

ROSACEA - IMPACT ON QUALITY OF LIFE. THE NEED OF EDUCATIONAL PROGRAMS FOR PATIENTS

ROZACEEA - IMPACT ASUPRA CALITĂȚII VIEȚII. NECESITATEA PROGRAMELOR EDUCAȚIONALE PENTRU PACIENȚI

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Abstract

Keywords:

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Due to its location on the face and other visible areas on the body, rosacea can affect patients' emotional status in various degrees. These psychological aspects and patient education should be taken into account when considering treatment options, because the patient's distress has the ability to affect both patient-doctor relationship and therapy adherence. Therefore, treatment goals for rosacea should be, besides the improvement on physical appearance by reducing telangiectasias, erythema, papules and pustules, to maintain remission, to prevent worsening to more severe stages of the disease and, also, to relieve the negative impact on patients' quality of life.

Rezumat

Cuvinte-cheie:

rozacee, calitatea vieții, RosaQoL, comorbidități psihologice, informarea pacienților

Datorită localizării la nivelul feței și al altor zone vizibile ale corpului, rozaceea poate afecta în diferite grade statusul emoțional. Aspectele psihologice, dar și educarea pacienților sunt etape importante ale demersului terapeutic, întrucât disconfortul psiho-emoțional poate afecta atât relația medic-pacient, cât și răspunsul la tratament. Prin urmare, dezideratele terapeutice în rozacee ar trebui să cuprindă, în afară de îmbunătățirea aspectului fizic prin reducerea telangiectaziilor, a eritemului, papulelor și pustulelor, menținerea stării de remisie, prevenirea agravării și a avansării la stadii mai severe ale bolii, dar și îmbunătățirea calității vieții pacienților.

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Introduction

Hundreds of years ago, rosacea has been described as “the curse of the Celts”, emphasizing the major handicap of facial erythema on social relationships, mainly because of its association with alcohol consumption⁽¹⁾ and the high prevalence of rosacea among individuals with I-II Fitzpatrick phototype, especially those of Celtic, Northern European heritage⁽²⁾.

Historically, facial erythema was a major cause for social stigmatization⁽³⁻⁵⁾. Nowadays, it is a known fact that facial blemishes affect the psychological, social and occupational aspects on patients’ lives⁽⁶⁾. These problems must be discussed when designing the treatment options⁽⁷⁾, since, on one hand, the improvement on the physical appearance relieves the negative impact on the quality of life and, on the other hand, the psychological burden and a distressed patient can greatly influence management options and outcomes⁽⁸⁾.

Questionnaires

Up to date, the main tools used to evaluate rosacea’s impact on the quality of life (QoL) have been the DLQI (Dermatology Life Quality Index) and WTP (Willingness to pay). DLQI documents the psychological impact on the QoL of over 40 dermatological illnesses, therefore it is not specific for rosacea. 11 studies used it in the attempt to quantify the emotional burden in rosacea patients and they proved that efficient treatment has a positive influence on the QoL⁽¹⁾.

One recent study used WTP system in rosacea and concluded that patients present a medium willingness to pay (WTP) and a relatively reduced impact on QoL; on average, rosacea patients were

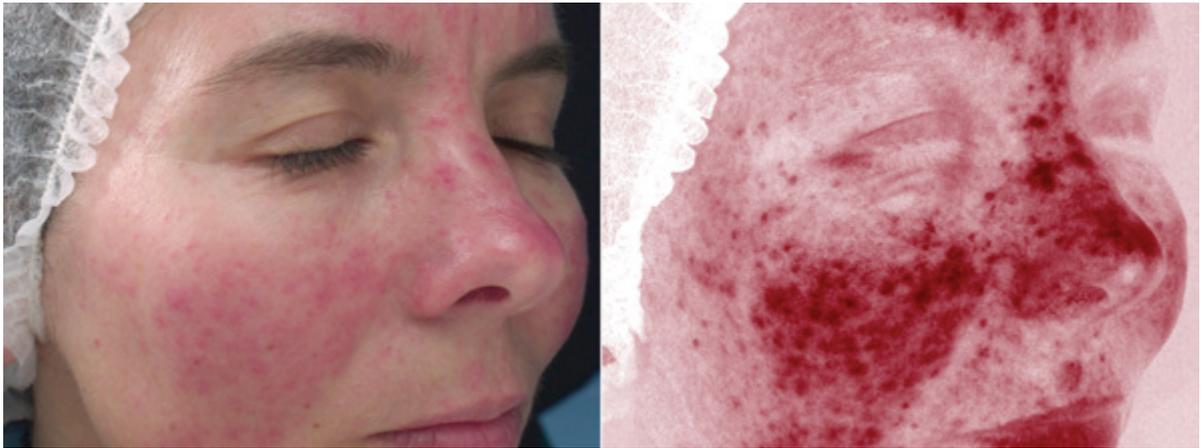
willing to pay 500 Euros to achieve healing, in comparison with vitiligo patients who were willing to pay up to 3000 Euros⁽⁹⁾.

In 2007, a group of researchers from the United States of America designed a rosacea-specific quality of life index, named RosaQoL, a 21 items questionnaire, developed to evaluate the burden of the disease on daily living. This instrument can also be used to compare the influence of different clinical stages of the disease on the QoL. After using this method, the authors concluded that the phymatous stage has the most profound impact on patient’s QoL^(10,11), while other researchers using RosaQoL demonstrated that flushing and skin appearance are some of the most critical factors for patients⁽¹²⁾. RosaQoL has been approved in USA and translated in some European countries (France, Germany, Italy, Spain).

