

The Cavendish Centre for integrated cancer care: assessment of patients' needs and responses

G. Peace, A. Manasse

The Cavendish Centre, Sheffield, UK

SUMMARY. The use of complementary therapies in combination with conventional medicine is increasing. In cancer care, as at the Cavendish Centre for Cancer Care in Sheffield, the range of therapies offered can include aromatherapy, massage, reflexology, shiatsu, acupuncture, homeopathy, counselling, visualization, hypnotherapy, relaxation, healing and art therapy. Before offering any therapy careful assessment of patients' needs is important as patients seeking complementary therapies may present with unrealistic hopes and expectations of benefit. There are wide variations in provision of services offering complementary cancer care throughout the United Kingdom but few offer a comprehensive assessment which is used as a baseline for both planning treatment and evaluating its outcome and which is conducted by a trained and objective practitioner who has no investment in any specific therapy. We describe the model of care developed at the Cavendish Centre with particular emphasis on the assessment process. Our model of assessment provides an opportunity for patients to tell their story, make sense of the illness experience, construct meaning from it and set realistic expectations for the chosen intervention. It also offers patients involvement and choice in decisions about their care. In addition we present evaluative data from a case series of 157 patients, 138 of whom (88%) reported improvement in their main concern on MYMOP (Measure Your Medical Outcome Profile). © 2002 Elsevier Science Ltd. All rights reserved.

INTRODUCTION

Assessment of a patient's needs prior to deciding on further management is widely accepted as fundamental in any context of medical care. In recent years the role and process of assessment have changed and widened in scope. There has been a shift in medical practice to include within the biomedical model a wider perspective which takes into consideration patients' views and preferences as well as quality and length of life.¹ The relationship between practitioner and patient is changing. There is more emphasis on partnership, shared decision making and responsibility.^{2,3} There is also a wider range of options available to patients when planning their care.⁴

There are implications for the way in which assessment will need to be carried out to accommodate these changes. The initial assessment may take longer to conduct. It is likely to be more comprehensive, more person centred and will involve patients more in decisions about treatment and management of their care. Time needs to be given to explain and discuss not only the opportunities but also the limitations of the treatment plan. Practitioners may also need additional knowledge of the appropriateness of combining conventional and complementary medicine. This is particularly relevant in the field of cancer care where the prevalence of the use of complementary therapies, which maybe in conjunction with other treatments such as surgery, chemotherapy and radiotherapy, is estimated as 31%.⁴

Gillian Peace RGN, RMN, BA Hons, MPhil Clinical Information Coordinator/ Assessor, The Cavendish Centre for Cancer Care.

Andrew Manasse MRCP, MRCPG Clinical Lead/ Assessor, the Cavendish Centre for Cancer Care. 27 Wilkinson Street, Sheffield S10 2GB, UK. E-mail: enquiries@cavcare.org Website: www.cavcare.org

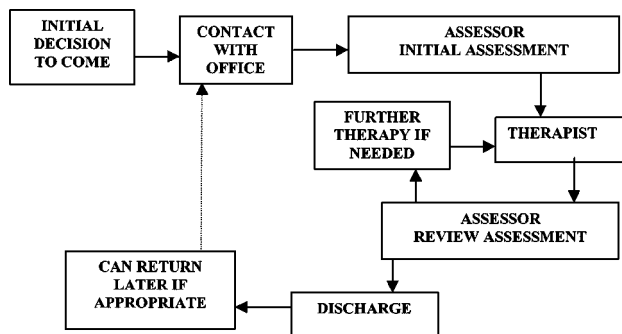


Fig. 1 The patient's path throughout the Cavendish Centre intervention.

CONTEXT

The Cavendish Centre is a Charitable trust. It is a multidisciplinary service offering support and complementary care, free of charge, to patients with cancer and to their carers, at all stages of the disease, (carers, in this text, are included in the term 'patients' for the sake of clarity). It serves Sheffield and the surrounding area. The aim of the service is to enable patients to live throughout the disease experience with maximum independence and optimum quality of life. The care given to patients at the Centre is in addition to and integrated with mainstream cancer care.

The range of therapies offered by the Centre include aromatherapy, massage, reflexology, shiatsu, acupuncture, homoeopathy, counselling, visualisation, hypnotherapy, relaxation, healing and art therapy. These therapies have been chosen because they are widely accepted as appropriate and relatively safe to use in the context of cancer care when practised by competent therapists.

