



Components of community model of dementia palliative care

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3 1 **Title:** Components of community model of dementia palliative care
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5 2 **Abstract**
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8 3 *Purpose:* The Model for Dementia Palliative Care Project will develop a service-delivery
9 4 model for community-based dementia palliative care. Many countries provide dementia
10 5 palliative care services, albeit with considerable variability within these. However, little is
11 6 known about what service providers consider to be the most important components of a
12 7 dementia palliative care model. This study aimed to address this knowledge gap.
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15 8 *Design/methodology/approach:* An exploratory design using a survey method was used, as
16 9 an initial phase of the wider project. A web-based survey was developed, piloted (n=5),
17 10 revised, and distributed within five healthcare jurisdictions: the Republic of Ireland, Northern
18 11 Ireland, England, Scotland, and Wales. The target population was health and social care
19 12 professionals, policy-makers, and academics interested in dementia and palliative care.
20 13 Content analysis of open-ended questions identified common themes; descriptive statistics
21 14 were applied to the closed-ended questions.
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24 15 *Findings:* Overall, N=112 complete surveys were received. Key care principles incorporated
25 16 the philosophies of palliative care and dementia care; many described 'holistic' and 'person-
26 17 centred care' as core. Important individual service components were support for carers,
27 18 advanced care planning, information, education and training, activities for 'meaningful living',
28 19 comprehensive disease management, coordinated case management, and linking with
29 20 community health services and social activities. Barriers included poor availability and
30 21 organisation of healthcare services, stigma, misconceptions around dementia prognosis,
31 22 insufficient advanced care planning, and dementia-related challenges to care. Facilitators
32 23 included education, carer support, and therapeutic relationships.
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35 24 *Originality/value:* This study, as part of the larger project, will directly inform the development
36 25 of a novel service delivery Model of Dementia Palliative Care for Ireland. The results can
37 26 also inform service planning and design in other countries.
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39 27 **Keywords:** dementia; palliative care; integrated care model
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41 28 **Author classification:** Research paper
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48 30 **Introduction**
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55 31 Dementia is recognised internationally as one of the most significant healthcare challenges.
56 32 Worldwide, around 50 million people have dementia, and there are nearly 10 million new
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3 33 cases every year (World Health Organisation, 2019). Dementia is a degenerative, life-limiting
4 34 illness. The average survival time from dementia diagnosis varies greatly depending on
5 35 gender, dementia sub-type, age and severity of symptoms at diagnosis; however, one
6 36 systematic review found that the average survival time is between 1.1-8.5 years (Brodaty *et*
7 37 *al.*, 2012). A more recent study of memory clinic patients, including those with young
8 38 onset dementia, found a median survival time post-diagnosis of just 6 years (Rhodius-
9 39 Meester *et al.*, 2019). As there are no current curative treatments, all treatment is
10 40 essentially palliative, and there is an imperative for research to improve the palliative care of
11 41 people with dementia (PwD). PwD and their carers have been shown to have palliative care
12 42 needs equal to those of cancer patients (Dempsey *et al.*, 2015). However, the palliative
13 43 care needs of PwD may be complicated by cognitive impairment, communication difficulties
14 44 and responsive behaviours; presenting unique challenges to palliative care (Denning *et al.*,
15 45 Sampson and De Vries, 2019). Qualitative research has shown that while in many ways the
16 46 basic palliative care needs of people are the same regardless of illness, families'
17 47 experiences differ, for example families report extra stress when their dying loved one
18 48 cannot be involved in decision making about their own end of life care (Fox *et al.*, 2017).
19 49 Although some national dementia strategies include a focus on palliative care, such as
20 50 Ireland, England, Northern Ireland, and Sweden, and Scotland, many do not (Nakanishi *et*
21 51 *al.*, 2015).

22 52 The principles of palliative care and of dementia care are innately complementary. Person-
23 53 centred care (Kitwood, 2011) is at the heart of good dementia care, and arguably (although
24 54 not always explicitly stated) also palliative care. Both emphasise a holistic approach,
25 55 recognising the importance of non-physical symptoms, and of quality rather than duration of
26 56 life. Both emphasise the patient-family unit, and espouse the importance of multi-way
27 57 communication and shared decision making, and of future care planning. A useful framework
28 58 for optimal dementia palliative care has been agreed (Van der Steen, 2014), including, in
29 59 addition to the above, continuity of care, recognition of dying, avoiding burdensome/futile
30 60 treatments, and health and social care professional (HSCP) education. Worldwide, there
31 61 remains a significant need to expand the research base for palliative and end-of-life care, in
32 62 recognition of emerging global priorities, moving beyond cancer to examine diseases such
33 63 as dementia (Denning, 2016). Within Europe, the Joint Programme-Neurodegenerative
34 64 Disease (EU JPND, 2014) suggested the following priorities for palliative and end-of-life care
35 65 research in neurodegenerative disease: needs assessment, the identification of transitions
36 66 along the pathway, and *consideration of effective models across Europe*. However, few
37 67 evidence-based models of dementia palliative care have been published.

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3 68 The Model for Dementia Palliative Care Project aims to explore existing models of palliative
4 69 care for PwD in the community (theoretical models from the literature and actual clinical
5 70 services), using a programme theory approach to describe key model components (context,
6 71 focus, resources/input, service activities, outputs), and then translate these into a model
7 72 relevant to the community. The principal aim is to develop a service delivery model
8 73 incorporating key activities, and to provide a cost estimate and value to potential users of the
9 74 model in Ireland. However, the model will be designed to be translatable to other healthcare
10 75 systems and contexts. Multiple methods are being employed, including an initial exploratory
11 76 survey to explore key healthcare stakeholders' views on what is a "good" model of palliative
12 77 care for PwD living in the community.

