6th Annual Conference

DEMENTIA: INNOVATIONS IN CARE

A CONFERENCE EXPLORING NEW INNOVATIONS IN DEMENTIA IN CARE SETTINGS

Thursday 12th April 2018
RADISSON BLU HOTEL, LITTLE ISLAND, CORK

MAIN SPONSOR

NMBI (CATEGORY 1)
ACCREDITATION PENDING
An overview of the development of Palliative Care Guidance in Dementia


Presented by

Alice Coffey

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Dementia Innovations in Care Conference, Northbridge House, St Luke’s Home, Cork
12th April 2018.
My objectives...

To outline

• Background to the development of four guidance documents
• Who was involved
• Steps in the process
• Future work
The IHF through the Hospice Friendly Hospitals initiative identified unmet needs regarding palliative care for patients with dementia.

IHF initiated a programme ‘Changing minds’ to promote excellence in end-of-life care for people living with dementia.

Call for expressions of interest in the development of the guidance documents in July 2014.

UCC submitted a combined application for the development of four guidelines: Medication management, Pain, Nutrition & Hydration, and Ethical Decision Making. These form part of a suite of 7 guidance documents developed by the IHF.

Project timeline 2014 - 2016.
Providing quality palliative care for people with dementia presents unique challenges, due to the person’s inability to verbally express preferences for their care as the illness progresses (Hayden et al. 2013).

The Irish National Audit of Dementia found that less than half of people with dementia who died in hospital were receiving end of life care (O'Shea et al. 2015).

Palliative care should be an integral part of the disease management framework, and should not merely have a role for end-of-life but throughout the trajectory of the illness (IHF, 2012).
AN ESPECIALLY VULNERABLE GROUP

People dying from and /or with dementia are an especially vulnerable group. Their end-of-life care needs may be complicated by cognitive impairment, a prolonged illness, pain, and communication difficulties and responsive behaviours.
PROJECT TEAM

- Dr Alice Coffey (Overall Project Lead)
- Dr Elaine Lehane (Lead: Medication management),
- Dr Nicola Cornally (Lead: Pain Management),
- Dr Joan McCarthy (Lead: Ethical decision making),
- Dr Irene Hartigan (Lead: Hydration & Nutrition)
- Dr Suzanne Timmons: Geriatrician Centre for Gerontology and Rehabilitation
- Dr Catherine Buckley: Representing Nurse Practice Development
- Ms Maura Flynn: Librarian
- Dr Kathy Mcloughlin: Research Support Officer

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PROJECT STEERING GROUP

- Prof. Geraldine McCarthy HSE,
- Prof. Cillian Twomey Geriatrician
- Ms Marie Lynch (Irish Hospice Foundation)
- Ms Eilish Quinlan (National Clinical Guidelines NCEC),
- Prof. Philip Larkin (UCD Palliative Care Research),
- Ms K O’Sullivan (Lay representative),
- Dr Margaret Clifford (Palliative Care Specialist),
- Ms Mary Mannix (Clinical Nurse Specialist in Dementia Care).
Development of the guidance documents followed the approach outlined in the National Clinical Effectiveness Committee Guideline Developers Manual (NCEC 2013)

STAGES 1 & 2
STEPS to guidance development

**STEP 1**
- Clarify context
- Select topic
- Determine objectives and scope
- Identify key stakeholders
- Establish guideline development group
- Outline communication and consultation process
- Determine resources
- Address and manage conflicts of interest

**STEP 2**
- Define key questions
- Search for clinical guidelines and research studies
- Screen and appraise clinical guidelines
- Appraise other research studies
- Adopt or adapt a clinical guideline/Develop new guidance
- Prepare a draft guidance
- Communicate and consult, External review
- Prepare final guidance document

Endorsement

SPECIALIST TEAMS
Frontline clinicians
National and International expert reviewers

STAKEHOLDERS:
Professional bodies
Patient and family representatives

EACH GUIDANCE TOPIC

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PROCESS: EACH GUIDANCE TOPIC

1. Completion of scoping review.
2. Collation of key review themes to inform the guidance and principles.
3. Preparation of Draft 1 of guidance document for comment by the project steering committee and national/international experts in the field.
5. Assimilation of feedback from external consultation to final draft.
6. Final version published
SCOPING REVIEW

• Search strategy specific to each topic
• Empirical Literature
• Grey literature clearing houses and professional bodies e.g. NICE
• Where specific guidance documents were sourced, these were critically assessed using the AGREE tool. (Appraisal of Guidelines for Research and Evaluation Instrument document (AGREE II, updated 2013).
Consultation: To facilitate expert and stakeholder involvement

- **First consultation** with experts in specific guidance area following completion of the literature review. National and International Reviewers for each document.

- **Second consultation** with stakeholders once guidance were drafted and accompanying factsheets published on the Irish Hospice Foundation website on Wednesday 4th November 2015.

- Consultation period ran until 23rd Nov 2015.

