SPIRITUAL SUPPORT IN END STAGE HEART FAILURE: A RANDOMISED CONTROLLED FEASIBILITY STUDY

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Overview

- 1. Why is it needed?
- 2. Our studies: what we did and what we found
- 3. Where do we go from here?

Other research team members

- Professor David Cohen (health economist)
- Dr Paul Jarvis (statistician)
- Jan Hillman (psychosocial counsellor)
- Rev Michael Marsden (chaplain)
- Jane Brooks (Nurse lead)
- Drs Huw Morgan, Barry Bowden (volunteer trainers)
- Dr Stephen Hutchison (Consultant Cardiologist)

GIG CYMRU NHS WALES
Bwrdd Iechyd Aneurin Bevan Health Board

University of South Wales
Prifysgol De Cymru

Nevill Hall Hospital, Abergavenny

USW, Pontypridd

1. Why is it needed?

- Evidence base
- Spiritual care: part of healthcare policy
- Poor care: Francis, Andrews, Winterbourne
- What's important to patients

Evidence: spirituality - QOL

- 13 studies e.g.

- Brady et al (1999(A case for including spirituality in quality of life measurement in oncology. Psychooncology, 8, 417-428
- Walsh K, King M, Jones L et al. Spiritual beliefs may affect outcome of bereavement: prospective study. *BMJ* 2002; 324:1551-1554.
- McClain CS, Rosenfeld B and Breltbart W. Effect of spiritual well-being on end-of-life despair in terminally ill cancer patients. Lancet 2003; 361:1603-1607.

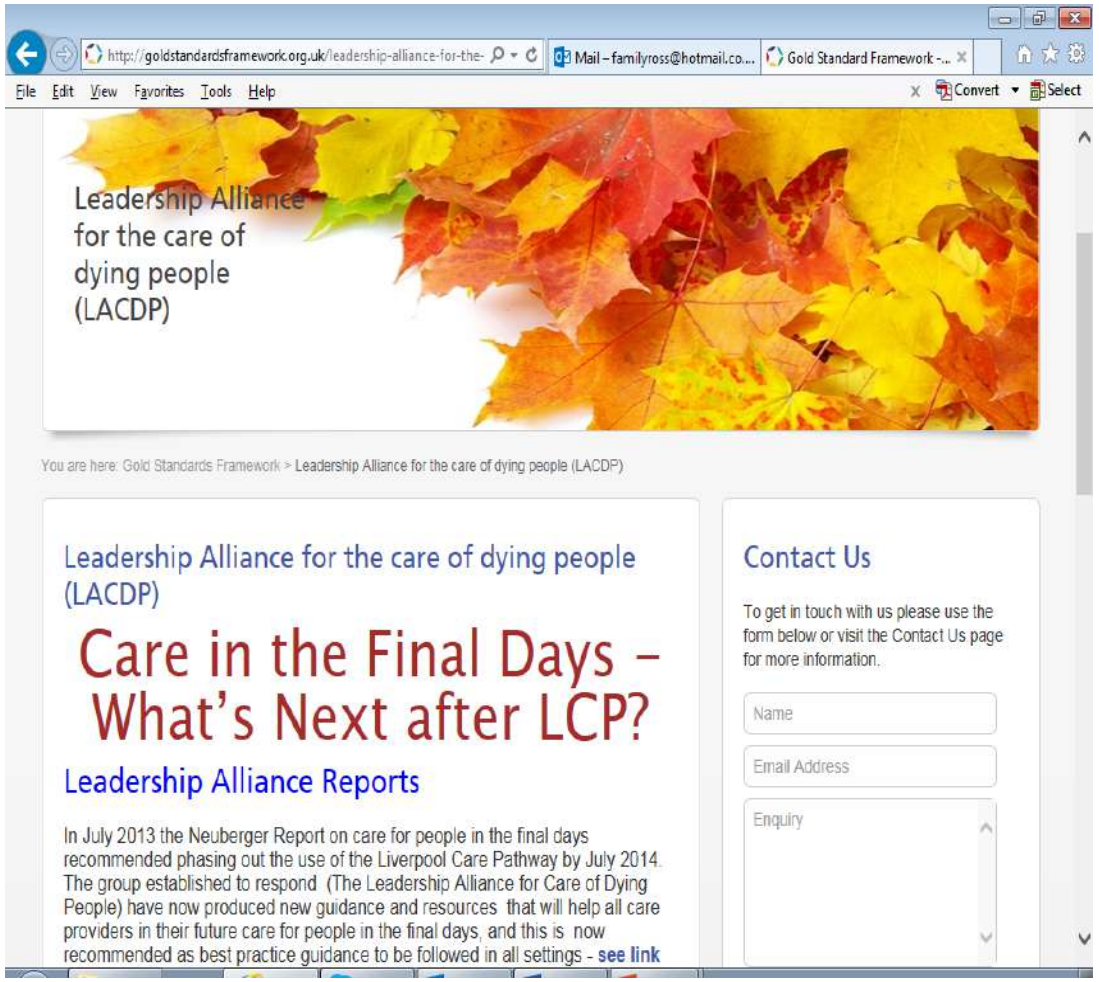
Evidence: Spirituality - mental health (depression, anxiety)

