EDITORIAL

Uncovering the Life-long Impact of Skin Disease on Major Life Changing Decisions

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There are (at least) three dimensions to the impact of skin disease on life quality (1). The focus in clinical settings and in research is usually on the impact on the patient "now". The next dimension, which is obvious to any dermatologist who has cared for a child with severe atopic dermatitis, is the impact on the quality of life of other family members or primary caregivers. The exhausted, sleep deprived and worried mother immediately comes to mind. But never forget the third dimension, arguably the most profound, the negative impact on the life course of the patient. This impact echoes through the coming decades because skin disease often influences a person's major life-changing decisions (MLCD).

In this issue, Fuentes-Barragán et al. (2) describe how they went back to the original qualitative article that revealed the MLCDs reported by patients across a range of skin and other conditions (3). Based on these reported affected decisions, they created a "one-off" series of questions which they used to record which and how many MLCDs were influenced in a series of adults with chronic atopic dermatitis (AD). As expected, they identified a wide range of affected MLCDs, with the most affected related to clothing, lifestyle, and sports activities. Those with severe AD experienced a greater impact on their MLCDs. Although there was of course considerable overlap, Fuentes-Barragán et al. did not use the validated series of questions that make up the MLCD Profile (MLCDP) (4), which were also based on the original qualitative article by Bhatti et al. (3). Nevertheless, their conclusions are of potentially great importance as they have demonstrated the wide range of MLCDs that are influenced in adults with chronic AD. The impact is profound, and even if a person's AD was (miraculously) completely controlled by one of today's biologics, the person's life would have irrevocably been steered differently by the disease. This is a powerful argument for early and effective intervention.

There is a similarly profound effect on MLCDs resulting from having severe psoriasis. Sanchez-Diaz et al. (5) reported that the most affected MLCDs were career choice, social relationships, choice of clothing, job performance, absenteeism, and choice of holiday destination. Furthermore Bien et al. (6) highlight the impact on other lifestyle factors such as physical activity, diet, smoking and alcohol use. They also identified that people who struggle with accepting their condition were more likely to experience negative effects on their life choices.

When the developers of the MLCDP first investigated this concept (7), they initially assumed that what constituted "major life changing decisions" would have already been defined in the literature. However, this was not the case. They therefore investigated the concept by asking a wide range of patients what would, for them, constitute a MLCD (3). The MLCDP was constructed from these responses (4).

The final version of the MLCDP consists of 32 items, each concerning a different MLCD, and the responder records whether or not that decision (if taken) has been affected, and if so to what degree. It is simple to calculate a score representing the total number of decisions affected, which provides an overall indication of how a person's life course has been influenced by their health condition. The MLCDP does not identify which MLCDs were of most importance to the person completing the questionnaire, but the subject may also record for each decision to what extent each decision had been affected, providing more nuanced information about specific life issues. The MLCDP questions cover five domains: education, job/career, family/relationships, social and physical.

The concept of MLCDs is interwoven with the concept of cumulative life course impairment (CLCI), as initially described in the context of psoriasis (8), but the two concepts have distinct characteristics (9). Life course impairment refers to the changes (usually permanent) in someone's life that have been caused by their health condition. Life course impairment therefore describes the overall long-term effect on a person's life caused by a health condition, whereas MLCDs, influenced by the health condition, are the key turning points that lead to life course impairment. CLCI can be quantified using DermCLCI-r, which assesses retrospective CLCI, and DermCLCI-p, which assesses current CLCI and future risk (10). Each tool consists of 30 items.

Just as having a health condition may have a current secondary effect on the lives of partners and other family members (11), there may also be a secondary effect on the MLCDs of partners and family members. This has been explored in the families of children with atopic dermatitis (12): parents and other caregivers reported that several of their own MLCDs had been strongly influenced by their caring responsibilities.

So why does understanding about MLCDs matter? In the clinic the emphasis is rightly on improving the current health of the patient. If successful, this in turn should allow the patient MLCDs to be less affected by their health, and more focussed on the person's direct personal choices. This will also have a positive effect on the wider social support group of the patient. Furthermore, the concept of MCLDs also places a focus on earlier and more effective interventions to lessen the impact of future clinical burden on patient quality of life. If patients are supported and treated earlier, perhaps certain negative lifestyle choices may be mitigated and addressed at crucial junctures in life reducing the burden on the patient as well as healthcare resources. However, cure may often not be possible, and so people with skin conditions may benefit from more comprehensive and holistic approaches such as counselling, psychological support and from better understanding how their future lives could be lived as they wished, despite their skin condition.

Conflict of Interest statement: Cardiff University receives royalties from some use of the MLCDP and FROM-16. AYF receives a share of these under standard university policy. A share of the royalties supports research in the university department in which FMA is employed.

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