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End-of-life care in general practice: A cross-sectional, retrospective survey of 'cancer', 'organ failure' and 'old-age/dementia' patients

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ABSTRACT

Background: End-of-life care is often provided in primary care settings.

Aim: To describe and compare general-practitioner end-of-life care for Dutch patients who died from 'cancer', 'organ failure' and 'old-age or dementia'.

Design: A cross-sectional, retrospective survey was conducted within a sentinel network of general practitioners. General practitioners recorded the end-of-life care of all patients who died (1 January 2009 to 31 December 2011). Differences in care between patient groups were analysed using multivariate logistic regressions performed with generalised linear mixed models.

Setting/participants: Up to 63 general practitioners, covering 0.8% of the population, recorded the care of 1491 patients.

Results: General practitioners personally provided palliative care for 75% of cancer, 38% of organ failure and 64% of old-age/dementia patients (adjusted odds ratio (confidence interval): cancer (reference category); organ failure: 0.28 (0.17, 0.47); old-age/dementia: 0.31 (0.15, 0.63)). In the week before death, 89% of cancer, 77% of organ failure and 86% of old-age/dementia patients received palliative treatments: (adjusted odds ratio (confidence interval): cancer (reference category); old-age/dementia: 0.54 (0.29, 1.00); organ failure: 0.38 (0.16, 0.92)). Options for palliative care were discussed with 81% of cancer, 44% of organ failure and 39% of old-age/dementia patients (adjusted odds ratio (confidence interval): cancer (reference category); old-age/dementia: 0.34 (0.21, 0.57); organ failure: 0.17 (0.08, 0.36)).

Conclusion: The results highlight the need to integrate palliative care with optimal disease management in primary practice and to initiate advance care planning early in the chronic disease trajectory to enable all patients to live as well as possible with progressive illness and die with dignity and comfort.

What is already known about the topic?

Physical, psycho-social and spiritual suffering at the end of life has been increasingly described for archetypal illness trajectory groups such as cancer, organ failure and frailty/dementia. There remains, however, a paucity of research comparing end-of-life care between illness trajectory groups.

What this paper adds?

This study reveals that organ failure patients receive less palliative care from their GPs than cancer and old-age/dementia patients, whereas old-age/dementia patients, the group most likely to lose decision-making capacity, have the least end-of-life discussions and advance care planning of the three patient groups.

Implications for practice, theory or policy

These results highlight the need to integrate palliative care with optimal disease management in primary practice and to initiate advance care planning early in the chronic illness trajectory to enable all patients to live as well as possible with progressive illness and die with dignity and comfort in line with their own preferences.

INTRODUCTION

During the last year of life, many people receive care within primary practice,^{1,2} and general practitioners (GPs) are central to the co-ordination and provision of this care.³ In the Netherlands, emphasis is placed on GPs providing palliative care.⁴ A 2011 policy brief from the Dutch Ministry for Health, Welfare and Sport stipulated that primary care professionals principally provide palliative care and address patients' and relatives' physical, psychosocial and spiritual needs.⁵ Important aspects of GP palliative care include recognising palliative care needs, referrals to specialist palliative care, effective communication regarding end-of-life issues and advance care planning (ACP).

Primary care is an appropriate setting for much palliative care, particularly for non-cancer patients.^{6,7} However, with non-cancer patients, GPs are less likely to know when to initiate palliative care,⁸ provide timely referrals to specialist services⁹ and discuss end-of-life issues and ACP.^{10,11} Nonetheless, non-cancer patients experience high levels of physical¹²⁻¹⁴ and psychosocial distress,¹⁵⁻¹⁷ which may benefit from a palliative approach. Differences in care between cancer and non-cancer patients are often attributed to non-cancer patients' less predictable illness trajectories.⁸⁻¹⁰ Non-cancer patients, however, are a diverse group with distinct illness trajectories. It is, therefore, crucial to compare patients' end-of-life care by trajectory group rather than the usual cancer and non-cancer dichotomy. The term 'end-of-life care' has been variously defined,^{18,19} however, it is used herein to describe the GP-reported care patients received before death,²⁰ which may or may not have included a palliative approach.

Inspired by observations that 'perceived course of dying' strongly influenced patients' care,²¹ Lunney et al.²² described three archetypal trajectories for progressive

chronic illnesses: cancer patients experience rapid predictable decline, organ failure patients (e.g. heart disease, chronic obstructive pulmonary disease (COPD)) experience a more gradual decline with serious intermittent episodes and frail/dementia patients experience gradual prolonged decline. Illness trajectory can affect treatment aims (to cure, prolong life or palliate symptoms), use of palliative care services and end-of-life communication. Subsequent research has examined the trajectories of physical, psychosocial and spiritual suffering at the end of life in various patient populations.^{14,16,23,24-26} Only two studies, however, have directly and quantitatively compared aspects of end-of-life *care* between illness trajectory groups: Lunney et al.²⁷ studied US patients' Medicare expenditure, whereas Beernaert et al.²⁸ investigated referrals to specialist palliative care services. No studies have examined different aspects of GPs' end-of-life care provision by trajectory group. Based on GPs' reports, this study describes and compares GP end-of-life care for patients who died from 'cancer', 'organ failure' and 'old-age or dementia' in the Netherlands. Specific objectives include estimating and comparing

- Importance of cure, life prolongation and palliation in the last week of life, 2–4 weeks before death and 2–3 months before death;
- Provision of palliative care by the GP and other services;
- Prevalence of GP–patient discussion of 10 end-of-life topics;
- Elements of ACP, specifically regarding preferred place of death, medical end-of-life treatment preferences and surrogate decision-makers.

