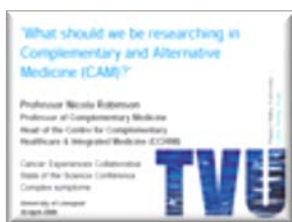


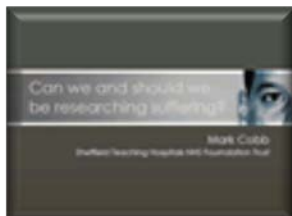
Introduction

The second State of the Science Meeting of the CECo Complex Symptoms theme took place on 10 April, at the Foresight Centre, University of Liverpool. Over 55 delegates attended including research partners, researchers from across the UK, hospice clinicians and specialist registrars in palliative medicine and representatives from primary, secondary and hospice care. Four thought provoking key note talks from eminent speakers from the UK and Europe set the scene. Professor Stein Kaasa, Chair of the European Association for Palliative Care Research Network and Professor in Palliative Medicine at the Norwegian University of Science and Technology; Professor Leslie Walker, Chair of Cancer Rehabilitation and Clinical Lead for the Division of Cancer at the University of Hull; Professor Nicola Robinson, Professor of Complementary Medicine at Thames Valley University and Chair of the Research Council for Complementary Medicine Research (see the included presentation slides that follow); and Reverend Mark Cobb, Senior Chaplain and Clinical Director at Sheffield Teaching Hospitals NHS Foundation Trust (see the included presentation slides that follow).

Click either of the two slide representations below to jump directly to that presentation.



Professor Nicola Robinson



Reverend Mark Cobb

'What should we be researching in Complementary and Alternative Medicine (CAM)?'

Professor Nicola Robinson
Professor of Complementary Medicine
Head of the Centre for Complementary
Healthcare & Integrated Medicine (CCHIM)

Cancer Experiences Collaborative
State of the Science Conference
Complex symptoms

University of Liverpool
10 April 2008



Outline of presentation

- What is CAM ?
- Who uses CAM ?
- How is it provided ?
- How should we research CAM ?
- Is there evidence of effectiveness ?
- What should we be researching in CAM ?

What is CAM ?

Health care which lies outside mainstream conventional medicine ?

Complex and ill defined ?



Examples of Complementary Approaches

Over the Counter treatments:

Herbal remedies Homeopathy
Vitamins, minerals and other food supplements



Mind Body techniques

Meditation, Mindfulness, Autogenics, Healing, Reiki

Complementary therapies (practitioner based)

Acupuncture	Chiropractic	Herbal medicine
Homeopathy	Osteopathy	Aromatherapy
Bach flower remedy	Massage	Reflexology
Nutritional medicine	Yoga	Ayurvedic medicine
Chinese herbs	Naturopathy	Traditional Chinese medicine

CAM use in the UK

- Herbal medicine 34%
- Aromatherapy 21%
- Homeopathy 17%
- Acupuncture 14%
- Reflexology 6%
- Massage 6%
- Osteopathy 4%
- Chiropractic 3%



Use of CAM in the UK

- Increasing
- Dissatisfaction
- Side effects
- Holistic approach
- Media
- Access
- Chronic disease



CAM use in cancer - palliative care and symptom management

- Prevalence of use - 7-75%
- Use varies according to geography, gender and disease diagnosis
- High patient satisfaction with CAM
- Doctors rarely informed by their patients
- Most patients use CAM to improve quality of life, boost immunity, relieve pain and/or control side effects related to cancer or its treatment

CAM use in Cancer

- Patients in the later stages of cancer; breast, prostate and paediatric patients use CAM more, perhaps twice as much.
- 86% of patients use CAM to complement their conventional treatment
- 68% using CAM found it helpful

Lewith (2006)

