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The effects of autoimmune blistering diseases on work productivity: A review[☆]

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ABSTRACT

This review examines the work productivity in patients with autoimmune blistering diseases (AIBDs). Work productivity and employment are important aspects of a patient's life, which can be affected by diseases. The Work Productivity and Activity Impairment Questionnaire (WPAIQ) is a validated instrument that can measure work productivity and assess the impact of disease on patients' work lives. There is currently a paucity of research that investigates the reason why AIBDs cause such a large impact on work productivity and whether AIBDs affect employment status. Using quality of life (QoL) instruments in conjunction with the creation of an adapted WPAIQ to examine the reasons behind work impairment may further characterize these effects and unveil a deeper understanding of stigmatization in the workplace as a factor of loss of work productivity.

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Introduction

Autoimmune blistering diseases (AIBDs) refer to a group of diseases that manifest as blisters due to the action of autoantibodies against adhesion proteins in the skin. The major subtypes of AIBD are pemphigus vulgaris (PV), pemphigus foliaceus (PF), bullous

pemphigoid (BP), mucous membrane pemphigoid (MMP), linear immunoglobulin A dermatosis, and epidermolysis bullosa acquisita (EBA; Murrell, 2015).

Dermatological diseases can lead to serious issues for patients in their daily lives and adversely affect their quality of life (QoL; Sebaratnam et al., 2012a, 2012b). Few studies have explored and quantified the effect of AIBDs on QoL (Rencz et al., 2015). However, there is an even greater paucity of research that specifically investigates their effect on employment, which remains an integral aspect of life and hence necessitates this literature review. In this review,

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we will examine the effect of AIBDs on QoL and more specifically on work productivity and whether further studies should be performed to address this issue.

Quality of life

QoL is a broad social concept that can be defined as an "individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (World Health Organization Quality of Life Assessment, 1995). AIBDs can severely impact QoL. The disfiguring nature of the disease and especially the visible skin lesions negatively affect self-confidence and limit social capacity (Sebaratnam et al., 2012a, 2012b). Hence, it is conceivable that workplace life and work productivity are also affected. Table 1 summarizes various studies that pertain to QoL and work productivity in patients with AIBDs and other dermatological diseases.

Several assessment tools exist to quantify and measure the impact of disease on QoL and enable the monitoring of the effects of disease and understand the facets of life that are most impacted, which is necessary to provide holistic care (Sebaratnam et al., 2012a, 2012b). These measurement tools generally fall into three categories: generic, skin-specific, and disease-specific.

The Medical Outcome Study 36-item Short-form (SF-36) survey is an example of a generic instrument that can be used to compare disease populations. The limitations of the SF-36 include its lack of specificity and how some measurements of improvement in QoL are limited on a 0-to-100 scale (i.e., scores over 100 are impossible and hence, further improvement in those specific areas cannot be documented; Chee and Murrell, 2011).

The Skindex is a skin-specific tool that has been refined in the form of multiple questionnaires, including Skindex-29, Skindex-17, and Skindex-16. A study that was conducted by Tabolli et al. (2014) using the Skindex-17 with 213 patients with pemphigus found that patients with active lesions had a worse QoL compared with patients without bullae. For the psychosocial component of the questionnaire, patients with bullae scored 42.4 ± 26.8 compared with patients without bullae who had a mean score of 30.9 ± 23.5 ($p < 0.01$). Higher QoL scores indicate better QoL. Item 13 of the Skindex-17, which measures frustration due to the disease, had a notably large difference between patients with and without active lesions. The authors suggested that the visibility of the lesions along with possible exudation of the bullae fostered stigma toward patients (Tabolli et al., 2014).

The Dermatology Life Quality Index (DLQI) is another example of a skin-specific measurement tool. Ghodsi et al. (2012) investigated 61 patients with PV and found an average DLQI score of 10.98 ± 6.9 , which indicates significant impairment. Higher DLQI scores indicate a worse QoL. Itching, burning skin, and mucosal burning were associated with higher DLQI scores (Ghodsi et al., 2012). However, the DLQI has been suggested to be more suited to measure the effects of skin conditions such as eczema or psoriasis (Chee and Murrell, 2011).

