QUALITY CULTURE
Our collective mindset for high-value care

#quality17
QUALITY CONFERENCE 2017
NHS Providers
Compassionate culture: Hearing and heeding patient and family voices in end of life care

Chair: Cassandra Cameron, Policy Advisor – Quality, NHS Providers
Speakers:
Dr Katherine Sleeman, NIHR Clinician Scientist, Consultant in Palliative Medicine, King’s College London
Bev Fitzsimons, Head of Improvement, The Point of Care Foundation
Patrick Walter, Soul Midwife, Soul Midwives
The value of palliative and end of life care

Katherine Sleeman
NIHR Clinician Scientist
King’s College London
Cicely Saunders Institute
Figure 3: Actual and projected births and deaths, UK, 1951–2056.
value = \frac{\text{quality}}{\text{cost}}
Dying without dignity

Investigations by the Parliamentary and Health Service Ombudsman into complaints about end-of-life care

“The experiences of people who are dying and their loved ones of the care provided by the NHS is a recurring theme in complaints.”
Figure 2: Overall quality of care by place of death in the last 3 months of life, England, 2015

- **Hospice (1,255)**: 79% Outstanding, 34.1% Excellent, 27% Good, 13.2% Fair, 7.6% Poor
- **Home (4,001)**: 79% Outstanding, 31.2% Excellent, 29.5% Good, 12.3% Fair, 9% Poor
- **Care home (5,667)**: 82% Outstanding, 36.5% Excellent, 32.3% Good, 12% Fair, 5.7% Poor
- **Hospital (9,250)**: 69% Outstanding, 25.1% Excellent, 35.6% Good, 17.7% Fair, 13.3% Poor
### Early Palliative Care: RCT evidence

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value = \frac{quality}{cost}
“Palliative care is most frequently found to be less costly relative to comparator groups, and in most cases, the difference in cost is statistically significant”
Curative treatment
Diagnosis
Palliative Care
Death

Curative treatment
Diagnosis
Palliative Care
Death
value = \frac{\text{quality}}{\text{cost}}
How many people will need palliative care in 2040? Past trends, future projections and implications for services

Thank you

Katherine.sleeman@kcl.ac.uk

@kesleeman
NHS Providers Quality Conference - Compassionate culture: Hearing and heeding patient and family voices in end of life care

Bev Fitzsimons
We are working to radically improve the way people are cared for and to support the staff who deliver care.
The Point of Care Foundation

Starting points

- Relationship between staff and patient experience
- Practical interventions + influencing policy and senior decision-makers

Aims

- Strengthen leadership for patient and staff experience across the system
- Effective interventions for better staff and patients’ experiences
- Innovations, and spreading ideas that work
Our starting proposition

- The lens is patients’ experience
- All improvements are rooted in patients’ and staff experience
- Patients are central to all activities
- The goal: equip staff with skills and confidence to understand patients’ experiences and include them in quality improvement
Concerns about standards of care

Major policy review of care

Many hospital admissions in the last weeks of life

Staff not always confident identifying “end of life”

Staff not always confident initiating end of life conversations

A great opportunity to improve care
Staff said...

‘I do not have enough experience to have conversations about dying, I am more confident when I know that death is imminent’

‘End of life decisions are often made too late to allow for participation in decision-making’

‘Dying is still a difficult subject no matter how often you have tackled this subject before’

A surgeon’s story

Hiro Tanaka
Consultant orthopaedic surgeon
Aneurin Bevan
University Health Board
Understanding patients’ experiences

- Observations of care
- Shadowing
- Focus groups
- Interviews (recorded/filmed)
Living well to the very end

- 8 teams across the South of England
- 20 teams nationally in the next cohort
- “Spread” – using peer to peer coaching and “rapid action” approach

Changes implemented in the current cohort
- care for relatives and the bereaved
- discharge co-ordination
- advance care plans
- information for patients
- car parking
- food
Shadowing patients
Interviewing and filming patients – experience based co-design
The conversation project
Royal United Hospital, Bath

