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Original Study

Effects of an Integrated Palliative Care Pathway: More Proactive GPs, Well Timed, and Less Acute Care: A Clustered, Partially Controlled Before-After Study

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ABSTRACT

Objectives: This study presents the design of an integrated, proactive palliative care pathway covering the full care cycle and evaluates its effects using 3 types of outcomes: (1) physician-reported outcomes, (2) outcomes reported by family, and (3) (utilization of) health care outcomes.

Design: A clustered, partially controlled before-after study with a multidisciplinary integrated palliative care pathway as its main intervention.

Setting and Participants: after assessment in hospital departments of oncology, and geriatrics, and in 13 primary care facilities, terminally ill patients were proactively included into the pathway. Patients' relatives and patients' general practitioners (GPs) participated in a before/after survey and in interviews and focus groups.

Intervention: A multidisciplinary, integrated palliative care pathway encompassing (among others) early identification of the palliative phase, multidisciplinary consultation and coordination, and continuous monitoring of outcomes.

Measures: Measures included GP questionnaire: perceived quality of palliative care; questionnaires by family members: FAMCARE, QOD-LTC, EDIZ; and 3 types of health care outcomes: (1) utilization of primary care: consultations, intensive care, communication, palliative home visits, consultations and home visits during weekends and out-of-office-hours, ambulance, admission to hospital; (2) utilization of hospital care: outpatient ward consultations, day care, emergency room visits, inpatient care, (radio) diagnostics, surgical procedures, other therapeutic activities, intensive care unit activities; (3) pharmaceutical care utilization.

Results: GPs reported that palliative patients die more often at their preferred place of death, and that they now act more proactively toward palliative patients. Relatives of included, deceased patients reported clinically relevant improved quality of dying, and more timely palliative care. Patients in the pathway received more (intensive) primary care, less unexpected care during out-of-office hours, and more often received hospital care in the form of day care.

Conclusions and Implications: An integrated palliative care pathway improves a variety of clinical outcomes important to patients, their families, physicians, and the health care system. The integration of palliative care into multidisciplinary, proactive palliative care pathways, is therefore a desirable future development.

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The importance of connecting multidisciplinary palliative care services into integrated palliative care (pathways) is increasingly recognized.[1] Early palliative care pathways, such as the Liverpool Care Pathway, that was widely embraced until its decline in 2014,[2] focused on the last days of life, and the process of dying within institutions. Contemporary pathways widen their scope: first, they do not merely focus on the terminal phase, but aim for the early, proactive identification of the palliative phase including Advance Care Planning (ACP).[3] Second, besides hospitals and nursing homes, they also aim to optimize *primary* palliative care.[1,4–6] They deal however with 2 problems. First, many pathways still not cover the full care cycle (primary, hospital, and pharmaceutical care), and are "moderately integrated."[7] Second, evaluations of integrated, proactive palliative care pathways often measure 1 type of results: either patients' (surrogates') experiences,[8,9] or (documentation of) end-of-life (EoL) communication, including advance directives,[10–12] or sometimes health care utilization, and the (mis)match with patients' preferences.[10,12–15]

This paper's objective is to present the design of an integrated, proactive palliative care pathway covering the complete cycle of care at the EoL, and to evaluate its effects using 3 types of state-of-the art[16] outcomes: (1) physician-reported outcomes, (2) outcomes reported by family, and (3) (utilization of) health care outcomes.

Methods

Design

The effects of the pathway were measured from December 2015 until November 2017. The design is a clustered, partially controlled before-after study with a multidisciplinary integrated palliative care pathway as its main intervention. It is clustered in the way that we clustered the data from patients in primary care facilities that had implemented the pathway (forming an intervention group) and from patients who received care from primary care facilities who had not implemented the pathway (forming the "comparison group"). We call it "partially controlled" because although we have data from both an intervention group and from a comparison group for most variables, we did not have "control data" for variables that were measured during the assessment at intake. The assessment was only done cross-sectionally and only among patients who were included into the pathway. To limit the (administrative) burden of measurements for patients, representatives, and caregivers, we combined the controlled before-after design with cross-sectional assessment, and noncontrolled elements (postmortem questionnaires by GPs and family members; see Table 1).

Setting and Participants

In this study, we chose the general practitioner (GP) practice as a "lens" through which we evaluate the effects of the intervention. Thirteen general practices in the (direct vicinity of the) Dutch city of Sittard functioned as the clustered intervention group. Eight general practices in this area functioned as the clustered comparison group. Here, care as usual was given to palliative patients.

