Advance Care Planning in the nursing home context

Prof. dr. Lieve Van den Block
Vrije Universiteit Brussel
End-of-Life Care Research Group
Aging and Palliative Care Research Programme
CONFLICT OF INTEREST DISCLOSURE

I have no potential conflict of interest to report

I thank the support of the Maruzza Foundation for co-hosting this session
What is Advance Care Planning?
ACP
“the ability to enable individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and health-care providers, and to record and review these preferences if appropriate”
Communication process
Not just about filling in advance directives or living wills

Early enough
For when people become incapacitated but also to allow people time to think about and prepare for future decision-making

With patient, family, professionals
Available guidelines for ACP conversations

• International articles

• Country specific guidelines for professionals (evidence- and consensus-based)

• Information campaigns
CLINICAL REVIEW

An introduction to advance care planning in practice

Anjali Mullick consultant in palliative medicine\textsuperscript{1,2}, Jonathan Martin consultant in palliative medicine and visiting fellow\textsuperscript{1,3}, Libby Sallnow specialty registrar in palliative medicine and research fellow\textsuperscript{1}

\textsuperscript{1}St Joseph’s Hospice, London E8 4SA, UK ; \textsuperscript{2}Newham University Hospital, London, UK; \textsuperscript{3}Harris Manchester College, University of Oxford, Oxford, UK
End of Life Care

Advance Care Planning: A Guide for Health and Social Care Staff
5 steps to the perfect gift

You’re critically injured or ill and can’t communicate. Who will speak for you and make decisions about your care? This holiday season, take these five steps – and give your family and loved ones the gift of knowledge and peace of mind:

1. **THINK** about what’s important to you
2. **LEARN** about different medical procedures and what they can or can’t do
3. **DECIDE** on a substitute decision maker – someone who is willing and able to speak for you if you can’t speak for yourself
4. **TALK** about your wishes with your loved ones
5. **RECORD** your substitute decision maker and communicate your wishes

We have the tools you need to start these conversations. **Visit:** Speak Up

[NICE, FRANCE - SEPTEMBER 20/22, 2017]
What are core themes in ACP communication?

- Information preferences
- Disease and prognoses awareness
- Broader values of the person, views on quality of life
- Experience of the present and fears about the future and the end of life
- Future care goals
- Specific advance decisions about the end of life

Conversations can follow a staged approach but not necessarily – depends on the person!
Booming research area since the 1990s

Prevalence studies
Qualitative studies
Intervention studies

What have we learned so far?
1. Increase in use of advance directives
2. Still initiated too late – eg in dementia, mainly with family
3. Interventions are not successful if reduced to filling in documents
SUPPORT Trial 1995 US

Intervention study 4000 patients randomized to usual hospital care or SUPPORT intervention (nurse led communication, documentation of preferences)

NO intervention EFFECT but it shook the medical world
1. Increase in use of advance directives
2. Still initiated too late – eg in dementia, mainly with family
3. Interventions are not successful if reduced to filling in documents
4. ACP can have positive patient and family outcomes
The impact of advance care planning on end of life care in elderly patients: randomised controlled trial

Karen M Detering, respiratory physician and clinical leader,\(^1\) Andrew D Hancock, project officer,\(^1\) Michael C Reade, physician,\(^2\) William Silvester, intensive care physician and director\(^1\)

**WHAT THIS STUDY ADDS**

- Coordinated advance care planning improves end of life care
- Advance care planning reduces the incidence of anxiety, depression, and post-traumatic stress in surviving relatives
- Advance care planning improves patient and family satisfaction with hospital care
1. Increase in use of advance directives
2. Still initiated too late – e.g. in dementia, mainly with family
3. Interventions are not successful if reduced to filling in documents
4. ACP can have positive patient and family outcomes
5. Implementation of ACP in practice is difficult
ACP policy in nursing homes established

Importance of ACP acknowledged

Yes, ... but changing practice appears very difficult, training communication skills is not enough

Implementation programmes needed that take into account context and change management
PHASE 1
DEVELOPING ADVANCE CARE PLANNING INTERVENTION IN NURSING HOMES

CONTEXT ANALYSIS & SYSTEMATIC REVIEW

STAKEHOLDER WORKSHOPS

THEORY OF CHANGE MAP = H° CAUSAL PATHWAY
preconditions at multiple levels:
resident, family
staff of different levels, volunteers, GPs/physicians
management and NH structure
FROM STAKEHOLDERS WORKSHOPS TO THEORY OF CHANGE MAP
Addressing multiple levels to achieve ACP outcomes