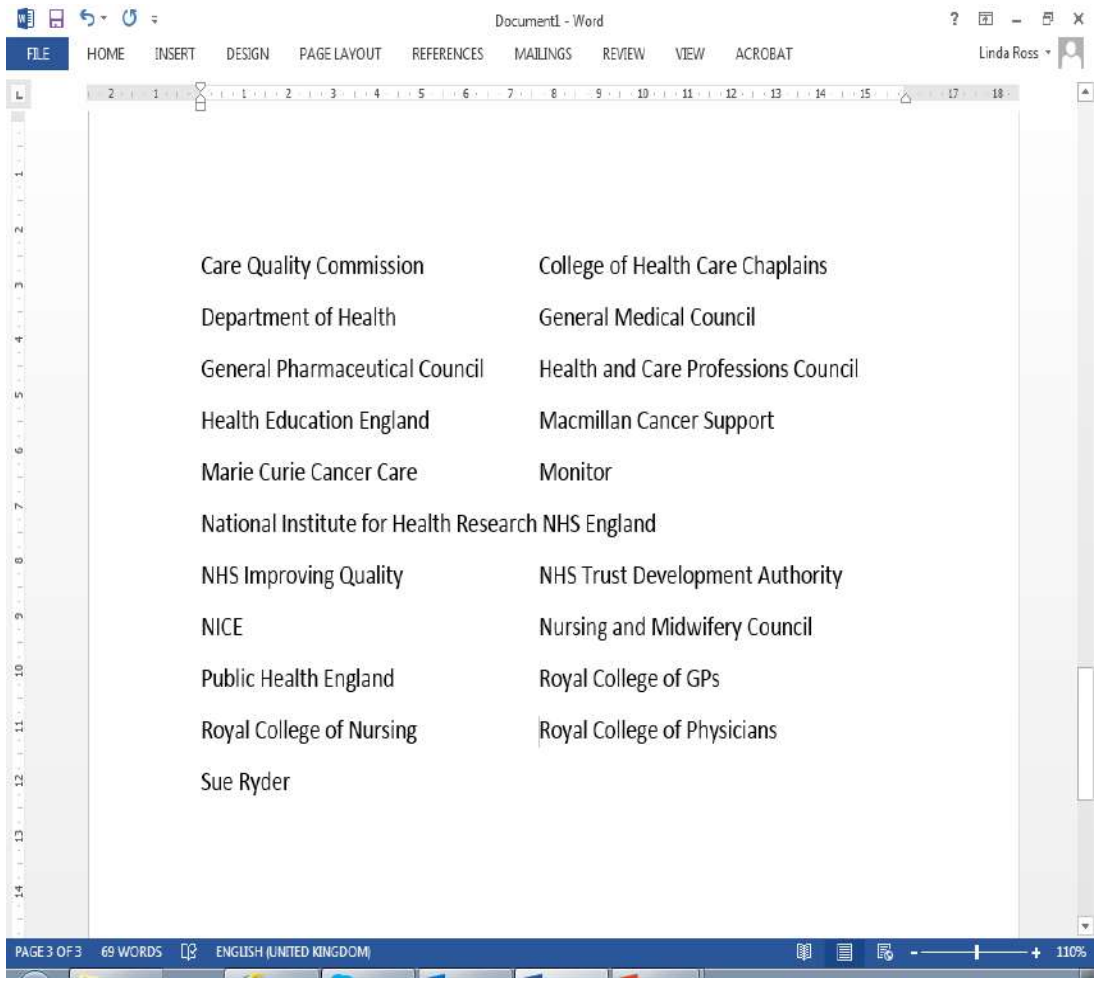
- 5 studies e.g.
- McClain CS, Rosenfeld B and Breltbart W. Effect of spiritual well-being on end-of-life despair in terminally ill cancer patients. *Lancet* 2003; 361:1603-1607.
- Bekelman et al (2007) Spiritual wellbeing and depression in patients with heart failure. J Gen Intern Med, 22, 470-477
- Nelson et al (2002) Spirituality, religion and depression in the terminally ill. Psychosomatics, 43, 213-220

Policy

Erasmus+ KA2 Grant Agreement Number: 2016-1-UK01-KA203-024467

Policy: LACDP 2014





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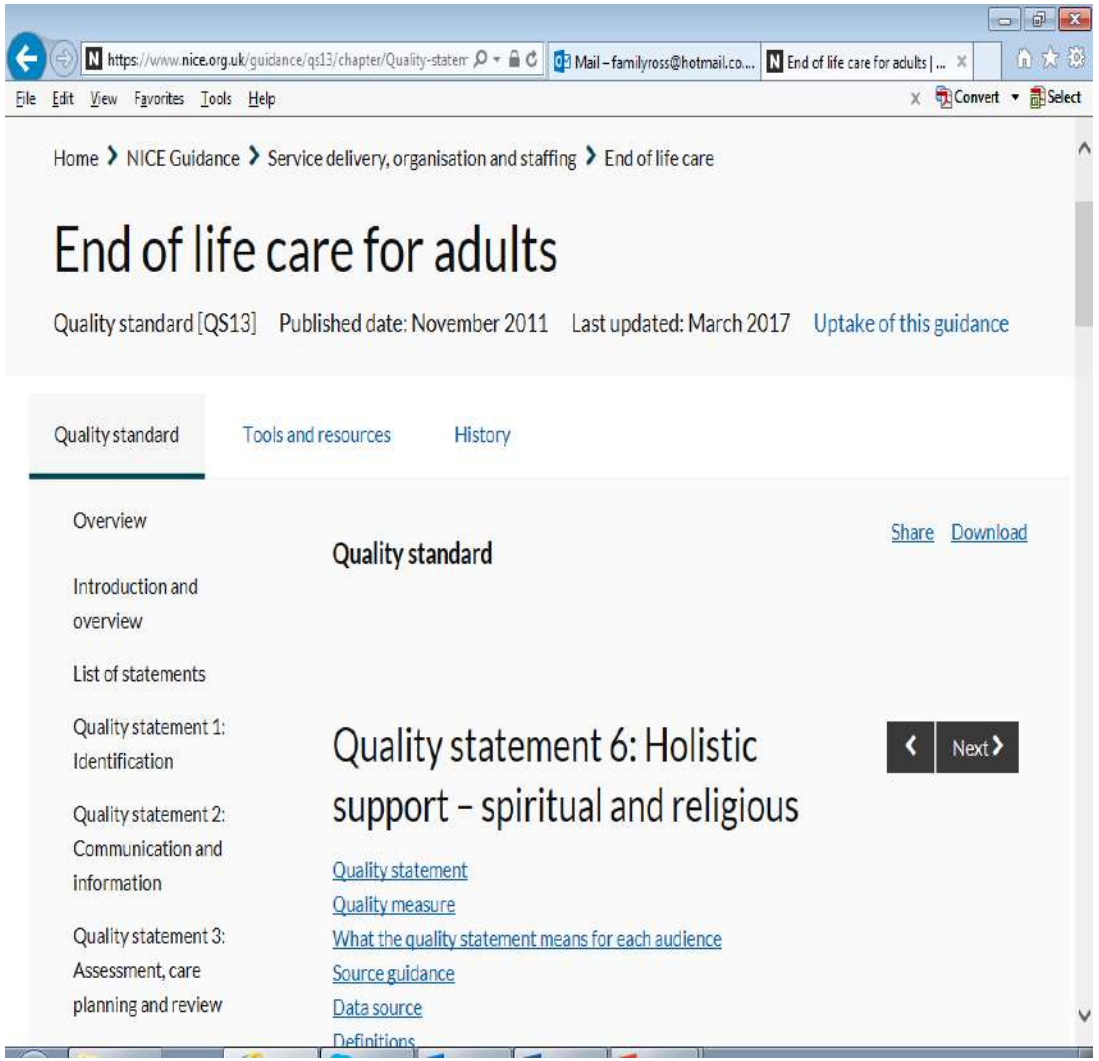

