The Importance of Family and Domiciliary Treatment of Immobile Patients with Chronic Wounds

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Summary: This study was conducted by a team of doctors and nurses, on a sample of selected immobile patients. The aim of the survey was to evaluate the impact that the immobile patient has on his family, the level of transmission of information between doctor and patient, the analysis of social economic context, new therapeutic strategies in the treatment of immobilised patients. When the domiciliary assistance services began to take care of an immobile patient, the family received a questionnaire with 23 questions. The study began in May 2003 and ended in September 2003, 481 patients were examined. The analysis of data shows that:

- The family does not know how to treat immobile patients, even though, in most cases, the family represents the place where the immobile patient is treated.
- The family does not have a good knowledge of prevention strategies and about the quality and the quantity of patient's diet, they do not make use of new dressings for pressure ulcers treatment.

INTRODUCTION

Most patients who require domiciliary treatments are elderly people affected by a variety of diseases. In the course of their clinical history they usually have consulted a number of doctors and specialists. However, the person who usually looks after this kind of patient at home often lacks the specific expertise required and their treatments are based on empirical evidence or, worse, on popular traditions.

The lack of knowledge of the care giver and the patient's family can be a consequence of doctors, nurses and health professionals being unable to give the necessary information to ensure the correct care of the patient, for example, to prevent pressure ulcers and for an appropriate diet. For the effective dissemination of information, it is essential to consider the patient and his family's cultural and socio-economic status, the amount of time that the family can dedicate to care provision and the age of the home care nurse who cares for him/her (in the last few years there has often been a lack of continuity of nursing care, so there is a difficulty in passing on information).

Our study was based on a sample of patients selected by a group of physicians and nurses working in public health centres situated in five regions in southern Italy – Campania, Puglia, Basilicata, Calabria, Sicilia. All of them have visited their patients in their own homes. All the patients that were included in the evaluation suffered from chronic wounds and required domiciliary treatment.

AIM

The aim of the study was to evaluate the requirements of this group of patients taking into consideration:

- Place of residence
- Treatment
- Incidence and the prevention of the pressure ulcers
- Diet
- Time dedicated to the patient
- Social services offered by public welfare
- The family economic and social conditions

MATERIAL AND METHODS

All subjects (patients or their families) were evaluated using a simple questionnaire composed by 23 questions with simple "yes/no" answers and numbers 1,2,3. The selected patients lived in: Naples and its southern provinces; Benevento and its provinces; Foggia; Crotone; Melfi and Catania and its southern provinces.

The questionnaire was divided into three parts: Part A (Table 1) had questions relating to pressure ulcers, Part B (Table 2) had questions about diet and Part C (Table 3) evaluated socio-economic status.

Table 1: questions relating to pressure ulcers

Are you immobilized?
Have you got any wounds on your skin?
Have you got any pressure ulcers?
Have you any other chronic wounds?
Do you make use of pressure ulcer prevention methods?
Do you make use of modern dressings?
Are you able to take care of you by yourself?
Are you receiving enteric nutrition?
Are you having parenteral nutrition?
Do you live with your family?
Does your nurse live with you?
Is your nurse non EU?
Are you able to chew food?

Table 2: questions about diet

Do you cook your food at home?
Does the cook stay at home?
Has he/she enough time to cook?
How many times in a day do you eat?
How many times in a week do you eat pasta?
How many times in a week do you eat meat or fish?
How long does it take to eat?
Do you measure the amount of water you drink in a day?
Do you follow a specific diet?
Do you usually drink sweetened drinks between your meals?
Do you use additional nutrition?
Do you eat liquidised food?
If yes, how many times a week?
Did anyone inform you about your caloric requirements?
If yes, who did that?

Table 3: questions relating socio-economic status

Do you live on your own pension?
Do you have any other means?
Do you have a civil disability pension?
Are these means enough?
Does your family help you?
Does the patient live in poor, non-hygienic or unhealthy conditions? (in the interviewer's opinion)
Are the social services present to improve his/her conditions?
If, yes, what kind of measures did they take?

