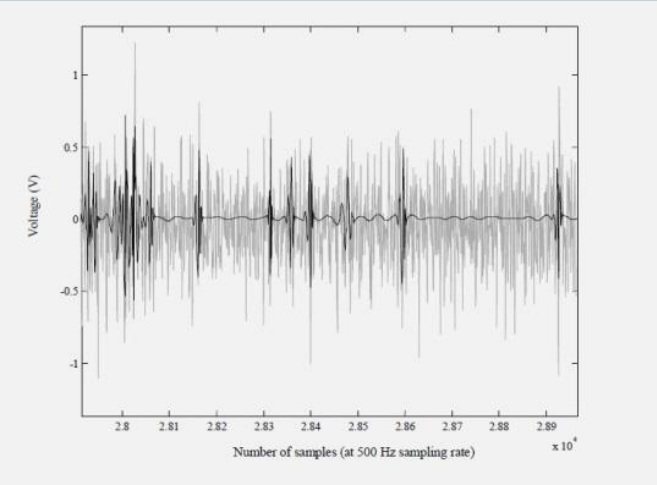
Signal to noise:
meeting palliative care needs in hospital



DEANS BUCHANAN
CONSULTANT IN PALLIATIVE CARE
NHS TAYSIDE

Signal to noise: attending to importance

Signal-to-noise ratio is a measure used in science and engineering that compares the level of a desired signal to the level of background noise. A ratio higher than 1:1 indicates more signal than noise.

While SNR is commonly quoted for electrical signals,

it can be applied to any form of signal….

Definition of SNR: Wikipedia 2015

Outline

- Personal view upfront
- Background information – death in Scotland
- Signals or noise?
  - Hospitals
  - “Choice” and “Preference”
  - “Home”
  - Illness, frailty and uncertainty
- Dying in hospital – signals and noise
- Key signals – dignity and personhood
- Summary

Personal view: would I *choose* to die in hospital?

- No, but……..
  - I don't think **location** is my first priority
  - My view is personal and not shared by all
  - My view might change
  - Even if I don't "choose" hospital, I still might die there. Circumstances do not always afford 'choice'
  - "Choices" are often better described as "trade offs"
  - "Illness uncertainty" is prevalent in 2015
  - Hospital death can be a "good" experience for people and their families

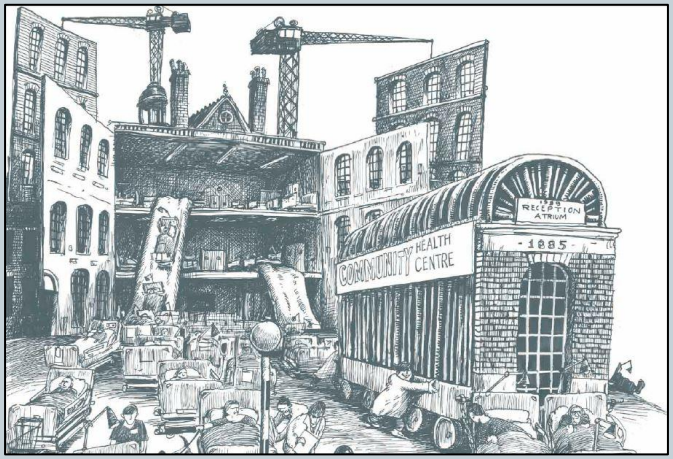
Death in Scotland

- Around 53,000 people die in Scotland each year from population of 5.4 million (ONS, 2015)
- Number of deaths per year is expected to rise by 9000 to 62,000 per year by 2037 (ONS, 2015)
- Location of deaths in Scotland:
  - Acute setting 52.3% (Decreasing)
  - Home 30.3% (Increasing)
  - Hospice 17.4% (Increasing)

  (Sharpe et al, BMJ Supportive and Palliative Care 2015)
- On a given day in Scottish hospitals:
  - 10, 743 people were in-patients in the acute setting
  - 28.8% (3,093) of those admitted died within the next year
  - **9.3% (1,027) died during that admission** (i.e. 1/3 of all the deaths)

  (Clark et al, Pal Med 2014)

Hospital



A hospital is only a building until you hear the slate hooves of dreams galloping on its roof. You listen then and know that here is no mere pile of stone and precisely cut timber but an inner space full of pain and relief. Such a place invites mankind to heroism.

