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Better Palliative Care for people with a Dementia: Summary of Interdisciplinary Workshop Highlighting Current Gaps and Recommendations for Future Research --Manuscript Draft--

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Abstract:	<p>Background: Dementia is the most common neurological disorder worldwide and is a life-limiting condition, but very often is not recognised as such. People with dementia, and their carers, have been shown to have palliative care needs equal in extent to those of cancer patients. However, many people with advanced dementia are not routinely being assessed to determine their palliative care needs, and it is not clear why this is so.</p> <p>Main Body: An interdisciplinary workshop on "Palliative Care in Neurodegeneration, with a focus on Dementia", was held in Cork, Ireland, in May 2016. The key aim of this workshop was to discuss the evidence base for palliative care for people with dementia, to identify 'gaps' for clinical research, and to make recommendations for interdisciplinary research practice. To lead the discussion throughout the day a multidisciplinary panel of expert speakers were brought together, including both researchers and clinicians from across Ireland and the UK. Targeted invitations were sent to attendees ensuring all key stakeholders were present to contribute to discussions. In total, 49 experts representing 17 different academic and practice settings, attended.</p> <p>Key topics for discussion were pre-selected based on previously identified research priorities (e.g. James Lind Alliance) and stakeholder input. Key discussion topics included: i. Advance Care Planning for people with Dementia; ii. Personhood in End-of-life Dementia care; iii. Topics in the care of advanced dementia at home. These topics were used as a starting point, and the ethos of the workshop was that the attendees could stimulate discussion and debate in any relevant area, not just the key topics, summarised under iv. Other priorities.</p> <p>Conclusions: The care experienced by people with dementia and their families has the potential to be improved; palliative care frameworks may have much to offer in this endeavour. However, a solid evidence base is required to translate palliative care into practice in the context of dementia. This paper presents suggested research priorities as a starting point to build this evidence base. An interdisciplinary approach to research and priority setting is essential to develop actionable knowledge in this area.</p>	
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2 **Summary of Interdisciplinary Workshop Highlighting Current Gaps and Recommendations for**
3 **Future Research**

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56 30 **Abstract**

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59 32 condition, but very often is not recognised as such. People with dementia, and their carers, have been

33 shown to have palliative care needs equal in extent to those of cancer patients. However, many
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48 workshop was that the attendees could stimulate discussion and debate in any relevant area, not just
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50 **Conclusions:** The care experienced by people with dementia and their families has the potential to
51 be improved; palliative care frameworks may have much to offer in this endeavour. However, a solid
52 evidence base is required to translate palliative care into practice in the context of dementia. This
53 paper presents suggested research priorities as a starting point to build this evidence base. An
54 interdisciplinary approach to research and priority setting is essential to develop actionable knowledge
55 in this area.

56 **Keywords:** Dementia; Neurodegenerative diseases; Interdisciplinary research; Research priorities;
57 Advance Care Planning; Personhood; Care at home.

59 **Background**

60 Dementia causes impairment of memory, problem-solving and communication, and in advanced
61 disease, the ability to perform everyday tasks[1]. Dementia is one of the major causes of disability and
62 dependency among older people and it is not a normal part of ageing. In the United Kingdom and
63 Wales, dementia is the leading cause of death[2]. Worldwide, 47.5 million people have dementia and
64 there are 7.7 million new cases every year[3]. There are at least 48,000 people in the Republic of
65 Ireland living with dementia; given the ageing population, this number is expected to increase to about
66 150,000 by 2046[4]. While recent population-based research suggests that the prevalence rate of
67 dementia in older people may actually be declining[5], due partly to improved healthcare, the number
68 of people affected by dementia directly or indirectly continues to rise as the population ages and the
69 number at risk rises.

70 There is a significant need to increase and expand the research base for palliative and end-of-life
71 care, in recognition of emerging global priorities[6], including moving beyond cancer to examine other
72 chronic diseases such as dementia[7]. Dementia is a life-limiting condition, but very often is not
73 recognised as a terminal illness. People with dementia, and their carers, have been shown to have
74 palliative care needs equal to those of cancer patients[8]. A palliative care approach is also favoured
75 by informal caregivers[9].

76 Palliative care can be defined as: “an approach to care that improves the quality-of-life of patients and
77 their families facing problems associated with life-threatening illness, through the prevention and relief
78 of suffering by means of early identification and impeccable assessment and treatment of pain and
79 other problems, physical, psychosocial and spiritual”[10]. This broad definition covers both i)
80 generalist palliative care (approach which involves all healthcare workers practicing palliative care
81 principles as a core skill, supplemented by some healthcare workers who are not engaged full time in
82 palliative care, but have had additional training and experience in palliative care); and ii) Specialist
83 Palliative Care services whose core activity is the provision of palliative care to individuals with more
84 complex and demanding care needs[11].