In general, good quality research studies concerning the use of complementary therapies in cancer and palliative care are few. However the need for evidence based on rigorous methodology has been recognised in this field. Meanwhile, where evidence is lacking, as Keely suggests, health professionals and commissioners of care need to 'fall back on wisdom, compassion, and a broad and inclusive conception of the role of health care services in reducing human suffering'.⁵

However for some therapies there is, in specific circumstances, evidence of effect. The following examples are taken from randomized trials. Acupuncture can relieve pain⁶ and nausea.⁷ Massage can be beneficial in reducing anxiety, tension, pain and depression.⁸

Counselling can reduce psychiatric morbidity.⁹ Hypnosis combined with relaxation, imagery and cognitive-behavioural training is used widely for cancer related anxiety, phobias, pain, nausea and vomiting.¹⁰ A survey also suggests that hypnosis can enhance coping skills.¹¹

Patient pathway through the Centre

Unlike most medical practice, patients are introduced rather than referred to the Cavendish Centre. Patients are given information about the Centre, mostly by specialist nurses and consultants soon after diagnosis, and then contact the Centre themselves. They make the choice whether and at what stage of their illness to seek help. Care seems to be more effective when patients participate in making decisions and taking some control over their health.^{3,12,13} Because patients choose the time which is right for them to come to the Centre it is important that there is a rapid response. Once they have made that decision all patients are seen for assessment within five working days of their initial contact, prior to being offered treatment. There is no waiting list.

Following the chosen course of therapy, patients have a review assessment, undertaken not by the therapist but by the same practitioner (the assessor) who conducted the initial assessment. There is therefore some degree of objectivity and patients feel free to criticise aspects of care if they wish. At this review the patient's progress is evaluated. Patients may then be offered more of the same type of care or a different therapy if new concerns have arisen. More commonly, they are discharged with the assurance that they can return for further help in the future if the need arises.

Patients are offered six sessions of therapy. The period of therapy is time-limited. Firstly because during therapy realistic goals must be set, which, if achieved, or even partially achieved, can give patients a sense of control over their situation and the confidence and hope to cope on their own. Secondly, as a charity, we have to limit the cost per patient.

Assessors and therapists

The assessors working at the Cavendish Centre include experienced doctors and nurses with a generalist background in conventional medicine. Each has knowledge of cancer, the disease process and its treatment, experience of working with cancer patients, together with knowledge of the range of

therapies offered by the Centre and the ways in which these therapies can be used as an adjunct to conventional cancer treatment. They are thus in a position to bridge conventional and complementary practice and enhance communication between the patient's medical team and the Centre. The assessors are responsible for the co-ordination, monitoring and review of the patient's care while attending the Centre. They also communicate with the mainstream health professionals involved with the patient's care.

The therapists working at the Centre and qualified and experienced both in their specific therapy and in its application to cancer care. All undergo a rigorous recruitment procedure, carry their own indemnity insurance and are bound by stringent contractual obligations. These include that therapists should not suggest or imply to a patient any unrealistic outcome to any therapy including prolongation of life or cure. Nor should they agree or suggest that a patient cease their current medical treatment or express or imply any criticism of treatment – past, present or proposed, by mainstream health professionals. In addition all therapists are committed to updating their knowledge and practice. All staff undergo regular appraisal.

PRINCIPLES AND CHARACTERISTICS OF ASSESSMENT

The purpose of assessment as practised at the Cavendish Centre is to enable the patient and assessor together to define the patient's most important needs and concerns in relation to the illness and then to decide on a plan of action. The aim is to match the patient's needs as closely as possible to a therapy and a therapist. Many health professionals may approach assessment with a similar purpose and aim. Our model emphasises three key factors.

The first factor is the degree of patient involvement. No conclusion is reached in which the patient has not participated, or with which he or she does not agree. Intervention is tailored, where possible to individual need and preferences are respected, including the wish of some patients for the assessor to take the leading role in choosing the complementary therapy he or she feels is most appropriate.

The second factor is the time taken to conduct the assessment. At the Cavendish Centre it takes approximately one hour to complete. The process is comprehensive in its scope, exploring the patient's physical, psychosocial and spiritual needs. It should allow time for discussion to enable patients to make informed choices, if wished, about future action. In addition time should be given to explain and help patients to understand and feel comfortable with the time-limited nature of the chosen therapy.

