Improving supportive and palliative care for adults with cancer

Research Evidence Manual

Part A

Marjolein Gysels and Irene J Higginson
Department of Palliative Care and Policy
GKT School of Medicine
King's College London
Weston Education Centre
Cutcombe Road
London
SE5 9RJ

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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.

Note that this evidence review is only concerned with the first topics selected for review in the NICE guidance. There are some limitations of this approach, particularly because of overlap between some of the topic areas and the studies of evidence. However, reviewing the evidence for supportive and palliative care is an extensive exercise, and in this review covered twelve different topics across all cancer types. Therefore, it was deemed pragmatic to present the evidence in stages, so that some of it could be available to aid health care planning.

2. 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?

3. Review Methods

Search strategy for identification of studies

Relevant studies for meeting the inclusion criteria were identified by:

a) Searching MEDLINE, EMBASE, CINAHL, CancerLit, the Cochrane Pain and Palliative Supportive Care specialist register, the Cochrane Effective Practice and Organisation of Care Group (EPOC) specialised register and the Cochrane Controlled Trials register.

b) The reference list of identified studies will be 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 October Week 5 2001): 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 2001 Week 49): 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 November Week 5 2001): 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.

CCTR (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 (2001, Issue 4): 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 October Week 5 2001): Search was limited to the cancer field only. The HITS were directly exported to REFMAN and the abstracts assessed.

EMBASE (1980 to 2001 Week 49): Search was limited to the cancer field. The HITS were directly exported to REFMAN, any duplicates removed and the abstracts assessed.

CINAHL (1982 to November Week 5 2001): 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 personnel 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.

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 was extracted in to table 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

The quality of individual research studies were graded following the criteria listed in the Table below. This is the same system used in the reviews undertaken by NHS Centre for Reviews and Dissemination at the University of York as part of the site-specific *Improving Outcomes* series. At this stage systematic reviews were not graded.

Grade I (strong evidence) – randomised controlled trial or review of randomised controlled trials	
Ia	Calculation of sample size and standard definition of outcome variables
Ib	Accurate and standard definition of outcome variables
Ic	Neither of the above
Grade II (fairly strong evidence) – prospective study with a comparison group (non-randomised controlled study or good observation study)	
IIa	Calculation of sample size and accurate, standard definition of outcome

	variables and adjustment of the effects of important confounding variables
IIb	One of the above
Grade III (weak evidence)	
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
Grade IV (weak evidence) – Cross-sectional study	

The quality of combined research was also graded using the hierarchy of evidence employed in the *Improving Outcomes* manuals:

- A – evidence derived from randomised controlled trials (RCTs) or systematic reviews of randomised trials.
- B – evidence from non-randomised controlled trials or observational studies
- C – professional consensus.

4. 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. We anticipate that during the period of consultation we may identify further evidence and that the consultation itself will identify some further studies. Further, the biography is not totally complete and we are still awaiting some papers that have needed to be requested from libraries or individual authors, and will subsequently be extracted or amended.

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 5071 references were identified by the electronic search strategies. After abstract assessment, 251 potentially eligible studies were identified and 36 systematic reviews. 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.

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.

5. Co-ordination and integration of care

Nature of the evidence

We have extracted the data into tables from eight individual studies that implemented interventions to improve the co-ordination of services. These studies are all good quality grade I evaluations (three grade IA and five grade IB). Three studies were carried out in the UK, one 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(1-7). Finlay et al. 1998(8) 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.(5).

Three of the studies focused on home care. Jordhoy et al.(5) 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.(7) evaluated a new home care approach for homebound patients, including a cost-effectiveness component to the intervention. Smeenk et al.(3) 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.(1) 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.(4) assessed the cost-effectiveness of this co-ordination service. Latimer et al.(6) 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.(1) and Smeenk et al.(3) a nurse co-ordinator provided the link between services, a community-based and a specialist nurse co-ordinator respectively. Jordhoy et al.(2;5) and Zimmer et al.(7) experimented with teams with different compositions. Jordhoy et al.(2;5) 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.(7) 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(3;7), the use of a collaborative home dossier, protocols for specific care(3), and predefined guidelines to keep the interaction between services optimal(2;5). Latimer et al.(6) 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.

