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Improved quality of care and reduced healthcare costs at the end-of-life among older people with dementia who received palliative home care

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Improved quality of care and reduced healthcare costs at the end-of-life among older people with dementia who received palliative home care: a nationwide propensity score-matched decedent cohort study

Abstract

Background. While palliative home care is advocated for people with dementia, evidence of its effectiveness is lacking.

Aim. To evaluate the effects of palliative home care on quality and costs of end-of-life care for older people with dementia.

Design. Decedent cohort study using linked nationwide administrative databases and propensity score matching.

Setting/participants. All home-dwelling older people who died with dementia between 2010 and 2015 in Belgium (N=23,670).

Exposure. Receiving palliative home care support for the first time between 360 and 15 days before death.

Results. 5,637 (23.8%) received palliative home care support in the last two years of life, of whom 2,918 received it for the first time between 360 and 15 days before death. 2,839 people who received support were matched to 2,839 people who received usual care. After matching, those using palliative home care support, in the last 14 days of life, had lower risk of hospital admission (17.5% vs 50.5%; relative risk [RR]=0.21), undergoing diagnostic testing (17.0% vs 53.6%; RR=0.20) and receiving inappropriate medications, but were more likely to die at home (75.7% vs 32.6%; RR=6.45) and to have primary care professional contacts (mean 11.7 vs mean 5.2), compared with those who did not. Further, they had lower mean total costs of care in the last 30 days of life (incremental cost:−€2129).

Conclusions. Palliative home care use by home-dwelling older people with dementia is associated with improved quality and reduced costs of end-of-life care. Access remains low and should be increased.

Key words. Palliative care, terminal care, end of life care, dementia, home care services, Big Data

Key statements

What is already known about the topic?

- For a growing number of people dying with dementia, palliative care has been widely advocated.

- Evidence on the effects of palliative home care interventions in dementia is lacking, potentially due to the ethical, legal and practical challenges of conducting traditional experimental studies in this context.

- The best possible alternative is to emulate such a target trial using a matched cohort study design with a high-quality matching on the propensity of receiving an intervention.

What this paper adds

- Using linked 2010 to 2015 nationwide administrative databases in Belgium and a validated set of dementia-specific quality indicators, we were able to evaluate the effects of palliative home care support on the quality and costs of end-of-life care in dementia.

- Of all home-dwelling older people who died with dementia between 2010 and 2015, only 23.6% had access to palliative home care support at some point in the last two years of life.

- Palliative home care use by home-dwelling older people dying with dementia in Belgium is associated with improved quality and reduced costs of end-of-life care.

Implications for practice, policy and research

- Our findings offer a firmer evidence base regarding the effectiveness of palliative home care support for older people with dementia.

- Considering these clear benefits of palliative home care support in dementia, the low and considerably late uptake highlights an urgent need to further improve timely access in dementia.

- Further studies exploring strategies to improve access to palliative home care of older people dying with dementia are urgently needed.

Background

A fast-growing number of people are dying with dementia.(1) In Europe, dementia is projected to affect about 18.8 million by 2050.(2) Palliative care has been advocated for older people with dementia, as this approach has the potential to improve their quality of life by addressing their multi-faceted physical, psychosocial and spiritual care needs for months or years until death.(3–5) Particularly in the home setting, it is important to deliver high-quality and cost-effective palliative care considering the increasing demand for care in this population combined with the shortage and rising costs of long-term institutional care services and older people's preference to live and die at home.(6–9) However, high-quality evidence on the effectiveness of home-based palliative care in dementia is lacking.

A 2016 Cochrane review on palliative care interventions in advanced dementia found only two low-quality studies, neither of which focused on the home setting.(10) A 2019 systematic review found that while palliative home care interventions in dementia could improve behavioural disturbances, enhance pain assessment and reduce costs, no robust conclusions on their effectiveness could be drawn due to the insufficient and weak evidence available.(11) This paucity of evidence may stem from the fact that conducting traditional experimental studies, such as randomised controlled trials (RCTs) in this context is difficult due to ethical, legal and practical concerns. RCTs are a strong design for providing evidence about causal relationships because they allow control over essential aspects such as temporality, confounding and experimental control.(12,13) Ethically and legally, however, we cannot randomise home-dwelling patients with dementia into receiving or not receiving palliative care (to control confounding) and prevent the latter from using palliative care when needed (to have experimental control).

