The NCI Office of Cancer Complementary and Alternative Medicine

Invited Speaker Series

The State of CAM in UK Cancer Care: Advances in Research, Practice and Delivery

Dr. Michelle Kohn, MB BS, BSc, MRCP (UK)
Complementary Therapies Medical Advisor to Macmillan Cancer Relief, UK and the Department of Health, UK

The NCI Office of Cancer Complementary and Alternative Medicine

Invited Speakers Series

The State of Complementary and Alternative Medicine in United Kingdom Cancer Care: Advances in Research, Practice and Delivery

CONTENTS

Preface…….3

Summary…….5

Slides…….9

Preface

The National Cancer Institute's Office of Cancer Complementary and Alternative Medicine (OCCAM) hosted Dr. Michelle Kohn, MB BS, BSc, MRCP (UK) for the third in its Invited Speakers Series, on March 26, 2003. Dr. Kohn is the Complementary Therapies Medical Advisor to MacMillan Cancer Relief, UK, and serves as Advisor to the Department of Health, UK.

Her presentation, **The State of Complementary and Alternative Medicine in United Kingdom Cancer Care: Advances in Research, Practice and Delivery,** describes some of the historical development of complementary medical practices in the UK, the relationship between palliative and support care and complementary medicine, and the growing interest by cancer patients in the U.K. in these interventions and practices. In addition, she describes UK organizations such as The National Cancer Research Institute, a collaborative body with representation from the Department of Health, Medical Research Council, Cancer Research UK, industry leaders, and several primary cancer research charities in the UK and their interest in complementary approaches. She also presents information from commissioned reports, such as The 1998 Complementary Therapies in Cancer Care, which may be of interest to US researchers, practitioners and the public.

The video cast of Dr. Kohn's presentation is available through the OCCAM website at http://cancer.gov/cam. This document is designed to provide a summary of Dr. Kohn's presentation and provide the materials necessary to follow her presentation on the web cast.

By describing some of the latest work from the UK, we hope this presentation will stimulate similar activities in the US and abroad, encourage potential collaborative activities with our UK colleagues and continue to develop interest in cancer CAM research.

Jeffrey D. White, M.D.
Director, Office of Cancer Complementary and Alternative Medicine
National Cancer Institute

Wendy B. Smith, M.A., Ph.D.
Program Director, Research Development and Support Program
Office of Cancer Complementary and Alternative Medicine
National Cancer Institute

The State of CAM in UK Cancer Care: Advances in Research, Practice, and Delivery

Dr. Michelle Kohn, MB BS, BSc, MRCP (UK)
Complementary Therapies Medical Advisor to Macmillan
Cancer Relief, UK and the Department of Health, UK

Summary

The United Kingdom did not acknowledge the practice of alternative medicine until 1858, with the advent of orthodox medicine and the passing of the Medical Registration Act. Prior to 1858, medicine was largely a free for all, characterized by open markets of herbalists, midwives, and healers, competing for custom with physicians, surgeons, and apothecaries. In the early 20th century, newly enacted legislation limited the claims that non-medically qualified practitioners could make, precipitating a sharp drop in the number of alternative practitioners, who operated without a regulating body.

In the 1960s, the United Kingdom witnessed a resurgence in the practice of alternative medicine; primarily fuelled by consumers' desire for greater control over their own well-being, and the perception that orthodox biomedicine was limited in terms of safety and efficacy. The orthodox biomedical community's response to the resurgence was initially negative. For instance, a 1986 British Medical Association (BMA) report associated alternative approaches to healthcare with witchcraft, and described alternative healthcare as a "passing fad." By the 1990s, the orthodox medical response grew more positive, exemplified by a 1993 BMA report, which coined the term "complementary," and recommended training in complementary therapies for doctors and other healthcare professionals. This served as a catalyst for the public to relinquish the perception of complementary and alternative care as unconventional.

In 1997, the Foundation for Integrated Medicine published a report on "integrated healthcare," a move that challenged the previous biomedical model of healthcare and held the promise of a more unified package of care. The House of Lords Select Committee report (2000) followed US protocol and adopted the term "Complementary and Alternative Medicine" (CAM), which represented a further shift in healthcare terminology and medical culture. This report also provided a classification system, which grouped therapies according to their professional regulation affiliation and evidence base. The recommendations put forth by the House of Lords Select Committee report were not met with blanket acceptance; cancer care providers were resistant to the shift in terminology and ideology. Orthodox cancer care practitioners commonly accept complementary use (i.e. alongside orthodox medical treatment), as opposed to alternative use (i.e. in place of conventional treatment) of non-orthodox medical treatments. Consequently, the term "CAM" is used in the research literature in the UK, but there are calls for greater clarification of terminology in both practical and research settings.

Lessons learned from the evolution of the palliative care movement are highly applicable to the embryonic field of complementary medicine. The 1950s were marked by great human suffering and pain, and antiquated methods of care. There were significant breakthroughs in technology and specific treatments for disease; however, much suffering remained unaddressed. In 1964, the concept of "total pain" was

introduced, a concept that addressed not only the physical symptoms of a disease but associated mental distress and social and spiritual problems as well.

Dame Cicely Saunders was a chief advocate for providing total care, and was primarily responsible for revolutionizing the hospice movement and pioneering the introduction of palliative care practices. In the post-war era, she intensively studied orthodox medicine and accumulated a wealth of research on pain and healthcare. Dame Cicely created a methodology, which consisted of listening, recording, and analyzing patient experiences to attain the goal of "living until you die," and almost single-handedly transformed the concept of "the hospice" into one of a charitable organization with a broad spiritual foundation. In subsequent years, she credited the success of the hospice and the palliative care movements to the introduction of new methods to assess quality of life and spiritual and existential distress, combined with continued efforts to ensure academic validity in patient care and research. By the 1980s, palliative care practice evolved into a fusion of technological intervention and a humanist approach to healthcare.

The value patients place on complementary approaches to attain total care was exemplified in the Complementary Therapies in Cancer Care (CTCC) report[1]. The CTCC report also highlighted the increasingly supportive attitudes of healthcare professionals to complementary practices. Surveys of health professionals revealed that the majority of those interviewed regularly volunteered information on complementary approaches and were keen to learn more. The report suggested that patients were pulled towards complementary medicine by various factors, most notably because it provided them with "touch, time, and talk." The CTCC report demonstrated that supportive care was emerging as an integral element of the cancer treatment continuum; a trend further validated by surveys indicating that as many as one third of women with breast cancer sought out complementary resources. In spite of increased support and use of complementary healthcare, fiscal pressures in the socialized health service confounded physicians' perceptions of the need for complementary practices. Issues surrounding evidence, training, regulation, ethics, confidentiality, and research in a clinical setting also contributed to stagnation in the expansion of complementary healthcare promotion by physicians.

To respond to the public and professional demand for further information on local resources, Macmillan Cancer Relief published the Directory of Complementary Therapy Services in UK Cancer Care[2] in 2002, listing complementary services available throughout the UK. Services in the Directory offered over forty types of complementary healthcare therapies. A full one third of the services offered complementary therapies in hospitals, another one-third in hospices, and one-fifth offered services in the voluntary sector. Touch therapies and mind-body therapies were the most common therapies listed in the Directory. Over 90% of the services in the Directory offered touch therapies, such as aromatherapy, massage, and reflexology, while mind-body therapies, like relaxation and visualization, were offered through over 80% of services. Healing and energy work,

---

[1] Complementary Therapies in Cancer Care. Abridged report of a study produced for Macmillan Cancer Relief, June 1999. Dr. Michelle Kohn author. Published by Macmillan Cancer Relief (UK).

[2] Directory of Complementary Therapy Services in UK Cancer Care, 2002. Published by Macmillan Cancer Relief (UK).

including reiki, spiritual healing and therapeutic touch, were available in over 40% of services. Creative therapies, such as art therapy, were also available through over 40% of the services, while over 20% of

the services offered nutritional and medicinal therapies. Services listed in the Directory frequently provided complementary therapy services to orthodox healthcare providers and staff, as well as patients. Encouragingly, 70 % of services provided therapeutic work free of charge to patients, orthodox healthcare providers, and staff.

Increased use and acceptance of complementary therapy practices and research inspired a restructuring of orthodox treatment methods for cancer. The 2000 National Cancer Plan (NCP) defined cancer treatment as a three-part system comprising diagnosis, treatment, and newly established "Supportive Care" practices. As a whole, complementary therapies were designated as one of eleven elements in the new supportive care model; the NCP guide will be published in 2004. In 2001, the Prince of Wales's Foundation for Integrated Health and the National Council for Hospice and Specialist Palliative Care Services began a collaborative effort to establish National Guidelines for the Use of Complementary Therapies in Supportive and Palliative Care[3]. The Guidelines are designed to enable healthcare providers and employees to set up and maintain services. The Guidelines address issues such as recruitment, configuration of teams, supervision, ethics, and accountability, in addition to appraisals of the most commonly used therapies and clinical considerations.

