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Letter to the Editor

Seeding the value based health care and standardised measurement of quality of life after burn debate

Dear Editor,

As experienced clinicians and researchers in burn care, we are impressed and energised by the continued progress towards One World, One Standard of Burn Care as initially promulgated by Dr David Mackie, Past President of the ISBI and reinforced at ISBI in New Delhi (2018). Sadly, we are unable to continue the discussion at burn clinician meetings in 2020 due to the impact of the COVID-19 pandemic. That said, we acknowledge and applaud the ongoing progress in critical care, infection control, nutritional support and continued innovations in surgery, dressing systems, reconstructive biotechnology and tissue regeneration. Mortality post-burn and the pathological framework of recovery is consequently and appropriately fading from the literature as preferred, contemporary outcome measures [1].

The global movement for value based, patient-centred care is also progressing rapidly and perhaps with the overlay of COVID-19, the world will take stock and consider what constitutes a positive outcome after a significant health event. So, what is the next evolutionary step towards *patient-centric* measurement of recovery after a burn? The obvious answer, for our unique patient population, may be *to measure scar outcomes* and the maturation and, or elimination of physical scarring. That is a noble and worthwhile pursuit accepted by a number of groups around the world [2,3]. That said, is this what patients *truly* care about and value the most? Without exception, every burn clinician has a patient whom they can identify, irrespective of major scarring, has moved on and rebuilt their lives or established a new meaning for living and, or stands as an inspiration to future patients.

Perhaps then, should we refocus our efforts on measuring the impact of scarring of the mind on recovery of quality of life (QoL)? No matter how fine the quality of post-burn scar is or how quickly skin repair occurs or when regeneration of wounded skin to normal appearance is a reality, nothing can unseen the sights or reverse the experience of the sensations of burn recovery.

What is *meaningful* to patients is the restoration of QoL, whatever that means to an individual. The World Health Organisation (WHO) defines this concept 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*" [4]. We therefore, purport that patient-reported outcome measures (PROMs), which quantify the individual's perception of aspects of their QoL; and, patient-reported experience measures (PREMs) are integral to collaborative care focussing on optimal, holistic outcomes. Further, repeated, real-time capture of surveys represent the patient voice about aspects of health that are directly assessed by a patient without the interpretation or bias from anyone else [5]. These surveys provide us with an important view of an individual's health across multiple domains which go beyond any pathophysiological measure and there is substantial literature validating PROMs in particular, for use after burn injuries [6,7].

We therefore suggest that, measuring and defining recovery of QoL for our patients is the next frontier to conquer in outcome measurement after burns. Yet, many clinicians struggle with the concept of assessing this multidimensional outcome in a biopsychosocial construct; face pitfalls in using QoL measures; and, do not know where to start in setting up systematic measurement or interpretation of the same. In a recent review on QoL after burn injuries, it was highlighted that consensus and a guideline on the measurement of QoL in burn patients might overcome these issues [8].

Thus, Mr Editor we wish to *invite comment* on what we see as the simplest, best practice goal for all multidisciplinary teams in measuring QoL recovery after burns. First and foremost, we purport that systematic measurement is key in monitoring the broad variability of responses that may be a reflection of the patient's experiences of the care they receive and the outcomes, both short and long term. Thus, we strongly suggest teams pilot a standardised schedule of 4-6 weeks, 3 months, 6 months, 12 months and 24 months after burn injury date which is in accordance with the most frequently used assessment time points [8].

Secondly, we *invite a debate* on what should be the *one survey* to be used from 2020 for systematic QoL benchmarking in adult burn survivors, worldwide. Notwithstanding, the availability of computerised adaptive testing, the instruments established and emerging include:

(a) Medical Outcome Study Short Form – 36 item (SF-36) [9] for generic QoL measurement in adult burn patients. The SF-36 is a widely applied instrument and the most often used generic instrument to assess QoL in burns [8,10], it is validated for use in the adult burn patient population [11], and it covers many domains that are also covered by the most applied burn specific QoL measure [12]. To reduce patient burden, the shortened, item-subset version (SF-12 v.2 Optum) or the reworded items of the SF-8 may be used, though the latter is not specifically validated in the burn population on account of the reworded items. One major disadvantage is the license fee payable to use and access the algorithm to interpret the survey responses.
(b) Burn Specific Health Scale – Brief (BSHS-B) [13] is one of the most commonly applied burn specific QoL measurement.