The best possible alternative is to emulate the aspects of an RCT using large administrative databases and a high-quality matching on the propensity of receiving an intervention.(14–16) The use of such methodology has been made possible by advances in digitalization and data storage which substantially improve the availability and quality of routinely-collected databases.(15,16) A previously conducted matched cohort study in Belgium using such linked administrative databases and propensity score matching found that palliative home care support improves the quality of end-of-life care and reduces resource use and costs for a general palliative care population in 2012.(17) However, it remains unknown whether palliative home care could have similar effects on end-of-life care for older people with dementia. We aim to evaluate the effects of palliative home

care support on the quality and costs of end-of-life care for older people who lived at home and died with dementia between 2010 and 2015 in Belgium.

Methods

Design

We conducted a propensity-matched decedent cohort study using linked nationwide administrative databases in Belgium (2010-2015).(18) Figure 1 depicts our study methodology. We reported our study following the RECORD statement (REporting of studies Conducted using Observational Routinely-collected Data).

Setting and participants

We included individuals aged 65 years and older at the time of death, who resided at home and did not have a recorded nursing home stay in the last six months of life, and died with dementia between 2010 and 2015. In Belgium, home-dwelling individuals, who are admitted in nursing homes and thus have a nursing home stay recorded in the administrative database, do not return to the home care setting. Dying with dementia was based on the underlying, intermediate and associated causes of death reported on the death certificate with ICD-10 codes (F01-F03 or G30) and whether or not they received dementia-specific medications up to ten years before death, using a medication algorithm (ATC code=N06DA01 or N06DA02 or N06DA03 or N06DA04 or N06DX01 or N06DA52). We included all deaths that occurred between 2010 and 2015 as there was no substantial change in legislation and uptake in palliative home care support in dementia within this period.(19) All participants were followed up until death and followed back up to 720 days before death.

Care for older people with dementia living at home in Belgium

Older people with dementia living at home typically receive care from health and social care workforce in primary care and specialist care services, e.g. neurologists. In Belgium, the primary care workforce essentially comprises general practitioners (GPs) together with community nurses, who deliver personal care, technical nursing procedures and psychosocial care, and social care workers, who deliver social support.(20) All specialist care services are accessible for patients without referral from GPs, while the written permission of GPs is needed to initiate palliative home care support for all health-insured people, who are seriously ill, have a short life expectancy (defined by law as 'more than 24 hours and less than three months') for whom curative treatment

is no longer an option and have an intention to receive end-of-life care and die at home (Table 1).(17,21-23)

Palliative home care support aims to address the multi-faceted care needs of this population in need of palliative care, including those with dementia. Ideally, the use of palliative care is progressive in nature and depends on the increasing needs of patients. Palliative home care measures include home visits by a multidisciplinary palliative home care team; home visit by a palliative care nurse or physiotherapist, or receiving financial allowance for palliative patients.(17,19,21)

Exposed group

Exposure was defined as receiving at least one type of palliative home care support measure for the first time between 360 and 15 days before death. Receiving any or the combination of the three measures was chosen as exposure, as we considered the different types of support to be the same intervention: initiation of palliative home care, and this operationalization of palliative home care support had also been used in previous studies.(17,19,21) We excluded those who received palliative home care support for the first time either between 720 and 361 days before death to avoid an overlap in the period used for the propensity score matching or in the last 14 days to avoid an overlap in the timing between exposure and outcome (temporality criterion). Using nomenclature codes and corresponding dates (coded in days before death), we identified the delivery and timing of a specific measure. Multiple measures were often delivered; hence, we identified the earliest initiation of the measure.

Unexposed group

The unexposed group included individuals who did not receive palliative home care support in the last two years of life, matched to people who received it.