Following the House of Lords Select Committee report (2000), the government pledged to fund research into designated priority areas to better understand CAM use. In 2002, the National Health Service Research and Development Programme commissioned work to examine CAM use in patients with cancer. The Programme specifically called for exploration of CAM patient populations, stages of illness (from diagnosis through to palliative and terminal care), impetus for use, perceived benefits of use, and comparisons with orthodox care.

The National Cancer Research Institute (NCRI) was established to allow for proficient strategic planning relating to cancer research. NCRI is a collaborative body comprised of the main funding supporters of cancer research, including the Department of Health, the Medical Research Council, Cancer Research UK, industry leaders, and several primary cancer charities, and was based on a model developed in collaboration with colleagues in the United States. Common scientific method allows for comparisons to be drawn on the types of research being conducted. CAM research guided by NCRI fits into three main categories: (1) prevention, (2) treatment, (3) control, survival, and outcomes.

At present, government spending in the areas most applicable to CAM, those of cancer control, survival and outcomes, and cancer prevention, remains low. Research activity in the UK is currently focused on complementary rather than alternative approaches, mind-body interventions and touch techniques in particular. Several researchers are developing the evidence base in these areas, collaborating with orthodox and complementary practitioners, to better understand the role and value of these

---

[3] National guidelines for the Use of Complementary Therapies in Supportive and Palliative Care, 2003. Published by the Prince of Wales's Foundation for Integrated Health and the National Council for Hospice and Specialist Palliative Care Services.

practices and design trials accordingly. Although there has been limited activity to date, this is more a reflection of the lack of CAM researchers, infrastructure, and funding than a lack of interest in the field.

Factors contributing to funding apprehension arise from a lack of effort to validate efficacy, a failure to focus on specific research questions, a lack of clarity in research goals, and insufficient understanding of how complementary mechanisms work. Researchers must first focus on therapeutic relationships and develop methodological tools to accurately and appropriately measure holistic practices. The future success of CAM research is contingent on patient-centered research. Including people affected with cancer in CAM research, improving the evidence base, developing better methodological tools, and concentrating on areas of most concern to patients, will foster increased use of CAM practices, as well as improve orthodox care. How society integrates the interplay of technological advances, the delivery of services, and the financing of healthcare will dictate how complementary therapies can assist individuals along their cancer journey.

9

The State of CAM in UK Cancer Care:

Advances in Research, Practice and Delivery

Dr Michelle Kohn MB BS, BSc, MRCP (UK)

March 26th 2003

10

Solomon Islands, South Pacific

11

Professor Tony Dickenson and team, University College London

12

Collecting medicinal herbs…

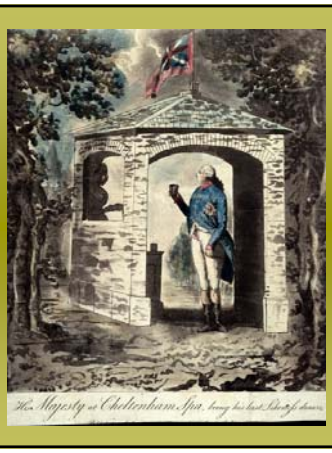
Detail from a 13th Century German manuscript. Pseudo-Musa, De herba vettonica

13

A hydrotherapy cure…

Gräfenberg, Germany Lithograph, c. 1860

14



King George III 'taking the waters' at Cheltenham, 1812

15

A woman patient at a spa is told by her doctor that the treatment for her fertility might be helped by the presence of a 'diverting friend' …

Lithograph by M. Stephane, c. 1896

16

Professor Mike Saks

Pro Vice Chancellor, University of Lincoln

Orthodox and Alternative Medicine

Politics, Professionalization and Health Care

17

The Past

18

Shift in Attitudes

- 1986 BMA Report passing fad'
- 1993 BMA Report Complementary medicine
- 1997 Foundation for Integrated Medicine 'Integrated healthcare'
- 2000 House of Lords Select Committee Report on CAM
- 2001 BMJ – 'Integrated medicine' coincided with conference at Royal College of Physicians

19

Foundation for Integrated Medicine

Integrated Healthcare:
A way forward for the next five years.
A discussion document, 1997

National Charity est. 1996 by The Prince of Wales

- Research and development
- Education and training
- Regulation
- Delivery mechanisms

Re-branded as Prince of Wales's Foundation for Integrated Health, 2002

20

House of Lords Classification Table

Table 11.1 Complementary and Alternative Medicine Disciplines as grouped by the House of Lords Science and Technology Select Committee 6th Report into Complementary and Alternative Therapies (November 2000)

Group 1	Group 2	Group 3
Professionally organised alternative therapies	**Complementary therapies**	**Alternative disciplines**
Acupuncture* Chiropractic Herbal med cine (nc udes Essiac*) Homoeopathy* Osteopathy	Alexander Technique Aromatherapy* Bach and other f ower remedies Bodywork therapies inc uding massage* Counselling stress therapy Hypnotherapy* Meditation* Reflexology* Shiatsu* Healing* Marharishi Ayurvedic Medicine Nutrit onal Med c ne* Yoga*	3a: Long established traditional systems of health care Anthroposoph ca medicine (ncludes Iscador*) Ayurvedic medicine Ch nese Herba Med cine* Eastern Medic ne Naturopathy Traditiona Chinese Med cine 3b: Other alternative disciplines Crystal therapy Dowsing Iridology K nesiology Radionics

Integrated medicine of today should be the medicine of the new millennium

BMJ 20 January 2001, Issue 7279

21

CAM Use

Recent surveys

- Rees et al, 2000 1,023 women with breast cancer, **31.5%** had consulted a CAM practitioner since diagnosis
- Lewith et al, 2002 – **32%** of those with cancer were receiving CAM, 49% not receiving CAM would have liked to

22

Cancer Care in the UK: A historical perspective

The evolution of palliative care

23

Etching showing a couple visiting the sick in a hospice where the man attempts to feed one some nourishment.

24

Dame Cicely Saunders O.M.

The evolution of palliative care
Journal of the Royal Society of Medicine, Volume 94 – September 2001

25

The past

The present

26

Macmillan Cancer Relief

27

" I want to see homes for cancer patients throughout the land, where attention will be provided freely or at low cost, as circumstances dictate. I want also to see panels of voluntary nurses, who can be detailed off to attend to necessitous patients in their own homes."

Douglas Macmillan, 1931

Macmillan Cancer Relief

A national cancer care charity founded in 1911

28

"Imagine a time when every person in the land has equal and ready access to the best information, treatment and care for cancer and unnecessary levels of fear are set aside."

Vision statement

Macmillan Cancer Relief

A voice for life; changing perceptions

29

"We always seem to hear the horror stories. But I know what a difference it makes if you're given hope."

A patient's view

Macmillan Cancer Relief

A voice for life; changing perceptions

30

- battle
- fight
- struggle
- struck down
- suffering
- victim
- stricken
- anguish

Macmillan Cancer Relief

A voice for life; changing perceptions

Oxford English Dictionary - definition

31

Cancer : *a malignant growth or tumour in different parts of the body, that tends to spread indefinitely and to reproduce itself, also to return after removal; it eats away or corrodes the part in which it is situated, and generally ends in death.*

As defined in 1888!

Macmillan Cancer Relief

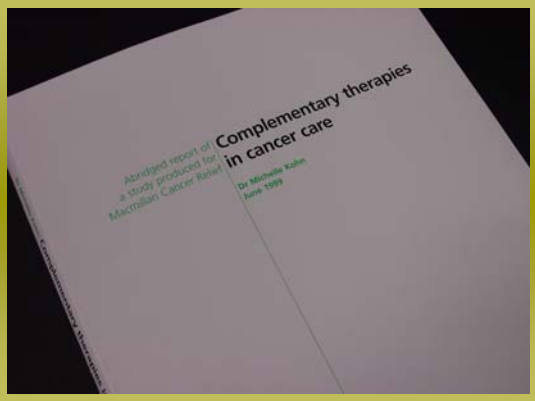
A voice for life; changing perceptions

Oxford English Dictionary - definition

32

Cancer : *a malignant tumour or growth of body tissue that tends to spread and may recur if removed.*

As defined in 1999!



33

Complementary Therapies in Cancer Care

Nurses' comments on therapies

Therapy	Comments
Aromatherapy	*'Yes please.'*
Reflexology	*'Nice, safe, probably nonsense.'*
Massage	*'Very relaxing.'*
Psychological interventions (e.g. relaxation)	*'Patients can do something for themselves.'*
Healing	*'It's a bit over the top.'*
Acupuncture	*'It seems to help with pain.'*
Homoeopathy	*'It interferes with medical treatment.'*
	'It lacks plausibility.'