The interventions were mostly directed towards patients who were terminally ill(2;5;6). Smeenk et al.(3) focused on the direct caregivers of palliative patients and Addington-Hall et al.(1) looked at the effect of the intervention on both patient and family. Finlay et al.(8) 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.(5) 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.(7) 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.(3) achieved positive effects on the quality of life of direct caregivers of terminal cancer patients, both 1 week after discharge and 3 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.(1) 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.(4) demonstrated the limited cost-effectiveness of the service with some transfer of costs between settings.

Latimer et al.(6) 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.

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(8).

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(3). Zimmer et al.(7) 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(8).

Tables of Evidence: Co-Ordination and Integration of Care

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Addington-Hall et al. 1992(1) & Raftery et al. 1996(4) 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 coordination 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
Finlay et al. 1998(8) 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(5) 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 cooperation 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	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.

			were offered an educational programme.		
Jordhoy et al. 2001(2) Norway Ia	To assess the impact of comprehensive palliative care on patients' quality of life. The intervention was based on cooperation 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 cooperation 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	Main quality of life end points: Physical and emotional functioning, pain, and psychological distress. This was assessed monthly by using the European Organization 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 favor of any treatment group on the main outcomes or other EORTC QLQ-C30 scales/items.

			educational programme.		

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Latimer et al. 1998(6) 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	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.

			family's understanding of the illness and care plans, and a chart of suggested therapies for symptom control.		

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Siegel et al. 1992(9) US 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(3) 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 coordinator, 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(7) 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 coordination 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.

References: Co-ordination and Integration of Care

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6. Communication skills

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(1). 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(1).

One prospective cohort study assessed satisfaction with medical care expressed as two scores, one of which measured satisfaction with communication and decision making(2).

Fourteen studies have undertaken interventions to improve communication with cancer patients through educational sessions. Two studies are grade I randomised controlled trials (3;4), one is grade IIa (15), three are grade IIb (5-7), two grade IIIa(8;16), and five grade IIIc(9-13).

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(10), Faulkner et al. (11), Maguire et al. (12;13), Klein(4), Fallowfield et al.(14). Maguire and Faulkner(10) evaluated workshops in communication and counselling skills run jointly for doctors and nurses working in hospital and community settings. Maguire et al.(12;13) assessed the impact of communication skills workshops on interviewing skills of health professionals. Faulkner et al. (11) implemented an intervention to improve the communication skills of doctors when giving distressing information. Klein et al.(4) experimented with the use of real-life patients to teach medical students. Fallowfield et al.(14) 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.(3) 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(7) 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.(15) 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.(16) 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(8) 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(5,6;9;14). Heaven & Maguire(9) conducted assessments of hospice nurses' communication skills before and up to nine months after training. Wilkinson et al.(6) evaluated a programme aimed at nurses' performance of patient assessment. A subset of these nurses was a follow-up at one year post-training(5).

Two studies experimented with organisational interventions to facilitate communication between patients and health professionals(17;18). Glimelius et al.(17) 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.(18) tested an intervention with researcher-mediated consultations. Lilly et al.(19) 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.(20) 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(21). Deutsch(22) and Hogbin et al.(23) carried out a study on the same topic, while Tattersall et al.(24) 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.(25), 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(26;27)experimented with routine telephone contact for patients to improve the adequacy of support.

The SUPPORT study(2) 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(8), medical students(4;7), or health professionals(6;9-14) in order to improve communication skills. Maguire & Faulkner(10) also focused on both doctors and nurses. Wilkinson et al.(5;6) carried out an intervention aimed at nurses, while Heaven & Maguire's(9) intervention was aimed at hospice nurses. Maguire & Faulkner(10), Faulkner et al.(11), Maguire et al.(12;13), and Heaven & Maguire (9) and Jenkins et al.(14) and Razavi(16) worked with health professionals. Fallowfield et al.(14) focused on senior oncologists.

The interventions working with material were also directed toward patients as well as health professionals(20). The telephone call interventions were provided for patients who were undergoing radiotherapy(26), patients during the potentially stressful period between completing radiotherapy and the first follow-up visit(27). The provision of audiotapes were interventions targeting patients and the public(21), and breast cancer patients and their carers(22-24).

