologic Studies Depression Scale (CES-D). Data were collected in structured interviews administered at the time of the patients' discharge and approximately 3 and 6 months later.	Psychosocial status improved from baseline to 3 months, and was about the same at 6 months later. Among caregivers with physical problems, the psychosocial status of those in the treatment group declined compared to those in the control group in the 3 months after discharge; an opposite pattern was observed in the following 3 months.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Pasacreta et al.[326] 2000 USA IIIb	To assess the goal of FCCEP to provide education and support for caregivers providing home care for an individual with a diagnosis of cancer.	A total of 187 caregivers provided complete data on two occasions. This was a convenience sample. Eligibility criteria: People identifying themselves as caregivers and currently providing care to a patient with cancer. The term caregiver was interpreted broadly and included any individual who had a personal connection and commitment to the patient.	*Design*– A short-term longitudinal pre-post test design. *Intervention*–The FCCEP was a 6-hour psychoeducation program for caregivers, also putting caregivers in touch with local resources in the community that can meet their needs. Group size ranged from 8 to 15 members. The FCCEP included basic content that focused on the medical realities of cancer such as managing symptoms, improving technical competence, and administering medication to patients in the home.	*Instruments:* Participant Profile Form collected demographic information of the caregiver, including medical problems, current health status, and co-morbid conditions. Caregiver Reactions Form measured subjective and objective reactions to the role of caring for a family member in the home. The Caregiver Demands Scale measures the presence or absence of specific caregiving demands, i.e. the experiences a caregiver reports while caring for an adult with a chronic illness. Data were collected before attendance and 4 months later.	The caregivers' [perceptions of burden remained the same or did not get any worse although the caregiving tasks increased in intensity Caregivers' perceptions of their own health actually improved over time. There was an increase in the number of caregivers who said they were well informed and confident about caregiving after FCCEP attendance.

Bereavement Support

The nature of the evidence

A systematic review for the topic area of bereavement support has not yet been undertaken. We identified eleven individual studies, six RCTs (three grade Ia, two Ib and one Ic), one grade IIb which was a controlled trial, and four grade III studies (two IIIa and two IIIc). The majority of the studies (six) were from the USA, of which five were RCTs. The remaining RCT came from Finland. Other countries which have contributed to the evaluation of interventions on this subject were Canada, the UK and Sweden.

Types of interventions

One study[327] has been conducted on how units assess the need for bereavement follow-up, and to determine the nature and extent of services provided for bereaved adults. This was done by a postal survey of palliative care services and teams which were identified in the 1992 Directory of Hospice services in the UK and Ireland.

Three studies assessed the impact of interventions related to a particular health care setting. A controlled trial evaluated the effects on the family of a comprehensive programme of terminal cancer care. Close relatives of patients who had died in the Palliative Care Unit at the Royal Victoria Hospital in Montreal (which had adopted many of the principles of hospice care but differed also in important respects) were compared with a matched group of relatives of patients who had died of cancer in other wards of the same teaching hospital[328]. A RCT investigated the role of hospice in reducing the impact of bereavement [329] by following survivors of patients who had received either hospice or traditional care. Hospice care encouraged active involvement of family members and significant others providing support groups and special counselling sessions during this terminal phase of the patient's illness. Hospice staff also attempted to maintain contact with the survivors by sending condolence letters and announcements of meetings and social functions. The purpose of the RCT undertaken by McCorkle et al [330] was to determine whether specialised oncology home care services provided to terminally ill cancer patients with lung cancer positively influenced bereavement psychological distress among survivors. This model provided personalised nursing care in the home setting and compared it with a standard home care programme delivered by an interdisciplinary team of health professionals and an office care programme provided by the patients' physician and outpatient staff. The latter was regarded as the control condition as it was available to all patients and their families.

We identified a few studies which scrutinised the impact of particular strategies which offered support for bereavement. Scruby & Sloan[331] experimented with bereavement counselling as a health promotion strategy. A quasi-experimental study[332] investigated the intervention of a supportive telephone call to grieving families. The intervention had the objective of providing a supportive environment in which feelings could be discussed, allowing the family members to ask questions about things bothering them, providing information about a possible support group in the area, and serving as a finishing point of the relationship between the nurse and the family. A study conducted by Stewart et al.[333] examined the impact of support groups on widowed seniors' loneliness, affect, and perceived support. A network of peers in support groups was created to enhance and supplement the depleted natural networks of the widowed seniors. The content of the discussion topics were determined by group decision making and the intervention processes and intervening factors were documented for replication and modification.

