Introduction

Historical overview of how management of life, health and death have changed over time
Consider the role and position of power of professionals, particularly medicine, in this process
Discuss the notion of empowerment in health care

Taking dying as an example

Never before in the history of humanity have the dying been removed so hygienically behind the scenes of social life; never before have human corpses been expedited so odourlessly and with such technical perfection from the deathbed to the grave.

Elias, 1985

A case study: Death in Staithes

David Clark

Early 20th Century death occurred in home, sick and dying cared for by family

- After death in home:
  - Laying-out – ‘Lying out’ board – local joiner (also local undertaker)
  - ‘Lying out’ responsibility of small number of women in village
  - Detailed care: Washing, tying jaw, wrapped in white sheet, woollen stockings, body covered, face covered with handkerchief – finest quality linen
  - After ‘lying out’ family and kin visit
  - Normal time no longer observed – clocks stopped, family sat up throughout night, mirrors and pictures covered, curtains drawn.

A case study: Death in Staithes

Village:

- Joiner made coffin
- One woman ‘bidder’ announced time and date of funeral. To every house to ‘bid’ household to attend
- Sunday funerals preferred despite double costs
- Coffin bearers close kin (same sex)
- ‘Waitresses’ at funeral tea - neighbours

A case study: Death in Staithes

Formalised community ritual:

- Bearers followed by women who would serve tea, minister, family, community
- From chapel 1.5 miles to nearest cemetery
- Grave digger threw soil on to coffin
- Back for funeral tea – time starts again.
- Women protracted mourning, not ‘allowed’ out for weeks/months after death inc attending chapel.
A case study: Death in Staithes

Today:
- Clocks and Covering of pictures abandoned
- Curtains closed day of death & funeral
- Death no longer only occur @ home
- Undertaking taken over by professional funeral directors
- Body removed from home, ‘bidding’ through papers, and catering arrangements etc

History

Church very influential
- Body sacred
- Strict mourning rituals

Dying and death managed at home
- Women as carers
- ‘Handywomen’ – neighbourhood layer out

Until 18th C medical profession little or no control over dying and death, only help make it speedy and comfortable.

End 19th church began to lose authority to scientific knowledge
- Acrimonious relationship – particularly re dissection

History

1874 The Births and Death Registration Act
- medical practitioner statutory duty to issue, without fee, certificate about cause of death
- body did not need to be examined except for cremation.

1902 Midwives Act confirmed subordinate status of midwives to doctors (‘handywomen’ in more deprived communities)

History

Towards end 19th C wealthy begin to see dealing with dead bodies as distasteful
- ⇒ undertakers
- neighbourhood layer-out continued in poorer areas

1935 only 56% of bodies seen after death by medic

1948 NHS – confirmed centrality of hospital in providing care

Antibiotics ⇒ better cure of infectious disease
- ⇒ women less practical experience of nursing

History

After 1948 home nursing supervised by DN
- ⇒ women’s knowledge/confidence about knowledge/nursing – decreased
- Seen as ‘lesser’ than professional
- ⇒ implications for layer-out

Chapel of Rests attached to undertakers early 1930s
- (before body @ home up to two weeks....)

Body from private sphere to public sphere
Funeral directors = high status
Women layer-out = show lack of respect for deceased.

Today: Medicine and Dying and Death

Place of Death 2007
- Hospital 58%
- Hospice 4%
- Nursing homes 16%
- Home 19%

Institutionalisation of death

Further breakdown available in NELCIN
Variations in Place of Death in England ( 2010)
www.endoflifecare-intelligence.org.uk
Today: Medicine and Dying and Death

Medical technologies ⇒ ‘power’ to prolong life/ ‘allow’ to die.
To die without medical involvement = exception
“Any fatality occurring without medical treatments is liable to become a coroner’s case. The encounter with a doctor becomes almost as inexorable as the encounter with death.” (Illich, 1976,198)

