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Effect of Home Care on the Place of Death of Advanced Cancer Patients

F. De Conno, A. Caraceni, L. Groff, C. Brunelli,[1] I. Donati,[2] M. Tamburini[1] and V. Ventafridda

Pain Therapy and Palliative Care Division, [1]Psychological Division and [2]Anesthesia and Rehanimation Division, National Cancer Institute, Via Venezian 1, 20133, Milan, Italy

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This study presents a prospective evaluation of the home care programme for patients with advanced cancer at the National Cancer Institute of Milan. Demographic, psychosocial and physical variables were evaluated. The Therapy Impact Questionnaire was used for symptom and quality of life assessment. The association of clinical and demographic variables with the place of death was investigated, considering that the aim of the home care programme is to follow up patients until death in their houses. Eighty-six per cent (86%) of patients died at home and 14% in hospitals. Multivariate analysis showed that only a higher degree of family support was associated with home death. Several changes in symptoms and quality of life items scores were seen, pain improved while physical debility and cognitive functions worsened throughout the home care duration to death. High intensity pain and dyspnoea were still present in, respectively, 23.8 and 15.3% of patients in the last week of life. Psychological distress was high at the end of life and did not seem to be affected by treatment. Home care is a feasible alternative for implementing palliative care in a selected population of patients with advanced cancer. Palliation of physical symptoms is more easily achieved than the control of psychological suffering. Family and economical issues implied by home care models should be part of the discussion in implementing palliative care for advanced cancer patients.

Key words: home care, advanced cancer, cancer pain, palliative care, quality of life, place of death
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INTRODUCTION

THE PREVALENCE of pain, other symptoms and suffering due to advanced cancer is an important clinical problem in oncology requiring appropriate evaluation and treatment. Guidelines for pain and symptom control are now available [1,2] which, if adequately implemented, should enable doctors to provide good palliative care to the majority of patients with advanced irreversible cancer [3].

Enormous national and regional differences still exist in the development of palliative care services. While in Great Britain, access to palliative care services is available in every health district [4], in Italy only a few are available and these are unevenly distributed throughout the country. Only four hospice in-patient facilities are available today for a population of 56 million. General practitioners provide primary care, but are not trained in palliative care and can make referrals to palliative care services only rarely.

Setting of care is a controversial issue in palliative care. Several models are available such as hospices, home–hospice services, palliative care specialised in-patient units. These models reflect the heterogeneity of health care providing systems, of patients' needs and cultures [5].

Most patients in Italy wish to die at home [6] and the same trend has been reported in non-Italian populations [7]. It was the idea of one of the authors (VV) that home care for terminal cancer could be a realistic approach, where no resources were allocated to palliative care or hospice programmes and where families already provided most of the care for the terminally ill and the elderly.

The home care programme of the National Cancer Institute of Milan, started in 1980, with the support of a private non-profit foundation, the Floriani Foundation of Milan (FF) and the Italian League against Cancer, Milan Section (LICTM).

Correspondence to F. De Conno.
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At that time, it was the only attempt in Italy to provide palliative care according to the hospice model to terminal cancer patients.

The aim of this study was to assess characteristics and outcomes of the NCI home care programme (HCP). A prospective evaluation of symptoms and quality of life was performed. All the patients were followed to death and the place of death (home or hospital) was used as dichotomous end-point of the analysis in an attempt to identify sociodemographic or clinical variables to predict place of death.

PATIENTS AND METHODS

Patients

All the patients referred to the NCI HCP from 1989 to 1991 were prospectively evaluated. The patients were mostly referred by the clinical divisions of the NCI or by general practitioners, and all had a proven diagnosis of cancer in advanced stage for which no further oncological treatment was advised. The criteria for admission to the HCP are the following:

- —prognosis estimated to be 2 months or less;
- —symptoms requiring a specific palliative evaluation;
- —performance status not allowing the patient to be seen in the out-patient clinic;
- —availability of some family support, identified in at least one family member living with the patient or/and willing to take active part in the patient care.

Home care intervention

A preliminary meeting with one or more family members was held in the outpatient clinic and the HCP was explained. On this occasion, part of the sociodemographic and clinical data were collected from the family and from previous medical records. The social worker evaluated the family resources and support system and planned a home visit to complete his/her interview with the patient.