- **Quality statement**
- People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences.

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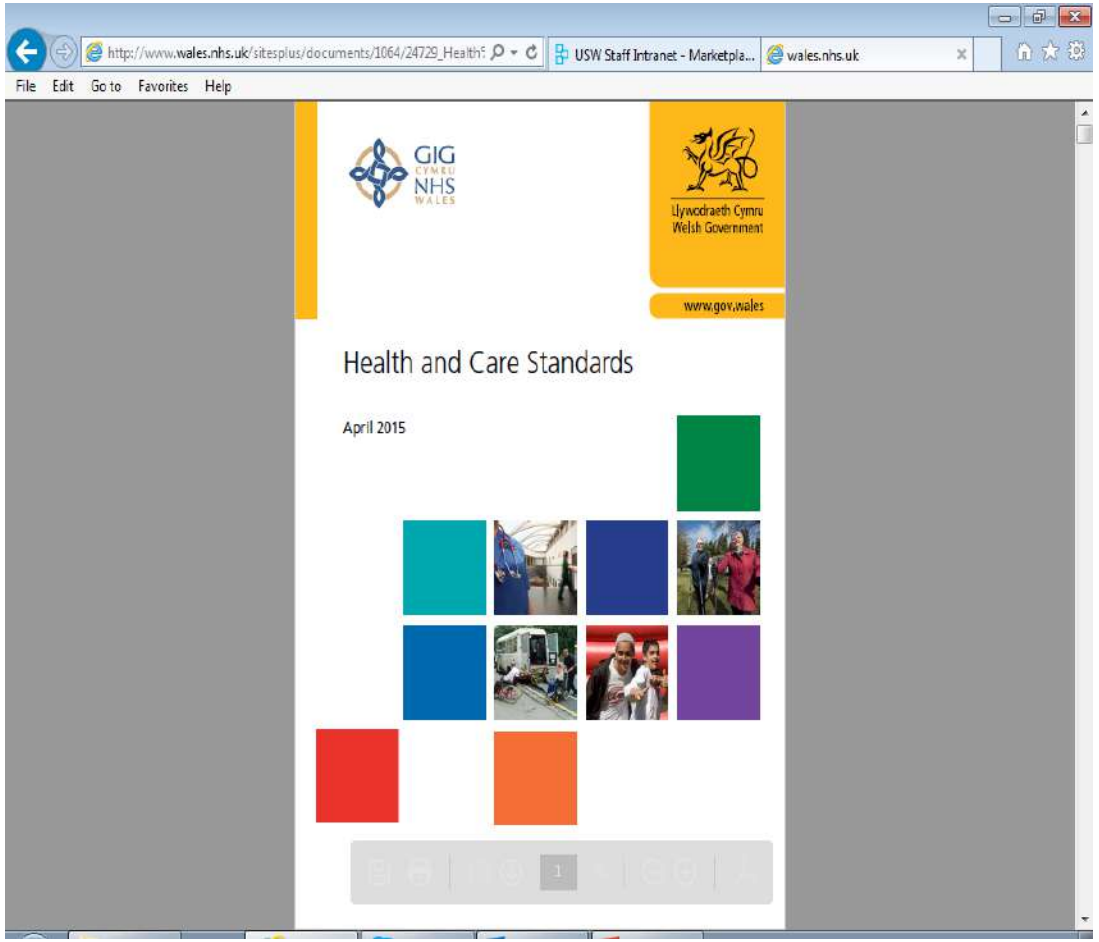
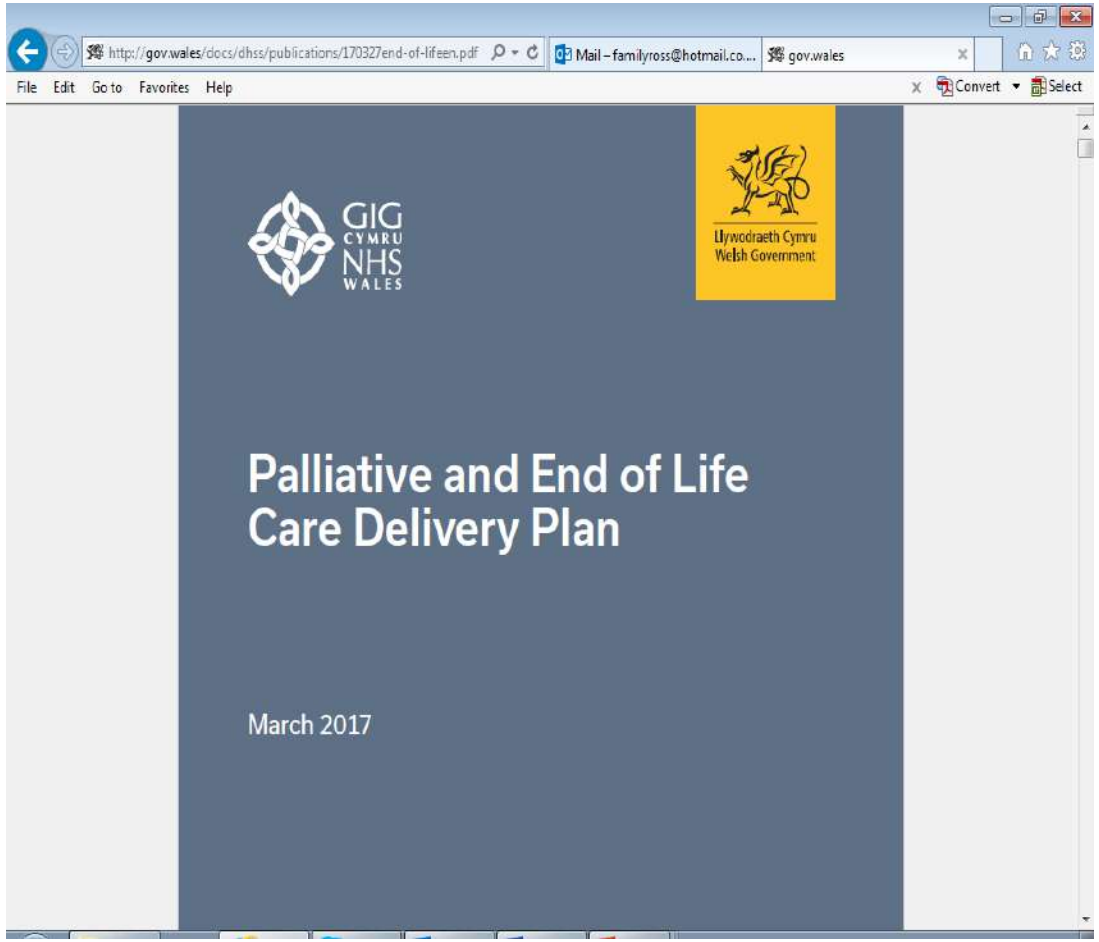
Policy: Wales