CAM use among people undergoing cancer treatment in UK: n=304

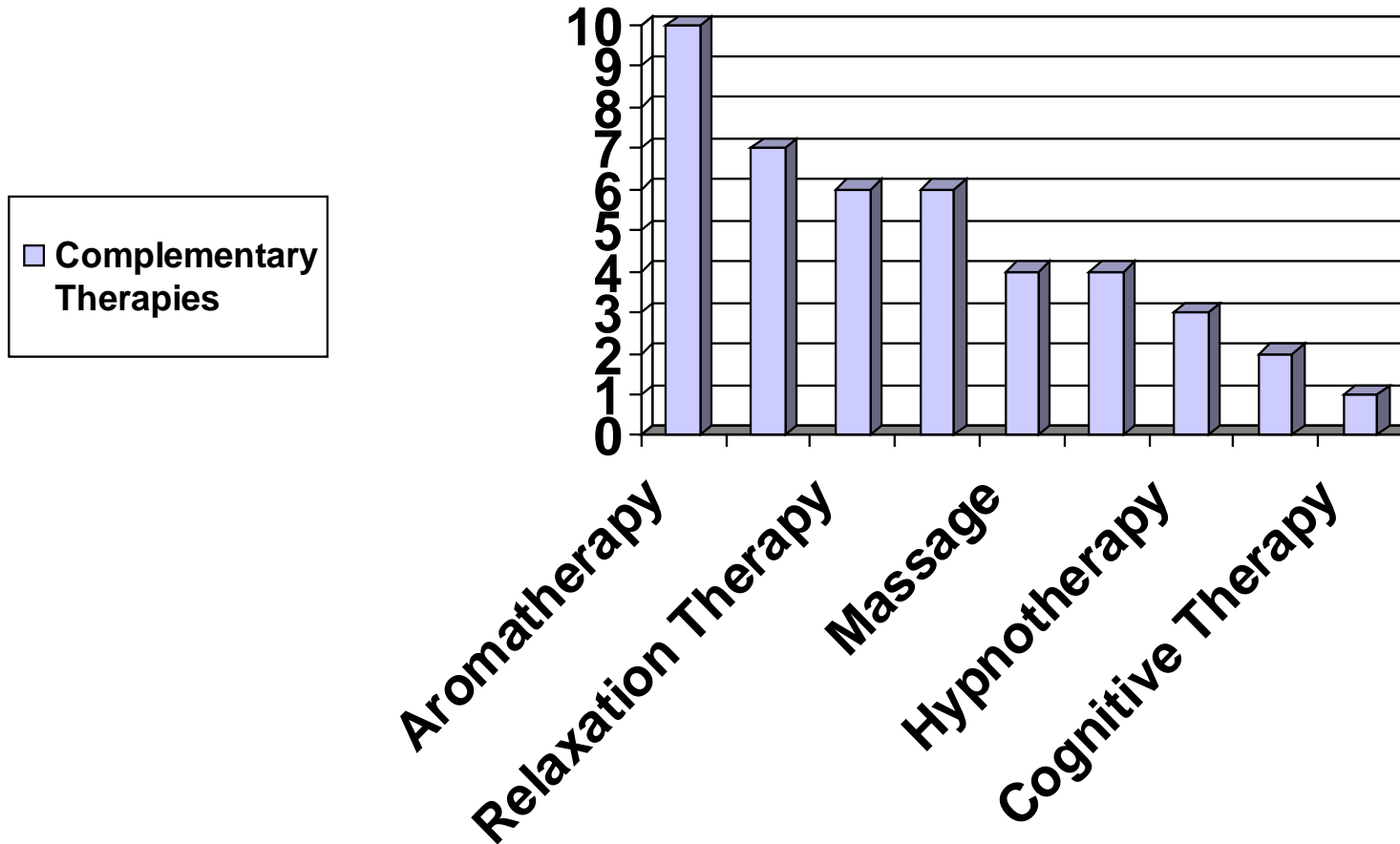
- 33% used CAM prior to diagnosis
- 29% used CAM since diagnosis
- 42% had sought help from a CAM practitioner
- 46% had bought over the counter treatments

CAM in UK Cancer Care

- >90% centres offer a 'touch/manipulative' therapy
- >80% of centres offer aromatherapy
- >80% provide at least one 'mind body' therapy

Macmillan Cancer Relief (2002)

