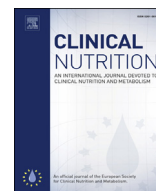




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Original article

Home Enteral Nutrition therapy: Difficulties, satisfactions and support needs of caregivers assisting older patients

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SUMMARY

Background & aims: The purpose of this study was to comprehend and describe the views, experiences and adaptations of caregivers who assist older patients treated with Home Enteral Nutrition. The objective was to gather empirical evidence to improve the delivery of Home Enteral Nutrition for old patients taking into account the caregivers' support needs.

Methods: A qualitative methodology with focus groups as data collection method was used to collect the testimonies of 30 informal and formal caregivers of older patients treated with Home Enteral Nutrition by the Clinical Nutrition Service of INRCA (Ancona) during 2014. Quantitative methodology was used to collect socio-demographic data. Partially modified Silver's "Home Enteral Nutrition Caregiver Task Checklist" was used to identify training needs. The constant comparison method was used to code and categorize data and to develop themes of focus groups. Simple descriptive statistics were used to summarize questionnaires.

Results: Five main themes were identified from focus groups: acceptance of the therapy, skill acquisition process, need for psychological and practical support at home from healthcare professionals, lifestyle adaptation, affirmation of life and family. All caregivers testified the initial fear and refusal to manage the nutrition pump and the therapy. They expressed the need to be trained gradually, starting during a patient's hospitalization, and continuing in the community. With reference to their overall QoL, it emerged that informal caregivers suffered mostly from the reduction of their free time while formal caregivers suffered social isolation and psychological burden. For both groups the monthly home visit was the most important element of the HEN service. Informal caregivers highlighted the importance of having their loved ones at home. Unsatisfied training needs were identified by the modified Silver's "Home Enteral Nutrition Caregiver Task Checklist".

Conclusions: This qualitative study underlined the challenges and adaptations of caregivers who assist older patients treated with Home Enteral Nutrition, which should be considered when defining clinical protocols and supporting caregivers.

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1. Introduction

Home Enteral Nutrition (HEN) is a life-sustaining therapy for hospital outpatients, which consists in administering enteral formulas into the digestive tract by a feeding tube [1]. It is indicated for

malnourished patients, and patients with oral feeding difficulties, who have a functional gastrointestinal tract, whose clinical conditions are stabilized and who can be treated at home [2]. Home Enteral Nutrition is the most common home infusion therapy. It is particularly frequent among old and frail patients, with multimorbidities, who need long term enteral nutrition due to persistent neurological dysphagia [3,4]. The eligibility of older non self-sufficient patients to receive HEN depends on their clinical conditions, as well as on the support of caregivers who have to guarantee the safety and efficacy of this type of nutritional treatment outside

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the hospital. Providing home therapy means, in fact, transferring responsibilities and risks from the hospital to the home. The physical and emotional demands placed upon caregivers impact their Quality of life (QoL), and the hazards of caregiving can convert them into hidden patients and influence the quality of the care delivered and the outcomes of the therapy [5]. To reduce these risks and to properly manage patients treated at home, caregivers changing needs for education, training, and other kinds of support, across the care continuum, should be identified and satisfied. As it is suggested by scientific literature, caregivers can be supported in different phases of caregiving process by two different kinds of interventions. The first kind of interventions are aimed to improve caregivers' preparedness and competency in providing safe and effective care to the patients by instrumental or informational support—e.g. providing training and information—which reduces their distress by reducing their load or by increasing their sense of certainty and control. The second kind of intervention supports the caregiver as a client, directly reducing caregivers distress and the overall impact on their health and well-being by the means of emotional and psychological support [6–8]. While the issues such as caregivers' stress, burden and psychological support needs have been widely studied for certain categories of patients—mostly cancer and Alzheimer patients—the HEN research concentrated almost exclusively on clinical issues. This has led to an absence of information regarding a key player for the safe delivery of HEN. Italian national and all international guidelines for the provision of the HEN therapy are also patient oriented and focus mainly on the definition of the types of technical support to provide to the patient and/or caregiver. This grounded theory study was performed to explore specific support needs of caregivers of older patients in long term HEN over time and to understand caregivers' perceptions of the HEN service provided by INRCA's Clinical Nutrition Unit [9,10]. A systematic identification and prioritization of unmet needs of caregivers was performed in order to better understand the dynamic and changing nature of the caregiving experience and to help improve the HEN service by planning interventions that are tailored to specific caregiver needs. We also wished to identify further research opportunities in this field.

