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Better care at the end of life

WHO Collaborating Centre for  
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# Cultural relativism: implications for palliative and end of life care

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## Plan for this session

- Concepts, concepts, concepts
- The setting
- Doing the work
- Manifestations of 'meaning' at the end of life
- Methodological reflections
- Translating the findings into the clinical setting

## Background to this study

*'The resilience of those who choose to work exclusively in this field is won by a full understanding of what is happening and not by a **retreat behind a technique** ...if we are to remain for long near the suffering of dependence and parting we need also to develop a basic philosophy and search, often painfully, **for meaning even in the most adverse situations**' (Saunders and Baines 1983)*

## Background to this study

- *'In most health care theorising, (the) white-dominant culture remains transparent and unspoken for the most part. ...positioned as 'normal'... **'being normal' is colonised by the idea of 'being white.'*** (Kirkham and Anderson *Advanced Nurs Sci* 2002; 25:1-17)

## A reasonable response...

- Cultural relativism or multiculturalism defined as “A social-intellectual movement that promotes **value of diversity** as a core principle and insists that **all cultural groups be treated with respect as equals**” (Macklin R. Ethical relativism in a multicultural society. *Kennedy Institute Ethics Journal* 1998;8(1):1-22.)

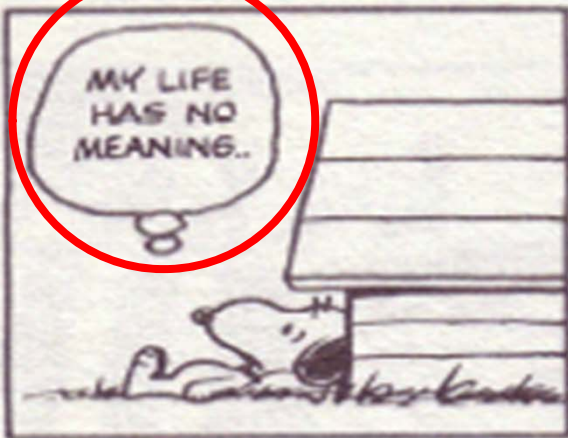
## A measure of society should be how we treat our most vulnerable members

- *We emerge deserving of little credit; we who are capable of ignoring the conditions that make muted people suffer. The dissatisfied dead cannot noise abroad the negligence they have experienced (Hinton 1967)*
- *We must avoid patients dying deaths they deplore.... (Christakis 1999)*

