

Review Article

General Knowledge and Awareness on Rare Diseases Among Primary Care Dentists in Bulgaria

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Abstract

Medical specialists play an important role in the process of diagnosing and treating rare diseases patients. General practicing dentists more often are active participants of the team that is responsible for the treatment of the patients. This is what led the authors to explore the knowledge and general awareness of general practicing dentists regarding rare diseases. An anonymous survey among primary dental practitioners had been conducted. The results show a serious deficit of knowledge and at the same time a desire for professional development and wish to expand the knowledge on rare diseases among the dental professionals. There is an urgent need for increasing the level of knowledge on rare diseases of primary care dentists by organizing seminars, workshops, distribution of brochures and participation in conferences. This will improve the quality of medical service provided by dentists to patients with rare diseases.

Keywords: Rare Diseases; Primary Dental Care; Knowledge

Introduction

In the European Union a disease is considered rare when it affects not more than 1 person in 2,000. The low prevalence is the common feature shared by all rare diseases, which altogether affect all biological systems. However, as about 6,000 different rare diseases exist, they have significant epidemiological relevance. Many rare diseases cause chronic health problems or are even life-threatening [1].

Many rare diseases affect multiple organs and thus demand that multidisciplinary healthcare professionals should work together. The multidisciplinary team takes decisions on diagnosis and treatment depending on pathology, biology, epidemiology and research. All team members play a specific role in the multi-step diagnostic work-up and all of them contribute to the decisional process leading to a therapy based on patients' specific disease and health status [2]. The multidisciplinary teams appear as a practical necessity for optimal coordination among health professionals and

good communication with patients [3]. Thus, the chances of effective recovery in a significant part of the patients are increased [4].

Many of the rare diseases are associated with changes in the area of the oral cavity. 900 rare diseases have oro-dental manifestations and about 250 rare diseases are manifested by the formation of voids in the mouth or other parts of the face [5-8]. Due to this reason the involvement of the primary care dentists in the management of rare diseases is becoming increasingly important as a part of the multidisciplinary approach to care. They are the ones who work closely with the patient and his/her family in a case of a rare disease with oro-dental manifestations [9]. The aim of this study was to explore the level of knowledge and awareness of general practicing dentists regarding rare diseases. Specific objective was to reveal whether the dentists are interested in the area of rare diseases.

Methods and Means

A team of dental specialists together with the Information Centre for Rare Diseases and Orphan Drugs (ICRDOD) in Plov-

div, Bulgaria, conducted anonymous survey among dental practitioners. A questionnaire was created in the form of an individual inquiry containing 17 questions, divided into three groups - professional data, issues related to diagnosis of rare diseases and evaluation questions upon the level of knowledge. A direct group survey has been held and 314 questionnaires were totally completed. Data was checked for accuracy of fulfilling and was statistically worked out with SPSS, 19.

Results

This study involved 89 men (28.3%) and 225 women (71.7%). More than the half of the participants (55.0%) have acquired a postgraduate degree in compare with 45.0% of those who have no postgraduate degree and about 65.0% of the respondents have work experience over 15 years. The dentists were asked questions concerning the definition of rare disease and the number of patients affected by rare diseases. Only 3.2%, respectively, 5.4% are the relative shares of correct answers (Chart 1), (Chart 2).

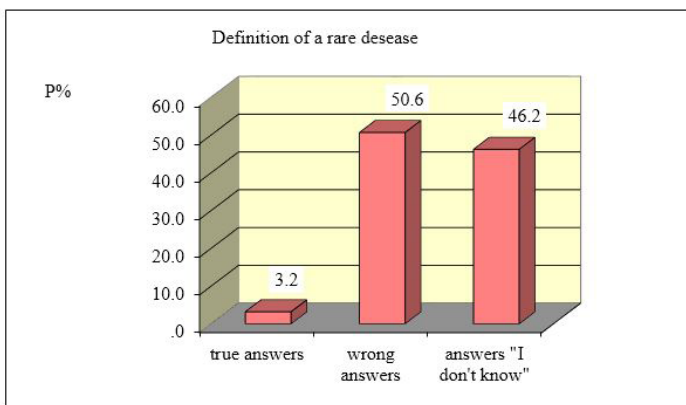


Chart 1: What is the definition of a rare disease?

