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Communication and swallowing difficulties in palliative patients: patients, families and/or caregivers perspective

Dificuldades de comunicação e deglutição em doentes em cuidados paliativos: visão dos doentes e familiares e/ou cuidadores informais

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ABSTRACT

Introduction: Many of the symptoms presented by palliative patients culminate in dysphagia and communication disorders. **Purpose:** To analyze the opinion of palliative care patients and their families and/or informal caregivers about the communication and swallowing difficulties. **Methods:** Exploratory, observational, cross-sectional study with a sample of 38 patients and 26 family members and/or informal caregivers. Data collection was carried out in a central university hospital and a Local Health Unit in Portugal, through two different questionnaires. **Results:** Data indicated that 55.3% of surveyed patients reported that they have difficulty in communicating and 34.2% signaled the “communicate with difficulty” option. In turn, 57.7% of families and/or informal caregivers refer this difficulty as primordial, and the highest percentage (30.8%) was also related to the option “communicate with difficulty”. The percentage of swallowing difficulties presented by the patient and referred to by family members and/or caregivers is high in both groups compared to communication difficulties. 68.5% of the patients surveyed refer difficulties to swallow liquids, while 71.1% mentioned difficulty in swallowing solid food. In the family and/or informal caregivers’ opinion, 80.8% of patients presented difficulty to swallow liquids and 84.6% difficulties in swallowing solids. **Conclusion:** The majority of the patients in Palliative Care present communication and swallowing difficulties and the most prevalent difficulty is swallowing solid food.

Keywords: Palliative care; Speech therapy; Speech, language and hearing sciences; Communication; Deglutition

RESUMO

Introdução: Muitos dos sintomas apresentados pelos doentes em cuidados paliativos culminam em disfagia e perturbações da comunicação. **Objetivo:** Analisar a opinião dos doentes em Cuidados Paliativos e de seus familiares e/ou cuidadores informais sobre as dificuldades sentidas na comunicação e na deglutição. **Métodos:** A amostra foi constituída por 38 doentes e 26 familiares e/ou cuidadores informais. A coleta de dados foi realizada em um hospital central e escolar e em uma unidade local de saúde em Portugal, por meio de dois questionários distintos. **Resultados:** Constatou-se que 55,3% dos doentes inquiridos afirmaram apresentar dificuldades para se comunicar e que 34,2% assinalaram a opção “comunico com muita dificuldade”, no questionário. Por sua vez, 57,7% dos familiares e/ou cuidadores informais também consideraram esta dificuldade como uma das primordiais, sendo que a maioria (30,8%) especificou, igualmente, a opção do questionário supramencionada. A percentagem de dificuldades de deglutição apresentada pelos doentes e referida pelos familiares e/ou cuidadores foi superior em ambos os grupos, comparativamente às dificuldades de comunicação. Na ótica de 68,5% dos doentes inquiridos, as dificuldades de deglutição ocorriam com líquidos, enquanto que 71,1% afirmaram apresentar dificuldades na deglutição de alimentos com consistência sólida. Na opinião dos familiares e/ou cuidadores informais, 80,8% dos doentes apresentavam dificuldades na deglutição de líquidos e 84,6%, na deglutição de sólidos. **Conclusão:** A maioria dos doentes em Cuidados Paliativos apresentou dificuldades de comunicação e deglutição, sendo as de deglutição mais referidas do que as de comunicação. As dificuldades de deglutição de consistências sólidas foram as mais prevalentes, nesta amostra.

Palavras-chave: Cuidados paliativos; Fonoterapia; Fonoaudiologia; Comunicação; Deglutição

Study developed at the School of Medicine, Universidade do Porto, Porto, Portugal.

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Conflict of interests: No

Authors’ contribution: CIFB, MTCM and JCAM conception and study design, review and approval of the final version of the article; CIFB writing of the article.

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INTRODUCTION

The objectives of rehabilitation and Palliative Care may seem incompatible and the potential contributions of rehabilitation seem to be inappropriate for the patients. On the opposite, an increasing number of studies has evidenced that rehabilitation responds to many of the Palliative Care patients' needs^(1,2). Patients with neurodegenerative conditions, neurological problems (such as cerebrovascular accident or traumatic brain injury), head and neck cancer and other types of advanced cancer, which entail cognitive-linguistic disorders, are some of the patients who can benefit from this type of intervention^(1,2,3,4,5,6). The effect of the medicines, fatigue and generalized weakness can cause respiratory difficulties, affect the mobility of the speech muscles and alter the memory, attention, access capacities and the lexical use of words.