METHODS

Study design and procedure

The study design was cross-sectional and retrospective, with a clustered sample. GPs from The Dutch Sentinel General Practice Network recorded demographic, health and care characteristics for all deaths of practice patients (aged 1 year or over) using a standardised registration form after death (1 January 2009 to 31 December 2011). Components of care recorded included treatment aims and palliative care provision, which GPs recorded for the last 3 months of life. This timeframe was identified as relevant to study on the basis of other literature.²⁹⁻³¹ GPs were also asked about the discussion of end-of-life topics and ACP. No timeframe was put on these questions because illness can affect timing.

The Netherlands Institute of Health Services Research (NIVEL) coordinated the sentinel GP network, which is based on a representative sample of health-care professionals that reports all cases of particular conditions to study disease prevalence and associated factors.³² Participating GPs completed the registration form by hand within a week of the patient's death, including any information from medical records and hospital physicians. Forms were sent to NIVEL.

Informed consent, patient anonymity and ethics approval

After being informed of the study objectives and procedures, participating GPs gave written informed consent at the beginning of each registration year. Strict procedures regarding patient anonymity were employed during data collection and entry; GPs gave every patient an anonymous reference, and any identifying patient and GP data (such as date of birth, postcode and GP identification number) were replaced with aggregate categories or anonymous codes. Ethical approval is not required for posthumous collection of anonymous patient data in the Netherlands.^{33,34}

Settings and study population

The Dutch Sentinel GP Network has been operating since 1970. The network is designed and managed to be representative for the Dutch population (for age, sex and population density) through stratified random sampling and aims to cover 1% of the population. Registered GPs (National GP Register held by NIVEL) are invited to participate on the basis of their practice population characteristics, keeping in mind the need to manage the representativeness of the network. GPs who accept the invitation to participate undergo a 2-month trial period to assess their motivation and reporting accuracy. The same procedure is used when replacing a GP who leaves the network.

To include only data from patients who could, in theory, have received palliative care, deaths registered as 'sudden and totally unexpected', or for whom suddenness of death information was missing, were excluded. Furthermore, only patients who were under their GP's care in the last year of life were included. This was determined from the patient's main place of residence in the last year of life; nursing home residents, cared for by an elderly-care physician were excluded, as were patients whose main residence was 'unknown' or 'other' (often institutions outside of the GP's care).

GPs recorded the primary cause of death: cancer, cardiovascular disease, pulmonary disease, neurological disease, cerebrovascular accident, old-age or 'other' (specified). Dementia was not a specific cause of death category, but dementia diagnosis (mild or severe), as reported by the GP, was recorded. To compare patients' end-of-life care, three groups were created: 'cancer', 'organ failure' and 'old-age/dementia'. The 'cancer' group included patients whose cause of death was any cancer; the 'organ failure' group included patients whose cause of death was cardiovascular or pulmonary disease; and the 'old-age/dementia group' included patients whose cause of death was 'old-age', patients reported to have severe dementia whose cause of death was 'neurological disease' and patients for whom the 'other' cause of death category was specified as 'dementia'. Neurological diseases other than dementia, cerebrovascular accidents and 'other' causes of death (apart from those specified as 'dementia') were excluded (Figure 1). Elderly patients whose primary cause of death was organ failure or cancer were categorised in those groups rather than the 'old-age' group. Disease trajectory groups were therefore based on the primary cause of death as reported by the GP, and co-morbidities were not considered.

[FIGURE 1]

MEASUREMENT INSTRUMENT

Patient and care characteristics collected included age, sex, cause of death, dementia diagnosis, main place of residence in the last year of life and place of death.

Treatment aims

GPs were asked to rate the importance of cure, life prolongation and palliation as treatment aims on a 5-point Likert scale during the following: the last week of life, 2–4 weeks before death and 2–3 months before death. The scale ranged from 1 (totally unimportant) to 5 (very important). As the importance of each treatment aim

was rated separately for each time period, multiple aims were possible within the same period.

Palliative care

GPs recorded whether they had personally provided palliative care. To capture all care considered to be of a palliative nature for this diverse patient group, GPs self-defined 'palliative care'. GPs were also asked whether the patient had received care from any other palliative care service (palliative care consultant, hospital palliative care unit (PCU), nursing home PCU, hospice or 'other') in the last 3 months of life.

