ADVANCE CARE PLANNING IN DEMENTIA: CLINICAL RECOMMENDATIONS

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No conflict of interest to declare
CONTENT

Background

Methods

Recommendations

THOM’s
DEFINITION OF ACP

ACP is the process by which patients, in conjunction with their physicians and loved ones, establish goals and preferences for future care, should he or she become incapable of participating in medical treatment decisions.

OUTCOME OF ACP IN PTS WITH DEMENTIA

– Better palliative outcomes
  – Less tube feeding
  – Fewer hospitalizations near the end of life
  – Greater enrollment in palliative care

Vandervoort et al. J Pain Symptom Manage 2014
SOME FIGURES OF ACP IN DEMENTIA

61% - 91% of older individuals wanted to discuss their end-of-life care

Only 45% of pts with dementia had some communication regarding end-of-life care
  – 16% about location of dying
  – 11% appointed a surrogate decision maker
  – 8% discussed medical treatment

Sharp et al. Br J Gen Pract 2013; DOI:10.3399/bjgp13X673667
CHALLENGES OF ACP IN PTS WITH DEMENTIA

– Diagnosis
  – Complex, uncertain in early stages

– Disease awareness

– Heterogeneity in trajectory of disease
  – Affecting competency to make decisions
AIM

To improve the prevalence, quality and consistency of ACP in people with dementia

To develop clinical recommendations providing support for healthcare staff in community, residential and hospital settings
CONTENT

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THOM’s
METHODS

1. Extensive literature search
   – Multidisciplinary group of authors
   – Six clinical research domains were defined based on experiences and bottle necks in own practice

Belgian Centre for EBM Cochrane (CEBAM) and ADAPTE procedures
METHODS: LITERATURE SEARCH

Search 1: Guidelines

Databases: G-I-N, NHS, NGC, NZGG, TRIP and SUMSEARCH using the following search terms: "advance care planning and dementia" OR "end-of-life and dementia" OR "advance directive and dementia" OR "palliative care and dementia" Since 2004

15

Search 2: Systematic reviews and meta-analyses

Databases: Cochrane Database of Systematic Reviews, Medline, Embase, CINAHL, and PsychINFO, using the following search terms: [advance care planning OR advance directive OR palliative care OR end-of-life OR living wills OR shared decision making OR advance decision OR advance statement] AND [dementia] Since 2004

39

Search 3: Primary studies
(focused literature search to fill in the gaps)


178

Database: EMBASE, using the following search terms: ("dementia alzheimer/exp/mj OR 'dementia alzheimer' AND ('advance care planning'/exp/mj OR 'advance care planning' OR 'advance directives'/exp/mj OR 'advance directives' OR 'shared decision making' OR 'end of life care'/exp/mj OR 'end of life care' OR 'palliative care'/exp/mj OR 'palliative care')

125
Total publications included: 67
METHODS

1. Extensive literature search

2. Development of recommendations
   – Based on available literature and expert opinion

3. Validation process
   – Two peer review focus groups
   – written feedback from experts
   – online survey by target audience

Belgian Centre for EBM Cochrane (CEBAM) and ADAPTE procedures
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THOM’s
32 RECOMMENDATIONS – 8 THEMES

1 Initiation of ACP (1c)
2 Evaluation of mental capacity (1c)
3 Performing ACP conversations (1c)
4 The role and importance of family (1b)
5 ACP when it is difficult or no longer possible to communicate verbally (1c)
6 Documentation of wishes and preferences, including information transfer (1b)
7 End-of-life decision-making (1c)
8 Preconditions for optimal implementation of ACP (1c)
1. INITIATION OF ACP

- Start ACP as early as possible
- Healthcare professionals should initiate ACP
- Integrate ACP into the daily care
- Adapt the communication style to the rhythm and level of the person
- Be alert for triggers and opportunities to start ACP and make use of any opportunity
1. INITIATION OF ACP

– Key moments may be
  – the period around diagnosis
  – while discussing the general care plan
  – when changes occur in health status, place of residence
  – Passing away of a loved person, another resident

– Don’t insist on ACP
  – if there is no disease awareness
  – if there is a clear indication that the person is not willing to discuss
2. ASSESSING MENTAL CAPACITY

- Mental capacity is
  - fluctuating
  - task-specific
- Assume maximal mental capacity
- Involve the person even in case of loss of capacity
2. ASSESSING MENTAL CAPACITY

– Formal clinical assessment should be considered
  – In doubt or in case of disagreement
  – When far-reaching consequences of decisions are expected

– Formal clinical assessment should include
  – A broad neuro-psychological assessment
  – An advice of a multidisciplinary team with expertise in dementia
3. THE ROLE OF FAMILY

- Involve as early as possible
  - Also in case the person has still full mental capacity
- Evaluate disease awareness
- Inform about disease trajectory/ possible end-of-life decisions
- Inform about surrogate decision making and laws on legal representative (if available)
4. ACP WHEN COMMUNICATION IS NOT POSSIBLE

- Keep a connection with the person with dementia
  - Respond to emotions
  - Attend to non-verbal communication
  - Observe behaviour to understand more about quality of life, fears and desires
- Ensure maximum participation of person with dementia
- Actively involve family or other close people
  - Take into account the life-history, values, norms and wishes of patient with dementia
5. PRECONDITIONS FOR OPTIMAL IMPLEMENTATION

– Provide training for health care professionals
– Foresee adequate support
– Integrate ACP into mission statement and policy
– Embed ACP in organizational culture
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THOM’s
TAKE HOME MESSAGE

- ACP is a process
  - Actively involving the person with dementia and his family
  - Discussing ‘best possible’ choices for future care
  - In agreement with the life-history of the person
- Recommendations
  - Want to support health care professionals in the process of ACP
  - Are based on literature and multidisciplinary experience
  - Require further evidence through high-quality research
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Thank you for listening.
2. ASSESSING MENTAL CAPACITY

**Ability to communicate a choice**

**Ability to appreciate the situation and its likely consequences**

**Ability to understand relevant information**

**Ability to manipulate information rationally**

**Competence**