These complications entail communication difficulties, mainly verbal and non-verbal and written communication, writing, understanding of language, prosody, voice quality and volume⁽³⁾. It can equally lead to swallowing difficulties (oral control of the bolus, extra-oral escape of solid foods and fluids, longer oral transit time, presence of cough and/or choking and regurgitation)^(3,4,5,6). Some of these problems impair the patients' understanding of their treatment alternative and can limit their choices and decisions^(4,5,6).

The speech, language and hearing therapist assesses the communication difficulties, guaranteeing the development of strategies to facilitate the communication process among all stakeholders (patient, family and/or informal caregivers, friends and interdisciplinary team), readapting the oral language or establishing effective non-verbal communication^(4,5,6). This professional is responsible for establishing oral communication alternatives (communication tables, gestures or the attribution of meanings to specific bodily expressions by the patient)^(4,5,7,8). When this is beneficial, the therapist should inform the patient about the possible use of the Augmentative and Alternative Communication method as early as possible and when the resources to maximize the residual functions (speech and motor capacities) are scarce^(3,6,7,8).

Augmentative and Alternative Communication intends to expand, complement or replace speech and is intended to maximize the function, support decision making, maintain the social relationships, reduce the anxiety and frustration and improve the quality of life^(7,8,9,10). The implementation of an Augmentative and/or Alternative Communication system involves training and adaptation. The patients' automatic use of this system without training cannot be predicted. It is crucial for the family to participate actively in this training and adaptation period. Furthermore, it should be highlighted that any Augmentative and/or Alternative Communication system should always be available for all team elements to know and use it^(8,9).

The focus of the speech, language and hearing therapist's activities on Palliative Care for dysphagia patients is to offer satisfaction and pleasure during meals with as much comfort as possible^(4,5,11,12,13,14). In fact, the patients' will should always be taken into account and respected, independently of their social, cultural or religious beliefs^(14,15,16). Oral feeding⁽¹⁶⁾ is the option the Palliative Care patients select most. Nevertheless, the therapist's intervention to maintain oral feeding should take place early, which sometimes does not happen and, therefore, the patients no longer feel this pleasure^(15,16,17). On the other hand, artificial food and hydration are considered treatments and require health professionals' intervention. Despite the lack of a broad consensus on artificial food and hydration and the fact that both may seem incoherent at the end of life, they can offer little or no benefit for the patients' quality of life^(17,18).

In this situation, after the health team provides the explanations needed, the patients and their relatives have to decide on the potential benefits of receiving artificial food and hydration or not^(15,17,18). Thus, based on the lack of studies that relate the speech, language and hearing therapist's activities in the Palliative Care teams in Portugal and the conviction that conditions are needed to include more therapists on these teams, this research is social and scientifically relevant. The objective in this study was to analyze the opinion of the palliative care patients and their relatives and/or informal caregivers about the communication and swallowing difficulties they feel.

METHODS

Approval for the project was obtained from the Ethics Committee and the Board of Directors, under protocol 384/13, and from the Ethics Committee and the Board of Directors under protocol 06/2014.

An exploratory, observational and cross-sectional study was undertaken. In view of the predominance of closed questions, it was considered as a quantitative study. Sixty-four individuals participated in a sample consisting of 38 palliative care patients and 26 relatives and/or informal caregivers. The following inclusion criteria were defined: palliative care patients, over 18 years of age, with cognitive skills needed to understand the questionnaire, who accepted to participate voluntarily. The relatives and/or informal caregivers should be the patients' main caregivers, not receive remuneration for this care and should also have intact cognitive skills needed to understand the questionnaire, answer it in writing and should accept to participate voluntarily. The participants were affiliated with two Portuguese institutions: *Hospital Geral de Santo António* – central and teaching hospital with an intra-hospital Palliative Care support team and ventilation support team for neuromuscular patients; *Unidade Local de Saúde do Norte Alentejano* – a local health service, consisting of two hospitals and one cluster of health centers. Approval for the study was obtained from the Palliative Care Unit of *Hospital Dr. José*

Maria Grande and from the Intra-Hospital Support Team in Palliative Care at Hospital Santa Luzia de Elvas.