In the organisational interventions all those involved in the care of the cancer patient, as well as the patient himself were targeted(17;18).

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(1). 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 (2) 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(26) and Munro et al.(27) 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.(27) a routine policy of such intervention for all patients cannot, given the present limitations on resources, be justified. While Hagopian & Rubinstein(26) 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(17;18). The intensive communication intervention, which Lilly et al.(19) 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 (21) 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.(22) evaluated the taping of consultations as positive based on a questionnaire on tape use and value of content. Tattersall et al.(24) 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.(25) 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(10) and Maguire et al.(12;13) the training method adopted improved health professionals' skills in effective interaction, and in Faulkner et al.(11) 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(11-13). In two studies, follow-up evaluations at six months showed that inhibitory behaviours had reverted to pre-training levels(12;13). 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(9). Wilkinson et al.(6), 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.(6) 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.(7) 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(8), and increased patient satisfaction with the assistance of physicians(4;20). 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(4). Fallowfield et al.(14) provides objective evidence for the effectiveness of training courses for senior doctors working in the vital area of cancer medicine. Jenkins et al.(3) 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 which was emphasised by the results of studies reviewed by Libert et al.(28). The other difficulty was the maintenance and consolidation of these communication skills.

Street et al.(15) 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.(16) 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).

Table of Evidence: Communication Skills

Systematic Reviews

Author, country	Aims of the review	Inclusion criteria	Outcome measures	Results
Stewart 1995(1) 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(7) 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(2) 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(25) 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(8) 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(22) 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(9) 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(14) 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(11) 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(17) 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(26) 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 practiced 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(23) 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(3) 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 behaviors 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 program. 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(4) 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(28) 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 emphasizing 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(19) 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(21) 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(10) 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(12;13) 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(27) 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.(16) 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(18) 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(15) 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(24) 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 summarizing 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(20) 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(6) 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(5) 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

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7. 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(1). The other systematic review included ten randomised controlled trials(2). There were 31 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 critical reviews were found(3;4).

Types of interventions

A Cochrane Review(1) evaluated the effects of providing audiotapes or summaries of consultations to people with cancer and their families. The systematic review by McPherson et al.(2) 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(5-10), or letters summarising the consultations, either in combination with tape recordings of the consultation or by themselves(1;11).
- The provision of an audiocassette recording of the consultation(1;4;12-16;32).
- A preparatory slide tape to educate patients prior to procedures(17).
- Video and booklet interventions about cancer pain and its management(18).
- An educational video to take home following the first consultation(19).
- Telephone help-lines supplying information and support to cancer patients, their significant others and the general public(20;21).
- Documentation of information and/or care: shared-care record containing appointments, a diary of significant events, medications, carers' addresses and contact numbers(22); patient information folders holding records of written materials given to the patient, according to the patient's informational needs(10). A computer based information system that is personalised using each patient's medical record(23).
- A structured patient-centred group educational programme(24;25).
- An educational session that taught basic problem-solving principles(7).
- A group psycho-educational program(26-28).
- An interdisciplinary team providing information(29) .
- Structured nurse interventions(30;31).

Most of the studies applied their interventions to patients(3-6;8;10-12;14-17;18;19;23;27-31,32). We also found studies which applied their interventions to both patients and their families(1;2;7;21); to both patients, their families and the public(20); and to both patients and their families and to health professionals(13;22).

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(3;5;6;8;10;17;27;29;31).

The emphasis of the interventions was on coping with the disease. The interventions were aimed at promoting understanding and psychological adjustment(1;2;4;9-12;14;15;19-21;27-29;31,32), symptom management(7;16;18;26;30), the continuity of care(7;22;23), and behaviour change(26).

