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Palliative Care Case Managers in Primary Care: A Descriptive Study of Referrals in Relation to Treatment Aims

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ABSTRACT

Background: Three important elements of the World Health Organization (WHO) definition of palliative care are: 1) it includes patients who may have cure or life prolongation as treatment aims besides palliative care; 2) it is not exclusively for cancer patients; and 3) it includes attention to the medical, psychological, social, and spiritual needs of the patients and their families. Case managers (nurses with expertise in palliative care) may assist generalist primary care providers in delivery of good palliative care.

Objectives: This study investigates the referral of patients to case managers in primary care with regard to the three elements mentioned: diagnosis, treatment aims, and needs as reflected in reasons given for referral.

Methods: In this cross-sectional survey in primary care among case managers and referrers to case management, case managers completed questionnaires for 687 patients; referrers completed 448 (65%).

Results: Most patients referred have a combination of treatment aims (69%). Life expectancy and functional status of patients are lower for those with a treatment aim of palliation. Almost all (96%) of those referred are cancer

patients. A need for psychosocial support is frequently given as a reason for referral (66%) regardless of treatment aim.

Conclusions: Referrals to case managers reflect two of three elements of the WHO definition. Mainly, patients are referred for support complementary to medical care, and relatively early in their disease trajectory. However, most of those referred are cancer patients. Thus, to fully reflect the definition, broadening the scope to reach other patient groups is important.

INTRODUCTION

ACCORDING TO THE WORLD HEALTH ORGANIZATION (WHO) definition of palliative care, the aim is to improve the quality of life of patients and their families facing the problems associated with life-threatening illness.¹ This definition has three key elements. First, the definition is not restricted to the terminal stages of disease, but the much broader term of “life-threatening illness” is used. There is an increasing awareness among palliative care experts that there is often no strict boundary between the curative and palliative phase, but rather a shift of emphasis in treatment goals; curative, life prolonging, and/or palliative treatments can co-exist² and may complement each other according to the needs of the patient. Second, palliative care is not only provided to terminally ill cancer patients, but also to those with other life-threatening diseases and conditions such as chronic obstructive pulmonary disease (COPD), heart failure, and age-related frailty. Third, the definition states that palliative care is aimed at improving the quality of life. This may include physical well-being; psychological, existential, and social factors; and the system surrounding the patient (family, friends). These key elements are not always reflected in actual care provision; palliative care still mostly involves cancer patients in the terminal stages of disease and is often provided with a strong focus on physical symptoms.³⁻⁶

In the Netherlands, palliative care for home-dwelling patients is mainly provided by generalist care providers, that is, general practitioners (GPs) and home care professionals.⁷ Palliative care case managers, nurses with expertise in palliative care, were introduced to assist GPs and district nurses (DNs) in the delivery of primary palliative care and patients and carers in obtaining the care they prefer.⁸ Case management is a heterogeneous concept of care that consists of assessment, planning, implementing, coordinating, monitoring, and evaluating the options and services required to meet the client's health and service needs.⁹ The patient advocacy model¹⁰ of case management used in the Netherlands¹¹ offers multidimensional coordination of care aimed at quality of care and is distinguished from the interrogative model that is more focused on clinical decision making and emphasises cost-effectiveness.

The question arises of whether the introduction of case management initiatives can facilitate provision of care according to the WHO definition of palliative care. The answer depends, among other things, on which patients are referred to case managers and if so at what stage of their disease trajectory. Therefore, this study examines the referral of patients to palliative care case management with the following research questions:

1. To what extent do patients referred to a case manager have curative or life-prolonging treatment aims or palliative treatment aims or a combination of these? And how does this relate to their life expectancy and functional status?
2. What are the patient and care characteristics of those referred to a case manager (including diagnosis), and are there differences in patients with differing treatment aims with regard to patient and care characteristics?
3. What are the reasons patients are referred to a case manager (including how these relate to different domains of palliative care), and are there differences in reasons for referral of patients with differing treatment aims?