The last factor concerns the evaluation and audit of the package of care offered at the Cavendish Centre. Assessment provides a baseline against which the effects of intervention can be measured and outcomes monitored. Our evaluation tool is a modified version of the Measure Your Medical Outcome Profile (MYMOP),¹⁴ which is patient generated, allowing patients to identify their own principal concerns and record patient relevant outcomes.

PROCESS OF ASSESSMENT

The model of assessment practised at the Cavendish Centre derives from that of Maguire and Faulkner.¹⁵ Patients are usually seen on their own. The presence of a partner, relative or friend can inhibit patients from disclosing their deeper concerns or fears. After the initial introduction between patient and assessor is made, a time limit for the consultation negotiated, and confidentiality confirmed, the first objective is to establish what expectations the patient has of the Centre and what the main reason is for coming. This is particularly important when complementary medicine is used as an adjunct to conventional care, because patients may present with unrealistic hopes and expectations of benefit. These expectations may have been fuelled by the plethora of self-help advice, information and products now available to the general public.

The patient's account of the disease can then be explored. The most effective way of ensuring that the patient's agenda, rather than the assessor's, predominates is to invite patients to describe their experiences from the time leading up to the diagnosis until the present. The narrative provides a framework to explore the physical, psychological, social and spiritual dimensions of the disease and treatment. Identifying what having cancer means for each patient is important. How people make sense of what is happening to them can be shaped by previous experience, culture, beliefs and personality,¹⁶ all of which have a bearing on the choice and outcome of treatment.

The narrative also enables identification of patients' concerns; how the cancer is affecting them and those close to them; what influences have led them to think and feel as they do and what factors might improve or exacerbate their perceived situation.¹⁷ It is important that the assessor explores the concerns which are pre-morbid and those caused by the disease or treatment to allow some measure of how much the illness has changed the patient's life. Providing patients with this opportunity to tell their story can be, for many, the start of the healing process, giving meaning, perspective and value to their experience.¹⁷ Furthermore it enables the assessor to identify patients' own strengths and sources of support. Exploring

these can affirm patients' capacity to cope, can engender hope, and boost confidence and a sense of control of the situation.

Having explored these aspects, the patient and assessor can then discuss what action may be appropriate. While it may seem clear to the assessor which intervention is indicated from patients' initial expectations and from the nature of their main concerns, this should not be assumed without exploring patients' own views on what might help with specific concerns. They may see their concerns in a different light having had them acknowledged and having expressed their distress.

After the patient and assessor have discussed the possible options available and made the choice of therapy together, the framework of care is explained, including the time-limited course of therapy, the need for review after six sessions and the integration of care with the patient's mainstream medical team.

THE IMPACT OF THE CAVENDISH CENTRE INTERVENTION ON PATIENTS' EXPECTATIONS AND ON THEIR IDENTIFIED CONCERNS

Assessment is an essential part of the Cavendish Centre intervention. It cannot, however, be evaluated in isolation from the complete Cavendish Centre intervention. As in Clover et al.¹⁸ we set out to evaluate the intervention as a whole 'package', but used MYMOP, a patient generated evaluation tool,¹⁴ rather than Hospital Anxiety and Depression Scale (HADS). We modified MYMOP slightly for the Centre's use. The word 'symptoms' in the original was altered to 'concerns' and well-being was divided into 'physical' and 'mental' as patients frequently made that distinction. In addition to the MYMOP questions patients were asked to score the extent to which they felt that their expectations had been met (see Figures 2 & 3).

METHOD

Patients, at initial assessment, stated their expectations of coming to the Centre. They then identified the one or two most important concerns in relation to their cancer at that time. These they scored for degree of severity; they also scored how they rated their physical and mental well-being. Apart from handing the questionnaire to the patient, explaining it and clarifying any uncertainties, the assessor took no part in its completion. Carers were treated in the same way as patients.

At the review, after the completion of therapy, patients scored to what extent their initial expectations had been met. They then re-scored the same concerns and the state of their physical and mental well-being. In all cases scores ranged from 5 = worst to 0 = best.

