

The 'problematisation' of death in hospital: a review of international palliative care policy in six countries

Jackie Robinson
 Palliative Care Nurse Practitioner, Auckland District Health Board
 Professional Teaching Fellow and PhD Candidate, School of Nursing, University of Auckland




Me....



Palliative care

- Predicated upon a specific philosophical approach to care which is embedded in the revivalist mode of a 'good death'
 - Pain free death
 - Open acknowledgement of the imminence of death
 - An 'aware' death in which personal conflicts are resolved
 - Death as personal growth
 - Death according to personal preference
 - Death at home surrounded by family and friends

(Clark 2008)

A 'Good Death'

- A natural death preferably at home
- Set up initially in opposition of mainstream health care
- Away from the highly technical, intervention focused environment of the acute hospital
- Yet, most deaths still occur in the hospital setting



People 'denied' die at home wish

© 14 November 2010 | Health

Too many people are dying in hospitals and care homes, and not at home the way they want to, says a report from Demos.

Of the 500,000 people who die each year in the UK, the think tank found only 18% die at home, yet 60% of people surveyed would like to.

Investing in community-based end of life care would also save the NHS money in the long term, the report says.

The Department of Health is reviewing funding for England. Services in the rest of the UK are funded locally.

The report, entitled **Dying for Change** predicts that by 2030 more people will die in hospital (65%) and fewer people will die at home (just one in 10 people).

In 10 years, Demos predicts that 20% of people will die in care homes, a figure currently at 17%.



- Palliative care has evolved:
 - WHO definition changed in 2002
 - Inclusive of all diagnoses with varied illness trajectories
 - Not limited by prognoses
 - Integrated with life prolonging (and curative) therapies
 - Increase in hospital based technology

I HAVE NO SPECIAL
TALENTS. I AM ONLY
**PASSIONATELY
CURIOUS.**
-ALBERT EINSTEIN

Original Article



Palliative Medicine
2015, Vol. 29(8) 703-710
© The Author(s) 2015
Reprints and permissions:
sagepub.com/journalsPermissions.nav
DOI: 10.1177/0969733015282941
pmj.sagepub.com
SAGE

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

Jackie Robinson^{1,2}, Merryn Gott¹, Clare Gardiner¹ and Christine Ingleton³

Abstract

Background: The acute hospital plays a significant role in caring for people with a life-limiting illness. Most research to date has focused exclusively upon the negative aspects of hospitalisation. Currently, there is little known about the benefits of hospital

Charities say letting people die at home could save millions for NHS

Marie Curie says many people with a terminal illness are in hospital unnecessarily, and not by choice, at the end of their lives



Charities involved in palliative care say more people should be helped to die at home. Photograph: iStockPhoto.com

The NHS could save millions of pounds if the majority of people who died of a terminal illness in hospital did so at home as most wished to do, charities have said.

Figures from the latest Office for National Statistics (ONS) survey of bereaved people found that 83% of those who died in hospital in 2013 had expressed a desire to die at home.

Palliative care: a public health issue

- Palliative care is a basic human right (WHO 2007)
- Increasing demand due to changing demographics
- An environment of global pressure to reduce government spending on health care
- Policy is seen as a mechanism to influence change at a public health level
- Many countries around the world have developed policy in palliative and end of life care



Aim

- To identify the factors that influence how the role of the hospital is envisaged within national policy on palliative and end of life care

Data Sources

- The Global Atlas of Palliative care (2014)
 - Countries which had achieved 'advanced integration' of palliative care with mainstream health care and had substantial impact upon policy (n=20)
- Any government led document written with the aim to identify gaps and inequities in current service delivery and provide recommendations for service development
- Excluded countries with legislation only
- Available in English
- England, Switzerland, Ireland, Australia, Singapore (and NZ)

Analysis (Braun and Clark 2006)

- Thematic analysis of documents
 - Familiarisation of documents
 - Coding of across the whole data set
 - Identify recurring themes from the coding
 - Development of key themes



