

# Care at the end of life: experience and support needs of older family caregivers of people with advanced cancer

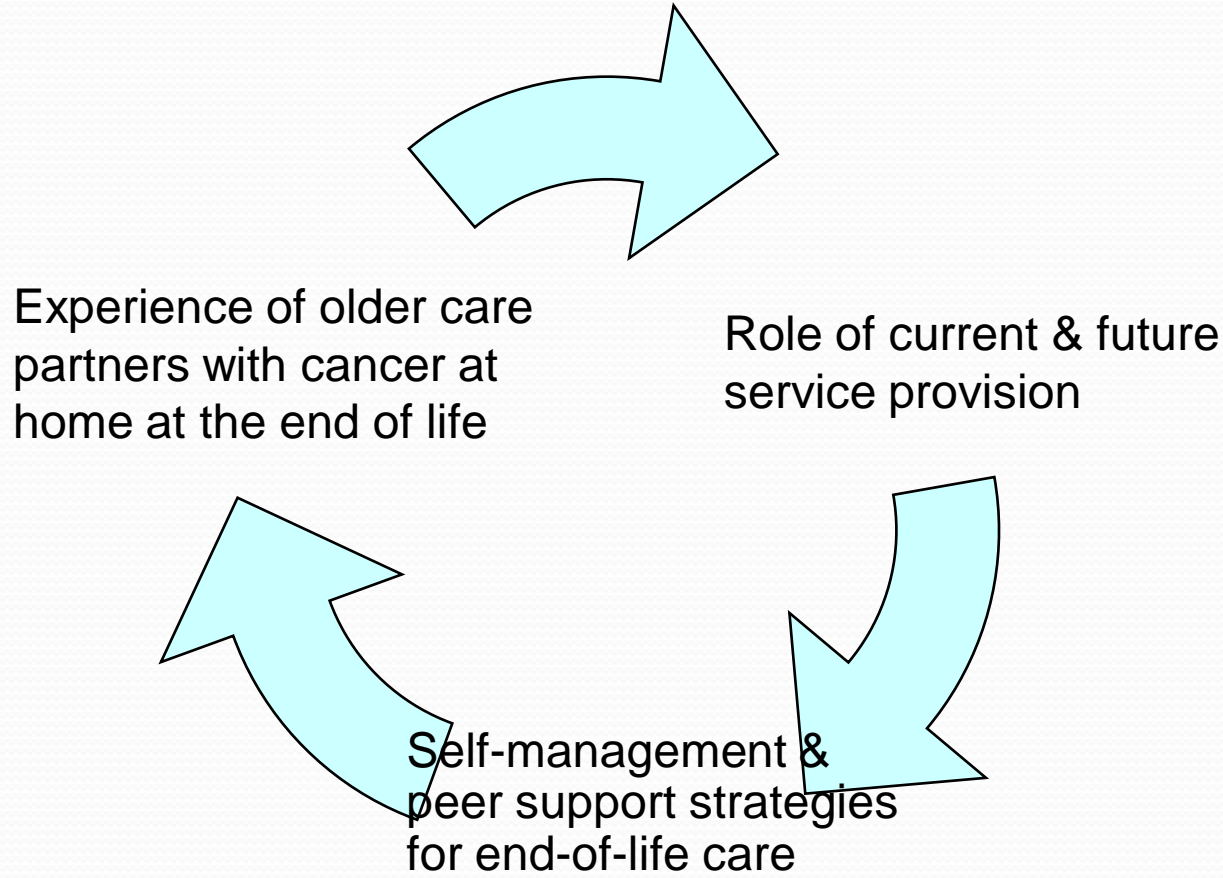


Cancer Experiences Research Collaborative/  
Dimbleby Cancer Care Research Fund

# Research team

- Christopher Bailey, Julia Addington-Hall, Jessica Corner, Susan Duke, Ali O'Callaghan (School of Nursing & Midwifery, University of Southampton)
- Michael Moore, Geraldine Leydon (Primary Medical Care, University of Southampton)
- Carol Davis (Southampton University Hospitals Trust)
- Roger Wilson (National Cancer Research Institute Consumer Liaison Panel)
- Jane Seymour (School of Nursing, University of Nottingham)
- Caroline Sanders (National Primary Care Research and Development Centre, University of Manchester)

# Care at the end of life: experience and support needs of older family caregivers



# Care of older adults research theme

- Key objectives:
  - To identify older adults' priorities in end of life care
  - To examine older adults' and informal carers' preferences for involvement in care decision-making
  - To understand older adults' preferences for place of care and develop interventions to improve opportunities to be cared for in a place of their choice at the end of life
  - To explore how older adults may be involved in the design of interventions related to preferred places of care and death

# Background

- Cancer & ageing:
  - Cancer risk increases with age
  - Ageing of population a determinant of future need
- Until four weeks before death, people who do/don't die at home spend on average 1.5 days per week or less in inpatient care
- Policy (or preference) encourages management of patients in community settings
- Limited evidence about complex needs of older people affected by cancer
- Importance of lay knowledge in managing health care need
- Little information about the nature of older people's 'caring partnerships' towards the end of life
- Little evidence to show what self-initiated strategies are (or could be) used, e.g.
  - peer education, web-based support

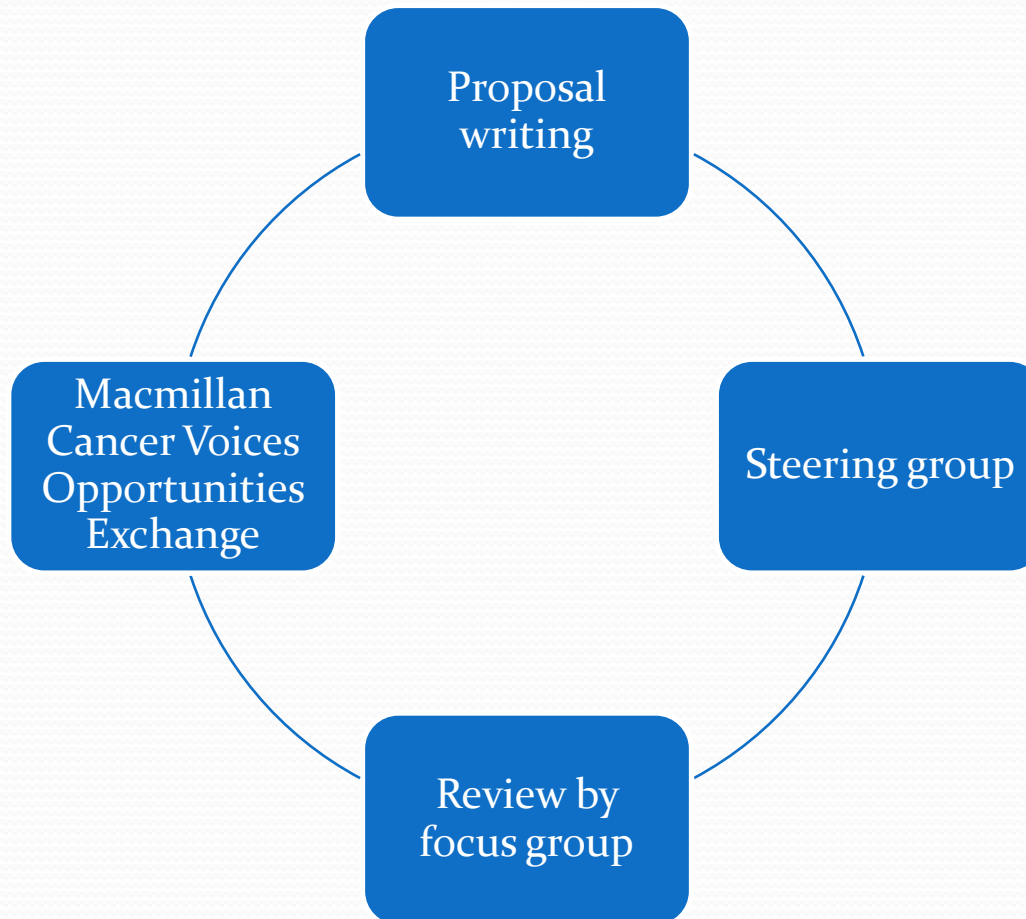
# Aims

- Describe the experience and support needs of older family members caring for an older partner or relative with advanced cancer at home
- Evaluate the role of current service provision in supporting family members providing end-of-life care
- Assess the feasibility of working with family caregivers to develop self-management and/or peer support strategies for end-of-life care

