Difficult conversations with families and patients about end of life care after stroke: what are the educational needs of health care professionals?

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BACKGROUND

End-of-life care after stroke is complex. Discussions with families and patients can be difficult. There is no stroke specific guidance or learning tool.

AIM

To identify learning needs and develop e-learning materials for end-of- life care after stroke.

METHOD

- A survey monkey questionnaire was sent to Scottish Stroke Nurses and Allied Health Professionals Fora, Royal College of Physicians of Edinburgh, NHS Lothian clinical leads, emergency physicians and general practitioners, palliative care teams and British Association of Stroke Physicians.
- We asked 'closed' questions about the value of educational materials on a range of specific topics (5 point likert scale), and 'open' questions to identify other learning needs.

RESULTS

599 replies were received over a fixed period of three weeks.

THE SIX TOP THEMES FOR LEARNING WERE

- How to have conversations about uncertainty of prognosis, time of death and trajectory of dying and giving bad news
- Dealing with anxious, distressed or aggressive relatives
- Communication within MDT and recording information from conversations
- Conversations about feeding and hydration
- Managing unrealistic expectations
- Conversations about stopping futile treatment









• Health care professionals report multiple learning needs for sensitive and effective communication about end-of-life care after stroke.

Question I - What is your background?



Question 2 - How many years have you been qualified?





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CONCLUSIONS

• There is a need to explore communication and documentation within teams caring for stroke patients at end of life.

• A STARs (Stroke Training and Awareness Resource) module has been developed to address these learning needs. The module is available from December 2015 at www.stroketraining.org



Question 4 - In the past year, how many patients following acute stroke who required end of life care have you been involved with?



Question 5 - What do you find is the most difficult aspect of having conversations with stroke patients and their families about end of life care? (Top 6 themes)

- bad news
- **2** Dealing with anxious, distressed or aggressive relatives **3** Communication within MDT and recording information from conversations
- **4** Issues around feeding and hydration
- **5** Managing unrealistic expectations
- **6** Stopping futile treatment



Uncertainty of prognosis, time of death/trajectory, giving

Question 6 - Would you value educational resources on the following topics?

How to have conversations with, and provide peer group support to, other members of the multidisciplinary team after the patient has died Discussing organ donation or post mortem sensitively

How to provide support to the family after the patient has died

healthcare professionals within the multidisciplinary team reached by phone

How to ensure a consistent message to patients and families from all Discussions with family members who live abroad or who can only be

Discussing resolving conflict within families about decisions

Definately Yes Probably Yes

Question 7 - Would you value educational resources on the following topics?

Discussing appropriateness of antibiotics if infection occurs **Discussing Cardiopulmonary Resuscitation** possible aspiration Discussing whether to start intravenous fluids Discussing whether to withdraw nasogastric feeding Discussing whether to start nasogastric feeding

Discussing oral feeding as part of "comfort care" accepting the risk of

Definitely Yes Probably Yes

Question 8 - Would you value educational resources on the following topics?

Unsure

How to involve families in decision making but without making them feel solely responsible for the decision

How to deal with unrealistic expectations from parents or families

Preferred place of death if a choice is appropriate e.g. hospital, home or alternative care

Likely mode of death and how long this might take

Discussing uncertainty of prognosis with patients and families

Discussing appropriateness of escalating treatment to high dependency or intensive care units

Definitely Yes

Probably Yes

Unsure





Unsure

