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EXPERIENCES IN HOME CARE OF CANCER PATIENTS

A new approach in cancer nursing

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Abstract

As a result of mutilating operative procedures, aggressive cytotoxic chemotherapy and terminal stage of the disease, tumor patients face frequent visits to the tumor center. They are often hospitalized and thereby excluded from family and home. To enable cancer therapy and supportive care on an ambulatory basis, a team consisting of two physicians, two nurses and one psychologist was settled in our department in November 1986. The purpose of this team was to transfer several oncological treatment modalities from the hospital to the homes of the patients. Apart from organizing the patients' discharge from the hospital and coordinating treatment, the main task of the team has been to follow the patient during the course of the disease and give psycological support. In our experience the possibility of home care has clearly improved the patients' quality of life.

Key words: Cancer patients, home care, ambulatory chemotherapy, terminal care.

Cancer therapy today is characterized by highly specialized and multimodal forms of treatment. The tumor patient has to face frequent visits to the tumor center and is often hospitalized. To shorten stay in hospital and to improve quality of life of chronically ill cancer patients, an investigational project has been started with the intention of transferring special forms of treatment to the patients' homes. In November 1986 a team consisting of 2 nurses, 2 physicians and one female psychologist was set up at surgical oncology unit of the University of Heidelberg.

The mobile home-care team regards itself as a link between hospital, general practitioner, community service nurses, and patient. According to the concept, the team is supposed to give support to the general practitioner, to the community nurses and to the relatives, so that treatments which require special skill and knowledge can be carried out at home. According to the special requirements of treatment and the resources available in each individual case, the general practitioner and the medical team discuss possible practical arrangements.

The team also trains the patients and/or relatives in specific treatment modalities, which is often a prerequisite for home therapy. In this context it is important to be familiar with the patient's social surroundings. Only then can the therapeutic concept effectively improve the patient's quality of life, maintain a high standard of treatment and, possibly, reduce the costs to the Health System (1, 2).

Patients and therapy

From November 1986 to December 1987 out-patient treatment was offered to 102 patients. All except 3 patients wanted to be treated at home. The most significant reasons for preferring home treatment were that the patients needed their families and regarded a hospital stay as a burden. With the assistance of the mobile team 99 patients were treated at home after a training phase in hospital:

- 46 patients received continuous chemotherapy
- 15 received nutritional support
- 25 received care after mutilating surgical procedures and
- 13 received terminal care.

Twenty-seven of these patients received i.v. chemotherapy and 19 hepatic-artery infusions. A total of 220 chemotherapy cycles were supervised (Table 1). The chemotherapy was administered via a subcutaneously implanted port and a special portable pump (1) which al-

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lowed continuous infusion. Experience has shown that a training phase in the hospital is necessary before home treatment (2, 3). Technical difficulties, uncertainty, or confusion concerning the handling or physical side effects may occur in the beginning of the treatment and can usually be eliminated by two initial therapy cycles in the hospital.

Nine patients received enteral and 6 parenteral nutrition (Table 1). The enteral nutrition was given with nasoenteral feeding tubes or via percutaneous endoscopic gastrostomies (PEG) (4) and the parenteral nutrition via an intravenously implanted Hickman-catheter (5). As several reports have shown, nutritional therapy may not prolong life, but it can improve the quality of life in part by improving a patient's ability to tolerate the side effects of various forms of treatment (6).

Thirteen patients entered the program in the terminal stage of their disease. For the majority of these patients a tumor specific treatment was not indicated. Most of them needed intensive supportive care, as pain-control, nutrition and basic care.

The personal preferences of the patient and family must be considered. Despite all the difficulties in providing home care for terminally ill patients, most people prefer to die at home (7).

To enable home care for these patients the following presuppositions are necessary:

- the patient himself must prefer home care;
- the patient's social surroundings, as family and friends, must be well known;
- a cooperative general practitioner and community service nurses must be available;
- medical technical equipment has to get organized by the team nurses;
- psycho-social support should be given to relatives or friends who participate in the care of the terminally ill patient. This is the main task of the psychologist in the team. The psychologist should also give psychological support to the other members of the team and help them to help the patient.
- the team should have on-call duty as it is very reassuring for the patient and his family that the team is always ready to help at home (8)

The team has gained further experience by home care of 25 patients after mutilating cancer surgery, including patients who were instructed about irrigation techniques at home. Patients with secondarily healing surgical wounds have also been treated at home in collaboration with the general practitioner and community service nurses.

