

## Short Communication

# Implementing Palliative Care Teams Specialized in Dementia in Two Countries: Experiences of Failure and Success

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**Abstract.** Much is known about palliative care needs of persons with dementia and their family. Less is known about how to successfully implement models that address those needs. We present specialist models in the Netherlands (2017-2018) and Northern Ireland (2016-2017) contrasting its evaluations. From implementation failure in the Netherlands compared with successful implementation in Northern Ireland, we learn that recognizing roles and competencies among all involved is essential in developing effective partnership relationships. All of this is facilitated by referral before the end of life and offering various training programs and in-patient and out-patient services and therapies to show benefits early.

**Keywords:** Dementia, evaluation, health services, hospice care, negative palliative care, results

## INTRODUCTION

In our aging societies, there is an urgent need to improve dementia care also at the end of life. Peo-

ple with dementia may be disadvantaged in multiple ways. For example, they risk medical overtreatment and undertreatment of symptoms and that the dementia is not always recognized as a progressive, terminal condition [1]. Specialized residential dementia palliative care has been introduced in the 1980s in the US [2–4]. However, other than such residential, or advance care planning programs, few services based on the current, growing evidence base on the specific needs in dementia at the end of life have been described and evaluated [5, 6]. Possibly, evaluations

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of less successful models remain unpublished while much can be learnt from failures. For example, interviews showed that an unpublished Dutch initiative failed because both family and nurses resisted transfer of the resident from a regular nursing home unit to a hospice unit specialized in advanced dementia [7]. Familiarity—the person with dementia, the family caregivers and nursing staff knowing each other, was prioritized over a tailored environment and specialized staff if this implied a late transfer to a new environment. Considering the relevance of failures to improve practice, we reflect upon failure versus success of two innovative services that each built upon recent insights into palliative dementia care.

## METHODS

Teams from the Netherlands and Northern Ireland learnt about the other initiative developing services during the evaluation phase that involved qualitative analyses of interviews and monitoring referrals, complying with the Helsinki Declaration. Discussions between the two teams comparing the initiatives and evaluations informed additional lessons learnt.

### *Netherlands*

In the Netherlands, setting up and piloting a mobile palliative care team specialized in dementia was informed by a mixed-methods study to understand what services are needed [7]. For this, in 2015 up to early 2016, we had 1) identified domains and recommendations from the European Association for Palliative Care (EAPC) dementia white paper [1] that were particularly relevant for the end-of-life or advanced stage; 2) performed focus group discussions with family caregivers of community-dwelling persons with dementia; 3) conducted interviews with experts involved in 15 initiatives from five countries.

Piloting a new consultation model of end-of-life care was announced as part of a larger 3-year dementia collaborative of academia and a large regional care organization [8, 9] (Table 1). Initial referral criteria were dementia with end-of-life care needs at home or in a nursing home in the region. Late 2017, we assembled and trained a multidisciplinary mobile team from the existing palliative home care team and nursing home staff in two half-day sessions. Monthly meetings to discuss possible cases and progress continued until the pilot ended September 2018.

For its evaluation, we planned qualitative interviews, and in the nursing homes affiliated with the organization also a pre-post-test survey for bereaved family [10]. We prepared for a main, controlled study with adequate power involving another large care organization in case the pilot was successful. Interviews by CAVL were transcribed verbatim and analyzed by assigning codes collated in themes by JTvdS with ATLAS.ti7 (version 7.5.18, ATLAS.ti, Berlin) and discussed with CAVL. We monitored referrals and reviewed cases that were discussed during the team meetings. The Medical Ethical Committee of the Leiden University Medical Center declared the initiative exempt from the Medical Research Involving Human Subjects Act (WMO) on 19 October 2017 (number P17.214).

### *Northern Ireland*

After spending two years building initial relationships between palliative care services and mental health and dementia services, the Hospice Enabled Dementia Partnership Project ran from May 2016 to December 2017 as a collaborative initiative [11]. The project was underpinned by the EAPC dementia white paper recommendations [1]. Referral criteria were: need for management of unresolved symptoms, end-of-life care, specialist palliative rehabilitation, or respite admission. Trained staff offered holistic assessment and therapies at home, day hospice, with options for in-patient and respite care (Table 1).

Evaluation included referral patterns, service activity, outcomes and the perceptions of family caregivers, health and social care professionals and policy makers collected through individual and group interviews [11]. The study was approved by NHS Research Ethics Committee (number 17/SS/0024).