RESULTS

The results of 304 consecutive records from February to November 1999 were reviewed. Of these 304 patients, 136 (45%) had not been seen for review and the reasons for this are shown in Table 1. There remained 168 patients who had been both assessed and reviewed and who had completed both MYMOP questionnaires. Of these 168, 11 did not complete one or both questionnaires: seven were too unwell, one required no further action after assessment and three were not completed for a variety of administrative reasons. There were 157 completed assessment and review questionnaires and these were used to evaluate outcomes. Not all questions on all questionnaires were answered but as the questions are evaluated separately, this does not effect the outcome.

133 (85%) of these patients were female; the age range was between 18 and 86 with the peak being from 50–59 years. There was no formal assessment of social class but it was our impression that while the majority were middle class, all social classes were represented. There was a slightly smaller proportion from ethnic minority groups than is represented in Sheffield as a whole. 74 (47%) had a diagnosis of breast cancer and 20 (13%) were carers.

Patients were asked at assessment to define their expectations of coming to the Centre and at review they scored the extent to which these expectations had been met (Fig. 4). 98 out of 156 (63%) scored 0 or 1 thus almost 2/3 indicated that their expectations were either completely or almost completely met. One patient did not answer this question.

All 157 patients identified concerns which they hoped would be helped by treatment. Each patient identified one and a smaller number identified two concerns. Table 2 shows the types and frequency of patients' expressed concerns, divided into groups. Approximately 1/3 of the concerns are physical and 2/3 are psychosocial. There is, however, considerable overlap and inter-relatedness between the two.

For each concern, and for patients' assessment of physical and mental well-being, the difference between the scores recorded at assessment and at review indicates the degree of change for better or worse following therapy. The greater the positive score, the greater the improvement; the greater the negative score, the greater the deterioration. (Fig. 5 & Table 3).

Fig. 5 shows these differences in each case. Thus for concern 1, 138 (88%) reported improvement while 17 out of 157 (11%) reported no change and only two patients reported being worse. The results for concern two are similar, while for physical well-being and mental well-being, the changes are less marked.

(After MYMOP)

FORM 2: REVIEW

Name: Reviewer

ID number: Date:

1. Considering what you were **hoping for** from us when you first came to the Centre, to what extent do you think that your hopes have been realised?

Please ring the number which most nearly fits your answer.

0 1 2 3 4 5
Realised Not realised at all

2. Remembering the **Concerns or Problems** which you had when you first came to the Centre, please circle the number which most nearly measures how bad the problem is now.

Concern 1.

0 1 2 3 4 5
No Problem Very bad

Concern 2.

0 1 2 3 4 5
No Problem Very bad

3. **How are you now in yourself?**

Please circle the number which most nearly fits with how you are:

Physically:

0 1 2 3 4 5
As well as can be As bad as can be

Mentally / feelings:

0 1 2 3 4 5
As well as can be As bad as can be

4. The treatment which you are receiving may not be the only thing affecting your problem. If there is anything else which you think is important, such as changes which you have made yourself, or other things happening in your life, please write it here.

5. Please tick the box to show how your medication has changed since your first assessment.

Not much change
Taking less medication
Taking more medication

If there has been a change please write down which medication has changed and how much of it you are now taking.

Fig. 3 Cavendish Centre patient centred outcome evaluation.

they do return at different stages of the disease and, because their concerns have usually changed, they are assessed in the same way as new patients. The high percentage of breast cancer patients includes those patients who returned for a second episode of care and were counted as two separate patients.

The characteristics of patients' concerns were similar to those found by Addington-Hall and McCarthy in their national interview survey investigating the quality of care of patients with

cancer in their last year of life. The focus of this study was on symptom control, communication and care in the community.²¹ A perhaps surprising exception in our sample was that none reported that lack of information was a major concern. It may be that Sheffield health professionals are particularly competent in this aspect of patient communication. The fact that pain ranks highest in the group of physical concerns is worrying and is again in agreement with Addington-Hall. It is perhaps partly because of the complexity of

Table 1 Showing numbers of patients assessed at the Cavendish Centre and considered for review of outcome, and giving reasons for exclusion			
Patients assessed and reviewed	number	168	55%
Patients assessed but not reviewed		136	45%
Reasons:			
ongoing therapy	46	15%	
lost contact	25	8%	
no further action*	25	8%	
died	23	8%	
patient stopped contact	14	5%	
moved away	3	1%	
Sub Total	136	45%	
Total		304	100%

*no further action: assessment was sufficient on its own, or Cavendish Centre intervention not appropriate.