85 Recent international reviews have highlighted the importance of palliative care in
86 neurodegeneration[12-14]. The Irish National Dementia Strategy placed a particular focus on
87 palliative care[15]. However, it is difficult to enact policy as the evidence base for the value of
88 palliative care for people with dementia is still lacking and many people with advanced dementia are
89 still not routinely being provided with palliative care in practice. Providing high quality palliative care
90 for people with dementia presents unique challenges, for example the person’s inability to verbally
91 express preferences for their care as the illness progresses, and the fact that the end-of-life phase
92 may be long and difficult to identify[16]. Research is also hindered by the lack of agreed outcome
93 measures, and the challenge of adapting existing tools for use with someone with advanced dementia
94 who is verbally non-communicative[17]. Assessment of symptoms can be further confounded by the
95 presence of concurrent illnesses.

96 In recognition of the importance of this challenge, the international research community has called for
97 more clinically-relevant, collaborative, and strategic approaches to palliative care research[18-22].
98 While many disciplines have recognised the importance of research in palliative care for
99 neurodegeneration individually, a problem is that researchers are tackling the problem from different
100 perspectives, theoretical frameworks, and using diverse methodologies; these are complementary but
101 require a platform for discussion, debate and collaboration. Furthermore, this discussion needs to be
102 interdisciplinary, and include academics, practitioners and service-users, as one discipline alone
103 cannot manage the complex physical, psychological, social, and ethical problems in palliative care for
104 people with dementia. It is important that priorities for future research are set so that questions
105 pertinent to dementia and palliative care in Ireland could be addressed effectively by researchers of
106 all relevant disciplines, to enable a strong evidence base to be developed.

108 **Main text**

109 ***Planning the workshop***

110 A consortium was established, representing two universities and five non-profit organisations for
111 dementia and palliative care. The goal of the consortium was to plan an interdisciplinary workshop to
112 explore the theme: “Palliative Care in Neurodegeneration with a focus on Dementia: Addressing
113 complex questions through interdisciplinary research and reflection.” The aim of the workshop was to
114 bring experts together from different disciplines to discuss this theme, to enhance cross-discipline
115 learning, and to identify and discuss research gaps, priorities and methodologies in palliative care in
116 neurodegeneration. There are other examples of using a similar approach to identify research
117 priorities in palliative care (e.g. Stevinson, Preston, & Todd[23]; Jones et al.[24]).

118 The consortium members identified a long-list of key priority areas for the workshop through review of
119 existing priority setting exercises. Members then conferred within their own organisations (this
120 included input from a wider stakeholder network of academics and researchers, clinicians, and people
121 affected by dementia) and a final short-list with particular relevance to the Irish context was agreed by
122 the consortium. Next, experts in the chosen priorities were identified by the consortium and invited to
123 the workshop. Five invited speakers presented at the workshop.

124 ***The workshop***

125 In total, 49 experts attended the workshop, representing academics, researchers, and clinicians, from
126 a range of relevant disciplines (see Table 1). All attendees were identified and targeted as leading
127 experts in Ireland in either palliative care, neurodegeneration, or both, and attendance was on an
128 invite only basis. There was also substantial Patient and Public Involvement in both the organisation
129 and attendance at the event, including family carers of people with dementia and representatives from
130 national voluntary and charitable organisations.

131 The workshop was highly participatory, and scheduled such that all delegates had ample opportunity
132 to partake in discussions throughout the day. The workshop included five facilitated discussions. In
133 these sessions, invited speakers gave a brief introduction to one of the pre-identified key themes, and
134 then an independent, second expert facilitated the consequent discussion with the floor. A longer
135 keynote presentation was delivered by a leading international expert. Two workshop consortium
136 members independently recorded the core discussion points as they arose, and also gathered and
137 collated anonymous written comments (each attendee received blank comment cards for each
138 session). The discussion points and the comments were synthesised by an expert in an afternoon
139 session with further brief discussion to clarify content and fidelity. The workshop closed with a
140 facilitated question and answer session with a panel of six experts, three of whom had presented
141 earlier.

142 ***Outcomes***

143 The purpose of this paper is to summarise some of the key research priorities and suggestions for
144 future research in dementia palliative care, based on core discussion points which arose during the

145 workshop. We have provided a general overview of a selection of these key topics against a brief
146 background literature. We conclude with specific priorities for future research which are taken directly
147 from discussions during the workshop. This paper is not intended as an exact summary of the
148 proceedings on the day, however video recordings of the workshop presentations are available
149 online.