34

Complementary Therapies in Cancer Care

Nursing practice survey – conclusions

- Most nurses (97%) are asked about complementary therapies
- Most (94%) volunteer information at some time
- 30% have taken courses in complementary therapies
- 15% practise complementary therapies
- Most would welcome information/education about complementary therapies (92%) and information on local therapists and resources (94%)

35

Complementary Therapies in Cancer Care

Doctors' comments on therapies

Therapy	Comments
Aromatherapy	*'The patient gets extra time with someone who can listen.'*
Reflexology	*'I'm happy for patients to try anything.'*
Massage	*'Great for muscle spasm.'*
Psychological interventions (e.g. relaxation)	*'I offer hypnotherapy – its been very worthwhile.'*
Healing	*'I'm sceptical, but if it helps, fine.'*
Acupuncture	*'I practise it – it helps localised pain.'*
Homoeopathy	*'I find the concept difficult to believe in, but I don't mind patients trying it.'*

36

Complementary Therapies in Cancer Care

Medical practice survey – comments

- *GPs have increasingly become maligned for their communication skills. It s just that we don t have time time permitting, perhaps complementary therapies would not be needed.'*

  GP, Birmingham

- *Evidence is Needed.'*

  Palliative care physician, Nottingham

- *'It keeps patients out of the surgery.*

  GP, Avon

- *'If it helps the patient, we should support it. But we must not mislead patients.*

  GP, Plymouth

37

Complementary Therapies in Cancer Care

Medical practice survey – conclusions

- Most physicians, (96%) are asked about complementary therapies
- Most, (92%) volunteer information at some time
- Therapies most widely offered are aromatherapy, reflexology, massage, and acupuncture
- 36% have taken courses in complementary therapies
- 20% practise complementary therapies
- Most would welcome information/education about complementary therapies (76%) and information on local therapists and resources (84%)

38

39

Complementary Therapies in Cancer Care

Barriers to integration

1. The role in cancer care
2. The dialogue (*or lack of*)
3. The appropriate research

40

Complementary Therapies in Cancer Care

Orthodox medicine – 'push' factors

- Failure to produce curative treatments
- Adverse effects of orthodox medicine
- Lack of time with practitioner, loss of bedside skills
- Dissatisfaction with the technical approach
- Fragmentation of care due to specialisation

41

Complementary Therapies in Cancer Care

Complementary therapies – 'pull' factors

- Media reports of dramatic improvements
- Belief that these therapies are natural
- Empowerment of patient
- Focus on spiritual and emotional well-being
- Provisions of 'touch, talk and time'

42

Complementary Therapies in Cancer Care

Rationing and prioritisation of services

'We can't pump money into massaging patients when we haven't got the money to cut their tumours out.'

Cancer surgeon

'How much of our resources are we prepared to put into complementary medicine compared to cancer treatments such as chemotherapy?

Consultant oncologist

43

Complementary Therapies in Cancer Care

Rationing and prioritisation of services

'Maybe oncologists would reconsider giving last-ditch chemotherapy to desperately sick patients if they had something else to offer. It may save money from the drug budget.

Palliative care physician

'Educated middle-class women mainly use complementary therapies. Such people can often afford private care. Often they are the worried well.

Consultant oncologist

44

Complementary Therapies in Cancer Care

Rationing and prioritisation of services

'The complementary therapy scheme is an essential part of the comprehensive care that should be available to all cancer patients.'

Consultant radiotherapist

Complementary Therapies in Cancer Care

Issues surrounding use

- **Evidence**
  'What's the evidence that being rubbed down with lavender oil is better than a day trip to France, a shampoo and set, or giving patients gift vouchers?
  Cancer surgeon
- **Training**
  'Doctors need training to have the knowledge and confidence to discuss complementary therapies with their patients.'
  Physician

Complementary Therapies in Cancer Care

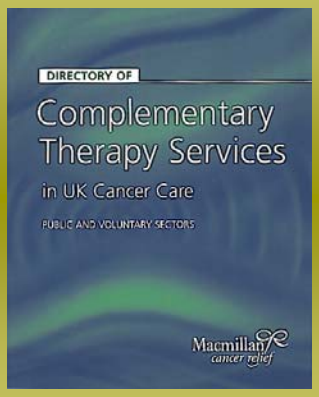
Issues surrounding use

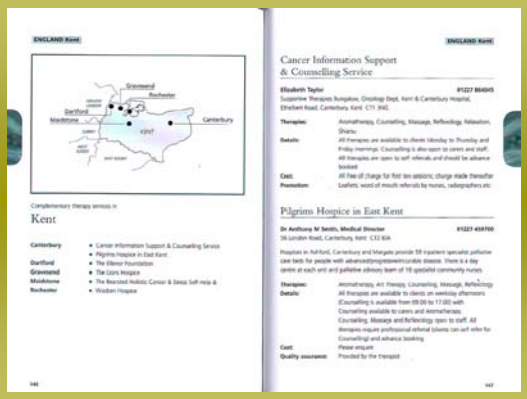
- **Training**
  'With all the new degree courses, there will be an increase in clinical practice but do the therapists have the clinical skills?
  Policy maker
- **Regulation**
  'My aromatherapist thinks it will inspire confidence if she tells me of her famous patients who come for treatments.'
  Patient

Complementary Therapies in Cancer Care

Future directions

- Research
- Regulation
- Education & training
- Information
- Collaboration





ENGLAND Kent

Cancer Information Support & Counselling Service

Pilgrims Hospice in East Kent

Kent

I believe this directory will be of great value both to cancer patients and health professionals.

Professor Mike Richards
National Cancer Director

Complementary therapy really can make a difference to the experience of cancer. In fact it should now be an integral part of any cancer treatment service.

Professor Malcolm McIllmurray
Macmillan Consultant in Medical Oncology
Royal Lancaster Infirmary

A very timely and worthwhile innovation by Macmillan to bring together this directory of complementary therapy services for people effected by cancer. I am certain it will prove to be an invaluable resource."

Professor Jessica Corner
Professor in Cancer and Palliative Care
School of Nursing and Midwifery, University of Southampton

Directory of Complementary Therapy Services in UK Cancer Care

Data set of > 320

	% of centres	number of centres
Hospice	36	119
Hospital	31	103
Voluntary organisation/group	18	59
Community	9	31
Other/not specified	5	18