# Methods

- Design
  - 2-year longitudinal study with qualitative interviews, observation, structured measure of service use
- Participants
  - 30 'care partnerships' ( $\geq 65$  years)
  - patients nominate caregiver
  - community palliative care services
  - GP practices
- Data collection
  - *Interviews*. Semi-structured, both 'care partners', min. 2 in first 28 days, min. 3 in total
    - e.g. met & unmet need, caregiving expertise, self-management strategies
  - *Observation*. One participant nominated care-related activity
  - *Structured measure*. Self-report data on service use before and between interviews.
- Data analysis
  - constant comparative method
  - explanatory model of care partnerships

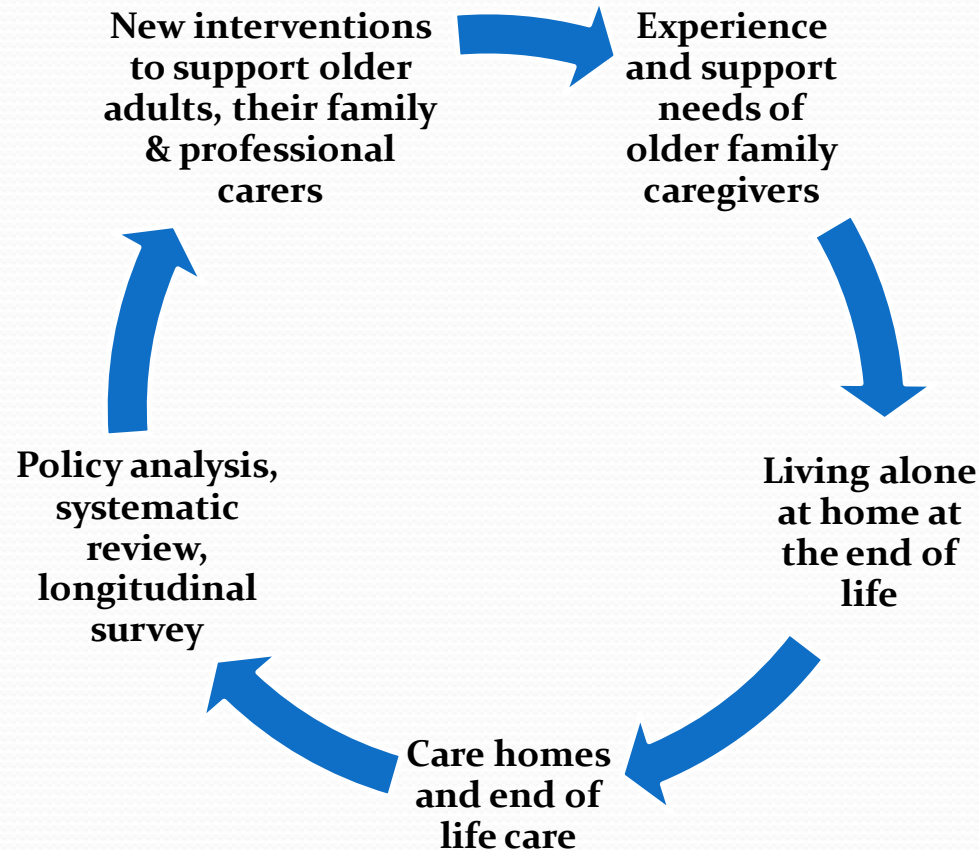
# Research partners



# Outcomes

- Understanding of
  - need
  - expertise
  - scope of (and for) self-management
  - support for older care partnerships at the end of life
- Recommendations for service development
- Framework for future intervention studies to support involvement of older caregivers in active management of a relative's condition and needs

# Older adults research theme: programmes of work



# Care at the end of life: experience and support needs of older family caregivers of people with advanced cancer



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# Depression and Demoralisation in Advanced Cancer

Professor Mari Lloyd-Williams Academic Palliative and  
Supportive Care Studies Group, University of  
Liverpool



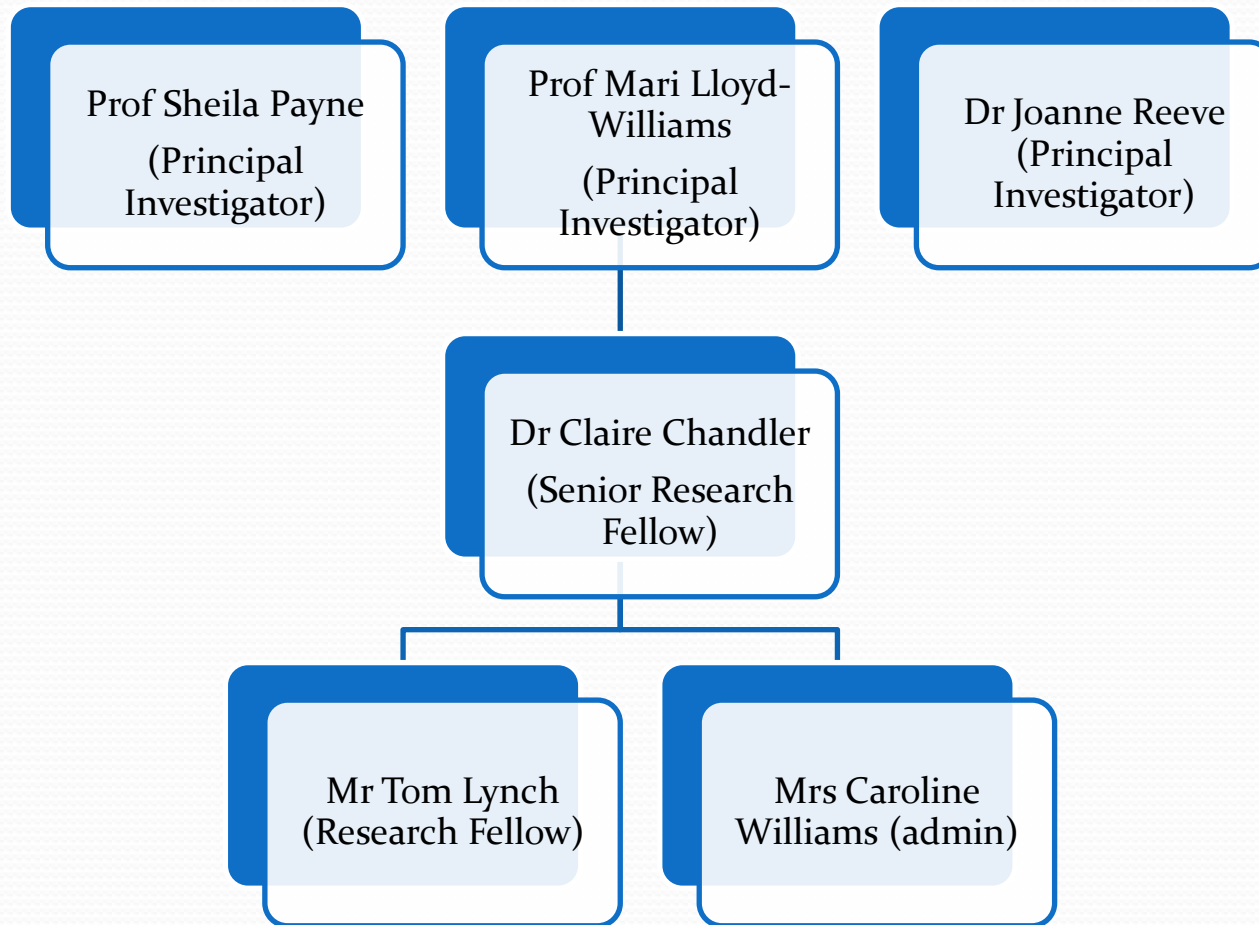
**St Luke's**  
HOSPICE  
Adding Quality to Life



# Who's who?

- Project funded by the BIG Lottery
- Grant-holders:
  - St Luke's Hospice, Sheffield
- Principal Investigators:
  - Mari Lloyd-Williams, Sheila Payne, Joanne Reeve
- Fieldworkers:
  - Claire Chandler, Tom Lynch
- Administrative Support:
  - Caroline Williams
- Advisory Groups:
  - Project Advisory Group
  - Steering Group

# Our Research Team Structure



# Aims & objectives of the study

## **Primary outcome**

- To determine the prevalence, aetiology and natural history of depression and demoralisation in patients with advanced cancer

## **Secondary outcome**

- Describe natural history of depression and demoralisation over a 24 week period
- Explore demoralisation as a concept in relation to terminally ill patients
- Which factors may be predictive / preventative for depression and demoralisation

# Which factors may be predictive / preventative for depression and demoralisation?

- How participants were told about their cancer; amount of information and support given at this time
- Pain and symptom burden
- Any recent alteration in treatment (e.g. treatment cessation)
- Spiritual beliefs

# Spirituality and depression

- Bauer-Wu & Farran (2005) – Psycho-spiritual factors (living a meaningful life, connectedness to a higher power) can buffer individuals against stressful life events such as cancer diagnosis.
- McClain et al (2003) – Depression highly correlated with desire for hastened death in individuals low in spiritual well-being but not those high in spiritual well-being.
- BUT, we do not yet know whether there is a correlation between demoralisation and spirituality.