Data sources

We used linked data from eight routinely-collected nationwide administrative databases in Belgium, including socio-demographic, healthcare, pharmaceutical, cancer registry, death certificate, population registry, census and fiscal databases. The Belgian healthcare system is funded through social security contributions and taxation, with a mandatory national health insurance covering the total population, combined with a private system of healthcare delivery based on independent medical practice, free choice of service provider and mainly fee-for-

service payment. Health insurance reimburses healthcare costs directly to the patient and all reimbursements are registered. Hence, the databases included data of all individuals registered with a Belgian sickness fund at the time of death (98.8% of all deaths).(18)

After obtaining approval from all relevant data protection agencies, data linkage was securely and ethically performed to guarantee anonymity of the individuals by a third party officially responsible for data protection and linkage in Belgium. Data were linked at individual level using a unique identifier and included person-level reimbursed healthcare use in the last two years of life (recorded as nomenclature codes), including dispensed medication in the hospital and community pharmacy (recorded as Anatomical Therapeutic Chemical Classification System codes). For all healthcare data, the exact delivery date is recorded (coded as number of days before death). We also have demographic, fiscal and death certificate data, including cause of death, coded using International Statistical Classification of Diseases, Tenth Revision (ICD-10) codification).(18,24)

Outcomes

Outcomes to determine quality of end-of-life care were based on a validated set of 28 quality indicators measuring the prevalence of specific healthcare interventions in the last 14 days of life and indicating appropriateness or inappropriateness of end-of-life care in dementia on an aggregated level (see quality indicators in Supplementary file 1).(25,26) This indicator set was developed for people with dementia using the RAND/UCLA Appropriateness method, involving literature review and expert consensus.(30) We used 22 of the 28 outcome measures, four of which indicate appropriate care. We excluded three indicators that overlapped with the exposure, one that could not be measured on an individual level and two that relate to individuals who permanently resided in nursing homes.(26) Based on specific healthcare consumption data, total direct medical costs of end-of-life care were calculated from a third-party and patient co-payment perspective, including inpatient, outpatient and total costs. Based on the exact dates of delivery, costs of care were calculated in the last 30 days of life and actualized to 2017.

Statistical analysis and propensity score matching

We used descriptive statistics to describe the characteristics of the cohort, stratified by exposed and unexposed groups. An included individual who received palliative home care support was matched to one who did not, based on an estimation of their propensity for receiving the support (Figure 1). To calculate propensity scores,

predictors for receiving the exposure, identified as relevant based on clinical knowledge and previous studies, were considered as baseline covariates.(17,27-31) These included age, sex, main diagnosis of the person with dementia based on the recorded underlying cause of death, household composition, education, annual income, region and degree of urbanisation of residence, care dependence and resource use. For temporality purposes, baseline was considered as the period between 720 and 361 days before death, except for cause of death. Because no information about main diagnoses is available for this period and different diagnostic groups were expected to differ strongly in terms of propensity for exposure, we assumed that the underlying cause of death category was indicative of a condition present in the baseline period.

For the propensity score matching we used a greedy 1:1 exposure–control propensity scores matching algorithm.(32) For every case, the best match was made first and a next-best match next, in a hierarchical sequence until no more matches could be made. Best matches are those with the highest digit match on propensity score. The algorithm proceeds sequentially to the lowest digit match on the propensity score (eight digit to one digit). No trimming was performed. Data on population characteristics, quality of care outcomes and costs were analysed using descriptive statistics. Risk ratios were calculated to measure the differences in outcomes between the exposed and unexposed groups. Costs for the matched exposed and unexposed groups were presented as estimated means along with the corresponding 95% confidence interval and standard error. All analyses were conducted using SAS Enterprise Guide, V9.4.

Ethics

Ethics approval was provided by the Committee for Medical Ethics of the University Hospital Brussels (UZ Brussel) (B.U.N. 143201627075) and the ethics committee of the Ghent University Hospital (B670201422382). The administrative data-linkage was approved by the national Belgian Data Protection Authority (project SA1/STAT/MA-2015-026-020-MAV) and by the Statistical Monitoring Committee (project STAT-MA-2015-026).