# Understanding diversity and conceptual sloppiness

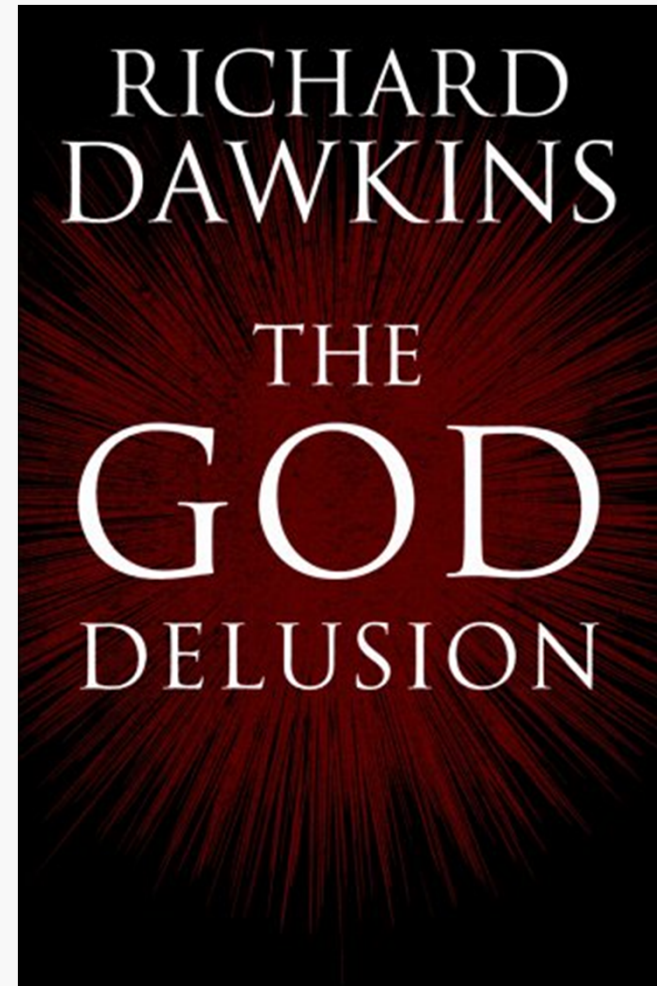






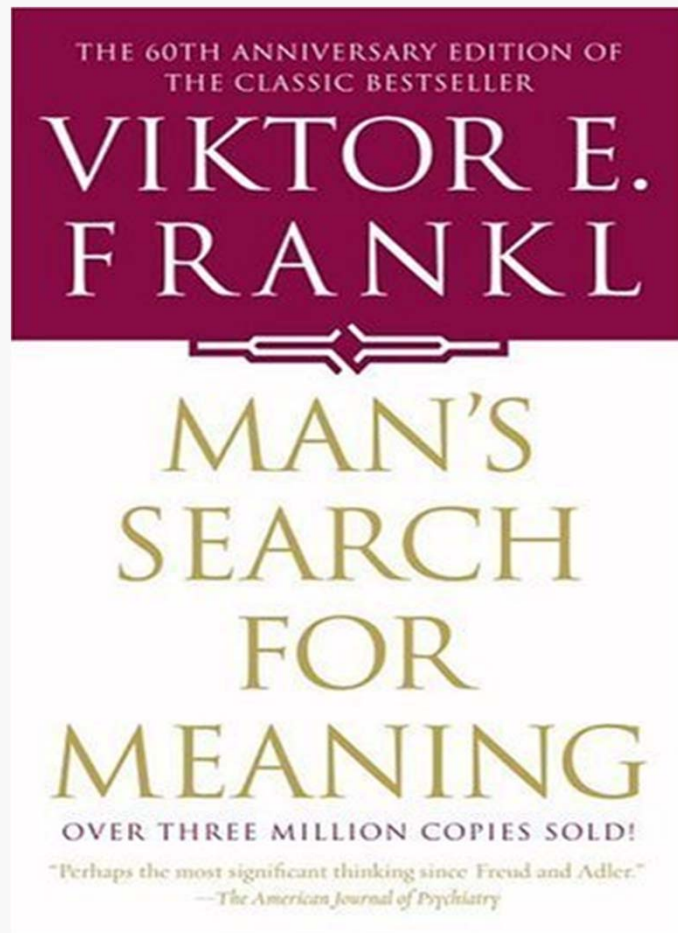
## Our eternal search for meaning

- Dawkin argues: *“there is no rhyme or reason in the universe, only blind pitiless indifference”*
- Basic human, psychological need to find meaning and purpose in life (particularly in times of crisis/at the end-of-life)





# Our eternal search for meaning



- *Those who have a 'why' to live, can bear almost any 'how'*
- *Our main motivation for living is our will to find a meaning in life*

## More definitions: religion and spirituality are...

- A system of faith and worship expressive of an underlying spirituality which is frequently interpreted in terms of particular rules, regulations and practises, as well as the belief in the content of the named religion. There is a clear acknowledgement of a power other than the self that some describe as God (Speck 2003)
- A search for existential meaning within a life experience, usually with reference to a power other than the self, not necessarily called 'God', that enables transcendence and hope (Speck 2003)