Table 1: Setting for complementary therapy centre

Directory of Complementary Therapy Services in UK Cancer Care

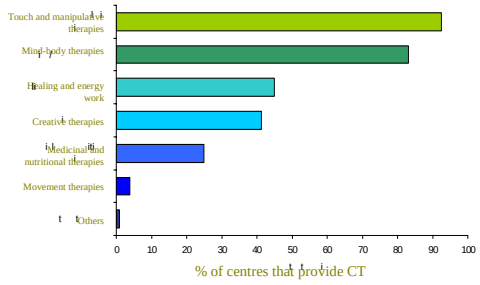


Figure 1: Percentage of centres who provide selected complementary therapies

Directory of Complementary Therapy Services in UK Cancer Care

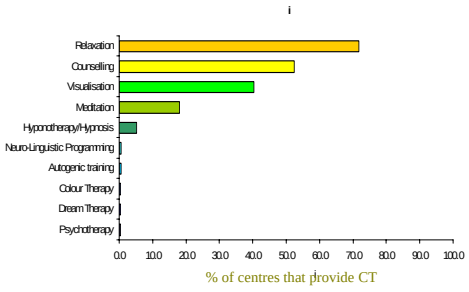


Figure 2: Percentage of centres who provide mind-body therapies

Directory of Complementary Therapy Services in UK Cancer Care

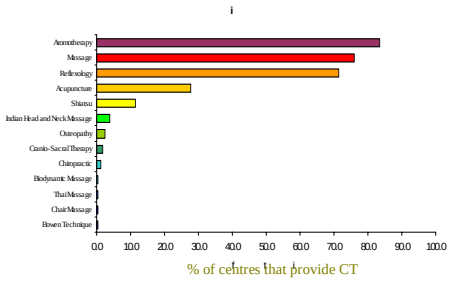


Figure 3: Percentage of centres who provide touch and manipulative therapies

Directory of Complementary Therapy Services in UK Cancer Care

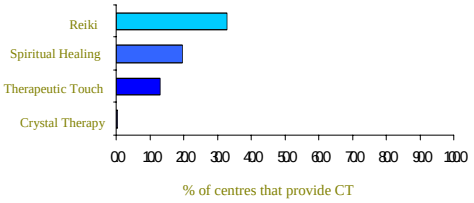


Figure 4: Percentage of centres who provide healing and energy work

Directory of Complementary Therapy Services in UK Cancer Care

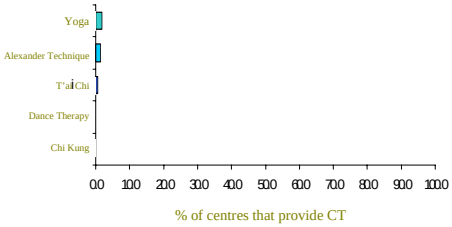


Figure 5: Percentage of centres who provide movement therapies

Directory of Complementary Therapy Services in UK Cancer Care

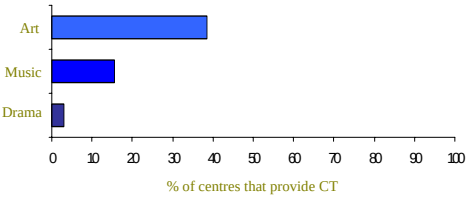


Figure 6: Percentage of centres who provide creative therapies

Directory of Complementary Therapy Services in UK Cancer Care

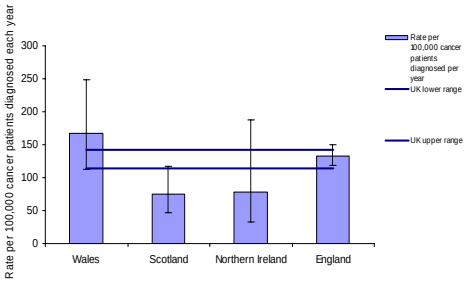


Figure 7: Rate of complementary therapy centres per 100,000 cancer patients diagnosed each year by region of the UK

Directory of Complementary Therapy Services in UK Cancer Care

Number of therapies	Percent
1 –2	10
3 – 4	22
5 – 6	24
7 – 8	20
9 – 10	12
11+	12

Table 2: Range of therapies offered by centres in the UK

Directory of Complementary Therapy Services in UK Cancer Care

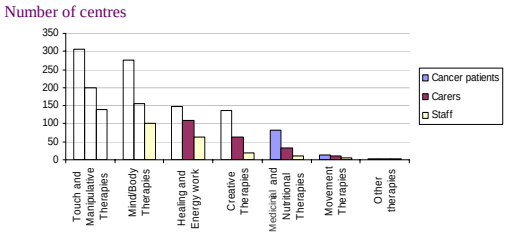


Figure 8: Number of centres offering various complementary therapies to cancer patients, their carers and staff

Complementary Therapies in Cancer Care

Summary points:

- > 90% of centres offer a 'touch and manipulative' therapy
- > 80% of centres offer aromatherapy, making it the most widely available therapy
- 80% provide at least one 'mind-body' therapy
- > 40 complementary therapies offered across the UK but one third are only available in 1% of centres

Complementary Therapies in Cancer Care

Summary points ctd

- 70% of centres have no charges for any complementary therapies to patients, carers and staff
- 80% of centres offer services to carers
- >50% of centres offer at least one complementary therapy to staff

The Present

The National Cancer Plan 2000

The concept of supportive care

- Introduced in the NHS Cancer Plan (2000)
- Acknowledged that supportive care should be provided throughout the patient's and carer's cancer journeys
- Positive concept
- Includes complementary therapies as one of 12 services to empower patients and their carers to develop strategies for living with cancer, and support them in the process

The Definition of Supportive Care

"Supportive care is that which helps the patient and their family to cope with cancer and treatment of it – from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease. **It is given equal priority alongside diagnosis and treatment."**

Developed by the National Council for Hospice and Specialist Palliative Care Services (NCHSPCS 2002)

The Definition of Palliative Care

"Palliative care is the active holistic care of patients with advanced, progressive illness. **Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount.** The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatment."

(NCHSPCS 2002)

The Principles of Palliative Care

Palliative care aims to:

- Affirm life and regard dying as a natural process
- Provide relief from pain and other symptoms
- Integrate the psychological and spiritual aspects of patient care
- Offer a support system to help patients live as actively as possible until death
- Offer a support system to help the family cope during the patient's illness and in their own bereavement

(NCHSPCS 2002)

69

Department of Health
Delivering the NHS Cancer Plan
Supportive and Palliative Care Strategy

Guidance on improving supportive and palliative care for adults with cancer

- Information
- Communication
- Symptom control
- Specialist palliative care
- Terminal care
- Rehabilitation
- Psychological support
- Spiritual support
- Social support
- Complementary therapies
- User involvement
- Support for carers including bereavement

Initiated by the DoH – developed under the auspices of NICE

70

Guidelines for the use of Complementary Therapies in Supportive and Palliative Care

The Prince of Wales's Foundation for Integrated Health

National Council for Hospice and Specialist Palliative Care Services (NCHSPCS)

The scope of the guidelines

Who are the guidelines for? Employers and/or providers of services

71

Guidelines for the use of Complementary Therapies in Supportive and Palliative Care

What will the guidelines cover?

- The initial development of a service
- Management and on-going development
- Configuration of teams/services – some examples
- Recruitment
- Volunteers
- Ethics and accountability

72

Guidelines for the use of Complementary Therapies in Supportive and Palliative Care

What will the guidelines cover? cont.

- Supervision
- Most commonly used therapies:
  massage, acupuncture, aromatherapy, reflexology, healing, homeopathy and hypnotherapy
- Clinical issues:
  cancer, motor neurone disease, Parkinson's disease, multiple sclerosis
- Clinical governance
- Other sources of information

73

Research

74

"In science you don't need to be polite, you only have to be right."

Winston Churchill

…we are witnessing today -- a revolution in medical science whose implications far surpass even the discovery of antibiotics, the first great technological triumph of the 21st century. And every so often in the history of human endeavour there comes a breakthrough that takes humankind across a frontier and into a new era."

Tony Blair

Remarks on the completion of the first survey of the entire human genome project, June 26th 2000

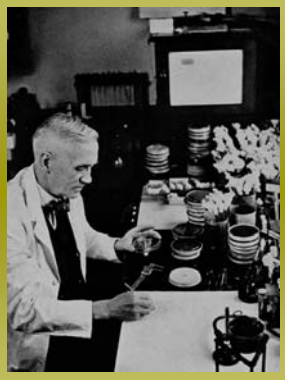
Today's announcement represents more than just an epic making triumph of science and reason. After all, when Galileo discovered he could use the tools of mathematics and mechanics to understand the motion of celestial bodies, he felt, in the words of one eminent researcher, *that he had learned the language in which God created the universe*.

Today, we are learning the language in which God created life. We are gaining ever more awe for the complexity, the beauty, the wonder of God's most divine and sacred gift."

Bill Clinton

Remarks from the US President on the completion of the first survey of the entire human genome project, June 26th 2000

Sir Alexander Fleming at work in his laboratory at St Mary's Hospital, London



Periodical, Britain Today 1942

Research Capacity

An analysis of cancer research funding in the UK
NCRI members

Association for International Cancer Research (AICR)	Charity	www.aicr.org.uk
Biotechnology and Biological Sciences Research Counci (BBSRC)	Government	www.bbscr.ac.uk
Ludwig Institute for Cancer Research	Charity	www.ludwig.ucl.ac.uk
Northern Ireland HPSS R&D	Government	www.rdo.csa.n-i.nhs.uk/rdo/index.html

An analysis of cancer research funding in the UK

The Common Scientific Outline (CS0) groups research into 7 broad areas:

- Biology
- Aetiology
- Prevention
- Early detection, diagnosis and prognosis
- Treatment
- Cancer control, survival and outcomes research

Scientific model systems

These areas are in turn, further subdivided to give a total of 38 individual CSO categories

An analysis of cancer research funding in the UK

Prevention

3.5 Complementary and alternative prevention approaches
Examples of science that would fit:

Discovery, development and testing of complementary/alternative prevention approaches such as diet, herbs, supplements or other interventions which are not widely used in conventional medicine or are being applied in different ways as compared to conventional medical uses

Hypnotherapy, relaxation, transcendental meditation, imagery, spiritual healing, massage, biofeedback, etc used as a preventive measure

An analysis of cancer research funding in the UK

Treatment

5.6 Complementary and alternative treatment approaches
Examples of science that would fit:

Discovery, development and clinical application of complementary/alternative treatment approaches such as diet, herbs, supplements, natural substances or other interventions which are not widely used in conventional medicine or are being applied in different ways as compared to conventional medical uses

An analysis of cancer research funding in the UK

Cancer control, survival and outcomes research

6.8 Complementary and alternative approaches for supportive care of patients and survivors
Examples of science that would fit:

- Hypnotherapy, relaxation, transcendental meditation, imagery, spiritual healing, massage, biofeedback, etc., as used for the supportive care of patients and survivors
- Discovery, development and testing of complementary/alternative approaches such as diet, herbs, supplements or other interventions that are not widely used in conventional medicine or are being applied in different ways as compared to conventional medical uses