Table 1

	Patients n	Cycles n	Days of home treatment n
Continuous chemotherapy			
Intravenous administration	27	139	728
Intraarterial administration	19	81	385
Total	46	220	1 113
Nutritional support			
Parenteral nutrition	6		446
Enteral nutrition	9		367
Total	15		813

Table 2

Complications

	Continuous chemotherapy	Parenteral nutrition
	Incidence/days of treatment	
Paravasation	24/1113	–
Catheter thrombosis	2/1113	–
Catheter sepsis	–	3/446

Table 3

Reasons and time for in-hospital treatment

	In-hospital patients	In-hospital treatment (days)
Extension of therapy	21	397
Change of therapy	15	207
In-hospital diagnostics	11	105
Complications within the scope of the program		
Medical	5	66
Psychosocial	6	123
Total	58 (in a total of 30 patients)	898 (898/15 378=5.8%)

Acceptance and limitations of home care

In the described home care only few complications have occurred, such as short-term delays in the course of infusions or needle dislocation during chemotherapy. Catheter thromboses or catheter infections have been somewhat more frequent (Table 2). Emergency situations because of technical treatment problems have been rare and usually caused by the disease itself.

The concept of home care can certainly not be realized for all patients (Table 3). Changes or exctensions of the therapy necessitated 709 in-hospital days for 30 of our patients. Complications during home care required only 189 days in hospital including also six readmissions, because the patients' relatives could not cope with home care any longer (9).

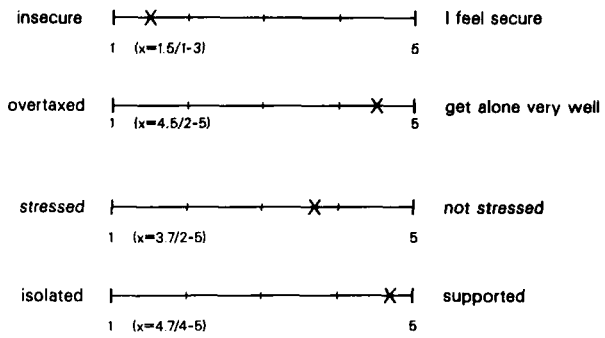

Fig. 1a. Estimation of the momentary mood by the patient on a 5-point-rating-scale.

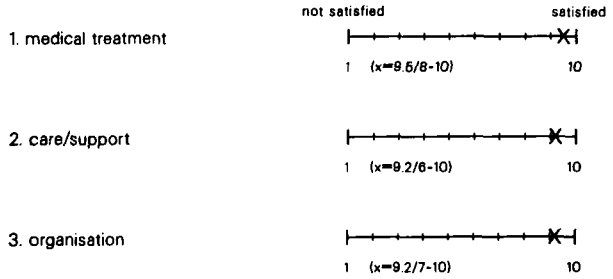

Fig. 1b. Estimation of satisfaction in medical treatment, care and organisation by patients cared for in the program on a 10-point-rating-scale.

Table 4

Judgement of 69 general practitioners concerning the mobile team

Value of the team	
Improvement in treatment and care	86%
No significant progress	6%
No answer	8%
Cooperation	
Very good	40%
Good	46%
Not good/difficult	9%
No answer	5%

The response to this form of out-patient care, which is still rather new in Germany, may generally be regarded as positive. By the impact of event scale of Horrowitz et al. (10), quality of life index of Queisser (see (11)) and self-developed questionnaires it was found that the home care obviously had a positive influence on the patients quality of life. The most significant advantages to the patients were:

- Avoidance of the burden of clinical stay 43%
- Maintenance of family life 36%
- Maintenance of occupational and recreational activities 21%

In the same investigation it was found that the patients felt the burden of the disease easier as long as they could stay at home. In spite of advancing disease, the quality of life improved, compared with in-hospital treatment (Fig. 1a+b). The activity of the mobile team was appreciated by the majority of the general practitioners and the cooperation was generally characterized as good. This was also verified by a questionnaire given to 69 general practioners with whom the team cooperated (Table 4).

Evaluation and outlook

The transfer of specific treatment modalities from the hospital to the homes of the patients is not new. There is for instance experience of dialyses (12) and parenteral nutrition at home (3). Home care have recently been made organizationally and logistically feasible by advances in the medical equipment industry (13). In cancer patients tumor specific therapy must often be replaced by supportive care which cannot be accomplished by the hitherto existing ambulatory treatment systems. Medical and psycho-social side effects of tumor disease and therapy need special attention and care. The recognition of these facts was the basis for establishing the present project.

A team of the type described can work effectively only in connection with an oncologic center and in close cooperation with the general practitioner and community service nurses. Medical or psycho-social problems can occur during home care which require readmission. General hospitals usually do not meet all requirements for palliative treatment due to lack of personnel and room. This deficiency in the treatment of cancer patients may be rectified by the organizing of hospices, specializing in the treatment and care of chronically ill cancer patients..

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