## RESULTS

### *Netherlands*

The new mobile dementia palliative care team members attended the training sessions, as did 12 of 28 nurses with the specific remit to improve palliative care in their nursing home (“aandachtvelders”). Despite announcing the launch of the team to local managers, team leaders, and general practitioners (GPs) in face-to-face meetings and with leaflets, there were no referrals. Only patients who were not yet at the end of life were being considered, mostly for eli-

Table 1  
Palliative care teams specialized in dementia in two countries

Mobile dementia palliative-terminal care team The Netherlands [8]	Hospice-Enabled Dementia Partnership Project Northern Ireland [11]
<p>A) LOCATION</p> <ul style="list-style-type: none"> <li>• A large care organization that provided home and nursing home care and participated in a program to improve psychosocial care for people with dementia in a rural province<sup>1</sup></li> <li>• A team of professionals was compiled from the organization, and mostly served the area’s main city</li> </ul> <p>B) KNOWLEDGE, SKILLS AND COMPOSITION OF THE TEAM</p> <ul style="list-style-type: none"> <li>• All professionals had already received basic training in providing palliative care more generally via the care organization. Two professionals were employed by the hospice and had experience in outreaching as (general) palliative care specialists to home and nursing homes</li> <li>• Additionally, all received two half days of interactive training in palliative care in dementia led by a palliative care nurse and trainer (CAvL)</li> <li>• With two specialist palliative care nurses visiting, team members to be consulted included a certified elderly care physician, psychologist, and spiritual caregiver</li> </ul> <p>C) PROGRAMME OF CARE</p> <ul style="list-style-type: none"> <li>• Consultation and support for professional caregivers in the nursing home and home care setting</li> <li>• Option for coaching on the job.</li> </ul>	<p>A) LOCATION</p> <ul style="list-style-type: none"> <li>• A public-health partnership model with a community-based specialist palliative care dementia team</li> <li>• Centered in one inner city, geographical region within a large Health Care Organisation and a large specialist palliative care hospice</li> </ul> <p>B) KNOWLEDGE, SKILLS AND COMPOSITION OF THE TEAM</p> <ul style="list-style-type: none"> <li>• Dementia Awareness Training, training on palliative care for people with dementia and family caregivers, and Understanding Behaviours in Dementia from the Alzheimer Society provided for staff as appropriate</li> <li>• Development of European Certificate in Holistic Dementia Care undertaken by both mental health/dementia and palliative care services</li> <li>• The multidisciplinary team worked in partnership with local mental health and primary care services</li> </ul> <p>C) PROGRAMME OF CARE</p> <ul style="list-style-type: none"> <li>• Holistic assessment of person with dementia and family caregivers</li> <li>• Dementia friendly day hospice for dual support of person with dementia and family caregivers</li> <li>• Dementia friendly in-patient unit for symptom management or respite. Quality assurance processes for dementia friendly building.</li> <li>• A creative therapy program for cognitive stimulation and well-being</li> <li>• A complementary therapy program offered to people with dementia and their family caregivers in their own home and day hospice</li> <li>• End-of-life care and support at home.</li> </ul>

<sup>1</sup>The 3-year “*Proeftuin Sociale Benadering Dementie*” dementia project represented an experimental learning and “research laboratory” for the development, piloting, implementation and evaluation of new ideas, interventions, methods, and institutional arrangements in dementia care. The main aim was to enable a better life for people with dementia and their loved ones. The project developed through a collaboration between the research institute Tao of Care, a major healthcare institute (De KwadrantGroep), case managers, GPs, gerontologists, and health insurers. The project also included, for example, the digital Narratives of Dementia Collection aimed at preserving and sharing the narratives of people with dementia and their caregivers (van Wijngaarden et al., 2018 [9]; refer to S1 File in that article for Background information about the project).

gibility. Therefore, eligibility was broadened to enroll earlier. This triggered consideration and more discussions of cases in which care may be, or may have been, improved through involvement of the new team.

Lacking referrals, evaluation of the initiative focused on cases that were discussed and reasons for the team not having been involved. Box 1 summarizes a case description based on observations and interviews with a bereaved spouse and a community nurse. It illustrates barriers to provide person-centered care and to involve the mobile team which also surfaced in analyses of team meeting notes and a group interview with trained nurses responsible for improving palliative care—one home based and the other nursing home based. Two basic attitudes hindered consulting the team.

Box 1 Case description<sup>1</sup> of declined consultation of the mobile palliative care team specialized in dementia in the Netherlands

Mr. A. was living with dementia at home with his wife when they participated in the dementia project. In addition to community nurse B., two project nurses were involved. Family ties were strong with four children living nearby. Mrs A. was in ill health herself, with high aspiration as to maintaining physical appearance of herself, her husband and her house. She felt overwhelmed with the burden of caring for her husband. However, Mr. A. resisted professional help. Mr. A. enjoyed connecting with some favorite nurses who sat with him to recall past good times.

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Three times, Mr. A. suddenly declined and all involved believed that death was imminent and the family were coming to say goodbye. However, Mr. A. recovered within a few hours. All were prepared, and fatigued of these situations.