Despite its widespread use, there is discussion about this instrument as it lacks a clear guide for scoring/calculation/algorithm); is less sensitive than SF-36 from one month post burn [11], and there is no evidence on test-retest reliability, validity and item-total correlations of the BSHS-B [7].

(c) 5-dimensional EuroQol instrument (EQ-5D) [14] is one of the most widely used generic QoL instruments. With only five items, low patient burden is one key advantage of its use. The EQ-5D has established psychometric properties for burn patients and is therefore proposed to use in burn recovery studies [15] and has multiple cultural translations. Disadvantages include the limited number of items and poorer descriptive capability of QoL compared to other generic instruments; as a consequence, it suffers from ceiling effects.

(d) Veterans RAND – 36 item (VR-36) is a generic QoL instrument that is similar to the SF36 with some modifications of response choices enhancing reliability and validity compared to the former. There is the short form version or VR-12 that is well established. The VR-12 has key adaptations which increase precision and validity compared to the SF36 and SF-12 version 1.0. The VR-6D is a utility metric derived from the 12 items of the VR-12 and also previously validated. The VR-36, VR-12 and VR-6D are available free to readers together with documentation and scoring algorithms upon registration with the authors (with the exception of an administration fee applied to for-profit organisations). The survey has multiple language/cultural translations, though less than the SF36 [16].

(e) The Life Impact Burn Recovery Evaluation (LIBRE Profile) is a Computer Adaptive Test developed to assess the social integration of burn survivors in the community. The recently established assessment has been validated for reliability and validity [17]. Benchmarks also have been advanced for interpretation of scores. The assessment is now undergoing translations of the fixed short form version in Spanish, Australian, Chinese and Japanese. The assessment is available from the senior authors on request.

As our final word, we do value and encourage choosing additional locally applicable measures, but we suggest that if all burn facilities around the world were to commit to collecting the same single QoL survey at least 4-6 weeks and 3 months after burns, we can begin to benchmark across cultures and jurisdictions. With a common, contemporary measure, burn clinicians could communicate more effectively about patient outcomes and support colleagues, in any environment of operation, with a focus on education and training for improvement and progress towards One World, One Standard of Burn Care.

Conflict of interest statement

There are no conflicts of interest to be reported for any authors with the exception of Prof Lewis Kazis. Co-author Kazis was involved in the original development of the VR-36/12/6D and LIBRE Profile survey instruments. These instruments are gratis for non-profit users with acknowledgement and thus, Prof Kazis does not have any direct financial gain through promoting these instruments.

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Letter to the Editor

Comments on "Comparative efficacy of intralesional verapamil hydrochloride and triamcinolone acetonide in hypertrophic scars and keloids"

Dear Editor,

With great interest, we read the study by Ahuja et al. in 2014 [1]. It concluded that verapamil was almost as effective as triamcinolone acetonide (TAC), which provided more options for the treatment of hypertrophic scars and keloids. Moreover, it suggested that verapamil could be an alternative of TAC or used in more or larger scars to reduce the side effects of TAC, simultaneously. Furthermore, a lot of interesting contents were mentioned in the discussion section.

While reading the discussion section, we noticed that they cited a Chinese study and considered that the 5-FU and TAC were weekly delivered intralesionally [2]. Unfortunately, when we viewed the original paper, we found that the injection regimen was every 4 weeks, rather than weekly delivery as mentioned in Ahuja et al. [1].

Additionally, in the evaluation of the treatment effect, the author used the Vancouver Scar Scale (VSS). However, they only compared the scores of each category and did not calculate the total score. Although the scores of some categories were zero, we still thought it was necessary to calculate the total VSS score as Abedini et al. when evaluating the final treatment effect [3].

Through this article, there is a question worth to considering, whether it is necessary to conduct a research on the injection frequency or whether a more frequent intralesional injection will get a better result.