# Targets

- 420 patients attending hospice day-care units to be interviewed at baseline, 8 weeks, 16 weeks and 24 weeks
- ~40 patients, selected according to their results on the questionnaires, for in-depth qualitative interview
- Data collection to be complete by March 2010 – need to recruit an average of 5 patients per week

# Quantitative Data Collection

## Projected scheme of work

							2008		2009			2010	
	Jun-07	Jul-07	Aug-07	Sep-07	Oct-07	Nov-07	Dec-07	Jun-08	Dec-08	Jun-09	Sep-09	Dec-09	Mar-10
obtain research governance	[Blue bar]												
engage hospices			[Pink bar]				[Pink bar]		[Pink bar]				
ongoing recruitment				[Green bar]									
follow up interview period										[Light Blue bar]			
<b>TARGETS</b>							35	165	245	375	420		
<b>ACTUAL</b>				35									

Note:

1. Recruitment from hospices will be for periods of ~3months at a time
2. New hospices will be approached 6-8 weeks in advance of recruitment phase
3. There will be ongoing recruitment from all hospices engaged with the study

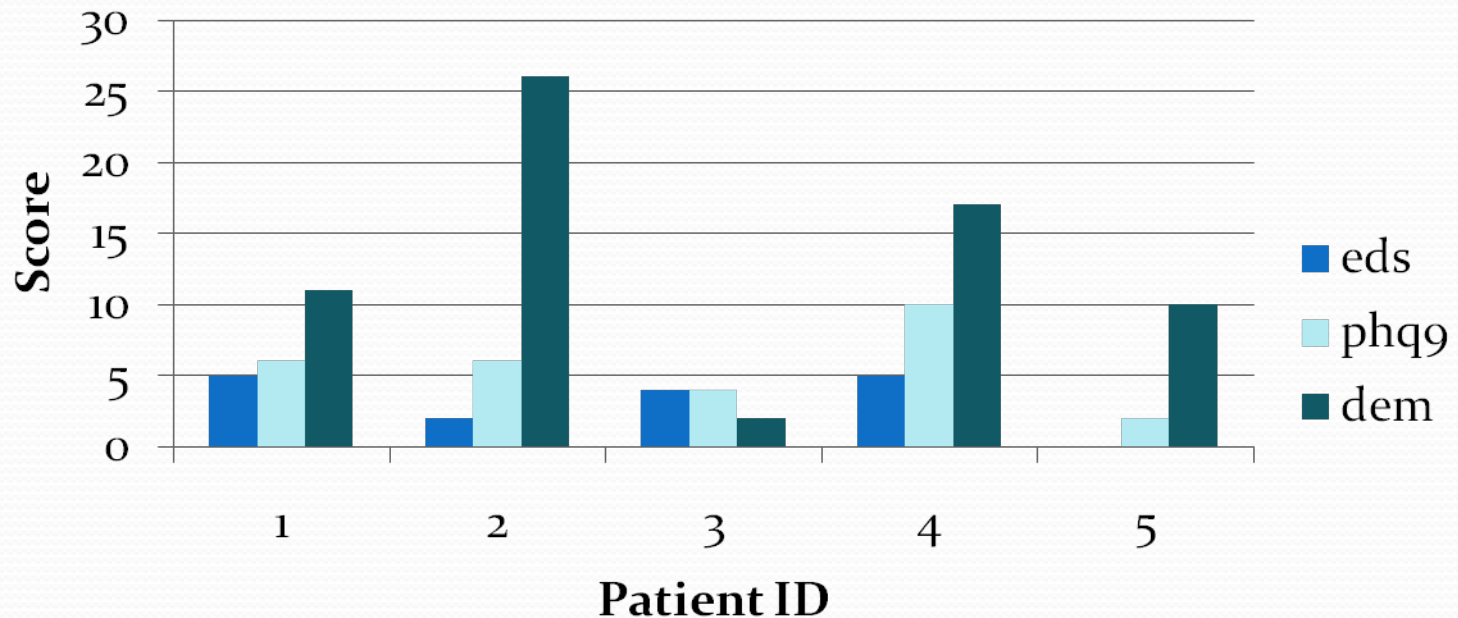
# Process

- Engage with hospice
  - Meet with hospice staff – give presentation
  - Obtain approval to recruit
- Agree start date for recruitment
- Recruitment Box
  - Stickers for hospice notes
  - Posters
  - Information leaflets and letters of introduction

# Baseline Interviews

- Informed consent
- Collect
  - Demographic information;
  - Abbreviated Mental Test Score;
  - Clinical information/symptoms;
  - Cancer diagnosis details;
  - Depression experience;
  - Complete Spiritual Questionnaire;
  - Agree mode of future contact – telephone / postal / face to face
- Complete questionnaires: ECOG; PHQ9; EDS; Demoralisation (delivery order varies according to allocated group)
- Inform GP and hospice staff that interview has been conducted
- Complete Concerns form (if appropriate)
- Enter data onto database

# Baseline Questionnaire Scores



## Cut-Off Scores

Demoralisation < 9 minimal depression symptoms

PHQ9 < 9 minimal depression symptoms

EDS < 13 low risk of depression

# Follow-up Interviews

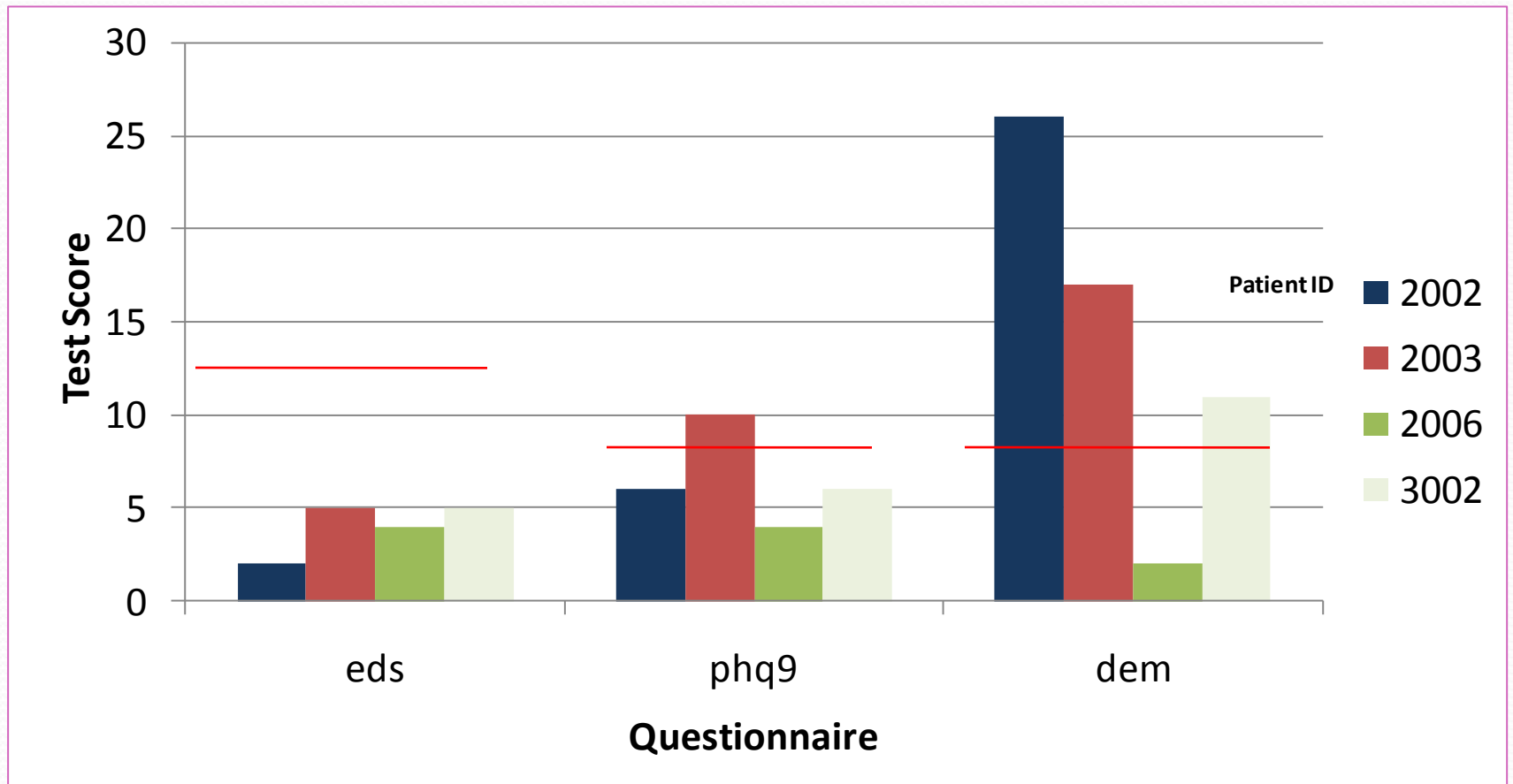
- Database alerts us when follow-up interviews are due
- Interviews booked and conducted by telephone (preferably)
- Complete questionnaires: ECOG; PHQ9; EDS; Demoralisation (delivered in same order as baseline)
- Data entered onto database