Quality of life

Because of its location in extremely visible places, rosacea may have a profound impact on patients’ lives⁽¹³⁾, who might suffer from anxiety, depression or social phobia⁽¹⁾.

In the XVIIth-XVIIIth century, rosacea, referred as “guta rosea”, was a very well known term associated with alcohol abuse, lack of refinement, shameful sexual habits and, overall, an unhealthy lifestyle. Rosacea was regarded as an illness of the lower social classes, especially people who worked in extreme weather conditions, while the term “cupe-rose” was even more shameful, being associated with inadequate moral conduct⁽¹¹⁾. It is therefore obvious that all of these misconceptions made rosacea a socially stigmatizing condition for many people in the past and, even though nowadays it is no longer regarded in such a shameful manner,



facial flushing and phymatous skin changes are still sometimes mistakenly attributed to alcohol abuse.

This is the reason why rosacea patients can experience embarrassment (70%), low self-esteem (75%), frustration associated with their disease, impaired social functioning^(14,15,16), all of these leading eventually to social and professional isolation^(17,18). Females seem to be more affected regarding overall emotional well-being by facial erythema, with potential implications on therapy outcome⁽⁶⁾.

One study comparing 40 patients with rosacea to healthy individuals, found that the first group suffered from anxiety and depression, felt less satisfied with their lives, had a worse perception on their health status, described difficulty functioning in everyday life and, interestingly, felt that they received poor social support⁽¹⁹⁾. Other studies revealed similar findings, rosacea being responsible for a decrease in patients' self-esteem, emotional status and social activities⁽²⁰⁾.

Psychological comorbidities

Similar to other dermatological conditions affecting visible sites, rosacea patients suffer from mental stress^(21,22) and social stigmatization, sometimes leading to psychiatric comorbidities. To make things worse, rosacea can flare up suddenly, on account of various factors, both emotional and environmental, but the treatment options still remain limited for many of its symptoms, which can only augment the patients' psychological burden.

Consequently, patients with rosacea may associate psychological comorbidities, such as anxiety disorders, social phobia^(23,24), or even depression^(25,26,27,28), especially if their dermatologic disease is correlated with cosmetic disfigurement.

Another interesting aspect is that psychological factors are considered potential triggers in rosacea, some studies even showing higher rates of depression among patients with rosacea (29,30). The largest of these studies used the data bases collected by the National Ambulatory Medical Care Survey and the outpatient component of the National Hospital Ambulatory Care Survey in the

USA and concluded that the percentage for depression in the rosacea group was 95%⁽²⁹⁾.

Other scientists evaluated the impact of stressful critical life events on rosacea sufferers, comparing them with healthy subjects. The results showed that critical life events were experienced with higher intensity of stress levels by people with rosacea and that their emotional state had a negative impact on the symptoms⁽³¹⁾.

Patient education

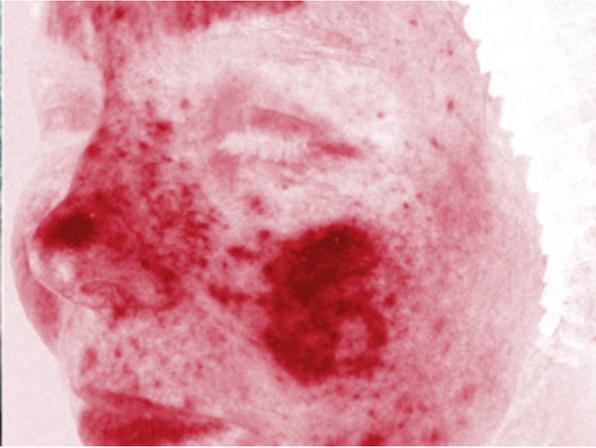
Treatment strategies should take into consideration all therapies available in order to reduce erythema, papules and pustules, to prevent relapses, to avoid exacerbations and, last but not least, to improve patient's quality of life. To summarize all these treatment aims, the triad of rosacea care comprises education, skin care and treatment.

A survey conducted in 2014 in some European countries (Germany, UK, France) and the United States which included 807 patients concluded that, during the patient-physician interaction, the key factors of patient's satisfaction were counseling, duration of consultation and the type of examination. In addition, stress management techniques, such as relaxation, yoga or breathing exercises have been proved to reduce stress and anxiety⁽³²⁾.

The evaluation of the Canadian Rosacea Awareness Program conducted in 1995 has shown that patients appreciated receiving verbal information as well as written material about rosacea from their doctor, but they also had a strong interest regarding skin care, make-up and the psychological aspects of rosacea⁽³³⁾. Patients strongly felt that written materials helped them to know and to avoid trigger factors, making it easier for them to live with their disease, while women considered that the use of cosmetic products to conceal skin lesions can help them to improve self-image and quality of life⁽³⁴⁾.

Conclusions

Rosacea is a chronic inflammatory skin condition affecting not only the patients' physical appearance but also their psychological status and



overall wellbeing. The estimation of patient's subjective health is therefore of great importance and psychological support, when needed, should be discussed and provided promptly because it may increase the efficacy of topical and systemic therapy, while greatly improving quality of life.

Patient education is another important factor in the management of rosacea. Verbal and written materials about trigger factors, sun avoidance, therapy options and make-up tips have been shown to improve therapy adherence and patient

satisfaction. In addition, stress management techniques should be discussed and recommended since they may help patients to reduce their stress and anxiety, with good results on the overall therapy outcome.

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