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20 78 The guiding research questions of the exploratory survey were:

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22 79 • What do stakeholders consider should be the key principles of care to inform a model
23 80 for dementia palliative care?
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25 81 • What do stakeholders consider to be the most important components or activities of
26 82 such a model?
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28 83 • How should such a model be organised?
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30 84 • What are perceived barriers to such a model, and how might these be overcome?
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36 86 **Methods**

37 38 87 *Survey development*

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40 88 To identify what stakeholders consider '*a posteriori*' to be important in a model of dementia
41 89 palliative care (based on their experience), a *de novo* survey was developed based on a
42 90 literature review and the expert opinion of the project advisory group, consisting of
43 91 academics and clinicians from dementia and palliative care.

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47 92 The majority of survey questions were open-ended, intended to elicit rich qualitative data.
48 93 Two closed-ended questions asked respondents to rate the importance of a variety of
49 94 'general aspects' and 'specific components' of a model for dementia palliative care (based
50 95 on components identified in the literature, augmented by suggestions from the advisory
51 96 group). These prompted respondents to rate aspects/components which they may or may
52 97 not have considered in their responses to the earlier open-ended questions, using a 4-point
53 98 Likert scale, with options 'not very important', 'somewhat important', 'very important', and
54 99 'essential'.
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3 100 A paper version was piloted among a convenience sample (n=5). Following feedback, a
4 101 modified electronic version was created using LimeSurvey®, and further piloted for usability
5 102 (n=3). The survey questions are provided in Table 1.

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8 103 <<< **INSERT TABLE 1 ABOUT HERE** >>>

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11 104 *Sampling*

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13 105 Surveys were distributed electronically in the Republic of Ireland, Northern Ireland, Scotland,
14 106 and England and Wales (five countries, with the latter two sharing a healthcare system). The
15 107 rationale for choosing these was their comparable healthcare systems, and good contextual
16 108 similarity to Ireland. A purposive and “snowball” sampling methodology was used (Palinkas
17 109 *et al.*, 2015). Inclusion criteria were HSCPs/managers/policy-makers or academics with
18 110 expertise in dementia palliative care. The initial purposive recipient pool was informed by
19 111 national healthcare databases and websites, the knowledge of the research team and their
20 112 extended networks, in each region, and by direct contact with service leads for dementia and
21 113 for palliative care in each country. Priority was given to targeting key stakeholders and
22 114 experts, over final sample size. Initial recipients were asked to forward the email to any
23 115 contacts they considered relevant, to increase inclusion.

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26 116 *Data analysis*

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29 117 Raw data were imported into Excel and cleaned. Descriptive statistics and graphs illustrated
30 118 the quantitative data. The open-ended questions provided abundant qualitative data, which
31 119 was analysed using Thematic Content Analysis (-following Braun and Clarke’s 2006⁹
32 120 framework). The first stage looked for key themes within individual survey questions, using
33 121 an inductive and descriptive approach; subsequent stages of analysis considered themes
34 122 across the full dataset deductively, driven by the guiding research questions. Three
35 123 researchers were involved in coding and analysis, and sections of data which were doubly
36 124 coded were compared to increase rigour of analysis and interpretation. Finally, to make the
37 125 data more “useful” for our programme theory informed approach we mapped out the key
38 126 inputs, activities, outcomes as a modified logic model. This is a graphic depiction of the
39 127 shared relationships between the resources, activities, outputs, and outcomes/impacts for a
40 128 healthcare program (Centres for Disease Control and Prevention, 2018).

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43 129 *Ethics*

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46 130 This study received ethical approval from the Cork Research Ethics Committee (reference:
47 131 ECM4(h)/ECM3(zzzzz)). The survey landing page provided detailed study information and
48 132 outlined that by completing and submitting the survey, participants were consenting to take
49 133 part.

134 *Funding*

135 This research was funded by the Health Research Board, who had no role in the research
136 design or conduct.

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138 **Results**

139 **Survey respondents**

140 After deleting cases with significant missing data, the final sample was 112. It wasn't
141 possible to calculate response rate, as some organisations didn't provide the number of
142 subscribers on their mailing lists, and owing to the "snowball" approach. Responding sample
143 details are in Table 2.

144 <<< **INSERT TABLE 2 ABOUT HERE** >>>

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146 **Ranking the features and activities of a model**

147 Survey participants ranked the importance of general aspects and specific activities of a
148 community dementia palliative care model. Results are shown in figures 1 and 2.

149 <<< **INSERT FIG 1 AND FIG 2 ABOUT HERE** >>>

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151 **Qualitative analysis of open-ended question responses**

152 Most of the data produced by the survey method was rich qualitative data. The four guiding
153 research questions were used to organise the final themes in the data, thus the results are
154 presented as addressing each research question below.

155 **I. What do stakeholders consider to be the key principles of care that should inform a 156 model?**

157 Responses merged the philosophies of palliative care and good dementia care, and included
158 domains of the framework for dementia palliative care (Van der Steen, 2014). Respondents
159 emphasised a "holistic" or "palliative care" approach, including the four pillars of palliative
160 care i.e. physical, psychological, social and spiritual care. Equally, many emphasised
161 person-centred care as a core philosophy, i.e. "*all care should be person-centred and
162 relevant to the individual's needs*". The latter may be summarised as combining
163 individualised care with the aim of optimising quality-of-life.