Outcome measures

The two systematic reviews(1;2) concurred with the results of the individual studies on giving information to cancer patients. Scott et al.(1) 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.(2), 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(3;4;13-15). Some studies found a better recall of the information given(14;32) but other studies contradicted this result(11). Also in Tattersall et al.(11) 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.(11), Hogbin et al.(32) and Ream & Richardson(3) reported that the levels of anxiety and depression remained unchanged with their intervention. Hogbin et al.(32) 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.(15) 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(16). However, audiotapes may be detrimental to patients with a poor prognosis(12). A minority of patients found that the use of audiotapes can increase patients' distress(14), also a minority found that the procedure interfered with the consultation(13;14) and those wanting minimal news found it unsatisfactory(11). 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.(32) 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.(6), Eardley et al.(9) and Mohide et al.(5) 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(6). This was strengthened by Mohide et al.(5) 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.(9) 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.(8). The results of this study showed that patients preferred booklets written at the level of grade eight English (thirteen 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.(33) 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(17) 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(18). 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(19). Almost all of them found that the video was very helpful and only a slight minority felt that this extra information was worrying(19).

Lechner and De Vries(20) and Venn et al.(21) 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(28), Derdiarian (25), Johnson(24;26), or individually(7;30) 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.(28), 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.(30), where empowering the patient with the relevant knowledge and skills improved symptom awareness, decreased symptoms and increased perceived support. Bucher et al.(7) reported more confidence in providing care and the feeling of being better informed about community resources. In the case of Robinson's intervention(26) compliance with medical recommendations increased. Information was found to be a necessary condition for behavioural change to occur(26).

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(22) or patient information folders(10) can contribute to the co-ordination of care provided by different services. Jones et al.(23) also showed that patients preferred computer systems that provided information from their medical records to systems that just provided general information.

There are three studies that show only partial effectiveness of the interventions applied. Helgeson & Cohen(27) 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.(31) 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.(32), remained significantly more anxious postoperatively than women who had mastectomies. Bloom et al.(29) 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.(31) 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(27). 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(2) 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 counseling. 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 counseling 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(1) 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(30) 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.(33) 1997 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 randomized 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 don't 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(29) 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 coordination 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(28) 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 Behaviors (IASC), and the Self-Care Inventory Wellness Promotion (SCIWPR). • Self-Help by the Inventory of Adult Role Behavior. • Psychological Adjustment by the Negative Affect Scale. • Confidence in Cancer Knowledge by a visual analog 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(16) 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(7) 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(8) Australia IIIc	An exploratory study to investigate factors which influence patient's satisfaction and utilization 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, utilization (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 utilized 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(18) 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(25) USA Ib	To assess the effects of an individualized 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 individualized 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(22) 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(13) 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	Patient population	Study design	Outcome measures	Results
Eardley et al. 1988(9) 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(27) 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(14) 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 analyzed 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(32) 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 S et al. 1984(6) 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(24) 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 center *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(23) 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(20) 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(31) 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(4) 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(12) 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 randomization 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(5) 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(15) 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)

Author, country Grade	Aims of study	Patient population	Study design	Outcome Measures	Results
Rainey 1985(17) 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(3) 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(26) 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 behavioral 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
Tattersall et al. 1994(11) 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 summarizing 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(19) 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(21) 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(10) 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); gyneacologic (*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.

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8. Psychological support

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(1) based their analysis on 45 studies and Devine & Westlake(2) on 116 studies. Sheard & Maguire(3) 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 (4). 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 (thirteen), 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(1), to assess psycho-educational programmes aimed at improving the psychological and physical well-being of cancer patients(2), and to assess the effect of psychological interventions on anxiety and depression in cancer patients(3). 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(4).

Psychological interventions for people with cancer made use of different approaches, such as educational based group interventions, carried out in a variety of ways(5-12). Bloom et al.(13), for example, experimented with an interdisciplinary team, Moynihan et al.(14) used a mental health nurse as therapist, Syrjala et al.(8) used a psychologist, and Bultz two psychologists as facilitator. Bucher et al.(15) 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.(16) tested a structured group intervention program, where the teaching was carried out by health professionals and/or patients themselves. Toseland et al.(17) offered both individual and group sessions given by an oncology social worker.

Mansson et al.(5), Maunsell et al.(18), Spiegel & Bloom(19), Classen et al.(20), Evans(10) reported on group support interventions. Maughan et al.(21) and McArdle et al.(22) delivered a more individually focused intervention where the support was provided by a specialist nurse. In Connor et al.(23) who examined the effects of a psychosocial intervention on denial-related coping ability, the patients were also approached individually. Schwartz(24) 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(25) 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(26) 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(8-10;27;28).