# Qualitative Data Collection

- 40 patients will be purposively selected to take part in an in-depth qualitative interview
- A selection of patients will be identified who meet the following criteria:

	Test	PHQ9	Demoralisation	EDS
Number Scoring	Above cut-off score	5	10	5
	Below cut-off score	5	10	5

# Range of Scores for 4 patients



# Current hospice recruitment...

- 8 hospices currently recruited; 4 from first phase (October – December 2007); 4 from second phase (January – March 2008).
- 2 of the hospices from the first and 2 from the second phases based around Lancaster; 2 of the hospices from the first and 2 from the second phases based around Merseyside.

# Current patient recruitment...

- 57 patients agreed to take part in the study
- 8 patients eligible but declined to participate
- 49 interviews completed to date

# Study Challenges

- Large prospective study
- Recruitment of patients in hospices where research is a new concept
- Attrition
- Missing data / data handling Liverpool Cancer Trials Unit and on-going support from engaged and interested statisticians vital

# Involvement of CeCo

- Study pre-dated CeCo but collaboration of CeCo partners
- CeCo members on steering group
- Research partners – not new in Liverpool but has been vital to study
- Hospices recruited to study – linking with wider CeCo activities
- Personal Development of 3 research staff within CeCo

# Possible Future Research

- What self management strategies can be developed / trialled for demoralisation
- Effective interventions for depression - non pharmacological and self management
- Further work exploring whether certain factors may be protective for depression / demoralisation

# Priorities and planning for end of life care: an action research project with older people

Presented by:

Jane Seymour, Sue Ryder Care Professor of Palliative and End of Life Studies, University of Nottingham

On behalf of:

The CECo '*older people theme*' core group

# Older Adult Theme: Aim



- To develop a programme of work relating to the improved care and support of older people and their informal carers, taking into account socio-demographic and ethnic diversity and introducing methodological innovation, especially in user involvement.

# Older Adult Theme: Strands of work



## 1. Self perceived priorities for end of life care:

*Socio-demographic diversity; challenges of living alone.*

## 2. Processes of care decision making at the end of life:

*Critical stance to 'choice' and 'control'; identifying information needs.*

## 3. Places of care at the end of life:

*Interventions to enable better quality of care in 'place'; care homes; advance care planning; understanding 'transitions'.*

# One challenge among many: User involvement

- Variety of modes and models: co researchers to advisors
- In the context of strong pressures to ‘do’ user involvement
- Going beyond tokenism?
- Consumerist and liberational models
- What does it mean for research?

# Making sense of user involvement

- How do such research approaches relate to more traditional models of research which place a high value on neutrality or objectivity?
- What role vis a vis users should researchers assume?
- How are issues of leadership versus collaboration resolved?
- Who owns the final project outputs?
- What are the implications for 'knowledge' and 'rigour' of close collaboration between researchers and users?

For a detailed discussion see: Beresford P (2003) User involvement in research: connecting lives, experiences and theory.  
[www2.warwick.ac.uk/fac/shss/mrc/userinvolvement/Beresford/](http://www2.warwick.ac.uk/fac/shss/mrc/userinvolvement/Beresford/)



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# Trends in social science research

- From detachment to engagement with research participants;
- From political neutrality to recognising the political nature of research activity;
- From observation of how 'it is', to empowerment and enabling change.

See for example: de Laine M ((2000) *Field-work, participation and practice. Ethics and dilemmas in qualitative research*. London: Sage



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# An example of work in progress



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# The peer education project: context and background

- Lack of attention to public education about end of life care, but...
- Increasing attention to advance care planning (ACP) and its promotion.
- Older people: the largest group of potential, but neglected, users of palliative care services;
- Some evidence of confusion and fear associated with ACP.
- ‘Top down’ nature of existing programmes of education



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## Peer education – sharing information with people of a similar age and background:

*“Older people have always been good educators for younger people but, with support we can educate each other on more serious issues like these”.*

## Building on earlier work:

Pilot project funded by the Health Foundation (2003-5)

*Listening events* in the UK, funded by Help the Aged .

Seymour J.E., Sanders C. et al (on behalf of the Peer Education Project Group) (2006) *Planning for Choice in End of Life Care. An Educational Guide*. London: Help the Aged.

Clarke A, Sanders C, Seymour JE, Gott M and Welton M (in press) Evaluating a peer education programme for advance end-of-life care planning for older adults: The peer educators' perspective. *International Journal of Disability and Human Development*.

Clarke, A, Seymour JE et al (2006) *Opening the door for older people to explore end of life issues*. London: Help the Aged.



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# Aim and Objectives

*Aim:* To refine and extend a peer education programme for advance end of life care planning in a range of care contexts and community groups.

## *Objectives*

- To work with older people and their from a range of community groups and care settings (n=up to 16) to evaluate an existing information resource for advance end of life care planning.
- To assess needs for new materials addressing concerns about advance end of life care planning.
- To collaboratively produce and assess new end of life education materials.
- To assess the feasibility and acceptability of a refined training programme to volunteer peer educators (n = up to 32).
- To assist peer educators in running peer education sessions within their communities and to assess the acceptability of these to discussants.
- To gain insights into the processes of engaging and working with older adults and those that care for them in a sensitive area of practice development and research.

# Project phases

1. Preliminary discussions/ interviews
2. Adaptation of peer education training
3. Collaborative development of new materials
4. Delivery of peer education training
5. Piloting and evaluating materials
6. Dissemination

**BOOKLET**  
**Peer Ed Training**  
**Peer Educators**

**Community Groups**

**Care homes & Extra  
Care Housing**

**Nurses**

**Home care  
Activists  
Bereavement groups**

**Residents  
Staff  
Relatives**

What are your expectations:  
(individual & organisational) from the  
project?  
How can we best understand your  
needs?

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project?  
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needs?

**Peer ed training**  
**Peer educators**  
**Materials**

# Methodological approach

- Action research
- Evaluation : using a framework to assess participatory working

<b>Equal access?</b>	<p>We were a team. Everyone's views were important and listened to.</p> <p>The completed guide was an achievement: a professional publication that we helped to produce.</p>
<b>Enhanced awareness?</b>	<p>It taught us new skills and reminded us of the importance of listening.</p>
<b>Encourage action?</b>	<p>Being elderly, it was a therapy for us; encouraging us to make a contribution. And we had some fun!</p>
<b>Enable action?</b>	<p>We would like the guide to become available to our peers and others. Some of us now feel confident to educate a group of our peers.</p>

**Summary of the PEds feelings about participating in the project using the ÄVS model as a framework for evaluation: from the pilot project**

# Progress so far....

- Recruited six community groups to the project
- Recruited five care home or extra care housing settings
- Nurses attached to mid Trent End of Life Care Network are participating
- Linked PhD study focused older South Asian people



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# Participant profile (so far)

- 30 men; 71 women: **total 101**
- 79 'white'; 22 black Caribbean
- Age range: 20's to late 80s

## **Of these:**

- 40 have been care staff (17 care home/ extra care home care assistants; and 23 qualified nurses)
- 42 have been members of community groups
- 6 have been members of a relatives' support group attached to a care home
- 13 have been care home/ extra care housing residents