Today: Medicine and Dying and Death

Hospice:
- Long history
- Associated with religious orders

Modern hospice movement
- Traced back to 1902 St Joseph’s hospice London (Irish Sisters of Charity)
- Dame Cicely Saunders – St Christopher’s 1967
- Emotional, physical, spiritual and social care

Today: Medicine and Dying and Death

1987 Royal College of Physicians recognised sub-specialty of palliative medicine
Increasing medical interventions in hospices
- Hospice becoming increasingly bureaucratised and institutionalised

Today: Medicine and Dying and Death

Concern (Biswas, 1993):
- Undermining fundamental principles of hospice movement?
- Full-time medical involvement – break with the past
- Worried that palliation of symptoms may lead to focus on dying moving
- Holistic treatment more difficult where medical interventions given increased emphasis
- Burn out?

Today: Medicine and Dying and Death

Defence (Ahmedzai, 1993)
- Palliative medicine allow earlier involvement
- “As more of the different symptoms and syndromes of the terminal stages of life become potentially palliable, will we see more examples of invasive and technological therapies being assimilated into previously low-tech hospice care? If so does that process represent intrusive medicalisation or the rational application of a better understood, and safer therapy to a wider pool of patients who may benefit?”

Conclusion

Nature of dying and death changed
Private ⇒ public domain
Lay-Women ⇒ professional (male)
Death occur in hospital
Dying @ home – monitored by medics
New priests of today?
Is medicalisation of dying and death an inherently good thing?
Have we lost anything, or is that romanticism?
Are health services beneficial?

- Consensus views
- Conflict views
  - Power
  - Control

Bio-medical model of disease

Disease is an organic condition: non-organic factors associated with the human mind are considered unimportant or are ignored altogether in the search for biological causes of pathological symptoms.

Disease is a temporary organic state that can be eradicated – cured – by medical intervention.

Disease is experienced by a sick individual, who then becomes the object of treatment.

Disease is treated after the symptoms appear – the application of medicine is a reactive healing process.

Disease is treated in a medical environment – a surgery or a hospital – away from the site where the symptoms first appeared.

Consensus views

Functionalism - Talcott Parsons (1951)

Sick role – dependant on motivation
  - Rights
  - Responsibilities

How adequate is the sick role for someone with:
  - food poisoning
  - Depression
  - asthma
  - HIV

Consensus views – cont’

Symbolic interactionism

- Based on roles developed by medical practitioner and patient, can be dynamic
- Focuses on power relations in the construction and management of health and illness
- Explores particularly the relationships that develop in hospitals as bureaucratic institutions that seek to define normality, and label deviants (Goffman 1968)

Conflict or critical views

Medicalisation
  - Expansion of control – Zola 1972
  - Marxist views - Navarro 1985
  - Medical gaze – Foucault 1976, 1979
  - Iatrogenic illness – Illich 1976
  - Demedicalisation of difficult arenas such as elderly care to label it as social care

Conflict or critical views

Feminist theory
  - How medical treatment involves male control over women’s bodies and identities
  - For women, a healthy body is tied to healthy sexuality and reproduction within the confines of lawful marriage (Turner 1987)
  - The regulation of women’s bodies by controlling their sexual expression and reproductive capacity is now conducted through medicine, whereas in the past religion played this role.
Power in health care

• What does this discourse about medicalization of death have to say about the distribution of power in health care between professionals and patients?
• How does this fit into the current political agenda of increasing consumer power?
• What is driving the user involvement NHS agenda?
• What about the ‘no decision about me without me’?

Empowerment is a continuous process comprising a series of conscious steps taken by individuals to gain access to economic, educational and health resources; to better express and defend their rights and in the process, gain greater awareness and control of the self. Empowerment is not about wrestling power from an individual or group of individuals and handling it over to another. It is the means to an end, not an end in itself.

Schuler & Hashemi, 1994

Back to dying

• End of life care strategy developed to empower patients to be more involved in their end of life care
• More open communication through dying matters
• Growing movement of advance care planning
• Patients starting to take a more active role in determining what they want
• Breaking away from medicalization of dying

References