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Position statement of the European Academy of Dermatology and Venereology Task Force on Quality of Life and Patient Oriented Outcomes on quality of life issues in dermatologic patients during the COVID-19 pandemic Running head: Quality of life during COVID-19 pandemic

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16

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Conflict of interest

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Abstract

The pandemic of COVID-19 is a global challenge for health care and dermatologists are not standing apart from trying to meet this challenge. The European Academy of Dermatology and Venereology (EADV) has collected recommendations from its Task Forces (TFs) related to COVID-19. The Journal of the EADV has established a COVID-19 Special Forum giving free access to related articles. The psychosocial effects of the pandemic, an increase in contact dermatitis and several other skin diseases because of stress, disinfectants and protective equipment use, especially in health care workers, the temporary limited access to dermatologic care, the dilemma whether or not to pause immunosuppressive therapy, and, finally, the occurrence of skin lesions in patients infected by COVID-19 all contribute to significant quality of life (QoL) impairment. Here we present detailed recommendations of the EADV TF on QoL and Patient Oriented Outcomes on how to improve QoL in dermatologic patients during the COVID-19 pandemic for several different groups of patients and for the general population.

Introduction

The pandemic of COVID-19 is a global challenge for health care.¹ Dermatologists are not standing apart from trying to meet this challenge. Many dermatologists have been infected and at least two have died because of COVID-19. Most dermatology organizations have placed statements on COVID-19 on their web sites. The European Academy of Dermatology and Venereology (EADV) has collected recommendations from its Task Forces (TFs) related to COVID-19. The EADV advises the public to adhere to official recommendations and advice to reduce the spread of respiratory viruses and risk of exposure during the COVID-19 outbreak; to follow the instructions and regulations of national and local health authorities; to follow current public health advice practices (protective measures and advice by the World Health Organisation); to disregard and stop the spread of fake news by checking sources and reliable fact-checkers; to respect hygienic measures and social distancing; and not to alter, interrupt or stop any chronic treatment without consulting your prescribing physician

(https://www.eadv.org/cms-

admin/showfile/12_Recommendations%20and%20general%20advice%20for%20p atients.pdf (Last access 12.05.2020). The Journal of the EADV has established a COVID-19 Special Forum

(https://onlinelibrary.wiley.com/doi/toc/10.1111/(ISSN).1468-3083.COVID-19) that gives free access to related articles.

The psychosocial effects of the pandemic,² an increase in contact dermatitis and several other skin diseases because of stress, disinfectants and protective equipment use, especially in health care workers,^{2,3} the temporary limited access to dermatologic care,^{4,5} the dilemma whether or not to pause immunosuppressive therapy,⁶⁻⁸ and, finally, the occurrence of skin lesions in patients infected by COVID-19⁹⁻¹¹ all contribute to significant quality of life (QoL) impairment. We would like to stress the importance of social isolation, social distancing, hygiene

measures including disinfectants and use of protective equipment, as well as the importance of strictly following national recommendations related to COVID-19 even though in some cases this may lead to a temporary impact on QoL. However, this negative effect on QoL can be reduced. The presence of skin lesions and disease severity are the main drivers of QoL impairment in patients with skin diseases but other factors (i.e. difficulties in social and leisure activities; difficulties in significant relationships with others, including partners, close friends, and/or relatives; embarrassment; self-consciousness; aggression and frustration) may also influence the decision of patients to seek advice from a dermatologist.¹² Therefore, in general, the prevention of skin diseases and of their relapses, effective treatment and skin care are the main strategies for QoL improvement and this is what we have therefore focused on in our TF statement. Nevertheless, methods that may target other QoL factors are also important. The EADV TF on QoL and Patient Oriented Outcomes (PO) is working on a review initiated by Prof. A.Y. Finlay (Cardiff) on methods to improve the QoL of patients, beyond medicines, and we consider that methods such as multidisciplinary educational programmes, psychologic interventions, counselling/support to promote behavioral changes, religious/spiritual well-being, music, and diet, all of which have been reported to improve the QoL of patients with skin disease, may be especially important during quarantine and self-isolation. Here we present detailed recommendations of the EADV TF on QoL and PO on how to improve QoL in dermatologic patients during the COVID-19 pandemic for several different groups of patients and

general population. Data on the principles of QoL assessment in patients with skin disease may be found in other publications of our TF.¹³⁻²²

COVID-19 patients with skin involvement (because of virus effects or side effects of treatment) – A range of different skin lesions in COVID-19 patients have been reported.⁹⁻¹¹ One presentation may be pseudo-chilblain (chilblain-like or pernio-like) lesions of the feet and/or hands.¹⁰ The American Academy of Dermatology (AAD) recommends that if a patient presents with a new onset of pseudo-chilblain lesions, potentially related to COVID-19, then there should be a discussion between the patient and physician on the appropriateness of selfisolation following national guidelines and testing, according to local testing guidelines (American Academy of Dermatology. Dermatological manifestations of COVID-19

https://www.aad.org/member/practice/coronavirus/clinical-

<u>guidance/dermatological-manifestations-covid-19</u>, last accessed 09 May 2020). That isolation, however, may lead to further reduction in QoL because of the impact of isolation on work, everyday activities and social life.