Discussion of end-of-life topics and ACP

GPs were asked whether they had ever discussed 10 end-of-life topics (see Table 3 for list) with the patient. In addition, GPs were asked about their knowledge of, and discussion with the patient about, preferred place of death, medical end-of-life treatment preferences and surrogate decision-maker appointment.

Data analysis

The personal and care characteristics of patients who died from cancer, organ failure and old-age/dementia were assessed using descriptive statistics. Differences between groups were assessed using Pearson's chi-square or Kruskal–Wallis tests. Treatment aims were dichotomised: 'important' and 'very important' (collectively referred to as 'important') were combined and separated from other responses. A new variable 'palliative care only important treatment aim' was created, indicating whether palliation was the only aim considered important for the patient at a given time interval.

Multivariate logistic regression was performed with generalised linear mixed models (GLMM) to analyse the association between patient group and binary outcome measures. Multi-level analyses accounted for the clustering of patient data by GP. For each separate GLMM analysis, age, sex, longest place of residence, place of death and dementia status were held constant. A variance component covariance structure was assumed and robust covariances specified. Analysis was carried out in SPSS20.

RESULTS

During the study, a maximum of 42 GP practices (employing up to 63 GPs) in any given year, providing GP services to 0.8% of the Dutch population (16,600,000³⁵), participated, and GP turnover was low.^{36,37}

GPs recorded a total of 1491 deaths. Of these, 688 patients were under their GP's care in the last year of life and died non-suddenly from cancer ($n = 453$), organ failure ($n = 162$) or old-age/dementia ($n = 73$) (Figure 1). The characteristics of these patient groups are shown in Table 1.

[TABLE 1]

Treatment aims

The proportion of patients receiving palliative treatments increased, whereas curative and life-prolonging treatments decreased closer to death for all patient groups. For organ failure patients, palliative treatments were less common, whereas life-prolonging and curative treatments were more common, at each time interval compared with other patient groups (Table 2, Figure 2). Two to three months before

death, cancer patients more commonly received curative (21%) and life-prolonging care (28%) than old-age/dementia patients (13% and 9% respectively). One week before death, however, the treatment aims of cancer and old-age/dementia patients were remarkably similar: 89% of cancer and 86% of old-age/dementia patients received palliative treatments, whereas 4% and 6%, respectively, received curative treatments (Table 2, Figure 2). Controlling for differences in patient characteristics between groups (age, sex, longest place of residence, place of death and dementia status), 2–3 months before death, the odds of receiving palliative care were significantly lower for organ failure compared with cancer patients. Two to four weeks before death, the odds of receiving palliative, or only palliative, treatments were significantly lower for organ failure and old-age/dementia patients compared with cancer patients (Table 2). In the week before death, the odds of receiving curative treatment were significantly higher for organ failure patients compared with cancer patients, whereas the odds of receiving palliative treatment were significantly lower for old-age/dementia patients compared with cancer patients, but comparable between organ failure and cancer patients (Table 2). The odds of receiving only treatments aimed at palliation in the last week of life were, however, significantly lower for organ failure and old-age/dementia patients than cancer patients (Table 2).

[TABLE 2]

[FIGURE 2]

Palliative care

More cancer patients (81%) received palliative care (either from their GP or another palliative care service) than old-age/dementia (68%) and organ failure (47%) patients. Controlling for patient characteristics, the odds of receiving palliative care were significantly lower for organ failure and old-age/dementia patients than cancer patients (Table 2). Because most palliative care was GP-provided, results were similar when solely examining GP palliative care provision: more cancer patients received palliative care from their GP (75%) than old-age/dementia (64%) and organ failure (38%) patients. Controlling for patient characteristics, the odds of receiving GP palliative care were significantly lower for organ failure and old-age/dementia patients than cancer patients (Table 2). Around one-quarter (26%) of cancer, 11% of organ failure and 10% of old-age/dementia patients received care from other palliative care services (such as a palliative care consultant, hospital PCU, nursing home PCU, hospice or 'other'). Controlling for patient characteristics, the odds of accessing such a palliative care service were significantly lower for organ failure than cancer patients; differences between cancer and old-age/dementia patients were not significant (Table 2).

Discussion of end-of-life topics and ACP

The prevalence of discussion of each end-of-life topic was highest for cancer, then organ failure and old-age/dementia patients. 'Physical complaints' were frequently discussed (with 92% of cancer, 77% of organ failure and 61% of old-age/dementia patients), whereas 'spiritual and existential problems' were infrequently discussed (with 46% of cancer, 27% of organ failure and 25% of old-age/dementia patients) (Figure 3, Table 3). The odds of discussing each topic (except 'primary diagnosis' and 'spiritual/existential problems') were significantly lower for organ failure and

old-age/dementia patients compared with cancer patients (Table 3). GPs were more frequently aware of cancer patients' preferred place of death, end-of-life treatment preferences and surrogate decision-makers, followed by organ failure and old-age/dementia patients (Table 3). Controlling for patient characteristics, the odds of the GP knowing the patient's preferred place of death were significantly lower for an organ failure patient and an old-age/dementia patient compared with a cancer patient (Table 3). Furthermore, the odds of the GP knowing the patient's end-of-life treatment preferences were significantly lower for an old-age/dementia patient compared with a cancer patient. The odds of appointing a surrogate decision-maker were also significantly lower for an old-age/dementia patient compared with a cancer patient (Table 3).