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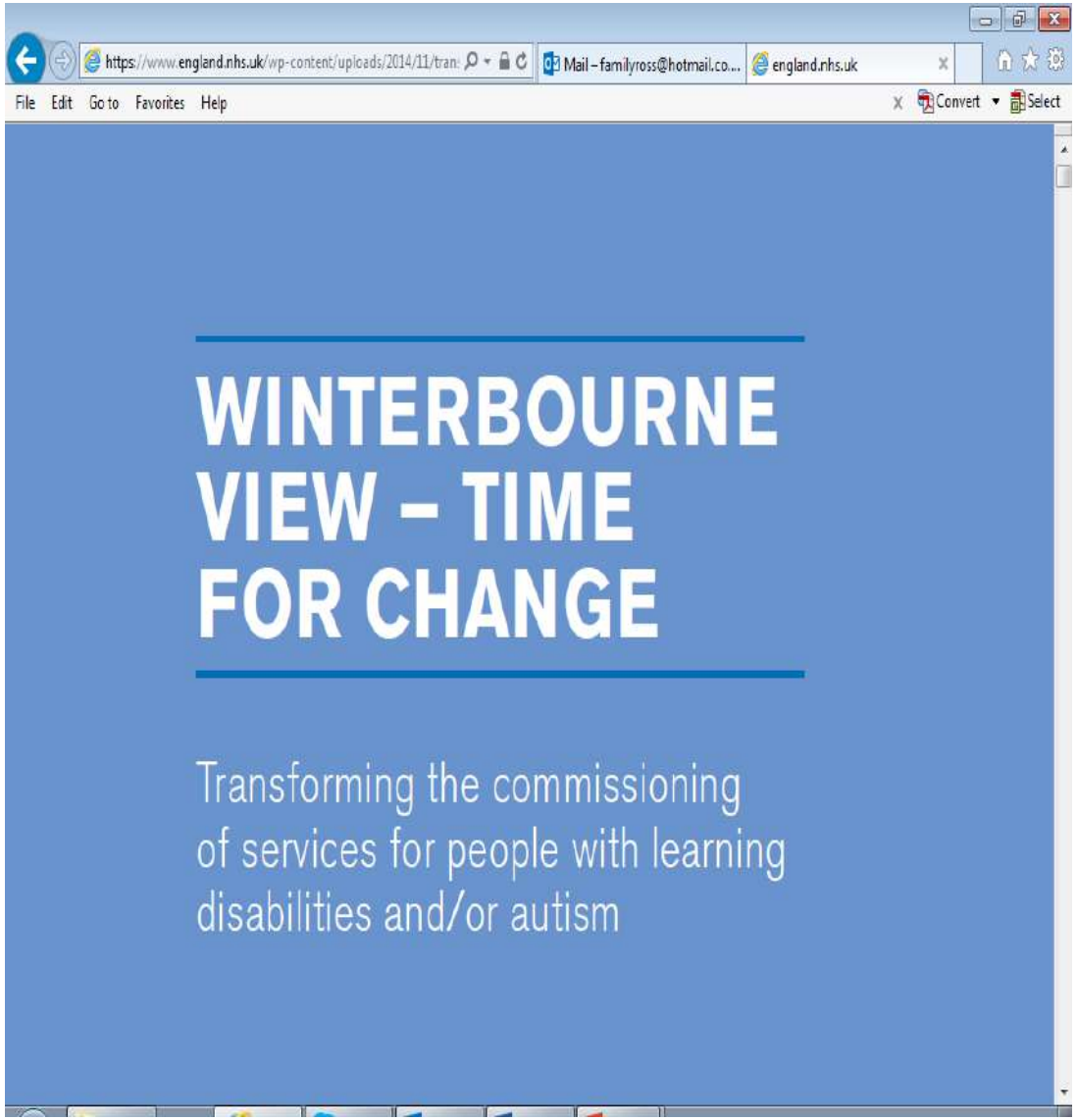
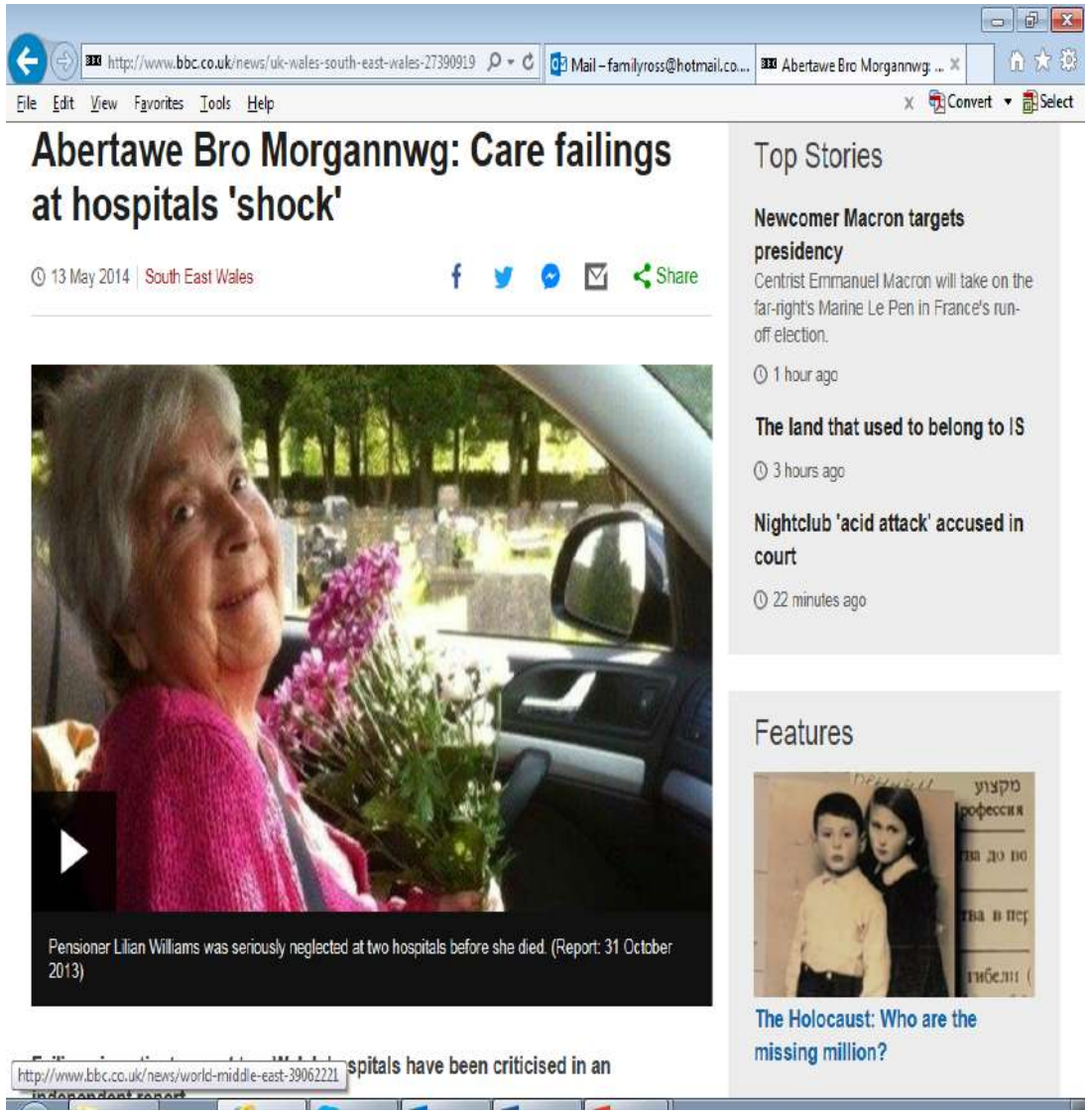
Poor care