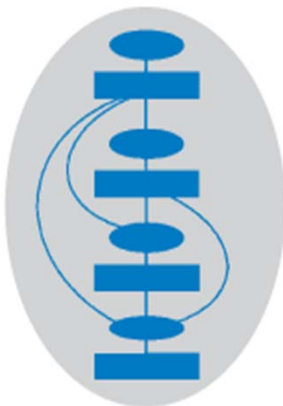
NHS

National Institute for  
Clinical Excellence

Guidance on Cancer Services

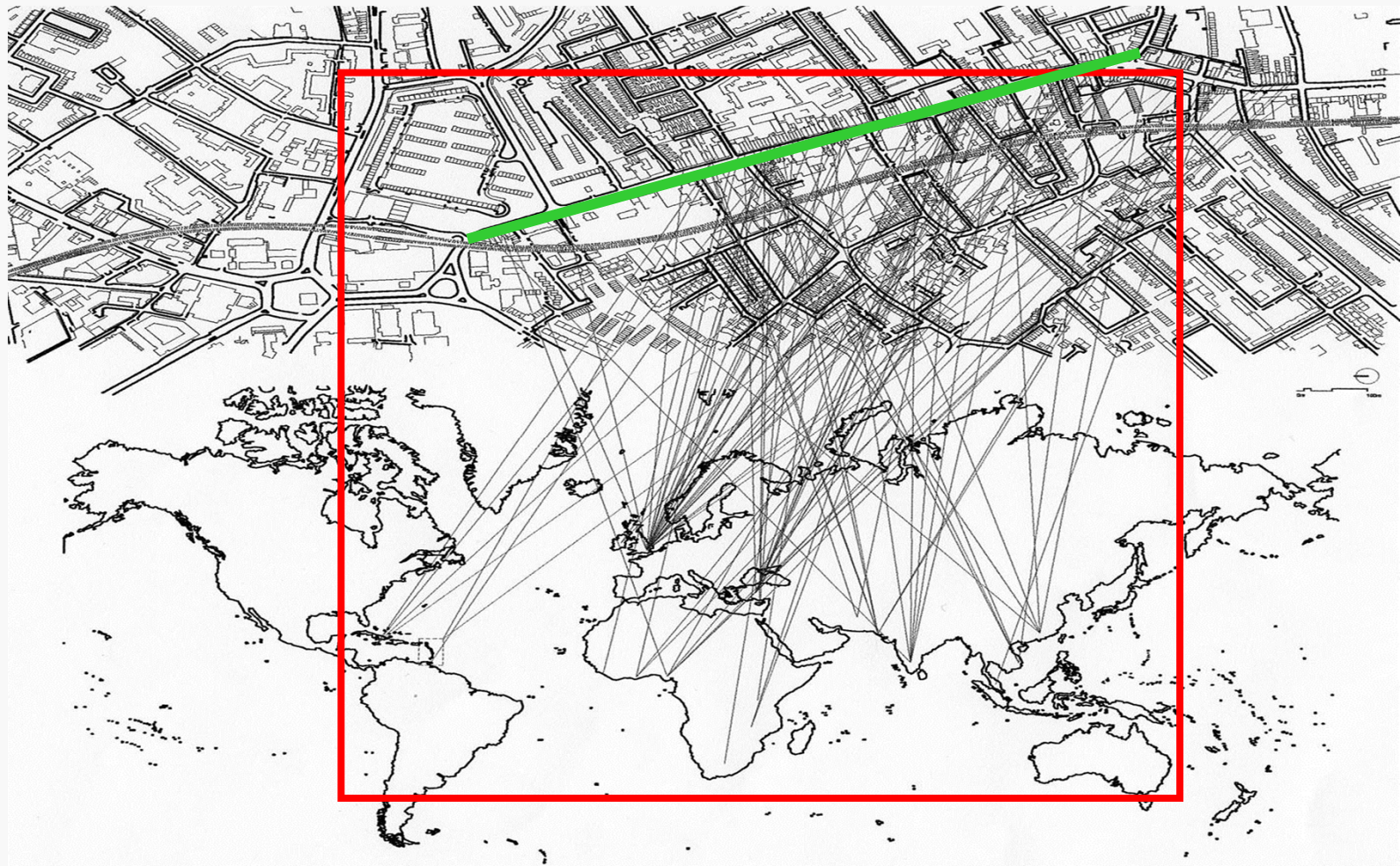
## Improving Supportive and Palliative Care for Adults with Cancer