[FIGURE 3]

[TABLE 3]

DISCUSSION

This study, the first to directly compare different aspects of GP palliative care by trajectory group, reveals less frequent palliative treatments, palliative care use, end-of-life discussions and ACP among organ failure and old-age/dementia patients than cancer patients. Comparing illness trajectory groups revealed that organ failure patients received the least palliative care, whereas old-age/dementia patients, the group most likely to lose decision-making capacity, had the least end-of-life discussions and ACP. Differences often remained after controlling for patient characteristic differences. GPs' seemingly limited recognition and discussion of the end of life for organ failure and old-age/dementia patients impedes palliative care provision; needs assessment; management of physical, psychosocial and spiritual suffering; and identification of end-of-life preferences.

The particularly infrequent provision of (GP or any other) palliative care to organ failure patients suggests that GPs have difficulty recognising that organ failure patients are at high risk of death, identifying their palliative care needs and referring them to other services. Results from a qualitative interview study of Dutch GPs³⁸ indicated that palliative care is rarely started early in the disease course for organ failure patients: GPs recognised organ failure patients' palliative care needs gradually, and late in the illness trajectory. The high prevalence of curative and life-prolonging treatments and low prevalence of palliative treatments for this group suggests that disease management is prioritised when setting treatment aims. Because organ failure patients might recover from acute episodes, life-prolonging measures may be appropriate right until death. Nonetheless, treatments with a palliative aim are also appropriate alongside optimal chronic disease management and have been recommended for kidney failure,^{39,40} heart failure⁷ and COPD.^{29,41} GPs, however, appear to find this difficult to implement. Organ failure patients may also have received more curative treatments for secondary diseases; it is not, however, possible to discern this from the data.

Although most old-age/dementia patients received palliative care from their GP (64%), end-of-life topic discussions and ACP were not common. Although GPs seemed to recognise a need for palliative care among old-age/dementia patients in the last 3 months of life, by this point, frailty or cognitive decline may prevent end-

of-life discussions and ACP. The findings raise doubts about the 'palliative care' provided for these patients: is patient-centred palliative care feasible without an understanding of patient preferences? It is imperative that ACP, which is feasible with elderly⁴² and dementia patients,⁴³ is started early to give patients an opportunity to take part in end-of-life decision-making.⁴⁴

Cancer patients had the most palliative care, palliative treatments, discussion of end-of-life topics and ACP. The relative predictability of cancer patients' decline should enable physicians to anticipate palliative care needs and initiate end-of-life conversations and ACP.²⁹ Claessen et al.³⁸ revealed, however, that the main impetus for Dutch GPs to initiate a palliative approach with cancer patients is a letter from the oncologist stating that curative options are no longer available. This highlights the difficulties GPs face combining disease management and palliative approaches even for the patient group with the most predictable illness trajectory.

As individual illness trajectories can vary widely, questions remain about the appropriateness of using population-based approaches to guide individual care.^{26,45} Expectations based on the common disease course, however, do strongly influence patient care. This care, and its underlying assumptions, deserve further attention to develop models of palliative care with an emphasis on need rather than predicted life expectancy.

Strengths and limitations

Nearly 100% of the Dutch population is registered with a GP,⁴⁶ and the Dutch Sentinel GP Network aims to be representative of the Dutch population for age, gender and population density, and covered up to 0.8% of the population. The retrospective, cross-sectional design enabled identification of patients nearing death. The retrospective nature of data collection was, however, subject to recall bias. Although this was minimised by weekly registration of deaths, GPs recalled aspects of care that may have occurred long before death (e.g. discussion of primary diagnosis).

Nursing home residents were excluded from analyses. In the Netherlands, these patients receive multidisciplinary care coordinated by the nursing home physician,⁴⁷ and a small number of Dutch nursing homes even have their own PCU.^{48,49} In contrast, nursing home residents in other countries may be cared for by their GP or have limited access to palliative care.^{47,50} Nursing home residents are characteristically disabled with chronic diseases or progressive dementia and need complex care and support.⁵¹ Therefore, the old-age/dementia group was relatively small in our study, leading to lower statistical power, with the most complex cases and older participants missing from analyses. This may have led to an overestimation of communication items and an under-estimation of palliative care for the group; this, however, would not have weakened the main findings. The trajectory groups were created from primary cause of death only, so co-morbidities were not considered.

Other limitations include absent GP characteristics, possible desirability bias and incomplete medical records. The aims of care provided in other settings (e.g. hospitals) were also open to GPs' interpretation. Furthermore, the study reports GP-defined communication; patients and physicians may differ in their perception of a 'discussion' and patients may have discussed end-of-life issues with other health, social or spiritual care professionals.