METHODS

Setting

In the Netherlands, there are 16.6 million inhabitants. Each year, about 77,000 people die of nonacute illnesses and 31% of these die at home.¹² GPs see on average three to five palliative care patients a year.¹³ DNs and home support workers who are confronted with end-of-life care see on average 10 palliative care patients a year.¹⁴ Less than 1% of GPs and of DNs have had advanced education to specialize in palliative care.¹⁵ There is a wide range of short courses available on palliative care.

Case management initiatives were identified in a nationwide survey⁸ and 13 of the 20 initiatives identified participated in the current study. Case management is provided by a nurse case manager; he or she visits the patient and their carers at home to discuss options for support. The case manager monitors whether care is delivered according to the patient's and carers' wishes. If patients and their carers wish, informational and psychosocial support is provided by the case manager. The case managers do not provide hands-on nursing care but can be part of a team that does. In the Netherlands, there are case management initiatives for patients with dementia,¹⁶ but such initiatives are not included in this study.

Procedure

For this study, when a patient was referred for case management the case manager filled in a questionnaire and sent a questionnaire to the person who referred the patient. The two questionnaires used the same unique identification number. If a patient was entered into the study but no questionnaire from the person referring had been returned, the researcher asked the case manager to send a reminder. Data were gathered from March 2011 until the end of February 2013. Initiatives with many patients could include every second person in the study instead of every patient, for time management reasons. This study is exempt from approval from an ethics committee.

Questionnaires

The questionnaire filled in by the case manager at the start of case management contained structured questions regarding characteristics of the patient, such as demographic data and questions on diagnosis, prognosis, and treatment aims.

Treatment aims were measured with the question, “How important are the following treatment aims for the patient at this moment?” for cure, life prolongation, and palliation; answers ranged on a 5-point Likert scale from “not important” (score=1) to “very important” (score=5).

The questionnaire for the person who referred to a case manager had three sections: 1) characteristics of the person who referred; 2) characteristics of patient care in the 30 days before referral; and 3) reasons for referral to and expectations from the case manager. All but one were structured questions; the question on reason for referral was open.

The questionnaires were drafted to study implementation and support provided by the case manager. The questionnaires were piloted on a small sample of respondents to ascertain that the questions were clearly formulated and relevant.

Data analysis

Patients were grouped according to the treatment aims at the time of referral using data from the questionnaire from the case manager. For cure and life prolongation a combined score was composed in which the highest score on either cure or life-prolongation prevailed. Three groups were defined:

1. Patients with cure/life prolongation as the main treatment aim (score 3 to 5) and for whom palliative care was not a treatment aim (score 1 or 2),
2. Patients with both cure/life prolongation and palliative care as treatment aim (both scores ranging from 3 to 5),
3. Patients with palliation as the main treatment aim (score 3 to 5) and for whom cure/life prolongation was not a treatment aim (score 1 or 2).

Patients who had either a missing score on the importance of palliation ($n=67$) or importance of cure/life prolongation ($n=35$) and those who scored low (score of 1 or 2) on all treatment aims ($n=3$) were excluded (see Fig. 1 for a flow chart of exclusion criteria). For the visualization of these three groups in Table 1, the “trajectory model” of Lynn and Adamson is used.²

[FIGURE 1] [TABLE 1]

The open question on reasons for referral to a case manager was categorized by the first author (AvdP). A sample of answers was also categorized by the second author (BO-P). Categorization was then discussed between AvdP and BO-P. This resulted in “fine-tuning” of categorization choices.

For answering the research question on the relationship between the treatment aims and life expectancy and functional status, data were reported and tested on all three groups with differing treatment aims. For the second and third question, comparisons were made between two groups: “early” (patients with a curative aim and a combination of treatment aims) versus “late” (palliative care treatment aim only).

Fisher's exact test was calculated for categorical variables except functional status, where Monte Carlo simulation was used, and the student's *t* test was performed for the one continuous variable (age). To allow for multiple testing, a Bonferroni adjusted *p* value was chosen for significance (calculated by dividing the value of 0.05 by the number of tests used to answer the research question).