The Manual



- Patients with cancer/carers should have opportunities for their spiritual needs to be assessed at various points in the patient pathway, ensuring that *spiritual elements of illness are taken into account*;
- Spiritual care for patients with cancer and their carers should be *an integral part of health and social care* provided in all care environments and should be open to similar levels of scrutiny and supervision as other aspects of non-physical care.

# Location, location, location



**Global Cities: Walworth Road, South East London, Suzanne Hall, 2008**



# Patients interviewed

	Caribbean (n=26)	white British (n=19)
<b>Gender:</b>		
<i>male</i>	17	10
<i>female</i>	9	9
<b>Age (mean)</b>	66.2 yrs (35-82 yrs)	72.6 yrs (34-88 yrs)
<b>Cancer site:</b>		
<i>breast</i>	2	4
<i>GI</i>	6	4
<i>GU</i>	11	4
<i>haematological</i>	2	3
<i>lung</i>	4	3
<i>site unknown</i>	1	1
<b>Location of interview:</b>		
<i>hospital</i>	11	5
<i>home</i>	15	14

# The questions

## Finding meaning:

- People often wonder why they became ill. Tell me in your own words your thoughts on this.
- I'd like to tell me in your own words about your symptoms, what they mean to you, and how they bother you.

## Sources of support and help:

- What's helped you to cope during these past few months?
- Tell me on your own words what makes you happy or brings you enjoyment, particularly as your illness has progressed

# Doing the work: a divesting methodology

- A very valuable lesson....
  - Sensitive perceptions require suspension of conventional expectation
  - Counter intuitive that when listening to terminally ill important to divest oneself from notion that dying was worst thing that could ever happen :
    - four decades of marital abuse (Jeanie)
    - struggle with alcohol dependency and recurrent depression (Becky)
- *Usually when you listen to some statement , you hear it as a kind of echo of yourself. You are actually listening to your own opinion (Longaker 1997:147)*

## Doing the work: becoming a reliable witness

- Many potential transformations of identity wrought by study participants
- Not infrequently promoted to status of reliable witness/confidante (Stanworth 2004).

- But credible accounts sometimes questioned:

**Becky:** *Do I sound sick? (laughs) Do I sound mad in the head?*

**JK to Becky:** *Do you sound mad in the head? No not at all. (WB34, GI cancer, 34 years).*



# Doing the work: researching the vulnerable at the end of life

Downloaded from [jme.bmj.com](http://jme.bmj.com) on 22 July 2009

## Research ethics

### Vulnerability in palliative care research: findings from a qualitative study of black Caribbean and white British patients with advanced cancer

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#### ABSTRACT

**Introduction:** Vulnerability is a poorly understood concept in research ethics, often aligned to autonomy and consent. A recent addition to the literature represents a taxonomy of vulnerability developed by Kipnis, but this refers to the conduct of clinical trials rather than qualitative research, which may raise different issues.

**Aim:** To examine issues of vulnerability in cancer and palliative care research obtained through qualitative interviews.

**Method:** Secondary analysis of qualitative data from 26 black Caribbean and 19 white British patients with advanced cancer.

**Results:** Four domains of vulnerability derived from Kipnis's taxonomy were identified and included: (i) communicative vulnerability represented by participants

participants are considered vulnerable, there is confusion about what this term implies and how it should be applied to research in general and palliative care in particular.