At some point, Mr A. increasingly became short of breath. The use of morphine was discussed with the GP and a project nurse who was in charge that day (nurse B. is not). The project nurse advised community nurse B. to use an observational tool to monitor shortness of breath and report the observations. Nurse B. refused because she felt this was not her task but a physicians should do this. Further, she would not involve the mobile team because she felt she had a good understanding of palliative care and did not need any advice from a team she did not know. She understood palliative care as a focus on the patient being calm and the family being satisfied.

Another crisis developed when Mr. A. started to get up at night and Mrs. A. felt she could not achieve her household duty goals. Also, both Mr. and Mrs. A. became increasingly distressed due to many different professional caregivers rushing in and out of their home, coming in to take over and both felt they were losing control of their lives. Mrs. A. decided a nursing home admission of Mr. A. was now unavoidable and eventually both agreed to admission. Mrs. A. retained hope that her husband could come back in the terminal phase when bedridden. However, Mr. A. died suddenly, from a heart attack.

In retrospect, Mrs. A. indicated that Mr. A. might have stayed at home (for longer) if only the nurses Mr. A. liked so much could have stayed longer and would also have been allowed to share some of her household chores. She would not want yet another person to enter her house for that. She was happy and proud that despite everything, they retained some independency, commensurate with their personalities. For example, little medication for pain relief was needed, as this was the way both Mrs. A and Mr. A wanted it: no intervening, a natural and fast death.

<sup>1</sup>Based on individual interviews of CvL with a bereaved spouse (91 minutes) and a community nurse (95 minutes) and observations of the project nurses who were involved in the larger dementia project without being part of the specialized mobile dementia palliative care team.

(a) “I feel we do well” without advice about palliative care

The mobile team had not been consulted because nursing staff felt the care they provided was just good, meaning that patients were calm—if needed through sedation—and family did not complain. *“I don’t think our team has recently experienced that we couldn’t resolve something.”* A norm prevailed to not allow the patient they knew well, and the care they provided, to be evaluated by other professionals who just step in, unless it was clearly unavoidable to admit lacking expertise or failing to address needs in crisis situations. A distant mobile team would be asked only with loss of control, or for specific time-limited requests for technical support for what nurses could not do themselves, typically placing a morphine pump or catheter.

When prompted, staff mentioned three situations in which they felt the mobile team might have supported them: 1) when a nurse was threatened with a shard of glass, 2) to help manage behavioral problems although they said the psychologist could do that too, and 3) to detect pain in noncommunicative patients with dementia<sup>3/4</sup>being unaware observation scales existed. However, they would rather consult the GP because of their medical expertise and because they valued GPs also knowing patients well, or a psychologist or colleague nearby whom they trusted.

(b) We wish to continue caring for our patient ourselves up to the end

Nursing staff wanted to retain their central role in protecting the best interests of patient and family whom they knew through spending time with them; a role which was increasingly rewarding to them towards the end of life. Nursing staff felt they were the ones with a good understanding of needs allowing to provide personalized care. There were concerns about the mobile team not being present enough, and them involving yet other professionals unnecessarily or be directive and overly active in terms of new goal setting and activities. Staff took pride in managing care also at the end of life and enjoyed connections then becoming closer and more intimate: *“the bond you have with the family or partner does become a lot more intense, I can tell you.”*

#### Northern Ireland

The hospice-enabled dementia partnership project generated a reciprocal relationship in cross working and learning between services that lacked a history of working together. Staff were satisfied with broadening of networks and learning to provide end-of-life care in dementia with positive

210 impact of therapies provided for patients and family  
211 caregivers [11, 12].

212 In brief, 100 people with dementia were referred to  
213 the project. The main reasons were care in last days  
214 of life ( $n=41$ ), holistic assessment ( $n=24$ ), pain and  
215 symptom assessment and management ( $n=28$ ), fam-  
216 ily caregiver support ( $n=6$ ), or respite care ( $n=1$ ).  
217 Advance care planning was conducted with 22 peo-  
218 ple. Most received care and support at home from  
219 a project nurse and a complementary therapist in  
220 partnership with the local mental health services,  
221 the Alzheimer's Society, district nurse and the pri-  
222 mary care team or GP. Twenty-seven attended the  
223 day hospice and one person was admitted to the  
224 dementia friendly in-patient unit for symptom man-  
225 agement. Eighteen people were discharged from  
226 the project after a median of 59 days. Forty-two  
227 persons died during the project's timeframe after  
228 a median of 22 days: 38 at home and four in  
229 hospital.