Results

Characteristics of study population

There were 634,445 deaths in Belgium between 2010 and 2015, of whom 529,534 individuals (83.5%) were aged 65 years and older at the time of death. Of these older people, 59,407 individuals (11.2%) died with dementia,

of whom 23,670 individuals (39.8%) resided at home in the last six months of life and thus were included in the study (Figure 2). In the last two years of life, 5,637 individuals (23.8% of the included population) received palliative home care support, of whom 1,720 (30.5%) received it for the first time within 14 days before death and 999 (17.7%) received it for the first time between 720 and 361 days (both excluded from the propensity score matching). Our final unmatched study population comprised 20,951 individuals, of whom 2,918 received palliative home care support for the first time between 360 and 15 days before death. Before matching, the exposed group differed considerably from the unexposed group in underlying cause of death, household composition, urbanization and care dependence (Table 2). For instance, compared to the unexposed individuals, the exposed individuals died considerably more often from cancer (8.1% vs. 29.7%) and were more care dependent (43.3% vs. 77.2%), which could have influenced both the exposure and the outcome. After matching of 2,839 exposed individuals to as many unexposed individuals with a corresponding propensity score, patient characteristics were balanced (Table 2 – "After matching columns"). For more information on the frequencies of the specific delivered measures that compose the exposure, please Supplementary File 2.

Effects on inappropriate end-of-life care in dementia

In the last 14 days of life, compared to the unexposed group, the palliative home care support group less frequently received inappropriate medications, e.g. statins with no decline in use (2.1% vs 6.9%; Risk ratio[RR]=0.29) or anti-hypertensives (22.7% vs 38.5%; RR=0.47), and underwent less surgery (0.2% vs 1.2%; RR=0.17) (Table 3). Compared with the unexposed group, fewer people in the exposed group were admitted to a hospital (17.5% vs 50.5%; RR=0.21).

Effects on appropriate end-of-life care in dementia

In the last 14 days of life, 75.7% of people exposed to palliative home care support died at home, compared with 32.6% of the unexposed individuals (RR=6.45; Table 3). People in the exposed group also had more contacts with GPs and other primary care professionals (mean 11.7 vs mean 5.2) than those in the unexposed group.

Costs of care

In the last 30 days of life, compared with the unexposed group, the group exposed to palliative home care support had lower mean total inpatient costs of care (€2156 vs €6269) but higher mean total outpatient costs

of care (€3007 vs €1024) (Table 4). Mean total direct medical costs of care for people in the exposed group were lower than for people unexposed (€5164 vs €7293).

Discussion

Main findings

We found that of the 23,670 home-dwelling older people who died with dementia between 2010 and 2015 in Belgium, only 23.8% received palliative home care support in the last two years of life (N=5,637), 30.5% of whom received it for the first time within only 14 days before death (N=1,720). In the propensity-matched population, people who used palliative home care support received less inappropriate and more appropriate care in the last 14 days of life and had lower mean total costs of care in the last 30 days, compared with those who did not use any palliative home care support.

Strengths and weaknesses

Because it is difficult to conduct traditional experimental studies that allow the making of causal inferences by controlling temporality, exposure and confounding,(33) most evidence on the effects of palliative home care in dementia comes from observational studies known to have different sources of bias.(11,34) Using large administrative databases, a validated set of dementia-specific end-of-life care quality indicators, and high-quality propensity score matching, our study is the first to offer a firmer evidence base on the effects of palliative care for home-dwelling older people with dementia. Using nationwide administrative databases on all deaths over a six-year period, our findings are generalisable to all older people with dementia in Belgium.(15) This study is also largely reproducible in countries that use comparable databases and have similar types of services and healthcare systems.

Nevertheless, our study has limitations. The most important one is probably a possible problem of residual confounding and confounding by indication. With the propensity score matching, we could eliminate confounding due to measured covariates but not for unmeasured covariates,(35) such as differing preferences and attitude towards care of patients and caregivers, their subjectively experienced symptom or caregiving burden or personality traits, which can affect both the exposure and outcomes.(36,37) Secondly, because we did not have diagnostic or comorbidity data, we had to rely on underlying cause of death for the matching procedure. Although we were able to match the exposed and unexposed groups based on their level of care