A Swedish study[334] tested whether a psychosocial intervention programme for relatives of cancer patients affected the endocrinological reaction patterns which are associated with psychiatric grief reactions after the loss of a close relative. An activation programme was offered to patients' relatives to give them the opportunity to take part in the care of the patient at the hospital.

The study by Hanson & Ashley[335] described the role of the advanced practice nurse in applying the Stetler Model for Research Utilisation and demonstrated the nurse's use of the model as applied to improving bereavement care. The Stetler Model guided formal review of selected research reports for applicability and feasibility of translation into clinical practice. Final recommendations were made for departmental implementation to improve bereavement care.

Two RCTs tested the effectiveness of interventions in early bereavement. One study aimed to determine whether a school-based educational programme could successfully promote the development of a more mature concept of death in early elementary school-age children[336]. This intervention is based on prior research suggesting that the lack of a mature concept of death may serve to heighten anxiety about death and interferes with successful adjustment to loss. The other study[337] evaluated the effects of a theoretically derived programme to prevent mental health problems in children who had experienced the death of a parent. The programme was designed to improve variables in the family environment which were specified as mediators of the effects of parental death on child mental health.

The studies were designed for and carried out with (a) newly bereaved relatives[331-333;337] including adolescent sons or daughters[337]; (b) carers of the terminally ill[328-330;334], (c) children of early elementary school-age[336], and (d) professionals[335]. The studies are divided into those which approach bereavement care as beginning after the death of the patient and those which take the terminal phase of illness into account as an influence on the way in which the bereaved relatives adjust to loss.

Outcome measures

The results from the survey Payne et al.[327] undertook show that bereavement follow-up is recognised as part of palliative care. However, heavy workloads, lack of time, and limited resources are obstacles to systematic bereavement support. The majority of palliative care units assess risk and this is carried out by nurses. Most relied on experience rather than standardised measures to target support. Informal assessment was regarded as more flexible and convenient but was associated with more problems. Nurses drawing on their experience were anxious about whether they were identifying the right people. Units using informal methods were less likely to have sufficient resources to provide ongoing support. Those using standardised instruments felt that their decisions were more objective. However, a study[338] which examined the Parkes' risk index from which most other assessment tools are derived revealed that the instrument could not be relied upon as a predictor of outcome and that nurses' judgement of a person's ability to cope was the most reliable in this respect. Bearing this in mind Payne et al[327]concluded that training and support needs of nurses involved in any form of risk assessment must be recognised.

Cameron and Murray Parkes' paper[328] reported that surviving family members from the Royal Victoria Hospital's Palliative Care Unit had significantly fewer psychological symptoms and less lasting grief and anger than did relatives of patients who had died elsewhere. Factors thought to have contributed to good outcomes were successful relief of pain, awareness by relatives of the imminent death of the patient and support given to relatives after bereavement. The hospice programme based in a Veterans Administration hospital which was evaluated by Kane et al.[329]provided practical, supportive and bereavement services but only a few of the significant others availed themselves of the service. The hospice significant others reported that their needs were met to a greater extent than the control significant others prior to bereavement, but terminated contact with the supportive staff after the death. Many found it difficult to return to the hospital because of unpleasant associations, and they felt that extended telephone support was inappropriate when there was no longer a patient on the ward. A hospice that is not part of an acute-care hospital may experience better attendance at bereavement functions.

