A systematic review describing components of palliative care interventions addressing the needs of people with dementia living in long term care: Mapping against EAPC domains of optimal palliative care for people with dementia

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INTRODUCTION

- Dementia is a progressive life-limiting illness, and a palliative approach to care is considered best practice in the advanced stage.
- The European Association for Palliative Care (EAPC) published a White Paper reporting consensus-based domains of optimal palliative care for people dying with dementia [1].
- Evidence suggests that palliative care for people with dementia dying in long term care facilities (LTCFs) is often suboptimal.
- The multidimensional aspect of palliative care necessitates complex, multicomponent interventions to best address the needs of people with life-limiting illnesses.

AIM

- To describe the components of palliative care interventions that have been, or are being, evaluated for people with dementia in LTCFs
- To examine the extent that these interventions address EAPC-defined domains, with a particular focus on shared decision-making

METHODS

- Four electronic data bases were searched: MEDLINE, CINAHL, PsycINFO, and CENTRAL
- The search strategy was informed by Murphy et. al (2016) Cochrane systematic review [2], including MeSH terms and keywords concerning palliative care, dementia and interventions.
- Additional information sources included: i) Google Scholar; ii) Reference lists of Murphy et al. (2016) [2] and Sampson et al. (2005) [3], and their included studies; and iii) Clinical trials registries for Australia and New Zealand, USA, the UK and Europe.
- Studies were eligible for inclusion if they were published in an English peer-reviewed journal, and described a palliative care intervention addressing the needs of people with dementia living in LTCFs. Inclusion was not restricted by study design. Interventions had to address domains 2 or 3 and ≥ 1 other domain as defined by the EAPC White Paper [1].
- Results were synthesised using a narrative approach [4], as was appropriate to the range of study designs and the review’s descriptive purpose.

Table 1 Summary of EAPC domains addressed by included interventions	1	2	3	4	5	6	7	8	9	10
	Applicability of palliative care	Person-centred care, communication and shared decision-making	Setting care goals and advance planning	Continuity of care	Prognostication and timely recognition of dying	Avoiding overly aggressive, burdensome or futile treatment	Optimal treatment of symptoms and providing comfort	Psychosocial and spiritual support	Family care and involvement	Education of the health care team
Boogaard 2018		✓					✓	✓	✓	
Mitchell 2018		✓	✓			✓				
Agar 2017		✓	✓	✓	✓					✓
Ampe 2017		✓	✓							✓
Brazil 2017	✓	✓	✓			✓	✓	✓	✓	✓
Hanson 2017		✓	✓			✓	✓			✓
Moore 2017	✓	✓	✓		✓	✓	✓	✓	✓	✓
Stacpoole 2017		✓	✓					✓	✓	✓
Amador 2016			✓	✓	✓					
Garden 2016			✓			✓				✓
van der Maaden 2016			✓		✓	✓	✓			
Nakanishi 2015	✓	✓	✓			✓	✓		✓	✓
Toye 2015	✓	✓	✓			✓	✓	✓	✓	✓
Reinhardt 2014		✓	✓			✓	✓		✓	✓
Stirling 2014	✓	✓	✓		✓	✓			✓	
Livingston 2013		✓	✓				✓	✓	✓	✓
Elliot 2012		✓					✓		✓	✓
Kuhn 2012	✓	✓	✓			✓	✓	✓	✓	✓
van der Steen 2012	✓	✓	✓			✓	✓	✓	✓	
Hanson 2011		✓				✓				
van der Steen 2011		✓			✓	✓				
Arcand 2009	✓	✓	✓		✓	✓	✓		✓	✓
Meller 2009	✓	✓	✓							✓
Kovach 1999			✓				✓			✓
Kovach 1996		✓	✓			✓		✓		✓
Number of studies (n = 24)	9	20	21	2	7	16	14	9	13	17

RESULTS

- Of 1,636 references identified, 45 met inclusion criteria, reporting on 24 interventions. Interventions and/or intervention components included:
 - Educational material
 - Educational outreach visits
 - Case management
 - Resident and/or family mediated interventions
 - Expansion/creation of a role
 - Audit and feedback
 - Environment modification
 - Telemedicine
 - Monitoring health care delivery
 - Clinical practice guideline
- No interventions were found that addressed all 10 considered EAPC Domains (see Table 1). Apart from Domains 2 or 3, the three most commonly addressed domains were:

Domain 10
Education of the healthcare team (n = 17)

Domain 6
Avoiding overly aggressive, burdensome or futile treatment (n = 16)

Domain 7
Optimal treatment of symptoms and providing comfort (n = 14)
- The least commonly addressed domains were:

Domain 5
Prognostication and timely recognition of dying (n = 7)

Domain 4
Continuity of care (n = 2)

References

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CONCLUSIONS

- Interventions currently offered for this population address almost all domains, to various degrees.
- Future research optimally needs to be theory-driven when developing dementia-specific interventions at the end of life, with the EAPC domains serving as foundation to inform the complex needs of this population.

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