dependence, we still lack information on other potential confounders, such as frailty and severity and aetiology of dementia, which could also affect the exposure and outcome. If such data would become available or other matching procedures are used (e.g. a difference-in-differences cross-temporal matching design instead of cross-sectional matching), this could limit residual confounding in future comparable studies.(38) Thirdly, because only the 30-day cost calculation was possible with our data, it does not strictly comply with the temporality criterion, though the potential corresponding bias is likely to be limited. Fourthly, the quality indicators on which we based our outcomes are not developed to express quality of care for individual patients.(26) Our study should therefore be considered as an evaluation of palliative home care support in dementia on an aggregated level, providing relevant information for commissioners and policymakers. Finally, although we combined all-reported causes of death and the medication algorithm to identify older people who died with dementia, a substantial proportion of older people with dementia might have still been excluded due to potential underdiagnosis of dementia in primary care.(39,40)

What this study adds

We showed that compared with the unexposed group, the group exposed to palliative home care support received better quality of end-of-life care in the last 14 days of life. In particular, we found that people with dementia who used palliative home care support had lower risk of receiving inappropriate medications, undergoing surgery and being hospitalised; had considerably more contacts with healthcare professionals in primary care; and had a higher chance of dying at home. These positive findings concur with an earlier study suggesting similar positive effects of palliative home care support for a general palliative care population and with other previous studies focused on palliative home care interventions in dementia.(11,17,34) Nonetheless, to our knowledge, ours is the first to confirm such positive findings for home-dwelling older people with dementia. A causal relationship between palliative home care support use and better quality of end-of-life care is plausible given that palliative care is aimed at improving the quality of life of patients and families facing problems associated with life-threatening illness, through prevention and relief of physical, psychosocial and spiritual suffering.(41) It also uses a multidisciplinary team approach, facilitating active care coordination between all involved caregivers, which contributes to enabling patients to stay at home for as long as possible and to preventing unnecessary hospital admissions.(4) Further, eliciting patient preferences is an essential part of palliative care, making it more likely that patient preferences are taken into account when end-of-life care

treatment decisions are made.(4) Finally, our findings showed that palliative home care support reduced total direct medical costs of care in the last month of life in older people with dementia. This also confirms previous findings suggesting that palliative home care can reduce resource use and estimated costs.(11,17,34)

Because our evidence suggests the effectiveness of palliative home care support in dementia, it is concerning that three out of four people with dementia who could potentially use palliative home care support did not do so, and of those who did use it, one in three received it for the first time only within 14 days of death. This concurs with widespread reports of suboptimal access to palliative care for people with dementia.(5) Potentially, GPs in Belgium, who like in many countries are gatekeepers for initiating palliative home care support, are not always aware that palliative care is appropriate for people living with dementia or are reluctant to initiate conversations on palliative care due to its connotation with dying.(42,43) Considering the protracted and unpredictable disease trajectory of dementia,(44,45) it is difficult, even for GPs, to identify when certain palliative care support measures might be appropriate, further hindering access.(36,46) Interestingly, about one in three of those who received palliative home care support died of cancer. Hence, having cancer might have been an important 'trigger' to initiating such support, which further highlights the difficulty of accessing such support for those with dementia.

Implications for practice, policy and research

Considering the progressive and terminal nature of dementia (44,45) combined with previous reports of suboptimal end-of-life care for this population,(47-49) our study highlights an urgent need to increase timely access to palliative home care support for older people with dementia. Strategies to achieve this might include active screening of people with dementia in primary care using pre-defined criteria based on patient needs and preferences rather than prognosis to 'trigger' the initiation of palliative home care support; raising awareness about the benefits of palliative care in dementia among primary care and secondary care professionals involved in dementia care; improving professionals' communication skills to introduce such sensitive topics; and introducing financial or other incentives to increase uptake.(4,7,31) Nevertheless, providing high-quality and comprehensive palliative care to improve the quality and reduce the costs of end-of-life care for more older people with dementia living at home is a highly demanding and complex work for the palliative care professionals in primary care.(50) In order to support these palliative care professionals in delivering palliative care to this population, there is an urgent need for continued and stronger public health investments in this

sector. Because there is still no known care approach that aims to improve the access of older people with dementia living at home to palliative care services,(11) further work is needed to develop and evaluate a care approach that for example could comprehensively address all factors that might play a role in the access to palliative home care support of older people with dementia living and dying at home.(36,51)

Conclusion

Palliative care has been widely advocated to improve the quality of life and dying for older people with dementia, but there has been limited evidence of its effectiveness in this population so far. Our study suggests that palliative home care support improves quality and reduces total direct medical costs of end-of-life care in dementia. Despite these clear benefits, uptake in this population is low and late. Further studies exploring strategies to improve timely access to palliative home care for older people dying with dementia are urgently needed.