The patient was seen at home by a palliative care physician (PP) and the home care nurse (HN). The PP scheduled a number of home visits with a minimum of one per week. The HN checked on the patient every day with visits or telephone calls as needed. This schedule was flexible to the needs of patients whose condition changed or deteriorated. The patient had a 12-h daytime on-call availability covering all the days of the week, holidays included.

The patient's general practitioner was always informed of the referral to the HCP, when he/she was not personally referring the patient, but his/her involvement in the HCP was seldom very active. This is due to the limited education and exposure GPs have in palliative care in Italy, and to the difficulties found in the metropolitan area of Milan in primary care in general, where GPs home interventions are much more limited than in more rural areas. The HCP includes volunteers specially trained and provided by the LICTM. Their intervention and role was planned and discussed with the patient and family at the first visit or at the time when it was felt to be useful. Volunteers did not provide professional care, but helped in generic care, company and social support. Psychologist and social worker home calls were offered on the basis of individual patient needs. The home care team met weekly to review cases and discuss specific issues.

The goal of the HCP is to keep the patient at home as long as possible, but in cases where, for different reasons, this is not possible, a hospital or hospice admission is facilitated. It is, therefore, possible to look at the number of patients who are admitted ultimately to die as 'failures' of the HCP.

Pain and symptom control were aggressively pursued following the WHO guidelines [3]. The whole service is provided at no direct cost to the patient. HCP costs are covered by a special fund from the Regional Health Governmental Agency, and by grants from the National Cancer Institute, FF and LICTM.

Instruments

The Therapy Impact Questionnaire (TIQ) was administered weekly for symptom and quality of life assessment. This questionnaire has been validated for quality of life assessment in advanced cancer patients and contains a list of symptoms, physical and psychosocial quality of life related items which are scored on a four-point categorical scale from 'none' to 'a lot' [8]. Sociodemographic data were collected by the social worker: family support, financial problems, housing conditions were assessed by the HN and by the social worker, then discussed at the weekly meeting and finally scored with an audit-like process on this occasion on a four-point scale from poor to very good on a special form [9]. A home care

Table 1. *Sociodemographic characteristics of the patient population* (n = 348)

Sex		
Male	182	52%
Female	166	48%
Age (years)		
≤61	116	33%
62–72	119	34%
>72	108	31%
Unknown	5	1%
Place of death		
Hospital/Hospice (HS)	49	14%
Home (HO)	299	86%
Marital status		
Married	235	68%
Separated/widow	62	18%
Single	39	11%
Unknown	12	3%
Education (years)		
5 or less	143	41%
5–8	41	12%
8 or more	110	32%
Unknown	54	16%
Financial conditions		
Not good	84	24%
Good	163	47%
Very good	32	9%
Unknown	69	20%
Housing conditions		
Not good	98	28%
Good	163	47%
Unknown	13	4%
Family support		
Not good	53	15%
Good	184	53%
Very good	92	26%
Unknown	19	5%

Table 2. Disease-related and homecare related variables (348 *patients*)

Primary pathology		
Lung	71	20%
Breast	58	17%
Colon rectum	38	11%
Other gastrointestinal tract	40	11%
Head and neck	35	10%
Female genitourinary tract	30	9%
Male genitourinary tract	26	7%
Others	20	6%
Unknown	16	5%
Multiple	14	4%
ECOG performance status		
1	11	3%
2	86	25%
3	121	35%
4	110	32%
Missing	20	6%
Assistance duration (weeks)		
Mean	5.7	
Q1–Q3 range	1–6	
Volunteer aid employed		
Yes	64	18%
No	283	81%
Unknown	1	<1%

Q1–Q3, first to third quartile.

Table 3. Association between the place of death and each of the sociodemographic variables (348 *patients*)

Variable name	*P* value*
Sex	0.020
Age	0.940
Marital status	0.093
Educational level	0.540
Financial conditions	0.040
Housing conditions	0.080
Family support	<0.001

*Fisher's exact test.