# Some emergent findings

*Care home/ extra care housing: residents*

## ***Resident in care home:***

*Well I don't really think about the end of life, you know, 'cos I had 60 happy years with my husband and I wouldn't wish him back to suffer again, you know, I had a happy life and I'm content now to live the end of my life in here. Because I've got a daughter, you know, and she's got multiple sclerosis. I used to live with her but it got too much for her, you know, with her own problems and... and I'm happy in here, good food, nice bed, what more could you wish.*

Frail older women aged 85+

## **Resident in extra care housing**

*To me, independence is important, so I think end of life care is getting the physical and psychological support you need to be independent, I think that's the most important thing. Well, information, access to information I think is important. And in my case it's feeling wanted I think, feeling that people like you, that you're not being a burden to people and that.*

Disabled woman with COPD, age 75 +

# Care home/ extra care housing: staff

*I have dealt with death on several occasions taking care of relatives and also sitting with somebody while they're at the very end of their life. It is hard.... You know, [you] try not to talk about it but to try and understand. I think that's enough from me because I'll start to cry.... it can be extremely hard and extremely harrowing watching these people pass over. It really can, you know. And it brings your own mortality into play as well because there's certain things that you see and you hear and you watch, you know, and you think God I hope that never happens to me. It can, it can be very difficult, very very difficult.*

Young female care assistant

# Community group members

*Well can I just say why I was keen to do it, is that all right?*

- **Yes, that would be a good idea.**

*Yes, if this had all been in place when my husband had lung cancer four years ago, it was a very difficult time, I hadn't seen anything like it before ever in my life, we'd been fortunate enough not to have to go in hospital, and I just found it terrible basically. And if one of these had been in place, people wouldn't have to have said, you do realise how poorly he is this, this, this and this and the other, and basically his wishes would have been known, so we wouldn't have to have made a lot of the decisions that we made ....*

Female member of community focus group discussion



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# Community group members

*M: death does not frighten me. It's the vehicle that I get to it that terrifies me. I don't want to have a bad vehicle. I don't mind it breaking down....I want it to be a nice easy ride.*

*F: I've already made a living will.... Which, on one of the forms from the Natural Death Centre in London, but I'm going to update it. Partly for practical reasons because I've moved, and I've got to change names and phone numbers and things, so it's going to make a mess of it, so I'm going to do a new one. But I haven't got any family, to speak of, nobody that matters. I've got four good friends who I call my 'funeral committee', and we all have a good laugh about it, and they will do exactly what I want. I have no intention of being wheeled around and fed with a tube and things like that - I'd rather be dead.*

**Members of community focus group discussion**



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# Issues encountered

- Complexity
- Working as co-researchers with the peer educators
- Users, stakeholders, or participants?
- Leadership or consensus in team dynamics
- What sort of research is this?
- Promises and expectations
- Change and reflexivity among the participants

# Conclusion

Thanks for listening!!



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**Narrative research methods in palliative care contexts-  
sketch of talk**

Professor Carol Thomas

**Introduction**

When deciding what to say in this talk, I first began to travel the road of talking about the debates that have taken place in the CECo Narrative Methods Theme about what narrative research is, and on the types of narrative analysis that one finds in the literature. These are matters that we have talked about a lot in narrative theme meetings.

However, I decided that I'd talk about the way that I understand narrative analysis – a way of thinking that I've developed over recent months in working on my cancer narratives project funded by the Economic & Social Research Council (ESRC)<sup>1, 2</sup>.

My journey towards an understanding of how I want to do narrative analysis has been a more challenging one than I'd

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<sup>1</sup> The study is funded by the Economic and Social Research Council (ESRC): Narratives of Living and Dying with Cancer: Sociological Perspectives, Ref: RES-000-22-2031.

<sup>2</sup> This ESRC study involves the re-analysis of interview data collected in two earlier studies (See Carol Thomas Lancaster University Webpage for publication details). Study 1: The Psychosocial needs of cancer patients and their main carers. This 3-year multi-method study (1997-2000) was funded by the R&D Directorate of the North West Regional Health Authority, with NHS Ethics Committee approval. It involved single in-depth interviews with 47 cancer patients (20 men, 27 women; age range 26-83 years) and 32 of their main informal carers (12 men, 20 women).

Study 2: Place of Death: patterns and preferences for place of death among terminally ill cancer patients and their carers. This 2-year multi-method study (2001-2003) was funded by the above source, with NHS Ethics Committee approval. It involved the completion of in-depth interviews series with 41 terminally ill cancer patients (17 men, 24 women; age range 41-88 years) and 18 of their main (co-resident) carers (5 men, 13 women).

anticipated. One has to think hard about research methods and the generation of knowledge. In particular, as an experienced qualitative researcher, I had to re-examine the difference between the qualitative analysis methods I was familiar with and narrative analysis methods *per se*.

*[GO TO POWERPOINT SLIDE 2]*

First : quantitative methods. What are we actually doing here? In palliative care research, for example, we are in the business of generating discrete variables through giving features and factors numerical values so that we can look at the statistical relationships between variables - whether its by undertaking multiple regression analyses, calculating odds ratios, multi-level modelling - or whatever we have been trained to do. Variables might be disease categories and features, or individual and social variables – age, sex, socio-economic status etc. We generate particular types of knowledge that we think of as ‘scientific’ in this way.

*The star constellation on PP slide 2 is a representation of this, where each star is a discrete variable.*

Turning to qualitative methods, we are dealing with word data – particularly word data in interview transcripts – sometimes lengthy interview transcripts. Our task is to interpret these data in ways that we have been trained to do as social scientists. One method that is widely used, and that I am very familiar with, is cross-sectional thematic analyses of interview transcripts.

*PP slide 2 representation: This is like building a dry stone wall.... imagine lines of word data constituting a theme on each stone (extracts from each interview transcript). Themes and sub-themes are built up horizontally across the whole dataset.*

Turning to narrative analysis: we treat an individual's narrative – their storied account – as a single case to be studied in detail. Thereafter, we might move on to compare cases.

### **Narrative analysis: the 'river' allegory**

[see PP slide 3]

I have developed the simple 'river allegory' to represent narrative analysis (Thomas, 2007) – as follows:

The interpreter of the interview transcript data engages with the text as if he or she were an observer of a stretch of river flowing past, but soon disappearing out of sight. The observer wades in, looking downstream, and attempts, with rigorous attention to detail, to discern and explain the river's currents as they move by. The visible section of the river provides strong clues as to the strength and interweaving character of the currents: tributary streams run into the river and exert their influence, rocky and sandy sections of the landscape are traversed and cut through, materials carried along from the river's unseen reaches upstream are deposited, and the river babbles past in places or moves sluggishly by in others.

Like the river itself, the life captured in words on a page is a force in creative motion. And like the river observer, the interpreter wades into the 'word data', and endeavours to make sense of the storylines or narrative threads that run *longitudinally* through the text; these are the 'currents' that convey meaning and contextual detail. To discern *and* explain the storylines, the interpreter empathetically studies both their content and their form, making use of information

shared on: the impact and influence of other people, present and past, on a life (the river's tributaries); the social and cultural landscape that is 'lived', present and past (the terrain traversed by the river); the events and experiences that are perceived by the narrator to be of significance (the material carried and deposited by the river as it passes by). The way that words are put together and expressed, with, for example, laughter or tears, is of significance to the interpretation of meaning (the sounds and appearance of the water).

*[See PP slides 3 & 4]*

### **One case**

**(the following is an extract featured in a forthcoming journal paper, and illustrates the application of the river**

**allegory:** Thomas, C. (2008) 'Cancer narratives and methodological uncertainties'. *Qualitative Research*, forthcoming.

Jean's story (all names are pseudonyms) illustrates my current thinking on how to employ a case-centred approach to narrative analysis that explores both the content and the form of the storytelling. Jean, with stomach cancer, participated in two lengthy interviews (two hours each) in the final months of her life. She was in her 80s, had experienced major stomach surgery, had mobility problems, took medication for pain, and was fully aware that her tumour could not be removed and would lead to her death. She lived alone in a rented council house, having been widowed many years earlier. With her nephew, Jean looked after her frail elderly sister, who lived close by and had a serious visual impairment; she had no children of her own.

Jean's illness narrative is particularly interesting because, in both interviews, it is told in a humorous and joyful style. In contrast with anticipated stylistic forms, her talk is frequently interspersed with laughter and merriment. Jean's detailed account of the episodes of dialogue that had occurred in clinic and hospice settings with doctors and nurses, all of whom she celebrates as "wonderful" and "helpful", tell stories of their astonishment and delight at her positive and humorous attitude: "He [doctor] said, I wish they were all like you, Jean".