Definitions of "vulnerability" vary, usually referring to individuals with limited cognitive abilities or diminished autonomy.<sup>10-12</sup> Vulnerable populations, however, may possess autonomy but lack capacity to communicate opinions regarding participation in research. Moreover, this definition does not adequately engage with the context (social as well as medical) of research participants, which may create situations of vulnerability. Kipnis presents a more helpful definition of vulnerability as being an *intrinsic* or *situational* condition that puts some individuals at greater risk of being used in research in ethically

# The experience and expression of cancer-related pain

ORIGINAL ARTICLES

JOURNAL OF THE ROYAL SOCIETY OF MEDICINE Volume 96 January 2003

## Symptom severity in advanced cancer, assessed in two ethnic groups by interviews with bereaved family members and friends

Jonathan Koffman BA MSc Irene J Higginson PhD FFPHM Nora Donaldson CStat PhD<sup>1</sup>

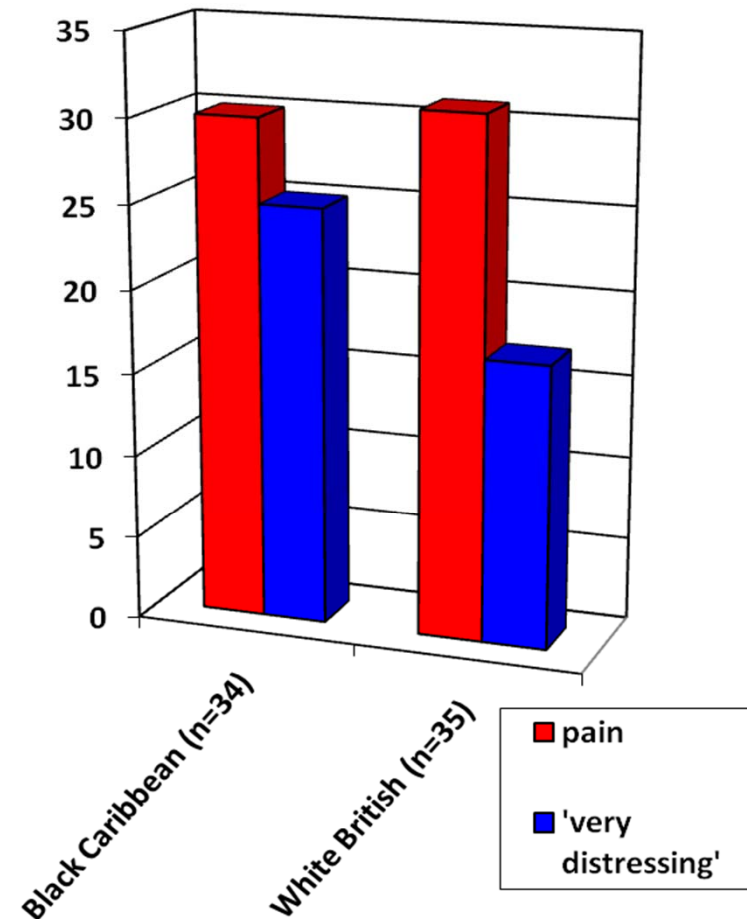
*J R Soc Med* 2003;96:10-16

### SUMMARY

Little research has been reported on the experience of cancer among minority ethnic communities in the UK. As part of a wider survey in inner London we interviewed bereaved family members or close friends of 34 first-generation black Caribbeans and of 35 UK-born white patients about symptoms and symptom control in the year before death with cancer. They were drawn from population samples in which the response rates were equal at about 46%.

Symptoms in the two ethnic groups were similar. However, multivariate logistic regression indicated greater symptom-related distress in black Caribbeans for appetite loss, pain, dry mouth, vomiting and nausea, and mental confusion. Respondents were also more likely to say, in relation to black Caribbean patients, that general practitioners (though not hospital doctors) could have tried harder to manage symptoms.