It was important for the interviewer to be very clear in asking the questions and explaining their meaning to the patient or to his/her family. It was also essential for the interviewer to distinguish between pressure ulcers and other chronic wounds.

RESULTS

The study began in May 2003 and ended in September 2004. 481 patients were examined and their details can be seen in Table 4.

Table 4: Age and Gender of Patients

Total patients	481
Female	301 (63%)
Average age	77.6 (53-94)
Male	180 (37%)
Average age	75.8 (52-88)

In total, 343 patients (71%) were permanently immobile; 486 patients (84%) had cutaneous wounds; 363 patients (89%) had pressure ulcers and 94 patients (23%) had chronic wounds. 227 bed-fast patients (47%) used pressure-relieving devices and only 181 patients were treated with modern dressings. This data is shown in more detail in Table 5.

Table 5: Answers to the questions relating to pressure ulcers

	Yes	No
Are you permanently immobilised?	343 (71%)	138 (29%)
Have you got any cutaneous wounds?	406 (84%)	75 (16%)
Have you got any pressure ulcers?	363 (89%)	43 (11%)
Have you any other chronic wounds?	94 (23%)	312 (77%)
Do you make use of pressure ulcer prevention strategies?	227 (47%)	254 (53%)
Do you make use of modern dressings?	181 (38%)	300 (62%)

Out of the 431 (90%) patients who were not self-sufficient, 409 patients (85%) lived with their family, 437 (91%) patients lived with the person who physically took care of them, and in 146 (30%) cases the patients were nursed by non EU care givers all day.

Among the patients having enteral nutrition, 25 (5%), there were 17 (4%) patients having parenteral nutrition and 399 (83%) patients who could chew and a further 34 (8%) could only swallow. For all the patients (except for those receiving enteral and parenteral nutrition) their food was cooked at home (including nursing homes for elderly people). In 85% of the cases the person who cooked for the patient was always at home and 89% asserted that they had sufficient time to do that. The time spent feeding the patient varied from 30 minutes for 38% to an hour for 45% and it was an hour and half for 17%. In 99.6% of cases the patient ate twice or three times a day. The types of food are summarised in Table 6. ▶

Table 6: Results for dietary questions

How many times in a day do you eat?	**1**	2 (0.4%)	**2**	157 (32.6%)	**3**	322 (67%)
How many times in a week do you eat pasta?	**2**	29 (6%)	**4**	161 (33%)	**6**	291 (61%)
How many times in a week do you eat meat or fish?	**Never**	22 (5%)	**<2**	130 (27%)	**>3**	329 (68%)

The remaining results can be seen in Table 7

Table 7: Dietary intake

	Yes	No
Do you measure the litres of water you drink in a day?	152 (32%)	329 (68%)
Do you follow a specific diet?	81 (17%)	400 (73%)
Do you make use of additional nutrition?	124 (26%)	357 (74%)
Do you usually drink sweetened drinks between your meals?	193 (40%)	288 (60%)
Do you eat liquidised food?	187 (39%)	294 (61%)
If yes, how many times in a week?	**2 times** 27 (14%) **4 times** 85 (46%) **6 times** 75 (40%)	
Did anyone inform you about your caloric requirements?	126 (26%)	355 (74%)
If yes, who did that?	**doctor**	126 (100%)

A total of 311 (81%) patients lived on a pension and 311 also had a civil disability pension. Only 115 (24%) of patients declared that they had additional means, while 48% declared that their income was sufficient. For 287 patients their income was subsidised by the family. At least 72 patients lived in poor, non-hygienic and unhealthy conditions and in poor socio-economic conditions in the opinion of the interviewer. Sixty-one patients received public welfare.

SEPARATION OF DATA AND ANALYSIS OF THE RESULTS

Following the analysis of the results, a close relationship emerged between immobility, lack of self-sufficiency and chronic wounds as shown in Table 8.

Table 8: clinical characteristics of the patients

Not self-sufficient	90%
Immobile	71%
Chronic wounds	84%

The study found out that 89% of patients suffered from pressure ulcers. The remaining 11% were affected by other kinds of chronic wounds. It is important to point out that 12% of patients presented with both pressure ulcers and other chronic wounds. This meant that the patient often required visits from a domiciliary nursing service from the social service of the local health centre.