McCorkle et al.[330] provided the first empirical evidence to link specific nursing models of home care for the dying with bereavement outcomes among survivors. In caring for patients dying from lung cancer the OHC nurses were able to reduce the overall level of psychological distress among patients' bereaved spouses. This was due to a more intimate family focused nursing model of care. The standard home care approach achieved significant positive outcomes among the lung cancer patients, but not among their surviving spouses. In a commentary attached to this paper Smeenk et al.[339] stressed the importance of this study as it addressed such a significant problem in society, and as the study suggested that by improving the quality of care using relatively 'simple' measures such as their oncology home care intervention, positive effects could even be seen on the caregiver's bereavement process. This was achieved without special interventions specifically aimed at bereavement. They also raised the question whether a similar intervention programme would have the same effect in countries with different health care structures as is the case for example in the UK or the Netherlands, with their strong emphasis on primary care.

The study undertaken by Scruby & Sloan[331] showed no benefit for the target population due to counselling. The authors suggested that anticipatory grief may have been responsible for this result and pointed out the difficulty of measuring the timing and degree at which this enters the life experience of the survivors of the terminally ill. Supplementary to this was the unusually high level of denial. The results also indicated the need for a scale aimed specifically at a bereaved population. Finally, strengthening community health services for survivors of the terminally ill was supported.

The findings from Kaunonen et al.[332] pointed to differences in despair and personal growth between the groups compared. The participants experienced the supportive telephone call positively for the most part. This indicates that there is a need for individual support after the death, given by nurses from the ward in which the deceased received care.

The outcomes of the study conducted by Stewart et al.[333] were evaluated by standardised measures which yielded quantitative data and the widows' perceptions of the impact of the intervention were elicited by interviews, producing the qualitative data. The statistically significant impacts of the intervention were enhanced support satisfaction, diminished support needs, and increased positive affect. There was a trend towards decreased social isolation and emotional loneliness. In the post-intervention semi-structured interviews, the bereaved participants reported increased hope, improved skills in developing social relationships, enhanced coping, new role identities, and less loneliness. The authors concluded that community health nurses can play an important role in mobilising support for isolated people experiencing painful transitions such as bereavement. Community health practitioners could benefit from lessons learned about timing, duration, and selection of sensitive outcomes. Future support groups would benefit from efforts to match members in terms of length of time since bereavement and an emphasis on the first two years following death of a spouse. Positive effects of support groups often do not appear until after the group has met for a substantial length of time. Situation specific measures are likely to be more sensitive than global health measures.

Theorell et al.[334] conducted systematic psychiatric observations and analysis of plasma levels of cortisol and prolactin approximately once a month. The relatives of the patients, after having been stimulated to take more active part in the care of the patient than is the case in usual wards, had a depressed serum prolactin level during the treatment period. During the terminal care period, when the patient was soon going to die, women in this group reacted with elevated serum cortisol levels but also with reduced mental exhaustion compared with women in the comparison group. After the death of the patient, women who were offered more active participation in the care of patients also showed less evidence of psychological emotion. These findings are consistent with the hypothesis that grief is activated by the intervention and that the active mourning may have prophylactic value to the relatives after the death of the patient.

The recommended changes achieved by the application of the Stetler Model for Research Utilisation[335] to improve bereavement care were both organisational and clinical in nature: a) develop written family assessment guidelines, including a list of risk factors for poor bereavement outcomes to be used as a nursing education tool; b) conduct in-service education programmes to teach the nursing staff how to identify families at risk for poor outcomes; c) revise the daily clinical nursing assessment documentation form. Design an area to include documentation of assessment of family or significant others' coping style, resources etc.; d) designate the psychiatric liaison CNS and clinical social workers as primarily responsible for the design and implementation of bereavement interventions; e) develop and distribute a comprehensive resource list of in-house psychosocial personnel to whom referrals for assistance with bereavement can be made; f) make available in all practice locations a package of institutional and community resources to bereaved families; g) nursing administration support for a mail and telephone bereavement follow-up programme.

The two studies in early bereavement reported positive results. Schonfeld & Kappelman[336] showed that a school-based intervention programme, even of short duration, can successfully advance the young child's understanding of death and its related concepts. The gain of the 3-week educational programme was equivalent to the amount of conceptual development that is seen in one year in the absence of intervention. The authors suggested that there be a conscious natural integration of information about death into pre-existing curricula and spontaneous class discussion for early elementary school-aged children. The experimental trial by Sandler et al.[337] also showed encouraging results, in terms of the programme's ability to modify the warmth of the parent-child relationship and decrease symptomatology in the children.