CAM offered by Marie Curie Cancer Care Day Centres 2002



Auricular Acupuncture

- Service provided at Lynda Jackson Macmillan Centre as a result of practitioner research demonstrating a reduction in hot flushes related to Tamoxifen use



Issues facing CAM

- Lack of regulation - National guidelines
- Concern of healthcare professionals
- Funding of services
- Integration within NHS
- Research evidence

Complex interventions are :



“Built up from a number of components, which may act independently and interdependently”

Complex interventions depend on

- Context
- Understanding the problem
- Optimizing the intervention
- Evaluating the intervention
- Implementing the intervention

Evaluating CAM

- Can we measure health ?
- Can specific effects be measured ?

What are the issues for measuring effectiveness of CAM ?

- Individual approach to treatment
- Measurement of health outcomes
- Complex interventions
- Diversity of practice
- Research methodology – blinding, sham

Issues for outcome measurement

- Changes in patients health and well being may not be adequately captured by existing health outcome measures
- Changes in health and wellbeing are patient centered and non specific
- Changes in expectations of patients as a result of treatment are poorly recorded

Which outcome measures ?

- Clinically important – patient and practitioner perspective
- Valid, repeatable and sensitive to change
- Multiple measures may be required to demonstrate change/benefit
- Individualized treatment may require individual outcomes

CAM outcome measures

- Searchable, interactive database developed by IN-CAM (Canada)
- Containing practical outcome measures relevant to CAM research - to facilitate and support assessment of CAM interventions through high quality research
- Framework of outcome domains to facilitate planning research
- www.outcomesdatabase.org

Is there evidence of effectiveness ?

The Role of Complementary and Alternative Medicine in the NHS

An Investigation into the Potential Contribution of Mainstream
Complementary Therapies to Healthcare in the UK

Led by Christopher Smallwood

www.freshminds.co.uk

Centre for Complementary Healthcare & Integrated Medicine (CCHIM)
Faculty of Health & Human Science, Thames Valley University

Reflexology for symptom relief in patients with cancer: A systematic review

Fellowes D, Gambles M, Lockhart K, Wilkinson S, Storey L, 2006



Results

- 378 studies retrieved
- 6 included (Hodgson 2000, Stephenson 1997, 200,2003, Smith 2005, Ross 2002)
- Reflexology carried out by qualified practitioners
- Reliable and valid assessment tools for physical and psychological symptoms and QOL (pain, fatigue, nausea, vomiting, constipation, anxiety, depression)
- Adverse side effects monitored

Conclusions

- Reflexology may be effective in reducing physical and psychological symptoms and improving quality of life
- Patients receiving placebo reflexology also showed improvements
- Equivocal results
- Methodological problems
- No firm conclusions to be drawn regarding the benefits of reflexology for patients with cancer

Acupuncture for Cancer symptom management

- Cancer related pain (Pan et al 2000)
- Dyspnoea (Pan et al 2000)
- Fatigue (Vickers et al 2004, Molassiotis et al 2007)
- Nausea and vomiting (Shen et al 2000)
- Depression and anxiety (Roschke et al 2000)
- Hot Flush (Wyon et al 2004, de Valois 2006)

Advantages of acupuncture

- Less sedating
- Less constipating
- 10-20%patients are opioid resistant
- Fewer chemotherapy related side effects



Evidence for other CAM approaches

- Hypnosis –pain, anxiety (Lioffi et al 2001)
- Mindfulness – anxiety, depression, stress (Speca et al 2000, Carlson et al 2001, 2003)
- Aromatherapy – anxiety (Fellows et al 2004)
- Music Therapy – anxiety (Hilliard 2005)
- Botanicals – nausea and vomiting (Boon et al 2004, Taixiang et al 2005), flushes (Kronenburg 2002)
- Energy medicine –QOL (Astin et al 2000, Ernst 2003, Vaghela et al 2007)
- Yoga –anxiety, insomnia, stress (OTT 2002)