The majority of the studies evaluating psychosocial interventions were directed at breast cancer patients. This included newly diagnosed non-metastatic breast cancer patients(18), early stage breast cancer patients(12;24;27), women receiving chemotherapy, radiotherapy, hormone therapy(13), women undergoing breast cancer surgery(22), women after breast surgery for cancer(13;16), women with metastatic breast cancer(6;8;16;19;20) and breast cancer survivors(7).

Other studies focused on patients who had undergone cystectomy for bladder cancer(5), women who had had major pelvic surgery(21), patients with testicular cancer(14) and cancer patients in general and their carers(15). Evans(10) and Moorey(9) both worked with patients who had different kinds of cancers and focused on those who were depressed and about to undergo radiotherapy(10). Other studies focused on patients who had abnormal adjustment reactions(9), and who had malignant disease screened for psychological morbidity(11), Bultz et al.(12) and Schwartz (24) targeted relatives of breast cancer patients. The intervention Toseland et al.(17) 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(5;7;9;20;22;25). In some trials this was offered as one arm among other options(8;9;13;27). The other interventions were mainly problem-focused. These were aimed at providing information and enhancing control(11;14;15;17), or they were carried out as one arm of a trial(10;13;28). Hosaka et al. (16) and Ambler et al.(29) 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(18;21)or included this as a component(14;28). Psychological interventions were also implemented for cancer pain relief(7;8;19), and as part of a trial(20).

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(1) 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(2) 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(3) 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.(4) 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.(15) 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(25)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(6) 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.(16) 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.(13) concluded that the patient counselling/information programme had a long-term positive value. Sandgren's study(26) achieved an improvement in mental functioning and distress levels with cognitive-behavioural therapy .The problem-focused intervention implemented by Helgeson et al.(27) as one arm of the trial was successful for early stage breast cancer patients, and Braden et al.(28) 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(29). 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.(9) 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.(11) achieves improvement in mental adjustment to cancer with APT, also with longer effects. Moynihan et al.(14), however, reported no benefit of adjuvant cognitive and behavioural treatment for patients with testicular cancer. This group of patients seemed to already 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.(27) in which emotion-focused therapy was given was not effective. The psychosocial intervention in Mansson et al.(5) was beneficial only to patients who had undergone one particular kind of surgery (cutaneous urinary diversion). Classen et al.(20) 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'(10) 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.(17) 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 (24) found that a problem solving technique, when regularly practised by first degree relatives of breast cancer patients, reduced their cancer-specific distress. Bultz(12) 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.(28) 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.(18) 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.(14) 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(7;8) and time of survival(19) reported positive results.

We have identified a study on burnout and more generalised psychiatric morbidity among gastroenterologists, surgeons, radiologists, and oncologists in the UK (Ramirez A. Mental health of hospital consultants: the effects of stress and satisfaction at work..The Lancet. 1996, Vol.347:724-728). 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

Meta-analyses

Author, date, country, grade	Aims of study	Inclusion/exclusion criteria	Study design and outcome measures	Results
Meyer & Mark(1) 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 patients 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 counseling 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(2) 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 counseling (various types) ▪ counseling 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(3) 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(4) 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 counseling, 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(29) 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(25) 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(13) 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 coordination 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(28) 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 Behaviors (IASC), and the Self-Care Inventory Wellness Promotion (SCIWPR). • Self-Help by the Inventory of Adult Role Behavior. • Psychological Adjustment by the Negative Affect Scale. • Confidence in Cancer Knowledge by a visual analog 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(15) 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(12) 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(20) 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(23) 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(6) 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(10) 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 Center 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 somatization (<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(7) 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 enrollment, 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, counseling, pharmacologic and/or behavioral 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(11) 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(27) 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(16) 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. 1997(5) 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 orthopedic 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 orthopedic 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(21) 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 gynecological cancer. 3. To explore the lived experience of illness following gynecological cancer from the women's perspective.	A total number of 36 women with a diagnosis of gynecological 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(18) 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, an 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(22) 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(9) 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(14) 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(26) 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(24) 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 eduction *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(19) 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(8) 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(17) 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.

