Talking About SUDEP: The Nursing Perspective
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## Disclosure

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<th>Name of Commercial Interest</th>
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Learning Objectives

• Following the program the participant will be able to
  1) Articulate the role of the nurse in providing patient education regarding SUDEP,
  2) Identify priorities for nursing regarding SUDEP
Dearth of nursing-specific literature

Textbook information is minimal

Aim

- Determine what when and how information about SUDEP is given to patients by clinical nurse specialists in epilepsy (CNSE)
- Follow up to the National Institute for Health and Clinical Excellence (NICE) epilepsy guidelines, 2002
- Stated that all patients and families should receive information on SUDEP

Method

- SUDEP physician questionnaire (Morton, et al, 2006) modified for CNSEs
- Mailed eleven question survey, 146 of 250 responded; 103 respondents qualified as CNSEs

Method

- Questions included
  - how often the patient/family is told
  - what prompts the discussion
  - influences on the nurse’s current practice
  - perceived impact of the discussion
  - specific situations when SUDEP is discussed
  - who should tell the patient about SUDEP
  - perceived impact on patient’s quality of life

Results

• With whom discussed?
  • All patients 6%
  • Majority of patients 50%
  • Few patients 37%
  • Did not discuss 3%
  • Physicians should discuss 4%

Results

• When discussed?
  • With specific risks 48%
  • With general risks 71%

Results

• Perceived patient/family response
  • Anxiety 49%
  • Improved adherence 62%
  • Avoidance of risk factors 59%
  • Depressed mood 13%
  • Anger 10%
  • Disbelief 23%
  • Objection from family/caregivers 16%
  • Regret with being told 20%

Results

• Perceived impact on patients’ quality of life
  • Improved 42%
  • Diminished 18%
  • No difference 41%
  • Four did not respond

Results

• Who should tell the patient about SUDEP?
  • Both CNSEs and neurologist 95%
  • Psychiatrists 70%
  • General practitioners 50%
  • Practice nurses 29%

• All of the CNSEs felt that patients should be told

Nursing Priorities

• More data specific to nursing practice are needed
  • Replicate Lewis survey with US, Canadian nurses
  • Identify opportunities to collaborate intra- and inter-disciplinarily to address the who, what, when, and how questions re: informing patients about SUDEP

• Assess nurses’ learning needs
  • determine best way to deliver SUDEP information
Considerations for Clinical Care and Practice

• Nurses, particularly advanced practice nurses, have a vital role to play in providing education to patients and families about SUDEP, particularly in assessing patient readiness to learn
• Nurses do not fear discussing death with patients
Considerations for Clinical Care and Practice

• Nurses have the knowledge and skill to discuss SUDEP within the context of the patient’s unique situation and in conjunction with other members of the interdisciplinary team