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Recent Reports

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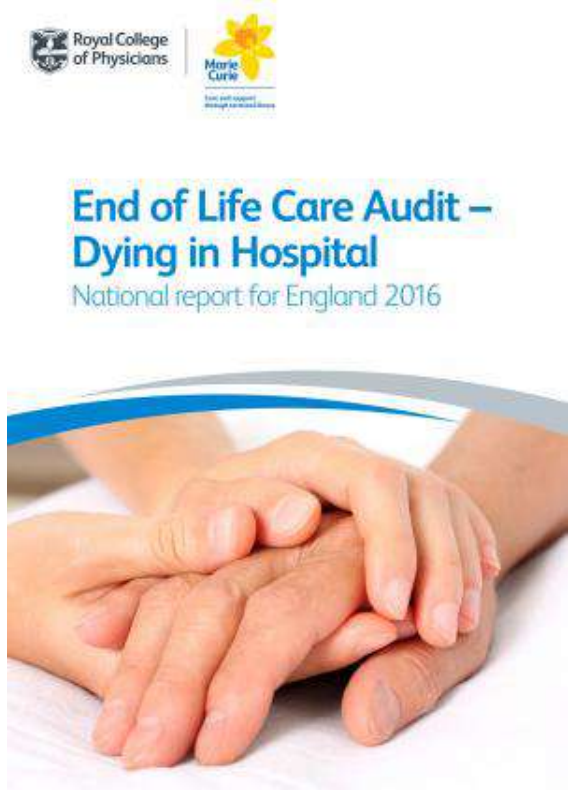
National care of the dying audit for hospitals, England