Summary of evidence for CAM

- Most CAM approaches in the treatment of cancer are safe when used in the hands of experienced CAM practitioners
- Common botanicals may interact with prescription drugs, should be used with caution, guided by knowledgeable oncologist
- Acupuncture, auricular acupuncture, therapeutic touch, massage, hypnosis are helpful to manage pain.
- Music Therapy, massage and hypnosis may have an effect on anxiety
- Acupuncture and massage possible therapeutic role in cancer fatigue
- Acupuncture and selected botanicals may reduce chemotherapy induced nausea and emesis
- Acupuncture, acupressure and muscle relaxation appear to relieve dyspnoea
- Hypnosis and guided imagery may be beneficial for anticipatory nausea and vomiting
- Transcendental meditation and mindfulness based stress reduction can play a role in management of depressed mood and anxiety
- Black cohosh, phytoestrogen rich foods, acupuncture may reduce flushing

How can we
continue to
build the
evidence ?





“To promote the development of high quality
complementary medicine research in the UK”

- Facilitation
- Information
- Dissemination

www.rrcm.org.uk

- **Review/appraisal of research on specific CAM in NHS priority areas**
 - 12 systematic reviews published in journals
 - 27 further systematic reviews on CAMEOL
 - 13 reviews of reviews transferred to the NLH CAM Specialist Library
 - 3 published papers on the methods
 - 3 papers on the overall project
 - Ongoing projects on cancer, mental health and qualitative research in CAM
 - Development of the NLH CAM Specialist Library www.library.nhs.uk/cam
- **CAM researcher network developed in 2003**
- **500 members and over 30 countries**

What should we be researching in CAM ?



Integrated healthcare ?



First hospital, Tianjin TCM College



Should we consider integrated healthcare ?

- The best of complementary and the best of conventional medicine
- Combined western and traditional diagnosis and treatment
- Availability of complementary medicine in conventional settings
- Patient centred approach



What should we be researching in CAM

- The best of complementary and the best of conventional medicine
- Combined western and traditional diagnosis and treatment
- Availability of complementary medicine in conventional settings
- Patient centred approach
- Mixed methods
- Cost effectiveness ?



“Of this I am quite sure, that if we open a quarrel between the past and the present, we shall find that we have lost the future.”

Extract from Winston Churchill's speech at the House of Commons, June 18, 1940

(<http://www.winstonchurchill.org/i4a/pages/index.cfm?pageid=418>)

References (1)

- Pan CX et al. CAM in the management of pain, dyspnea and nausea and vomiting near the end of Life: A systematic review. J of Pain and symptom Management 2000;20(5): 374 -387
- Molassiotis A et al. Use of CAM in cancer patients: a European survey Annals of Oncology 2005;16:655-663.
- Mansky PJ et al. Complementary medicine in Palliative care and cancer symptom management. The Cancer Journal 2006;12(5): 425-431.
- Thompson EA et al. Outcome measures for holistic, complex interventions within the palliative care setting. Complementary Therapies in Clinical Practice 2008;14: 25-

References (2)

- Cohen A et al Acupuncture: Role in Comprehensive Cancer Care- A primer for the oncologist and review of the literature . Integr Cancer Ther 2005;4: 131-143.
- Sood A et al. A critical review of Complementary Therapies for cancer related fatigue. Integr Cancer Ther 2007;6(1): 8-13.
- Molassiotis A et al The management of cancer- related fatigue after chemotherapy with acupuncture and acupressure. Complementary Therapies in Medicine 2007;15: 228-237.
- Lioffi C, White P. Efficacy of clinical hypnosis in the enhancement of quality of life of terminally ill cancer Patients. Contemp Hyp 2001;18:145-160

Professor Nicola Robinson
Professor of Complementary Medicine
Head of the Centre for Complementary
Healthcare & Integrated Medicine (CCHIM)
Chair of Research Council for
Complementary Medicine (RCCM)

Faculty of Health & Human Sciences
Thames Valley University
+44 (0)20 8209 4172
nicky.robinson@tvu.ac.uk
www.cchim.com



Can we and should we
be researching suffering?