150

151 **Discussion topics**

152 **1. Overview of Research in neurodegenerative disease**

153 There is an imperative for the development of research into the care of people with
154 neurodegenerative disease, as at present there are no curative treatments, and the aim of care is to
155 provide the best supportive and palliative care for these patients and their families. There have been
156 several documents and discussions about the future of this research including the Priority Partnership
157 Project in 2015, which was based on a wide consultation on the future priorities for research in
158 palliative care, initiated by Marie Curie and facilitated by the James Lind Alliance[25]. Ten areas were
159 prioritised, and of these, the following four have particular relevance to neurodegenerative disease:
160 access to palliative care; Advance Care Planning; determination of patient needs; assessment and
161 treatment of pain when communication is complex (see Table 2).

162 The longer list of suggested research topics is also relevant, specifically: the best way of providing
163 palliative care to people with dementia; swallowing problems at end-of-life; drooling, which often
164 accompanies reduced swallowing; assessment of distress in dementia; carer support and training for
165 carers; continuity of care; understanding the person's needs in neurological disease and dementia.

166 Within Europe, the Joint Programme - Neurodegenerative Disease Research (JPND) has been
167 considering the research priorities and suggested the following: needs assessment, the identification
168 of transitions along the pathway (such as the move to institutional care), and consideration of effective
169 models across Europe[26]. Suggested priorities include quality improvement and research funding to
170 establish effective strategies to achieve them. Specific priorities within these two related domains
171 have been identified (Table 3). These areas may now be considered in greater depth and it is hoped
172 that there will be opportunities for funding to look at these areas.

173 A recent Consensus document on neurological palliative care has been produced and endorsed by
174 the European Academy of Neurology and the European Association for Palliative Care[14]. This
175 Consensus has suggested areas for development in the palliative care for all patients with chronic
176 and progressive neurological disease, considering in particular: ensuring palliative care approach
177 included in overall care, communication and Advance Care Planning, symptom management,
178 multidisciplinary team approach, family support, carer support, bereavement care, discussion of end-
179 of-life care and the recognition of end-of-life care and the identification and use of triggers for
180 palliative care[14]. Research into these areas would help to facilitate these developments and provide
181 the evidence base that is so often missing. A Delphi Study on palliative care for people with dementia,

182 produced as a White Paper from the EAPC[27], found that the areas for research that received the
1 183 highest importance ratings were person-centred care, communication and shared decision making;
2
3 184 optimal treatment of symptoms and providing comfort, setting care goals and advance planning.
4

5 185 Together, these documents suggest that the palliative care needs of people with neurodegenerative
6 186 diseases, including dementia, requires more research and there needs to be a unified approach,
7
8 187 linked to existing evidence, and at all levels – locally, nationally, across Europe, and across the world.
9
10 188 Such an approach should be informed by regional priorities and may be guided using specific
11 189 frameworks and models of care.
12
13 190

15 191 **2. Frameworks for planning and conducting research in palliative care and dementia**

17 192 Dementia is a devastating illness which can affect every one of us in some way. Most widely, we all
18 193 know someone with dementia and its symptoms and might all aim to achieve prevention in our own
19
20 194 lives; a smaller number of us provide support and care for those so affected (and ourselves may need
21
22 195 support); and an even smaller number attempt to address these needs through research and practice
23 196 development.
24

25 197 The life-long journey is fraught with difficulty: those affected by dementia experience pain, loss of
26 198 appetite, poor swallow, general fear and agitation, relationship problems and mental illness,
27
28 199 infections, pressure ulcers and communication difficulties. If so affected, we need substantial help
29
30 200 with activities of daily living and we might suffer social stigma and even the side-effects of treatments.
31
32 201 The journey is at once unique to each of us, yet we must navigate it together and make decisions at
33 202 all levels about where to place our emphasis.
34

35 203 Two frameworks are offered to guide our thinking. First is the Health Career model devised by
36 204 Hodges[28] which can be seen in Figure 1. The model distinguishes four domains: sciences; political;
37
38 205 sociology; and interpersonal, and challenges us to consider the potential to influence health outcomes
39
40 206 from a range of viewpoints. From the mechanistic side, science and politics attempt to deal with cause
41
42 207 and effect, costs and benefits, trade-offs and “hard” evidence to shape services. From the humanistic
43 208 side come psychology, ethics, culture and sociology to address fear and stigma of illness, death and
44
45 209 dying; addressing our relationships in support of one another. Hodges recognises the complexity of
46
47 210 disease and, through his model, challenges modern thinking about how we address these challenging
48
49 211 and interrelated symptoms of a complex disease. Interested readers are referred to this blog[29] for
50
51 212 further reading. This model may provide a useful theoretical and conceptual framework for
52
53 213 researching dementia and palliative care.