RESULTS

Response

A total of 687 patients were included in this study and 448 (65.2%) questionnaires from referrers were received. Questionnaires from referrers were mostly from professionals ($n=421$; 94.0%) with a minority from nonprofessionals ($n=27$; 6.0%). Professionals were mostly nurses (81.1%); a further 9.4% were GPs and the remaining 9.5% were other professionals (e.g., social workers or medical specialists). Work setting of the professional was hospital for 62.3% and primary care for 37.7%. Nonprofessional referrers were children of the patient (36.0%), the partner of the patient (24.0%), the patient him or herself (20.0%), or others (e.g., friends or relatives) (20%).

Patient and care characteristics of patients referred to a case manager

The life expectancy and functional status of patients referred to a case manager can be seen in Table 1.

Patients with a palliative treatment aim were older (mean age 71 years, standard deviation [SD] 12 years, $p<0.000$) and more often male (61%, $p=0.002$) than those with combined treatment aims (mean age 65 years, SD 13 years, male 47%). There are no other differences between the two groups with different treatment aims (see Table 2).

[TABLE 2]

Reasons for referral to a case manager

The question, "Why did you refer this patient for case management?" was answered by 440 (98.2%) referrers. However, 33 answers gave no insight into the reason for requesting case management (e.g., "We refer every patient," or "terminal cancer"). When disregarding these, 407 (92.5%) answers remained. Most referrers gave answers that could be allocated to one (46.9%) or two (40.0%) categories, but a single open answer was allocated to up to five categories. In Table 3 examples of open answers are given.

[TABLE 3]

All categories were mentioned in both groups, with psychosocial support being the largest category in both groups; there were no differences between the two groups in treatment aims (see Table 4).

[TABLE 4]

DISCUSSION

The majority of patients referred to a case manager have a combination of treatment aims and are almost exclusively cancer patients. Reasons for referral cover all aspects of palliative care but psychosocial aspects are mentioned most. Patients with treatment focussing on palliative care are more often male and older than those with a combination of treatment aims. There are no differences in reason for referral for patients with a sole palliative care treatment aim compared with patients with combined treatment aims.

Strengths and limitations of this study

This article is part of a prospective study on case managers and information was gathered at the moment of referral; recall bias therefore will be low. However, of the 20 case management initiatives identified in the Netherlands, 7 did not participate in the current study. Also, this study is conducted within the Dutch health care system where almost all patients are enrolled with a GP, one of the main providers of primary palliative care. Referral to and expectations of case management may be different in health care systems with other characteristics. Furthermore, we do not know why patients are not referred to a case manager as we asked only about those who are referred. Further research is needed to investigate whether case managers actually meets expectations.

Case management is delivered to patients with a combination of treatment aims

A majority of patients referred to a case manager are receiving a combination of curative/life prolonging and palliative care. The data on life expectancy and functional status suggest that prognosis and functional status govern the balance between treatment aims; both life expectancy and functional status were highest in the group with a sole curative treatment aim, lower in the group with combined aims, and lowest in the group with a sole palliative treatment aim. In our study, most patients were relatively able to function in everyday life, had an estimated life expectancy of more than 3 months, and had curative and/or life-prolonging treatment aims along with palliative care. This suggests that patients are referred to case managers relatively early in their disease trajectory, when discussions on the balance of treatment aims are still relevant and they are still able to engage in discussions on preferred care, including shifts from focus on curative or life-prolonging to palliative treatment aims.

Case management is delivered to cancer patients

Those referred to case managers are almost exclusively cancer patients. The high proportion of cancer patients in palliative care services is common; in a recent comparison between Canada, the United States, Germany, and England, only the United States had a percentage of 41% patients in hospice and palliative care with a cancer diagnosis, the other countries had percentages of 90% or higher.⁴ This can be

explained by the relatively predictable illness trajectory of cancer. However, we did not find a difference in diagnosis between the earlier and later referred group, whereas one would expect more late referrals with a diagnosis other than cancer given the more unpredictable trajectory. Another cause might be that palliative care originated in cancer care; this may mean that it is easier to establish a working relationship with oncology departments in hospitals so palliative care services receive more referrals of oncology patients. To broaden the scope of palliative care case managers, incorporation of medical and nursing knowledge with regard to noncancer patients, for instance by involving nurses with other specializations (such as heart disease), is needed. Use of tools developed for administrative identification of patients with palliative care needs, specifically including noncancer patients,^{17,18} may provide an aid. For a more general change of culture among care providers, impact of interventions such as Gold Standards Framework¹⁹ and PaTz²⁰ on knowledge and skills of palliative care provision to noncancer patients should be assessed.