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3 164 Some respondents addressed the core philosophies more generally, highlighting the care
4 principles of “empathy” including respect, dignity and compassion. Respecting PwDs’ wishes
5 165 to stay at home was mentioned, as was respecting the families’ wishes. Others included
6 166 end-of-life care specifically:
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10 168 *“A model focussed on wellbeing and quality-of-life that is open and honest about what to*
11 169 *expect during the end-of-life process for people with dementia” (Occupational Therapist,*
12 170 *acute hospital)*
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18 172 **II. What do stakeholders consider to be the most important components/activities of a**
19 173 **model?**

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21 174 *Interventions to support “meaningful living”.* This theme concerned having access to specific
22 175 interventions targeting the four pillars of palliative care. These activities should be
23 176 meaningful to the PwD and help to maintain wellbeing. Examples included cognitive
24 177 stimulation/rehabilitation therapies, reminiscence therapy, social activities, music/art
25 178 therapies, gardening, and respite facilities in local areas. Wherever possible these should be
26 179 offered as home-based interventions, with follow-up.

27
28 180 *“Access to regular therapies brought to the person in the community. Not for them to*
29 181 *travel to the service!” (Clinical Nurse Manager, social care)*
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32 182 Others mentioned social activities e.g. *“support for PwD to attend a match, go to the pub,*
33 183 *mass or visit a friend”.* The importance of *“regular re-assessment of needs”* was highlighted
34 184 so the PwD is referred to the appropriate treatments, therapies and supports.
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38 185
39 186 *Support for the carer* was a component considered essential for this community model.
40 187 Having formal and peer-support networks for carers and families was highlighted to provide
41 188 emotional and social and practical support. Sitting services, effective respite, 24/7 support,
42 189 and fast access to services were all critical to *“ease carer burden”* and support them to care
43 190 for their loved one at home for as long as possible. Of these factors- increasing home help
44 191 availability- was considered most critical:
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46

47 192 *“Appropriately trained home care and funding for it” (Medical Social Worker, acute care)*

48 193 *“Lack of home care packages- huge barrier to delivering community palliative care”*
49 194 *(Consultant in Geriatric Medicine, acute hospital and hospice)*
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3 195 Importantly, the family should be part of the care team and involved in care decisions. Some
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5 196 respondents felt that this could be improved in the context of palliative care, for example
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7 197 HCPs “*do not always listen to family members when they are trying to tell them about pain*”
8 198 (Admiral Nurse, community palliative care).

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12 200 *Information, education, and training* was a key theme. It’s important that PwD and families
13
14 201 are offered education, at an appropriate pace, about the nature of the disease, and what
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16 202 palliative care supports are available should they need them.

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18 203 Suitably trained and motivated staff are needed. Dementia professionals should all be able
19
20 204 to provide generalist palliative care support. Equally, palliative care staff should have training
21
22 205 in dementia care, and/or a dementia specialist should be available to palliative care teams or
23 206 situated in hospices. As one Dementia Specialist Nurse in a hospice setting wrote:

24
25 207 “*I think there is lack of understanding on what advanced dementia is and how it presents.*”

26 208 *(Mental Health Nurse Specialist in Dementia, Hospice)*

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29 209 Other related activities were access to education courses, specifically around advanced
30
31 210 dementia and end-of-life care in dementia for both families and professionals, and moving
32 211 and handling training for carers.

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34 212 Information resource packs were suggested so that the PwD or carer can self-refer to
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36 213 services. One respondent suggested having a manned information stand at clinics “*for*
37 214 *handing out information and whatever the client or family member may need at that time*”
38 215 (Care Home Liaison Nurse, community).

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43 217 *Supportive and safe environments* which are comfortable and familiar to the PwD was also
44
45 218 mentioned, often referring to supporting PwD to live in their homes as long as possible.
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47 219 Having “*access to suitable equipment as needed*” to allow care at home was considered
48
49 220 important, along with “*providing equipment as a matter of urgency*”. Adopting “*preventative*
50 221 *approaches*” e.g. falls prevention was related.

51
52 222 Creating wider dementia friendly environments in the community through advocacy,
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54 223 education and “*more local community awareness raising*” was highlighted. Enabling
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56 224 environments where hospital, community & primary care providers are supported to provide
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58 225 palliative care were discussed. Supportive environments are important throughout all stages
59 226 including a “*therapeutic environment at preferred place of death*”.

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5 228 *Symptom management* was another common theme; aspects discussed were, management
6
7 229 of pain; bowel and bladder; skin care; behaviour; medication; nutrition; swallowing; and
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9 230 prevention and management of delirium; falls. Where possible these should be managed at
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11 231 home, by the carer, supported by community care teams. In advanced disease more
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13 232 expertise from the MDT might be needed, e.g. the palliative management of pain (especially
14
15 233 for people who cannot verbally express pain), medication, and controlling symptoms. Access
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17 234 to the MDT within primary care was suggested.

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19 236 *Advanced care planning (ACP)* was a key activity. ACP should be undertaken early, and
20
21 237 reviewed regularly. Several respondents expressed that PwD and their family should be
22
23 238 encouraged to engage in ACP following diagnosis; to use this opportunity of contact to
24
25 239 discuss the importance of having conversations about the end-of-life stage early in the
26
27 240 disease prognosis:

28 241 *“A plan from diagnosis, where the post-diagnostic team gently start to discuss ACP with the*
29
30 242 *person and family- this can be updated/changed as needed whilst the person still has*
31
32 243 *capacity. This will then influence the care given in the palliative stages!” (Palliative Care*
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34 244 *Nurse Specialist, hospice and community)*

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37 246 *Excellent end-of-life care.* To ensure a ‘good’ death, PwD should be supported to die at their
38
39 247 preferred place (e.g. home or hospice), and effective symptom and pain management with
40
41 248 an appropriate tool to recognise pain must be provided. Trained HCPs are key *“to ensure a*
42
43 249 *respectful and dignified passing”*. Bereavement support and end-of-life counselling are
44
45 250 crucial to support the carer.