Jean sustains this performance of her positive and undisturbed identity in both interviews, and her easy, naturalistic, style of storytelling suggests that she is just 'being herself'. There is no hint of someone actively working toward the reconstruction of an identity disrupted by a diagnosis of terminal cancer – in marked contrast to many other cancer narratives in the dataset. Jean, whose advanced age must not be forgotten, provides many clues that enable an interpreter to make sense of her accepting outlook. These reside in the narrated fragments of her life story, told at different stages in the two interviews and conjure up a working class woman who grew up in 1920s and 30s northern England in what sociologists describe as traditional urban working-class community settings.

Throughout her life, Jean resided in neighbourhoods marked by relative material deprivation and gendered divisions of labour, but where shared values of reciprocity and mutuality were much in evidence. Referring to her lifelong inclination to help others, Jean says: "We always had to help people. I think that's where it comes from, actually, that I have to help somebody if I can. I was brought up [by my mother] like that." She spends a considerable amount interview time recounting a life, past and recent, in which she provided practical and emotional support to individuals of all ages,

especially women. She was no stranger to hard-times, including previous episodes of her own serious illness; but neighbours and friends had always come to her aid. Now, in her time of need, she maintained her cultural expectation that shared values of *give and take* would play their part: 'I've done for people, now they will do for me'. Indeed, her expectation has been met, as the following extract indicates:

R ... and I'm quite pleased because Julie, that's a friend, I used to take her dog out, as I think I told you

I Oh yes

R twice a day – and she's been like an angel, she does my shopping – most of it – and I trust her with money – so I make sure that she always has something – mind you, she gets a bit stropky, but I cut her to size – (laughs)

I You cut her to size? (laughs)

R I say to her, OK, you're not going shopping for me, then – and she says ... I say, love, cos she knows all my business - I told her, because then she knows what to do and how I'm situated, and I would tell her anything, I would trust her with my life – and she's always having a giggle – so I said to her, if you don't take it, you don't go! And she said, "all right, but I feel awful" – so I slip her money like – and she goes to college at night, she only works part time, you know – she's only young, I think she's in a 40s. I've told her, I've said, you've got a life of your own, love, don't think you've got to keep coming here. And we phone each other – well, if I think there's something, I phone her

and tell her and I'm never in a rush, I tell her – don't rush anything, cos I'm OK – so she gets me food, me bread and whatever I want and, I mean, it takes some doing, I know she's on her own with her partner, like, and he's as good, cos sometimes he does the shopping and she brings it, you know – so I treat him as well – but I don't tell anybody, I told you, like, because that money was given me [a benefit payment arranged by the specialist palliative care nurse] ...

.. I had it all in my mind what I was going to do with [the benefit money] – I would make sure that Julie was OK, and that, and when she goes on holiday, I always slip her an envelope and then she plays heck after (laughs). So I'm quite happy cos I know that I can be good to people I want to be good to

I Cos it sounds like Julie is quite important to you.

R Oh, she is.

I You'd not be able to...

P I'd not be able to do without her – and that is honest – and she only lives [locally], you know. She is, she's really good,

*[interview extract on PP slide 5]*

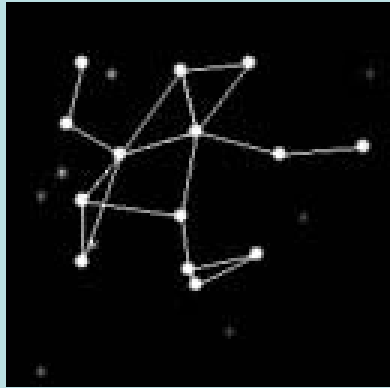
This extract tells us that Jean sees the informal care provided by Julie and her partner as crucial to her well-being. It also features related narrative threads that run throughout Jean's account: the weighty symbolic and practical value of 'pounds, shillings, and pence', and the importance of trust. 'Slipping' a small amount of money to a person who helps her out in the ways described is Jean's

meaningful way of maintaining the norms of give and take when she can no longer run errands for others; Jean loved to give trusted people presents and ‘treats’, and took pleasure in their responses. This relational perspective is woven into the moral fabric of her life, as is her oft-cited belief that there are always ‘people worse off’, and that one therefore ‘mustn’t grumble’. Overall, Jean’s narrative portrays a woman whose life has been characterised by hard-knocks but also relational enrichment premised on reciprocity. The latter quality appears to hold an important key to Jean’s capacity to take the cancer diagnosis in her stride.

Jean weaves together biographical threads to sustain an identity marked by resilience, forbearance, and good humour. The oft-cited medical sociology concepts *biographical disruption* and *loss of self* do not fit with her story. And the presence of *social support* in Jean’s life – an important factor in coping with cancer thrown up in the original projects’ cross-sectional analyses of interview transcripts – is unable to capture the subtleties of Jean’s illness experiences. Understanding *how* and *why* social support plays out in peoples’ lives requires the analytical antennae associated with sociological narrative analysis.

# **Narrative research methods in palliative care contexts**

Professor Carol Thomas  
Lancaster University





# ***Narrative analysis: the 'river' allegory***

## **River currents:**

- wade in to study the currents.
- look at the strength and interweaving character of the currents
- consider the tributary streams run into the river and exert their influence
- look at rocky and sandy sections of the landscape traversed and cut through
- look at the materials carried along from the river's unseen reaches upstream
- listen as the river babbles past in places, or moves sluggishly by in others.

## **Narrative themes:**

- life as force in creative motion.
- like studying the currents, make sense of the storylines or narrative threads that run *longitudinally* through the text, paying attention to both form and content.
- [tributaries] the impact and influence of other people, present and past.
- [landscape traversed] : social and cultural landscape that is 'lived', present and past
- [material carried and deposited]: the events and experiences that are perceived by the narrator to be of significance.
- [the sounds and appearance of the water]: way that words are put together and expressed, with, for example, laughter or tears

## Jean's story – a short extract (in 80s, stomach cancer, hospice attendee)

**Jean** ... and I'm quite pleased because Julie, that's a friend, I used to take her dog out, as I think I told you

**Int** Oh yes

**Jean** twice a day – and she's been like an angel, she does my shopping – most of it – and I trust her with money – so I make sure that she always has something – mind you, she gets a bit stroppy, but I cut her to size – (laughs)

**Int** You cut her to size? (laughs)

**Jean** I say to her, OK, you're not going shopping for me, then – and she says ... I say, love, cos she knows all my business - I told her, because then she knows what to do and how I'm situated, and I would tell her anything, I would trust her with my life – and she's always having a giggle – so I said to her, if you don't take it, you don't go! And she said, "all right, but I feel awful" – so I slip her money like – and she goes to college at night, she only works part time, you know – she's only young, I think she's in a 40s. I've told her, I've said, you've got a life of your own, love, don't think you've got to keep coming here. And we phone each other – well, if I think there's something, I phone her and tell her and I'm never in a rush, I tell her – don't rush anything, cos I'm OK – so she gets me food, me bread and whatever I want and, I mean, it takes some doing, I know she's on her own with her partner, like, and he's as good, cos sometimes he does the shopping and she brings it, you know – so I treat him as well – but I don't tell anybody, I told you, like, because that money was given me [a benefit payment arranged by the specialist palliative care nurse] ... .. I had it all in my mind what I was going to do with [the benefit money] – I would make sure that Julie was OK, and that, and when she goes on holiday, I always slip her an envelope and then she plays heck after (laughs). So I'm quite happy cos I know that I can be good to people I want to be good to

**Int** Cos it sounds like Julie is quite important to you.

**Jean** Oh, she is.

**Int** You'd not be able to...

**Jean** I'd not be able to do without her – and that is honest – and she only lives [locally], you know. She is, she's really good,

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# Study Update: Predicting Weight Loss in People with Cancer

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Vanessa Halliday

Research Dietitian

NCRI Capacity-Building Grant Holder



The University of  
**Nottingham**

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# Collaborators

- Professor Julia Addington-Hall
  - Dr Tony Arthur
  - Dr Jane Hopkinson
  - Professor Davina Porock
  - Dr Andrew Wilcock
  - Professor Simon Langley-Evans
-

# Professional and Research Background

- Oncology and Palliative Care Dietitian
- Teacher Practitioner
- Hayward House Palliative Care Research Team
- CECo
- NCRI Capacity Building Grant 2007-2009
- Registered for PhD Nutritional Sciences



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# The Evidence Base

## Anorexia Cachexia Syndrome

- Multifactorial
    - Malnutrition
    - Weight loss
    - Anorexia
    - Systemic inflammation
  - Malnutrition, weight loss and anorexia present in up to 85% of people with cancer
-

---

# Consequences of Anorexia Cachexia Syndrome

- Physical effects
  - Poorer treatment outcomes
  - Increase in adverse symptoms
  - Psychological impact
  - Reduced quality of life
  - Cachexia – a significant cause of death
-

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# Management of Anorexia Cachexia Syndrome

- Supportive dietary care and counselling
  - Nutritional support
  - Pharmacological management
  - Physical activity
-

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# Aim of Study

To identify people with cancer who are at greatest risk of future weight loss by the development of a simple and practical screening tool.