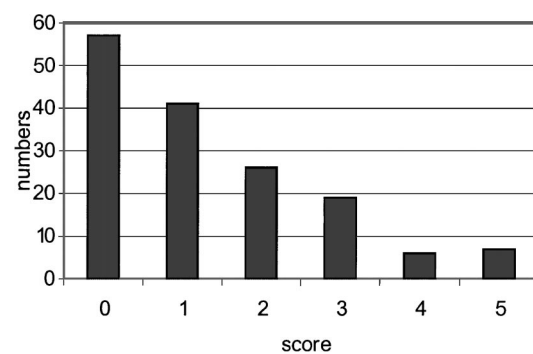


Fig. 4 Patients' score of the degree to which expectations have been met. n = 156. 5 = expectations not met at all. 0 = expectations fully met.

eliciting the components of pain. There is overlap and inter-relatedness between the physical and emotional aspects of pain. Patients' experience of physical pain tends to be greater the lower their levels of spirits and hope. It takes time and skill to elicit all aspects of the patient's pain.

The object of assessment at the Cavendish Centre is to define patients' concerns and to arrange appropriate treatment to meet them. It is not directly related to patients' physical and mental wellbeing. The results clearly show that improvements in concerns are greater than for mental wellbeing and even greater than for changes in physical wellbeing. A typical example is a patient who rated her expectations as completely met and her main concern, inability to relax, as having improved. Yet the state of her physical and mental wellbeing were rated worse at review than at assessment. This was due to a breast reconstruction which had gone wrong. She said of the therapy (aromatherapy) 'it completely relaxed me' and of the therapist (who is also a counsellor) 'she was good to talk to... it had a longterm effect - made me more laid back - I don't get so het up about things.' These results suggest that the process of assessment may have a direct effect on outcome, as we have shown that the degree of change is greatest in those areas most directly addressed by assessment. We propose to explore this hypothesis in a further study.

Table 2 Concerns expressed by patients at assessment				
Group	Concerns	Numbers	Total	%
Physical	Pain	17	53	29
	Poor sleep	11		
	Menopausal symptoms	9		
	Exhaustion	9		
	Various physical	4		
	Lymphoedema	1		
	Nausea/Vomiting	1		
Emotional	Anxiety, fear, panic, uncertainty	32	59	33
	Relationship problems	9		
	Depression, unhappy	7		
	Unsorted feelings: guilt, anger, loss of dignity	7		
	Loneliness, isolation	2		
	Bereavement	1		
	Body image	1		
Stress management	Need for relaxation	20	34	19
	Stress	12		
General support	Needle phobia	1	12	7
	General coping	7		
	Need to be listened to	2		
	Coming to terms with the experience of cancer	2		
Hospital treatment related	Need to keep going	1	12	7
	Worry related to hospital treatment including physical and emotional effects	12		
Help with positive outlook	Self help strategies	9	9	5
TOTAL*			179	100

*TOTAL = 179 i.e. > 157 because some patients voiced more than one concern.