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48 252 **III. How should a model be organised?**

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50 253 *Comprehensive support.* Current services were criticised as *“very limited and sporadic”*.
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52 254 Respondents felt that a broad range of services should be available, so that a
53
54 255 comprehensive care plan can be tailored to individual situations, including financial,
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56 256 emotional, physical, social, spiritual and bereavement support, and practical advice.

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3 257 There should be regular comprehensive needs assessment throughout the PwD's journey.
4 258 This included receiving regular and standardised palliative care needs assessments, and
5 259 specialist palliative care (SPC) for patients with complex needs.

8 260 It's important that services are flexible and responsive to ensure timely identification of, and
9 261 appropriate responses to, potential crises:

12 262 *"the model should be flexible so that it can be truly patient-centred" (Admiral Nurse Lead,*
13 263 *community)*

16 264 No one model will be able to support the various needs of individuals at different times of
17 265 their dementia journey, so a flexible model is key:

20 266 *"Each individual will need support and advice at different points in their journey." (Admiral*
21 267 *Nurse Lead, community)*

24 268

26 269 *Integration of services.* This involves integrating primary care, community palliative care,
27 270 mental health, voluntary organisations, etc., with good links to acute services. Excellent
28 271 communication between these settings is a necessity. Many felt that dementia and palliative
29 272 care services must be integrated, i.e. that generalist and specialists should work together, for
30 273 example that a Geriatrician remain primarily involved in care throughout, with support from
31 274 SPC as required.

36 275 Many highlighted the importance of a key worker to *"develop a relationship with family and*
37 276 *PwD to coordinate support"* that is truly comprehensive, i.e. linked in with all relevant
38 277 services.

42 278 *"Having a key worker (such as Admiral Nurse) involved start to finish to coordinate care and*
43 279 *ensure a palliative care approach is achieved from point of diagnosis through to after death*
44 280 *support for families" (Admiral Nurse, hospice)*

47 281

49 282 *System level.* At the highest level, key elements included that the model is linked to other
50 283 relevant pathways, is provided as part of 'mainstream' services, that adequate facilities
51 284 within services are available, that electronic patient data is available to facilitate
52 285 communication, and that there is a *"feedback loop"* from service users to enhance the
53 286 component services.

58 287

288 Access. Many felt that PwD should have equal access to SPC as people with cancer or any
289 other life-limiting condition.

290 *“People need to be identified as having a chronic disease and to be on the palliative care*
291 *register so regular monitoring of their care is given” (Admiral Nurse, charity)*

292 Ease of access to all services was also stressed, whether palliative-, dementia-, or care-of-
293 the-older-person specific, to help PwD to remain at home. Services should be available
294 nationally so a PwD is not limited by their locality, and services should be available free at
295 point of access.

296

297 *Palliative care consideration from diagnosis.* A greater emphasis on addressing the needs of
298 PwD from diagnosis to end-of-life is needed. Not everyone diagnosed with dementia is
299 placed on the palliative care register (where available), which highlights the lack of
300 recognition that dementia is a terminal illness. A *“recognition by all that a palliative approach*
301 *to dementia care is best”* is crucial for successful organisation. The need for a clearly defined
302 pathway for dementia aligned to an end-of-life care framework was also expressed:

303 *“There needs to be a clearly defined pathway for dementia aligned to the End-of-Life Care*
304 *Operational System phases as to who will be involved and lead and how and where*
305 *handovers should take place on a planned basis” (Assistant Director, primary/community*
306 *and secondary care)*

307

308 **IV. Who should be involved?**

309 *Multidisciplinary approach.* Many professions and disciplines were mentioned as important
310 for a community model of palliative care for dementia, including GPs, community teams,
311 consultant geriatricians, psychogeriatricians, old age psychiatrists, dementia and palliative
312 care nurse specialists, community/public health, psychiatric nurses, psychologists, social
313 workers, therapists, and spiritualists. Furthermore, physiotherapists, dieticians, pharmacists,
314 voluntary groups (e.g. Alzheimer UK or Alzheimer Society of Ireland), volunteers, and local
315 ‘grass roots’ leaders were also mentioned. Finally, the PwD and carer were included in the
316 MDT by numerous respondents. It is important that the MDT works together and coordinates
317 all inputs to *“place as little burden [as possible] on carers and family”*, while including them in
318 care and care planning. Involving district nursing teams in palliative care approaches is also
319 crucial. Recognising the role of every HCP is important, for example the role that SLTs and

OTs can play in managing communication difficulties and adapting homes quickly and safely was expressed:

“SLTs have a huge and largely unrecognised role in managing cognitive communication difficulties and dysphagia, which is an invariable consequence of dementia”. (Speech and Language Therapist, private practice)

V. What are perceived barriers to a model?

Poor Organisation of Healthcare Systems

Lack of resources. Respondents discussed many problems at the wider healthcare service level. A lack of funding and resources was mentioned frequently. One respondent felt that there is an *“over reliance on voluntary agencies to plug holes in the health system”*. Dementia palliative care was seen as being costly to provide considering the required home care, 24-hour care, including care for the carer, and rapidly rising numbers of PwD. There’s a lack of community palliative care (for any illness), and inadequate home supports including overnight support and on-call GPs. Person-centred care interactions require time, when HCPs are already stretched; currently community care is too focused on completing tasks. There is also a perceived shortage of disciplines such as consultants and nurse specialists, and specialists in dementia with palliative care training, and vice versa. Where good pockets of services existed, this was inequitable and varied by location.