‘I do not have enough experience to have conversations about death and dying, I am more confident when I know that death is imminent’

‘End of life decisions are often made too late to allow for participation in decision-making’

‘Dying is still a difficult subject no matter how often you have tackled this subject before’

‘It is perhaps still a subject that isn’t often talked about until absolutely necessary’

RUH Bath results

More “end of life” discussions with patients and families

Better care planning

Better communication with primary care

More confidence among staff
Driver Diagram

- Treat me well
  - Individualised tailored care
  - Symptom control
  - Spiritual care
  - Preferred place of care discussions

- Treat my family well
  - Fully and regularly updated
  - Overnight facilities
  - Parking facilities
  - Open visiting
  - Bereavement support

- Treat the staff well
  - Adequate staffing levels
  - Good understanding of current issues in patient care
  - De-brief sessions
  - Support from specialists
  - Good ward leadership

Good end of life care

University Hospital Southampton
NHS Foundation Trust
“I was informed of how unwell my mother was and that the plan was to keep her comfortable, on her day of admission in AMU. Once she was admitted to a ward and the bad news had sunk in I felt like I needed more information about what happens next and what to expect over the next few days, but I wasn’t sure who to ask on the ward and the nurses seemed so busy and did not provide us with any further information on my mother’s medical condition.”

“Watching a relative pass away is awful- but having a bit more knowledge of what’s happening would have lessened the stress levels even though it is a very upsetting time for me and my family”

“It would have been useful having access to food nearby as I did not want to leave my father for too long, having to go all the way to the canteen or main entrance worried me he could of passed away without me there, and was also too far for my 91 year old mother to have to go for food”

“Noise and lack of privacy on wards to have private and sensitive conversations”
Relatives:

• Refurbished Family room with sofa bed
• Complementary tea, coffee and biscuits
• Vending Machine within department
• Free Meals for relatives provided by Medirest (Hospital catering)
• Information leaflet & posters
• 2 Allocated Parking Spaces
• League of Friends funding for future improvements
Staff:

• Teaching sessions for Nursing Staff
  – Build Confidence
  – More Frequent updates to relatives, especially out of hours.
  – Become experienced at breaking bad news
  – Feeling more confident in giving anticipatory medications/syringe drivers

• Teaching sessions for Junior Doctors
  – Build confidence
  – Improve EOL drug prescribing
  – Improve confidence in breaking bad news

• End of Life Medication Bundle

• End of Life Care Facilitators to support ward staff
Numbers of Deaths on 7A this year

- End of life care is a significant part of our ward and nursing activity
- Numbers of deaths on medical wards are comparable to hospice units
- 10-15% of patients admitted to acute medicine will die in hospital
What we learnt from shadowing

• Practical Issues
  - I got a parking ticket!
  - I would have liked a cup of tea
  - Somewhere to rest – a comfortable chair
  - Thank you for the side room

• Environment
  - The door was wedged open with a yellow bin and then slammed shut
  - There was a lot of noise outside the room
• Communication and understanding

  The nurses just “pop” their head around the door, they don’t come in for a chat

  When are the doctors rounds?

  The consultant gave me a hug

• Patient comfort and dignity

  I know nurses have to handover but my dad is in pain

  His mouth is so dry …

  He is always clean and well looked after
What have we changed to date?

- Ward sympathy card: now routine
- Education sessions for nursing staff on use of anticipatory medicines: plan to evaluate
- Improved link with chaplaincy
- Nurse present when doctors talk to families about end of life care
- Improved use of side rooms for end of life patients
- Changes in timings of daily ward rounds and greater nurse involvement with potential to challenge and discuss on-going medical interventions
- Starting to develop information leaflet for patients and relatives
- Pursuing funding to buy a fold out bed for relatives
Want to know more? We’re going on tour!

Regional events showcasing our work

Cambridge  21st June 2017
Nottingham  6th July 2017
Birmingham  20th July 2017
Manchester  14th September 2017
Leeds  28th September 2017
Newcastle  12th October 2017
London  26th October 2017
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