Table 4. Estimates of the probability of dying in the hospital according to the categories of the sociodemographic variables (348 *patients*)

Variable name	Odds ratio	95% CI
Gender		
Female	2.090	(1.12–3.90)
Male	1	
Age (years)		
≤61	1	
62–72	0.971	(0.469–2.008)
>72	0.867	(0.405–1.858)
Marital status		
Single	2.356	(1.044–5.321)
Widow/separated	1.149	(0.479–2.758)
Married	1	
Educational level		
<5 years	1.247	(0.606–2.566)
5–8 years	1.662	(0.640–4.318)
>8 years	1	
Financial conditions		
Not good	8.450	(1.079–66.280)
Good	6.150	(0.805–47.034)
Very good	1	
Housing conditions		
Not good	1.650	(0.883–3.117)
Good	1	
Family support		
Not good	9.724	(3.362–28.119)
Good	2.610	(0.962–7.082)
Very good	1	

chart was used to record therapy changes, drug consumed and any other home interventions performed.

Statistical analysis

Descriptive statistics were used to show the intensity and frequency of physical and psychosocial symptoms.

The associations between the place of death and each of the sociodemographic and clinical variables were examined using Fisher's exact test for $r \times c$ contingency tables [10]. In order to determine which of the associated variables and variable interactions were significant in explaining the place of death, a multivariate analysis was performed using log-linear models with binomial error [11]. Patients whose data were missing on any variable were not included in the analyses involving that variable. All the tests were two-tailed and $P < 0.05$ was considered significant.

In looking at the TIQ results, the Wilcoxon signed rank test was used to test for significant changes in scores. Due to the high number of tests performed, $P < 0.00156$ was considered significant in this analysis according to Bonferroni adjustment [12].

RESULTS

Descriptive clinical and sociodemographic statistics

The sociodemographic data and the diagnoses of the 348 patients seen in the HCP from 1988 to 1991 are shown in Tables 1 and 2. The relatively high number of missing data for the financial conditions and education level is explained by the delayed implementation of the social worker evaluation in the programme.

The age distribution demonstrates an elderly population (mean age 65.5 years) with the majority of patients older than 62 years. The distribution of the primary pathologies reflects the most common causes of cancer related death (lung, breast and gastrointestinal tract cancers). The duration of the assistance ranged between 1 and 6 weeks for 50% of the patients, but for a significant number of them (112 patients), this was shorter than 2 weeks. The ECOG performance status is in agreement with the advanced clinical conditions that are among the inclusion criteria for the programme.

Only 14% of the study patients died in a hospital or hospice (HS group). The causes for the final admissions were symptoms and complications requiring hospital-type evaluation and care (49%), lack of family resources to continue home care (47%) and housing conditions not compatible with the care of very ill patients (2%). Eighty-six per cent of patients died at home (HO group).

Table 5. In the first two columns the prevalence of high intensity symptoms is given at baseline evaluation and at the last assessment (last week of life) for 236 patients with at least two evaluations (>2 weeks of assistance). Only answers to the TIQ questions = 'molto' (a lot) or 'moltissimo' (very much) were considered. Possible answers: not at all; slight; a lot; very much. Columns 3 and 4 show significant changes of symptom score between the first and the last week of assistance in the same group of patients. Wilcoxon's signed rank test was used for significant changes in score