54 214 The second framework is the more familiar schematic timeline, see Figure 2. The palliative care
55 215 continuum offers a somewhat more one-dimensional or simpler view of the journey from screening for
56 216 disease in an otherwise healthy population, through diagnosis into a zone where elements of curative
57
58 217 and palliative care combine to achieve quality-of-life, right up to (and including) death and (for those
59
60 218 close by) bereavement support. The long course of the illness allows some potential to navigate the
61
62 219 journey, address secondary prevention and consider rehabilitation models in order to achieve as good
63
64
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220 a quality-of-life as possible. There are other models of palliative care involvement, including a varying
221 involvement, according to need, throughout the disease progression – as shown in Figure 3. This
222 model is of particular relevance in progressive neurological disease, such as dementia, where there
223 are times of specific deterioration such as in feeding or breathing, but at other times the disease
224 progression is slow.

225 Within the holistic remit of palliative care lie four primary components: the physical, social, spiritual
226 and psychological. These frameworks aim to inform thinking, and highlight gaps in our knowledge
227 where multi-professional, inter-disciplinary views, expertise and effort can be brought together to help
228 make sense of complex issues in dementia. Specific research priorities have been identified (Table 2)
229 and go some way to highlight the current unanswered questions. Hodges Health Career Model and
230 the Palliative Care Continuum can help to ensure that the journey ahead is well-travelled. Future
231 research could usefully explore the intersection of these two models.

232

233 **3. Research priorities in Advance Care Planning for people with Dementia**

234 In the United Kingdom and Ireland, various policy documents have called for improvements in care for
235 people with dementia towards the end-of-life by promoting the use of ‘Advance Care Planning’[30-33].
236 In Ireland, pioneering legislation was introduced in 2015 in the form of the Assisted Decision Making
237 (Capacity) Act[34], which provides the legal guidance to uphold the autonomy and dignity of the
238 person with dementia, and may be an exemplar for other countries. It has been suggested that
239 everyone should be encouraged to identify their needs, priorities and preferences for end-of-life
240 care[30]. This may seem to be a challenge for those with mental capacity, but will be especially
241 challenging for people with cognitive impairment and language deficits which reduces their ability to
242 express their preferences. Autonomy in decision making depends upon consciousness of our past
243 and future thoughts and actions in the same way as we are conscious of our present thoughts and
244 actions[35]. However, as dementia progresses, in particular, the ability to consider future thoughts[36]
245 and actions become compromised and this affects the capacity to make decisions[37].

246 *Proxy decision making.* Older people often trust loved ones to make healthcare decisions on their
247 behalf[38] and want those decisions to be in keeping with their own wishes and preferences[39].
248 Family carers are assumed to know what these wishes and preferences would have been had the
249 person with dementia not lost capacity[40] and professionals often rely on family members to predict
250 and articulate these preferences with assumed accuracy[41]. However, research shows this
251 assumption to be misplaced[37], with family carers often not able to accurately reflect the preferences
252 of a person with dementia in the absence of prior discussions or a documented advance care
253 plan[42]. Proxy decision making can be confounded as such decisions may be impossible to separate
254 from the family carers’ own views and furthermore, where the family carer has supportive (or other)
255 care needs of their own. Accordingly, the limits and potential of proxy decision making in the Irish
256 context, require further clarification and research.

257 *Future research priorities for Advance Care Planning in Dementia.* Overall there is little evidence to
1 258 support Advance Care Planning in dementia as a specific intervention. We need to test a feasible and
2 259 acceptable Advance Care Planning intervention for families affected by dementia[43] and to test it
3 260 over time. However, given the average life span of a person with dementia[44], this presents the
4 261 researcher with considerable challenges. Funding for such a study that would recruit people with
5 262 dementia from an early stage, when they are more likely to have the capacity to develop an advance
6 263 care plan; through to end-of-life, to be able to measure its effectiveness, may render it unfeasible in
7 264 respect of normal funding time scales.

12 265 These long time scales assume that the only evidence for practice comes from long term prospective
13 266 trails. Other forms of ethical decision-making can be informed by professional and personal
14 267 experience of patients and family members. However, as noted above, there is scant evidence on the
15 268 compatibility of the priorities and wishes of the family carer and the person with dementia, and if these
16 269 change over time, converging or diverging, and if it is influenced by the progression of the disease or
17 270 by transitions in care. Such evidence as exists suggests their perspectives differ greatly at the
18 271 outset[42, 45] but, could an intervention be developed that works systemically with the whole family to
19 272 develop a realistic, shared decision making approach? We know that families affected by dementia do
20 273 benefit from early and ongoing practical and emotional support[46], but can this be extended to
21 274 prepare them for potential changes and aid decision making in the context of the realities of care
22 275 towards the end-of-life[47]? To do this, we need to develop a greater understanding of what factors
23 276 influence the agreement or divergence of views, or how these issues are handled in skilled practice.