Psychosocial support is mentioned most as reason for referral to case managers

Whereas all domains of palliative care are mentioned by referrers, the need for psychosocial support is mentioned most. In a study on nurse specialists in palliative care (MacMillan nurses), emotional support was the most common reason for referral.²¹ Psychosocial support transcends disease-specific knowledge. It might be that the patient's need for psychosocial support may be a more suitable pointer for the start of palliative care than life expectancy or diagnosis, because life expectancy is difficult to assess and diagnosis bears the risk of a focus on cancer patients. Existential or spiritual aspects are rarely mentioned explicitly, but acceptance of disease and/or dying is mentioned for 10% of patients. This resonates with a generally found lack of attention to spiritual issues in palliative care.²² On the other hand, it would be unlikely that the need for existential/spiritual care was mentioned as a main reason for referral to a case manager, as referral to an existential/spiritual counsellor would be the more obvious path in that situation.

It appears that patients are referred when the referrer expects that care may be complex or time-consuming, either because the situation at home is considered inadequate or because the referrer considers that the patient and carer may benefit from some psychosocial assistance in dealing with their situation. This seems especially true for referral earlier in the palliative care trajectory for patients with combined treatment aims. This group had less contact with their GP and DN than the group with a sole palliative treatment aim (although not significant). Also, the GPs and DNs may have less time to address psychosocial issues or may find addressing them difficult.^{23,24} It remains to be seen whether case management is the best solution, or whether the GP and DN should be involved earlier.

Conclusion

Case management referral in primary palliative care fulfils two of the three relevant elements of the WHO definition of palliative care in that it attracts referrals before the terminal stage of the disease and covers all domains of palliative care, with an

emphasis on psychosocial support, making it complementary to medical care provided in the hospital and by primary care providers. However, those referred to a case manager are almost exclusively cancer patients. Future efforts to improve palliative care case management should focus on broadening the scope to include patients with diagnoses other than cancer.

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AUTHOR DISCLOSURE STATEMENT

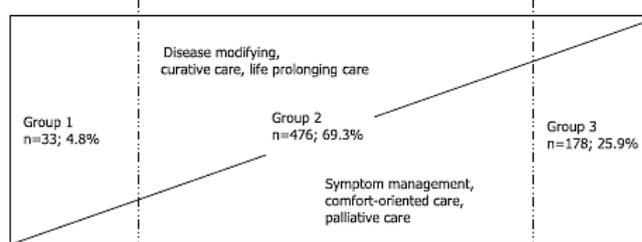
No competing financial interests exist.

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TABLE 1. LIFE EXPECTANCY AND FUNCTIONAL STATUS IN RELATION TO TREATMENT AIMS FOR PATIENTS REFERRED TO A CASE MANAGER IN PRIMARY PALLIATIVE CARE



	<i>Sole curative aim (n=33)</i> n (%)	<i>Combination of aims (n=476)</i> n (%)	<i>Sole palliative aim (n=178)</i> n (%)	P value ^a
Life expectancy of patient at start of case management				0.001
Estimation not given	16 (48.5)	240 (50.4)	60 (33.7)	
Estimation given	17 (51.5)	236 (49.6)	118 (66.3)	
Life expectancy of patient when estimated				> 0.000
< 3 months	0	39 (16.5)	58 (49.2)	
3 to 6 months	2 (11.8)	55 (23.3)	43 (36.4)	
6 months or longer	15 (88.2)	142 (60.2)	17 (14.4)	
Functional status (ECOG)	(n=33)	(n=474)	(n=177)	> 0.000
Fully functional	6 (18.2)	43 (9.1)	5 (2.8)	
Limited to small/light activities	16 (48.5)	187 (39.5)	39 (22.0)	
Bedridden < 50% of the time	8 (24.2)	101 (21.3)	36 (20.3)	
Bedridden > 50% of the time	2 (6.1)	96 (20.3)	56 (31.6)	
Fully in need of support	1 (3.0)	47 (9.9)	41 (23.2)	

^aBoldfaced numbers are significant according to Bonferroni adjusted $p < 0.017$ in Fisher's exact test (life expectancy) or Monte Carlo simulation (functional status).