Patients identified by GPs or medical specialists (geriatricians and oncologists) as "palliative," using the Surprise Question,[24] the RADPAC,[25] or the SPICT[26] were asked to participate in the pathway. Furthermore, their GPs functioned as participants in the survey part of the study, that asked GPs for their experiences. Finally, family members, who had been closest to deceased included patients, were asked by the GPs to fill out questionnaires after the death of the patients (see Table 1 for more details).

GPs in the control practices not only delivered "care as usual," but also filled out questionnaires about patients who died during the intervention period, and handed out questionnaires to the family member of a deceased patient, who was closest to the patient. Later, also data were collected on health care utilization by deceased patients who received care from these "control" GP practices.

Both in the intervention as in the control practices, GPs took the initiative for the data collection via questionnaires. Data on health care utilization was collected by the researchers (see Table 1 for more details).

The Intervention: Design of the Integrated Palliative Care Pathway

The pathway that had been developed by a multidisciplinary team[27] roughly consists of 8 crucial elements: (1) early and proactive identification of the palliative phase, (2) assessment of needs of patients at intake encompassing all domains of palliative care: physical, social, practical and spiritual care, (3) a weekly multidisciplinary meeting, (4) a medication review, (5) a timely conversation about EoL wishes and needs (shared decision making, resulting into a multidisciplinary proactive care plan, (6) good coordination and communication between intra- and extramural health care professionals, covering the entire care cycle, (7) a postmortem interview with the informal caregiver(s), and (8) continuous monitoring of achieved outcomes (eg, quality of death and dying). A more extensive flowchart of the care pathway is available in the supplementary materials.

- Early and proactive identification. The surprise question: "Would I be surprised if this patient was to die in the next 12 months?" is used to identify patients who are at a high risk to die within 1 year.[24] If the answer to this question is "no," the GP or medical specialist is aware of the fact that this patient might be palliative and will try to include the patient into the pathway. In addition, other (more medically oriented) identification tools are used such as the RADboud indicators for PAlliative Care Needs (RADPAC) indicators and the (Supportive and Palliative Care Indicators Tool (SPICT). The RADPAC helps to identify palliative patients with chronic obstructive pulmonary disease (COPD), congestive heart failure (CHF), and malignancy.[25] SPICT is used to help us to identify people at risk of deteriorating and dying with 1 or multiple advanced illnesses for holistic, palliative care needs assessment and care planning.[26]
- The assessment. Approximately 1 week after inclusion into the pathway, an assessment of the patient is performed by the GP or the Medical Specialist, consisting of several components. During a face-to-face conversation with the patient, the following validated scales are "scored":
    - ○ The Distress Thermometer[28]: This questionnaire includes both a Distress Thermometer (DT) and a Problem List (PL). The DT questionnaire measures the levels of distress and emotional burden the patient has experienced during the last week. Questions are answered on a thermometer (range 0–10). The PL questionnaire is a more plane questionnaire (yes/no questions) that is used as a tool for problem inventory on several domains (practical, family/social, emotional, religion/spiritual, and physical).