Poor quality of services. Other services may be available, but not fit for purpose, typically existing community services. *“No alternative to long-term care”* was frequently mentioned as a barrier. Options for respite were poor, as were dementia-friendly leisure activities.

Poor organisation and delivery. Barriers were also identified in how the system is organised. There is an *“over-reliance on the medical model”*, on providing physical care. This is compounded by the poor integration between health and social care:

*“Professionals are working in silos with poor communication between disciplines”.
(Programme Manager, health agency)*

Services are difficult to navigate in the context of a complex decision framework. Many PwD aren’t assessed for needs until there is a crisis. Hence, there is a need for *“a good referral pathway or link to specialist services without having to go through A&E”*. Another problem

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3 352 was that as nursing homes are viewed as already providing end-of-life palliative care, they
4 are deprioritised for SPC input.
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9 355 *Attitude.* Some felt that there is a general lack of interest in society, and among some HCPs,
10 in advancing dementia care as a priority, the following quotes are illustrative:
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13 357 *"[there are] few consultants with a specialist interest in this area."* (Consultant in Geriatric
14 *Medicine, acute hospital and hospice)*
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16
17 359 *"Specialist palliative care staff feel that this is not where their skills and practice should be*
18 *directed"* (Nurse Consultant End of Life, community)
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22 23 362 **Misconceptions of Dementia Palliative Care**

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25 363 *Misconceptions about dementia* were frequently cited as barriers. Dementia is not being
26 recognised as life-limiting, preventing HCPs from appreciating the benefit of palliative care
27 364 involvement. It was also felt that there is a general stigma in society (including among HCPs)
28 365 about dementia, that PwD may be *"written off"*. Related was a fear of non-cognitive
29 366 symptoms of dementia (i.e. responsive behaviours) stemming from a lack of education.
30 367 Many HCPs who aren't dementia specialists may not feel confident in caring for people with
31 368 non-cognitive symptoms manifesting through behaviour.
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39 371 *Misconceptions about palliative care* were also pervasive. Not surprisingly, palliative care is
40 372 *"focused mainly on cancer patients"*, although some, particularly in England, reported that
41 373 their local SPC service would see PwD. Equating palliative care with end-of-life care or SPC,
42 374 was common.
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46 375 *"Some healthcare professionals believe that palliative care can only be provided by SPC*
47 *services"* (Clinical Nurse Specialist, community palliative care)
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50 377 These misconceptions led to access barriers; some hospices won't accept PwD, and other
51 378 hospices felt unable to manage the longer term needs of PwD.
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55 56 380 **Delivery of Dementia Palliative Care**

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58 381 *Advance Care Planning.* A lack of ACP was a significant and common barrier identified. Too
59 382 late referrals to SPC impeded excellent end-of-life care, and reactionary interventions

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3 383 impeded good care throughout the illness. Respondents felt that there is also a “*lack of*
4 384 *robust training for health professionals*” to deal with all stages of dementia and not just
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6 385 diagnosis.
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9 386 “*Much of geriatric training has been in diagnosis and management with little focus on ACP*
10 387 *and end-of-life.*” (Consultant in Geriatric Medicine, acute hospital and hospice)
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12 388 One respondent recounted her experience of the reluctances of HCPs to engage in early
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14 389 ACP:

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16 390 “*The main gap in our area is with the post-diagnostic team being reluctant to become*
17 391 *involved in ACP discussions*” (Palliative Care Nurse Specialist, hospice and community)
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22 393 There appears to be no clear guidance on when and by whom this discussion should take
23
24 394 place among HCPs particularly when dealing with early stage dementia.
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28 396 *Dementia specific barriers.* Dementia that isn't diagnosed, or delayed diagnosis, impedes
29 397 effective palliative care. Difficulties in prognostication or staging dementia were
30 398 acknowledged. Physical needs assessments, including pain, are more difficult in PwD and
31 399 require specific skills. Some felt that it takes more time to care for PwD, and that they need a
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33 400 higher level of home support.
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37 402 **VI. What would facilitate implementation of a model?**

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39 403 *Funding.* Sufficient funding is essential for adequate resources and increase staffing levels,
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41 404 particularly within the community. With adequate funding, the core components of the model
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43 405 can be supported.
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48 407 *Education and training.* This included training in dementia and in palliative care for all HCPs
49 408 who are interacting with PwD. Specific topics may include communication, including non-
50 409 verbal communication, specific training in ACP and end-of-life for both healthcare
51 410 professionals and carers, reminiscence for PwD and carers, education with carers in the
52 411 home “*on what to expect with palliative illness and dementia*”, and broader education on
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54 412 living with dementia:
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3 413 “Education on what the world is like for someone living/dying with dementia - for healthcare
4 414 professionals, family, carers and community groups so that individuals in the wider
5 415 community know how to support someone with dementia” (Dementia Champion, hospice)
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11 417 *Carer support.* Any model requires significant unpaid or informal caring from a family
12 418 member, who may often be older, frail, and/or ill themselves. Respondents mentioned group
13 419 community supports, courses in caring, and better respite options.