Symptom	% first week	% last week	% worse	% better	% no change	No. of total of patients	*P*
Physical items							
Pain	51.2	23.8	7.2	38.7	54.0	236	0.0001*
Anorexia	27.1	26.9	9.7	19.6	70.3	236	0.0003
Weakness	22.0	17.4	11.4	13.9	74.5	236	0.47
Constipation	10.2	8.9	7.2	8.4	84.3	236	0.72
Dyspnoea	8.5	15.3	12.7	4.2	83.0	234	0.0063
Cough	7.2	4.2	2.9	6.7	90.2	236	0.16
Sleeping problems	7.2	5.5	4.2	5.9	89.9	236	0.8
Dry mouth	6.8	9.8	8.8	4.6	86.4	235	0.61
Dysphagia	5.9	5.9	3.8	3.8	92.4	236	1
Vomiting	5.9	4.7	3.8	5.5	90.6	236	0.42
Nausea	5.5	2.5	1.6	5.0	93.2	236	0.10
Stomach ache	5.1	1.3	0.8	4.6	94.4	236	0.0195
Drowsiness	4.7	15.7	13.9	1.6	84.3	236	0.0001†
Confusion	2.5	8.0	7.6	2.1	90.2	235	0.0029
Diarrhoea	2.5	1.3	0.4	2.1	97.4	236	0.1875
Headache	1.7	0	0	1.6	98.3	236	0.12
Hiccup	1.3	0.8	0.4	0.8	98.7	236	1
Sweating	1.2	2.5	2.5	1.2	96.1	236	0.78
Itching	1.2	0.8	0.8	1.2	97.8	236	0.75
Tremors	0.8	0.8	0.4	0.4	99.1	236	1
Dizziness	0.4	0.4	0.4	0.4	99.1	236	1
Psychosocial items							
Have you:							
Been feeling ill	55.8	62.0	29.6	17.9	52.9	236	0.064
Had difficulty with work or housework	87.7	95.6	37.2	6.6	56.6	236	0.0001†
Had difficulty with usual free time activity	86.3	95.1	42.1	7.6	50.2	236	0.0001†
Required help to eat, dress, go to the toilet	59.8	88.8	56.8	4.5	38.5	236	0.0001†
Had difficulty relaxing	48.2	62.1	40.8	10.7	48.4	216‡	0.0001†
Had difficulty concentrating or paying attention	45.5	57.1	37.2	13.7	48.9	216‡	0.0001†
Felt depressed	45.3	49.7	26.9	16.5	56.4	216‡	0.25
Felt anxious or scared	36.8	41.3	25.5	19.8	54.5	216‡	0.37
Felt nervous, restless or irritable	30.9	36.6	22.5	16.9	60.5	216‡	0.0577
Felt insecure	30.9	37.1	26.1	16.4	57.4	216‡	0.0312
Had arguments with family	1.4	4.9	4.0	1.0	94.8	216‡	0.0313
Felt alone	3.6	2.0	1.0	2.5	96.4	216‡	0.31

*Improved. †Worsened. ‡20 patients were too ill to be asked.

The duration of hospital stay of the HS group ranged from 1 to 125 days (mean ± S.D., 20.3 ± 25.5, median = 14) while the home care period covered 69.7 ± 90 days (mean ± S.D., median 42 days). 32 of the patients who finally died at home were also admitted to the hospital occasionally. Duration of these intercurrent admissions ranged from 2 to 60 days (12.8 ± 13.3, mean ± S.D., median = 8), and their home care period lasted a mean of 69.5 days ± 60.3 (median = 48). Symptom evaluation and medical reasons induced hospital admission in this group in 69% of cases, family and patient's desire were considered substantial in contributing to 31% of admissions.

Place of death predictors

The association of clinical and sociodemographic variables with the place of death showed that, among the clinical variables, only drowsiness, urinary catheterisation (more frequent in the HO group) and presence of metastases (more frequent in the HS group) were associated with the place of death. However, multiple testing could have produced false positive significant results.

The sociodemographic variables showed a stronger relationship with the place of death (Table 3). When a multivariate analysis was performed, only familiar assistance showed a strong independent prognostic value on the place of death.

These results are shown in Table 4 in terms of odds-ratios, indicating the excess of the probability to die in the hospital for a category in comparison with the reference category (odds ratio = 1 if there is no difference), for example, assuming 'men' as reference category, the probability of a woman dying in hospital is more than twice as great as that of a man.

Home care programme outcomes (symptom control)

Since, in a significant group of patients, the brief duration of the assistance did not allow two evaluations, Table 5 reports

Table 6. *Palliative therapies: frequency are given for the group of patients who died at home* (299 patients)

Opioid	86%
Steroid	68%
Non-steroidal anti-inflammatory	68%
Gastroprotecting	57%
Benzodiazepines	54%
Neuroleptics	48%
Anti-emetics	33%
Diuretics	37%
Laxatives	29%
Antispasmodics	38%
Antimycotics	25%
Cardiotonics	20%
Antibiotics	14%
Radio/chemotherapy	8%
Hormonotherapy	11%
Barbiturates	8%
Antidepressants	6%
Epidural catheter	1%

data only for the group of patients for whom two evaluations were available (236). The table reports the prevalence of high intensity symptoms (scored as 'molto' = a lot or 'moltissimo' = very much) at the baseline evaluation and at the final assessment in the last week of life, and the frequency of improvement, worsening or unchanged symptoms comparing scores at the same times. Table 6 shows the types of treatments employed in the home care of the whole patients population (348).