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# Components of the Screening Tool

1. Systemic inflammation
2. Weight loss and malnutrition
3. Appetite and symptoms



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# 1. Systemic Inflammation

- One item
- C-Reactive Protein (CRP)
- Elevated plasma concentrations  $> 10\text{mg/L}$  associated with adverse function and prognosis



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## 2. Weight Loss and Malnutrition

- Three items
  - Malnutrition Universal Screening Tool (MUST)
  - Recommended by NICE
  - Validated in general population
  - May not be specific enough to use in people with cancer
-

## Step 1 BMI score

BMI kg/m <sup>2</sup>	Score
>20(>30 Obese)	= 0
18.5-20	= 1
<18.5	= 2

+

## Step 2 Weight loss score

Unplanned weight loss in past 3-6 months	
%	Score
<5	= 0
5-10	= 1
>10	= 2

+

## Step 3 Acute disease effect score

If patient is acutely ill and there has been or is likely to be no nutritional intake for >5 days  
**Score 2**

If unable to obtain height and weight, see reverse for alternative measurements and use of subjective criteria

## Step 4

### Overall risk of malnutrition

Add Scores together to calculate overall risk of malnutrition  
Score 0 Low Risk Score 1 Medium Risk Score 2 or more High Risk

## Step 5

### Management guidelines

### 0 Low Risk

#### Routine clinical care

- Repeat screening  
Hospital – weekly  
Care Homes – monthly  
Community – annually for special groups e.g. those >75 yrs

### 1 Medium Risk Observe

- Document dietary intake for 3 days if subject in hospital or care home
- If improved or adequate intake – little clinical concern; if no improvement – clinical concern – follow local policy
- Repeat screening  
Hospital – weekly  
Care Home – at least monthly  
Community – at least every 2-3 months

### 2 or more High Risk Treat\*

- Refer to dietician, Nutritional Support Team or implement local policy
  - Improve and increase overall nutritional intake
  - Monitor and review care plan  
Hospital – weekly  
Care Home – monthly  
Community – monthly
- \* Unless detrimental or no benefit is expected from nutritional support e.g. imminent death.

#### All risk categories:

- Treat underlying condition and provide help and advice on food choices, eating and drinking when necessary.
- Record malnutrition risk category.
- Record need for special diets and follow local policy.

#### Obesity:

- Record presence of obesity. For those with underlying conditions, these are generally controlled before the treatment of obesity.

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## 3. Appetite and Symptoms

- Twelve items of Appetite and symptoms questionnaire (ASQ)
  - Developed from the eight item Council on Nutrition Appetite Questionnaire (CNAQ)
  - Validated with general population in USA
  - Content validity testing and modification in Nottingham
-

# Appetite and symptom questionnaire

Please tick the box that most closely reflects your experiences with appetite and symptoms at the present time.

1. My appetite is...

- very poor
- poor
- average
- good
- very good

2. When I eat I feel full...

- without having eaten anything
- after eating only a few mouthfuls
- after eating about a third of a meal
- after eating over half a meal
- after eating a full meal

3. Before eating, I feel hungry...

- rarely
- occasionally
- some of the time
- most of the time
- all of the time

4. I enjoy the food I do eat...

- most times
- often
- sometimes
- rarely
- never

5. At present I eat...

- less than one meal a day
- one meal a day
- two meals a day
- three meals a day
- more than three meals a day

6. At present I eat (in addition to or instead of meals)...

- no snacks
- one snack a day
- two snacks a day
- three snacks a day
- four or more snacks a day

7. Compared to before I was ill, food tastes...

- much worse
- worse
- just as good
- better
- much better

8. At present I have...

- no changes in taste
- mild taste changes
- moderate taste changes
- severe taste changes
- no taste at all

9. I feel sick or nauseated before I eat or when I eat...

- most times
- often
- sometimes
- rarely
- never

10. Most of the time my mood is...

- very sad
- sad
- neither sad nor happy
- happy
- very happy

11. Most of the time my energy level is...

- very high
- high
- moderate
- low
- very low

12. Most of the time my pain is...

- very mild or no pain
- mild
- moderate
- severe
- very severe

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# Overview of Study Design

## Phase I

- Reliability of an appetite and symptom questionnaire
- A short-term longitudinal study, with two test-points one week apart

## Phase II

- Development of the screening tool
  - A longitudinal observational study with two test-points, three months apart
-

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# Expected Outcomes

1. An estimate of the reliability of the Appetite and Symptom Questionnaire
  2. A screening tool to predict clinically significant weight loss over three months
  3. To determine the optimal cut-points and overall performance of the developed screening tool at predicting clinically significant weight loss at three months.
-

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# Phase I Sample (n=35)

## **Patient inclusion criteria**

- >18 years
- Diagnosis of cancer
- Receiving radiotherapy

## **Patient exclusion criteria**

- Radiotherapy to the head, neck or upper GIT
  - Any condition impairing their ability to swallow.
-

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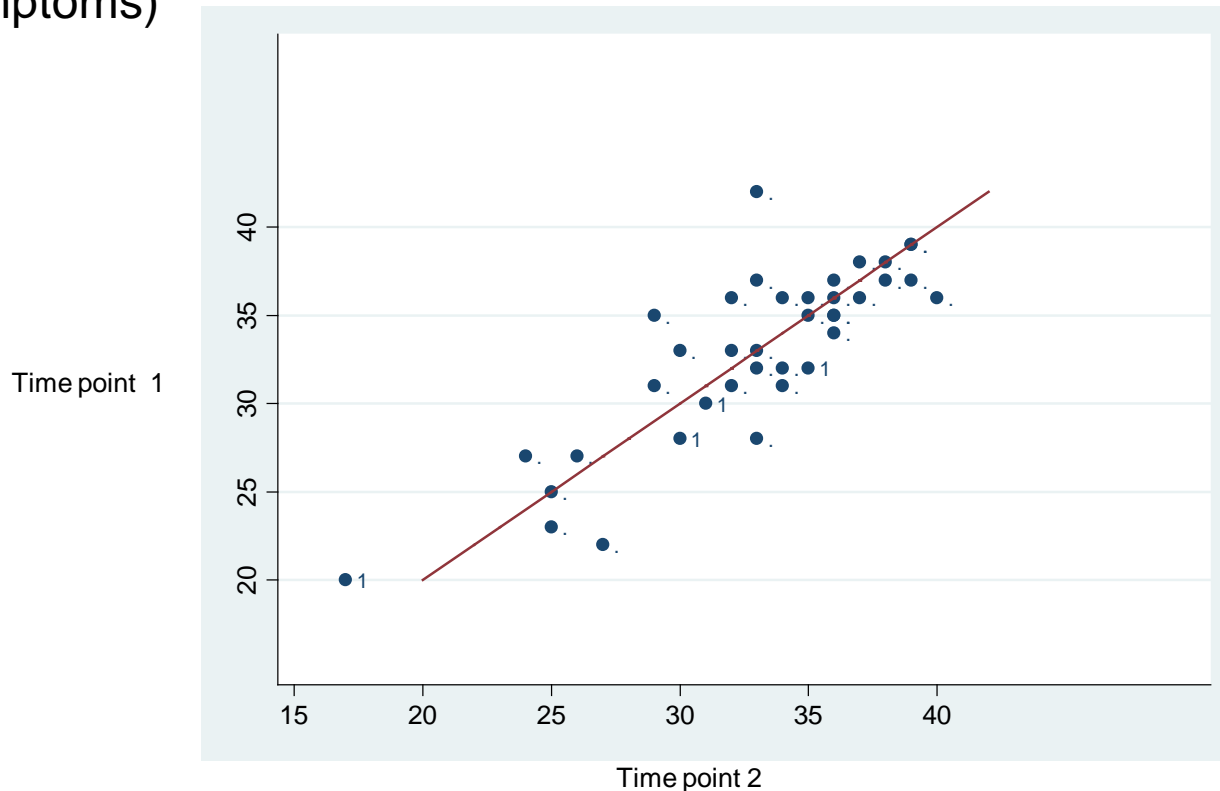
# Phase I Recruitment