An analysis of cancer research funding in the UK

Types of research being conducted

Analysis of the Cancer Research Database (CRD) by CSO has provided information on the balance between different types of research in the collective UK portfolio as follows **[see figure 1]:**

Biology	41%
Treatment	22%
Aetiology	16%
Early detection, diagnosis and prognosis	8%
Cancer control, survival and outcomes	6%
Scientific model systems	5%
Prevention	2%

Nature Reviews Cancer **3**:

An analysis of cancer research funding in the UK

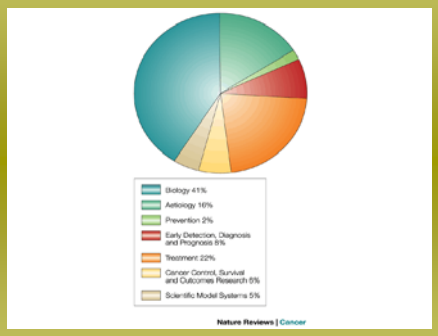


Figure 1 | **Proportion of total NCRI partners spend by CSO.**

An analysis of cancer research funding in the UK

Some reasons given to explain differing levels of spend within the combined research portfolio are as follows:

Biology

- The UK has an excellent reputation for high quality biological research relevant to cancer
- This research area is fundamental to better understanding of cancer, necessary for the development of improved, rationally based treatment and prevention strategies

An analysis of cancer research funding in the UK

Treatment

- Co-ordination and networking particularly beneficial
- NCRI partners are working together to ensure development of coherent national approach to clinical cancer research
- National networks for clinical trials have been reorganised through NCRI action
- NCRI action has also brought about provision of new government investment in research infrastructure within the NHS

An analysis of cancer research funding in the UK

Cancer control, survival and outcomes research

- Much of the research is aimed at understanding and improving those factors that affect a patient s experience of cancer
- Type of research is probably less expensive than some other fields of research
- Spend is low in this area

An analysis of cancer research funding in the UK

Prevention

- Spend on research aimed at direct application of interventions designed to prevent cancer is low
- Other elements of prevention research like identification of suitable targets and preventive interventions and investigation of factors that cause cancer are well supported across several CSO categories

An analysis of cancer research funding in the UK

Most NCRI partners predominantly fund biology, aetiology and treatment research. Few focus their research activities on prevention and cancer control with the exception of Macmillan Cancer Relief, which is active only in the area of cancer control, survival and outcomes research.

[The percentage of NCRI member spend by CSO is shown in figure 2]

Nature Reviews Cancer **3 :**
An analysis of cancer research funding in the UK

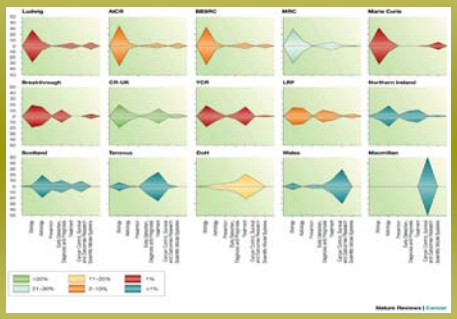


Figure 2 | **Percentage of each NCRI members' spend by CSO**.

An analysis of cancer research funding in the UK

Disease site funding analysis

40% of the NCRI partners spend is disease specific. This is compared with incidence and mortality figures.

The key observations are:

- The relative proportion of funding of different tumour sites generally follows the increasing disease burden associated with those tumours (e.g. breast, colon, rectal and prostate)

An analysis of cancer research funding in the UK

- There are some cancers where the relative funding is higher than the pattern of disease burden (e.g. leukaemia, ovarian, cervical)
- There are some where spend is significantly lower (e.g. lung, pancreas, stomach, oesophagus and bladder)

O'Toole L, Nurse P and Radda G. An analysis of cancer research funding in the UK. *Nature Reviews / Cancer*. February 2003, Volume 3

Cancer Research UK

Examples of CAM research within the CR-UK portfolio

Professor Leslie Walker, Institute of Rehabilitation, University of Hull School of Medicine

A randomised controlled study of the relative psychoneuroimmunological effects of relaxation therapy and guided imagery, alone and in combination, in patients with colorectal cancer

Cancer Research UK

Examples of CAM research within the CR-UK portfolio

Deborah Fenlon, University of Southampton, School of Nursing and Midwifery

The use of relaxation therapy as an intervention for hot flushes in women with breast cancer

Cancer Research UK

Examples of CAM research within the CR-UK portfolio

Professor Ken Fox, Department of Exercise and Health Sciences, University of Bristol Centre for Sport, Exercise & Health

Studentship: The role of exercise in the enhancement of quality of life and mental well-being of recovering cancer patients in the UK

CANCER RESEARCH UK

99

Cancer Research UK

Examples of CAM research within the CR-UK portfolio

Professor Stephen Morley, Academic Unit of Psychiatry and Behavioural Sciences, University of Leeds School of Medicine

Attention management as an adjunctive treatment for cancer pain

CANCER RESEARCH UK

100

Cancer Research UK

Examples of CAM research within the CR-UK portfolio

Dr Amanda Daley, Sheffield Hallam University

Effects of exercise therapy upon quality of life in women who have had breast cancer

CANCER RESEARCH UK

101

NHS Research & Development Programme

Commissioning Brief

Research on the Role of Complementary and Alternative Medicine (CAM) in the Care of Patients with Cancer

102

NHS Research & Development Programme Commissioning Brief

Following the House of Lords Select Committee report on CAM:

"Research into the CAM genre itself, including social research into the motivation of those patients seeking CAM and the usage patterns of CAM."

The focus is on:
CAM therapies as an adjunct to conventional forms of treatment and in palliative/supportive care.

103

NHS Research & Development Programme Commissioning Brief

- The budget available is up to £300,000
- The outputs will help to inform both the provision of integrated services within the NHS and the future research agenda for CAM in the cancer field

104

NHS Research & Development Programme Commissioning Brief

Research questions

Proposals should address some or all of the following areas of interest:

- How are perceptions of CAM treatments influenced by personal background, sources of information, the nature and stage of the disease, the orthodox treatment received or proposed, and professionals' views? How are preferences for or against CAM treatments determined?
- What are patients' expectations of cancer care and how far and in what ways are these met by CAM therapies? Do these expectations change at successive stages of illness?

NHS Research & Development Programme Commissioning Brief

Research questions

- What aspects of different CAM treatments and of the therapeutic relationship are particularly valued, and how are these compared with the experience of orthodox treatments? In what way do patients' interactions with orthodox and CAM practitioners differ?
- Are there measurable effects on quality of life among those receiving CAM treatments?

NHS Research & Development Programme Commissioning Brief

Patient groups

Groups of interest include the following:

- Patients receiving potentially curative treatment (which might be surgery, radiotherapy and/or chemotherapy)
- Patients who have received potentially curative treatment and are now clinically free of disease
- Patients with metastatic disease who are receiving or have been recommended orthodox anti cancer treatment
- Patients with advanced disease who are receiving or are candidates for palliative care

NHS Research & Development Programme Commissioning Brief

Research methods

- Proposals should be supported by systematic review of the relevant literature
- Researchers may propose the study designs which are considered most informative in addressing the questions set out above but should include a strong qualitative component
- Applicants are asked to justify their proposed study methods and sampling strategy
- The research team will be multidisciplinary and likely to have representation from social sciences, CAM, cancer specialties, health services research and patients

NHS Research & Development Programme Commissioning Brief

Grants Awarded – December 2002

1. **Dr Philip Tovey**
   Principal Research Fellow, School of Healthcare Studies, University of Leeds
2. **Professor Jessica Corner**
   Professor in Cancer and Palliative care, School of Nursing and Midwifery, University of Southampton
3. **Dr Alison Shaw**
   Non Clinical Lecturer. Division of Primary Healthcare, University of Bristol

Marie Curie and CAM

- The Marie Curie Palliative Care Research and Development Unit seeks to improve care for those affected by life-limiting illnesses
- Encourages & carries out research into a broad spectrum of issues relating to palliative care
- Its work includes investigations into a wide range of subjects and issues, including aromatherapy massage, constipation in cancer patients and communication skills for healthcare professionals
- The unit is based at the Royal Free and UCL Medical School, London, headed by Dr Susie Wilkinson.

111

Professor Leslie Walker
The Institute of Rehabilitation
The University of Hull

112

Professor Leslie Walker
The Institute of Rehabilitation, The University of Hull

Research

The research strategy is to collaborate with clinicians and basic scientists.

