

INTERDEM Taskforce Palliative and End of Life Care -Meetings September 2023-February 2024

Initial Meeting – 18th September 2023 (online)

1. Introductions

Karen Harrison-Dening: Head of research and publications at Dementia UK the home of Admiral Nursing. A nurse. Longstanding interest in palliative and end of life care. PhD in advance care planning. Inpugged into national guidelines in the UK on dementia and palliative care.

Jenny van der Steen: affiliated with two Dutch universities as a researcher, epidemiologist in palliative and end of life care. Current trial on palliative care in dementia combination of the work of Kevin Brazil and Namaste Care in dementia.

Tamara Backhouse: based at the University of East Anglia in the UK. Postdoctoral fellow, research in care homes, home care, hospital care, focused on the advanced stages of dementia. Recent fellowship on refusals of care in advanced dementia. Background as a care worker in care homes.

Lieve van den Block: I'm professor of aging and palliative care at the University of Brussels. Research on palliative and end of life care in nursing homes and also within primary care. Current projects specialist palliative care service use among people with dementia in primary care. Also looking into supporting people with dementia and their family in advanced care planning conversations outside of the professional context and developing online tools. Also starting up navigation interventions, navigating people to the right resources also within their community.

Siren Eriksen: Norwegian National Central Health, head of research and development within cognition and dementia. Professor in nursing at the University of South-Eastern Norway currently supervising a PhD self-reporting or pain. Previously developed e-learning courses for GPs, nurses and nursing assistants within palliative care and dementia.

Raymond Koopmans: elderly care physician and Professor of elderly care medicine. Working at the Radboud University Medical Center in Nijmegen and but also at a long term care organization. Interested in young onset dementia and palliative care.

Melissa Van Eersel: University Medical Centre in Groningen in the Netherlands and I support Lisa in her studies.

Lisa von Dala: PGR student at the University Medical Centre in Groningen, Netherlands. Nurse by background and researching advanced care planning in people with young onset dementia, the final goal of the project will be developing communication tool that helps and healthcare professionals to discuss advanced care planning.

Zena Aldridge: social care nurse fellow working for the National Institute of Health and Social Care Research. I work also with the National Health Service here in the UK as a clinical advisor on dementia and for one of our commissioning boards as a clinical and care speciality advisor. PhD explored the experience of nursing home staff when making decisions in advanced dementia to enable a good death.

Louise Robinson: An academic GP and professor at Newcastle University. Previous programme grant end of life care in dementia, further work looking at primary and community care and t the role of expert nurses and more integrated care, which includes forward care planning and supportive care. Also developed a massive open online course in advanced dementia and planning for care towards and at the end of life.

Emma Wolverson: Clinical psychologist, Research Lead Dementia UK, Reader Aging and Dementia at the University of Hull. Research interest in people with dementia who are very distressed at the end of life and cared for within mental health / psychiatric settings. How we can upskill mental health staff in palliative and end of life care to prevent behaviour overshadowing.

2. Aims of the taskforce

Emma shared the aims of the taskforce which can be found here: [Taskforces | Interdem website](#)

First year is focused on establishing the group and identifying our shared interests and priorities.

3. Bio sketch of members

As part of establishing who we are Emma proposed a survey or database be circulated to collate peoples interests, expertise, clinical backgrounds.

It was agreed that the aim would be to create a bio sketch of the taskforce – that can be shared externally with other networks and used in grant writing. It will also highlight gaps in our expertise-areas where we are not researching.

It was also suggested that we might ask who has an active patient and public involvement group in the area that might be able to support future work.

LR suggested also monitoring what other INTERDEM taskforces members are in as there may be opportunity for overlap.

There was also a suggestion that we collate details of funding calls within countries and across countries early on that we might consider as a taskforce.

Actions: Emma draft survey of members and share. ALL to complete.

Collate relevant funding calls

4. Establishing priorities for the taskforce

White paper on optimal palliative care was shared with the agenda. The suggestion was that this group could use this as a starting point to identify research priorities for this group. Emma asked members to consider which domains needed updating because there is new research in the area. Which domains relate to INTERDEM's manifesto. Which domains this group has expertise in. Jenny stated that we not to consider ACP as this has been reviewed and will be published shortly.