The findings suggest a need for better assessment and management of cancer symptoms in first-generation Caribbean Londoners, guided by a deeper understanding of cultural influences on their responses to advanced illness.





*Pain has an element of blank;  
It cannot recollect  
When it began, or if there were  
A day when it was not.  
It has no future but itself,  
Its infinite realms contain  
Its past, enlightened to perceive  
New periods of pain.*

Emily Dickinson (1830–86). Completed Poems. 1924

# Making sense of pain: intersection of body, mind... and culture

*Palliative Medicine* 2008; 22: 350–359

## Cultural meanings of pain: a qualitative study of Black Caribbean and White British patients with advanced cancer

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IJ Higginson King's College London, Department of Palliative Care, Policy and Rehabilitation, London

- Pain not sole creation of anatomy and physiology
- Emerges at ***'intersection of bodies and minds'*** (Morris 1991)
- Private and public faces of pain – take place within social context



## Meanings of pain

Meaning	Description	Sub-categories
Pain as a challenge	A task or hurdle that needs to be overcome	Mastering the Challenge  Unable to meet the challenge
Pain as an enemy	An unfair attack by hostile force	
<b>Pain as a test of faith</b>	<b>Associated with confirmation of religious belief</b>	<b>Meeting a test of faith</b> <b>Unable to overcome test of faith</b>
<b>Pain as a punishment</b>	<b>Characterised by theme of wrongdoing</b>	<b>Justified or unjustified punishment</b>

## Pain: meeting a test of faith

### **Matilda, Caribbean woman with breast cancer:**

*To see how strong I am, how strong my faith is, how much I believe in him. I don't know if you ever read in the Bible about Job and the songs erm, you know, in the Bible, this book, song of Job. ... And even his wife turned around and said, "You silly man," or whatever, "Stupid man. Curse God and all that." And he's saying to her, he's so, so determined, he said, "No, woman, you can't be like that. You can't curse God and all that," and he kept his faith. ... I'll keep hanging on, and I'm hanging on till the last minute. (Patient B13)*

## Pain as a 'justified' punishment

- Punishment interpreted at level of mankind considered justified/acceptable:

*Franklyn: Sin is a little word name 's' 'i' 'n'. I know what it comes from:- disobedience.*

*JK: Disobedience?*

*Franklyn: Disobedience.*

*JK: If I'm hearing you right, did you have anything to do with it?*

*Franklyn: I'd say no and I'd say yes. But I've explained it to God, but it doesn't matter to you! ...When God made this world and put man here, he didn't just put us here and say: "Alright, just stay and enjoy yourself on me!"  
(Patient B07)*



Contents lists available at ScienceDirect

## Social Science & Medicine

journal homepage: [www.elsevier.com/locate/socscimed](http://www.elsevier.com/locate/socscimed)



### “I know he controls cancer”: The meanings of religion among Black Caribbean and White British patients with advanced cancer

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#### ABSTRACT

There is evidence that religion and spirituality affect psychosocial adjustment to cancer. However, little is known about the perceptions and meanings of religion and spirituality among Black and minority ethnic groups living with cancer in the UK. We conducted

- **ALL** Black Caribbeans compared to 13/19 White British patients volunteered views on religion
- Two Black Caribbean and one older White British referred to ‘spirituality’

Meaning	Interpretation	Examples
<b>Comprehending cancer</b>	<b>Understanding cancer as explicable rather than disordered life event</b>	<i>God means everything to me. He's my life, He's always been there in my hardest times, my happiest times, He's everything to me. He's brought me this far and <b>I know he controls cancer</b>, and whatever He decides, then I'll go along with it. (BC17, GI cancer, 57 years)</i>
<b>Living with cancer and its progression</b>	<b>Belief in God and prayer producing positive state of mind</b>	<p><i>I've got faith in prayers. It keeps me fit and well. I say some prayers and I feel relaxed and know that I'm gonna be helped. (WB31, breast cancer, 88 years)</i></p> <p><i>My faith is that <u>strong</u>. I can walk through glass, it won't cut me. Faith can move mountains (BC11, lung cancer, 70 years)</i></p>
<b>Cancer promotes religious faith and belief in God</b>	<b>Cancer experience and its progression embraced rather than viewed as source of burden</b>	<i>Probably my future life will be better than this. We're promised a <u>better life</u> and I'm looking forward to that. A far better life than this one. (BC18, GU cancer, 82 years)</i>



