End of Life Care - What Matters?

Brooks Young, P.[1] Fife, S.[2] Dobie, J.[3] Dunn, S.[4] Smith, T.[5]

Edinburgh Napier UNIVERSITY

Aim

To capture the delivery of end of life care (EOLC) within NHSL in real – time, from the perspective of patients, those important to them and health care staff.

Method

Unannounced visits to 71 ward areas across 14 sites: acute hospital and in-patient complex care areas. Participants: 22 patients, 5 families/ carers and 136 staff (Nurses, Doctors, CSWs, ANPs, Ward Clerk, pharmacist). Care note reviews: observation: 1-1 and group discussion

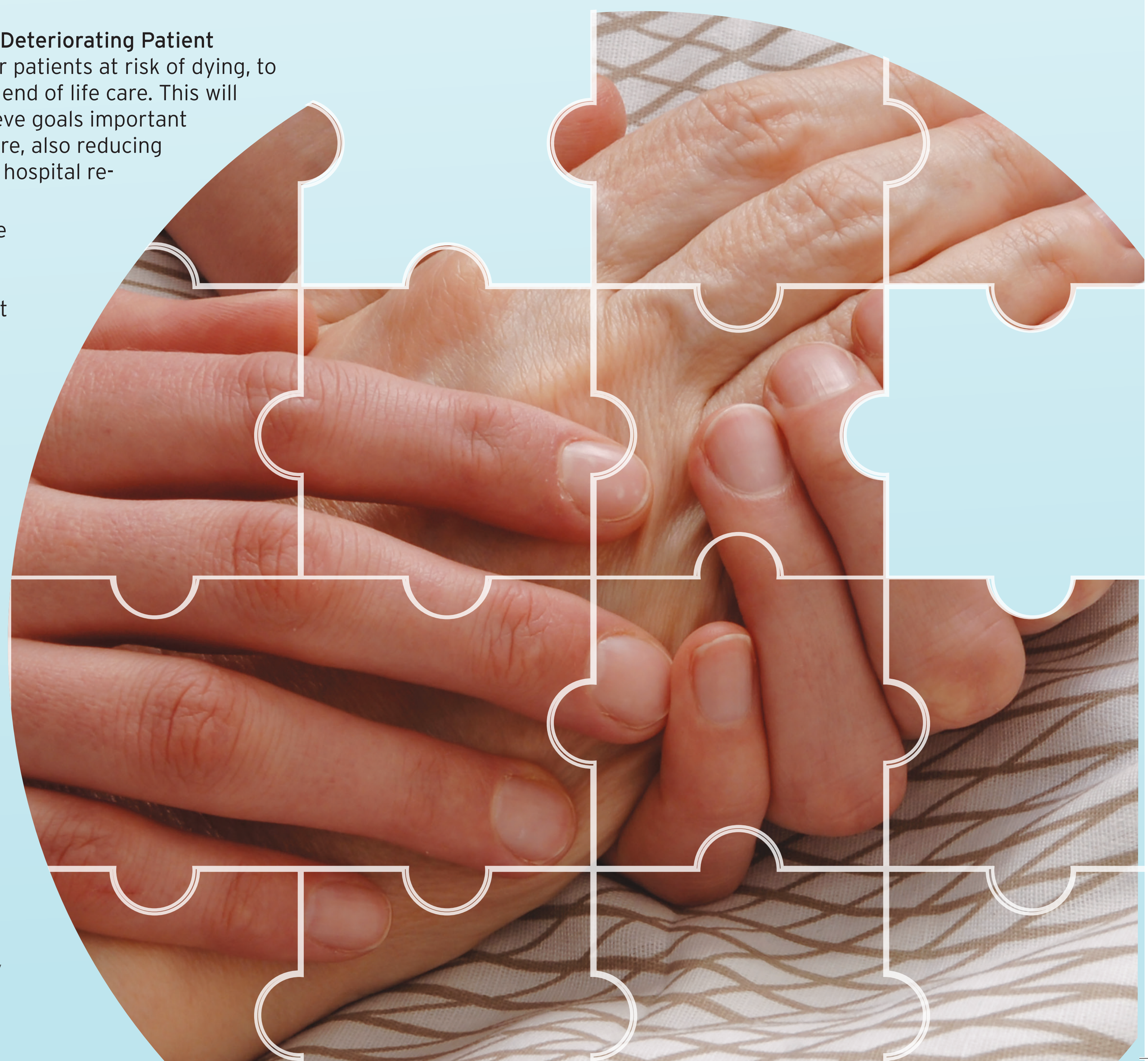
Key findings

- All participants identified the primary importance of **'human connections'** and a person-centred approach to EOLC. Professionals were expected to have technical expertise in managing the dying process, however for patients and families; good communication, joint understanding of the goals of care, consideration of what mattered to the person and as much time as possible to prepare, supported a good death & family coping with bereavement.
- National media attention on the LCP has caused anxiety for families and staff and impacted on practice. 6/71 areas still used the LCP.
- Key actions for improvement including the need to; Increase visibility within NHSL organisation re the key role of in-patient areas in providing good EOLC: address public expectations and education needs re the dying process and care at the end of life, including appropriate use of IV/SC fluids; better 'upstream' care planning - from when the risk of dying is identified, to prepare families and support effective transition to end of life care where recovery is not possible; improve facilities for relatives eg privacy.
- Staff requested a clinical document for EOLC. Concern that improvements to care achieved via LCP implementation and education would otherwise not be sustained.
- Examples of excellent care were observed by the reviewers and reported by carers and staff however, this high quality of care was frequently not demonstrated in clinical documentation.
- Decision-making that EOLC was appropriate and communication with families was poorly documented by nursing & medical staff, including individualised care goals and need for food and fluids. This is of concern in demonstrating NHSL and individual professional's responsibilities, heightened by the current national focus on this aspect of EOLC.
- Examples of good practice included approaches to ensuring patient and family/carers wishes and needs are documented and acted upon e.g. structured tools for Advance Care Planning.

Next steps

Our EOLC programme is informing development locally and nationally including:

- Testing of new documentation.
- Developing a structured approach within the **Deteriorating Patient Programme** to support upstream planning for patients at risk of dying, to support effective transition to recovery or to end of life care. This will integrate advance care planning to help achieve goals important to the patient, including preferred place of care, also reducing inappropriate interventions and unnecessary hospital re-admissions.
- Lothian is a Scottish pilot site for the Institute of Healthcare Improvement **Conversation Ready Healthcare Programme** and also the **Compassionate Cities Programme** to support public awareness of death & dying.



Audit: 2370 deaths
Interviews: 15 Bereaved Carers
Questionnaire feedback >400 staff
Staff focus groups x 5

Clinical Quality Indicator for EOLC Education Programme: 5851 staff
EOLC Care Home programme
Diagnosing Dying Systematic Review

NHS Lothian

1. Lead Nurse & Clinical researcher NHSL/ Edinburgh Napier University
2. Nurse Consultants Cancer & Palliative care NHSL CHCP
3. EOLC Facilitator NHSL CHCPs
4. SCN, NHSL
5. Practice Educator, Marie Curie Hospice