COVID-19 patients with skin involvement should be reassured that their lesions are not by themselves life-threatening and that they usually have no serious consequences. However, antihistamines, corticosteroids, emollients and other medicines may be prescribed, based on the clinical presentation and symptoms. Drug reactions should be treated in accordance with standard recommendations. Patients with skin diseases infected by COVID-19 – Worsening of the clinical course of pre-existing skin diseases because of COVID-19 infection has not so far been reported. A difficult clinical decision is whether or not to stop immunomodulatory or immunosuppressive treatments in patients infected by COVID-19 who have psoriasis, atopic dermatitis, hidradenitis suppurativa or autoimmune blistering diseases. Even before the COVID-19 pandemic it was reported that concerns about biological treatment discontinuation created uncertainty and insecurity and resulted in fear and negative beliefs about the future.²³ A literature review examining biologic therapy compliance and persistence in chronic inflammatory diseases showed that its irregular use was associated with lower clinical effectiveness.²⁴ Meanwhile, maximal improvement of disease severity is important to reach normal QoL in psoriatic patients.²⁵

The AAD recommends that patients on systemic immunosuppressive agents who have tested positive for COVID-19 or who exhibit signs/symptoms of COVID-19 should discontinue or postpone the systemic immunosuppressive agents until the patient recovers from COVID-19. This is consistent with guidelines on the management of patients with active infections on systemic non-biologic and biologics therapy (American Academy of Dermatology. Guidance on the use of immunosuppressive agents.

https://www.aad.org/member/practice/coronavirus/clinical-guidance/biologics, last accessed 09 May 2020). A group of specialists in autoimmune blistering diseases considered that azathioprine, mycophenolate mofetil/sodium, cyclophosphamide, methotrexate, and cyclosporine may be stopped for the duration of COVID-19 symptoms, whereas topical corticosteroids, prednis(ol)one $\leq 10 \text{ mg/d}$, dapsone/sulfapyridine, doxycycline/tetracycline, colchicine, and intravenous immunoglobulins can be continued.⁸ The European Task Force on Atopic Dermatitis (ETFAD) noted that immune-modulating drugs used for treating AD also affect the severity of co-morbidities such as asthma, chronic obstructive lung disease, eosinophilic esophagitis, kidney disease and severe allergies and that the abrupt termination of a stable systemic treatment regimen may lead to exacerbations of AD and other comorbidities.⁶ Lebwohl et al., based on "precoronavirus era" studies noted that discontinuation of some biologics can result in loss of response when treatments are reintroduced or even result in the formation of antibodies to the discontinued biologic. They concluded that these factors must be considered when advising patients about continuing or discontinuing biologic therapies.⁷ All published recommendations reach a common conclusion that there is a lack of practical experience; that it is important to assess the risk/benefit ratio before any decision to pause biologics and immunosuppressants; and that it is important to adhere to the advice from local health authorities in each country. However, there is an optimistic report from Italy that all patients with psoriasis on biologic therapies who were hospitalized because of COVID-19 infection survived and recovered from infection²⁶, there are case reports on successful recovery from COVID-19 of patients that for different reasons did not pause treatment with biologics^{27,28} and an anecdotical report on improvement of the respiratory condition, normalization of body temperature and progressive relief of myalgia and fatigue symptoms after self-administered injection of guselkumab by a psoriatic patient.²⁹

Patients with skin disease at a risk of COVID-19 infection – A number of skin diseases may be exacerbated by stress, by toxic substances and allergens found in disinfectants and cleansers and to a lesser degree by the use of protective masks. These items may increase pruritus in this group of patients.³⁰ Significant correlation of occupational contact dermatitis and hand eczema severity with QoL was previously reported.^{31,32} Therefore, preventive and treatment measures are very important for QoL improvement.