Table 1
Outcomes and How They Were Measured

Outcome Measures and How Data Were Retrieved	Questionnaire/Scale	Details About Scale/Data
0) Assessment at intake of patients Data collected in 13 intervention-practices, and 8 comparison-practices. No pre-intervention (t=0) measurement.	Hospital Anxiety and Depression Scale (HADS):	Measures symptoms of anxiety or depression on a 0–21 scale. A 8–10 score requests awareness; 11 or higher presumes the presence of a certain degree of anxiety or depression[17,18]
	Lastmeter	Measures on a 0–10 scale, the need for physical, psychological, social, and spiritual care in palliative patients[19]
	EDIZ	Measures the experienced burden among informal caregivers on a 0–9 scale, where 0–3 means little pressure; 4–6 moderate pressure; 7–9 severe[20]
1) Questionnaire among GPs, within 2 weeks after death of a patient Data collected in 13 intervention-practices, and in 8 comparison-practices. No pre-intervention (t=0) measurement.	Palliatieve Thuiszorg (PaTz):	Measures the perceived quality of the (organization) of the palliative care, and the (preferred) place of death[6]
2) Questionnaire among family members of deceased patients within 6 weeks after death Data collected in 13 intervention-practices, and in 8 comparison-practices. No pre-intervention (t=0) measurement.	FAMCARE	Asks family members about experienced quality of care through the patients' eyes[21,22]
	QOD-LTC	Asks family members of the deceased patient to reflect upon the quality of, and the wellbeing during the process of dying[23]
	EDIZ	Measures the experienced burden among informal caregivers on a 0–9 scale, where 0–3 means little pressure; 4–6 moderate pressure; 7–9 severe pressure[20]
3) Administrative data about health care utilization Data (health care activities during patients' last 6 months of life) manually retrieved from the 13 'intervention - general practices'. Data extraction form was used. Sampling: 1) patients who had been included into the pathway, and died during the intervention period (t=1). 2) randomly selected number of patients from these practices, who had died before implementation (t=0). Procedure repeated for a comparable number of patients in the 8 comparison practices.	From patient records in general practices	Activities that we expected to occur *more often* in intervention practices: normal consultations; long consultations; consultations by telephone; intensive care; communication; palliative home visits and consultations; Activities that we expected to occur *less often* in intervention practices: consultations and home visits during weekends and out-of-office-hours; ambulance; admission to hospital.
Hospital's DRG-information-system (DIS) data. Sampling: patients from the 13 intervention GP practices, who died during (t=1), or 6 months before start of intervention period (t=0), and used any hospital care during last 6 months of life. This was repeated for an approximately equal number of patients from the 8 comparison GP practices.	From patient records in the Hospital:	Activities that we expected to occur more often in patients from intervention practices: outpatient ward consultations; day care. Activities that we expected to occur *less often* in patients from intervention practices: ER visits; inpatient care, (radio) diagnostics; surgical procedures; other therapeutical activities; ICU activities.
Data from the Pharmaceutical Information System of one of the Pharmacists, who could select patients in the system, from both the 13 intervention GP practices, and from the 8 comparison GP practices. Sampling: Patients from intervention GP practices who died during the intervention period. An approximately equal number of patients from the comparison-practices, who also died during this period was randomly selected. Medication that was prescribed during the last 6 months of the lives of both patient groups was analyzed.	From pharmacists in the region (by ATC-code)	Medication that we expected to be prescribed *more* during the last 3 months of life: opioids (NO2); laxatives (A06); hypnotics/anti-psychotics/sedatives (N05); antiemetics (A04); corticosteroids (H02), and during the last 2 weeks of life: drugs for obstructive airway diseases (R03); Diuretics (C03). Medication that we expected to be prescribed *less often*, *or not at all* during the last 3 months of life: statins (C10); antihypertensives (C02); antithrombotics (B01), and during the last 2 weeks of life: drugs used in diabetes (A10).

- The LASTmeter[19]: a questionnaire that measures, on a 0 to 10 scale, the need for physical, psychological, social, and spiritual care in palliative patients.
- EDIZ[20]: The "Ervaren Druk door Informele Zorg" – "Experienced pressure through informal care" questionnaire measures the pressure experienced due to informal care by the main informal caregiver. The EDIZ questionnaire asks the main informal caregiver to value several statements on a 5-point scale. Total scores range on a 0 to 9 scale, where 0 to 3 means little pressure; 4 to 6 moderate pressure; 7 to 9 severe pressure.
- HADS[17,18]: The Hospital Anxiety and Depression Scale questionnaire measures symptoms of anxiety or depression on a 0 to 21 scale. An 8 to 10 score requests awareness; 11 or higher presumes the presence of a certain degree of anxiety or depression.
- CAM[29]: The Confusion Assessment Method questionnaire is a tool to screen for delirium. It is part of the assessment that is discussed with the patient directly after inclusion as well and is answered by the caregiver focusing on the situation of the patient at the moment the assessment is discussed. The CAM questionnaires includes 2 parts. Part 1 is an assessment instrument that screens for overall cognitive impairment. Part 2 includes only those features that were found to have the greatest ability to distinguish delirium or reversible confusion from other types of cognitive impairment.

Based on the answers given, scores are automatically calculated. The last part of the assessment consists of several questions that need to be answered by the main practitioner about the situation of the patient and the knowledge and insight the patient is having into his situation. Patients are also asked about the 3 most important values, wishes and needs for the last phase of life.