(R Selzer – Taking the world for repairs, 1987)

Hospital

Hospital

"A place where strangers who are suffering can be cared for as honoured guests?"

Hospital end of life care data

- Complaints
  - "50% of complaints relate to end of life care in hospital"
    - Not clear where this statistic comes from, DoH
    - 3-7% of complaints related to end of life issues in hospital (2013, snapshot review of complaints, NHS England/Wales)
    - Scotland – no clear data
- There is clear data of deficit in care quality for some in hospital
- The majority of people in Scotland die in hospital
- Specialist palliative care input improve patient outcomes

Hearn & Higginson, Pal Med (1998)

Quality markers of death by location

	Home	Hospital	Care Home	Hospice
EOLC outstanding or excellent	53%	33%	51%	59%
EOLC 'Good'	28%	36%	33%	26%
EOLC Good to outstanding	*81%*	*69%*	*84%*	*85%*
Treated with dignity	72-78%	56.8%	61.4%	80-86%
Pain relieved all of the time	19%	39%	46%	63%

National Survey of Bereaved People in England (ONS, 2013b)

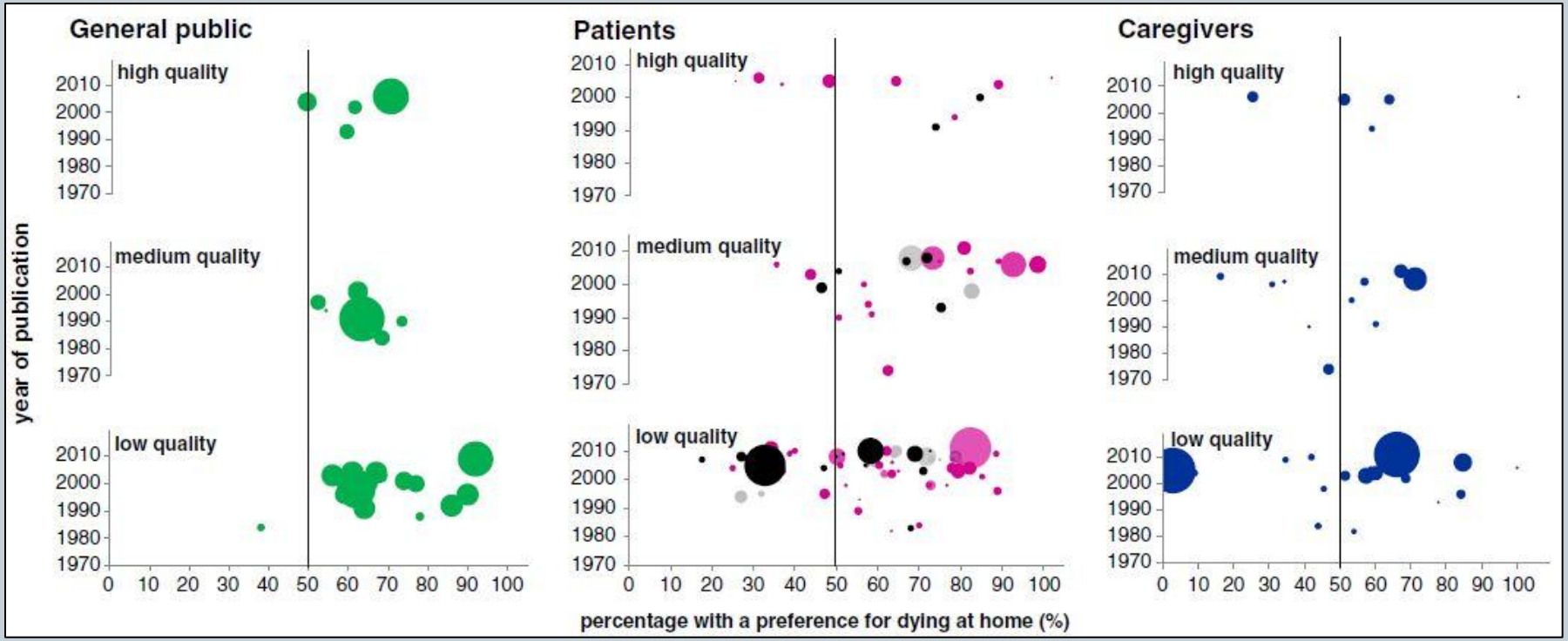
Choice and preference at the end of life

