



## Research Article

# Standardized Patient Satisfaction Questionnaires to Assess Patient Experience in a Multidisciplinary Epidermolysis Bullosa Clinic

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**Capsule Summary:** Epidermolysis Bullosa is a rare dermatological condition with multisystem involvement. Clinical approach includes integrated multidisciplinary team input and a bespoke individualized approach to management. Assessment of patient satisfaction of the care provided is a fundamental aspect any service to assess patient's unique needs, identify deficits and recognize areas for improvement.

**Keywords:** Epidermolysis bullosa, Patient satisfaction, Multidisciplinary clinics, Patient experience.

## Introduction

Epidermolysis Bullosa (EB) is a rare heritable debilitating dermatological condition with multifaceted organ system involvement and sequelae. The hallmark of EB is a disordered or deficient ultrastructural protein that renders the skin and mucous membranes fragile causing it to blister at the slightest friction with potential life-threatening complications [1,2].

Based on the international consensus meeting in Vienna in 2007; there are four major subtypes of EB defined by the site of blistering within the layers of the skin. These are Simplex, Dystrophic, Junctional, and Kindler EB; with epidermolysis simplex being the most common. Recent advances in molecular biology have now identified more than 100 pathogenic variants in at least twenty-one major genes that are accountable for a myriad of phenotypes with variable clinical severity [3].

EB and its subtypes have variable worldwide prevalence which is yet to be determined precisely. The incidence and

prevalence are estimated to be 19.6 and 8.22 per 1 million live births respectively, as reported by the United States National Epidermolysis Bullosa Registry [5]. The prevalence of EB is theoretically expected to be higher amongst families where consanguinity prevails. Whilst we do not have any robust prevalence data on the United Arab Emirates, in Kingdom of Saudi Arabia the prevalence is estimated to be 16 per 3 million [5] This may well be explained by the high prevalence of consanguinity that is documented in the Arab population.

This genetically acquired disease form of bullous dermatoses is incurable and can manifest at birth or in early childhood. Subsequent multisystem clinical manifestations and complications of the disease result in significant health burden often necessitating numerous healthcare visitations. This can negatively impact on growth, activities including school or day-care attendance, psychological wellbeing, body image, family dynamics and financial status. Bruckner et al reported that most of the parents of children with EB had profound impact on their life choices, with many deciding to reduce their working hours 69.9% or give up work entirely 57.0%, while for 46.2% the disease was a factor in a divorce or separation [6]. Therefore, the corner stone to management remains supportive with wound care, infection prevention, and disfigurement amelioration, addressing their comorbid multi-system complications and aiming at improvement of the quality of life for patients and their families.

Multidisciplinary clinics (MDC) for paediatric patients with complex comorbidities, such as children with EB, has emerged as a crucial pillar of their care in many centers around the world.

There are numerous published data highlighting the importance of MDC approach to the delivery of quality, highly specialized, and targeted care. [2,7] However, to our knowledge there is paucity of paediatric data on the quantitative measurement of patients' and their families' satisfaction level as an indicator of quality of care.

### Objective

The rationale for EB MDC at our institute, the biggest paediatric tertiary hospital in the country UAE is to enable access to one-stop sub-specialty expertise. The MDC includes the following specialties, paediatric dermatology, general paediatric, paediatric gastroenterology, paediatric ophthalmology, paediatric dentistry, pain management team, clinical dietitian, and a social worker. This MDC not only looked after the primary disease manifestation but also actively sought prevention and treatment of anticipating complication. This is the first and the only MDC EB clinic not only nationally but also in the (GCC) Gulf region, therefore it was important to engage our service users to help shape a patient focused high quality service. The objective of our study is therefore to measure parents' satisfaction as a reflection of the quality of care with a view to improving our EB MDC.

### Methodology

A descriptive cross-sectional study conducted in Epidermolysis Bullosa (EB) MDC at our institute. The Institution's Research and Ethics committee approved study.

A survey was distributed by email to all parents attending EB MDC from December 2020 to December 2021. Parents were requested to fill in the survey anonymously to minimize bias. The electronic survey included three parts; the first part enclosed an electronic consent form. The second part addressed parent's demographic information including relationship to patient, level of education, distance travelled to reach the clinic, and availability of home help. The last part consisted of Patient Satisfaction Questionnaire short form (PSQ-18), which is a validated international questionnaire to evaluate patient satisfaction, [4] formed of eighteen questions related to seven categories of patient satisfaction which are general satisfaction, technical quality, interpersonal manner, communication, financial aspects, time spent with doctor, accessibility, and convenience. Responses to each question was quantitatively measured using a 5-point scale (1 =lowest satisfaction, 5 = greatest satisfaction). Two internationally certified translators translated the survey to Arabic.

Total number of patients attended the EB MDC during observation period was 19 patients. Parents of fifteen patient were recruited in the survey, three parents were not contactable, and only one parent declined to participate. Data collected from the electronic medical record system included EB type, detected mutation, parents' consanguinity, and anthropometric

measurements. Demographic data were also obtained on all recruited patients.