230 Analyses of group and individual interviews with  
231 family and professional caregivers identified four  
232 themes, "Impact of dementia," "Information and  
233 learning needs," "Value of the service," and "Working  
234 in partnership" [11] the last two of which contrasted  
235 with findings in the Netherlands. Northern Ireland  
236 family caregivers valued its impact on the person: "*It*  
237 *is just the interaction and the stimulus which people*  
238 *need at whatever stage of the dementia,*" and them-  
239 selves: "*This is just a beautiful place to come ... it*  
240 *is terribly essential. There are quite a lot of carers*  
241 *here and we are all in the same boat.*" A profes-  
242 sional commented "*If you're working in partnership*  
243 *with people and you're working as a team, one of*  
244 *the most important things is respecting each other's*  
245 *roles ... so respecting what each other brings to the*  
246 *team. I think not being too precious about your role*"  
247 [12].

## 248 DISCUSSION

249 We compared two initiatives setting up specialist  
250 services for palliative dementia care. In the Nether-  
251 lands, essentially no partnership developed between  
252 the mobile team that covered palliative and dementia  
253 care expertise, and the dementia care professionals  
254 and GPs who were offered the services. From imple-  
255 mentation failure in the Netherlands compared with  
256 successful implementation in Northern Ireland, we  
257 learn that building up transdisciplinary relationships  
258 between staff of dementia and palliative care services

259 takes years, and time is also needed for persons with  
260 dementia and family to relate to healthcare profes-  
261 sionals who are new to them.

262 The Northern Ireland initiative was of a larger  
263 scale, and hospice care is resourceful in Great  
264 Britain. However, building of trust and recogniz-  
265 ing roles and competencies among all involved was  
266 also essential to integrate palliative care more gen-  
267 erally across Europe [13] and fear of teams taking  
268 over patient care was already reported in 1981 in the  
269 first mobile terminal-care team evaluation [14]. To  
270 allow time, in the case of dementia, access should  
271 not be limited to the end of life but based on needs  
272 of all involved [15]. Further, learning needs can be  
273 met through partnerships of dementia and palliative  
274 care services and reciprocal learning. In terms of  
275 Damschröder's implementation framework [16], the  
276 process of engaging "through a combined strategy of  
277 social marketing, education, role modeling, training  
278 and other" turned out important, as was "knowl-  
279 edge and beliefs about the intervention." Creating an  
280 optimal "implementation climate" takes time for all  
281 stakeholders to perceive the initiative's benefits and  
282 feel partner in the change process. It may therefore  
283 be helpful to offer, from the start, a wide range of  
284 visible interventions to address different needs such  
285 as appealing psychosocial in-patient and out-patient  
286 programs as in the Northern Ireland initiative. Clear  
287 benefits may increase perceptions of referral being  
288 meaningful (Box 2).

289 Box 2 Key recommendations to increase viability  
290 of new palliative dementia care initiatives  
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- Caring for persons with dementia requires a relational approach, and the relational aspect of continuity of care is supported through involving palliative dementia care services before the terminal stage
- Relationships of trust are essential for collaboration between palliative and dementia care partners. These are fostered by recognizing roles and competences mutually
- Benefits of the services should be clear in an early stage, helped by offering a range of training programs and in-patient and out-patient services and therapies including dual therapies to both the person and family caregiver (knowledge and favorable beliefs about the intervention [16])<sup>1</sup>

- Time is needed, up to years of preparation and involving stakeholders to feel partner in the process of developing partnerships
- Preparing the implementation through research and education, based on evidence and consensus guidelines, is not enough; there is a need to engage the wider community in various ways [16]<sup>2</sup> adopting a public health approach such as when aiming at buy-in of general practitioners

<sup>1</sup>“Knowledge and beliefs about the intervention:” “Individuals’ attitudes toward and value placed on the intervention as well as familiarity with facts, truths, and principles related to the intervention” [16].

<sup>2</sup>“Engaging:” “Attracting and involving appropriate individuals in the implementation and use of the intervention through a combined strategy of social marketing, education, role modeling, training, and other similar activities” [16].

Both initiatives were about professional collaboration: in neither initiative, public or patients were directly involved. Limitations of comparing the evaluations include sparse data from the Netherlands because the service remained unused. Nevertheless, we felt a need to publish lessons learnt. Future studies should consider resource and workforce issues, for example, to also support 24-hour telephone consultation [14, 17] and costs of involving additional professionals. There have not been before-after studies and trials on palliative dementia care in community settings that employ a control group such as usual care or generic palliative services [4]. Embedded pragmatic trials are being pilot-tested [18] and appropriate quality indicators including on spiritual and cultural aspects of care [19] are relevant to this end.

Nevertheless, comprehensive dementia-specific specialist palliative care services that achieve a public health partnership model successfully [11] while built upon international evidence and consensus-based guidelines potentially address a wide range of fluctuating complex needs as shown in recent evaluation studies in Australia, Singapore, and Israel [5]. It can be regarded as promising best practice awaiting further evaluations and prioritization of the most cost-effective elements.

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