“Location of death” preferences

- Policy indicators have elevated “location” as proxy for quality
  - England, QIPP: “Percentage of people who die in their usual place of residence”
  - Scotland, HIS and integration measure: “Proportion of the last six months of life spent at home or in a community setting”
- Preferences for home death
  - Patients: 31-87%
  - Carers: 25-64%
  - Public 49-70% (Gomes et al, 2013)
- No study reports 100% preference for any specific location
- Preference is not a single concept:
  - Preference if situation was ideal
  - Preference during the existing situation

Townsend et al *BMJ* 1990; 301: 415–417.

Preferences for home death



Number of dots = number of studies. Area of dot = study size,
Black dots = >50% non-cancer. Pink dots = >50% had cancer. Grey = unknown.

Heterogeneity and changes in preferences for dying at home: a systematic review.
Gomes et al. BMC Palliative Care, 2013, 12:7

Why might choice change?

- 20% of people changed preference as they neared end of life (Gomes et al, 2013)
- Reasons for changing preference to hospital included:
  - Uncontrolled **pain**
  - Other **symptoms** not controlled
  - **Treatment** of reversible conditions
  - Reduce **caregiver burden**
  - Inability to sustain **safe** care at home
  - Worried about effects on **children**
- Hospital can be thought of as a familiar, 'safe space' (Gott et al, 2014 and Reyneirs et al, 2014)

Home

Concepts of "Home"

- Sociological
  - Physical location/space/base for family
  - Place of continuity/permanence
  - Connection with significant others
  - Financial asset
- Psychological
  - Security and safety
  - Privacy
  - Locus for emotional/life experiences
- Health
  - Less well explored
  - "Homely" healthcare environments
  - Hospital at home
- "A homely healthcare environment is one that supports spiritual expression and social interaction but allows privacy and access to caring activities of staff." (Rigby et al, Pal Med 2010)

Meaning of "home" at the end of life

- Collier et al – "A video-reflexive ethnography study"
- Patients were asked:
  - "If you were to make visible to clinicians what is most important to your care what would you want them to see and know?"
  - If you are unable to be at home, what would it take for you to "be at home" or "feel at home" here in this place?'
- Emerging themes:
  - No place like home
  - Safety
  - Hospital can become home
  - Home can become hospital
  - Hospital connecting to home
  - The built environment

Collier et al, Pal Med, Online first 2015

“Home”: Where your needs are met and your personhood fulfilled?