Data were entered and analysed using the one-way analyses of variance, test of correlation and 2-sample t-test. All variables were subjected to descriptive analysis. PSQ-18 scores were reported as means and standard deviations. The total satisfaction scores were tested for normality. Multicollinearity was checked between independent variables, and the accepted level of significance was set below 0.05 ( $P < 0.05$ ).

### Results

A total of nineteen patients with genetically confirmed EB were recruited from our MDC. The mean age of the patients was 7.5 years and female to male ratio was 8:7. Most of the parents were consanguineous n=17 (90%). Total number of responders to the survey was 15.

Two thirds of the responders had low education level 10/15 (66.7%), and one-third 5/15 (33.3%) held either a bachelor's degree or master's degree. Most of the responding parents 10/15 (66.7%) reported that they travelled more than 50 km on appointment day. Majority of the parents 11/15 n=11 (73%) did not have any home help such as home nurse or babysitter (Table 1).

Characteristics	N(%)
Patient Gender	
Female	8 (53.3)
Male	7 (46.7)
Responder/Patient Relationship	
Father	8 (53.3)
Mother	7 (46.7)
Responder Education Level	
High School	5 (33.3)
No Schooling	5 (33.3)
Bachelor's degree	3 (20)
Master's degree	2 (13.3)
Kilometers Travelled to access MDT clinic	
>50 Km	10 (66.7)
20 – 50 Km	4 (26.7)
< 20 Km	1 (6.6)
Home nurse assistance	
Yes	4 (26.7)
No	11 (73.3)

**Table 1: Survey Responders profile Summary (N = 15)**

About parental satisfaction survey, similar questions were grouped into seven categories of satisfaction (communication,

interpersonal manner, technical quality, financial aspects, time spent with doctor, accessibility, and convenience) measured on a 5-point scale (1 =lowest satisfaction, 5 = greatest satisfaction), the mean score for general satisfaction was 3.4±1.09. The mean scores for the rest of the satisfaction categories by order, from highest to lowest, was as the following, 3.67± 0.86 for time spent with doctor, 3.53±1.08 for communication, 3.53±1.08 for financial aspects, 3.4±1.09 for technical quality, 3.2±1.37 for interpersonal manner, and 3.13±0.71 for accessibility and convenience (Table2).

Characteristics	Gender		P-value
	Male Mean $\pm$ SD	Female Mean $\pm$ SD	
General Satisfaction	3.07 $\pm$ 1.17	3.69 $\pm$ 1	0.299
Technical Quality	3.29 $\pm$ 0.89	3.09 $\pm$ 1.13	0.721
Interpersonal Manner	3.14 $\pm$ 1.31	3.25 $\pm$ 1.51	0.886
Communication	3.71 $\pm$ 0.91	3.38 $\pm$ 1.25	0.555
Financial Aspects	3.64 $\pm$ 1.31	3.06 $\pm$ 0.94	0.355
Time spent with doctor	3.58 $\pm$ 0.73	3.75 $\pm$ 1	0.698
Accessibility and Convenience	3.14 $\pm$ 0.57	3.13 $\pm$ 0.86	0.963

Table 2: Correlation between Parental Satisfaction and Patient Gender

Moreover, parental satisfaction was analysed against the demographic predictors. About gender, there was no significant correlation between parental satisfaction and either participating parent or patient gender P-value >0.05 (Table 2). The overall parental general satisfaction for male patients and female patients were 3.07 and 3.69 respectively. Age of the patient did not have any correlation with parental satisfaction.

Parents who travelled < 20 Km showed higher satisfaction in most of the measured satisfaction categories, however, statistically not significant P-values>0.05 (Figure 1).



Figure 1 Responder Satisfaction in relation to Distance

Analysis of parental satisfaction against responders’ level of education did not reveal any statistically significant correlation. The highest parental general satisfaction was for responders holding high school degree 3.9/5, followed by the responder holding master’s degree then bachelor’s degree, 3.5 and 3.3 respectively. While the least general satisfaction was reported in responders whom did not complete high school education scoring 2.9 on the PSC Q (Figure 2).

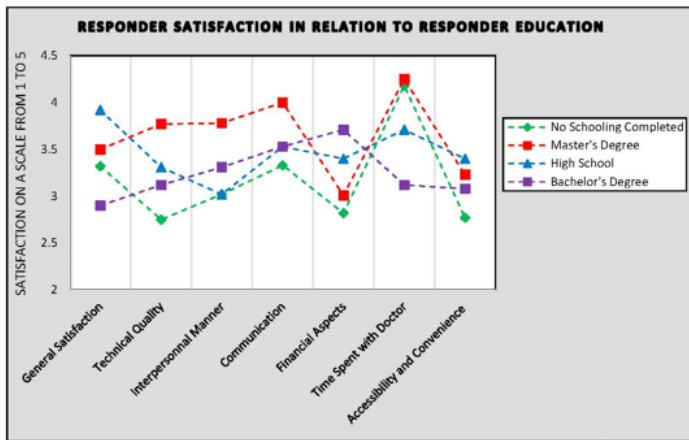


Figure 2 Responder Satisfaction in relation to Responder Education

Moreover, results showed that parents who had home support were more satisfied in time spent with the doctor and communication in comparison to parents who did not have help at home with P-value > 0.05 (Figure 3).