- The weekly multidisciplinary meetings (MDO) are an important proactive component of the care pathway. With input from the GP or medical specialist and the assessment, this team (eg, GP, geriatrician, oncologist, pharmacist, spiritual caretakers) maps wishes and potential problems the patient might experience covering the 4 domains of palliative care. Besides, this multidisciplinary team is available for consultation during the entire palliative phase.
- The medication review consist of the several steps. First, the pharmacist plans a conversation with the patient (medical review) to discuss the patient's medication use. Then the pharmacist performs a pharmaceutical analysis; the pharmacist critically reviews the patients' medication use, asking the question whether medication can be added to comfort the patient, and what medication could be stopped because it is not necessarily needed (anymore). After the review, the pharmacist will consult with the GP or the Medical Specialist.
- Timely conversation about EoL wishes and care plan. After the assessment and MDO the GP or the Medical Specialist informs the patient and his family about the MDO discussion and makes an inventory of their needs, whishes, values, and desires. This results into a shared multidisciplinary care plan.
- Good coordination and communication between intra- and extramural health care workers, patient, and family covering the entire care cycle. In the care path we have appointed a chain director who is in charge of the organization of the whole care path. Moreover there are 3 coordinators from different specialties: oncology, geriatrics, and 1 from the GP site, managing the patient flow within the care path. Each patient is appointed to a care coordinator who is available for questioning, discussing and adjusting the care plan.
- Postmortem interview with the informal caregiver(s). Six weeks after a relative died who was included in the care path a postmortem interview is planned in which questions will be asked about burdensome symptoms and treatment of these symptoms, end of life communication, quality of care in this phase, the place where the relative died and if this was according to his/her wishes and why not when this is the case. Also the grieving process of the relative is discussed and his or her burden in end of the life.
- Continuous monitoring of achieved outcomes (eg, quality of dying). Outcomes are measured and closely monitored continuously during the whole process. The section "measures," which follows, shows what outcomes are measured and monitored.

Measures

We wanted our study to give a broad overview of the pathway's possible effects, covering most of the outcome-fields that were recently described as a standard set of "outcomes that define successful ACP."[16] Besides some cross-sectionally measured variables at assessment (HADS,[17,18] Lastmeter,[19] EDIZ[20]), the outcomes we measured encompassed (1) *physician outcomes*: perceived quality of palliative care[6]; (2) *patient/family outcomes*: FAMCARE,[21,22] QOD-LTC,[23] EDIZ[20]; and (3) *health care utilization* in primary, hospital, and pharmaceutical care.

Data Sources

We used 6 types of data (sources). Data for the assessment were collected (1) at the intake of patients into the pathway. Data on physician outcomes were measured (2) via GPs, who filled out questionnaires within 2 weeks after the death of a patient. Patient/family outcomes were measured through (3) questionnaires filled out by family members of deceased patients, within 6 weeks after their death. Data on health care utilization was based on (4) electronic patient records in general practices; (5) administrative data on health care activities and procedures within the hospital; (6) pharmaceutical data from the involved pharmacists.

Statistical Methods

We used IBM Statistics SPSS v25 for statistical analyses. We performed descriptive statistics for the total sample of included patients, and for family members who filled out questionnaires. Differences in answers to questionnaires, given by GPs from intervention-practices, and from control-practices were tested for statistical significance. A Fisher Exact test was used because of the small sample size with very skewed distributed outcomes, and therefore the expected numbers in the cells of the cross table could be less than 5.The same test was used to test for statistically significant differences between the answers to the FAMCARE questions about experienced quality of palliative care, as given by family members of deceased patients within and outside the palliative care pathway. We used a *t*-test to test for differences between the answers of family members in the intervention, and in the comparison group to the EDIZ, and the QOD-LTC scales. A *t*-test was appropriate here because these all scales were normally distributed. For the health care utilization in both primary and secondary care, we computed a Rate Ratio (RR) between the average number of (types of) health care activities per patient during the last 6 months of life of patients who died *before* the intervention period ($t = 0$), and *during* the intervention period ($t = 1$). We performed a repeated measures Poisson regression analysis to test for the differences in RRs (rate T1/rate T0) between patients who were included into the pathway (intervention group) and patients who were not included into the pathway (comparison group). We added 95% confidence intervals (CI) for this rate of RR. For pharmacological care we used Fisher exact test to test the differences in percentages of deceased patients in the intervention and the comparison group, who used or did not use certain types of medication. A P value $< .05$ was considered to be statistically significant, based on 2-sided testing.