Mark Cobb

Sheffield Teaching Hospitals NHS Foundation Trust

Outline

- the significance of suffering
- the nature of suffering
- ways of understanding suffering
- current research and its problems
- conclusions

THE NATIONAL COUNCIL FOR PALLIATIVE CARE

About Us



Subscribe



Events



Palliative
Care
Explained



News
Room



Publications

[Home](#) | [Contact Us](#) | [Donate](#) | [Users & Families](#) |
[Accessibility](#) | [Links](#) | [Site Map](#) | [Search](#)

Choose one...

[Online Library](#)

Welcome

A warm welcome to the National Council for Palliative Care's website. Our continuing mission is to ensure that all those suffering from life threatening conditions, who need palliative care, receive it.

Latest . . .

NCPC seeks Deputy Director of Policy Development [more](#)

NCPC Latest Publications: The Mental Capacity Act in Practice

Quick Links ...

[Dementia Project](#)

[Submit MDS Returns Online](#)

[Internal Cardioverter Defibrillators](#)

[Workforce Survey 2007 Results](#)

A
B I L L

TO

Enable a competent adult who is suffering unbearably as a result of a terminal illness to receive medical assistance to die at his own considered and persistent request; and to make provision for a person suffering from a terminal illness to receive pain relief medication.

Assisted Dying for the Terminally Ill Bill (2004)

When a person suffers they experience:

1. finitude: an intimation of their own mortality
2. vulnerability: an exposure of self to the power of others
3. dissolution: a fracturing of their own personhood
4. disruption: a destruction of normal family and community life

Pellegrino & Thomasma 1997

“Suffering occurs when an impending destruction of the person is perceived; it continues until the threat of disintegration has passed or until the integrity of the person can be restored in some other manner.”

Cassel 1982

Research

- Narrative
- Concepts
- Care
- Measurement

Human need	Goals of care	Therapeutic modality
For connection in the midst of suffering.	Encouraging meaning and purpose.	Narrative Therapy.
To make sense of current life situation.	Acknowledging suffering.	Meaning based cognitive therapy.
For purpose and authenticity.	Strengthening connections with others.	Meaning based existential therapy.
For significance.	Optimal palliative care.	Strengthening social supports and family supports or therapy.
To “take a break” from suffering.		Physical symptom management.
To have physical symptoms treated.		

Table 1
Mini Suffering State Examination (MSSE)

Suffering items	Yes (1)/no (0)
1. Not calm	
2. Screams	
3. Pain	
4. Decubitus ulcers	
5. Malnutrition	
6. Eating disorders	
7. Invasive action	
8. Unstable medical condition	
9. Suffering according to medical opinion	
10. Suffering according to family opinion	
MSSE score, total	
MSSE score interpretation:	
Low level of suffering	0–3
Intermediate level of suffering	4–6
High level of suffering	7–10

Research

- conceptual problems
- the silence of suffering
- measuring suffering

Can we and should we?

- attending to suffering is an ethical obligation for healthcare
- why do people experience suffering?
- how can we recognise when people are suffering?
- how might suffering be alleviated or avoided?

Key References

Adunsky A et al (2008) Mini-Suffering State Examination: Suffering and Survival of End-of-Life Cancer Patients in a Hospice Setting. *Am J Hosp Palliat Care* 24; 493 - 498

Aminoff BZ et al (2004) Measuring the suffering of end-stage dementia: reliability and validity of the Mini-Suffering State Examination. *Archives of Gerontology and Geriatrics* 38 (2004) 123–130

Cassel, EJ (1982) The Nature of Suffering and the Goals of Medicine. *NEJM*. Vol 306: pp. 639-645

Johnston N & Scholler-Jaquish A (eds) (2007) *Meaning in Suffering*. Madison: University of Wisconsin Press

Lethborg C, Aranda S & Kissane D. (2008) Meaning in adjustment to cancer: A model of care. *Palliative and Supportive Care*, 6, 61–70

Oakley A (2007) *Fracture: Adventures of a Broken Body*. Bristol: The Policy Press

Pellegrino, ED & Thomasma, DC (1997) *Helping and Healing*. Washington, D.C.: Georgetown University Press

Scarry, E (1985) *The Body in Pain: the making and unmaking of the world*. New York: Oxford University Press