Possible priority areas/ areas of focus:

- Young onset dementia

Raymond – stated he wanted to update this Delphi specifically regarding people with young onset dementia and is it is this covered currently by the EAPC. Jenny stated the White paper on palliative care was for all people. There is so little research in this area though.

- Prognostication and timely recognition of dying

Lots of discussion that clinically it was felt that little progress had been made here and that as such prognostication, and the timely recognition of dying could be an area of focus. Lots of people shared experiences that most health and social care professional still do not recognize dementia as needing palliative care input.

- Applicability of palliative care

We discussed the challenges in defining palliative care. We spoke about the name ‘palliative care’ and associated challenges e.g., some people regard palliative care as specialized teams referred to at the end of life when symptoms are complex. We discussed the overlap between palliative care and good dementia care, but that good dementia care is sadly not delivered universally. The term supportive care was also discussed.

Lieve -also raised the importance of good palliative care integrating other conditions alongside dementia and referred to an ongoing Delphi into referral criteria into specialist palliative care in dementia that might be of interest.

5. Patient and public involvement

We discussed the importance of involving people with dementia and carers themselves in priority setting. Karen mentioned work on asking people with dementia about a good death with dementia in Brazil and UK due for publication shortly.

The European Working Group of people with dementia was one group mentioned we can work with as it is good to have the perspective of so many different European countries.

Karen mentioned the importance of ensuring we also heard from people with late onset dementia not just younger people.

Action- contact the group and alert them to our work and plans

6. Next steps

Emma to share a survey or excel to collect bio sketch from members

Next meeting at INTERDEM meeting in Helsinki – Emma to find if people can join online or now.

Palliative and End of Life Care task force meeting

Interdem Helsinki -16 October 2023

Agenda

1. Review the results of the online survey shared with taskforce members
2. Agree priorities and focus
3. Agree how often to meet

1. Results of the survey

Emma shared an online survey with taskforce members following the last meeting. We had eight responses. The results:

White paper domain we have the most expertise in: family support domain.

White paper domain we felt needed updating: psychosocial domain.

Analysis of the free text response questions also highlighted interest in ethics, young onset dementia and managing distress:

The group again discussed that the applicability domain perhaps also needs more work, dementia still not recognized as a terminal condition. There is still no narrative about dying well with dementia.

2. Agreeing priorities and focus of the taskforce.

We agree the following three priorities for the taskforce with some leads identified:

- Updating the psychosocial domain of the white paper

Following the group survey, we agreed to prioritize updating the psychosocial domain. The work will start with a literature review to look at what has been published since the White Paper. Perhaps with a focus on psychosocial interventions which aim to reduce distress. To also include anything related to YoD (which the initial White Paper did not).

Lead: Emma

Action: Emma will draft a review protocol and share. To present initial scoping results at next meeting.

- Mapping palliative care across different countries

A second proposal for the group was to map palliative dementia care across our countries and compare. We could consider provision, care models, but may also cover education, for example assess if there is content in curricula of undergraduates. Raymond highlighted the EU Impact study (Jasper Riet Paap) in dementia and cancer a while ago- papers will be shared with minutes. We could check if we could use this as a basis and update or decide to compile our own set of items. Collating some quantitative descriptive data may be helpful.

Possible Leads: Jean-Bernard and Ana Barbosa? TBC

Action- to agree leads, to look at IMPACT work and whether this can be used as a template. Share initial plan at next meeting.

- Ethics of assisted dying

We spoke as a group about how euthanasia is allowed in some of our countries (in Netherlands, Belgium, in Canada) but not in others. We discussed how there is little guidance for professionals on how to discuss the topic in countries where it is not allowed. As the taskforce is also about end-of-life care this topic could fit.

Possible leads: Giovanni and Arlene

Action: to consider what our work might look like this this area.

Other opportunities to collaborate:

Raymond suggested collaborating on updating the editorial in JAMDA a while ago, hypothesizing what would be different in YOD palliative care. There have been some studies since. And the EAPC task force ACP in dementia has paid attention to it, with a paper in progress about what is and what is not different in YOD, and consensus within a purposefully sampled subgroup of YOD experts.