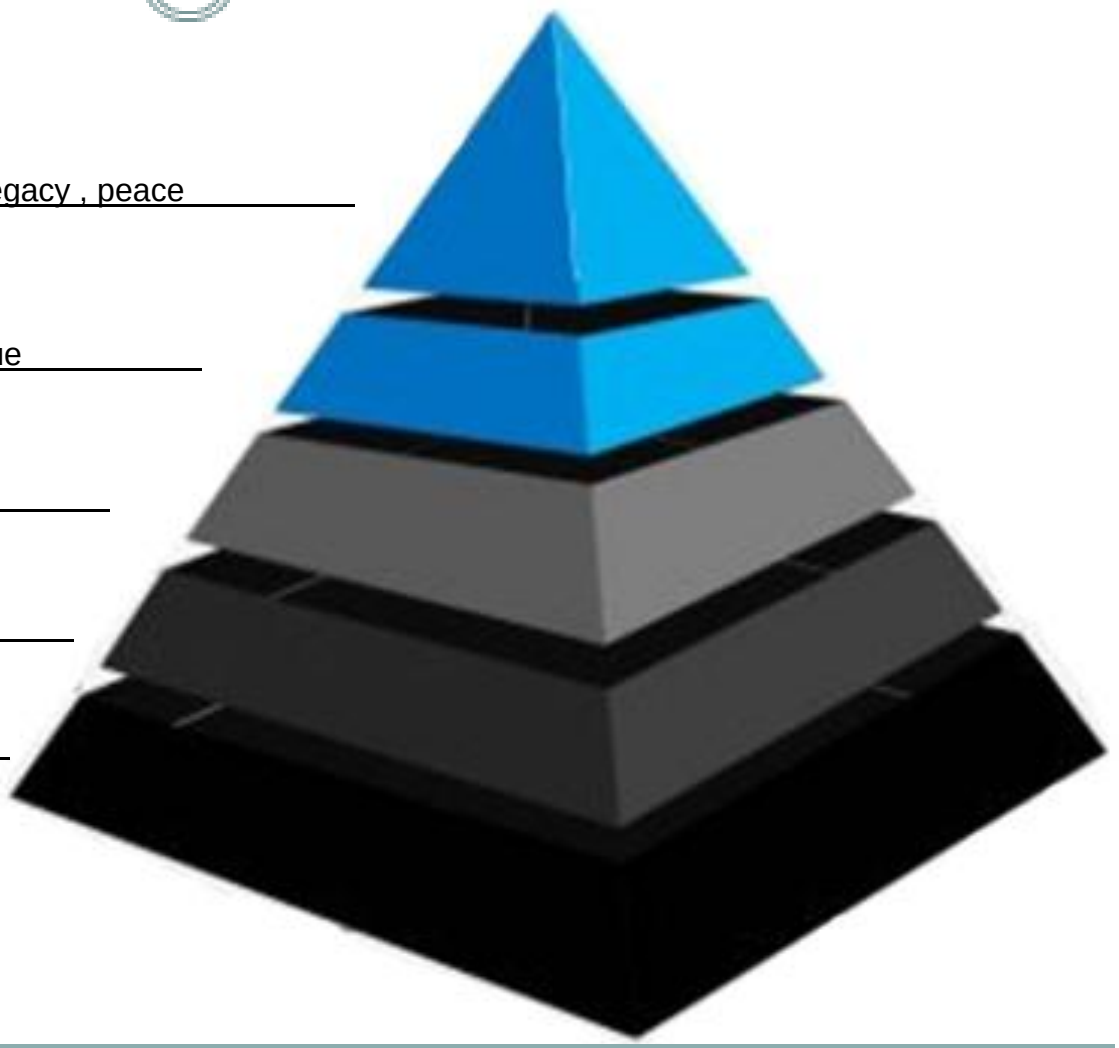
Self Actualisation
Morality, creativity, acceptance, generativity, legacy , peace

Esteem
Self-esteem, dignity, respect, confidence, value

Love and Belonging
Family, friendship, intimacy, honour

Safety
Security, safety, shelter, fears reduced

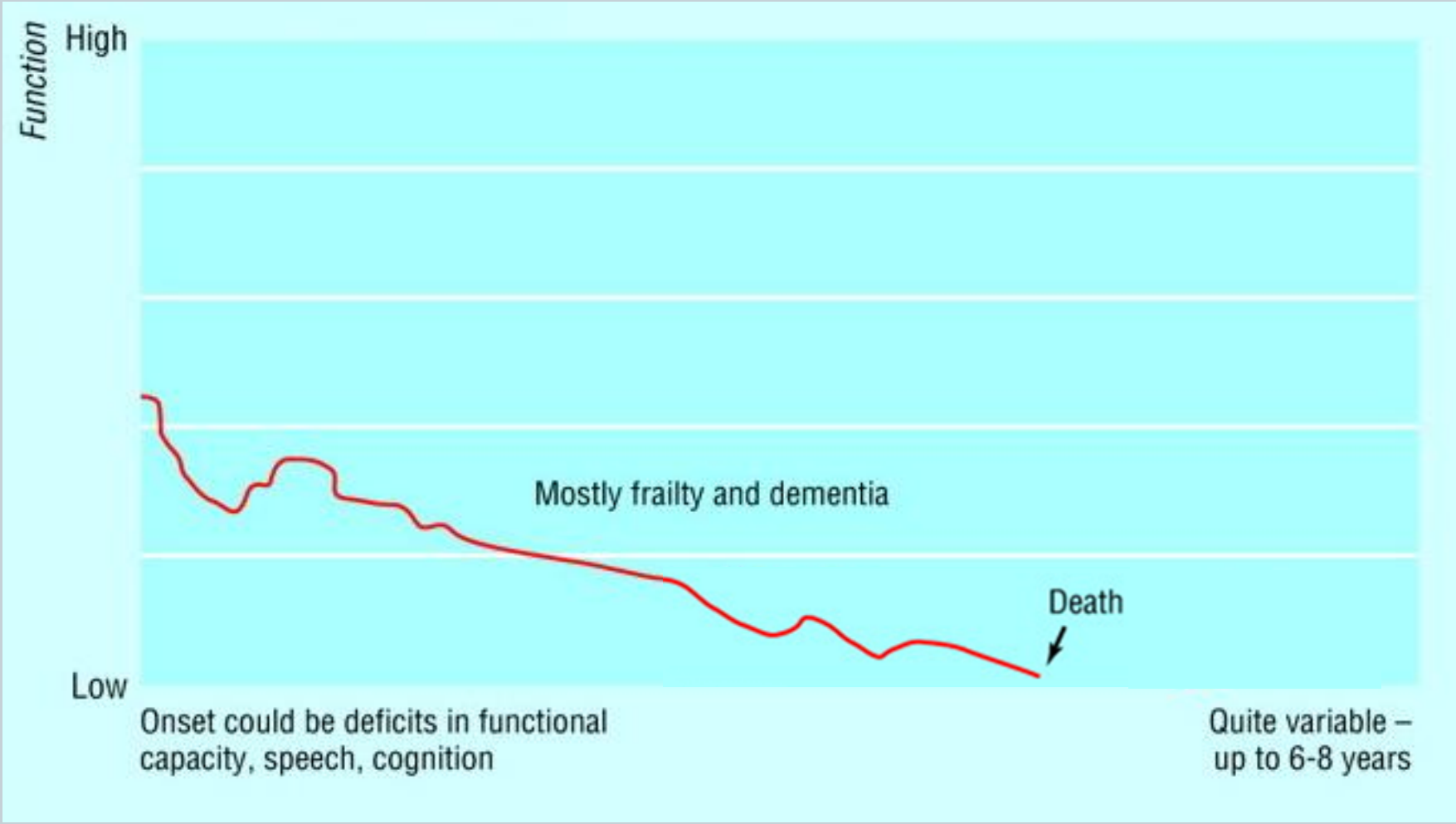
Physiological
Food, water, comfort, care needs