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16 420 “Respite is critical to keeping people in their own homes especially as the illness
17 421 progresses.” (Consultant Nurse in Palliative Care, acute hospital)
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22 423 *Therapeutic relationships.* Respondents felt it essential that staff are friendly, know the PwD
23 424 and family well, and practice clear, effective communication. This would facilitate person-
24 425 centred care. The model should strengthen relationships between PwD and their carers as a
25 426 supportive family is often the key element which enables PwD to remain in the community.
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31 428 *Other facilitators.* A range of practical elements were mentioned as facilitators, these
32 429 included: transport to community services, assistive technologies, home equipment, reliable
33 430 assessment and prognostication tools.
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38 39 432 **Logic Model**

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41 433 A logic model (figure 3) was developed to illustrate how the emergent themes might be
42 434 translated to a healthcare model. Key themes were mapped onto the elements of ‘input’,
43 435 ‘intervention’, ‘components’, ‘intermediate and long-term outcomes’, and ‘contextual and
44 436 external factors’.
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48 437 <<< **FIGURE 3 ABOUT HERE** >>>
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52 53 439 **Discussion**

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55 440 A model of care broadly describes a framework that brings together regulatory,
56 441 organisational, financial, and clinical aspects of service provision to outline best practice in
57 442 patient care delivery (NCPPC, 2019). While current practices around dementia palliative
58 443 care are suboptimal, having clear models will assist healthcare providers in different
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3 444 countries provide better care and to a higher standard. Although increasingly dementia is
4 445 being recognised as a terminal illness and palliative care is being increasingly promoted, a
5 446 challenge remains in defining what works, and/or would work well in real-life practice. This
6 447 survey addressed this challenge. Responses were collected from stakeholders across five
7 448 different countries with four healthcare systems and a relative degree of consistency was
8 449 observed, with key themes emerging. While the initial model will be developed for an Irish
9 450 context, the current results have wider relevance.

14
15 451 The seminal EAPC white paper (Van der Steen, 2014) identifies 11 domains of optimal
16 452 dementia palliative care, namely: person-centred care, communication and shared decision-
17 453 making; optimal treatment of symptoms and providing comfort; setting care goals and
18 454 advance planning; continuity of care; psychosocial and spiritual support; family care and
19 455 involvement; education of the health care team; societal and ethical issues. prognostication
20 456 and timely recognition of dying; avoiding overly aggressive, burdensome or futile treatment;
21 457 and applicability of palliative care. All of these domains emerged as themes within our
22 458 survey, reinforcing their relevance. However, our “bottom-up” qualitative approach
23 459 highlighted some interesting nuances within these themes. Furthermore, by framing the
24 460 results in a logic model we highlight what a service-delivery model of dementia palliative
25 461 care might look like, and the interplay between different model domains or components.

26 462 There was a significant degree of consistency in the responses provided by key
27 463 stakeholders, even across the different regions; these are represented in the modified logic
28 464 model. The inputs required for the model include funding and resources, and staff education
29 465 and time, however longer-term outcomes may provide a cost saving to the health service,
30 466 e.g. less unnecessary hospital admissions (O'Shea and Monaghan, 2017).

31 467 As highlighted in the logic model, contextual and external factors must be considered when
32 468 planning the implementation of this model, such as the ageing population and current
33 469 attitudes towards dementia by the public, politicians, and HCPs. Raising awareness about
34 470 palliative care and dementia among the general public is important to normalise this
35 471 connection. Creating awareness and educating about dementia generally will help to
36 472 develop supportive communities and environments for PwD and their carers, which is
37 473 important for PwD to remain living at home for longer (Lin, 2017).

38 474 Potential core components of the model were identified as person-centred care,
39 475 comprehensive care, integrated care, accessible care, timely care, and care for carer.
40 476 However, the different model components are inextricably linked, for example: having rapid
41 477 access to services supports care at home; earlier access to services promotes earlier ACP
42 478 and better end-of-life outcomes. The broad components can be aligned with existing

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3 479 frameworks such as the Irish National Clinical Programme for Palliative Care's 'eight
4 480 foundations'(NCPCC, 2019), and the 'six ambitions' of the UK's Ambitions for Palliative and
5 481 End of Life Care framework (2015); both of which were developed as relevant for the
6 482 palliative care of all adults with a life-threatening illness. However, many issues specific to
7 483 dementia have been highlighted, hence a specific integrated model for dementia palliative
8 484 care is crucial (Van der Steen, 2014; Tolson *et al.*, 2017). Our study indicated the perceived
9 485 importance of components that would perhaps not be part of usual palliative care services,
10 486 to support *meaningful living*", such as cognitive stimulation/rehabilitation therapies,
11 487 reminiscence therapy, etc. The need for *supportive and safe environments* is also quite
12 488 dementia specific. The particular challenges of non-cognitive symptoms manifesting through
13 489 behaviour were also highlighted, along with difficulties in prognostication.

20
21 490 Reflecting the above unique needs of a PwD, it is not surprising that providing information,
22 491 education, and training is integral to the implementation of this model. Others have noted
23 492 that a skill and discipline mix, alongside an investment in staff development, is required for
24 493 effective dementia palliative care (Tolson *et al.*, 2017). Even if a SPC service does not
25 494 provide a dementia palliative care service, as people live longer and dementia in the older
26 495 population becomes more frequent, more people in the service will have co-morbid
27 496 dementia. Therefore, it is imperative that SPC professionals upskill in dementia care.
28 497 Equally, dementia care professionals need to recognise that a palliative care approach can
29 498 be (and often already is) provided by all disciplines caring for older people and/or those with
30 499 dementia, and to upskill where appropriate. Critically, these two services must work together
31 500 within an integrated care model. Further recognition of the value of different non-medical
32 501 disciplines will also support comprehensive care.

33
34 502 Person-centred care is recognised as a core value for dementia care (Kitwood, 2011). This
35 503 dovetails nicely with the holistic approach of palliative care. To facilitate this, HCPs must
36 504 communicate effectively with each other whilst including the PwD and their family through
37 505 regular follow-ups. ACP is a key activity, associated with better end-of-life outcomes for PwD
38 506 and their carers (Dixon *et al.*, Karagiannidou and Knapp, 2018). All HSCPs can play a role in
39 507 facilitating ACP (Scott *et al.*, 2013).