There is little focus on pressure ulcer prevention. Indeed if we compare the data of immobile patients with that of patients who already used pressure ulcer prevention equipment before intervention from a healthcare professional, we note a remarkable difference as 71% of the patients were immobile but only 47% had pressure ulcer prevention equipment. However, if we separate the data and we compare general data with that of patients registered in Asl Venosa 1 (Melfi), Basilicata and those registered in Crotone (Calabria), we note that in these areas there was a greater use of pressure ulcer prevention equipment. In these two districts 84% and 82% of patients respectively had prevention equipment compared with the overall 47%. The reasons for this differed between the two regions.

In the Basilicata area it is possible to reuse pressure ulcer prevention equipment; thus making them more immediately available to a greater number of patients and, in addition, focusing attention on the importance of pressure ulcer prevention. In Calabria the positive results are the result of very thorough care practices operated by both local health organisations and hospital healthcare professionals to ensure that good and appropriate care is taken of non-self-sufficient patients, the elderly, oncologic and neurological patients. The success of these practices underlines the need for health professionals everywhere to recognise that both hospital and territorial health centres have to work together to achieve quality care.

However we must point out that the prescription of pressure ulcer prevention devices does not necessarily reduce their incidence as shown in Table 9.

Table 9: pressure ulcer incidence and use pressure ulcer prevention equipment in different regions

	Pressure ulcer incidence	Use pressure ulcer prevention equipment
Basilicata	100%	84%
Calabria	89%	82%
Campania	76%	46%
Puglia	81%	51%
Sicilia	100%	20%

This data underline the fact that the most frequently used method for pressure ulcer prevention in immobile patients (alternating pressure air mattress) cannot, by itself, prevent the occurrence of pressure ulcers. However, as we did not have a record of the date of pressure ulcer development and the equipment used prior to pressure ulcer treatment, this finding must be treated with caution.

In a high percentage of patients, the chronic wounds were treated with a traditional dressing (gauze, metallic silver, etc.); only in 38% had modern dressings been used. Scientific evidence shows the superiority of this kind of modern product and their limited use is a direct consequence of the low priority given to pressure ulcer prevention and treatment and the subsequent lack of practical experience of the health professionals who treat these ulcers every day. The general data do not totally explain the differences between local and regional situations. A higher percentage of use has been found in some places (Calabria – 71% and Basilicata – 61%). This data can be explained taking into account that these areas consist of small communities where it is easier to run and support formative training for health care professionals,

However, the data does not emphasise one of the major benefits in the treatment of pressure ulcers in those geographic areas – the patient's family. In many cases, the family plays the most important role in the treatment of this kind of patient; the family takes care of him/her. The study showed that 89% of patients lived with their families and in 85% of cases the person providing nursing care was always there. In 30% of cases a nurse performs this function. These data are not universal, in the big cities we find a higher percentage of foreign nurses. In the metropolitan area of Naples the percentage is 39%, whereas in Crotone it is 27% and in the province of Catania it is only 20%. In agricultural areas, such as the province of Benevento, this figure reduces to 3%.

A foreign nurse can cause problems with communication, if there is a lack of understanding between the nurse and the health team. Such problems become more serious if communication with the family is also taken into consideration. There is a "triangle" of communication linking the health team, the family and the attendant. The possibility of misunderstandings occurring about both the therapy (information from the physician to the attendant) and the communication of possible changes in the clinical state (information from the attendant to the physician) is high. These potential communication problems can have serious repercussions on the validity of the treatments.

Another serious problem (illustrated by the analysis of the data of this study) is the poor knowledge of the patient's nutritional state and his/her requirements. In 74% of the cases, the family has no information about the immobile patient's protein and caloric requirements, and, above all if he/she has pressure ulcers. In addition, 73% of the patients do not follow specific dietetic plans. However, the small number of patients, who do have this information, were diabetics and, as a consequence, are already following a specific diet. Their diet, therefore, represents only a part of metabolic disease treatment and it is not part of the information included in a therapeutic plan aiming to prevent complications caused by under nourishment.