Funded by the Medical Research Council, Cancer Research UK, the HTA Programme and the NHS R&D Executive, current studies includes:

- Psychoneuroimmunological studies
- Psychosocial aspects of cancer screening
- The evaluation of different models of providing psychosocial care
- The evaluation of the effects of complementary interventions on quality of life

113

Professor Leslie Walker
The Institute of Rehabilitation, The University of Hull

Current clinical trials:

- A randomised, controlled, clinical trial of the effects of reflexology on quality of life (including mood, adjustment, function, coping and patient satisfaction) in women with early breast cancer (180 patients: 3 years commencing May 2002)
- A randomised, controlled trial of the relative effects of relaxation therapy and guided imagery, alone and in combination, on host defences, mood, adjustment, quality of life and patient satisfaction in patients with colorectal cancer. (180 patients: 3 years commencing January 2003)
- A randomised, controlled trial of reflexology versus relaxation therapy and guided imagery on host defences, mood, adjustment, quality of life and patient satisfaction in patients with advanced lung cancer. (180 patients: 3 years commencing April 2003)

114

Dr Jane Maher
Mount Vernon Cancer Centre, University College London

115

Dr Jane Maher

A common sense approach?

1. Reviewed which CAMs used
2. Identified, screened & trained cohort of therapists
3. Introduced therapies one by one: context of care package
4. Focus on shared language

116

Dr Jane Maher

A common sense approach?

5. Measurement tools
6. Focus group end of pilot
7. Published regular reports
8. Co investigators Cancer Research UK randomised controlled trial

Mount Vernon Cancer Centre

117

What are the priorities?

- Develop an evidence base for new safe medicine
- Develop information for patients & professionals about CAMs
- Improve orthodox care through learning from CAMs

118

More evidence is our only priority..

… there is only medicine which has been adequately tested & medicine which has not…

Angell & Kassirer NEJM 1998, 339:839-841

119

Shared understanding is the priority…

The real issue for conventional medicine…is to learn from alternative practices…to regain the *knowledge* we have lost in *information*

Davidoff Ann Intern Med 1998, 129:1068-1070

120

Dr Jane Maher

Who will fund research into areas which do not result in a profitable product?

- Developing the tools which measure things not serious enough" to be pathological
- To explore the links between mind, body & spirit
- Therapeutic relationship

121

Dr Jane Maher

Stamp out non-evidence based practice…

- By 1995 >70% of cancer centres and hospices in the UK offered at least one complementary therapy
- Commonly aromatherapy massage
- Charitably funded

122

No evidence for it…?

- Cooke B, Ernst E. Aromatherapy : a systematic review Br J Gen prac June 2000, 493-496
- The reviewers conclude that the effects of aromatherapy *are probably not strong enough* to be useful

Stamping out non evidence based practice…

Does this mean that aromatherapy massage should cease in UK cancer centres and hospices?

The cost of getting evidence

To demonstrate a (significant) increase in success rate between massage with & without aromatherapy would need a sample size of over 1000…

Andrew Vickers BJGP June 2000

A patient's view…

"To be honest, I don't really care if it works for 100 other people or not, it works for me and that's enough…"

Evidence & common sense

"Some cancer centres have a hairdresser who comes round the wards – **it makes people feel better** – have we got to do a randomised trial now to prove it's a good idea?"

Volunteer support centre

Dr Jane Maher

Stamping out non-evidence based practice…

- UK Patients will continue to receive aromatherapy massage in the UK
- (American patients will also continue to receive multiple fractions of RT for bone metastases…)

Dr Jane Maher

Three lessons…

- Value the people skills of therapists
- Develop a shared language to produce high quality information & design high quality studies
- Develop better tools to measure non-pathological distress

Dr Jane Maher

Aims

- To evaluate the effectiveness of aromatherapy massage in improving the life quality of cancer patients
- A multi-centre randomised study in a 'real life setting
- Clinically important outcome measures

Dr Jane Maher

Multiple perspectives of investigators

- Nurse/therapist (Dr Susie Wilkinson)
- Oncologist (Dr Jane Maher)
- Psychiatrist (Professor Amanda Ramirez)

CR-UK/ICRF/Marie Curie/Macmillan Cancer Relief
Mount Vernon Cancer Centre
Clatterbridge Cancer Centre

Dr Jane Maher

Multiple settings

- Cancer centre
- Radiotherapy department
- Hospice
- Cancer support and information centre

Appropriate target group

- Advanced but not terminal disease
- Measurable distress (HADS/STAI)

Dr Jane Maher

Problem : Therapies had different meanings for patients

- Aromatherapy - passive
- Need permission
- Not self help

- Relaxation - active
- Don't need permission
- Self help

Walker et al, 1999

Dr Jane Maher

Lessons

- Long set up time
- Expensive (£300K)
- Multiple perspectives
- Multiple end points
- Need a common language
- Difficult to accrue
- Not all complementary therapies are the same!

Using traditional acupuncture for hot flushes and night sweats in women taking Tamoxifen
A pilot study

de Valois B,[1] Young T,[1] Hunter M,[2] Lucey R,[1] Maher E J[1]

[1] Supportive Oncology Research Team, Lynda Jackson Macmillan Centre, Mount Vernon Hospital, Rickmansworth Road, Northwood, Middlesex HA6 2RN

[2] Cancer Research UK London Psychosocial Group, Guy's, King's & St Thomas' School of Medicine, St Thomas' Hospital, London SE1 7EH

Objective

To evaluate the effectiveness and acceptability of using traditional acupuncture to manage hot flushes and night sweats experienced by women taking Tamoxifen as an adjuvant treatment for breast cancer.

Dr Elizabeth Thompson

Consultant Homeopathic Physician and Honorary Senior Lecturer in Palliative care – Bristol Homeopathic Hospital

1. Homeopathic approach to symptom control in the cancer patient
2. Clinical Trials Steering Group and Regional Complementary Therapy Research Group
3. Association of Palliative Medicine Task Group for Complementary Therapies reviewing holistic tools to create a handbook of tools

Dr Elizabeth Thompson

4. Research projects investigation levels of psychiatric morbidity and coping strategies in cancer patients using CAM

- Plan to take part in multi-centred trial with TRAUMEEL (stomatitis for adults undergoing BMT)
- Plan to conduct RCT with iscador re supporting immune function and QoL

5. MD thesis RCT of women with breast cancer and menopausal symptoms using homeopathy. Assessment of symptom control, mood disturbance and QoL
6. Homeopathic consultation – the process

Dr Elizabeth Thompson

References:

- The Homeopathic Approach to the Treatment of Symptoms of Oestrogen Withdrawal in the Breast Cancer Patient. A Prospective Observational Study
  Thompson E.A. Reilly D. (accepted for publication Homeopathy Feb 2003)
- A Pilot Randomised Placebo-Controlled Trial of Homeopathy in the Management of Menopausal Symptoms in Breast Cancer Survivors
  Thompson E, Douglas D, Norrie J, Reilly D. Oral presentation
  8th International Conference of CAM, Exeter University
  Homeopathy in cancer care.Br Homeopath J. 2000 Apr;89(2):61-2.

A Nutraceutical Approach to Glioma Management

Dr Bali Rooprai /Professor Geoffrey Pilkington

Institute of Psychiatry, King's College, London.

Dr Bali Rooprai /Professor Geoffrey Pilkington

Citrus flavonoids:

- Several reports suggest that citrus flavonoids have anti invasive, anti proliferative and anti angiogenic effects in other cancers
- No reports of effects of citrus flavonoids in brain tumours apart from our studies

Dr Bali Rooprai /Professor Geoffrey Pilkington

Research plan to study the effects of citrus flavonoids on gliomas

Effects of citrus flavonoids on parameters of brain tumour invasion in cell cultures derived from adult & paediatric brain tumour biopsies.

Tissue Culture	Blood-Brain Barrier (Animal and Human)
Dr. Bali Rooprai	Dr. David Dexter
Miss Maria Christidou	Miss Maria Christidou

141

Dr Bali Rooprai /Professor Geoffrey Pilkington

Protocols used to study the Effects of Citrus Flavonoids on Gliomas

- Viability assays
- Flow cytometry
  (Collaboration with Dr. Davies, Cancer Research UK)
- Time lapse video microscopy
  (Collaboration with Dr. Zicha, Cancer Research UK)
- Blood-Brain-Barrier
  (Collaboration with Neurosurgeons at King s College Hospital)
- Gene expression of degradative enzymes (proteases)
  (Collaboration with Prof Edwards- University of East Anglia)

142

Dr Bali Rooprai /Professor Geoffrey Pilkington

Cumulative results

CITRUS FLAVONOIDS (Tangeretin/nobiletin)
- downregulation of Proteases (MMPs) mediating invasion

ISOFLAVONES (Soya/Red Clover)
- upregulation of NCAMs & reduction of cell motility

RED GRAPE SEED EXTRACT
- downregulation of CD44 & upregulation of NCAMs
- Angiogenesis ?