40
41 508 Having a 'key worker' is an important component of the model which can help to keep the
42 509 lines of communication open between the PwD, their families, and the care team. A support
43 510 worker role has been shown to improve the quality-of-life of the PwD and the carer, reduce
44 511 carer burden, improve symptom severity and reduce institutionalisation rates (Goeman *et al.*,
45 512 *Renehan and Koch*, 2016). The role is facilitated by ensuring that the key worker/support
46 513 worker has a skilled background, providing ongoing follow-up (home visits, via phone) that is

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3 514 based on needs and that they have the time and ability to develop relationships
4 515 (Goeman *et al.*, ~~Renehan and Koch~~, 2016).

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7 516 Most PwD live in the community (Pierse *et al.*, ~~O'Shea and Carney~~, 2019). Support for family
8 517 members and carers to provide care is essential to a community-based model. Effective
9 518 respite options (O'Shea *et al.*, 2017), and community and out-of-hours support services are
10 519 needed to support the PwD to remain at home (Kim *et al.*, 2012). This support needs to be
11 520 available and offered to carers regularly regardless of their health status, as any carer is
12 521 prone to experience burnout which may result in the carer feeling that they can no longer
13 522 care for the PwD at home (Donnelly *et al.*, 2015).

14
15 523 Another key strength of the current draft model is that it considers what aspects of palliative
16 524 care may be delivered to PwD at any disease stage; many frameworks focus on palliative
17 525 care for advanced dementia only (Tolson *et al.*, 2016). Aspects like approaching ACP early
18 526 in the disease and having a skilled dementia key worker who can link into palliative care
19 527 supports early if needed, extend the remit of palliative care to a whole disease focus.

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21 528 For any such model to be successful, its implementation must be carefully considered
22 529 (Moore ~~et al~~ *et al.*, 2015). Tolson ~~et al~~ *et al* (2016) discuss the Prudent Healthcare
23 530 Paradigm- the delicate balancing act between effective and efficient policy making and policy
24 531 implementation in relation to advanced dementia. This paradigm acknowledges the
25 532 economic pressures and inequalities in provision which mean that existing care systems
26 533 cannot simply expand to meet the challenge of their ageing populations. Instead
27 534 transformational change is required in which everyone takes responsibility for health and
28 535 wellbeing in a united and integrated way. In many countries the context for such a change is
29 536 positive. In Ireland, and other European countries, there is a rapidly growing recognition by
30 537 governments, healthcare systems, and policy groups of the importance of palliative care for
31 538 non-cancer illnesses including dementia. Ireland has a National Dementia Office with a
32 539 specific remit to implement the National Dementia Strategy, and of note the strategy,
33 540 perhaps reflecting its relatively later development (in 2014) than strategies in other European
34 541 countries, has a very strong focus on palliative care. However close working with the Irish
35 542 National Clinical Programme for Palliative Care would be critical to successful
36 543 implementation.

37
38 544 Some limitations of the current study should be noted. The survey was modest in size with
39 545 n=112 respondents across five countries. Positively, distribution was targeted so that
40 546 respondents represented key informed stakeholders, however no claims to
41 547 representativeness can be made. Furthermore, the components represented in the logic
42 548 model are tentative, and the final model will need to be informed by further research,

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3 549 including site visits and evaluations and further in-depth stakeholder consultation to include
4 550 PwD. These components however shed light onto what the potential model might look like,
5 551 and are a useful starting point to inform further research.
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8 552 **Conclusion**

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10 553 Utilising a palliative care approach can improve the outcomes for PwD and their carers,
11 554 especially when a PwD's illness progresses to advanced dementia. Such outcomes may
12 555 include improved quality-of-life for both the PwD and their family, improved quality-of-care,
13 556 better clinical outcomes, more PwD dying in their preferred place, improved patient
14 557 experiences, cost saving to the health service, and PwD being treated with respect, dignity
15 558 and compassion. While the relevance of a palliative care approach for PwD is now widely
16 559 accepted, the challenge has remained in how to achieve this in practice. The results of this
17 560 study address this by informing a wider research project to develop a service-delivery model,
18 561 initially for Ireland, but with potential for adaptation by other national health services, or other
19 562 key groups who provide dementia and or palliative care services..
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Table 1. Survey question items

Open-ended items	
Question 1	What do you think a good model of palliative care for people with dementia in the community looks like?
Question 2	What principles of care should inform such a model?
Question 3	In your opinion who are the key people/professionals who should be involved in a model for palliative care for people with dementia in the community?
Question 4	In your opinion, what are the key activities (e.g. component, intervention, other) that should be included in a model for palliative care for people with dementia in the community?
Question 5	Do you have any other comments relating to the above questions?
Question 6	Please list any current barriers that you can think of to providing palliative care to people with dementia living in the community.
Question 7	Please comment on any ways in which these barriers might be overcome.
Question 8	We would like to hear about examples of good practice. Please provide any example, from your experience, of what has worked well in the past for providing palliative care to people with dementia. This can be a model, component, a way of working, or other.
Closed-ended items	
Question 9	<p>Below we have listed some general aspects of a good model of palliative care for people with dementia. Please tell us how important you think each aspect is, by choosing from <i>Not very important, Somewhat important, Very important, or Essential</i>.</p> <ul style="list-style-type: none"> Enhanced access Standardised assessment tools Information continuity Incorporation of existing guidelines on pharmacological and non-pharmacological treatments Defined pathways for specialist service input Mechanisms to measure user experience Care for people at all stages of illness (i.e. early to advanced dementia) Based on a theoretical framework Evidence-based Other (please specify)
Question 10	<p>Below we have listed some specific components of a good service for palliative care for people with dementia. Please tell us how important you think each component is, by choosing from <i>Not very important, Somewhat important, Very important, or Essential</i>.</p> <ul style="list-style-type: none"> Care planning Case management Advance care planning Advocacy Patient and carer support Support during transitions of care Information resources Directories of local services Other (please specify)