Maslow’s hierarchy of need. Zalenski, R Jn of Pal Med. 2006

Illness, Frailty and Uncertainty

Frailty and illness trajectory



Scott A Murray et al. BMJ 2005;330:1007-1011

Frailty and palliative care interventions

- Symptom control
  - Remember reduced resilience to side effects of medication. Use non-pharmacological measures. Remember delirium is common
  - "Start low and go slow" BUT "Get there" approach to titrations
  - Review medications and rationalise
  - Does pain contribute to "homeostenosis" and directly worsen frailty?
- Plan ahead
  - Acknowledge uncertainty in prognosis and focus on "health consequences" as frailty worsens
  - Goals of care will be dynamic and need to be incrementally established
- Vulnerability
  - Frail persons can be vulnerable in the wider sense of the word
  - Capacity issues need to be considered
  - Frail persons may have a "quiet signal" in the midst of "healthcare noise" – listen for it, listen to them

(Shega et al, J Am Ger, 2012)

Acknowledging uncertainty

- Important clinically
- Fits the lived experience of the people with ill-health and allows planning to resonant with experience
- Doesn't fit agendas to "standardise" care well
- Policy targets need to be careful of acknowledging this:
  - *"Percentage of end of life spent at home or in a community setting in the last 6 months"*
  - Proportion of people who die in hospital
  - Proportion of people who die in their usual place of residence

- "Reactive" health-care still has a place Gott et al, 2013
  - 6.7 % of admissions potentially avoidable for pal care patients (580 admissions, median age 84 years)

Dying in hospital

INDIVIDUALS' SIGNALS IN THE MIDST OF NOISE

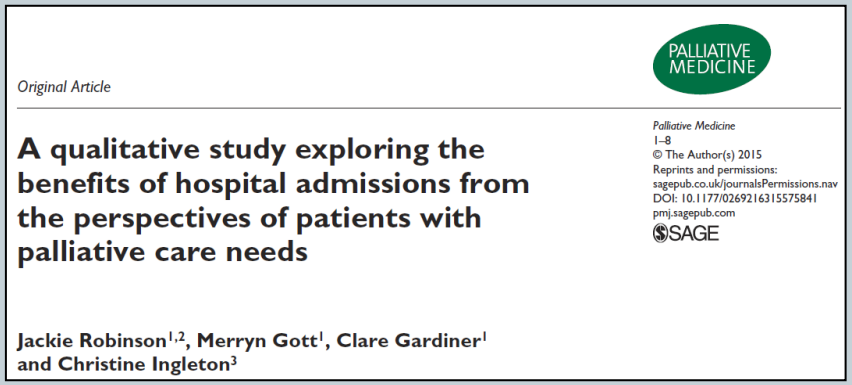
Dying in Hospital

- Reasons patient may die in hospital:
  - Active choice to remain
  - Too unwell for transfer out of acute setting
  - Unexpected decline during investigations or treatment
  - Social structure not able to 'cope'
  - Late recognition of dying and change of goals of care