Action: Raymond to share the initial paper.

3. Meeting frequency

We agreed to meeting 6 times a year initially whilst we are a new group. Subgroups could meet in-between to focus on these workstreams as needed.

Action: Emma to circulate meeting dates.

Next meeting: 14th December 11am UK time.

Meeting Minutes: Palliative and End of Life Care task force meeting

Online -14th December 2023

Present: Ana Barbosa, Siren Erickson, Raymond Koopmans, Jean-Bernard Mabire, Tamara Backhouse, Arlene Astell, Lieve Van Den Block, Nathan Davies- and Jenny van der Steen & Emma Wolverson (chairs and minutes).

Apologies: Louise Robinson, Zena Aldridge, Hanneke Smaling, Tofunmi Aworinde, Anne Marie Rokstad, Racheal Kelley, Karen Harrison Denning.

Review minutes of last meeting: all actions to be picked up in this meeting.

1. Updating White Paper Domain Eight - Psychosocial and spiritual support

The aim is to see if the recommendations in this domain need updating or if there are new recommendations to make, and whether we would review literature on effectiveness or take a broader scope. Emma and Jenny presented options- review of reviews, scoping reviews and reviews in each of the recommendation areas. We may not want to limit a review to the effectiveness of interventions given that we may not fare well on reports of effectiveness in providing or updating or deleting recommendations.

To avoid overlap and not adding to the literature, we need to focus on palliative care interventions. Lieve- reflected the challenge of how we define palliative care interventions given that most are not labelled as such (an issues that might make for an interesting opinion piece of editorial from our TF). Pragmatic choices have included a focus on dying and terminal care or advanced dementia. Psychosocial palliative care interventions potentially adds to the literature but needs a clearly defined

population. The literature on spiritual care in dementia has expanded in recent years and spiritual caregiving often already focuses on end of life or is part of a palliative approach.

Nathan stated that he has a review started on psychosocial and carer interventions as part of the EMBED care study in people nearing the end of life search terms include palliative, terminal, hospice.

Siren – highlighted the importance of focusing on the voices of people with dementia themselves. Edison, Harrison Denning and colleagues have a paper on interviews with people with dementia on their perceptions of end of life in light of a diagnosis of dementia (under review). Siren shared meta syntheses she has conducted (see reference list at end):

Lieve also highlighted this review by Miranda et al., 2019 (see reference list). Jenny shared a Note similar review for nursing home setting by Kochovska et al., 2020 (see reference list).

Tamara – has offered to help with the work.

Actions

- Jenny, Karen and Emma meet Nathan to discuss his review and whether that can inform a review of the White Paper recommendations.
- Jenny, Karen and Emma to draft a protocol to share at the next meeting

2. Mapping palliative care across different countries (Jean-Bernard and Ana Barbosa)

Ana and Jean-Bernard shared a proposal to map palliative care for people with dementia in different European countries, emphasizing a focus on existing reports and policies, perhaps also education. This will:

- Help us identify gaps and disparities in the availability, accessibility, and quality of palliative care services across different countries in Europe.
- Create an opportunity to share best practices, successful models, and innovative approaches to palliative care.
- Identify areas that may require further research.

Lieve highlighted the need for clear purpose and clear questions to drive this work.

Country Selection: European countries represented in the Palliative Care and End of life INTERDEM taskforce – UK, Netherlands, Belgium, France, Italy, Norway. Members would act as co-workers collecting data from their country. Siren proposed that she could provide information from Norway, and is able to read and provide information from Sweden and Denmark.

Mapping exercise:

- To Identify and summarize overarching European policies and guidelines related to palliative care and dementia. Jenny shared example mapping exercises (Nakanishi et al 2020; Duerpos et al 2017 and Sampson et al 2015 -see reference list).
- Identify and review existing reports and policies related to palliative care and dementia in each country.
- Identify and map existing resources, facilities, and care professionals providing palliative care for dementia patients in each country (Jenny noted the medical discipline that provides most of the care (being responsible for it) for people with dementia at the end of life in Netherlands, Germany and Switzerland. In other countries it's more GPs, palliative care physicians, geriatricians. We could ask to estimate the proportion in a survey?)
- If needed:

- contact organisations, for example Alzheimer Europe, the European Association for Palliative care and national associations
- identify key stakeholders (researchers, palliative care consultant; palliative care specialist nurses) that may be able to provide further insights

Data Analysis -Compile the info and identify common themes, best practices, and areas where collaboration is encouraged.