Discussions between clinicians and patients regarding spirituality in end-of-life care only occurs in 15 per cent of cases, and in an additional 27% of cases, people important to the patient had these discussions. This suggests that only in 42% of cases the patient and those important to them were asked about their spiritual needs



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What's important to patients

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Elderly patients' perceptions of their spiritual needs and care: a pilot study

Linda A. Ross (nee Waugh) BA RGN PhD

First published: October 1997 Full publication history

DOI: 10.1046/j.1365-2648.1997.00393.x View/save citation

Cited by (CrossRef): 23 articles Check for updates Citation tools

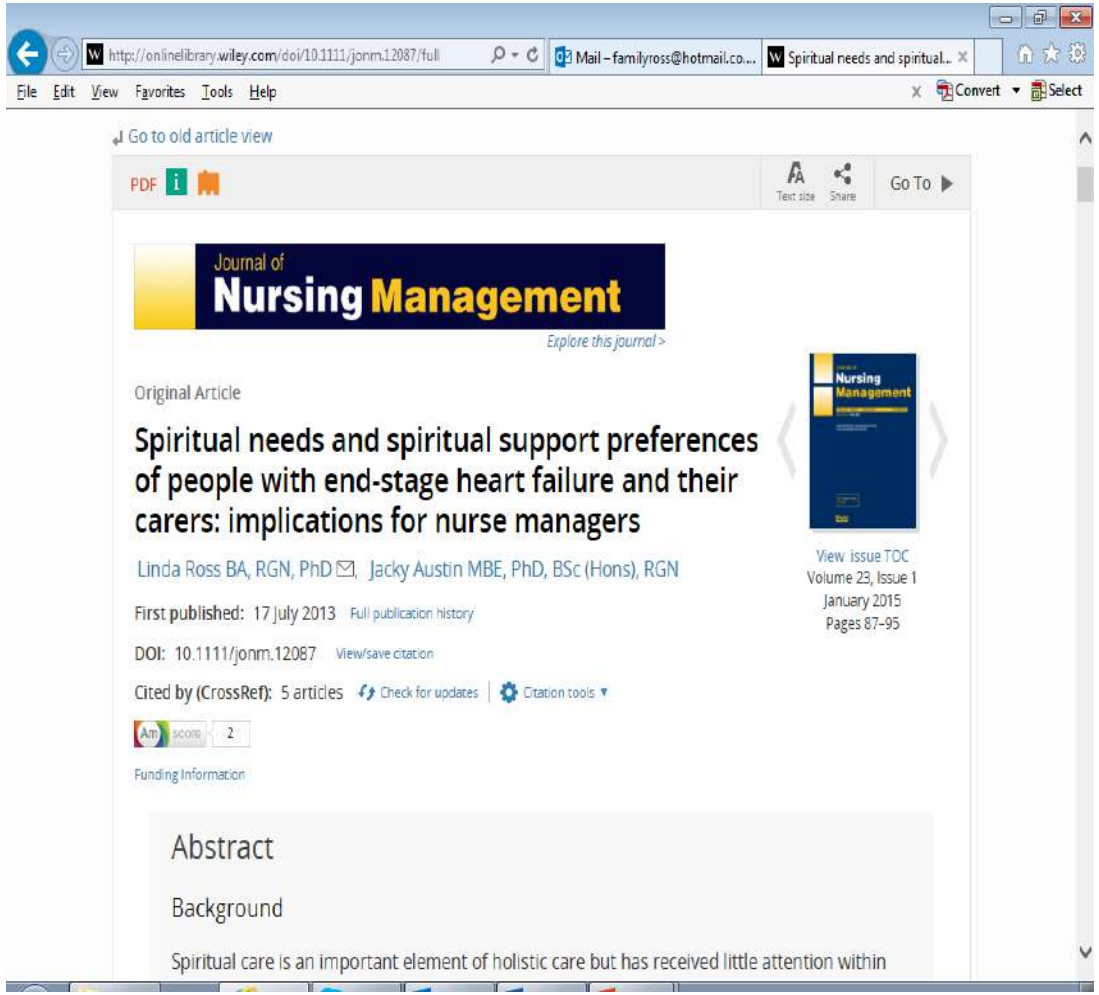
View issue TOC
Volume 26, Issue 4
October 1997
Pages 710–715

The study was conducted when the author was Research Fellow in the Department of Management and Social Sciences, Queen Margaret College, Edinburgh.

Dr. L. Ross, 22 Cardinal Drive, Lisvane, Cardi_ CF4 5GD, Wales.