Results

Sample Characteristics at Intake

A total of 99 patients were included into the integrated palliative care pathway: 44% men and 56% women; 59% of the patients died while being included in the palliative pathway, with a median time of 58.5 days in the pathway. Table 2 gives general descriptives for the group. The average age was 74 (SD 13.95). Most patients in the pathway were diagnosed with cancer (37%), followed by CHF (11%). At intake, the average LAST score, that measures on a 0 to 10 scale the need for physical, psychological, social, and spiritual care in palliative patients was 5.19 (SD 2.79). The Depression score was 4.13 (SD 5.53); whereas the Anxiety score was 2.29 (SD 3.25); both scores are relatively low, because anxiety or depression are scored on a 0 to 21 scale, with an 8 to 10 score requesting awareness, and a score 11 or higher presuming the presence of a certain degree of anxiety or depression.

GP's experiences and reported quality of care

GPs in the intervention practices completed and returned 37 (63%) of the 59 questionnaires. In the control practices, 71 (97%) of the 73 questionnaires were completed and returned. Table 3 shows that, based on GPs' reporting, more patients *died at home* or in near-home settings in practices that participated in the care pathway (97.3%) than

Table 2
Characteristics of the Sample (Intervention Group)*N=99

	n (%)	Mean	SD
Age		77	14
Sex			
Female	55 (56)		
Died Dec 2015 – Nov 2017?			
Yes	59 (60)		
No	40 (40)		
LAST score at intake	77	5.19	2.79
Score Anxiety scale at intake	99	2.29	3.25
Score Depression scale at intake	99	4.13	5.53
Score EDIZ intake	99	3.35	2.92
Diagnosis			
COPD	4 (4)		
Congestive heart failure	11 (11)		
Cancer	37 (37)		
Kidney failure	4 (4)		
Neurology	4 (4)		
Dementia	6 (6)		
Liver disease	1 (1)		
Missing	32 (32)		

*Data in Table 2 were gathered during an assessment at the intake of patients who were included in the pathway. These data were gathered cross-sectionally, and only among patients in the intervention group (not in the primary care facilities whose patients functioned as a comparison group). It was only under this condition that the medical professionals, as well as the ethical review board agreed on this part of data collection.

in the control practices (77.5%) (*P* = .006). GPs in the pathway also seem to *act more proactively*, given the fact that 73.0% of the GPs in the care pathway were aware of the nearing death more than 3 months before death versus 52.1% of the GPs in the control practices (*P* = .04). GPs in the pathway also initiated palliative care more often ≥3 months before death (54.1% vs. 28.17%, *P* = .011). This proactive attitude is underpinned by GPs' responses to statements 2, 3, and 4 (see Table 3) about timely and anticipatory palliative treatment. GPs in the pathway state significantly more often that they acted proactively ("needs and desires had been timely assessed"; "palliative care was given in time"; "acted sufficiently proactive"). Higher percentages, but not statistically significant were reported on other statements: "dying process went well"; "patient was in control in care process"; "mentioning EoL early caused tensions".

Patients' representatives' experiences and reported quality of care

GPs handed 29 questionnaires to representatives of the 59 deceased patients in the pathway (49.2%). Of these, 9 questionnaires (31.0%) were completed and returned. In the comparison group, 59 questionnaires were handed to representatives of the 73 deceased patients (80.1%), of which 30 (50.8%) were completed and returned. Against the background of this very low number of completed questionnaires, it seems that the quality of dying is slightly higher in the care pathway; especially for the domains *"preparational tasks"* (patient prepared for dying) and *"closure"* (holistic approach), although not statistically significant. On the other hand, the experienced pressure of representatives seems higher in the care pathway, although not statistically significant. Besides, the experienced pressure after death of the patient is considerably higher than at the time of inclusion into the pathway (6.00 vs. 3.35; see Table 2). Furthermore, representatives of patients who died in the pathway were statistically significantly more satisfied with the timeliness of treatment of symptoms than representatives of those who died outside the care pathway.