31 277 We also lack knowledge as to whether an Advance Care Planning intervention is a viable option for
32 278 people in different stages of dementia. Often capacity assessments are not always carried out to
33 279 consider specific decisions in respect of end-of-life care preferences so further study is warranted on
34 280 how we can ensure people with dementia in the moderate to advanced stages of the illness are
35 281 supported to engage in the decision making processes for their end-of-life care. We also need to
36 282 establish the stability of these views over the dementia journey.

41 283

44 284 **4. Research Priorities in Personhood in End-of-life Dementia care**

46 285 'Person-centred care,' since its rise in popularity in the 1980's, has become a catchphrase for good
47 286 dementia care. However, while the phrase is central to policy and education on dementia, many
48 287 people with dementia have not experienced improvements in care. The primary proponent of person-
49 288 centred care in dementia, Tom Kitwood[48], made a very insightful statement in his book, *Dementia*
50 289 *Reconsidered*:

54 290 *"It is conceivable that most of the advances that have been made in recent years might be*
55 291 *obliterated, and that the state of affairs in 2010 might be as bad as it was in 1970, except that it*
56 292 *would be varnished by eloquent mission statements, and masked by fine buildings and glossy*
57 293 *brochures"* p.133

294 If we are to ensure that person-centred care is more than a name-check in a mission statement, it is
1 295 essential that we explore the meaning of personhood right along the spectrum of dementia to end-of-
2 296 life care. Personhood is a standing or status that is bestowed on one human being, by others, in the
3 297 context of relationship and social being. It implies recognition, respect and trust. It is a commitment on
4 298 behalf of one to recognize the unique contribution of all human beings: primarily the person living with
5 299 dementia, but also the family carer, the volunteer, the unqualified assistant and healthcare
6 300 professionals[48].

10 301 For the research community there are many hurdles to surpass before we can realize this challenge.
11 302 It can be difficult for ethics committees to accept the necessity of involving vulnerable people in
12 303 research as co-researchers[49], a position which has led to a silence of the voice of people with
13 304 dementia for too long. This position serves to reinforce the idea that people with dementia may not
14 305 have a worthwhile contribution to make or that they are too vulnerable to require anything of them. Of
15 306 course these concerns are to be taken seriously but the larger danger may well be the resulting lack
16 307 of voice.

22 308 Assuming ethical permissions, there is an emerging but neophyte literature on the methods required
23 309 to elicit useful data when people with dementia are taking part in research studies. As people with
24 310 dementia are not in any way homogenous, the skills required are hugely varied not just from person to
25 311 person, but from day to day and week to week, depending on context and many other factors we are
26 312 yet to fully understand.

30 313 One example that explores the uniqueness of human response at the later stages of dementia is the
31 314 AwareCare study[50]. They proposed that if care staff can be trained to identify signs of awareness
32 315 this should support greater responsiveness and facilitate the expression of awareness. They found
33 316 seven spontaneously occurring stimuli (e.g. someone nearby) and three introduced stimuli (e.g. call
34 317 by name), with 14 response categories sub-divided into movement (eyes, face, head, arm and body)
35 318 and sounds. Importantly, use of the tool led to relatives rating improvements in wellbeing and quality-
36 319 of-life of the person with dementia.

41 320 There is a great need for creativity in research to generate knowledge that supports the translation of
42 321 person-centred care not just as a watch-word for good care but as an illumination of how that may be
43 322 practiced.

44 323

49 324 **5. Research topics in the care of advanced dementia at home and in 24-hour care**

51 325 In Ireland and the United Kingdom, acute hospital care is under huge pressure with large overspends
52 326 on unplanned emergency admissions. Older people occupy increasing numbers of acute care beds,
53 327 and most people with dementia present to the Emergency Department or and/or acute medical
54 328 assessment unit in the last six months of life[51]. Good care at home may help avoid this, and the
55 329 associated costs, as well as supporting good outcomes. Advanced dementia care at home has been
56 330 piloted by Treloar et al.[52] and further described by the Kings Fund[53]. Data from studies have