Abstract

This paper describes a pilot study, in a small sample of elderly patients, designed to ascertain their perceptions of their spiritual needs and care. According to the nursing literature, spiritual care is part of the nurse's role. But it is not clear what spiritual needs are or how nurses are expected to give spiritual care. Ten patients from a care of the elderly assessment unit located in a hospital in Edinburgh, Scotland were interviewed about their spiritual needs in the



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Original Article

Spiritual needs and spiritual support preferences of people with end-stage heart failure and their carers: implications for nurse managers

Linda Ross BA, RGN, PhD, Jacky Austin MBE, PhD, BSc (Hons), RGN

First published: 17 July 2013 Full publication history

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Funding Information

View issue TOC
Volume 23, Issue 1
January 2015
Pages 87–95

Abstract

Background

Spiritual care is an important element of holistic care but has received little attention within

Evidence: spiritual support

- 8 studies e.g
- Balboni et al (2010) provision of spiritual care to patients with advanced cancer: associations with medical care and QOL near death. J Clin Oncol, 28, 445-452

- BUT unmet spiritual needs associated with poorer QOL (Astrow et al 2007)

European Association of Palliative Care

- ‘Spirituality is the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred.

The spiritual field is multidimensional:

- **1.Existential challenges** (e.g. questions concerning identity, meaning, suffering and death, guilt and shame, reconciliation and forgiveness, freedom and responsibility, hope and despair, love and joy).

- **2.Value based considerations and attitudes** (what is most important for each person, such as relations to oneself, family, friends, work, things nature, art and culture, ethics and morals, and life itself).

- **3.Religious considerations and foundations** (faith, beliefs and practices, the relationship with God or the ultimate).

- http://www.eapcnet.eu/Themes/ProjectsTaskforces/EAPCTaskforces/SpiritualCareinPalliativeCare.aspx accessed 9/1/18
- Puchalski et al (2014) Improving the spiritual dimension of whole person care: reaching national and international consensus. J Palliat Med,17, 642-656

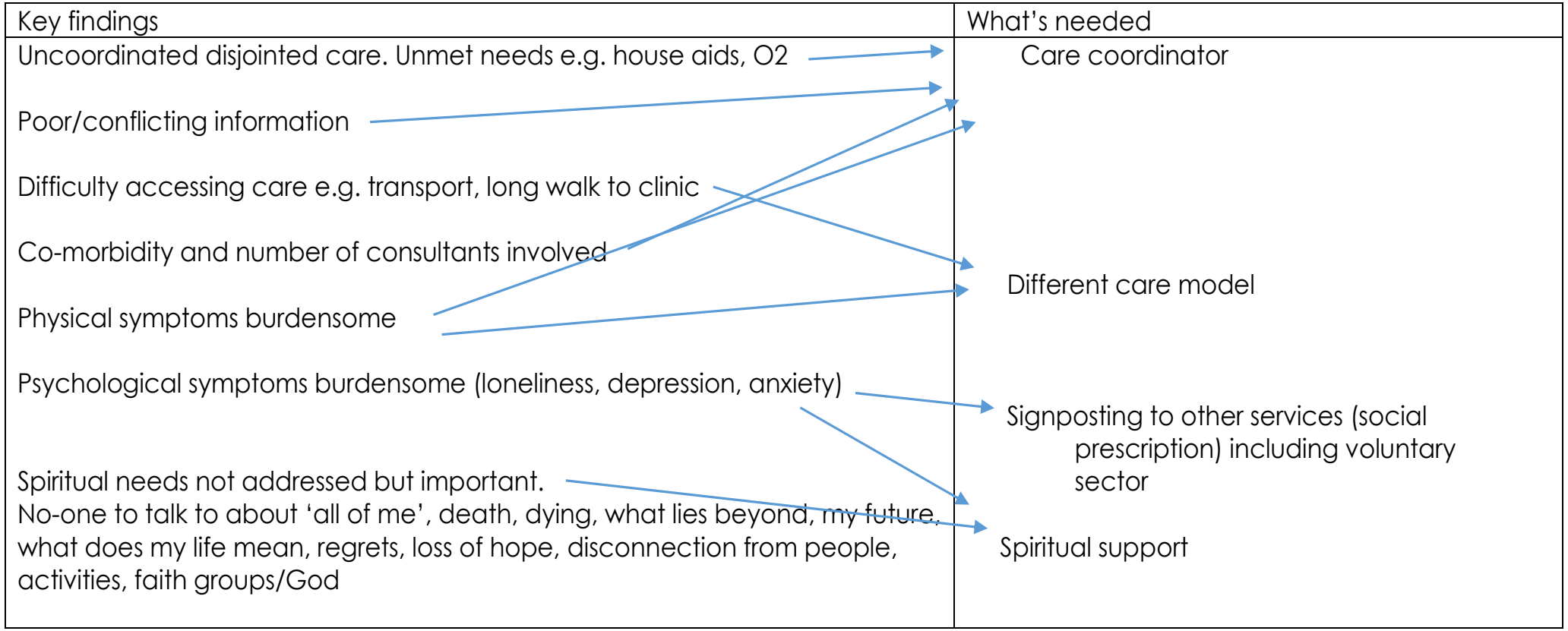
2. Our studies: what we did and what we found

Study 1: Multidisciplinary cardiac rehabilitation

BHF Excel*e*nce Award 2006

- Austin J, Williams WR, Ross L, Moseley L, Hutchinson S. (2005) **Randomised controlled trial of cardiac rehabilitation in elderly patients with heart failure.** European Journal of Heart Failure, 7, 411-417.