ECOG, Eastern Cooperative Oncology Group.

TABLE 2. CHARACTERISTICS OF PATIENTS IN RELATION TO TREATMENT AIMS FOR PATIENTS REFERRED TO A CASE MANAGER IN PRIMARY PALLIATIVE CARE

	Total ^a (n=687) n (%)	Combination of aims (n=509) n (%)	Palliative aim only (n=178) n (%)	P value ^b
Main diagnosis				0.476
Cancer	663 (96.5)	493 (96.9)	170 (95.5)	
Other than cancer	24 (3.5)	16 (3.1)	8 (4.5)	
Type of cancer ^c				0.003
Lung	166 (25.5)	124 (25.6)	42 (25.1)	
Colon	90 (13.8)	68 (14.0)	22 (13.2)	
Breast	68 (10.4)	56 (11.5)	12 (7.2)	
Hematological/lymphatic	40 (6.1)	38 (7.8)	2 (1.2)	
Prostate	37 (5.7)	27 (5.6)	10 (6.0)	
Other	251 (38.5)	172 (35.5)	79 (47.3)	
At least one secondary diagnosis	283 (42.4)	198 (39.7)	85 (50.3)	0.019
Most common secondary diagnoses (more than 1 answer possible) ^d				
Heart diseases	89 (31.4)	60 (30.3)	29 (34.1)	0.577
Diabetes	70 (24.7)	54 (27.3)	16 (18.8)	0.176
Lung diseases	59 (20.8)	37 (18.7)	22 (25.9)	0.202
Service use of patient in 30 days before referral to case management (more than 1 answer possible) ^e				
General practitioner (GP)	298 (67.4)	204 (63.8)	94 (77.0)	0.009
Out of hours service of GP care	38 (8.6)	22 (6.9)	16 (13.1)	0.056
District nurse	86 (19.5)	58 (18.1)	28 (23.0)	0.282
Specialist (from hospital)	366 (82.8)	276 (86.2)	90 (73.8)	0.003
Social worker	46 (10.4)	41 (12.8)	5 (4.1)	0.008
Palliative care consultant or consultation team	32 (7.2)	19 (5.9)	13 (10.7)	0.101
Spiritual counsellor	23 (5.2)	17 (5.3)	6 (4.9)	1.000
Residential circumstances				0.003
With partner and children	92 (13.5)	79 (15.6)	13 (7.5)	
With partner	363 (53.4)	264 (52.2)	99 (56.9)	
With children	27 (4.0)	23 (4.5)	4 (2.3)	
Alone	171 (25.1)	126 (24.9)	45 (25.9)	
Other (e.g., living in an institution or temporarily living with family)	27 (4.0)	14 (2.8)	13 (7.5)	
Informal carers (more than 1 answer possible)				
None	5 (0.7)	3 (0.6)	2 (1.2)	0.606
Partner	415 (61.3)	316 (62.7)	99 (57.2)	0.207
Children	459 (67.8)	332 (65.9)	127 (73.4)	0.073
Other family	210 (31.0)	163 (32.3)	47 (27.2)	0.217
Other (e.g., friends, neighbors)	233 (34.4)	188 (37.3)	45 (26.0)	0.007

^aNumber of missing observations between 0 and 19.

^bNo significant values according to Bonferroni adjusted $p < 0.002$ in Fisher's exact test.

^cPercentages of types of cancer given in relation to cancer patients; $n = 663$.

^dPercentages of types of secondary diagnoses given in relation to patients with at least one secondary diagnosis; $n = 283$.

^eLower number of respondents because this question is from the questionnaire the referrers filled in (group with combined aims, $n = 320$; group with palliative aims, $n = 122$; total $n = 442$).

TABLE 3. EXAMPLES OF REASONS FOR REFERRAL TO A CASE MANAGER AS REPORTED IN AN OPEN QUESTION

Reason given for referral

Support from the general practitioner leaves something to be desired. Husband and wife communicate poorly with each other. Hopefully, the situation at home can be improved with case management. There is not much time left.