Declaration of conflicts of interest

The authors have no conflicts of interest to declare.

Research ethics (also to be found in the Methods section)

Ethics approval was provided by the Committee for Medical Ethics of the University Hospital Brussels (UZ Brussel) (B.U.N. 143201627075) and the ethics committee of the Ghent University Hospital (B670201422382). The administrative data-linkage was approved by the national Belgian Data Protection Authority (project SA1/STAT/MA-2015-026-020-MAV) and by the Statistical Monitoring Committee (project STAT-MA-2015-026).

Data management and sharing

In accordance with Belgian law, approvals for access to the administrative databases and the database integrating all databases were obtained from two separate national sectoral committees for privacy protection. As stated by the Sectoral Committee of Social Security and Health – Department Health and the Data Protection Authority (subcommittees of the Belgian Commission for the Protection of Privacy), we could not make the supporting data openly available due to ethical concerns regarding sensitive and potentially-identifying data. Additional information about the data, codes, syntaxes and access regulations are available upon request.

References

1. Alzheimer's Association. Alzheimer's disease facts and figures: Alzheimer's Association Report. Alzheimer's Dement. 2019;15:321–87.

2. Alzheimer Europe. Dementia in Europe Yearbook 2019: Estimating the prevalence of dementia in Europe. Luxembourg city; 2020.

3. Van den Block L. The need for integrating palliative care in ageing and dementia policies. Eur J Public Health. 2014;24(5):704–5.

4. van der Steen JT, Radbruch L, Hertogh CMPM, de Boer ME, Hughes JC, Larkin P, et al. White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. Palliat Med. 2014;28(3):197–209.

5. Worldwide Hospice Palliative Care Alliance. Palliative care and dementia statement-Worldwide Hospice Palliative Care Alliance. First WHO ministerial Conference on Global Action against Dementia. 2015.

6. Samus QM, Black BS, Bovenkamp D, Buckley M, Callahan C, Davis K, et al. Home is where the future is: The Bright Focus Foundation consensus panel on dementia care. Alzheimers Dement. 2018;14(1):104–14.

7. Fox S, FitzGerald C, Harrison Dening K, Irving K, Kernohan WG, Treloar A, et al. Better palliative care for people with a dementia: summary of interdisciplinary workshop highlighting current gaps and recommendations for future research. BMC Palliat Care. 2017;17(1):9.

8. Ewbank L, Thompson J, McKenna H. NHS hospital bed numbers: past, present, future. 2017 [cited 11 May 2020]. Available from: https://www.kingsfund.org.uk/publications/nhs-hospital-bed-numbers

9. Gomes B, Calanzani N, Gysels M, Hall S, Higginson IJ. Heterogeneity and changes in preferences for dying at home: A systematic review. BMC Palliat Care. 2013;12(7):1–13.

10. Murphy E, Froggatt K, Connolly S, O'Shea E, Sampson EL, Casey D, et al. Palliative care interventions in advanced dementia. Cochrane database Syst Rev. 2016;12:CD011513.

11. Miranda R, Bunn F, Lynch J, Van den Block L, Goodman C. Palliative care for people with dementia living at home: A systematic review of interventions. Palliat Med. 2019;33(7):726–42.

12. Jones DS, Podolsky SH. The history and fate of the gold standard. Lancet. 2015;385(9977):1502–3.

13. Bothwell LE, Greene JA, Podolsky SH, Jones DS. Assessing the Gold Standard — Lessons from the History of RCTs. N Engl J Med. 2019;374(22):2175–81.