In 94% of cases the main food is pasta and they eat pasta four to six times in a week. While 68% eat meat or fish more than three times in a week, some 5% of patients never eat meat or fish at all. When considered in a general way this would not seem negative, but if we consider them in relation to the lack of a dietetic plan and to the lack of knowledge of patients' caloric-protein requirements, they acquire a negative meaning. What is shown is the complete inadequacy of many caregivers when required to establish the nutritional requirements of such patients and consequently to help them adapt their own dietary habits in both a qualitative and quantitative sense.

This has some consequences:

- Nutrition is considered in a numeric way (breakfast, lunch and dinner = 3 meals) and the quantitative, qualitative and nutritional sides of it are not considered. More and more often the physicians intervene with noticeably under-nourished patients even if the relatives assert that they eat.
- The care givers do not have sufficient knowledge of dietary requirements and so do not use additional nutrition, such as caloric- protein integrative. Only 26% of patients have used supplementary integrative food.
- 39% of the patients eat liquidised food as an alternative meal and in inadequate amounts.
- 32% of the patients know how much water they drink in a day. This does not permit an efficient and accurate water and electrolyte balance to be maintained. This goal could be easily attained through the catheterization of immobile patients with pressure ulcers, during all their treatment.
- Only the 40% of patients drink sweetened drinks between the meal times. This could be used to give them an additional source of calories, for example, fruit juices included in an adequate dietetic plan.

Most families bear the cost of the health care for their own immobile family members. In fact, in 287 (60%) of the cases this support includes care provided by the nuclear family. In 48% of cases the patients thought their own income was sufficient. This is usually when in the same patient's family there are pensions, civil invalidity subsidy, other yield sources, together with economic and material family support, so it is not necessary to seek the help of a nurse. However, if we separate the data, we note how the economic difficulties increase in the geographic areas where the family is not as supportive and the patients need care from nurses. This causes an enormous increase

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of expenses in order to provide this support. For example, in the metropolitan area of Naples only 37% of patients think their income is sufficient. However, only 44% of patients are helped by their family compared with the overall figure of 60%, and 39% of families need assistance from nurses compared with 30% total data. These data suggest that patients' income is only usually enough when there is the added support of the family in both economic and material terms.

Most patients do not have sufficient means. In addition, we have to consider the 72 (15%) patients who, in the interviewers' opinion, were living in poor, non-hygienic and unhealthy conditions. Their loneliness makes their condition worse and makes them more fragile. It is in these cases that the social services have had to intervene, but the help has been partial and insufficient. Unfortunately, 11 patients of this group did not have any help from social services at all.

CONCLUSIONS

In most cases, both the economic burden and the provision of nursing care for immobile patients is carried by their families. The high incidence of pressure ulcers is increasing the load of work and the difficulties when treating the patient at home. Family carers do not have the specific knowledge and experience to treat this kind of patient and cope with their problems. They do not have the appropriate knowledge either in the field of prevention or in the quality and amount of nutrition required.

Most health centres are opening domiciliary nursing services. The problem is to provide adequate services to meet their institutional task. It is necessary to improve the assistance, to make it effective and to involve the several levels of assistance available: domiciliary, territorial and hospital.

Domiciliary integrated assistance and Domiciliary Hospital Assistance are surely an adequate answer, but they cannot be sufficient to cope with such a big problem, especially because the domiciliary presence often only occurs when the patient is in the acute phase of his chronic illness. This study shows that many caregivers lack information and the necessity for health and social professionals to have appropriate knowledge in order to treat the patient in his own home and to inform and educate his family.

It is necessary to stipulate cooperation protocols between Local Health Centres and care givers in the provision of care to immobilized patients. The presence of home carers is still very limited. The burden of immobile patients with pressure ulcers cannot be completely left only in their family's hands. Especially in the current climate where the typology of family is changing and there are not the extended family members available to care for immobile relatives.