331 indicated substantial savings as a result of advanced dementia care at home. Sampson et al[51]
1 332 found that care costs over the six months before death were higher in care homes or continuing care
2 333 (£37,029) than for those living at home (£19,854). The Housing 21 Dementia Voice project in
3 334 Westminster[54] reported that “over a 24-month period, it is estimated that the Dementia Voice Nurse
4 335 service wholly or partly contributed to savings of £314,440 through the avoidance of hospital, nursing
5 336 and residential home admission and the use of ambulance services”. Results from the Hope for Home
6 337 study[52] indicated that total savings of home care compared with nursing home care for 14 patients
7 338 was approximately £700K and that 57% of participants died in their own home. An audit of 23 patients
8 339 cared for by the Greenwich Advanced Dementia service in 2009 found that, in total, these patients
9 340 were cared for at home for 6,205 days or approximately 886 weeks. Savings to local health and social
10 341 care commissioners from these patients were estimated at between £200 and £350 per week, saving
11 342 upwards of £177,200 to £310,100 for these patients. These savings are notional as the numbers of
12 343 people using the service are too small to enable commissioners to release money from closing
13 344 beds[53]. Using similar assumptions, the Greenwich Advanced Dementia Project estimates that it
14 345 saved over £2 million caring for 100 patients. However, this data is “soft” and formal economic
15 346 analysis of such services is very difficult. There is a real need for better quality economic data to
16 347 complement patient-focused outcome data.
17 348

27 349 Despite the possible economic savings, supporting the care of people with advanced dementia at
28 350 home is poorly understood and rarely prioritised by statutory services. Central to enabling care at
29 351 home for a person with advanced dementia, is carer resilience. The START (STrAtegies for
30 352 RelaTives) trial implemented a manualised intervention programme and aimed to improve carer
31 353 coping strategies. The trial demonstrated reduced depression and anxiety in family carers of people
32 354 with Dementia at 8 months and 2 years post intervention and also suggested savings[55].
33 355

37 356 Palliative care of a person with dementia at home also depends upon skilled healthcare, and
38 357 expertise that enables competent professional advice to support carers in what they are doing. The
39 358 principles of care of the Oxleas Advanced Dementia Service are good guiding principles, these are
40 359 outlined in Table 4.
41 360

46 361 **6. Other research priorities**

47 362 In addition to the aforementioned themes, there were a number of recurring issues raised during
48 363 discussion sessions during the workshop; these are discussed briefly in the following paragraphs and
49 364 summarised in Table 2.

53 365 i. Research design, including the choice of appropriate methodologies, can be challenging in palliative
54 366 care and dementia. By nature, large scale trials and longitudinal studies will be difficult and may not
55 367 always be feasible. It is also critical to identify the best ways to capture the potential benefit of
56 368 Advance Care Planning in palliative care and dementia. A research priority must be the identification
57 369 and validation of appropriate outcome measures to explore benefit (if any) of palliative care. It was
60 369

370 agreed that this still-emerging research area would benefit from smaller scale studies in the short-
1 371 term, including: quality improvement studies, smaller pilot studies, and observational studies to better
2 372 inform interventions in future trials. This aligns with the recommendations of the Medical Research
3 373 Council (MRC) framework for the evaluation of complex health interventions[56]. The MRC framework
4 374 was developed in light of the limitations of randomised control trials, mainly limited contextual data,
5 375 and outlines the steps for process evaluation, i.e. methods to assess fidelity and quality of
6 376 implementation, clarify causal mechanisms and identify contextual factors associated with variation in
7 377 outcome.

12 378 ii. There is a research gap concerning our understanding of the lived experience of the person with
13 379 advanced dementia. In this context Public and Patient Involvement (PPI) in research is critical.
14 380 However, it is important that PPI is not incorporated as a token exercise, but rather researchers must
15 381 aim to achieve useful and actionable outcomes and goals through patient and public participation in
16 382 research. It is essential that people with advanced dementia are also included in research. For this to
17 383 happen, innovative research methods must be utilised, as many people living with dementia at this
18 384 advanced stage will be verbally non-communicative.

24 385 iii. Palliative care for dementia, and neurodegeneration has been supported in policy for some years,
25 386 however in practice this is a new area for many healthcare staff and there is a need for it to be
26 387 actioned in routine practice across disciplines. Therefore, research needs to investigate the optimal
27 388 methods to change healthcare workers' behaviours concerning palliative care for their patients with
28 389 dementia. There are various recognised methods, some may be ethically questionable, such as
29 390 financially incentivising nurses and other healthcare staff. A better course may be to look at
30 391 implementing education programmes, and critically assess the sustainability of change following an
31 392 education intervention. These programmes might include methods to help staff to get to know the
32 393 person with dementia better, to improve quality of care, etc. Overall, research is needed to investigate
33 394 which methods are the best way to sustain positive changes in staff behaviours for the long-term.