Health care utilization

We studied the utilization of *primary care* during the last 6 months of life of 97 patients who received care in primary care facilities that belonged to the "intervention group"; 47 (48.5%) of these patients had already died during the 12 months before the implementation of the pathway (iT = 0), 50 patients (51.5%) died during the 12 months after the implementation, and had been included into the pathway (iT,=,1). We also studied primary health care utilization during the last 6 months of life of a comparison group of 48 patients outside the intervention practices: 31 of them had died before the introduction of the pathway in the intervention practices (cT=0); 17 of them died after the pathway had been implemented in the intervention practices (cT=1). Table 4 shows the average number (SD) of activities per cluster for each group. It also shows the rate ratio for T=1/T=0, where an RR below 1 indicates a reduction in health care utilization after the implementation of the intervention and an RR larger than 1 an increase in health care utilization. We also divided the RRs in order to see whether the effect in the intervention group is (statistical significantly *P* ≤ .005) larger (RR<1) than in the comparison group. Patients who received *primary care* in the intervention practices (both in the baseline as well in T-1) received more activities per cluster and more intensive (eg, more long home visits instead of normal consultations) primary care during their last 6 months of life than patients who received care in primary care practices that formed the comparison group. However, the use of "normal consultations" (rate of RR 0.39 95% CI 0.26–0.66), and "acute out-of-hour consultations" (rate of RR 0.36; 95% CI 0.17–0.74) decreases statistical significantly sharper after the introduction of the palliative care pathway in the intervention practices than in the control practices. At the same time, there is a statistically significantly sharper increase of the use of the activity

Table 3
Results of Postmortem GP Questionnaire, Based on PaTz-list* Q8

Questions:	Care Pathway (n = 37)	Comparison Group (n = 71)	*P*-Value (Fisher)
What was the actual place of death? (nearly[†]) at home	36 (97.3)	55 (77.5)	**.006**
How long before death did you take into account the death of this patient? > 3 months	27 (73.0)	37 (52.1)	**.040**
How long before death did you start palliative care? > 3 months	20 (54.1)	20 (28.2)	**.011**
Statements:			
1. "Patient's dying process was good"	29 (78.4)	54 (76.0)	.648
1. "Patient's needs and desires were timely investigated"	35 (94.6)	56 (78.9)	**.030**
1. "Palliative care was timely given"	34 (91.9)	55 (77.5)	**.042**
1. "I acted sufficiently proactive and anticipating"	36 (97.3)	56 (78.9)	**.005**
1. "Patient was in control about the process of care"	32 (86.5)	55 (77.5)	.219
1. "Discussing the nearing death proactive caused tension for me"	6 (16.2)	9 (12.7)	.570

*Sample sizes in various subgroups varied depending on response rates, attrition (including death), and loss to follow-up.

[†] Nursing home, home care, hospice, palliative unit.

Table 4

Health Care Utilization in Primary and Secondary Care Before and After the Implementation of the Pathway in Intervention and Comparison Group[*]

Moment of measuring (number)	Palliative Care Pathway (Intervention Group) (N = 97)		RR Intervention T1/T0	Comparison Group (N = 48)		RR Comparison T1/T0	RR Intervention vs. RR Comparison (*P*-value)	95%-BI Rate RR Intervention vs. RR Comparison
	iT0 (n=47)	iT1 (n=50)		cT0 (n=31)	cT1 (N=17)			
Primary care utilization								
Consultations	13.49 (10.83)	5.68 (4.63)	0.42	5.22 (3.33)	5.65 (4.36)	1.08	**0.39 (0.001)**†	0.23–0.66
Consultations long	0.68 (2.39)	0.70 (1.42)	1.03	0.71 (1.44)	0.29 (0.98)	0.41	2.48 (0.384)	0.32–19.17
Consultations phone	15.27 (12.19)	12.54 (12.10)	0.82	11.48 (7.39)	11.23 (7.66)	0.98	0.84 (0.508)	0.50–1.41
Home visits	6.94 (8.77)	5.54 (8.80)	0.80	4.16 (5.82)	6.82 (8.02)	1.64	0.49(0.125)	0.19–1.22
Home visits long	1.34 (2.49)	2.34 (3.18)	1.75	0.90 (2.02)	0.00 (0.00)	-	-	-
Intensive (home) consultations	0.00 (0.00)	11.78 (12.05)	-	0.00 (0.00)	0.00 (0.00)	-	-	-
Communication	3.94 (5.77)	19.94 (13.83)	5.07	2.58 (4.26)	5.41 (6.16)	2.10	**2.42 (0.055)**†	0.98–5.94
Palliative (home) consultations	0.02 (0.14)	0.30 (0.76)	14.1	0.00 (0.00)	0.21 (0.69)	-	-	-
Contacts out of office hours	2.91 (3.38)	1.78 (2.14)	0.61	2.00 (2.37)	3.41 (2.69)	1.71	**0.36 (0.005)** †	0.17–0.74
Moment of measuring (number)	Pall Care Pathway (Intervention group) (N= 78)		RR Intervention T1/T0	Comparison Group (N= 39)		RR Comparison T1/T0	Rate RR Intervention vs. RR Comparison (P-value)	95%-BI Rate RR Intervention vs. RR Comparison
	iT0 (n=41)	iT1 (n=37)		cT0 (n=24)	cT1 (N=15)			
Hospital care utilization								
# Hospital admissions	1.78 (2.07)	2.18 (5.75)	1.22	1.48 (2.35)	0.76 (1.35)	0.63	1.92 (0.239)	0.65–5.72
# ER visits	2.24 (1.99)	1.59 (1.52)	0.71	1.42 (1.47)	0.93 (1.03)	0.66	1.08 (0.851)	0.49–2.37
# Outpatient ward visits	8.63 (6.28)	8.54 (6.34)	0.99	7.6 (6.08)	4.80 (4.06)	0.63	1.57 (0.089)	0.85–2.89
# Treatments day care	0.78 (2.07)	1.00 (2.41)	1.28	1.54 (3.13)	0.33 (0.49)	0.22	**5.93 (0.024)**†	1.27–27.69
# Clinical treatments	12.76 (14.83)	9.57 (16.24)	0.75	9.21 (14.44)	6.13 (8.33)	0.67	1.13 (0.834)	0.37–3.42
# Diagnostics	3.51 (3.22)	3.03 (3.45)	0.86	3.16 (3.03)	2.73 (4.08)	0.86	1.00 (0.997)	0.39–2.55
# Surgical procedures	0.49 (0.81)	0.54 (1.88)	1.11	0.29 (0.55)	0.20 (0.56)	0.69	1.62 (0.634)	0.22–11.64
# Other therapeutical treatments	2.97 (3.88)	4.51 (6.36)	1.52	3.00 (4.87)	1.73 (3.19)	0.58	2.63 (0.131)	0.75–9.20
# Radio diagnostics	6.46 (4.99)	6.00 (5.28)	0.93	4.75 (3.66)	4.13 (3.64)	0.87	1.07 (0.843)	0.56–2.02