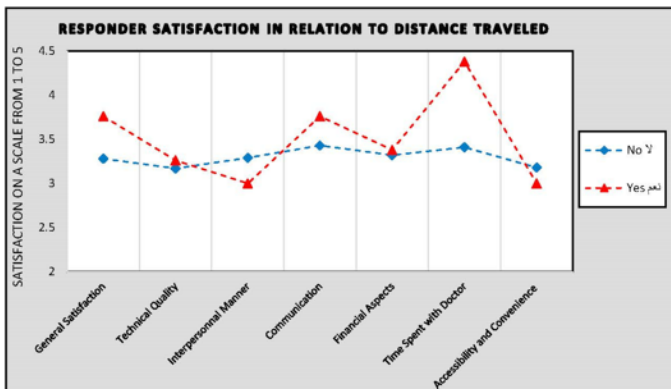


Figure 3 Responder Satisfaction in relation to getting home help

## Discussion

Epidermolysis bullosa is a rare disease that causes significant morbidity and mortality in affected patients. It has a significant negative burden on health-related quality of life and places a substantial socioeconomic burden on patients with epidermolysis bullosa and their caregivers [2,8,9,10].

Multidisciplinary (MDT) clinics are now a well-recognized approach to provide optimal patient-centred and consistent care. Centralization of MDC to healthcare facilities with the needed expertise is crucial particularly with rare conditions such as EB. This justifies in part why almost two third of our patients had to travel a long distance, more than 20 km, to access the provided services and had lower satisfaction rates that is statistically insignificant. Additionally, it might explain why the satisfaction

category concerning accessibility and convenience scored the lowest on the overall satisfaction scale.

In this study, most of the parents were consanguineous, which is expected for autosomal recessive conditions to be more prevalent in population with a high degree of consanguineous marriages.

Interestingly, there was no statistically significant parental gender influence on satisfaction rates towards the EB MDC. However, previous studies have reported a relationship between patient satisfaction and gender [11]; Woods et al found that female patients were less satisfied than males toward hospitalization care; while Chandra found that female's patients expressed higher satisfaction toward outpatient department compared to their counterpart male patients [12].

In our study, responders' satisfaction scores in relation to different education level were inhomogeneous and difficult to interpretate, in contradiction to a previous study in Iraq, which reported that low education was associated with better patient satisfaction [13]. This may be explained by the fact that parents with lower education are less aware of their rights and benefits of the quality of medical services. Authors of the study believe that this finding is arbitrary and does not necessarily represent a true difference.

Although of interest; satisfaction rates couldn't be compared between different EB types as the survey questions were answered by parents anonymously and majority of responders were unaware of the actual type of their child had.

## Limitation

This Cross-sectional research has a few limitations. Since this first MDT EB clinic of its kind in our country was launched in 2020, most of the patients are currently referred from either the local neonatal units or paediatric departments who are aware of the service, or by word of mouth from parents. The small numbers of patients recruited may reflect the lack of national awareness of the service or rarity of the disease. Our results and publication of our work will hopefully increase public awareness, and therefore enable more patients to access this service. Whilst we appreciate that our follow-up of patients is short as the clinic has only running for a year, our intention is to re-audit our practice after we have addressed the issues that are highlighted by our users to be deficient. Given the rarity of this disease, any anecdotal experience or data that is published would be informative in improving quality of services, as robust cross-sectional studies are not always the optimal research type to study rare diseases [14]. Multicentre collaboration, data sharing and exchanging institutional clinical experiences will all contribute to improve the service that we can provide to the patients who are diagnosed with this very rare yet debilitating disease.

## Conclusion

Multicentre collaboration, sharing of data and institutional clinical experiences all contribute to improvement of service provision of this very rare yet debilitating disease. Getting all involved specialties in one MDC clinic not only reduces the number of visitations to the hospital, but also enables different specialists to coordinate their management plans to achieve a better medical approach and subsequently a higher level of satisfaction for service providers and users.

Parents of children with EB attending the MDT EB clinic our institution were very satisfied with an overall reported score of  $3.4 \pm 1.09$  measured through the standardized PSQ-18. In this study patients' satisfaction rates measured were the highest for the time spent with doctors and their communication, while technical quality, accessibility, and convenience scored the lowest. Demographics used in this study did not point out a statistically significant influence on satisfaction scores.

The authors of this study propose that augmenting the MDC experience with targeted awareness campaigns and support groups will lead to enhancement in the perception of care, therefore improving overall parental satisfaction. In addition, combining all involved specialties in one MDC not only reduces the number of visits patients have to pay to the hospital, but also enables different specialists to coordinate their management plans to achieve a better medical approach, and subsequently a higher level of satisfaction for all parties.

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