Implications of the evidence for recommendations

The evidence supports the idea of including the terminal phase of the cancer patient in bereavement care. The results of the studies reviewed suggested that the survivor's psychological distress could be ameliorated depending on how their loved one is cared for before death[328;330;334]. Scruby & Sloan[331] also supported this idea by critically considering the negative results of their study and introducing the concept of anticipatory grief which could have occurred in the study population. They realised that by extending the study to include the period before death could perhaps have provided plausible explanations for their negative results. Also Schonfeld & Kappelman[336] applied their educational intervention to children 4-8 years of age, long before death is likely to enter the children's' lives in an emotionally threatening way and thereby having a preventive value.

The recommendations stress the assessment of carers' needs with respect to bereavement on an ongoing basis. The literature underscores this as an important aspect of bereavement care, especially when individuals at high risk for negative outcomes are identified early and early intervention is possible[333]. Accurate assessment measurement tools are needed which are currently lacking. These instruments should be generated directly based on the clinical judgement of staff. It has been shown that nurses' judgement of a person's ability to cope was the most reliable predictor of outcome[338]. However, nurses now have shorter contact with the patient than in the past, and they spend less time as inpatient. It was just this kind of close relationship with a nurse which was responsible for the positive results that were achieved with the specialised oncology nursing home care intervention implemented by McCorkle et al.[330].

Another issue involves the selection of relevant and sensitive outcomes. Health professionals should consider the outcomes that are relevant and matter to the bereaved relatives. Social support, affect and loneliness measures, for example, may inform the matching of specific people to specific interventions[333]. We have not encountered studies which took cultural differences into account in the delivery of bereavement support.