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9. Specialist Palliative Care

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 (1;2). In addition, to finding new literature this 2001/2 review appraised the existing five reviews(3).

The 2001/2 systematic review included 44 original studies, of which 7 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 (4-8), one defined itself as a ‘critical’ review(9). These were of limited quality; using a standardised review appraisal system(10) 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), 8 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 (1) review has been undertaken.

Types of interventions

The 2001 review (1;2) 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(11;12) were not of true specialist palliative care services, but rather of services that worked with specialist palliative care.

Outcome measures

In the 2001 review (1;2), 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(13) 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 (14;15). 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(12;16), 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(17) shows positive effects of home care nurse contacts on the utilisation of services. McCorckle et al(18) also showed better outcomes in symptom distress and independence than the control group. Zimmer et al(19) 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(20) found that cost containment is occurring among home care users due to decreasing hospital days and the reduced mean daily cost of hospitalisation.

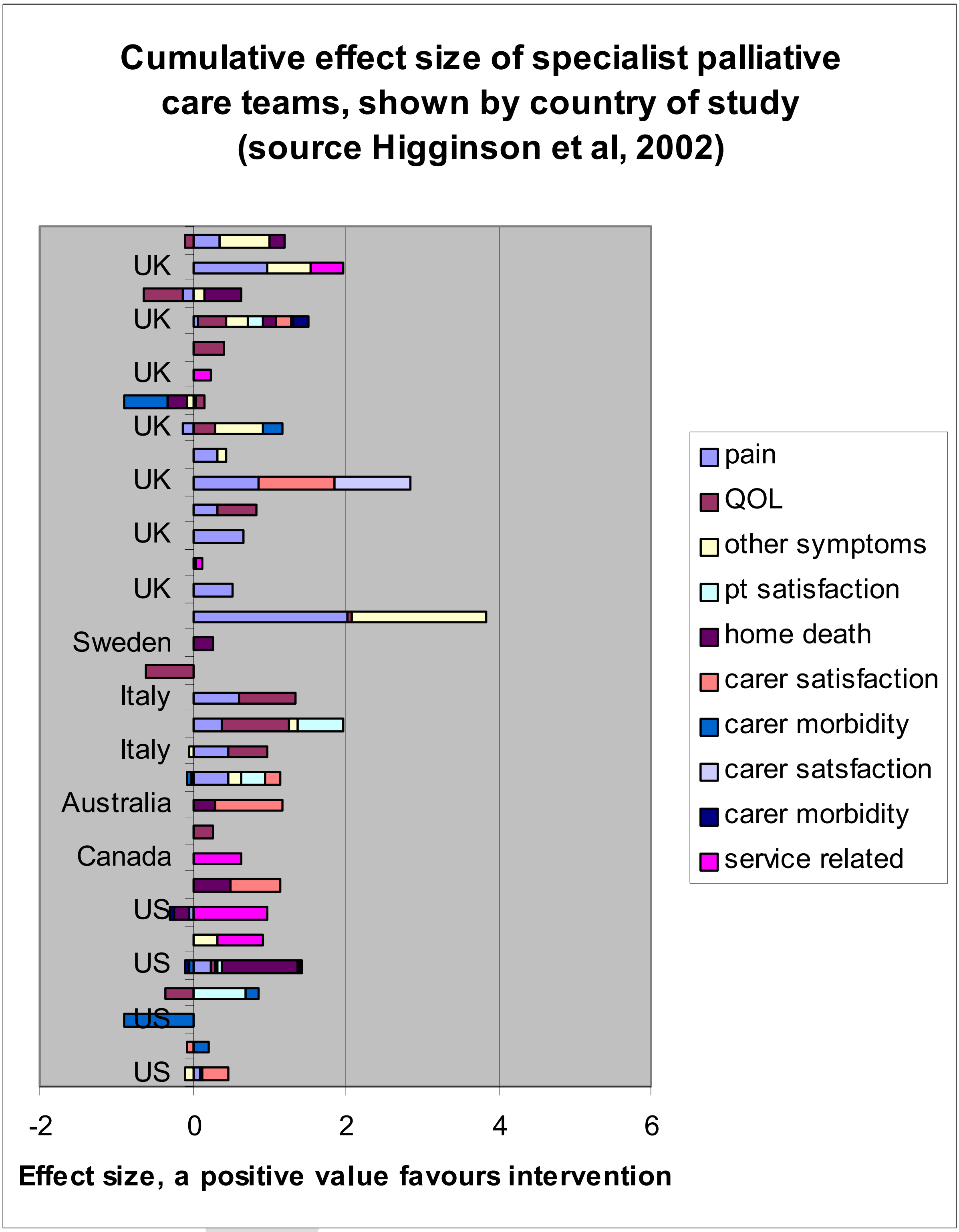
Kane et al(21) shows no substantial differences in cost or effectiveness between the study and the control group, but the patients and their families appreciated the qualitative differences in hospice care. The co-ordinating service study(11) reported that few differences were found in symptoms and symptom control, service provision and satisfaction, and psychological support. A recent study by Jordhoy et al(22) 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)(2). 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.