Table 2. Respondents' Demographic Data (N=112)

(Primary) discipline	N	Country/Region	N	Gender	N
Nursing	50	England	43	Female	79
Community & Social Care	15	Republic of Ireland	25	Male	13
Doctor	11	Northern Ireland	22	Missing	20
Academia	8	Wales	5		
Physio, OT, SLT, Psychologist	8	Scotland	2		
Other	7	Missing	15		
Missing	13				

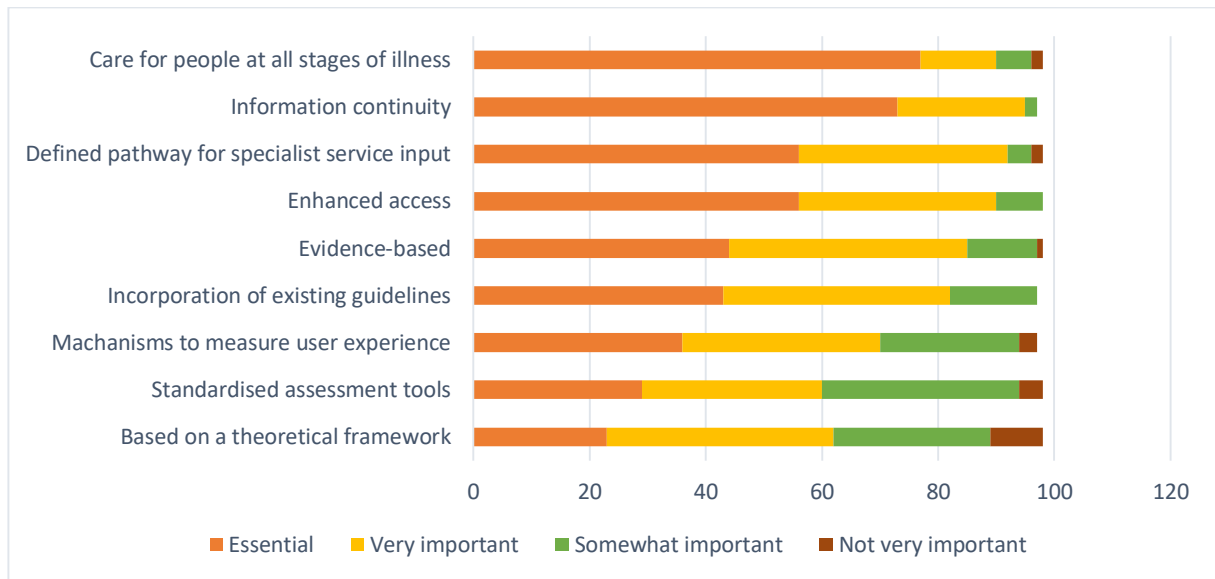


Fig 1: Ranking of general aspects of a good model of palliative care for people with dementia.

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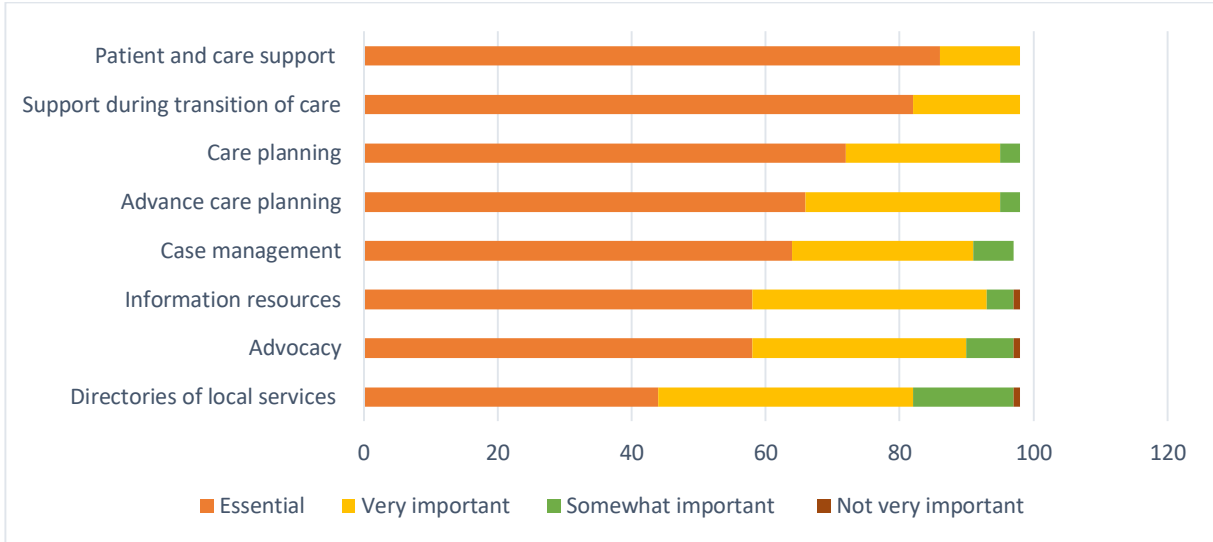


Fig 2: Ranking of specific components of a good model of palliative care for people with dementia.

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