

Remaining at home to the end

QUALITY IN ADVANCED PALLIATIVE HOME CARE

In Sweden there is a developed organization for advanced palliative home care. This study shows that the family members approve the help and care from the teams. Almost everyone would choose this care-arrangement if they were confronted with the same situation again.

BACKGROUND

In Sweden as in the rest of the world, the number of hospital rooms is cut down. Studies have shown however, that most people want to stay in their own homes when serious illness strikes, if they can receive the same care they would get in a hospital. In the county of Östergötland we have developed an extensive organization for advanced home care of the terminally ill. 35 percent of our terminally ill cancer patients have been able to remain in their own homes lifetime out under the palliative home care provided by nine teams of professional helpers.

What does our Palliative home care consist of? Concisely a Doctor is in charge of a multiprofessional team, which includes nurses, around the clock emergency help, and direct access to hospital beds.

PURPOSE AND METHOD

The purpose of this Survey was to depict the quality of Palliative Home Care from the viewpoint of immediate family members of a person who had died in his own home under the program of Palliative home care. The questions asked concerned symptoms, quality of help, confidence and assurance.

There were 99 family members included in the survey. The majority of the family members who answered were women (63%) and they were either married to or a special friend of the patient. The average age of the patients was 76 years and 74 percent of them had been diagnosed as having cancer. Most of the other patients in the survey suffered from heart or lung illnesses.

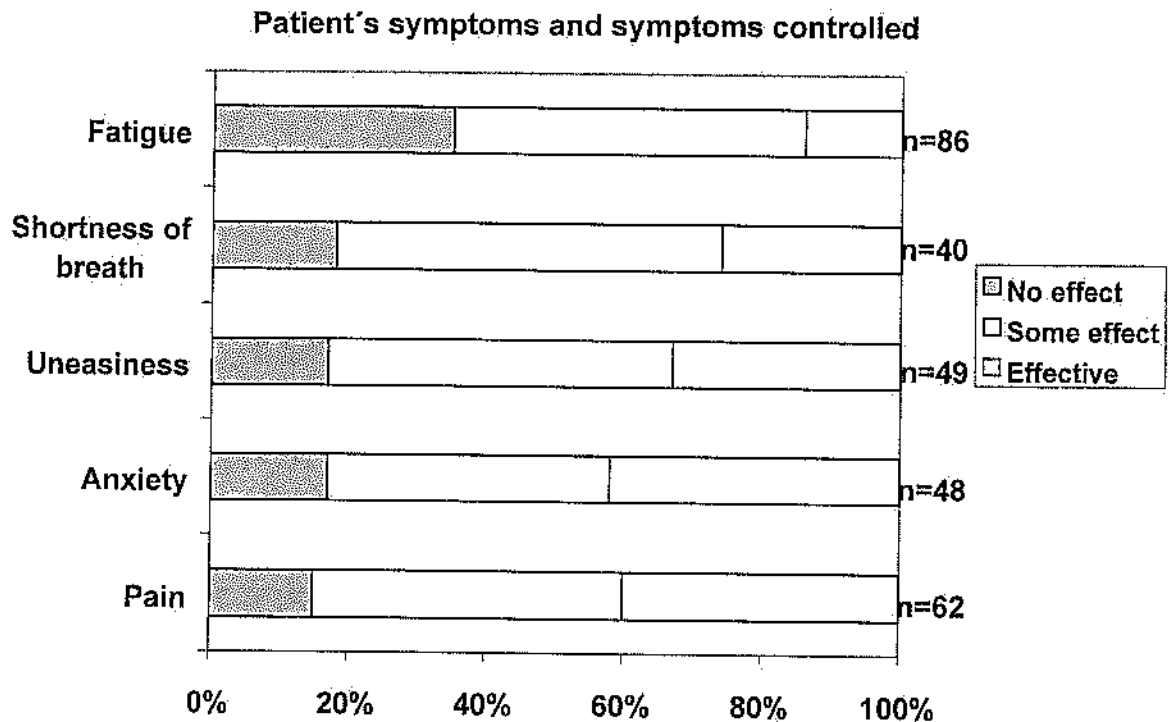
This survey covered the patients of three of the teams in the Palliative home care responsible for 100 000 inhabitants. The survey covered a 12 month period for the most part in 1999. The material was gathered consecutively as each family was contacted and asked to fill in a questionnaire – between 4 and 7 months after the death of the patient. The questionnaire consisted of two parts. The first part was 26 questions to be answered on a likert-type-questions-scale. The other part was three open-ended questions about good and bad aspects of Palliative home care and good advice to the staff to improve future service.