References: Specialist Palliative Care

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Research Evidence Tables - Specialist Palliative Care

Individual studies

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Addington-Hall et al & Raftery et al(1;2) 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.

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Axelsson et al(3) 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)

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Axelsson & Sjoden(3) 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 patient's QoL items when approaching death. 35% of patients were pain free during their terminal month

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Bennett & Corcoran(4) 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.

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Bloom(5) 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).

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Bredin et al. U.K. 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.

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Dessloch et al(6) [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.

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Dunt et al(7) 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.

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Edmonds et al(8) 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

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Ellershaw et al(9) 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.

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Grande et al.(2 papers) 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* Patients 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.

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Higginson et al(10) 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.

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Higginson & McCarthy(11;12)(x2 papers) 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.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Higginson & Hearn(13) 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).

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Hinton(14) 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

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Hinton(15) 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	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*	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

		01/08/84 to 31/07/86		Not evaluated *Economic* Not evaluated	from others.

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Hughes et al(16;17) 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 Center 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.

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Johansson et al. 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	• 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).	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.

			individual support and rehabilitation. C= - Rehabilitation. - Standard care.	- 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.	

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Jones & Jones et al(18;19) 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.

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Jordhoy et al, 2000 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 cooperation 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.

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Kane et al. 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, Center 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.

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McCorkle et al. 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.

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McCusker & Stoddard 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(20) 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 whom 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.

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McMillan(21) 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.

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McMillan & Mahon(22) 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(23) 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(24) Wales, UK	To evaluate the changes that had been	Year 1: mean age: 60yrs, range 4-90 yrs	Survey of all in-patients with cancer or HIV.	*Patient / carer* Patient: pain assessment	Regular teaching required to maintain

IIIb	implemented to improve care of cancer and HIV patients at UHW	Total sample: 178 Year 2: mean age: 61 yrs, range 14-91 yrs Total sample: 146 All hospital in-patients with cancer / 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	and drug chart *Professionals / services* Increased adherence to clinical guidelines Prescribing rationale	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. 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(25-35) (x9 papers and book) 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(36) 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(37) 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(38-41) 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]	Semi-structured interview - self-assessment of surviving spouses of patients who had died from cancer	*Patient / carer* Severity and duration of pain, distress and anxiety (max and min intensity of each	No significant difference between SCH and other hospitals in the area in terms of the severity of reported pain

		Spouses of patients under 65 years who had died from cancer in London Boroughs of Lewisham & Bromley between 1977-1979	[replication of 1967-1969 study] Interventions Reactions of patient and surviving spouse to each phase of terminal care	symptom). Post-bereavement anxiety and grief score.	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 (42) 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

Author, country, grade	Aims of the study	Participants	Study design	Outcome measures	Results
Seale(43;44) 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(45) 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	*Patient / carer* Health & medical (physical condition); patient's emotional state; family's emotional state; pain & comfort; social-psychosocial assessment; spiritual	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

			15 patients and their families. *Interventions* Hospice home care program, the number of evaluative observations ranged from 2 to 15 (mean 4.67)	need	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(46) 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(47) 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(48) 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(49) 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	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).

		years; patients no longer subject to oncological procedures; patients treatable analgesically with pharmacological programme (WHO)			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(50) 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(51;52) 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	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	*Patient / carer* Major outcome variables: medical - survival, pain medication, place of death; nutritional - weight, changes in dietary intake; psychosocial - social & demographic descriptors, mood	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.

		to 6 months; resident within geographic catchment area of North Shore University hospital, primary care giver required for patients treated at home	transporting the medical staff and equipment visited the patient at home.	profiles.	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(53) 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(54) 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 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(55) [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. 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 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 1999 UK	To identify and review all experimental and descriptive studies which evaluated a model of specialist palliative care, and used quality of life a 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. 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.