- 4 weeks
  - September –October 2007
  - 51 approached
  - 38 recruited
  - Majority breast and prostate cancer
  - 38 completed study
-

# Phase I Results

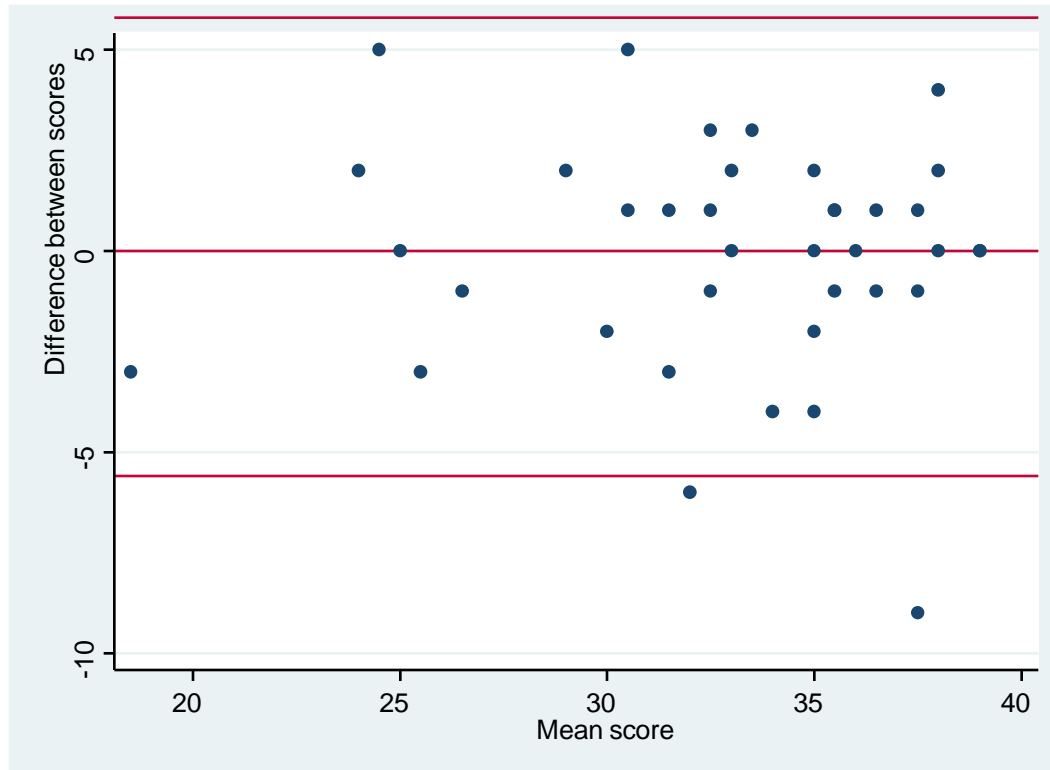
## Scatter Plot – Line of Regularity

Total ASQ score (higher scores represent fewer appetite problems and symptoms)



# Extent of Agreement

## Bland- Altman Plot



# Assessment of Reproducibility of ASQ using Kappa Statistic

Question number	Question theme	Un-weighted kappa	Weighted kappa
5	Number of meals	1.00	1.00
2	Satiety	0.75	0.82
10	Mood	0.67	0.74
7	Taste compared to pre illness	0.64	0.74
8	Taste changes	0.60	0.68
6	Number of snacks	0.52	0.63
11	Energy level	0.58	0.59
12	Pain	0.56	0.54
3	Hunger	0.46	0.54
4	Enjoyment of food	0.42	0.53
9	Nausea	0.41	0.53
1	Appetite	0.37	0.51

Value of kappa

<0.20

0.21 – 0.40

0.41 – 0.60

0.61 – 0.80

0.81 – 1.00

Strength of agreement

Poor

Fair

Moderate

Good

Very good

# Internal Consistency of the ASQ using Cronbach's Alpha

ASQ Baseline	ASQ +1 Week	CNAQ	SNAQ
0.76	0.74	0.47	0.51

Intraclass Correlation Coefficient = 0.841 (95% CI 0.748 to 0.935)

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# Phase II Sample (n=185)

## Patient inclusion criteria

- >18 years
- Diagnosis of primary lung or upper GI cancer

## Patient exclusion criteria

- BMI < 18.5
  - Lost > 10% of their pre-illness stable body weight
  - Lost between 5 and 10% of their pre-illness stable body weight with a BMI < 20
  - Receiving enteral tube feeding or parenteral nutrition.
  - Unable to be weighed.
-

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# Phase II - Progress To Date

- Recruitment started October 2007
  - 37 patients recruited to date
  - 5 patients completed
  - Finish date estimated December 2008
-

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# The Future

## Phase I

- Validity and reliability paper

## Phase II

- Recruitment - December 2008
- Data analysis
- Publication

## Phase III

- Qualitative exploratory study
-

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# Plurality in CAM, and its implications for practice and research in palliative care

Dr John Hughes  
CECo Research Fellow  
University of Liverpool

## CAM within palliative care

- Between 30% and 50% of cancer patients use CAM therapies.
- Many cancer care services offer CAM.
- Dearth of research evaluating effects of CAM.
- CAM associated with inherent methodological problems, including blinding; placebos; administering representative treatments; and, utilising outcome criteria capable of detecting treatment effects.

(Molassiotis et al 2005; Scott, Molassiotis et al 2005; Macmillan Cancer Relief 2002; Hughes and Lloyd-Williams, 2008; Verhoef, Lewith et al, 2005, 2004; Elder, Lewith et al 2006)

# The problem of plurality

- CAM therapies have competing theoretical frameworks underpinning practice.
- Acupuncturists in the UK generally affiliate to one of two broad theoretical bases.
- Traditional acupuncture, based on traditional oriental medical principles, and western acupuncture, based on anatomical, physiological and pathological principles.

(Acupuncture Regulatory Working Group, 2003; BMA, 2000; Mills and Budd, 2000; Dale, 1997)

# Exploring acupuncturists' perceptions of treating patients with rheumatoid arthritis

- Qualitative study exploring the impact of practitioner affiliation to a traditional or western theoretical base.
- Significant inter-affiliatory differences were identified in the treatments acupuncturists administer to patients with RA and in the scope and emphasis of intended therapeutic effects.

Hughes et al (2007)

“When I first started going I was going in on my knees, but I came out and I was skipping”

- Follow up study outlined the experiences of patients with RA who had received treatment with acupuncture, again exploring the impact of practitioner affiliation.
- Affiliatory differences also influence patients' experiences of being treated with acupuncture, and their perception of treatment outcomes.
- Acupuncturist affiliation has demonstrable implications for practice and research.

(Hughes, paper submitted)

# Single point acupuncture at P6 versus individualized western acupuncture

- Acupuncture at P6 can alleviate chemotherapy related nausea and vomiting.
- However, some patients still fail to respond to acupuncture at P6 and/or prescribed antiemetics.
- P6 not the only point ascribed as having antiemetic effects.
- Adding acupuncture points or individualizing treatment may increase effectiveness.

# Single point acupuncture at P6 versus individualized western acupuncture

- Randomized pilot trial.
- 40 consecutive patients who meet inclusion/exclusion criteria will be recruited.
- Treatments administered by BMAS acupuncturist with western theoretical framework.
- Weekly treatments for six chemotherapy cycles.
- Primary outcome criteria: Rhodes Index of Nausea & Vomiting; MASCC Antiemesis Tool
- Breast Cancer Campaign (<£15,000)

# Exploring the characteristic factors which contribute to homeopathic treatment

- Currently equipoise in relation to the efficacy of homeopathic treatments.
- However, previous clinical trials may be methodologically flawed.
- In particular, previous trials have assumed what the active treatment ingredients are for homeopathy.

# Exploring the characteristic factors which contribute to homeopathic treatment

- Qualitative narrative study, which aims to explore homeopaths' perceptions of the characteristic factors of the treatments they administer to patients with life limiting pathologies.
- Homeopaths recruited from differing theoretical frameworks (approx 20)
- Exact methodological details, and source of funding TBC.

Hughes and Bingley



## Plurality in CAM, and its implications for practice and research in palliative care

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