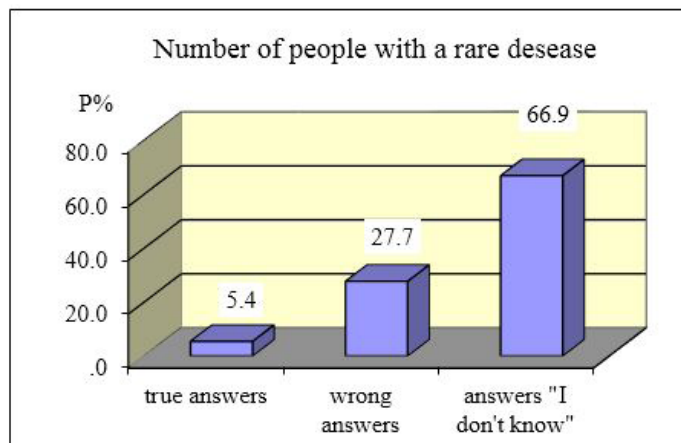


Chart 2: How many people are affected by a rare disease?

Dental practitioners were asked to indicate the oral symptoms of three rare diseases. Less than 19.0% of respondents had

given correct answers for the appointed diseases. Dental specialists are adamant in their reply to evaluations of the level of their knowledge on rare diseases - 85.7% believe that they haven't got sufficient knowledge of this area. At the same time, it is encouraging that almost 94.0% of the respondents are willing to expand their knowledge of rare diseases issues.

Discussion

In regard to the voluntary participation in the survey the results show that women are more interested in the topic of rare diseases. This could be explained with the fact that women are more empathic than men. The relatively high part of respondents with work experience over 15 years is connected with good possibility for the dentists to have already certain awareness on rare diseases as the bigger the experience is, the better the possibility is of having the chance to follow a patient with a rare disease. Of course, it is quite possible that a dentist could not have a rare disease patient through his whole professional life due to the low prevalence of these diseases.

The results of the study show that the infrequent prevalence of rare diseases is connected with a serious deficit of knowledge that often induces uncertainty, ambiguity and unpredictability in routine primary care. However, patients with rare diseases frequently have a strong need for complex and multidisciplinary treatment. Expertise and knowledge are required, but they are often located in dispersed centers of expertise, and are thus disconnected from the local healthcare environment of patients. The lack of standardized healthcare guidelines due to the great variance of symptoms and treatment processes within each disease pattern is also a reason for the insufficient knowledge level of the general practicing dentists.

In contrast with the above mentioned is the fact that the study results reveal strong positive attitude among the general practicing dentists towards expanding knowledge regarding the field of rare diseases. The honest self-estimation of the knowledge level and the desire for professional development could be a solid basis for improvement of the awareness and knowledge of general practicing dentists regarding rare diseases. Thus, the adequate and on time diagnosing and treatment of patients will be insured. As a logical consequence the patient and his family will be helped to cope with the difficulties in managing the course of the disease, the gradual recovery and maintenance of optimal functional abilities [4]. Through organizing seminars, workshops, distribution of brochures and participation in conferences on rare diseases it is desirable to answer to the need for increasing the level of knowledge on rare diseases of Bulgarian dentists.

Conclusions

General practicing dentists more often are active participants of the team that is responsible for the treatment of the patient. In

cases in which the oral symptoms are well manifested the general practicing dentist help the right diagnose and treatment. The general practicing dental professionals should be able to establish an individual contact with each patient with a rare disease and to conduct a seasonable and correct treatment. They are tasked with creating a new type of individual, patient-centered solutions to improve rare diseases patients' long-term healthcare situation. There is an urgent need for increasing the level of knowledge on rare diseases of primary care dentists. Accurate and on time answer to this need will improve the quality of medical service provided by dentists to patients with rare diseases.

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