RESULTS

Symptoms

There were five questions regarding the symptoms of the patient and how well the symptoms were controlled. The number of patients having these symptoms is shown on the right side of the diagram. 86 of 99 family members responded that the patient experienced fatigue during the time that they had charged in the home. 62 patients suffered from different degrees of pain,

This diagram shows how the family member experienced the treatment of these symptoms regarding the patient who had the symptoms. Answers were on a scale of one to nine.



Fatigue seems here to be the biggest problem. 35 percent of the family members answered that the patient did not experience relief from the symptoms. This result is expected, as fatigue clearly belongs to the symptoms of cancer. It is still a serious result and shows this symptom is difficult to treat. The best results were achieved regarding anxiety and uneasiness. 4 of 10 answered that the patient benefited greatly from the help given.

The results were good on the questions regarding in general terms how the family experienced the care was given. 71 percent said that the treatment of the symptoms functioned well. 86 percent answered that the overall care was good.

Quality of Service Given

The family members reported on the questionnaires a high regard for the quality of the service given the patient. The questions were about staff attitude, staff available when called, did the helper come when he said he would, aids arrangements and confidence in the program offered. As much as 9 of 10 family members answered quite or very good in most of the questions.

Help for family members

Some of the questions concerned how the family member experienced the advanced treatment and the support the family member got from the staff. A majority of the family members experienced anxiety and uneasiness during the course of the treatment. Just 20 percent did not experience these feelings. 9 of 10 answered that immediate contact and help in a crisis situation was good. 8 of 10 felt that that they could have a longer personal talk with a team member.

When it concerned psychological help during the treatment period and after the death of the patient the results were not as good. 25 percent were not completely satisfied with the help given after the death of the patient.

Overall satisfaction

Family members liked the care given and the care people. 9 of 10 felt that the help offered in the Advanced Palliative Home Care was – to the patient – an ideal arrangement. Almost everyone (97%) answered that if they were to choose again, they would again choose the Palliative home care program.

Open-ended questions

Four main aspects were identified from the open-ended questions: The staff competence, attitude and communication and the accessibility of service. These aspects were mentioned in both a positive and negative context.

Members of family had experienced a feeling of security, and this feeling included also the patient. It was positive that the patient had been able to remain at home through the Palliative home care. But it also meant an intrusion to privacy. Additional suffering was caused, e.g. by the responsibility the family member had felt for the patient.

"Our home turned into an institution. The family had few opportunities of relaxation from the illness. We felt that we had lost privacy, especially the children's. Little attention was taken e.g. that we needed undisturbed sleep during the night when the drip often was given"

"My husband could remain in our home during the whole disease trajectory, sleep in his own bed, spend time with the children, grandchildren and friends (as long enough strength still was there) and yet knowing that doctors and other staff were accessible 24 hours a day. It felt secure and a privilege to have it like that in a difficult time"

CONCLUSION

The most usual symptom was fatigue and the helping persons were not able to do much about it. Overall the family members approved the help and care. The exception was that they felt a need for better psychological help both during the treatment and after the death of the patient. The family members expressed confidence in the help and care given and would choose Palliative Home Care if confronted with the same situation again. The open-ended answers added information to the answers given on the scaled questions. The most frequent answers were positive aspects of the staff and feeling secure in the own home.

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