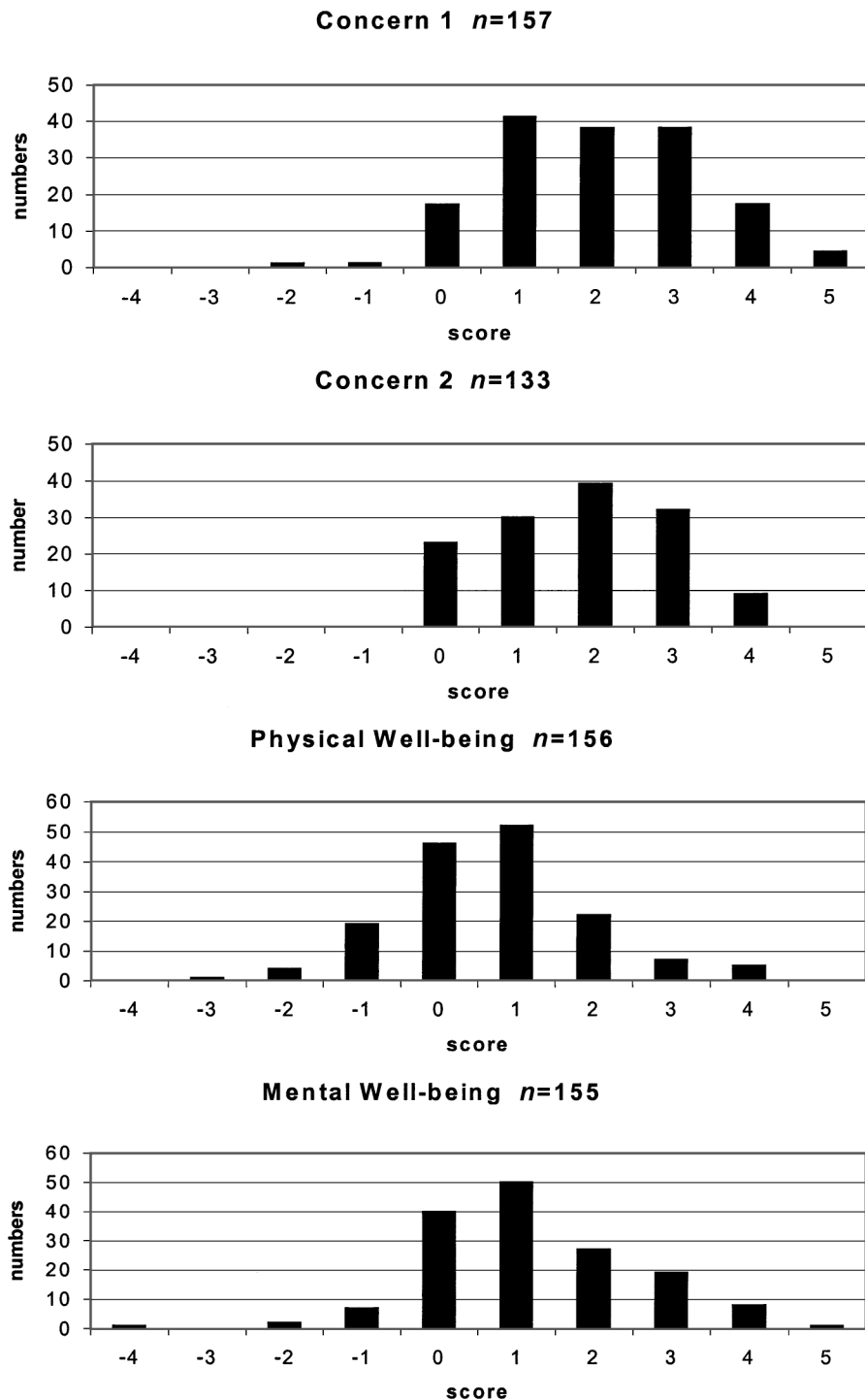


Fig. 5 Differences between scores at assessment and review shown for each category evaluated: The greater the difference the greater the change. Positive scores indicate improvement.

CONCLUSION

Not every patient with cancer chooses to use complementary therapies in addition to their conventional treatment. However for those health practitioners who are responding to the increasing demand for a pluralistic healthcare service, a more focussed approach to the assessment of patients' needs seems necessary. The Cavendish Centre has developed a model of care which strives to provide effective therapy in a safe and supportive climate in which patients are enabled to unburden

their fears, make sense of an experience which upsets every aspect of their lives, and make decisions about a positive way forward. In addition patients' own strengths and sources of support are harnessed enabling them to cope better with change and to become as independent as their circumstances allow. The model of care ensures that time is given to listen to the patient, and enables health professionals from a variety of backgrounds to work together with the aim of meeting each patient's expressed need. We conducted this audit in order to answer the question as to whether we were achieving this

Table 3 Analysis of changes following Cavendish Centre intervention

	Concern 1 n = 157	Concern 2 n = 133	Physical well-being, n = 156	Mental well-being, n = 155
Patients reporting better:				
n	138	110	86	105
(%)	(88)	(83)	(55)	(68)
Patients reporting no change:				
n	17	23	46	40
(%)	(11)	(17)	(30)	(26)
Patients reporting worse:				
n	2	0	24	10
(%)	(1)	(0)	(15)	(6)
Mean difference in score (after-before)	2.03	1.80	0.69	1.18
Median difference in score (after-before)	2	2	1	1
Min, Max difference in score (after-before)	-2, 5	0, 5	-3, 5	-4, 5
Comparison of initial and final mean scores (Wilcoxon signed-ranks matched-pairs test)	<i>P</i> < 0.0001	<i>P</i> < 0.0001	<i>P</i> < 0.0001	<i>P</i> < 0.0001

aim. The evidence presented here suggests that we have been successful in doing so.