(Referral of a patient with combination of treatment aims)

The patient was admitted through the emergency department with acute stomach pains. Expected diagnosis was appendicitis or perforated cecum. During surgery an inoperable tumor was found. The patient was very shaken by this unexpected bad news. Went home without knowing “what next.” Desperation and tension were high. A lot of questions.

(Referral of a patient with sole palliative care treatment aims)

Bad prognosis. Exhaustive treatment with chemo and radiotherapy. The spouse is overburdened. The patient has a high risk of spinal cord injury, but he insisted on going home; receives probe feeding.

(Referral of a patient with combination of treatment aims)

The capacity of the patient and carer to bear this burden is insufficient. Extra support is necessary in monitoring chemotherapy. Psychosocial support.

(Referral of a patient with combination of treatment aims)

Support for the patient and family—provide information and reassurance. Timely identification of problems and proactive care (e.g., pain, tightness of the chest). It is important that the patient and family see a familiar face and have one contact person.

(Referral of a patient with combination of treatment aims)

The husband and wife did not want home care, wanted to be independent as long as possible with help from family and friends. The wife was worried about when to arrange for extra help and how to do this quickly when the situation deteriorates fast.

(Referral of a patient with sole palliative care treatment aims)

TABLE 4. REASONS FOR REFERRAL TO A CASE MANAGER IN RELATION TO TREATMENT AIMS, AS REPORTED IN AN OPEN QUESTION^a

	Total (n=407) n (%)	Combination of aims (n=297) n (%)	Palliative aim only (n=110) n (%)	P value ^b
Need for psychosocial support (at least one reason mentioned)	309 (75.9)	236 (79.5)	73 (66.4)	0.009
Support for the patient and carer	180 (44.2)	141 (47.5)	39 (35.5)	0.033
Acceptance of disease and/or dying	45 (11.1)	32 (10.8)	13 (11.8)	0.726
Living situation of patient; patient is living alone	37 (9.1)	31 (10.4)	6 (5.5)	0.173
Extra attention for carer, prevention of overburdening the carer	34 (8.4)	24 (8.1)	10 (9.1)	0.840
Living situation of the patient; partner is ill as well	15 (3.7)	11 (3.7)	4 (3.6)	1.000
Living situation of the patient; relationship problems	9 (2.2)	9 (3.0)	0	0.121
Living situation is inadequate for reasons other than above (e.g., lack of social support)	45 (11.1)	40 (13.5)	5 (4.5)	0.012
Difficulty with accepting medical or nursing care	12 (2.9)	5 (1.7)	7 (6.4)	0.020
Patient needs more time for information or support than can be provided within regular care	8 (2.0)	4 (1.3)	4 (3.6)	0.220
Need for medical/nursing knowledge (at least one reason mentioned)	142 (34.9)	104 (35.0)	38 (34.5)	1.000
Anticipating care needs	65 (16.0)	47 (15.8)	18 (16.4)	0.880
Monitoring of pharmacotherapy (e.g., oral chemotherapy or pain medication)	35 (8.6)	31 (10.4)	4 (3.6)	0.029
Specialized palliative care knowledge is needed	31 (7.6)	18 (6.1)	13 (11.8)	0.060
High symptom burden or comorbidity	27 (6.6)	21 (7.1)	6 (5.5)	0.659
Need for information and care coordination (at least one reason mentioned)	134 (32.9)	87 (29.3)	47 (42.7)	0.013
Practical information for the patient and carer	62 (15.2)	45 (15.2)	17 (15.5)	1.000
Guiding the patient to care in accordance with preferences of the patient/supporting patient in arranging care as preferred	47 (11.5)	26 (8.8)	21 (19.1)	0.005
Coordination of care	29 (7.1)	16 (5.4)	13 (11.8)	0.031
There are problems with care providers (e.g., difference of opinion between family and GP on care provision)	7 (1.7)	6 (2.0)	1 (0.9)	0.680

^aMore than one category per answer possible.

^bNo significant values according to Bonferroni adjusted $p < 0.003$ in Fisher's exact test.

GP, general practitioner.