CHOKEBERRY EXTRACT
- downregulation of MMPs & CD44

LYCOPENE (Tomatoes)
- reduction of motility

SELENIUM
- induction of apoptosis

143

Dr Bali Rooprai /Professor Geoffrey Pilkington

Clinical trial:

Nutraceutical Approach to Glioma Management

- Tangeretin
  [citrus flavonoids]
  200 mg/day

- Isoflavones
  (red clover/soya)
  350 mg/day

- Red grape seed
  300 mg x twice daily

- Chokeberry extract
  (flavonoids /lectins)
  200 mg/day

- Lycopene (tomato)
  25 mg/day

- Selenium
  200 µg/day

144

Dr Bali Rooprai /Professor Geoffrey Pilkington

Clinical trial: nutraceutical approach to glioma management

- Ethical approval obtained from King's College Hospital in November 2000
- Have to activate trial within 3 years
- Negotiated with all suppliers for flavonoids (from USA and Israel) for the trial
- There is NO FUNDING to activate the trial yet

145

Dr Jacqueline Filshie
Consultant in Anaesthesia & Pain Management
Royal Marsden Hospital, London and Surrey
Honorary Senior Lecturer, Institute of Cancer Research

The Use of Acupuncture in Symptom Management in Palliative Care

146

Dr Jacqueline Filshie

Breast Pain

Dr Jacqueline Filshie

Breast Pain

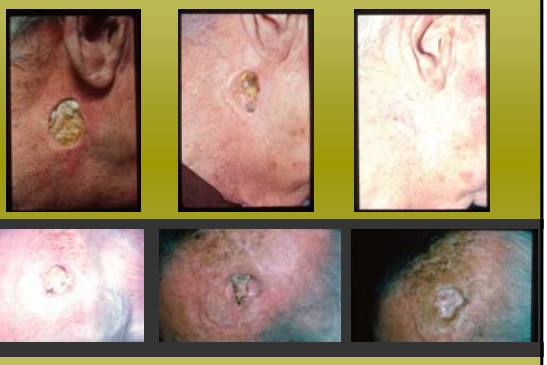
67 patients age n=56 Timescale one month

Average pain	improvement p<0.001
Worst pain	improvement p<0.001
Distress levels	improvement p<0.001
Interference with lifestyle	improvement p<0.001
Pain behaviour	improvement p<0.001
Anxiety	marginal fall
Depression	significant fall p<0.05

Filshie, 1997

147

Radionecrotic Ulcers



148

Dr Jacqueline Filshie

Advanced cancer related breathlessness

149

Dr Jacqueline Filshie

Advanced cancer related breathlessness

Pilot study 20 patients

- Subjective improvement of breathlessness
  Borg VAS P<0.005
- Objective improvement of breathlessness
  Respiratory rate P< 0.02
- Profound sense of relaxation
  P<0.005
- Limited duration
- 14/20 marked symptomatic relief from treatment

Filshie et al, 1996

150

Dr Jacqueline Filshie

Anxiety, sickness and dyspnoea - indwelling ASAD points

151

Dr Jacqueline Filshie

Acupuncture can mask cancer and serious problems, therefore should be given or supervised by a physician with knowledge about the clinical stage and treatment

An energetic diagnosis alone may be risky in these patients

The British Medical Acupuncture Society has made the whole safety issue of AIM available free of charge via its website:

www.medical-acupuncture.co.uk

152

CAM Research - General

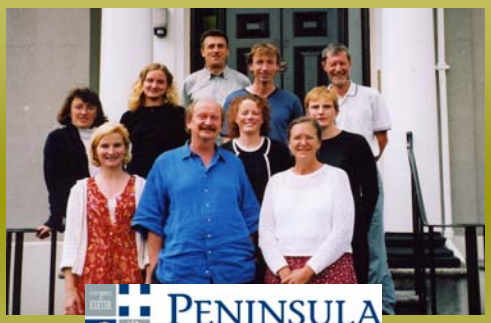
Funders of Research in CAM

- NHS R&D Programme (within both the Health Technology Assessment Programme and Regional Programmes)
- The UK Research Councils
- Other medical research charities – some with a specific interest in CAM
- Commercial and industrial sources
- Also, university based institutions and centres within departments of medicine, hospital sites, primary care, private institutions

Dr George Lewith

University of Southampton
Complementary Medicine Research Unit

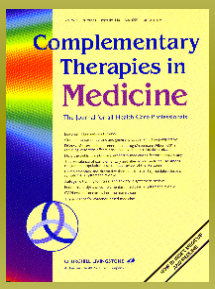
- Randomised controlled trials investigating the use of acupuncture in disabling breathlessness (in submission to Thorax)
- A survey of the use of complementary medicine within the cancer care directorate in Southampton University Hospitals Trust (Complementary Therapies in Medicine, 2002)
- An investigation using qualitative techniques into the drivers behind CAM use in cancer and palliative care (Department of Health grant involving cooperation between the School of Medicine and the School of Nursing and Midwifery, University of Southampton).

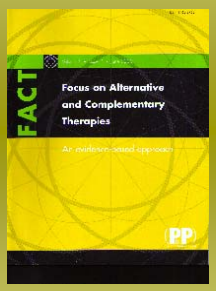


PENINSULA MEDICAL SCHOOL
UNIVERSITIES OF EXETER & PLYMOUTH

Professor Edzard Ernst
edzard.ernst@pms.ac.uk

Peninsula Medical School





Dr. Adrian White

The School of Integrated Health at the University of Westminster

- The largest higher education provider of CAM professional training in the UK
- Students can study CAM from undergraduate through to PhD level
- Clinical training is based within the University training clinic and placements with other health care providers, for example hospices
- Research initiatives within the School include assessing the production and safety of plant based interventions, and the development of a clinical governance framework for CAM practitioners working in primary care

http://www.wmin.ac.uk/sih/

UNIVERSITY OF WESTMINSTER

Research Council for Complementary Medicine (RCCM)

The aims:

Facilitation of appropriate research. Foster a network of researchers 'Complementary and Alternative Medicine Researcher Network (CAMRN) and promote, undertake, commission and facilitate research.

http://www.rccm.org.uk

Research Council for Complementary Medicine

Research Council for Complementary Medicine (RCCM)

Exploration of the relationship between CAM and conventional medicine

Dissemination

To collect, review and disseminate research-based information about CAM treatments and philosophies, to provide the public, government organisations, researchers and practitioners with an evidence-base.

Research Council for Complementary Medicine

Research Council for Complementary Medicine (RCCM)

Database of research citations in CAM

This Centralised Information System in Complementary Medicine (CISCOM) contains over 83,000 records and applies a specialist thesaurus in order to index and retrieve the citations. More than 3,500 of these records relate to CAM research in cancer.

Research Council for Complementary Medicine

Research Council for Complementary Medicine (RCCM)

The development of a database of CAM in cancer care is underway.

- Funded by the UK Department of Health
- This development includes the synthesis, through a systematic review and appraisal process, of the research literature relating to 10 CAM therapies and their use in cancer
- Undertaken in association with the School of Integrated Health at the University of Westminster -Dr Janet Richardson

www.rccm.org.uk

Research Council for Complementary Medicine

Jos Kleijnen

THE UNIVERSITY of York

Building CAM Research Capacity

Department of Health

Strategy to Develop CAM Research Capacity

"an environment that supports and values the development of research skills and experience, enables access to research training opportunities and resources to undertake research activity, provides secure and attractive career pathways and encourages the development of high quality research projects."

Professor Cliff Bailey
NHS Research Capacity Development Programme

Department of Health

Strategy to Develop CAM Research Capacity

The structure of the capacity building initiative will comprise four elements:

1) Identification of host academic institutions, with a demonstrable track record of appropriate research activity and collaboration with CAM organisations, to provide methodological advice, skills development and research support.
2) Personal award schemes at postdoctoral and training fellowship levels.
3) Establishment of a commissioning mechanism.
4) Development of a research support network.