    (Dunlop et al, 1989 Pal Med)
  - Non-cancer versus cancer
    - More likely to die in hospital with non-malignant disease(s)
  - Live alone
  - Deprivation
  - Ethnicity not a major factor in Scotland (Sharpe et al, 2013)

Benefits of hospital

- Longitudinal study
  - 14 Patients
  - GSF "positive"
  - Semi-structured interviews



Original Article

PALLIATIVE MEDICINE

A qualitative study exploring the benefits of hospital admissions from the perspectives of patients with palliative care needs

Jackie Robinson[1,2], Merryn Gott[1], Clare Gardiner[1] and Christine Ingleton[3]

Palliative Medicine
1–8

DOI: 10.1177/0269216315575841
pmj.sagepub.com
SAGE

- Themes emerging
  - Being cared for and feeling safe
  - Receiving care to manage at home
  - Relief for family
  - Feeling better and/or getting better

- Most participants said preference was to come to hospital **even if** they had been able to access the care they received at home

“Noise” in hospitals

- Failure to recognise dying
- “Biomedical” predominance
- “Death as a contested space” – decisions to make
- System geared towards cure and disease control
- Pressures of “throughput” and loss of “time”
- Moving and boarding of patients
- Fragmented teams and loss of continuity

Patient dying in hospital: an honoured guest in an honoured place?

- Hospital deaths will continue and probably increase
- There is a need to purposefully improve them, not ignore them
- Improvement will include:
  - Environment
  - Space
  - Time
  - Skills
  - Focus on personhood and dignity
- Maslow's hierarchy may give some insight
  - To ascend the pyramid then 'lower' levels must be in place first and a **vision** of the higher levels must exist

S Donelly, Quarterly Journal of Med 2013

2020 vision and integration

"Here is a radical suggestion – make hospitals good places for old people"

Prof Marion McMurdo, Tayside, BMJ 2013

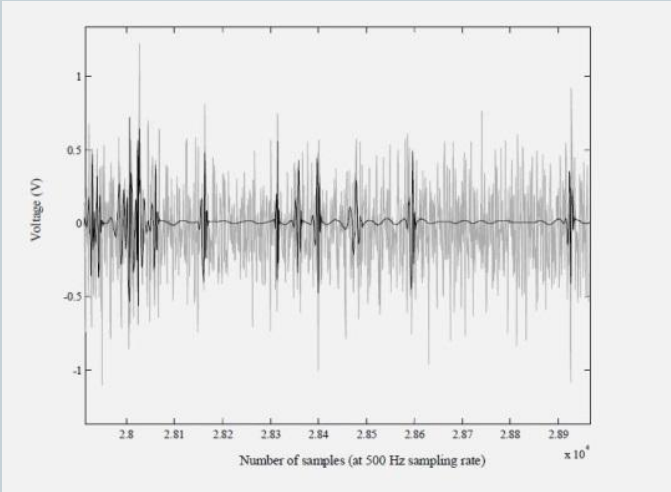
What is a ‘good’ hospital death?

“Home” at hospital?

(Khan et al. Nature Clin Olic, 2014)

Key Signals

DIGNITY AND PERSONHOOD



Dignity - context

- Dignity is encouraged in all aspects of healthcare
- Research shows that it is welcomed by people facing end of life (Chochinov et al. 2002)
- Dignity remains a key theme in government agenda on end of life (DoH, 2014; 2013; 2008)
- However "dignity" remains a subjective term (Vosit-Steller et al. 2013)
- Upholding dignity could be improved upon in the acute setting (Pringle, Johnston & Buchanan 2015)
- Healthcare professionals struggle to employ dignity because of lack of understanding, education and training (DoH, 2013)

