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Development and clinimetric evaluation of the mouth impairment and disability assessment (MIDA)

Marie-Andrée Couture [a], *Valérie Calva* [a], *Ana de Oliveira* [b], *Léo LaSalle* [a], *Nancy Forget* [c], *Bernadette Nedelec* [a,b,c,*]

[a] *Hôpital de Réadaptation Villa Medica, Canada*
[b] *Centre de Recherche, Centre Hospitalier de l'Université de Montréal (CRCHUM), Canada*
[c] *School of Physical and Occupational Therapy, McGill University, Montreal, Quebec, Canada*

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ABSTRACT

Introduction: Burns of the face and mouth region have a profound impact on function. Currently the outcome measure that is most commonly used in the burn care literature is horizontal and vertical opening. Impairment-based outcomes such as this do not capture the functional implications of these injuries in spite of the devastating impact they can have on burn survivor's lives.

Purpose of the Study: To generate an assessment that evaluates the impairments, activity limitations, and participation restrictions associated with mouth injuries and prospectively collect data to examine the clinimetric properties.

Methods: A multistep assessment development process was undertaken including a comprehensive literature search and review, burn care expert and burn survivor interviews, generation of a preliminary version and field-testing, modifications based on field testing and updated literature review, and further field testing with data collection of 23 burn survivors. Clinimetric properties were examined by evaluating: whether there was a ceiling or floor effect, the internal consistency, construct validity, and responsiveness.

Results: The mouth impairment and disability assessment (MIDA) has a 28 item self-report portion, divided into four subscales, completed by the patient and an impairment-based section completed by the burn therapist. Two items demonstrated a ceiling effect, one was removed the other retained. There was strong and statistically significant ($p<0.0001$) correlation of the symptoms subscale as well as vertical opening with the functional activities subscale of the MIDA. The functional activities subscale demonstrated good internal consistency and the symptoms subscale was adequate. Re-evaluation approximately seven and a half months after the baseline evaluation demonstrated a statistically significant change with time and treatment.

Conclusions: The MIDA now offers clinicians the ability to assess mouth impairment and disability of burn survivors who have sustained burn injuries to their face and mouth region.

* *Corresponding author at*: McGill University, Faculty of Medicine, 3654 Promenade Sir William Osler, Montréal, Québec, H3G 1Y5, Canada.
E-mail address: bernadette.nedelec@mcgill.ca (B. Nedelec).

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1. Introduction

The distressing, and sometimes devastating, impairments and disabilities that can occur after a burn of the face and mouth region, due to either the initial injury or subsequent scar contracture formation, are all too familiar to burn survivors and burn care specialists. These injuries may have a profound impact on function, but these limitations are not currently captured by the outcome measures published in the literature.

Traditionally, oral outcomes postburn are measured by quantifying the excursion of oral movement. Although the term "functional" is commonly used, a true measure of function is rarely included [1]. Hashem and Al Khayal [2] described a classification of oral contractures following burn injuries in children based on the type of contracture, the aetiology, the involved structures, the surgical treatment, and the type of orthotic device that was applied. Koller et al. [3] used a faciometer to quantify the range of motion after facial burns. The faciometer was used to quantify the maximal excursion during standard face movements including lifting their eyebrows, showing their teeth, smiling and pursing their lips. However, neither of these classifications or measures included any information about the functional limitations associated with the injury or the patient's satisfaction with the outcome.

It has been advocated that when measuring outcomes following burn injury the World Health Organization's International Classification of Functioning, Disability and Health (ICF) [4] should be used [5]. This taxonomy classifies and describes the body structure and function, activities and participation and environmental factors that can lead to impairment and disability. Because advances in acute burn care have increased survival rates, there has been a shift in the burn care community's focus towards long-term outcomes. This shift has created an increased awareness that there is a need to quantify the residual disability after a burn injury by defining the activity limitations and participation restrictions rather than simply quantifying the body structure and function impairments [6]. However, the classifications and measures described above only quantify the oral impairments that occur, and do not provide any information about the activity limitations and participation restrictions that can result after a burn in the mouth region.

Thus, we contend that there is a need for the development of a clinically relevant and practical mouth evaluation that quantifies the impairments, activity limitations and participation restrictions, as well as patient satisfaction, associated with burn injuries to the mouth region. The expectation is that this measure will be used to evaluate the outcome in clinical practice as well as be used for clinical research. This research may focus on describing the recovery profile or evaluating the outcome of clinical and/or surgical interventions that are intended to optimize mouth function. Thus, the primary goal of this project was to develop and validate a measure that would quantify the impairment, activity limitations, and participation restrictions that burn survivors suffer after a burn injury involving their mouth, as well as their satisfaction with the outcome.

2. Methods

We undertook a multistep iterative process described below.

2.1. *Step (1) comprehensive literature search and review*

A comprehensive literature review was conducted January 2008 using Ovid MEDLINE and keywords such as 'burns' and 'mouth injury' or 'mouth disease' and 'outcome assessment (health care)' or 'recovery of function'. All articles that discussed the evaluation of burn survivors, who had sustained injuries in the mouth region, and of existing measures that evaluated the impairment, activity limitations or participation restrictions experienced by patients with any diagnosis or condition that had an impact on mouth function, was reviewed and the reference list searched [2,3,7–12]. The literature was summarized and information about the outcomes and outcome issues after a burn injury and the concomitant impact of burn injuries and other conditions on mouth structure and function and activity limitations and participation restrictions was extracted. This foundational overview provided a framework for the development of the evaluation structure and content, as well as the line of inquiry that was used for the questions during the interviews with experts and burn survivors described below.

2.2. *Step (2) expert and burn survivor interviews*

Six burn care specialists (3 occupational therapists, 2 physiotherapists, 1 physician) were asked to identify the domains or activities that they believed were impacted when burn survivors sustained burns of the mouth region. They were asked to consider the entire spectrum of recovery across time. This spanned from the time when the patients were extubated, throughout their rehabilitation until, when possible, normal structure and function was re-established, or patients were discharged from care since their improvement had plateaued and it was ascertained that no further gains were being accomplished. Their responses could include impairment-related outcomes (i.e. active mouth opening), functional activities, symptoms (i.e. pain), or anything else that they deemed important. A convenience sample of two burn survivors, who had sustained burn injuries in the mouth region and were currently undergoing treatment, were also interviewed and asked the same questions and provided the same directives as listed above for the experts.

2.3. *Step (3) preliminary version*

Once the literature was reviewed and summarized, and the interviews completed, a preliminary French version of the Mouth Impairment and Disability Assessment (MIDA) was developed (Évaluation sur les Déficiences et les Incapacités reliées à une atteinte de la Bouche– ÉDIB). The generated items were based on the literature review and interviews, reduced based on consensus of burn survivors and burn care specialists, and the presentation and scaling optimized [13]. The items were divided into three domains: functional activities, symptoms and active mouth opening. The first two domains

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