Finally, differences in end-of-life care do not necessarily imply that inequities exist. Equity in health care implies equal access to available care for equal need, equal utilisation for equal need and equal quality of care for all.⁵² This study does not examine care need. Previous research among non-cancer populations has, however, revealed high prevalence of distressing symptoms (among organ failure,^{12,13,53} frail older and dementia^{14,54} patients) and psychosocial and spiritual distress at the end of life (organ failure patients¹⁵⁻¹⁷), indicating considerable palliative care needs.

CONCLUSION

The study highlights a particular need in primary practice to integrate palliative care with optimal disease management for organ failure patients and to initiate ACP early in the chronic illness trajectory for old-age/dementia patients to enable patients to live as well as possible with progressive illness and die with dignity and comfort in line with their own preferences.

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Declaration of conflicting interests

The authors report no conflicts of interest.

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TABLES AND FIGURES

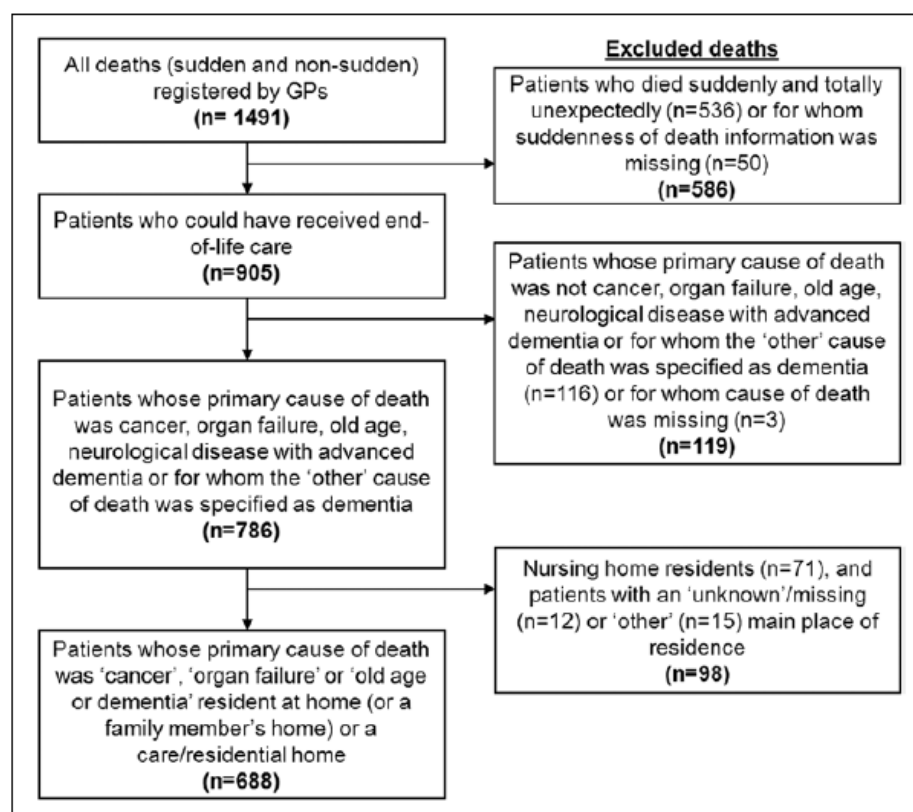


Figure 1. Selection of patients who died non-suddenly from 'cancer', 'organ failure' and 'old-age/dementia' who were under their GP's care in the last year of life.
GP: general practitioner.

Table 1. Patient characteristics, N = 688.

| Patient characteristics | | Cancer | Organ failure | Old-age/dementia | p value ^a |
|---|--|---------------|---------------|------------------|----------------------|
| | | n = 453 | n = 162 | n = 73 | |
| | | n (%) | n (%) | n (%) | |
| Age | ≤64 | 121 (27) | 10 (6) | 1 (1) | <0.001 |
| | 65–84 | 269 (59) | 71 (44) | 18 (25) | |
| | ≥85 | 63 (14) | 80 (50) | 54 (74) | |
| | Mean (SD) ^b | 71.67 (12.13) | 82.23 (10.09) | 87.70 (6.74) | |
| Sex | Male | 248 (55) | 81 (51) | 20 (28) | <0.001 |
| | Female | 201 (45) | 78 (49) | 52 (72) | |
| Longest place of residence in the last year of life | Home/with family | 428 (95) | 133 (82) | 41 (56) | <0.001 |
| | Residential or care home | 25 (6) | 29 (18) | 32 (44) | |
| Place of death | Home/with family | 278 (62) | 45 (29) | 29 (40) | <0.001 |
| | Residential or care home | 22 (5) | 27 (18) | 31 (43) | |
| | Nursing home | 29 (7) | 42 (27) | 4 (6) | |
| | Hospital | 73 (16) | 35 (23) | 5 (7) | |
| | PCU/hospice (Elsewhere n = 15) ^c | 44 (10) | 5 (3) | 3 (4) | |
| Dementia diagnosis | Severe | 4 (1) | 4 (3) | 23 (33) | <0.001 |
| | Mild | 12 (3) | 22 (14) | 10 (14) | |
| | None | 420 (96) | 130 (83) | 37 (53) | |

SD: standard deviation; PCU: palliative care unit.