We endorse the following recommendations of the EADV Task Force on Contact Dermatitis: to use soap without fragrance, preservatives and with a low sensitizing potential or to use hydro alcoholic solutions with glycerin followed by additional regular use of a fragrance-free emollient; to protect the hands with a fragrance-free, lighter moisturizing lotion during the day after each handwashing procedure and a fragrance-free, lipid rich moisturizer before bedtime; to use a double set of gloves for prolonged periods and careful cleansing of such gloves with hydro alcoholic solutions (in order to minimize sweating and skin irritation, cotton gloves should be worn underneath as liners); to use dressings at pressure points on the face and ears to prevent rubbing from masks and goggles, such as hydrocolloid dressings, or to fix these dressings with dimethicone polymers or silicone gels to minimize the risk of adverse cutaneous reactions from mechanical friction; and to restrict the duration of wearing of protection equipment.³ Italian data suggest that a lot of dermatologic patients were completely unprepared, upset, and disoriented by the lock down. Some patients could not understand the crisis and demanded full attention, quite aggressively.³³ The absence of the possibility to consult a dermatologist in the usual face-to face fashion and receive treatment recommendations has the potential to cause significant decrease of HRQoL. Teledermatology (TD) and phone consultations should be widely used and temporarily replace normal consultations except of course for emergency cases, during the pandemic. For example in the report from Italy, patients being followed-up for chronic dermatoses were provided with the opportunity to contact their dermatologists by telephone or e-mail and to submit clinical images to them.³⁴ The EADV TD TF has recommended the ways how in which distance consultations may be carried out in dermatology (<u>https://www.eadv.org/cms-</u>

<u>admin/showfile/9_Dermatology%20during%20times%20of%20social%20distanci</u> <u>ng.pdf</u> (last accessed 14 May 2020): TD may be considered asprimary, secondary or tertiary TD. In primary TD the doctor interacts directly with the patient; in secondary TD the interaction is mediated by the GP; tertiary TD is a way of communication and consultation among doctors. In each of these approaches it is possible to use a store and forward (SAF) modality (patient information such as a photograph, historical and background information is sent online as digital files to a clinician who reviews the data hours or days later); take part in a real time interaction or a hybrid approach, a combination of both. Generally, patients should follow the recommendations of their dermatologists received before the pandemic. The ETFAD recommends the continuation of all immune-modulating treatments, including immuno-suppressive therapy, since exacerbations of underlying diseases can have a large negative impact on patients' immunity. They also suggest that the recommendations for patients at risk issued by the local health authorities in each European country should be strictly followed.⁶ Experts on autoimmune blistering diseases also endorsed these recommendations.⁸ Systemic treatment is usually prescribed to patients who have severe refractory signs and dramatically impaired QoL. If possible, long-term systemic treatment should be continued in a standard regime and may help patients avoid both clinical and psychological consequences of treatment discontinuation and associated decrease of their QoL. Nevertheless, it is important to follow local recommendations in each case.

Healthcare professionals with skin lesions induced by COVID-19 prevention measures – A high prevalence of contact dermatitis because of disinfectants and individual protective equipment use has been reported among healthcare professionals working with COVID-19 infected patients.³⁵ The recommendations of the EADV TF on Contact Dermatitis³, presented above, are especially important to this group of health professionals. Several prevention programmes for patients with occupational hand eczema and occupational contact dermatitis showed a very significant short-term and long-term (up to 5 years follow-up) positive effect on the clinical course of diseases and on QoL.³⁶ The EADV TF on QoL and PO highlights the importance of using this experience to organize prevention programmes for healthcare professionals working with COVID-19 patients. This is an urgent task. Both internet and face to face options can be used for this purpose based on local realities.

General population – The outbreak of contact dermatitis caused by hand washing and by wearing of protective equipment is expected not only among healthcare professionals but also in the general population, because of the extensive use of disinfectants and protective masks. The recommendations of the EADV TF on Contact Dermatitis³ will be also helpful for this group. Educational information may be spread using mass media, social media and text messages. It should be placed on the web sites of related professional and patient organizations.

Relationships with partners, family members and friends are an important part of QoL.

QoL of family members and partners of: COVID-19 patients with skin involvement, patients with skin disease at a risk of COVID-19 infection and healthcare professionals with skin lesions induced by COVID-19 prevention measures – Skin diseases are known to have a major impact on the lives of patients and their families.³⁷ The 'Greater Patient' concept was proposed to describe the immediate close social group affected by a person having skin disease.³⁸ Most of the studies on family QoL in dermatology have been focused on parents of children with skin diseases.¹⁸ Parents of school children with skin disease are generally less stressed, tired, and exhausted than parents of preschool children with skin disease.³⁹ We presume that parents of small children with skin diseases and children infected by COVID-19 with skin manifestations will have the highest QoL impairment. Parents of children with skin diseases at a risk of COVID-19 should receive information on effective preventive measures and access to online or phone consultations if needed. Family members of adults may also benefit from mutual activities (i.e. changes of behavior, religious/spiritual well-being, music, diet, etc.) and, of course, from good and supportive relations inside the family.

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