

MEDICO SOCIAL APPROACH
TO RARE DISEASES IN THE ORAL CAVITY

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INTRODUCTION

The oral cavity is a localization in which rare diseases can be diagnosed.- some of the oral cancers, which are encountered on extremely rare basis; maxillary lymphoid tumors; different types of oral lesions; juvenile xantogranuloma encountered with the Erdheim–Chester disease; marble disease (a rare disease of bones and teeth). The rare diseases often lead to an invalidity of the individual, which requires the application of specialized medico – social approach.

AIM

Determination of the social aspects of behavior from the medical and other specialists on discovering of a rare disease in the oral cavity.

MATERIAL AND METHODS

Evaluation of the quality of life and application of social rehabilitation are relevant to the medico-social approach. The personal rating scale was developed, based on analysis and evaluation of the impaired function in the contingent, tested. (*Application 1*) In order to validate it, a pilot study of 30 patients was carried out, yielding a value of Cronbach' coefficient – $\alpha = 0.91$. External validity was assessed, comparing ratings by two independent scorers – the researcher and a dental doctor. Nineteen patients were evaluated. The results showed a high correlation – $P < 0.001$ (Kendall coefficient $r_{xy} = 0.98$).

Application 1

Quality of life rating scale in patients with oral cavity and jaw cancer

Please, assess patient’s quality of life, by ticking the box, if he/she has the respective functional impairment. Rating scale is provided on a separate sheet.

Name of patient.....

Quality of life:

- Impaired: speaking
- feeding
- disfigurement
- presence of pain

Score (grade).....

Ratings

Grade 0 – good quality of life
(no impairment present)

Grade 1 – mildly reduced quality of life
(presence of pain only)

Grade 2 - moderately reduced quality of life
(two impairments, present –speaking and feeding)

Grade 3 – significantly reduced quality of life
(three impairments, present)

Grade 4 – severely reduced quality of life
(all impairments, present- speaking, feeding, presence of disfigurement and pain)

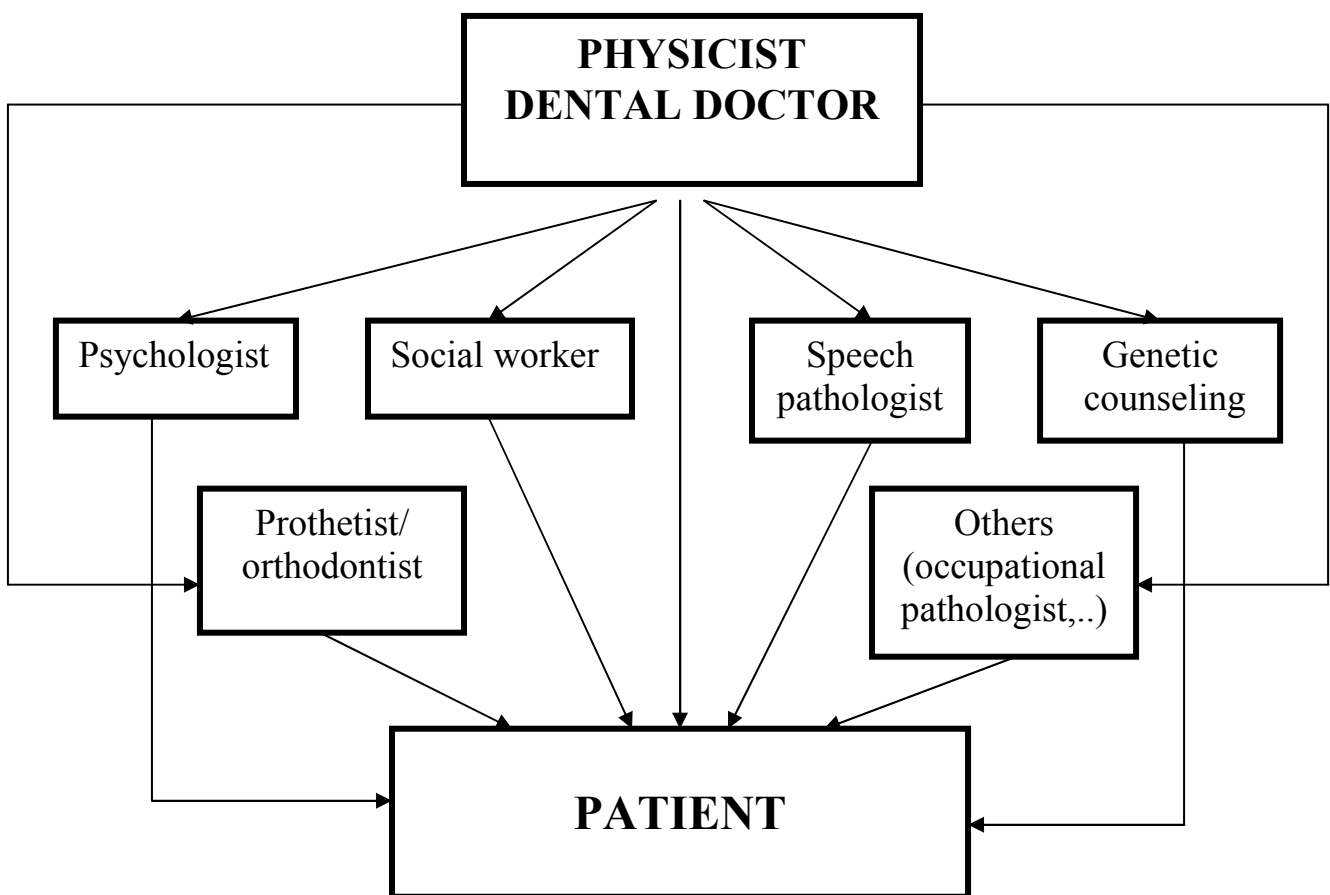
RESULTS AND DISCUSSION

The first step of the medico-social approach towards the patient: The speaking and chewing/swallowing functions are usually damaged by the rare diseases. Sometimes the aesthetics is also damaged. All these factors are impeding the normal life of the patient and can turn him into a social autistic. Using the scale, doctors can quickly assess the life quality and build a social rehabilitation team as soon as the disease is discovered.

The second step of the medico-social approach towards the patient: The social rehabilitation is performed by a team of professionals – *the physician or dental doctor*, that controls the rest of the team; *the psychologist*, that is in charge of the psychic balance of the patient; *the social worker*, helping the patient and its family with their problems, relevant to the disease; *the genetic counseling*; *the legal adviser*, *the occupational therapist*. The speaking ability of these patients is troubled, so the team usually includes a *speech pathologist*, a *nutritionist*, and of course a dental doctor- *prothetist/ orthotist*, and *other specialists*- depending on the problems.(Fig.1)

Figure 1

**SOCIAL REHABILITATION TEAM FOR EXECUTION OF THE
REHABILITATION OF PATIENT WITH RARE DISEASES IN THE
ORAL CAVITY**



CONCLUSION:

The complex approach, which includes: early diagnostics, adequate and quick assessment of the quality of life and social rehabilitation appropriate for every particular case are capable of improving the quality of life and increasing the length of life expectancy of the patients with rare diseases in the oral cavity. The application of medico-social approach is in unison with the *“Rare Disease: Understanding this Public Health Priority”*, *Eurordis 2005* about the priorities in the field of the social health, relevant to the patients with rare diseases.