Valid percentage reported. Missing values, n (%): age – 0; sex – 8 (1.2); longest place of residence – 0; place of death – 16 (2.3); and dementia diagnosis – 26 (3.8).

^aTest for differences, Pearson's chi-square.

^bTest for difference, Kruskal–Wallis (non-parametric).

^cNot included in analysis.

Table 2. Importance of treatment aims and palliative care use, N = 688.

| | n (%) | Cancer | | Organ failure | | Old-age/dementia | |
|---|----------|-----------|----------|---------------------------------|---------|-----------------------------|--|
| | | n = 453 | | n = 162 | | n = 73 | |
| | | OR (ref.) | n (%) | OR (CI) ^a | n (%) | OR (CI) ^a | |
| Treatment aims important 2–3 months before death | | | | | | | |
| Curative | 89 (21) | 1 | 41 (28) | 0.83 (0.48, 1.43) | 9 (13) | 0.55 (0.24, 1.28) | |
| Life prolonging | 119 (28) | 1 | 50 (34) | 1.44 (0.88, 2.37) | 6 (9) | 0.44 (0.13, 1.45) | |
| Palliative | 307 (70) | 1 | 83 (57) | 0.60 (0.36, 0.99)* | 49 (70) | 0.58 (0.24, 1.41) | |
| Only palliative | 221 (55) | 1 | 50 (38) | 0.59 (0.34, 1.03) | 41 (67) | 0.86 (0.36, 2.05) | |
| Treatment aims important 2–4 weeks before death | | | | | | | |
| Curative | 37 (9) | 1 | 34 (22) | 1.12 (0.64, 1.95) | 7 (10) | 1.52 (0.66, 3.54) | |
| Life prolonging | 69 (16) | 1 | 43 (29) | 1.71 (0.94, 3.09) | 2 (3) | 0.33 (0.07, 1.65) | |
| Palliative | 374 (85) | 1 | 100 (67) | 0.42 (0.26, 0.68)*** | 53 (75) | 0.37 (0.18, 0.77)** | |
| Only palliative | 321 (77) | 1 | 66 (49) | 0.41 (0.25, 0.68)*** | 47 (73) | 0.39 (0.17, 0.89)* | |
| Treatment aims important in the week before death | | | | | | | |
| Curative | 17 (4) | 1 | 27 (17) | 2.40 (1.19, 4.85)* | 4 (6) | 2.83 (0.99, 8.07) | |
| Life prolonging | 36 (8) | 1 | 23 (15) | 1.26 (0.58, 2.73) | 1 (1) | 0.80 (0.29, 2.21) | |
| Palliative | 398 (89) | 1 | 121 (77) | 0.54 (0.29, 1.00 ^b) | 62 (86) | 0.38 (0.16, 0.92)* | |
| Only palliative | 372 (88) | 1 | 98 (70) | 0.49 (0.27, 0.87)* | 57 (86) | 0.35 (0.14, 0.86)* | |
| Palliative care received from the GP or another palliative care service | 355 (81) | 1 | 68 (47) | 0.29 (0.17, 0.49)*** | 47 (68) | 0.25 (0.11, 0.56)*** | |
| Palliative care received from the GP | 331 (75) | 1 | 59 (38) | 0.28 (0.17, 0.47)*** | 45 (64) | 0.31 (0.15, 0.63)*** | |
| Involvement of other palliative care service ^c | 110 (26) | 1 | 15 (11) | 0.37 (0.15, 0.91)* | 7 (10) | 0.43 (0.15, 1.25) | |

OR: odds ratio; CI: confidence interval; GP: general practitioner.

Valid and unadjusted percentage reported. Missing values, n (%): treatment aims 2–3 months before death – curative, 41 (6), life prolonging, 43 (6.3), palliative, 35 (5.1), palliative only, 91 (13.2); treatment aims 2–4 weeks before death – curative, 34 (4.9), life prolonging, 38 (5.5), palliative, 27 (3.9), palliative only, 75 (10.9); treatment aims in the week before death – curative, 27 (3.9), life prolonging, 28 (4.1), palliative, 13 (1.9), palliative only, 58 (8.4); palliative care received from the GP or another palliative care service – 36 (5.2); palliative care received from the GP – 17 (2.5); and involvement of other palliative care service – 58 (8.4).

^aMultivariate logistic regressions performed using generalised linear mixed models. Fixed effects included illness trajectory group (OR and CI shown), age, sex, longest place of residence, place of death and dementia status.

^bless than 1.00 at 3 decimal places.

^cPalliative care services available in the Netherlands: hospice care, palliative care consultation, palliative care unit (based in a hospital, nursing home or residential home) and other (but only included if it is a palliative care service).

*p < .05; **p < .01; ***p < .001.