40 395 iv. Another priority is to develop useful and transferrable models of best care. In developing these, the
41 396 key questions are: how to best integrate palliative care and dementia care, and identification of the
42 397 facilitators and barriers to such integration; how to integrate care not only across disciplines but also
43 398 sectors, including acute, community, residential care; and determining the existing access to
44 399 specialist services for people with dementia. A small number of existing clinics have pioneered
45 400 models of palliative care for dementia or other neurodegenerative illnesses, and these can serve as
46 401 exemplary models of excellence. Learning from existing models that are performing well may be done
47 402 through a cross-case analysis to identify the core principles and practices that are happening at each
48 403 site, mapping across the models to look at the commonalities and differences and build a taxonomy of
49 404 that model. Thus (as above) more conceptual research is needed, in addition to large scale trials and
50 405 studies. In any model, cost effectiveness is critical, but it is impossible to accurately measure cost
51 406 effectiveness unless the model of care is properly described. The development of these frameworks
52 407 would be highly useful as they could be subsequently replicated in multiple sites.

60 408

409 v. Other topics that arose at this workshop included “chemical restraint” and the issue of inappropriate
1 410 antipsychotic prescribing; dying at home, particularly transferring people at end-of-life from an acute
2 411 hospital setting to die at home, and the effect of this on quality of death and dying; palliative care in
3 412 primary care; improving staff and carers’ recognition of need (i.e. if a need is not recognised by
4 413 others, it will never be addressed); the potential use of technology to assist in assessment where
5 414 communication is limited, and in supporting care provision; exploration of potential conflicts in the
6 415 views of the person with dementia, their family and healthcare workers towards end-of-life. The
7 416 considered application of frameworks (such as Hodges Model) may provide a useful mapping
8 417 framework for priority setting and enable other areas requiring attention to be highlighted.
9 418

15 419 **Conclusions**

17 420 The care experienced by people with dementia and their families has the potential to be improved
18 421 through using palliative care frameworks. However, a solid evidence base is required to inform how to
19 422 achieve such improvements. As a relatively new field, there are significant methodological and
20 423 content areas where research is needed. An expert consortium has highlighted priorities for future
21 424 research (Table 2). Integrated care may improve outcomes, notably quality-of-life, for people with
22 425 dementia[57], hence an interdisciplinary approach to research and priority setting is essential to
23 426 further actionable knowledge in this area. It is also imperative that there needs to be a unified
24 427 approach at all levels – nationally, across Europe, and across the world.

25 428 This paper summarises key topics in dementia palliative care, based in part on a consensus
26 429 workshop, and the research priorities discussed here were not identified through systematic or
27 430 empirical research studies. Further, the priorities were discussed primarily with relevance to the Irish
28 431 context, and while most are common to international dementia research, there may be country-
29 432 specific priorities owing to unique cultures, different healthcare systems, different state of current
30 433 research, etc. However notable strengths of this paper, and the workshop which stimulated its
31 434 development, are that the consensus group included targeted national and international experts from
32 435 a variety of academic and professional disciplines, and had substantial Patient and Public
33 436 Involvement. A literature review was also performed to place the research priorities discussed into
34 437 context of international research literature.

35 438 We have highlighted some of the research priorities for palliative care and neurodegeneration, as
36 439 discussed by a consortium of multidisciplinary experts. We have also suggested two models or
37 440 frameworks that may be useful in mapping out topics to guide research in palliative care for people
38 441 with dementia and continue to prompt further questions.
39 442

40 443 **Declarations**

41 444 ***Ethics***

42 445 Not applicable
43 446

447 **Consent for publication**
1 448 Not applicable
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3 449
4 450 **Availability of data and materials**
5
6 451 Not applicable
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8 452
9 453 **Competing interests**
10 454 The authors declare that they have no competing interests.
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12 455
13 456 **Authors' contributions**
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15 457 Authors STF, CF, KHD, KI, WGK, AT, DO, ST drafted the original manuscript. CF, KHD, KI, WGK,
16 458 AT, DO, SG, ST suggested / made revisions to the manuscript, which were collated by STF. STF, CF,
17 459 KHD, KI, WGK, AT, DO, SG, ST approved the final draft of the manuscript.
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25 464
26
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31 469 the design of the workshop or in writing the manuscript.
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37 472 **Abbreviations**
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39 473 EAPC – European Association of Palliative Care
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41 474 JPND - Joint Programme - Neurodegenerative Disease Research
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43 475 MRC - Medical Research Council
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45 476 PPI – Patient and Public Involvement
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38 **Figure Legends**

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41 615 **Figure 1.** Showing the four quadrants of Hodges’ Health Career Model (1989) that provide a unique
 42 616 systematic way to think about research to inform holistic care.