Dissemination -Produce a short joint report, Present at AE conference, Blog for INTERDEM website/ others, Academic journal

Questions to consider

- Do we want to identify training programmes and educational initiatives for care professionals involved in palliative care for people with dementia at this stage or would this be a different piece of work?
- Do we want to involve people with dementia from the very beginning of this exercise?
- Do we need to plan updates? Eg every 3 years?

All agreed the need for clear inclusion and exclusion criteria – Jenny has some examples from another project that can help.

Lieve shared a helpful paper by Povodic et al., 2021 (in ref list).

Actions:

- Jenny to send Ana some examples from her work on place of living and death policy analysis.
- Ana and Jean-Bernard to draft a data extraction spreadsheet to share for comments (initial with TF leads (Emma, Jenny & Karen) and then wider TF).

2. Ethics of assisted dying (Arlene)

Arlene and Giovanni have started scoping the literature.

The team recognised this is a controversial topic in some countries and need to take care.

All agreed we need to be clear on what we are trying to achieve. Our aim is not to create a consensus statement on assisted dying for people with dementia.

It was felt that it was important to focus on the perspectives of people with dementia and also to examine whether attitudes had changed over time, perhaps also on dilemma's for family A review by Scheere-Feitsma et al., was mentioned -see ref list)

Lieve has a student project looking at how attitudes are changing for people with dementia.

Raymond reported there are several studies in the Netherlands mainly focusing on the views of GPs.

Nathan reflected than in research people sometime allude to assisted dying but don't say it –it could be interesting to consider how we tease this out. Lieve agreed having done studies in US and Belgium on ACP in young-onset dementia and noted significant cultural differences in Belgium interviewees immediately thinking of euthanasia even if no opinion on it (high awareness because of a societal debate similar in the Netherlands). Legislation differences impact on how people respond.

Siren reflected how in Norway this is still a taboo topic but attitudes in student nurses might be changing.

Tamara shared useful papers by Diehl-Schmid et al., 2017; Tomlinson & Stott., 2015- see ref list. Nathan shared a paper by Nimmons et al., 2023 – see ref list. Lieve shared a paper by Van Rickstal et al., 2023 – see ref list.

Action:

- Arlene and Giovana to present further ideas at the next meeting.

Other opportunities to collaborate

Raymond- and team are updating his editorial on young-onset dementia.

Action: all to send papers of interest that might support writing this. Arlene shared a paper from Alothman et al., 2022.

Jenny – explained that with Edison de Vidal, she has been considering starting an ISTAART interest group with the American Alzheimer's Association, perhaps only in 2025 and link up with Interdem later on when we have a clearer view on how we can collaborate or take a useful different focus.

Date for next meeting – this will be February a doodle pool will be shared

Reference List

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Meeting Minutes: Palliative and End of Life Care task force meeting

Online -13th February 2024

Present: Ana Barbosa, Siren Erickson, Raymond Koopmans, Jean-Bernard Mabire, Tamara Backhouse, Arlene Astell, Jenny van der Steen, Zena Aldridge, Tofunmi Aworinde, Karen Harrison

Dening, Serena Sabatini, Natashe Lemos Dekker, Anne Marie Mork Rokstad, Emma Wolverson (chair and minutes).

Apologies: Louise Robinson, Lise Vandaele, Nathan Davies.

Review minutes of last meeting: all actions to be picked up in this meeting.

3. Updating White Paper Domain Eight - Psychosocial and spiritual support

The aim is to see if the recommendations in this domain of the White Papers need updating or if there are new recommendations to make.

Following the last meeting, Emma, Jenny and Karen have met with Nathan Davies and Catherine Evans. Nathan and his team have started a review on psychosocial interventions in palliative and end of life care as part of the EMBED care study. They plan to complete most searches and have a draft in May 2024.