14. Hernan M, Robins J. Using Big Data to Emulate a Target Trial When a Randomized Trial Is Not Available. Am J Epidemiol. 2016;183(8):758–64.

15. Pastorino R, De Vito C, Migliara G, Glocker K, Binenbaum I, Ricciardi W, et al. Benefits and challenges of Big Data in healthcare: An overview of the European initiatives. Eur J Public Health. 2019;29:23–7.

16. Murdoch TB, Detsky AS. The Inevitable Application of Big Data to Health Care. JAMA. 2013;309(13):1351–2.

17. Maetens A, Beernaert K, De Schreye R, Faes K, Annemans L, Pardon K, et al. Impact of palliative home care support on the quality and costs of care at the end of life: A population-level matched cohort study. BMJ Open. 2019;9(1):1–9.

18. Maetens A, Schreye R De, Faes K, Houttekier D, Deliens L, Gielen B, et al. Using linked administrative and disease-specific databases to study end-of-life care on a population level. BMC Palliat Care. 2016;15(1):86.

19. Maetens A, Deliens L, Van den Block L, Beernaert K, Cohen J. Are We Evolving Toward Greater and Earlier Use of Palliative Home Care Support? A Trend Analysis Using Population-Level Data From 2010 to 2015. J Pain Symptom Manage. 2019;58(1):19-28.e10.

20. Kringos DS, Boerma WGW, Hutchinson A, Saltman RB. Building primary care in a changing Europe: Case studies. European Observatory on Health Systems and Policies. 2015.

21. Houttekier D, Cohen J, Van Den Block L, Bossuyt N, Deliens L. Involvement of palliative care services strongly predicts place of death in Belgium. J Palliat Med. 2010;13(12):1461–8.

22. Federale Evaluatiecel Palliatieve Zorg. Evaluation report palliative care 2014 [Evaluatierapport palliatieve zorg 2014]. 2014. Available from: http://www.palliatief.be/template.asp?f=k_en_e_levenseindezorg.htm

23. Federale Evaluatiecel Palliatieve Zorg. Evaluation report palliative care 2017 [Evaluatierapport palliatieve zorg 2017]. 2017. Available from: http://www.palliatief.be/template.asp?f=k_en_e_levenseindezorg.htm

24. World Health Organization. International Statistical Classification of Diseases and Related Health Problems 10th Revision. 2019 [cited 10 Jun 2020]. Available from: https://icd.who.int/browse10/2019/en

25.   De Schreye R, Houttekier D, Deliens L, Cohen J. Developing indicators of appropriate and inappropriate end-of-life care in people with Alzheimer's disease, cancer or chronic obstructive pulmonary disease for population-level administrative databases: A RAND/UCLA appropriateness study. Palliat Med. 2017;31(10):932–45.

26.   De Schreye R, Smets T, Deliens L, Annemans L, Gielen B, Cohen J. Appropriateness of End-of-Life Care in People Dying With Dementia: Applying Quality Indicators on Linked Administrative Databases. J Am Med Dir Assoc. 2020;0(0):1–9.

27.   Davies N, Klapwijk MS, van der Steen JT. Palliative care in dementia. In: Textbook of Palliative Care. Springer International Publishing; 2018. p. 1–23.

28.   Wiggins N, Droney J, Mohammed K, Riley J, Sleeman KE. Understanding the factors associated with patients with dementia achieving their preferred place of death: A retrospective cohort study. Age Ageing. 2019;48(3):433–9.

29.   Mataqi M, Aslanpour Z. Factors influencing palliative care in advanced dementia: A systematic review. BMJ Support Palliat Care. 2020;10(19):145–56.

30.   Gomes B, Calanzani N, Curiale V, McCrone P. P, Higginson IJ, Brito M de. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. Cochrane Libr. 2013;(6):93.

31.   Mogan C, Lloyd-Williams M, Harrison Dening K, Dowrick C. The facilitators and challenges of dying at home with dementia: A narrative synthesis. Palliat Med. 2018;32(6):1042–54.