What the data collection instrument is concerned, a survey by questionnaire was chosen (one for the patients and another for the relatives and/or informal caregivers). Two original questionnaires were conceived, due to the fact that no tool existed in this context that had been validated for the Portuguese population. The questionnaires rested on the bibliographic review, which offered greater and better knowledge on the areas related and studied. The initial versions of each questionnaire were reviewed by a group of experts, including professionals from the fields of Medicine; Nursing; Speech, Language and Hearing Therapy; Physical Therapy; Occupational Therapy; Psychology; Nutrition and Social Service. The experts were contacted personally and by e-mail. This phase was crucial, as it permitted verifying the relevance of the questions for the study objectives, correcting and/or modifying the questionnaires, paying attention to the technical vocabulary used and checking the writing and the order of the questions. The version that resulted from this expert review was defined as the final version. Departing from a background agreement on the days and periods for the data collection, the questionnaires were applied. After clarifications about the study objectives and its anonymous and voluntary nature, finally, the participants' consent was requested. The cover page of the questionnaires contained a brief presentation of the study and the researchers' contact info, while the final page displayed the informed consent. The informed consent form was completed in two copies and detached from the questionnaires. The participants kept one copy and the researchers the other. The questionnaires were applied face-to-face. All questions were read and the answers of all patients and relatives and/or informal caregivers were written down.

After the collection, the data were inserted in a computerized database and processed in the statistical software SPSS® (Statistical Package for the Social Sciences) – version 22.0. In addition, the contents of the open questions were analyzed.

RESULTS

The total number of subjects who indicated communication difficulties was higher than the subjects who mentioned the opposite. By the way, it can be added that 34.2% of these patients affirmed that they communicated with great difficulty (answers ranging between “I communicate without difficulties” – 44.7%; “I communicate with some difficulty” – 21.1%; “I communicate with great difficulty” – 34.2%; “I am unable to communicate” – 0% and “I don't know” – 0%). Most participants referred some difficulty to swallow saliva and water. Most patients also selected the alternative “I swallow with some difficulty” when they were asked about difficulties to swallow meat or other solid foods (Table 1).

Table 1. Distribution of patients in function of their communication and swallowing difficulties

Variables	n	%
Patients' difficulties to communicate		
I communicate without difficulty	17	44.7
I communicate with some difficulty	8	21.1
I communicate with great difficulty	13	34.2
Patients' difficulties to swallow saliva and water		
I swallow without difficulty	12	31.7
I swallow with some difficulty	13	34.2
I swallow with great difficulty	8	21.1
I am unable to swallow	5	13.2
Patients' difficulties to swallow meat and other solid foods		
I swallow without difficulty	11	28.9
I swallow with some difficulty	13	34.2
I swallow with great difficulty	8	21.1
I am unable to swallow	6	15.8
Total	38	100

When the same questions were asked to the relatives and/or informal caregivers, it was verified that the majority considered that the patients communicated without difficulties. Nevertheless, the total percentages indicated that the communication difficulties prevailed. Concerning the difficulties to swallow saliva and water, meat or other solid foods, as mentioned by the patients, the majority considered that they presented some difficulty (Table 2).

The sociodemographic data of the palliative care patients and their relatives and/or informal caregivers have been described in Tables 3 and 4.

DISCUSSION

These study results showed that 55.3% of the investigated patients affirmed difficulties to communicate and that 34.2% marked the option “I communicate with great difficulty” in the questionnaire. In turn, 57.7% of the relatives and/or informal caregivers also considered this to be one of the fundamental difficulties and the majority (30.8%) marked the same option in the abovementioned questionnaire. Despite the lack of Portuguese studies focused on the prevalence of communication difficulties in Palliative Care caused by speech or language difficulties, which could be used to compare the results, in other countries, these two variables have been related and investigated. In one study, it could be concluded that 27% of the 335 hospice patients presented communication problems. Most of these patients demonstrated difficulties to talk and language or cognitive changes⁽¹⁹⁾.

Table 2. Distribution of family members and/or informal caregivers in function of the communication and swallowing difficulties they consider the patients to have

Variables	n	%
Difficulties the family members and/or family caregivers consider the patients to have in order to communicate		
Communicates without difficulties	11	42.3
Communicates with some difficulty	5	19.2
Communicates with great difficulty	8	30.8
Does not communicate	2	7.7
Difficulties the family members and/or informal caregivers consider the patients to have in order to swallow saliva and water		
Swallows without difficulty	5	19.2
Swallows with some difficulty	10	38.5
Swallows with great difficulty	5	19.2
(S)he is unable to swallow	6	23.1
Difficulties the family members and/or informal caregivers consider the patients to have in order to swallow meat or other solid foods		
Swallows without difficulty	4	15.4
Swallows with some difficulty	11	42.3
Swallows with great difficulty	5	19.2
(S)he is unable to swallow	6	23.1
Total	26	100

In this research, the percentage of patients and relatives/caregivers who mentioned swallowing difficulties was higher in both groups when compared to the communication difficulties. Thus, according to 68.5% of the patients questioned, the swallowing difficulties were related to the fluid intake, while 71.1% affirmed difficulties to swallow solid foods. According to the relatives and/or informal caregivers, 80.8% of the patients presented difficulties to swallow fluids and 84.6% to swallow solid foods. Research has been undertaken in this respect in other countries. One study intended to identify the most common symptoms in hospice patients in the final seven days of life. The authors concluded that 50% of the sample presented dysphagia⁽²⁰⁾.