More dissemination of the different ways of offering supportive and complementary care within an integrated setting is necessary. Studies describing the process, context and methods of audit are needed so that the benefits and risks of different modes of delivery and the appropriateness of services to meet local needs can be better evaluated. We might then learn whether the Cavendish Centre model might be usefully replicated in other contexts of care.

ACKNOWLEDGEMENTS

We would like to thank the following for their help with this paper: Professor Mike Campbell, Professor of Medical Statistics, Sheffield Professor Rob Coleman, Professor of Medical Oncology, University of Sheffield Professor Malcolm Reed, Professor of Surgical Oncology, University of Sheffield Ms Kate Thomas, Deputy Director, Medical Care Research Unit, University of Sheffield Dr Paul Manasse for statistical help.

REFERENCES

- Department of Health. A Policy Framework for Commissioning Cancer Services: A Report by the Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales. Department of Health 1995.
- Coulter A. Paternalism or partnership? Editorial *BMJ* 1999; 319: 719-720.
- Coulter A, Entwistle V, Gilbert D. Sharing decisions with patients: is the information good enough? *BMJ* 1999; 318: 318-322.
- Ernst E, Cassileth BR. The Prevalence of Complementary/Alternative Medicine in Cancer. A Systematic Review. *Cancer* 1998; 83: 777-782.
- Keeley D. Editorial. Rigorous assessment of palliative care revisited. *BMJ* 1999; 319: 1447-1448.
- Filshie J. Acupuncture for malignant pain. *Acup Med* 1990; 8: 38-40.
- Dundee JW, Yang J. Prolongation of the antiemetic action of P6 acupuncture by acupressure in patients having cancer chemotherapy. *J R Soc Med* 1990; 83: 360-362.
- Wilkinson S. Aromatherapy and massage in palliative care. *Int J Palliative Nurs* 1995; 1: 21-30.
- Maguire P, Tait A, Brooke M, Thomas C, Sellwood R. Effect of counselling on the psychiatric morbidity associated with mastectomy. *BMJ* 1980; 281: 1454-1456.
- Syrjala KL et al Relaxation and imagery and cognitive-behavioural training reduce pain during cancer treatment: a controlled clinical trial. *Pain* 1995; 189-198.
- Finlay IG, Jones OL. Hypnotherapy in palliative care. *J R Soc Med* 1996; 89: 493-496.
- Aldridge D. The delivery of health care alternatives: discussion paper. *JRSM* 1990; 83: 179-182.
- Street RL, Voight B, Geyer C, Manning T, Swanson GP. Increasing Patient Involvement in Choosing Treatment for Early Breast Cancer. *Cancer* 1995; 76: 2275-85.
- Paterson C. Measuring outcomes in primary care: a patient generated measure, MYMOP, compared with the SF-36 health survey. *BMJ* 1996; 312: 1016-20.
- Maguire P, Faulkner A, Regnard C. Eliciting the current problems of the patient with cancer - a flow diagram. *Pall Med* 1993; 7: 151-156.
- Faulkner A, Peace G, O'Keeffe C. When a Child has Cancer. Chapman and Hall London 1995.
- Greenhalgh T, Hurwitz B. Narrative based medicine. Why study narrative? *BMJ* 1999; 318: 48-50.
- Clover A, Last P, Fisher P, Wright S, Boyle H. Complementary cancer therapy: a pilot study of patients, therapies and quality of life. *Complem Thera Med* 1995; 3: 129-123.
- Salisbury C, Bosanquet N. Letter. Assessing palliative care is difficult *BMJ* 2000; 320: 942.
- Zollman C, Vickers A. ABC of complementary medicine. Users and practitioners of complementary medicine. *BMJ* 1999; 319: 836-838.
- Addington-Hall J, McCarthy M. Dying from cancer: results of a national population-based investigation. *Palliative Medicine* 1995; 9: 295-305.