32.   Parsons LS. Performing a 1 : N Case-Control Match on Propensity Score. 2004.

33.   Hill HA, Kleinbaum D. Bias in observational studies. In: Encyclopedia of Biostatistics. Oxford University Press; 1999. p. 323–9.

34.   Pereira MJ, Tay RY, Tan WS, Antonio J, Molina DC, Ali NB, et al. Integrated palliative homecare in advanced dementia: reduced healthcare utilisation and costs. BMJ Support Palliat Care. 2020;1–9.

35.   Heinze G, Jüni P. An overview of the objectives of and the approaches to propensity score analyses. Eur Heart J. 2011;32:1704–8.

36.   Erel M, Marcus E-L, Dekeyser-Ganz F. Barriers to palliative care for advanced dementia: a scoping review. Ann Palliat Med. 2017;6(4):365–79.

37.   Friedman B, Veazie PJ, Chapman BP, Manning WG, Duberstein PR. Is personality associated with health care use by older adults? Milbank Q. 2013;91(3):491–527.

38.   Gozalo P, Plotzke M, Mor V, Miller SC, and Teno JM. Changes in Medicare Costs with the Growth of Hospice Care in Nursing Homes. N Engl J Med 2015;372:19.

39.   Connolly A, Gaehl E, Martin H, Morris, Purandare N. Underdiagnosis of dementia in primary care: Variations in the observed prevalence and comparisons to the expected prevalence. Aging Ment Health. 2011;15(8):978-84.

40.   Amjad H, Roth DL, Sheehan OC, Lyketsos CG, Wolff JL, Samus QM. Underdiagnosis of Dementia: an Observational Study of Patterns in Diagnosis and Awareness in US Older Adults. Journal of General Internal medicine. 2018;33:1131-38.

41.   World Health Organization. World Health Organization's definition of palliative care. [cited 10 Jun 2020]. Available from: http://www.who.int/cancer/palliative/definition/en/

42.   Carter G, van der Steen JT, Galway K, Brazil K. General practitioners' perceptions of the barriers and solutions to good-quality palliative care in dementia. Dement. 2017;16(1):79–95.

43.   Horlait M, Chambaere K, Pardon K, Deliens L, Van Belle S. What are the barriers faced by medical oncologists in initiating discussion of palliative care? A qualitative study in Flanders, Belgium. Support Care Cancer. 2016;24(9):3873–81.

44.   Lunney JR, Lynn J, Foley DJ, Lipson S. Patterns of Functional Decline at the End of Life. 2003;289(18):2387–92.

45.   van der Steen JT. Dying with dementia: What we know after more than a decade of research. J Alzheimer's Dis. 2010;22(1):37–55.

46.   Paap J van R, Mariani E, Chattat R, Koopmans R, Kerhervé H, Leppert W, et al. Identification of the palliative phase in people with dementia: a variety of opinions between healthcare professionals. BMC Palliat Care. 2015;14:56.

47.   Meeussen K, Van den Block L, Echteld M, Boffin N, Bilsen J, Van Casteren V, et al. Older people dying with dementia: a nationwide study. Int psychogeriatrics. 2012;24(10):1581–91.

48.   Penders YWH, Albers G, Deliens L, Miccinesi G, Vega Alonso T, Miralles M, et al. End-of-life care for people dying with dementia in general practice in Belgium, Italy and Spain: A cross-sectional, retrospective study. Geriatr Gerontol Int. 2017;17(10):1667–76.

49. Miranda R, Penders YWH, Smets T, Deliens L, Miccinesi G, Vega Alonso T, et al. Quality of primary

palliative care for older people with mild and severe dementia: an international mortality follow-back

study using quality indicators. Age Ageing. 2018;47(6):824–33.

50. Midtbust, M.H.; Alnes, R.E.; Gjengedal, E.; Lykkeslet, E. Perceived barriers and facilitators in providing

palliative care for people with severe dementia: The healthcare professionals' experiences. BMC Health

Serv Res. 2018; 18(1):709.

51. Sommerbakk R, Haugen DF, Tjora A, Kaasa S, Hjermstad MJ. Barriers to and facilitators for

implementing quality improvements in palliative care - results from a qualitative interview study in

Norway. BMC Palliat Care. 2016;15:61.