DISCUSSION

The results of this study are to be appreciated in their specific context. The population is selected by two main factors, referral pattern, mainly families seeking help for providing better home care for patients, and by our own selection criteria, requiring the existence of some family support to implement the HCP. It should be added that, until recently, no hospice-like admission was available for advanced cancer patients in Milan. It is, therefore, not surprising that 86% of the patients died at home. Another important characteristic of this population is the short-term prognosis and, therefore, the short duration of the home care period that in 50% of cases did not exceed 6 weeks.

The most interesting result is perhaps that, although many admissions (49%) were requested for symptom control and for disease-related complications, 47% were due to family problems in the group of patients dying in hospital, and only sociodemographic variables were significantly associated with the place of death. Family support proved to be the strongest independent factor associated with home death (Table 4). This is in agreement with other studies showing that family related and socio-economical factors are best predictors of the place of death [13–15].

Home deaths are decreasing in developed countries [15–17]. At the same time, the preference for dying at home is often expressed in survey studies: 64% of interviews in a population based study in Italy [6], 53% in England [18] and 70% in Japan [19].

A recent epidemiological study performed in Genoa demonstrated that the trends of home cancer-related death rate can be influenced by offering home care services. Indeed, between 1985 and 1990, it increased from 28 to 33% in association with the development of palliative home care services for patients with advanced cancer [20].

The prevalence of distressing symptoms was not greatly different from data of other palliative care centres (Table 5), and indicates that severe uncontrolled pain had a major role in patients being referred for symptom control to our HCP (50% of all cases). Also, the impact of physical disability and symptom severity is reflected in this patient population by the high scores on the TIQ psycho-social subscales, showing that physical, psychological and cognitive domains were much more affected than social interaction and support.

Symptom control is the focus of any palliative care programme, and our data showed (Table 5) that cognitive impairment and physical disability tend to worsen approaching death [21]. Pain was the only symptom showing substantial improvement throughout the HC course to death. Poor pain management is, indeed, a frequent reason of referral to our HCP. There was, however, a significant group of patients still experiencing severe pain in their last week of life (23.8%). These data can only partially be compared with previous surveys due to difference in assessment methods, but emphasises, in agreement with other authors, the importance of pain control in palliative care [5, 22–25]. Among the other symptoms, dyspnoea showed an increasing trend and poor control, also in agreement with previous observations [23, 24, 26]. Psychosocial distress, as evaluated by the TIQ (depression, anxiety, irritability, feeling insecure), did not show significant changes from the first to the last weeks of care. It is possible that this is a simplistic method of analysis for looking at psychological variables, or that even though physical symptoms can often be relieved, psychological distress and suffering when death approaches are more difficult to treat and should, therefore, prompt more specific and specialised efforts.

It can be concluded that home care is feasible in advanced cancer patients with actively supporting families. Our experience suggests that if home care services were to be potentiated and intensified, symptom control and comfort care could be improved, and the choice of admission to hospice or specialised palliative care units could be reserved for very difficult symptoms or when family support is lacking. This does not go without important financial and social costs [27] which are faced by patients and families. Psychological coping abilities can influence choice of care setting [28] and, vice versa, setting of care can influence family members psychological reactions to the patient suffering [29].

It is a challenging issue of health care politics and of cost-effectiveness evaluation which model should be pursued for improving the care of patients dying with advanced cancer [27,30], but it is our strong feeling that home care services have a role in humanising the care of this patient population, and in providing together with other facilities such as hospices and palliative care units, a comprehensive setting of care.

The model proposed for home care has two important characteristics: it does not require sophisticated development of palliative care to be implemented; and it delivers terminal care at costs which are lower than hospital admission costs for the health care system [31], even though financial and psychological costs for families should be carefully evaluated [25].

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