- A consultation form was developed to facilitate **n=640** stakeholders i.e. relevant professional bodies and organisations, service and family representatives and to the dementia contact database held in the Irish Hospice Foundation.
1. Layout and Design
(a) The language used is clear and easy to understand
(b) Easy to follow

2. Content: Principles (specific to each topic area)
e.g. Has the guidance document covered relevant areas which staff may need guidance on when assessing and managing

3. Rigor (Methodology)
Has an appropriate level of rigour been applied to the development of the guidance?

4. Stakeholder involvement
Have relevant stakeholders been included in the development of these guidance

5. Overall assessment
Would you recommend this guidance document for use in practice?

6. General comments
Consultation response

• Submissions were reviewed by collating data from the specific questions within each of the feedback forms.
• Data was collated into an Excel sheet and frequency of responses noted. Thematic analysis of qualitative comments received was also conducted.
• Generally very positive and offered areas of constructive feedback for consideration by the team on each topic.
• Valuable information and advice which has shaped the final document.
• The guidance documents were then submitted for final internal review and published on the IHF and UCC websites.
INTENDED PURPOSE
• For information and educational purposes.
• To assist caregivers of people with dementia by providing an evidence-based framework for decision-making.
• Not intended as sole sources of guidance.
• Not to replace clinical judgment or establish a protocol for all individuals with dementia.
• Do not purport to be a legal standard of care.
• Not to override individual responsibility of healthcare professionals to make decisions appropriate to the individual.

CONTENTS
• Introduction to the topic
• Themes from the Literature Review
• Overarching principles to guide practice
• Guidance
• Case studies
• Links to further resources – websites
• Appendices – e.g. useful tools
GUIDANCE DOCUMENT 5

Pain Assessment and Management

Why is this important?

The pain experience can be extremely challenging for people living with dementia and many variables such as depression, fatigue and agitation can influence responses.

Pain can be:
- Physical - e.g. head pain, haemorrhage or diabetes (i.e. painful)
- Psychological - Grief, uncertainty around diagnosis or symptoms etc.
- Social - loss of independence, changing family and friend relationships
- Spiritual - fear of the unknown

Central to the philosophy of palliative care is effective pain management, working within the concept of "total pain" as being physical, psychological, social and spiritual.

Recognise, Assess and Reassess for Pain

- Staff should gather a comprehensive pain history from the person with dementia, their family and other healthcare professionals who have treated the person with dementia in the past.
- Self-report from the person with dementia should be sought regardless of level of dementia.
- Observe for pain behaviors.
- Summarize the report and deal with it.
- Use pain assessment tools that are selected based on the person's needs and communication level, not on what is easiest available.
FACT SHEETS

Recognise, Assess and Reassess for Pain

A simple PAIN mnemonic® to assist caregivers to recognise and identify that pain might be present

P - Pick up on mood changes
A - Assess verbal cues
I - Inspect facial expressions
N - Notice body language

Decision tree for recognising pain

COULD THIS MEAN PAIN?
NON SPECIFIC SIGNS IN PEOPLE WITH DEMENTIA

Facial Expression
- Is his/her expression distorted?
- Frowning?
- Looking frightened?
- Eyes tightly closed?

Vocally
- Is his/her voice:
- Groaning?
- Crying out?
- Asking for help?
- Chanting? Crying?

Body Movement
- Is his/her body movement:
- Tense?
- Rigid?
- Restricted?
- Is his/her resisting care?

Changes/worsening?
- Inter personal interaction?
- Mental status?
- Routine?
- Wandering?

YES Could this mean pain?

NOT SURE

Rule out: Fear; Thirst/Hunger; Too hot/cold; Delirium/hallucination; Urge to urinate, defecate or vomit; Infection

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The Irish Hospice Foundation
Decision-making on the appropriate management of hydration and nutrition issues in the end-of-life care of a person with dementia.

Guidance:
1. Develop and agree a decision-making pathway to ensure multi-disciplinary assessment and discussion takes place.
2. Information must be given to the person with dementia (if appropriate)/ family/caregivers in a balanced manner, outlining feeding practices and benefits/burdens of each method.
3. Ensure all members of multi-disciplinary team, including person with dementia if appropriate/family/carers, receive verbal and written documentation regarding decision made and implications of same.

Case Study Example
Chioma Matthews lives in a residential care setting for older people. She has vascular dementia and has been admitted to hospital with aspiration pneumonia.

- Planning for future care: e.g. MDT assessment and care planning.
- A person centred approach: e.g. the stated wishes of the person [Act at all times in good faith and for the benefit of the relevant person’ (Assisted Decision-Making (Capacity) Act 2015 Pr.2 S.8(7)(e))]
- A Palliative Care Approach
- On-going goal orientated assessment and decision-making on the appropriate management of hydration and nutrition issues in the end-of-life care of a person with dementia.

Case Studies Provided
E.g. Hydration & Nutrition
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April 2018.

Formal Launch Guidance documents

UCC September 2016

Available online
The implementation of evidence based practice (EBP) guidance for pain, hydration and nutrition and medication management in dementia palliative care practice

A multi-site Participatory Action Research (PAR) approach in three Long Term Care (LTC) facilities.
• I have outlined the background to the development of four guidance documents for palliative care in dementia (Pain, Hydration & Nutrition, Medication Management and Ethical Decision Making). The steps in the process and informed you of future work.

• I wish to acknowledge and thank the Irish Hospice Foundation who funded the project; the excellent project team and topic expert groups and the steering group.

FINALLY

THANK YOU

QUESTIONS?
REFERENCES


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