[*] Sample sizes in various subgroups varied depending on response rates, attrition (including death), and loss to follow-up.

“communication” (rate of RR 0.39; 95% CI 0.26–0.66), and a (though not statistically significant) increase of the activities “long home visits,” “intensive home visits,” and “palliative home visits” in the intervention practices compared with the control practices.

Hospital care utilization during the last 6 months of life of 78 patients who belonged to primary care practices that (later) implemented the palliative care pathway, was as follows. From the 41 patients who formed the baseline (iT = 0), 37 died in the period after implementation (iT = 1). In the comparison group (39 patients who received hospital care during the last 6 months of their lives, and who belonged to primary care facilities that did not implement the care pathway), 24 patients died before the introduction of the pathway in the intervention practices (cT = 0), whereas 15 of them died after the pathway had been implemented in the intervention practices (cT = 1).

Furthermore, patients from primary care practices that implemented the palliative care pathway had an overall higher use of *hospital* care (both at baseline T = 0, as well as after the intervention T = 1) than patients from practices in the comparison group. If a decrease in hospital care utilization is seen after the introduction of the pathway, this is also the case for patients in the control practices. Only the *increase* in day-care in the intervention group vs. the *decrease* in day-care in the comparison group is a statistically significant difference.

We also analyzed the *use of medication* of 53 (90%) of the 59 patients, who died after they had been included into the pathway. For 11 types of medication, the expected and desired decrease or increase of prescription was analyzed. We found that for all types of medication for which we expected such as a higher prevalence in the intervention group, the prevalence was indeed higher. There was, however, only 1 statistically significant difference: the antiemetics. Four types of medication were expected to have a lower prevalence in the intervention group. This was only true for the statins, whereas the diabetics showed an even higher prevalence in the intervention group (see Supplementary Table).

Discussion

This study investigated 3 groups of possible effects of the implementation of an integrated, multidisciplinary palliative care pathway: GPs’ experiences, experiences and satisfaction of relatives of patients, and health care utilization (primary care, hospital care, and medication).