Tables of Evidence: Bereavement

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Cameron & Murray Parkes[328] 1983 Canada IIb	To evaluate the effect of the service provided by the Palliative Care Unit (PCU) upon surviving relatives of patients who had died and comparing them with a matched group of relatives of patients who had died in other wards of the same hospital.	A total of 59 were interviewed and satisfactory matching was obtained from 20 pairs.	*Design*– Controlled trial, using comparison to sex, relationship to deceased and living arrangements before and since bereavement comparison group from control wards. *Intervention*–Relatives were exposed to the comprehensive service programmes which included facilitating expression of anticipatory grief , providing optimal care and symptom control for the dying, fostering open communication between the patient and loved ones, and encouraging the survivor to be present at the time of death.	Demographic information, the amount of warning and consequences of the death, and a health-adjustment inventory of 32 questions covering psychological aspects of bereavement and mental health. Interviewed by telephone 1 year and 2 weeks after bereavement	¾ of the control group felt that their health had deteriorated after bereavement and had not yet begun to improve. 50% were taking sleeping pills and almost as many were taking tranquilizers. In the intervention group only 40% reported deterioration in health, one fifth was taking sedatives and one of them (5%) was taking tranquilizers. The control group was more likely to exhibit signs of continuing psychological stress and persisting grief and they had a tendency to express feelings of persisting irritability and anger (85%). This was the case in only 5% of the intervention group.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Hanson & Ashley[335] 1994 USA IIIc	To describe the role of the advanced practice nurse in applying the Stetler Model for Research Utilisation, to demonstrate advanced practice nurse use of the model as applied to improving bereavement care, and to discuss problems and opportunities that they encountered when applying a research utilisation model to a clinical problem.	A group of 16 advanced practitioners with a wide range of oncology clinical expertise.	*Design*– Observational study. *Intervention*–The use of the Stetler model in a research utilisation effort aimed at improving bereavement outcomes. *Data*– Sources: Published articles identified through computerised literature searches; both assessment- and intervention focused research articles were selected for review. Synthesis: The Stetler model guided formal review of selected research reports for applicability and feasibility of translation into clinical practice.	The scientific rationale in which to ground future bereavement care practices.	Recommended practice changes (both organisational and clinical): (i)Develop written family assessment guidelines, including a list of risk factors for poor bereavement outcomes to be used as a nursing education tool. (ii)Conduct in-service education programs to teach the nursing staff how to identify families at risk for poor bereavement outcomes. (iii)Revise the daily clinical nursing assessment documentation form. Design an area to include documentation of assessment of family or significant others' coping style, resources. (iv)Designate the psychiatric liaison and clinical social workers as primarily responsible for the design and implementation of bereavement interventions. (v)Develop and distribute to clinical nursing staff a resource list of in-house psychosocial personnel to whom referrals can be made. (vi)Develop a packet of institutional and community resources available to bereaved families. (vii)Provide nursing administration support for a proposed mail and telephone bereavement follow-up program for relatives of deceased patients who had undergone bone marrow transplants.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Kane et al.[329] 1986 USA Ia	To assess the role of hospice in reducing the impact of bereavement.	A total of 96 survivors of patients participated. I=56. C=40.	*Design*– RCT *Intervention*– Terminally ill cancer patients who agreed to participate in the study were randomly assigned to receive either hospice or traditional care. Significant others were interviewed 6 weeks after the death of a patient and again at 6,12 and 18 months.	The anxiety measure was adapted from The Rand Health Insurance Study. The depression measure was a modification of the Centre for Epidemiologic Studies (CES-D) scale, developed by the National Institute of Mental Health. There were additional interview questions on health care utilisation and altered physical activity adapted from the National Centre for Health Statistics' National Health Interview Survey.	There were no significant differences in the anxiety or depression between hospice survivors. Neither were there significant differences in bed days, physician visits or scores on a 6-item health scale, even when the survivor's initial health status was held constant. No clear pattern of differences emerged in social participation, contacts with friends or relatives, smoking or drinking behaviours.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Kaunonen et al.[332] 2000 Finland Ib	To assess the impact of a supportive telephone call on grief 4 months after the death of a family member.	*Criteria for participation:* the family member had to have died in a hospital setting, the participant was named in the hospital documents as the significant other, and was older than 18.	*Design*– quasi-RCT *Intervention*– A supportive telephone call after the death of a family member.	The Hogan Grief Reactions Checklist (HGRC) to measure the intensity of grief. Postal questionnaire. The qualitative data were analysed using content analysis.	The results pointed to differences in despair (t=2.83; df=199; p=0.005), personal growth (t=-2.19; df=194; p=0.030), detachment (t=1.93; df=208; p=0.048), and disorganisation (t= 2.08; df=204; p=0.039) between the groups. The participants experienced the supportive telephone call positively for the most part. Negative experiences were associated with promises to call in which the calls never reached the participant.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
McCorkle et al.[330] 1998 USA Ia	To determine whether specialised oncology home care services provided to terminally ill patients with lung cancer positively influenced bereavement psychological distress among survivors, compared with other models of care.	A total of 46 carers participated in the program. The final spousal sample had a mean age of 58 years and were predominantly female.	*Design*– A repeated measures design in tandem with a randomised clinical trial. *Intervention*– forty six patient-spousal dyads were randomly assigned to: an oncology home care group (OHC), a standard home care group, or an office care control group. Patient-spousal dyads were entered into the study 2 months after the patient's diagnosis of lung cancer and received follow-up until the patient died. Bereaved spouses continued to receive follow-up for 25 months after the patient's death.	Spousal psychological distress was measured using the Brief Symptom Inventory (BSI).	Psychological distress was significantly lower initially among spouses of patients that received the OHC intervention compared with the other two groups. Significant mean group differences were found on the subscales of depression and paranoid ideation; marginal group differences were found on the subscales of hostility and psychoticism. There were no significant differences among the groups at 25 months.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Payne & Relf[327] 1994 UK IIIc	To assess the extent and prevalence of bereavement support services provided by palliative care units in the UK. To explore the methods used to allocate bereavement support services.	Palliative care units, including inpatient units, hospital support teams and MacMillan services, identified from the directory of Hospice services in the UK and Ireland. Single handed Macmillan nurses were excluded.	*Method*– A postal questionnaire survey was conducted. A total of 187 responses were returned, a response rate of 47%.	• Type of service. • Allocation of bereavement services. • Evaluation of current methods of assessment.	156 respondents (84%) provided follow-up and a further 13 (7%) were planning bereavement services. Only 48 (25%) units undertook formal standardised risk assessment procedures to allocate appropriate services; in 41 units (85%) this was done by a nurse. Of the remaining 125 units , 58 (46%) reported basing their decisions on clinical impressions.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Sandler et al[337]. 1992 USA Ib	To evaluate the effects of a theoretically driven program to prevent mental health problems in children who experienced the death of a parent	A total of 26 families with one or more children from ages 7-17 were from two different sources.	*Design*– RCT *Intervention*–Families were randomly assigned to an immediate(T) versus a 6-month delayed treatment control condition. If more than one child in the family was 7to 17 years old, one child was randomly selected as the target child to be assessed. The parent and child in each family were assessed on all variables prior to random assignment to conditions and 6 months later. The second assessment occurred after the completion of the program for T group and prior to the beginning of the delayed program for the C group	• Parental demoralisation. • Parental warmth. • Family cohesion. • Stable positive events. • Negative events. • Family coping by reframing. • Discussion of grief-related issues. • Parent perceptions of support. • Children's satisfaction with family support. • Depression. • Conduct disorder.	Significant improvements in: Parental perceptions in warmth of their relationship with their children, parental satisfaction with social support, family discussion of grief-related issues. Parental ratings of decreased conduct disorder and depression problems and overall problems in older children