Wellcome Trust

Funding of research in CAM

- 4 major panels, each with their own scientific remit (neurosciences, infection and immunity, physiology and pharmacology and molecular and cell
- CAM research must fall within the biomedical remit and the science is judged by peers must be of sufficiently high quality (to avoid bias, scientific officers go to great lengths to select referees with the necessary expertise to peer review proposals)

Wellcome Trust

Funding of research in CAM

- CAM is reviewed through the panel system enhances its credibility among other areas of science rather than being viewed as a second rate science
- Majority of funded research is in counselling and nutrition
- The Trust's History of Medicine Programme offers opportunities to explore the development and understanding of CAM therapies by exploring the cultural, social and economic contexts of these areas

Issues in CAM Research

Issues in CAM Research

- Safety
- Efficacy
- Effectiveness
- Cost effectiveness

- The role
- Plausibility
- Pseudoscience

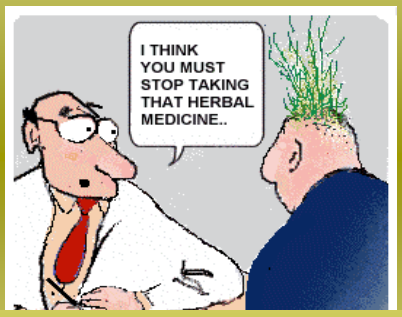
- Funding
- Prioritising

- Trial design
- Outcome measures
- Measuring tools

- Placebo response
- Therapeutic relationship

- CAM vs orthodox practitioners – perspectives
- Shared language
- Dialogue

Addressing Safety



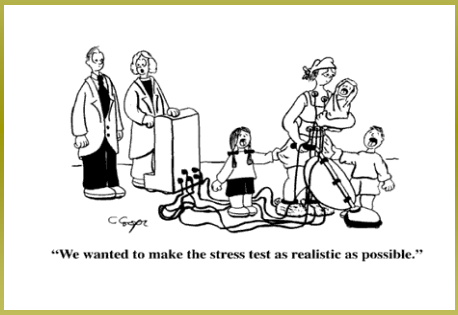
Plausibility

Pet Diagnostics

Can canines detect cancer?

Church J and Williams H. Another sniffer dog for the clinic? *Lancet* 2001. Sept 15; 358(9285): 9300

Trial Design



The reasonable man adapts himself to the world: the unreasonable man persists in trying to adapt the world to himself. Therefore all progress depends on the unreasonable man.

George Bernard Shaw

Challenges of dealing with alien language…

The human body is an electromagnet, producing a radiating energy field ('aura') affected by incoming **energy** channelled through the healer

Dealing with claims…

"the essential oil germanium is very effective for menopausal problems, diabetes, blood disorders, throat infections … applications from frostbite to infertility

Worwood VA, The Fragrant Pharmacy 1991 : 25

Collaboration

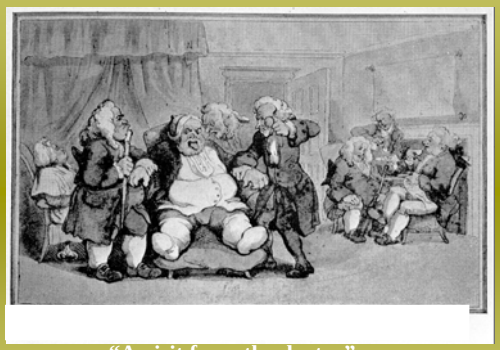
Oxford English dictionary definition

Consort traitorously with the enemy

OR

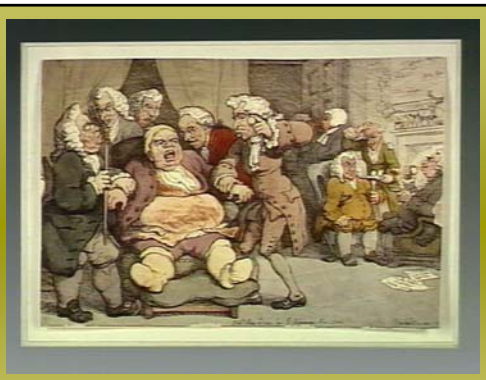
Work jointly with each other

The Therapeutic Relationship



"A visit from the doctor"

Print, by Thomas Rowlandson, Smith, R.A.L., Bath, London, Batsford, 1944.

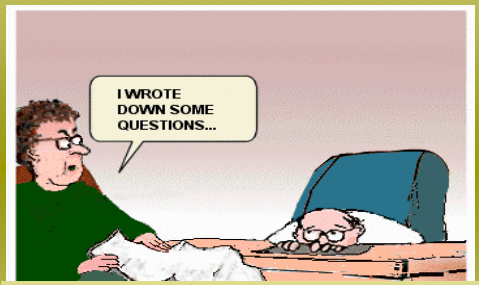


"The consultation, or last hope"

Engraving, May 12, 1808, by Thomas Rowlandson

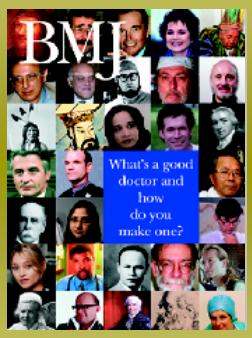
"A gouty patient in his room full of unproductive doctors"

Coloured etching by Thomas Rowlandson, 1808.



The Therapeutic Relationship

The Therapeutic Relationship



BMJ 28th September 2002 – Issue: 7366

183

Courtesy of The Advert s ng Arch ves

184

Measurement Tools

Developing a tool to measure holistic practice:
a missing dimension in outcomes measurement within complementary therapies

- **Long AF, Mercer G, Hughes K.**
  Health Care Practice R&D Unit, University of Salford, UK.

185

Dr Charlotte Paterson

Measure Yourself Concerns and Wellbeing (MYCAW)

Follow up form (self completion version)

Today s date .....
Look overleaf at the concerns that you wrote down before (please do not change these).

On this side of the form, circle a number to show how severe each of those concerns or problems is now:

Concern or problem 1: 0 1 2 3 4 5 6
Not bothering me at all — bothers me greatly

Concern or problem 2: 0 1 2 3 4 5 6
Not bothering me at all — bothers me greatly

186

Dr Charlotte Paterson

Wellbeing:

How would you rate your general feeling of wellbeing now ?
(How do you feel in yourself?)

0 1 2 3 4 5 6
As good as it could be — As bad as it could be

Other things affecting your health

The treatment that you have received here may not be the only thing affecting your concern or 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.

What has been most important for you?

Reflecting on your time with this Centre, what were the most important aspects for you? (write overleaf if you need more space)

Thank you for completing this form.

187

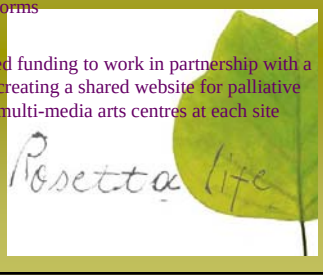
Spirituality and Clinical Care

BMJ 21st December 2002 Vol 325 Issue: 7378

188

Rosetta Life

- Rosetta Life is an artist-led organisation enabling people with life threatening illnesses and their families to explore their experiences through video, photography, drama, poetry, fiction and other art forms
- We have now received funding to work in partnership with a network of hospices creating a shared website for palliative care users served by multi-media arts centres at each site



189

Patient Centred Research

190

Macmillan Cancer Relief

Developing a research programme

- Improving the evidence base
- Involving people affected by cancer in research
- Ensuring that research in areas prioritised by people affected by cancer are taken forward
- Influencing the research priorities of other funders

191

Macmillan Cancer Relief

User involvement in shaping the agenda

Ensuring people affected by cancer are involved in research

- CancerVOICES, is a well established and widely respected network of over 400 user representatives
- The CancerVOICES Reference Group will act as key advisors on the development of the research strategy

Macmillan cancer relief

192

Macmillan Cancer Relief

The User Involvement Programme has been established as one of Macmillan s five key service programmes for 2002 and beyond

Macmillan cancer relief

193

Complementary Therapy in Cancer Charity Group

- Macmillan Cancer Relief
- Prince of Wales's Foundation for Integrated Health
- Marie Curie Cancer Care
- Breakthrough Breast Cancer
- Bristol Cancer Help Centre

Collaborative Group supported by HRH the Prince of Wales to promote and encourage research in the field

194

195

The Future

196

Issues in CAM Research

- Safety
- Efficacy
- Effectiveness
- Cost effectiveness

- The role
- Plausibility
- Pseudoscience

- Funding
- Prioritising

- Trial design
- Outcome measures
- Measuring tools

- Placebo response
- Therapeutic relationship

- CAM vs orthodox practitioners – perspectives
- Shared language
- Dialogue

197

Delivering Care

- **Technology**
- **Delivery**
- **Finance**
- **Society**

198

How complementary therapies can help patients during their cancer journey

Conveying the patient's voice

"It's acupuncture that's helped me to cope with the chemo."
Maggie on the reduction in nausea she experiences since she started having acupuncture before each chemotherapy treatment

"I've learnt to carry on the relaxation at home too. I sleep better and don't get so worked up."
Arthur, who attends a weekly relaxation group

"Massage simply makes me feel better and more able to cope."
Rose, whose husband has cancer

199

Dr Michelle Kohn

MB BS, BSc, MRCP (UK)

Complementary Therapies Medical Advisor to Macmillan Cancer Relief (UK)
and
Advisor to the Department of Health (UK)

NCI's - OCCAM
March 26th 2003