Findings

- Documents were published over a 10 year period (2001-2011)
- WHO definition of palliative care was adopted by all documents
- Research evidence used to support unmet need and recommendations to improve care
- Integration of palliative care with mainstream healthcare
- Minimal evidence of consumer consultation

Key themes

- Preferences for place of care and place of death outside the hospital setting
- Unnecessary or avoidable hospital admissions
- Quality of care in hospital



Theme 1: Preferences for place of care and place of death

- Achieving patient preference was considered a key quality indicator
- Not achieving patient preference and/or death in hospital was seen as a poor quality death
- Frequent referencing made to home as the preferred place of death for most people
- Yet most people die in hospital

“...given the opportunity and right support, most people would prefer to die at home. In practice, only a minority manage to do so. Many people die in an acute hospital, which is not their preferred place of care.” (Department of Health, England p7)

Theme 2: Unnecessary or avoidable admissions

- Factors contributing to unnecessary admissions
 - Failure of community services to meet patient needs
 - Difficulties in identifying those who would benefit from palliative care
 - Timeliness of referral to palliative care services

“Patients who are identified late in the course of an illness usually have poorer outcomes of care and unnecessary hospital admissions.” (Ministry of Health, Singapore p32)

“At least part of the additional costs of providing improved care in the community and in care homes will be offset by reductions in hospital admissions and length of stay.” (Department of Health, England p16)

Theme 3: Quality of hospital care

- Research findings were used to highlight very poor quality palliative care
- Very few policies made mention of strategies to improve care instead focusing on avoidance of hospital
- All acknowledged the role of hospital palliative care teams
 - To improve care provision
 - Reduce length of stay
 - Increase patient time spent at home
 - Reduce costly hospital based interventions

“The care provided by hospitals was more subject to criticism than any other type of care. It found a wide range of problems with inpatient hospital care. These included an uncaring attitude, poor symptom control, and difficulty extracting information from doctors. Poor communication was reported as the most prominent criticism...” (Department of Health and Children, Ireland p53)



Making a choice about place of care and place of death

- Not an over riding priority for patients at the end of life
- Preference varies with age, gender and ethnicity and is influenced by previous experience and concerns about being a burden
- Choice assumes a preference for individualized autonomous decision making
- Requires a willingness to talk openly about death and dying
- The meaning of home is contextualized to a person's current state of health
- Preference does not remain static throughout the illness

Avoidance of hospital admissions

- Suggests that hospitalization in this cohort is a problem
- Most common reason for hospital admission is symptom control that is unable to be managed by a GP
- Increasing technology to manage symptoms will require more hospital level care
- Definition of what constitutes an avoidable admission is unclear

Poor quality palliative care in hospital

- Largely due to study design what is known about patient and family experiences of palliative care in hospital is limited
- Despite experiencing difficulties many patients experience significant benefit being in hospital
- Some patients express a preference for hospital care during periods of acute illness

Discussion

- Government policy is developed in response to a 'social problem' implying something needs to change
- Themes identified in this review suggests that palliative care and death in hospital has been 'problematized' within palliative care policy
- Underpinned by the revivalist model of a good death

Summary

- Western understandings of a 'good death' have informed the development of palliative care policy
- A 'cherry picking' approach to the use of research is evident throughout palliative care policy
- Emphasis on inadequate care and a focus on avoidable admissions 'problematizes' palliative care in hospital
- A focus on avoidance of hospital admissions and associated cost savings is seen as a solution

More research

- What are patients understanding of the role of the hospital during a period of acute illness?
- Where does the acute hospital sit in the modern integrated model of palliative and end of life care?
- How do we achieve a 'good death', whatever that means for the individual and their family, regardless of the care setting?

"Research evidence, however 'robust', is not politically neutral. Rather, it is generated, interpreted and used in particular contexts by and for particular interest groups. Hence, EBM needs to interface with political science."

Tricia Greenhalgh (2015)

What is needed?

- A co-design approach to elicit patient and families views on
 - What needs to change in terms of service delivery
 - Priorities for research
 - Identify the 'problems' to solve through policy
 - Develop the solutions for service development

A long way to go....