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48 618 **Figure 2.** Showing the Palliative Care Continuum as one-dimensional journey from screening and
 49 619 diagnosis to end-of-life care. Evidence is required to inform practice in all segments (coloured).

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55 621 **Figure 3.** The model of dynamic involvement of palliative services based on trigger points (adapted
 56 622 from NHS England, End of life in long term neurological conditions: A framework for Implementation,
 57 623 pg.11).

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Table 1. Details of professional backgrounds of workshop delegates.

Discipline	n
Nursing	11
Consultant Physician	8
<i>Palliative Medicine</i>	4
<i>Geriatrician</i>	2
<i>Neurologist</i>	1
<i>Old Age Psychiatrist</i>	1
Psychology	7
Voluntary Sector	7
Medical Researchers	4
Law	3
Family Carers	2
Pharmacy	1
General Practitioner	1
Neuroscience	1
Microsystems	1
Physical Sciences	1
ICT For Healthcare	1
Speech And Language Therapist	1

Table 2. Selection of research priorities set through the James Lind Alliance and revised for Ireland by All Ireland Institute of Hospice and Palliative Care (2015)

Priority research questions identified by James Lind Alliance and All Ireland Institute of Hospice and Palliative Care (2015)
How can access to palliative care services be improved for everyone regardless of where they are in the UK? James Lind Alliance #2
What are the benefits of Advance Care Planning and other approaches to listening to and incorporating patients' preferences? Who should implement this and when? James Lind Alliance #3
What are the best ways to begin and deliver palliative care for patients with non-cancer diseases (such as COPD, heart failure, MND, AIDS, multiple sclerosis, Crohn's disease and stroke)? James Lind Alliance #6 / AIHPC #9
What are the best ways to assess and treat pain and discomfort in people at the end of life with communication and/or cognitive difficulties , perhaps due to motor neurone disease (MND), dementia, Parkinson's disease, brain tumour (including glioblastoma) or head and neck cancer, for example? James Lind Alliance #10
Priority research questions identified in May 2016 workshop
What are the limits and potential of proxy, i.e. family carers, decision making?
How to best to include people with dementia in research studies, to achieve useful and actionable outcomes?
What is the economic benefit, if any, of care at home services for dementia, and other neurodegenerative disease?
What are the factors that contribute to and build carer resilience in advanced dementia care?
How can assessment and support through video technology be utilised?
What are the most appropriate outcome measures to explore benefit (if any) of palliative care? These need to be validated in dementia, Parkinson's disease, motor neuron disease, etc.
What are the optimal methods to effect change in staff behaviours concerning palliative care for their patients with dementia?
What is the optimal transferrable model of dementia palliative care?
What is the incidence of, and how can we limit, chemical restraint through inappropriate antipsychotic prescribing in advanced dementia?
What is the effect on quality of death and dying, of being transferred from an acute hospital to die at home?

How can recognition of need be improved among primary care and other healthcare workers of palliative care needs in their patients with dementia, and other neurodegenerative disease?

Table 3. JPND Palliative and End-Of-Life Care Research in Neurodegenerative Diseases Suggested Priorities.

The following areas are suggested priorities in two related domains:

Improvement of Quality

1. Support for transnational networking, aiming for multi-professional engagement in palliative care research across EU
2. Co-ordination of best practices across EU member states
 - Working groups looking at developing evidence
 - a. Advance care planning
 - b. Cognitive impairment and challenges
 - c. Effectiveness of education
 - d. Primary care involvement in planning for palliative care
 - e. Engagement with voluntary groups

Research Funding

3. Collaborative research, especially enhancing and using existing population and disease based longitudinal cohort studies
 - Looking at triggers / transitions leading to changes in care
4. Support of research into identification of best practices for needs assessment
 - Multi-method
 - Interdisciplinary

Table 4. Principles of care of the Oxleas Advanced Dementia Service.

A core belief of the Oxleas Advanced Dementia Service is that anyone cared for at home with advanced dementia deserves care co-ordination and on-going support. The service combines mental and physical health expertise, to look competently after patients with advanced dementia living at home and to:

- Comprehensively assess and plan ahead;
- Co-ordinate care;
- Respond quickly when needs are changing;
- Establish a palliative care framework with a focus on maximising quality-of-life, helping to avoid or shorten unnecessary and traumatic hospital admissions, treatments and investigations, and replace them with home care whenever possible;
- Offer excellent care towards the end-of-life;
- Relieve the carer from having to navigate alone within a complex care system while grieving.