[Precondition 1] An external trainer is available who is able to:
1) give management, CAP and head nurse(s) an explanation about the ACP guidance document
2) train the ACP reference persons
3) give adjusted support throughout the different implementation phases of ACP in the nursing home

[Precondition 2] The ACP reference persons are able:
1) to conduct and follow-up ACP conversations with residents and their family according to the guidance document
2) to adapt conversations to the residents’ cognitive capacity
3) to (initially with the support of the external trainer)
   a. train nurses to conduct ACP conversations according to the guidance document,
   b. educate other staff and volunteers to recognize triggers for ACP
4) to lead reflection sessions, including yearly audits, together with CAP, trained nurses and/or head nurses
5) to discuss ACP of residents during multidisciplinary meetings

[Precondition 3] All trained nurses are able to conduct and follow-up ACP conversations with residents and their family according to the guidance document

[Precondition 4] All staff and volunteers:
1) are able to recognize triggers in residents and their family
2) are willing to have ACP conversations according to their own competencies
3) know how to pass on information to ACP reference persons

[Precondition 5] The management and the board of directors are willing to implement ACP and have a written ACP policy and guidance document available

[Precondition 6] All care professionals, the CAP and the management know the ACP policy and are willing to act accordingly (intention)

[Precondition 7] All GPs in the region who are involved in the care of a nursing home resident 1) know the ACP policy and 2) are willing to take into account the wishes and preferences of their patients in end-of-life decision-making and to engage in ACP of their patients (intention)

[Precondition 8] All residents and their families know of the ACP policy

[Precondition 9] Residents and/or family are willing and able to engage in ACP and to discuss wishes and preferences

[Precondition 10] Current wishes and/or preferences regarding future care/treatments (including end-of-life care) and/or regarding legal representatives of residents, are known to the ACP reference persons - as far as possible for and preferred by the resident and/or his/her family

[Precondition 11] Current wishes and/or preferences are known to care professionals and GPs

[Precondition 12] There is a written record of the current wishes and preferences (including existing living wills) and the ACP process, that is accessible to all care professionals

Primary outcome: Improved correspondence between care/treatments received (including end of life care) and the identified current wishes and preferences, as far as possible

Secondary outcomes: Residents and their family feel involved in planning for future care/treatments and are more confident that end-of-life care will correspond to their wishes and preferences
PHASE 2
FEASIBILITY AND ACCEPTABILITY TESTING

- GROUP DISCUSSION WITH MANAGERS, HEAD NURSES, COORDINATORS
- INDIVIDUAL INTERVIEWS WITH STAFF
- MATERIAL REVIEW BY EXPERIENCED TRAINER RESIDENT/FAMILY
Intervention components linked to ToC map
- External ACP trainer aiding with stepwise implementation (8 months to one year)
- Working with management to ensure engagement
- Working with leaders/coordinators to tailor and concretise the intervention components
- Training of ACP reference persons within the facility
- In-service (regular) training of staff and volunteers
- Regular information to GPs
- Regular information to residents, family
- ACP conversations guide and documentation system (and access)
- ACP follow-up part of multidisciplinary meetings
- Regular reflective sessions
- Monitoring and audit
Materials

ACP+ Tools and conversation instruments

ACP+ Guidance documents

ACP+ training manuals
PHASE 3
NEXT STEPS

Cluster RCT

OUTCOME EVALUATION

PROCESS EVALUATION
Key messages

• There is no quick fix to a complex problem
• Training in communication and ACP of staff is not enough
• **Nursing home context = “weak” context**
  – Low educated staff with limited training in ACP
  – High staff turnover
  – Often lack of multidisciplinary input
  – Funding sometimes restricted – time pressure for staff
• **Nursing home context = complex context**
  – Complex trajectories, multimorbidities, dementia
  – Pending death not always recognized
  – Length of stay becoming shorter
• To ensure ACP interventions are implemented in daily practice and sustained, they need to
  – be **tailored** to the context and the individual facility
  – become part of **routine** daily responsibilities
  – multicomponent: target multiple interacting **levels**
  – be implemented **stepwise**
Acknowledgments

Joni Gilissen, MSc
Lara Pivodic, Dr.
Luc Deliens, Prof. Dr.
Robert Vander Stichele, Prof. Dr.
Chris Gastmans, Prof. Dr.

LVDBLOCK@vub.be

Research supported by Research Foundation Flandres
Session supported by the Maruzza Foundation