Another study was developed to verify the most prevalent symptoms in the last six months of life for head and neck cancer patients. Among the 93 patients who participated in the study, 45% presented dysphagia, the second most frequent symptom, preceded by pain⁽²¹⁾. Another study was developed to described the characteristics of the dysphagia in palliative care patients with malign conditions but without a diagnosis of head and neck cancer. The results supported the hypothesis that patients suffering from cancer that does not affect the head and neck equally present the risk of developing oropharyngeal dysphagia symptoms⁽²¹⁾. Despite the existence of these studies, no bibliographic support was found that distinguished between difficulties to swallow liquid and solid foods in palliative care

Table 3. Sociodemographic data of the patients

Variables	n	%
Gender		
Female	18	47.4
Male	20	52.6
Age group		
≤ 40 years	5	13.2
]40-60] years	10	26.3
]60-80] years	19	50.0
> 80 years	4	10.5
Marital status		
Single	6	15.8
Married or living in a stable union	29	76.3
Separated or divorced	2	5.3
Widowed	1	2.6
Education level		
No formal education	6	15.8
Primary education or up to 3rd cycle	26	68.4
Secondary education	4	10.5
Higher education	2	5.3
Professions according to National Classification of Professions		
Top public management, directors and top levels of companies	2	5.3
Specialists in intellectual and scientific professions	2	5.3
Intermediary technicians and professionals	2	5.3
Administrative staff and similar	4	10.5
Service staff and vendors	7	18.2
Laborers, artisans and similar workers	8	21.1
Unqualified workers	5	13.2
Students	4	10.5
Retired	2	5.3
Unemployed	2	5.3
Total	38	100

patients. Other studies reveal the most evidenced changes in the swallowing of liquid or solid foods, depending on the body structures affected and on the disease stage^(15,17).

In this research, the difficulties to swallow solids were the most mentioned, which may be related to the fact that most patients and relatives and/or informal caregivers indicated the diagnosis Amyotrophic Lateral Sclerosis as the motive for their current clinical situation. These patients' main difficulties were related to the swallowing of solids, the increased meal times and needs to consume smaller portions^(17,22,23). Nevertheless, the clinical diagnosis was not included in the questionnaires, neither the disease stage, that is, whether the disease was in the initial phase or not. The study mentioned cites this type of difficulty in an initial phase and, therefore, no lessons can be drawn concerning this fact.

Table 4. Sociodemographic data of family members and/or informal caregivers

Variables	n	%
Gender		
Female	16	61.5
Male	10	38.5
Age group		
≤ 40 years	3	11.6
]40-60] years	16	61.5
> 60 years	7	26.9
Marital status		
Single	1	3.8
Married or living in stable union	22	84.6
Separated or divorced	1	3.8
Widowed	2	7.8
Education level		
Primary education or up to 3rd cycle	14	53.8
Secondary education	6	23.1
Higher education	6	23.1
Professions according to National Classification of Professions		
Specialists in intellectual and scientific professions	1	3.8
Intermediary technicians and professionals	5	19.2
Administrative staff and similar	4	15.4
Service staff and vendors	5	19.2
Laborers, artisans and similar workers	3	11.6
Unqualified workers	4	15.4
Students	1	3.8
Retired	1	3.8
Unemployed	2	7.8
Degree of parenthood with the patients		
Husband/wife	11	42.3
Son/daughter	5	19.2
Other	10	38.5
Mother	4	15.4
Daughter-in-law	1	3.8
Father	3	11.6
Informal caregiver	2	7.8
Total	26	100

CONCLUSION

Most Palliative Care patients presented communication and swallowing difficulties, mainly referring to the latter. The difficulties to swallow solid consistencies were the most prevalent. The results obtained can offer a valid contribution, with large-scale benefits for the patients, their relatives and/or informal caregivers, for the health professionals and for the evolution of Palliative Care in Portugal.

Communication and swallowing disorders cause a great

impact in people's quality of life, independently of their severity. In that sense, a comprehensive assessment and a suitable and professional intervention are crucial, even when the curative treatments do no longer offer benefits for the patients.

It would be interesting to engage in the education of Palliative Care teams in Portugal and to provide them with further knowledge on Speech, Language and Hearing Therapy and the therapist's role. In another sense, it would be fundamental for these health technicians to discover the potential benefits of their interventions in the different clinical contexts.

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