Dignity conserving care

ANALYSIS

Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care

Kindness, humanity, and respect—the core values of medical professionalism—are too often being overlooked in the time pressured culture of modern health care, says **Harvey Chochinov**, and the A, B, C, and D of dignity conserving care can reinstate them

The late Anatole Broyard, essayist and former editor of the *New York Times Book Review*, wrote eloquently about the psychological and spiritual challenges of facing metastatic prostate cancer. "To the typical physician," he wrote, "my illness is a routine incident in his rounds while for me it's the crisis of my life. I would feel better if I had a doctor who at least perceived this incongruity… I just wish he would… give me his whole mind just once, be bonded with me for a brief space, survey my soul as well as my flesh, to get at my illness, for each man is ill in his own way."[1]

Broyard's words underscore the costs and hazards of becoming a patient. The word "patient" comes from the Latin patiens, meaning to endure, bear, or suffer, and refers to an acquired vulnerability and

EDITORIAL, p 167

Harvey Max Chochinov
professor, department of psychiatry, University of Manitoba. CancerCare Manitoba, Winnipeg, MB, Canada R3E 0V9
harvey.chochinov@cancercare.mb.ca

Accepted: 15 May 2007

patient's self perception, underscores the basis of dignity conserving care.[8]

Yet, many healthcare providers are reticent to claim this particular aspect of care, which is variously referred to as spiritual care, whole person care, psychosocial care, or dignity conserving care.[9-12] This reluctance is often framed in terms of lack of expertise or concern about how much time this might consume. Yet, when personhood is not affirmed, patients are more likely to feel they are not being treated with dignity and respect.[13] Not being treated with dignity and respect can undermine a sense of value or worth.[5] Patients who feel that life no longer has worth, meaning, or purpose are more likely to feel they have become a burden to others, and patients

Chochinov, BMJ (2007)

The Patient Dignity Question (PDQ)

- Developed by Chochinov et al. (2005) at the Palliative Care Research Unit, University of Manitoba, Canada.

- One question:

*"What do I need to know about **you as a person** to give you the best care possible?"*

Asked by healthcare professional to person receiving end of life care

Responses are written up, agreed with the patient and displayed on the patient's chart/notes

Patient Dignity Question in Acute Setting

- 30 patients, 17 HCPs and 4 family members
- Outcome measures and interviews pre and post PDQ
- Results
  - PDQ can improve levels of empathy perceived
  - PDQ increased new information around personhood
  - All participants would recommend the use of the patient dignity question in hospitals

Johnston B, Pringle J, Gaffney M, Narayanasamy M, McGuire M & Buchanan D, BMC Pal Care, 2015

Qualitative results

Patient perspective theme	Verbatim examples
Attributes and Attitudes	***"I appreciate the whole team…people try …they can't do enough for you"*** **(p23)**
Know me as a person	***"I am not just a patient with cancer. I have a family. A life."*** **(p16)**
Time and place	***"Lack of communication is a big thing for me…. nobody comes across and speaks to you"*** **(p18)**
HCP perspective theme	**Verbatim examples**
Care & communication	***"I've tried to keep the (PDQ) summary in mind when speaking to the patient"*** **(p16)**
Enlightenment and emotions	***"(The PDQ) allows staff to get a bit of insight into the patient that is not always obvious when first meeting the patient"*** **(p5)**
Family member perspective theme	**Verbatim examples**
Individualised care	***"I looked at this (PDQ response) and thought "this is you", so knowing this would help staff to have an idea… (I'm) happy for anything that improves care for people- I think this might"*** **(p20)**
Taking the time	***"(The nurses) are plagued with paperwork; it deters them from spending time with the patients"*** **(p29)**

Johnston B, Pringle J, Gaffney M, Narayanasamy M, McGuire M & Buchanan D, BMC Pal Care, 2015

Ethics of reciprocity – amplifying signals

- Patient dignity question
  - Considers what is needed to value the person - on their terms
  - Brief intervention
- "This is me"
- "Who I am"
- Golden Rule
  - "Do unto others as you would have them do unto you"
  - "Hurt not others with what pains yourself"
  - "Don't do to others what you don't want them to do to you"
- The "Granny" test
  - If this person was your own granny/mum/dad/daughter/son etc – how would you want them to be cared for?