The Autoimmune Bullous Disease Quality of Life (ABQoL) questionnaire is the only disease-specific tool used for patients with AIBDs (Sebaratnam et al., 2013). The advantage of disease-specific tools is their ability to capture the small changes in specific diseases, which general tools such as the SF-36 or DLQI may miss. The ABQoL questionnaire targets the facets of QoL that are affected more in patients with AIBDs, which owes to its content validity (Sebaratnam et al., 2013). The ABQoL questionnaire is scored out of 51 points. Above 20 points is considered a high score and indicates worse QoL and below 7 points is considered low.

In the initial validation study, the ABQoL score was 11.5 ± 5.5 for patients with PV and 8.4 ± 5.5 for patients with BP. The ABQoL questionnaire was found to have poor convergent validity with the SF-36 and moderate convergent validity with the DLQI. The Cronbach alpha

score was 0.84, which affirms the test's internal consistency (Sebaratnam et al., 2013). The ABQoL questionnaire was also found to be significantly more sensitive than the DLQI in terms of discriminative validity (Sebaratnam et al., 2013). Findings from a study that was conducted in the United States supported the reliability of the ABQoL questionnaire, with a Cronbach's alpha score of 0.90.

In terms of validation across different cultures and languages, the ABQoL questionnaire has also been validated recently in American English (Sebaratnam et al., 2015), Mandarin and Polish. The Chinese study reported the ABQoL scores as 17.23 ± 1.35 for patients with PV and 16.60 ± 2.90 for patients with BP (Yang et al., 2017). The Polish study reported a mean ABQoL score of 16.3 ± 9.9 for all patients, with 17.4 ± 12.4 for patients with PV and 15.7 ± 9.5 for patients with BP (Kalinska-Bienias et al., 2017).

AIBDs are chronic illnesses and patients may require aggressive, long-term treatment. When measuring QoL, discriminating between disease effect and treatment effect can prove to be difficult. The Treatment of Autoimmune Bullous Disease Quality of Life (TABQoL) questionnaire, which is a tool to measure the impact of AIBD treatment, was developed from the pilot ABQoL questionnaire. The TABQoL questionnaire was found to have high convergent validity with the ABQoL questionnaire, moderate convergent validity with the DLQI, and low correlation with the SF-36. The Cronbach alpha score was 0.892, which confirms internal consistency and construct validity. The utilization of the TABQoL questionnaire in conjunction with the ABQoL questionnaire or DLQI may be useful to document changes in QoL due to treatment intensity or side effects (Tjokrowidjaja et al., 2013). The TABQoL questionnaire has been validated in Polish and Mandarin (Kalinska-Bienias et al., 2017; Chen et al., 2017).

Work productivity instruments

As established in the literature, the deleterious effects of AIBDs can unfold in many domains of a patient's life. Measuring work productivity is important to assess the efficacy of treatment and demonstrate whether treatment is helping patients manage their diseases while remaining employed. Having a chronic illness results in days off work and reduced productivity while employed (Prasad et al., 2004). The loss in work productivity in patients with diseases such as psoriasis have been proven to result in an enormous economic burden (Chan et al., 2009). Quantifying loss in work productivity is invaluable to economic evaluations of healthcare (Tang, 2015).

Several instruments exist to calculate loss of work productivity. Prasad et al. (2004) examined six different instruments including the Work Productivity and Activity Impairment Questionnaire (WPAIQ), Work Limitations Questionnaire (WLQ), Health and Work Performance Questionnaire (HPQ), Health and Work Questionnaire (HWQ), Endicott Work Productivity Scale (EWPS), and Health and Labor Questionnaire (HLQ). The researchers concluded that the WPAIQ and WLQ offer more advantages over the other instruments and their psychometric properties (i.e., validity and reliability) have been more comprehensively tested in previous literature (Prasad et al., 2004). Tang (2015) supported this finding but asserted that more extensive psychometric testing does not necessarily substantiate the claim that the WPAIQ and WLQ are superior instruments.

A notable advantage of the WPAIQ is its relatively short recall period of 1 week compared with the WLQ, which has a recall period of 2 weeks and is important to minimize recall bias (Prasad et al., 2004). A limitation of the WPAIQ is its inability to assess task-specific productivity because questions only exist to assess overall reduced productivity (Prasad et al., 2004). A limitation of the WLQ is that it does not measure absenteeism, which is defined as the percentage of work hours missed (Tang, 2015). Absence from work should be an important aspect to consider because that is likely to affect work

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