**Psycho-Oncology**

*Psycho-Oncology* (2011)

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**‘The greatest thing in the world is the family’:  
the meaning of social support among Black  
Caribbean and White British patients living  
with advanced cancer**

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**A ‘convoy of support’: Sherwin, 67 yr old Black Caribbean man with lung cancer:**

*They always want me to come down to have dinner with them. Or they will phone up and find out if I'm feeling hungry. And I say, "Yes", and they will bring some food to eat, and all that. (BC02, lung cancer, 67 years)*

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News > Politics > David Cameron

## David Cameron aims to make happiness the new GDP

Prime minister acts on pledge to find out what makes the nation content



Allegra Stratton, political correspondent  
guardian.co.uk, Sunday 14 November 2010 21.41 GMT  
[Article history](#)



*"Well-being can't be measured by money or traded in markets. It's about the beauty of our surroundings, the quality of our culture and, above all, the strength of our relationships."*

# What is happiness?

- Happiness from ‘hedonistic’ view concerns maximisation of pleasure and minimisation of pain
  - occurs when pleasurable experiences and sensory gratifications outweigh painful experiences
- ‘Eudaimonic’ happiness results from actualisation of individual potential and fulfilling one’s ‘daimon’ (Ryan and Deci 2001)



## Transcendence at the edge of life

- *Because God made me like this. He made me contented and happy. He justifies me and he gives me peace. He gives me love and happiness. He's the source. (B09, Rosemary, 75 years, GU cancer)*
- *Yeah, believe in God, because as I said, sometimes when I wake up in the morning and the way I feel and I pray to God and you think to yourself, "Am I going to stay like this all the days of my life? Am I going to feel like this all the days of my life?" and you feel different, you feel strong, you feel healthy, you feel happy in your mind. (B20, Clyde, 60 years, GU cancer)*

## Transcendence at the edge of life

**Harry:** *I believe there is hope for me when I die. That make me happy.*

**JK:** *Can you please tell me a bit more about that so I can understand what you mean?*

**Harry:** *Well there is one passage in the Bible that God so loved the world that he gave his own son. So when it talks about everlasting life, it is not talking about this life but one after this one. I do believe in it. (BC26, Douglas, )*



## Study reflections

- Racialised differences between researcher/participant:
  - affect ‘veracity’ and ‘accuracy’ of what participants’ prepared to report (Gunaratnam 2003)
  - Social hybridity
- Study cross-sectional:
  - no potential to explore meanings over time

## So what does all this mean in the clinical encounter?

- Cancer has many faces; need to go beyond 'binary' assessment of symptoms
- Religion and belief in God *maybe* very central features to the illness experience
  - multiple meanings shape cancer experience
- Importance of narrative and listening to patient's story (Saunders 1964)

## So what does all this mean in the clinical encounter?

- *“What does it profit a doctor if he can prescribe opioids yet not know how to listen actively to those who need his help and humanity? Palliative medicine and pain control are as much exercises in communication as they are applied pharmacology” (Doyle 1989)*

## So what does all this mean in the clinical encounter?

- The area of London we serve (St. Christopher's Hospice) is home to an increasing diversity of culture, and that means we must listen ever more carefully to what people want.

***Nevertheless, it is perhaps surprising how many basic human needs remain constant:*** the need to talk and to be heard, the need to be cared for and valued, the need to find meaning and reconciliation – especially on life's final journey (St. Christopher's Hospice 1998)