Summary

Choice, uncertainty and reality

- Home remains the first choice of the majority of people. It is not the choice of 100% of people
- The majority of people in Scotland die in the acute setting – this may not change dramatically
- Not all circumstances afford choice
- Not all circumstances can be anticipated and planned out of ill-health
- As part of a comprehensive approach to end of life care Hospitals must be able to provide high quality end of life care for all.
- This requires purposeful and deliberate attention to the 'signals'

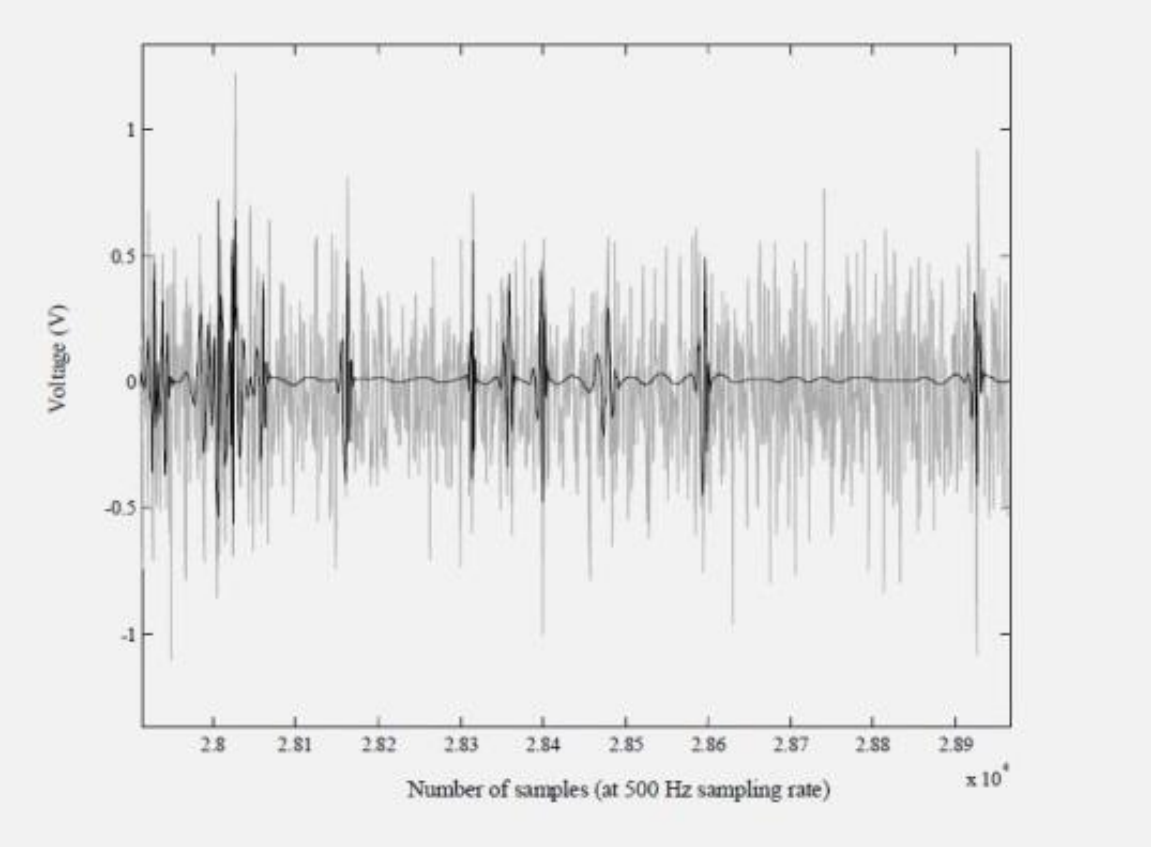
Attending to importance across **all** settings

- "We must attack the problem on every side: hospital services must be improved and extended, staff in residential homes increased, and voluntary as well as profit-making institutions helped in return for an approved standard of care"

Review of Glyn Hughes, H.L. (1960). Peace at the Last. A survey of terminal care in the United Kingdom. London: The Calouste Gulbenkian Foundation p.195

- 'Hospital and community care are not alternatives, neither are they in competition; they are both parts of a comprehensive pathway for frailty and both need to be used at times but planned for appropriately'

Gill Turner, Vice-President British Geriatric Society, HSJ, 2014



In the midst of 'noise', those whose 'signals' are fragile need to be recognised as worthy of time, focus and attention