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Schonfeld et al.[336] 1990 USA Ia	To determine whether a school-based educational program could successfully promote the development of a more mature concept of death in early elementary school-age children.	A total of 184 children of 4-8 years old (prekindergarten through second grade). They were recruited from the Baltimore City Public School, from predominantly lower socioeconomic and racially balanced families.	*Design*– RCT Randomisation by coin toss *Intervention*–A series of six 30- to 45-minute presentations about the concepts of death and affective reactions to death was provided over a 3-week period.	The Smilansky Death Concept Questionnaire was administered in the form of a structured interview.	*Significant improvement in:* The total death concept score (mean gain of 4.16), the total score for human death (mean gain of 1.81),the total score for animal death (mean gain of 2.35), the factor of causality (mean gain of 0.86),the factor of inevitability and old age (mean gain of 1.76). *No significant improvement in:* Irreversibility and finality.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Scruby & Sloan[331] 1989 USA Ic	To evaluate the effectiveness of bereavement counselling as a health promotion strategy.	A total of 30 recently bereaved key persons of cancer patients cared for on the palliative care unit of the Princess Elisabeth Hospital in Winnipeg. Over half (16) of the people sampled were spouses, 10 were children of the patient, the remainder were close relatives. Age: 62.5 (median), 31-85 (range). Gender: 22 female, 8 male.	*Design*– RCT *Intervention*– I=Bereaved relatives receiving in-home bereavement counselling (10). C= 2 groups (10 in each group).	Instruments: Heimler Scale of Social Functioning. All respondents were followed for 18 months. Measurements were taken at six points during this interval on the experimental group and the first control group. The second control group was measured only twice over the 18 months (at the beginning and the end) to control for a potential learning effect.	All groups reacted in the same manner over the 18 months. None of the levels tests were significant.