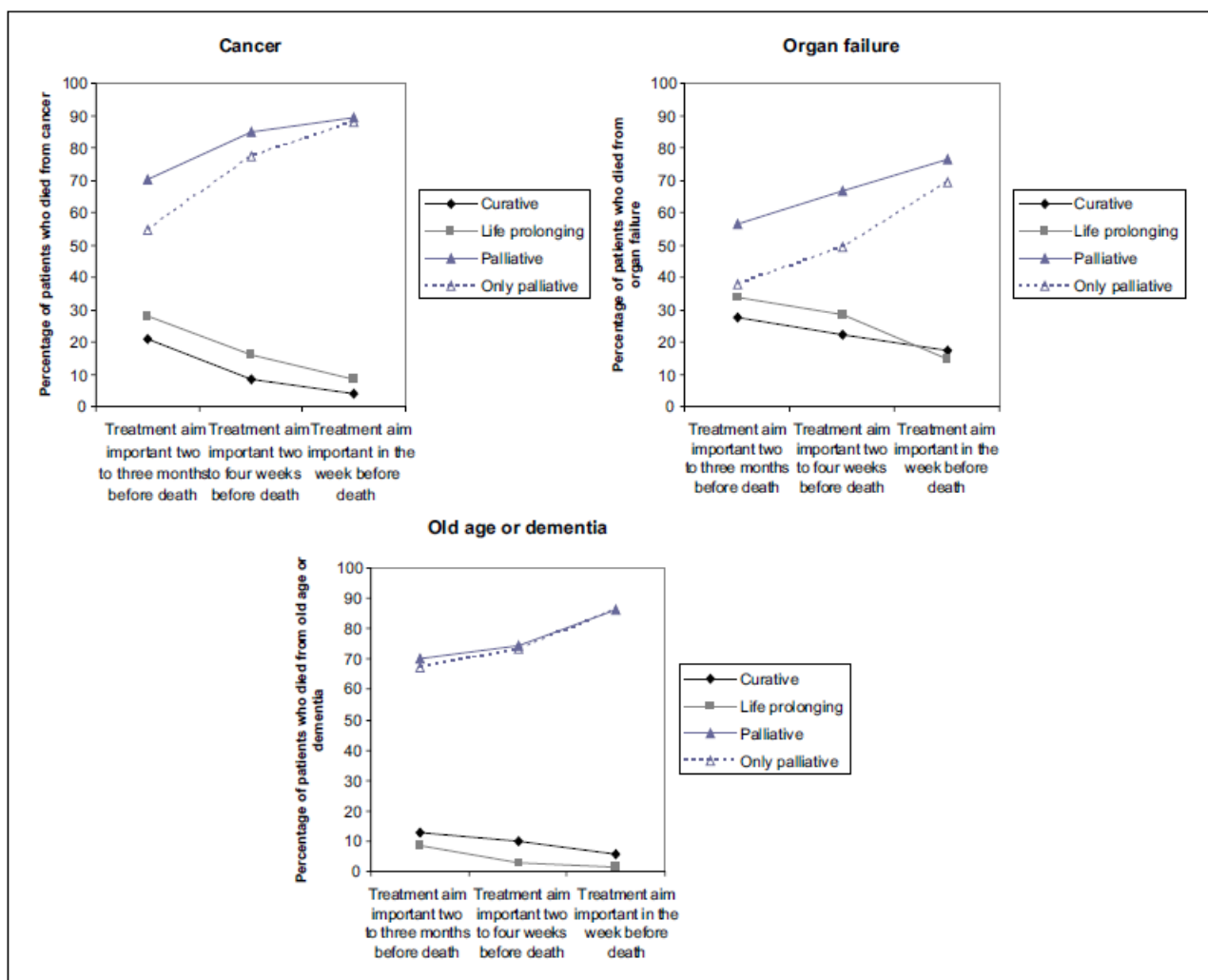


Figure 2. Treatment aims important at three time periods before death, N = 688.