First, GPs reported not only that palliative patients die more often at home (their preferred place of death), but also that they now act more proactively toward palliative patients. We consider this to be the result of the assessment at intake, where needs, desires, and possibilities of care at the EoL are extensively assessed. This is also supported by earlier evaluations of interventions that prioritized the understanding of patients’ preferences for place of death and that supported patients to achieve their wishes.[30] Also, the more proactive attitude of GPs is seen in other studies, where the proactive assessment and palliative treatment were set as priorities.[31–33]

Second, relatives of deceased patients who were included into the pathway reported improved quality of dying (although not statistically significant) and more timely palliative care. Similar results have been reported elsewhere as a result of early identification and assessment of the palliative patient, and is thus strongly underpinned by current literature.[10,12,13,34,35]

Third, we found mixed results for the pathway’s effect on health care utilization. Our results are in line with what could be expected of a palliative care pathway in which GPs play an important role in the early detection of the palliative phase and the thorough assessment of needs and desires of patients and their relatives. These contacts require more (frequent), and intense GP time to listen carefully and to plan care in advance. The current body of literature on proactive palliative care and health care utilization focuses on hospital care utilization. Many studies report the utilization of less (acute) hospital care at the EoL after the implementation of (integrated) pathways with early initiation of palliative care.[15,22,36,37] Our results, however, do not show a statistically significant decrease of hospital admissions, ER visits, and diagnostic, surgical, and other therapeutic activities in the hospital for patients in the pathway. This is most likely because more severe (already terminally) ill patients were included into the pathway compared with the clustered control practices. However, because no (clinical) assessment was done for patients who died in control practices, no data are available to test this hypothesis. Besides, baseline hospital care utilization by patients from intervention-general practices was already higher compared with hospital care utilization by patients in control practices. Finally, our findings regarding medication prescriptions (more comforting medication was provided to patients who were included into the pathway) are underpinned by other studies that also found an increase in prescribed symptom-specific medication and a reduction in medication prescribed for comorbid disease, if appropriate palliative care was given.[38]

A first strength of this study is the broad spectrum of outcome variables. Moreover, they cover most of the outcome-fields that were recently described as the golden standard: "outcomes that define successful ACP."[16] Because palliative care is more than just ACP (which is an important, but only 1 part of palliative care), our set of outcomes also cover other important fields, such as support, self-management, and goal attainment. In its broadness of outcomes our study mimics other literature that holds plea for an expansive set of measures in the evaluation of palliative care.[39]

Second, we were able to follow the implementation of the pathway for 2 full years, providing us the opportunity to study the pathway for a reasonable period of time after start-up problems had been overcome.

The *first* limitation is the design of the study. Because we were not allowed to randomize practices and patients, there was only limited control of the inclusion of practices and patients: a task that was exclusively performed by physicians. This might have caused the relatively low number of inclusions (99 patients during the evaluation period of 2 years), as well as the relatively low number of completed questionnaires, especially by family members. This very low response rate, and the conversations we had about this with GPs, seems to indicate that it was too burdensome for GPs to ask family members of deceased patients to fill out a questionnaire within 2 weeks after death. The same goes for the family members who did receive a questionnaire: only 9 of the 29 family members managed to complete this task during the period of loss and grief. Moreover, the higher response rates in the comparison group indicate that GPs and family members in the intervention group experienced the spreading, respectively filling out of questionnaires even more problematic than those in the comparison group.

Second, because we (as researchers) were given only limited space for data collection, some data, that would have provided more insights into the effects of the pathway, are currently lacking. For example, no data are available on sample characteristics of the comparison group; no data are available that characterize the GP practices, and also there are no data on the health care trajectories (and outcomes) of those who did not choose to participate into the pathway. We suggest future studies to be aware of such limitations and discuss research prerequisites extensively in advance with health care workers who implement the intervention.

Third, patients themselves were not involved in the evaluation study. Physicians judged that this would be too burdensome for palliative patients. We think it is good thing that physicians protect the interests of their patients; however, we believe that careful patient involvement in palliative care research is possible and fruitful, which is also supported by the literature.[40]

Fourth, one could wonder why there is no skewing in the distribution of the outcomes. Many of the measures used have a ceiling effect and there are social expectations that bias the reporting toward the positive. We recommend that future studies take this into account.

Conclusion and Implications

The integration of palliative care into multidisciplinary, proactive palliative care pathways is a desirable future development with multiple advantages for patients and their relatives, as well as physicians. More research is needed of course, with the involvement of patients themselves and larger samples, but our findings, supported by other literature, underpins the further development of integrated palliative care pathways.

Ethical Approval

Ethical approval for this study was given by the institutional review board of 1 of the 8 University Medical Centers in the Netherlands (file number: 2015–2096), based on the protocol, the questionnaires, and other materials, such as information for GPs, patients, and their family members.

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Supplementary Data

Supplementary data related to this article can be found online at https://doi.org/10.1016/j.jamda.2020.10.025.

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