Author, country, grade	**Aims of the study**	**Participants**	**Study design**	**Outcome measures**	**Results**
Stewart et al.[333] 2001 UK IIIa	To examine the impact of support groups on widowed seniors' loneliness, affect, and perceived support.	A total of 23 women over the age of 50 participated in the groups. Age: range=54 to 77 yrs mean=66 yrs. Most of these widows lived alone.	*Design*– Pretest-posttest-delayed posttest within subjects design. *Intervention*–Four support groups, consisting of nine, eight, six, and five participants. The groups met for one hour weekly, for a maximum of 20 weeks.	*Instruments:* Arizona Support Interview Schedule (ASSIS): to assess widows' support. Positive and Negative Affect Schedule(PANAS). Emotional/Social loneliness Inventory (ESLI). Qualitative data on perceived impact, elicited postintervention. Pretest: demographic data on age, length of time since bereavement, number of years married, and living arrangements. Pretest, posttest, delayed posttest (3 months following the intervention): measures of support need and satisfaction, affect, and loneliness/isolation.	*Significant impact on:* Support satisfaction, diminished support need, positive affect. *Non-significant impact on:* Negative affect. Loneliness and isolation. Although these decreased. The latter was supported by the qualitative data. *Postintervention interviews:* Diminished loneliness and isolation, increased hope, role learning, and new friendships.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Theorell et al.[334] 1987 Sweden IIIa	To assess whether a programme for activation of relatives affects the grief process and the endocrinological reaction patterns.	A total of 72 relatives. Close female relatives (wives, siblings or children) of patients treated for cancer . Persons with serious illness and age exceeding 80 years were not included	*Design*– Observational study. *Intervention*– I= an activation programme for the relatives where they were offered the opportunity of taking part in the care of the patient at the hospital (36). C=only customary attention was given to the relatives in this group (36). The relatives were observed during the treatment period, terminal care period and one and two months following the death of the patient.	Systematic psychiatric observations and analyses of the plasma levels of cortisol and prolactin were made approximately once a month. Psychiatric observations: • Anxiety • Depression • Mental exhaustion.	During treatment period: The psychiatric scores did not differ between the groups, but the prolactin levels tended to be lower in the intervention group (p=0.06). *During the terminal phase:* the plasma cortisol levels were significantly elevated in the intervention group but not in the routine group. *At one and two months after death of the patient:* the mental exhaustion scores were significantly lower in the intervention group.

15. Research in supportive and palliative care: an appraisal of current evidence and future issues

Introduction

This short section on research has been added at the request of the Editorial Board who are making the proposals for best practice and service configurations supported by evidence of effectiveness. The nature of research in supportive and palliative care in cancer is somewhat different to that found in some other areas of cancer care, particularly drug and other therapies. Therefore it was felt that a short section examining the current conclusions about the best service configurations for supportive and palliative care and the evidence that underpins these would be valuable in the development of services in the future.

Nature of the evidence

Evidence in supportive and palliative care comes forward in three main forms. There is evidence of need, of importance (to those affected by cancer and to society), and evidence of an effective solution.

Without doubt there is ample evidence of need for effective supportive and palliative care among patients affected by cancer. This is evidenced by studies over many years that have demonstrated concern and problems in communication, information, psychological support, symptom control, care of the dying, bereavement support, care for patients and families, the need to involve users, palliative care, spiritual support, social support, and the need to orientate services around the issues faced by patients and families at a time when patients and families themselves are feeling vulnerable and often are less able to be proactive or demanding. There is also some evidence that this is important to those affected by cancer. However, there is little work which demonstrates the relative priority that cancer patients give to supportive and palliative care versus other components of cancer care or other components of health care. Studies of the relative importance of these components of care amongst society are less well described, but nevertheless some studies which have taken a societal view to priority setting have indicated that palliative and terminal care, and good communication are among the top 15 health care priorities identified by members of the general public.

These two forms of evidence demonstrate that there is a health care concern which requires attention. Where the evidence is weaker in supportive and palliative care is in determining the most effective solution to meeting individuals important needs. Nevertheless, in some areas there is extremely good evidence of effectiveness, particularly if randomised and observational studies are included. In areas such as information giving, communication, specialist palliative care, psychological support, information from experimental randomised controlled trials and observational studies indicates that training, professional interventions and services can help to alleviate problems and difficulties for patients and families. The evidence is less clear on the details of the intervention, on the groups of individuals and problems that benefit in particular and the priorities for the future. Each of these areas and recommendations regarding future service configuration, support and research are made below.

However, a first recommendation, given the wealth of evidence regarding need and importance, and the relative dearth of evidence regarding effective solutions, must be that:

- future research should focus on determining effective solutions rather than on redetermining need and
- that new services and many existing services should be developed or continued to be developed within an evaluation framework, which is rigorous and properly funded.