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10. General palliative care

Nature of the evidence

For the topic area of general palliative care we extracted the data of fourteen studies into tables. These were all grade I studies (five grade IA and three grade IB), except two grade II (a and b) studies. Eleven studies came from the USA, one from Spain, one from the UK and one from the Netherlands.

Types of interventions

Most of the studies focusing on symptom control experimented with educational interventions(1-8). Other studies(4;9) experimented with the combination of educational interventions and organisational measures. Elliot et al(4) implemented their intervention in the clinical community by making use of opinion leaders and developing practice guidelines, and Desbiens et al.(9) through the mediation of nurse clinicians. Two studies, Borras et al.(10) and Kane et al.(11) were organisational interventions, Borras et al(10) focusing on home care and Kane et al(11) on the role of the hospice in symptom control.

Borras et al.(10), Kane et al.(11) and Ferrel et al.(5), Schuit et al.(12) were concerned with pharmacological interventions and the technical area of pain and symptom control. Borras et al.(10) was a feasibility study of chemotherapy at home compared with hospital treatment. Schuit et al.(12) 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.(11) evaluated the role of the hospice in pain control, and Ferrel et al.(5) experimented with a pain management educational intervention, also adding a non-drug component to the trial.

Bredin et al.(3), Desbiens et al.(9), Elliott et al.(4), Ganz et al.(6), Spiegel and Bloom(7), Syrjala et al.(8) each provided multifaceted interventions, either with the emphasis on pain-related knowledge Ferrel et al.(5), Lasch et al.(2), knowledge and attitude(2), or psychological support(3;4;7;8). 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. 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(6-8).

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.(3). One study targeted patients having moderate pain(1) and another study breast cancer survivors(6). Ferrel et al.(5) also included caregivers in his intervention. Desbiens et al.(9) reported an intervention mediating between patients and professionals, and Elliott et al.(4) and Schuit et al.(12) were interventions applied in the clinical community. Lasch et al.(2) provided an educational intervention for nurses.

Outcome measures

The outcomes of the organisational interventions focused on a variety of outcomes. Borras et al.(10) 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 concludes 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.(11), demonstrates that pain is controlled equally effective by conventional 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(4) was achieved. The educational intervention for general practitioners Schuit et al.(12) 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.(2) 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.(9) 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.

The studies providing pain-related knowledge have positive results. Ferrel et al.(5) 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.(1) 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(3), in improving quality of life and sexual functioning for breast cancer survivors(6), in survival for patients with metastatic breast cancer(7), and in pain relief for patients with persistent cancer(8).

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.(9), and Oliver et al.(1). The recognition of the importance of dying in the place of choice is a realistic proposal as home care increasingly becomes an option(10), and Kane et al.(11) 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

Author, country, grade	Aims of the study	Patient population	Study design		Results
Borras et al. 2001(10) 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. 2001(3) 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	population	Study design	Outcome measures	Results
Desbiens et al. 1998(9) 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, counseling 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
Elliott et al. 1997(4) USA Ib	To improve the knowledge, attitudes, and clinical behaviors 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(5) 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(6) 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 enrollment, 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, counseling, pharmacologic and/or behavioral 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	
Hainsworth 1996(13) 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		Results
Kane et al. 1985(11) 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.	t 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(2) 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(14) 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 ten 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. Randomization 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 counselling, 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	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.

			that would be helpful in providing care.		

Author, country, grade	Aims of the study	Patient population	Study design	Outcome measures	Results
Oliver et al. (1) 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 enrollment. 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
Schuit et al. 2000(12) 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(7) 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(8) 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* – Compairing 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.

References: General Palliative Care

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