2nd: interviews with 16 NYHA IV heart failure patients/carers on 4 occasions over a year in 2008/9 about their spiritual needs and spiritual support preferences (Ross L and Austin J (2013) Journal of Nursing Management, 23, 1, 87-95)



Publication

- Ross L & Austin J (2013) Spiritual needs and spiritual support preferences of people with end-stage heart failure and their carers: implications for nurse managers. JNM, DOI: 10.1111/jonm.12087

Study 3: 2010-2011

Addressing these needs/ service provision

Study 4: 2014-2016

REPORT

SPIRITUAL SUPPORT IN END STAGE HEART FAILURE: A RANDOMISED CONTROLLED FEASIBILITY STUDY

Linda Ross, Reader[1]
Jackie Austin, Consultant Nurse[2]
Paul Jarvis, Statistican[1]
Sara Pickett, Health Economist[3]

Aims

1. To make recommendations to inform the design of a future RCT to investigate the effect of spiritual support on specified outcomes in patients with end stage heart failure e.g. uptake/drop-out rates, time, effort, questionnaire information etc

2. To investigate the effect and cost effectiveness of spiritual support on spiritual wellbeing, health related QOL, anxiety/depression if the sample size was sufficient, or to explore trends worthy of further investigation if the sample size was insufficient.

Method

47 patients with end stage heart failure (NYHA 3b/IV)

25 standard care

22 standard care + spiritual support
(1 hr discussion with trained volunteer)

Measures completed at 0, 2, 4, 6 months

Measures

- Spiritual wellbeing: WHO SRPB QOL Field Test Instrument
- Anxiety, depression: HAD
- Health related QOL: EQ5D (EuroQol)
- NHS Resource Use Questionnaire
- Confounding factors (changes in circumstances, life events, symptoms, medication)
- Demographics
- Satisfaction with service (intervention group)

Primary findings (Aim 1)

1. Recruitment: 133 invited, 104 accepted pack, 47 enrolled (uptake 35%), 38 took part (18 control, 20 intervention)

15 (32%) dropped out (9 baseline, 3 at mth 2, 3 at mth 4)

31 complete data sets (all 4 time points)

2. Data collection took longer than expected:

18 mths to recruit 47 and 2 yrs to collect data

9 months to recruit 65 and 15 mths to collect data

3. Considerable effort needed

4. Measures suitable: Kansas City? Spiritual wellbeing?

5. Information about WHO-SRPB: change in scores with an intervention. Useful for calculating effect size in follow-on study

6. Nurses initially uncomfortable with/lacked confidence in having end of life conversations

7. Spiritual support was valued by those receiving it

Secondary findings (Aim 2)

1. Spiritual wellbeing negatively correlated with anxiety (Rho ranging from -.306 to -.385, $p<0.05$) and depression (Rho ranging from -.342 to -.648, $p<0.05$)

2. No significant effects were identified for the intervention (spiritual support) on spiritual wellbeing, QOL, anxiety or depression.

BUT, trends worthy of further exploration

-Positive effect of SS on QOL (+4 in intervention group, -8 in control group) and anxiety (-1.2 in intervention group and +0.8 in control group) at 0-2 months but not on depression or SWB.

-Negative effect (increased depression +.9) of withdrawal of SS from experimental group at study end (months 4-6).

-Lower health resource cost per experimental patient (£204) over the study period; SS may be cost effective if rolled out to more patients within routine care.

3. Where do we go from here?

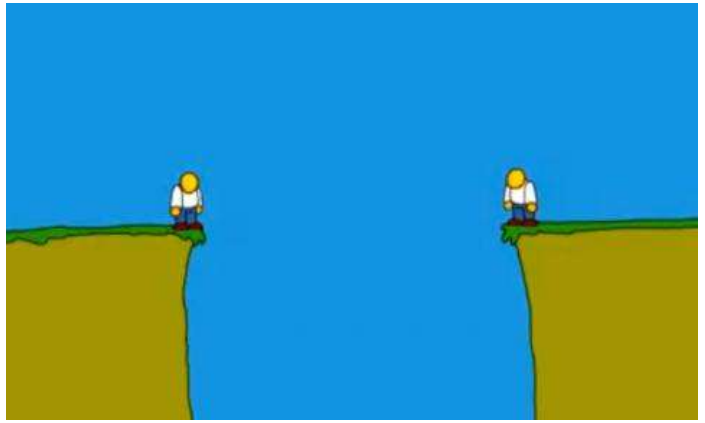
Gaps identified from our studies

- Spiritual support valued but needs further testing
- Care co-ordination
- Signposting to other services
- Different care model

Literature & current policy: the gaps

CARE

- **Early identification** of palliative care needs (‘streamlined assessment’)
- **Holistic assessment** of pt and family. ‘finding out what’s most important to the person’. **Needs led**.
- Involving carers and voluntary organisations.
- ‘The big conversation’
- **Extending the reach** to non-cancer groups i.e. heart failure
- **New care pathways**: ‘novel service development’, innovative care models’, ‘integrated care models’, based on NICE guidelines and quality statements, partnerships e.g. cardiology and palliative care
- Preferred place of care/death.
- Need for **ACP**
- Need for **care co-ordinator**
- Co-production.
- Prudent healthcare.
- Need for **staff training** in end of life conversations



New RCT: different care model

- Holistic, ensuring the inclusion of spiritual support
- Needs led for patients and carers: using PROMS (in 4 domains) to assess need and guide care
- Co-ordination of care: PROMS feeding into monthly MDT meetings to ensure what's important to patients (in 4 domains) is top of the agenda. Signposting.
- Fidelity: ensuring we deliver what we are meant to

- The team:

HF nurses

Cardiologists

Palliative care teams

ACP team

GP palliative care leads

Marie Curie/Velindre/HOtV

British Heart Foundation

Patients/carers

Quality Improvement Team

Chaplaincy

Clinical Trials Unit

Stats, Health Economics

Study 5

Does a PROMS based needs led care model incorporating Spiritual Support improve QOL of patients with heart failure and their carers?

Needs led care

Person centred care (patient and carer)

Co-production

Prudent healthcare

Training/education

‘Nursing and midwifery students’ perceptions of spirituality, spiritual care, and spiritual care competency: a prospective, longitudinal, correlational European study’

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