Interventions

In the systematic review of evidence two main difficulties were encountered. First, in many instances the intervention was not clearly described in the papers. This limitation is often a result of a lack of publishing space within journals and the fact that it is often felt that providing detailed accounts of the intervention is not of great interest to an international readership. However, lack of information about interventions makes drawing conclusions about their relevance in different circumstances and settings more difficult. It also makes it difficult for others to independently and accurately reproduce this in another setting. The second problem with interventions is that when information about the intervention is available they are often highly varied from setting to setting, making it difficult to draw conclusions about the overall effectiveness of a group of interventions. This is demonstrated clearly in the area of specialist palliative care, where teams work in different ways with different policies, different staffing mixes and different training backgrounds. Thus, it is difficult to draw conclusions about the best model of working. There are few studies that compare different components of interventions to determine the best way of providing training or care. In some areas of supportive and palliative care there is a clearer development with earlier trials mapping the exact nature of the intervention and later studies testing this rolled out in a wider framework. A good example of this is the development of studies examining communication skills training. However, in other areas of supportive and palliative care the research base underpinning the intervention is not so clear.

Therefore, we recommend that in the future:

- Detailed descriptions of interventions and service configurations are made available when evaluations are published and
- Wherever possible studies should use a research base to develop interventions, building on existing research and indicating where interventions deviate from those already established.
- Future research should compare different service configurations and interventions.

Populations, patients and carers or families

Many of the studies very clearly identified the populations, patients and families who were included in the study. Conducting research on patients who are highly distressed, have severe symptoms or are dying is very difficult. Many of the studies made extremely bold and rigorous attempts to recruit from representative samples of patients and families and to collect data in an ethical, sensitive and meaningful way. It was clear from some of the research that interventions effective earlier in care needed to be different or modified in advanced disease, or in groups of people who were elderly or from different cultural or ethnic backgrounds. There was very limited research into the needs, and preferences of effective interventions for individuals from different cultures.

We recommend that

- clear descriptions of the populations, patients and carers included seen by individual services and comparison of how these compare with the general population is made and
- future research should investigate effective care for those from different cultures.

Study design

Although we did not specifically search for qualitative studies we found our strategy elicited both quantitative and qualitative research studies. Some studies had a triangulated approach combining the data from both quantitative and qualitative sources.

The NICE guidance provides a hierarchy according to study design with a well designed experimental study and in particular a randomised controlled trial providing the highest evidence, falling to the lowest evidence being from consensus among professionals. While this hierarchy is useful, it does not take account of the relevance or pertinence of the individual studies to the question or problem affecting the patients and families, nor to the health care context in which the service is operated.

- We recommend that in the future it might be worthwhile combining scores of a traditional hierarchy of evidence based on study design with an estimate of the pertinence or relevance of the study using, for example, some kind of signal score.

A further consideration is the integration of qualitative studies. Qualitative designs can examine the effectiveness of interventions, or can provide more detailed interpretations of need or descriptions of interventions. Currently, no robust hierarchy of qualitative studies that examine the effectiveness of interventions are available. It is possible to use qualitative research to compare interventions.

- We recommend that hierarchies based on high quality qualitative research are developed.

Outcome measurement

A major challenge in the field of supportive and palliative care is to devise outcome measures that are sensitive and appropriate to the intangible nature of critical issues such as symptom control, psychological well being, quality of life, quality of death, quality of care. Great progress has been made in developing robust and sensitive outcome measurement, but in many areas these are still relatively crude. In addition, information is lost because many services do not routinely collect information about their important outcomes in the way that biological markers and clinical parameters are recorded in other clinical settings.

- We recommend that a system of routinely collecting some limited outcome information is included in the care of cancer patients in addition to the biological markers.
- We further recommend that future research develops prospective measures of outcome for patients at all stages of disease and their carers.

Systematic review methods

Some specific difficulties were encountered with the systematic review. Firstly, the electronic database searches and our search strategy did not detect all important studies, even some important randomised controlled trials. It is likely that some of the key words and search terms used to detect studies in supportive and palliative care do not always detect the important studies. Therefore, our search had to be augmented by consultation with experts, grey literature searches and follow up of references. The database of evidence should be a resource for others in the future, but it will require updating as even during the course of this project we are aware of new studies that require including.

Given the number of qualitative studies in this field we feel that it would be timely to conduct some qualitative reviews, particularly in those areas where the quantitative data is not so apparent. These could include, for example, spiritual support, user involvement, social support. Such work would require not only a new review, but also methodological development of qualitative systematic review methodologies, such as the conduct of a meta-ethnography. We recommend that future research in this area be developed.

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