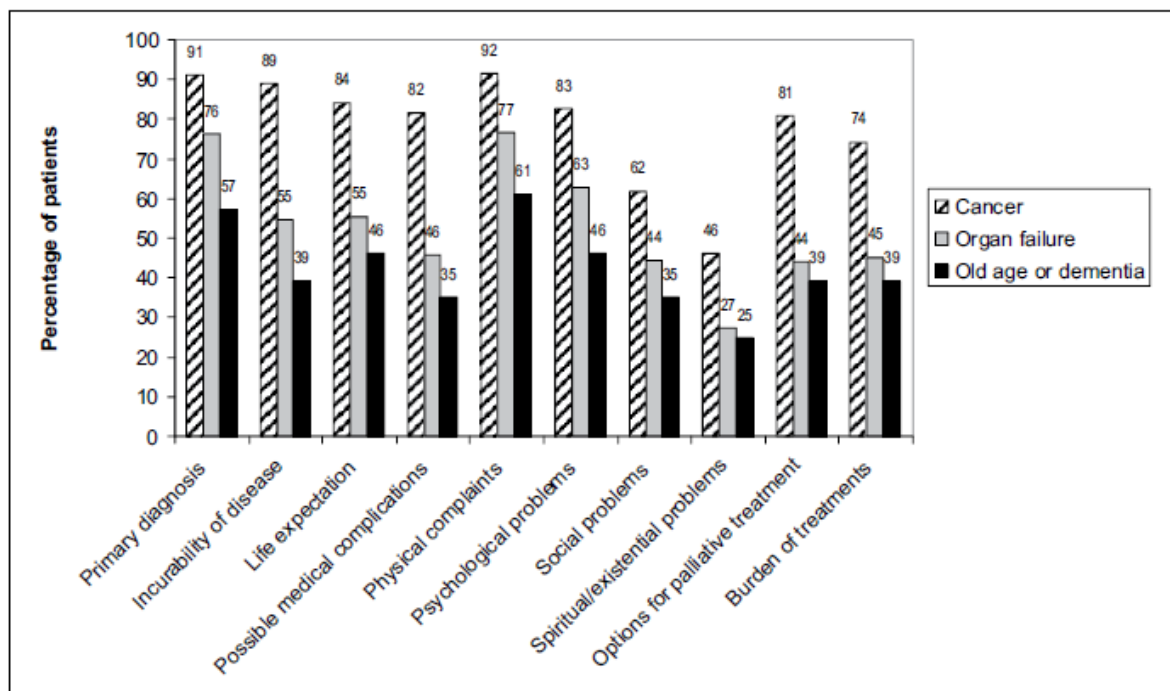


Figure 3. Prevalence of GP-patient discussion of end-of-life topics.
 GP: general practitioner.

Table 3. Patient–GP communication and advance care planning, N = 688.

| | n (%) | Cancer | | Organ failure | | Old-age/dementia |
|---|----------|-----------|----------|----------------------|---------|----------------------|
| | | n = 453 | | n = 162 | | n = 73 |
| | | OR (ref.) | n (%) | OR (CI) ^a | n (%) | OR (CI) ^a |
| End-of-life topics discussed | | | | | | |
| Primary diagnosis | 411 (91) | 1 | 121 (76) | 0.72 (0.41, 1.26) | 41 (57) | 0.23 (0.09, 0.59)** |
| Incurability of disease | 401 (89) | 1 | 87 (55) | 0.30 (0.18, 0.48)*** | 28 (39) | 0.12 (0.05, 0.29)*** |
| Life expectation | 379 (84) | 1 | 88 (55) | 0.41 (0.26, 0.64)*** | 33 (46) | 0.19 (0.08, 0.43)*** |
| Possible medical complications | 367 (82) | 1 | 72 (46) | 0.30 (0.18, 0.52)*** | 25 (35) | 0.26 (0.13, 0.51)*** |
| Physical complaints | 413 (92) | 1 | 122 (77) | 0.40 (0.21, 0.73)** | 44 (61) | 0.22 (0.10, 0.53)*** |
| Psychological problems | 373 (83) | 1 | 99 (63) | 0.50 (0.31, 0.81)** | 33 (46) | 0.23 (0.12, 0.45)*** |
| Social problems | 278 (62) | 1 | 70 (44) | 0.63 (0.41, 0.98)** | 25 (35) | 0.44 (0.22, 0.88)** |
| Spiritual/existential problems | 208 (46) | 1 | 43 (27) | 0.70 (0.40, 1.23) | 18 (25) | 0.52 (0.25, 1.08) |
| Options for palliative treatment | 365 (81) | 1 | 70 (44) | 0.34 (0.21, 0.57)*** | 28 (39) | 0.17 (0.08, 0.36)*** |
| Burden of treatments | 333 (74) | 1 | 71 (45) | 0.42 (0.26, 0.66)*** | 28 (39) | 0.36 (0.18, 0.70)** |
| Advance care planning | | | | | | |
| Preferred place of death known | 331 (74) | 1 | 76 (48) | 0.54 (0.32, 0.90)* | 43 (59) | 0.32 (0.15, 0.70)** |
| End-of-life treatment preferences known | 271 (61) | 1 | 70 (44) | 0.71 (0.40, 1.25) | 28 (38) | 0.44 (0.20, 0.96)** |
| Surrogate decision-maker appointed | 159 (36) | 1 | 42 (26) | 0.83 (0.49, 1.39) | 13 (18) | 0.42 (0.20, 0.89)** |

GP: general practitioner; OR: odds ratio; CI: confidence interval.

Valid and unadjusted percentage reported. Missing values, n (%): primary diagnosis – 6 (0.9); incurability of disease – 6 (0.9); life expectation – 7 (1.0); possible medical complications – 8 (1.2); physical complaints – 6 (0.9); psychological problems – 7 (1.0); social problems – 7 (1.0); spiritual/existential problems – 7 (1.0); options for palliative treatment – 6 (0.9); burden of treatments – 8 (1.2); preferred place of death known – 7 (1.0); end-of-life treatment preference known – 7 (1.0); surrogate decision-maker appointed – 9 (1.3).

^aMultivariate logistic regressions performed using generalised linear mixed models. Fixed effects included illness trajectory group (OR and CI shown), age, sex, longest place of residence, place of death and dementia status.

*p < .05; **p < .01; ***p < .001.