To compliment this work Emma, Jenny and Karen with support from Tamara and Serena will draft a protocol for a scoping review on spirituality. A scoping review was felt to be most appropriate given the nature of the research into spirituality. The protocol will be shared for comment with this group.

The aim will be to bring together the two reviews to consider whether, based on the evidence, any update is needed to the recommendations in the White Paper. The plan is to use a Delphi approach with the group to consider any potential changes.

Languages- as a group we can read Portuguese, Norwegian, Swedish, Danish, French, Dutch, German and Spanish which will allow us to widen the number of articles we can include.

Actions

- Jenny, Karen and Emma to draft protocol for sharing with the group

2. Mapping palliative care across different countries (Jean-Bernard and Ana Barbosa)

The aim of this work is to map palliative care for people with dementia in different European countries, with an emphasis on existing reports and policies. The aims are to identify differences in terms of what is available, the quality of services and to identify gaps and future research.

Who to include: not all countries are represented and we could contact wider INTERDEM members. Natashe also has contact with Brazil and Arlene has links with Canada. Agreed to prioritise European countries but to include wider countries where possible.

Two questionnaires have been created for feedback from the group, 1 for general mapping and 2 for more specific details.

Jenny shared a paper she had written [Geriatrics | Free Full-Text | Palliative Care in Advanced Dementia: Comparison of Strategies in Three Countries \(mdpi.com\)](#) and suggested we could provide a case and ask each country to consider what care a person with dementia and their family would receive. Could the case in the paper also be used in this survey.

Zena stated we need to be clear about what we mean by specialist palliative care services for people with dementia.

Actions: ALL to share any comments on the draft questionnaires attached to the minutes.

4. Ethics of assisted dying (Arlene)

We recapped the aim of this theme was to explore, what information are people being given where assisted dying is legal and where it isn't legal who is having conversations with people with dementia about this. How is information being shared and in what format.

Arlene requested more support in this theme to make progress – Natashe did a PhD in this area and has written on the topic, Siren is also interested, Anne-Marie has supervised a PhD recently looking at nurses experiences of discussing the topic, Zena is also interested and has been approached by a masters student on the topic.

Raymond shared a paper Euthanasia in Dementia: A Narrative Review of Legislation and Practices in the Netherlands and Belgium - PubMed (nih.gov) and discussed his experiences of challenges of the interpretation of advance statement regarding euthanasia.

Karen stated that Dementia UK's Admiral Nurses (specialist Dementia Nurses) would support- that she could look at calls to the national helpline of the topic of assisted dying and also the experiences of Admiral Nurses on discussing the topic with people with Dementia.

Action: those interested in joining Arlene on this theme please email her directly arlene.astell@northumbria.ac.uk

Other opportunities to collaborate

Zena – is looking for people to speak at a webinar being facilitated by the Global Observatory for Long Term Care, the topic is pain at end of life in long term care. 24th September, 1pm Vienna time. Online event. Broad audience, academics, clinicians, and care home staff. If you are interested in speaking, please contact Zena zena.aldridge@nihr.ac.uk

Arlene- project just starting with those with advanced dementia and limited communication funded by the Alzheimer's Association of America. Arlene is looking for people to join the projects expert advisory group. Please contact Arlene if this is of interest arlene.astell@northumbria.ac.uk

Raymond – update editorial on palliative care on young onset dementia. The journal are interested in an updated editorial and work on this has started. The group were pleased this work was underway.

Emma- is looking for those who are interested in the end of life care for people with dementia within mental health wards. If anyone is aware of these wards in their country or interested in comparing experiences please contact Emma emma.wolverson@dementiauk.org

New publications

Palliative Care in Nursing Home Residents with Young-Onset Dementia: Professional and Family Caregiver Perspectives Palliative Care in Nursing Home Residents with Young-Onset Dementia: Professional and Family Caregiver Perspectives - PubMed (nih.gov)

Nurturing attentiveness: a naturalistic observation study of personal care interactions between people with advanced dementia and their caregivers Nurturing attentiveness: a naturalistic observation study of personal care interactions between people with advanced dementia and their caregivers | The Gerontologist | Oxford Academic (oup.com)

Date for next meeting –April a doodle pool will be shared