2. Methodology

2.1. Study design

The study protocol was approved by INRCA's ethics committee in compliance with Italian national rules and regulations. Both qualitative and quantitative approach was used for data collection. Qualitative methodology based on grounded theory was used to collect the testimonies of caregivers [11,12]. Quantitative methodology was used to collect socio-demographic data and to identify specific training needs of caregivers.

2.2. Participants

Formal and informal caregivers of patients treated with HEN by INRCA's Clinical Nutrition Unit were contacted via telephone and asked to participate in the study. Three focus groups composed, respectively, of 5, 8 and 9 informal caregivers, and one focus group of formal caregivers i.e. people paid to assist patients, who were not healthcare personnel (8 participants), who had at least 6 weeks experience at enrolment and who gave their written consent, were created. According to INRCA's protocol, at the moment of patient's discharge from the hospital, family members and formal caregivers who assist the patient are supported and trained to implement the HEN therapy. The training is carried out by skilled dieticians and concerns the use of the infusion pump, the use and correct storage

of enteral feeding formulas, the administration of drugs and water through an enteral feeding device, the medication of the tube site, the identification of complications and their prompt resolution. Caregivers are assisted also in the community by the provision of all the material which is regularly delivered directly to patients' homes (feeding formulas, sterilized medication kits, antiseptics, infusion bag) and by one monthly follow-up home visit which is performed by trained nurses. The home visiting staff re trains caregivers during the first home visits, controls, each time, the proper management of the therapy by caregivers, diagnoses and, if possible, solves the tube related complications and informs the hospital physician specialized in Clinical Nutrition about patient's conditions. Video consultation and data exchange, through technological devices, between the home visiting staff and the hospital staff are also routinely carried out during the home visit and caregivers are supported by the feedback information about their caregiving activities and patient's conditions.

2.3. Qualitative measures

The use of grounded theory is recommended when a phenomenon is unknown and information has to be collected directly from individuals who have to deal with the phenomenon [13,14]. This qualitative approach allows to generate theories on certain issues, grounded in data collected in the field. We identified the focus group methodology as best suited to collect the impressions, the experiences and the views of caregivers and to identify the most proper kinds of support for caregivers of older patients in long term HEN in different moments of the caregiving process. We adopted Krueger and Casey's framework for constructing focus group questions. We pilot tested the questions to ensure that they were understandable. The focus groups were conducted to achieve diversity in the information obtained and they were continued until a clear pattern of responses emerged and subsequent meetings produced repetitious information [15]. Two trained interviewers conducted the focus groups. Questions were divided into three categories: first, caregivers were asked to introduce themselves and express their emotions and feelings at the beginning of their experience of caring for a patient treated with HEN; second, the caregivers were asked about technical and practical aspects and difficulties of managing the nutrition therapy; finally, caregivers were asked to evaluate different aspects of their QoL and to express their needs. Each focus group lasted approximately 50–90 min. Meetings took place in the INRCA hospital in Ancona. All interviews were audio-taped with permission. A number of strategies was used to maintain an objective viewpoint. Our research team was aware of the need for neutrality and the importance of capturing the views of all participants. The environment where focus groups were held was prepared to facilitate an open discussion.

2.4. Quantitative analyses

Socio-demographic data and information on training and overall service received were gathered for all participants using a study specific questionnaire. In order to identify caregivers' training needs and preparation, we also utilized the "Home Enteral Nutrition Caregiver Task Checklist", proposed by J. H. Silver, which was partially modified according to the characteristics of our training program and nutrition therapies [16]. Four additional items were added to the original version as suggested by investigators based on their experience (managing safety and emergencies and managing oral feeding of patients who are also fed by mouth) for a total of 36 items. The check list was composed of 36 enteral nutrition and caregiving-related tasks that were classified into two groups: overall care (items 1–11) and home enteral nutrition-related (items

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