

Table SI. Clinical characteristics reported by Italian respondents affected with epidermolysis bullosa

Variable		Number	Percentage
Pain			
	No	21	37.5
	Yes	35	62.5
Itch			
	No	16	28.6
	Yes	40	71.4
Blisters			
	No	1	1.8
	Yes	55	98.2
Crusts			
	No	13	23.2
	Yes	43	76.8
Atrophic scars			
	No	19	33.9
	Yes	37	66.1
Chronic wounds			
	No	32	57.1
	Yes	24	42.9
Mucosal involvement			
	No	26	46.4
	Yes	30	53.6
Malnutrition			
	No	36	64.3
	Yes	20	35.7
Joint deformities			
	No	37	66.1
	Yes	19	33.9
Functional disability			
	No	27	48.2
	Yes	29	51.8
Tooth loss			

	No	37	66.1
	Yes	19	33.9
SCC			
	No	46	82.1
	Yes	10	17.9
Wheelchair use			
	No	45	80.4
	Yes	11	19.6
Gastrostomy			
	No	50	89.3
	Yes	6	10.7
Oesophageal dilation			
	No	36	64.3
	Yes	20	35.7

SCC: squamous cell carcinoma

Table SII. Italian version of Quality of Life in Epidermolysis Bullosa (QOLEB) questionnaire factors and factor loadings

QOLEB Items		Emotions subscale	Functioning subscale
QOLEB01.	Does your EB affect your ability to move around at home?	0.39	0.67
QOLEB02.	Does your EB affect your ability to bath or shower?	0.04	0.86
QOLEB03.	Does your EB cause you physical pain?	0.50	0.53
QOLEB04.	How does your EB affect your ability to write?	0.24	0.68
QOLEB05.	Does your EB affect your ability to eat?	0.10	0.69
QOLEB06.	Does your EB affect your ability to go shopping?	0.23	0.74
QOLEB07.	How does EB affect your involvement in sports?	0.38	0.63
QOLEB08.	How frustrated do you feel about your EB?	0.85	0.14
QOLEB09.	Does your EB affect your ability to move around outside of your home?	0.53	0.66
QOLEB10.	How does your EB affect your relationships with family members?	0.63	0.66
QOLEB11.	How embarrassed do people make you feel about your EB?	0.82	0.09
QOLEB12.	Have you needed to, or do you need to modify your home (installing ramps etc.) due to your EB?	0.09	0.76
QOLEB13.	Does your EB affect your relationships with friends?	0.62	0.36
QOLEB14.	How worried or anxious do you feel because of your EB?	0.82	0.31
QOLEB15.	How are you or your family affected financially by your EB?	0.52	0.45
QOLEB16.	How depressed do you feel because of your EB?	0.86	0.21
QOLEB17.	How uncomfortable are you made to feel by others (e.g. teasing or staring) because of your EB?	0.81	0.15

Principal Components Analysis (PCA). Rotation Method: Varimax with Kaiser normalization. The rotation converged in 3 iterations

Table SIII Results of Quality of Life in Epidermolysis Bullosa (QOLEB) questionnaire in Italian patients

Item N.	Score	Patient N. (%)
1. Ability to move around at home	0	25 (44.6%)
	1	19 (33.9%)
	2	7 (12.5%)
	3	5 (8.9%)
2. Ability to bath/shower	0	31 (55.4%)
	1	10 (17.9%)
	2	1 (1.8%)
	3	14 (25%)
3. Physical pain	0	7 (12.5%)
	1	27 (48.2%)
	2	17 (30.4%)
	3	5 (8.9%)
4. Ability to write	0	34 (60.7%)
	1	8 (14.3%)
	2	13 (23.2%)
	3	1 (1.8%)
5. Ability to eat	0	24 (42.9%)
	1	15 (26.8%)
	2	15 (26.8%)
	3	2 (3.6%)
6. Ability to go shopping	0	23 (41.1%)
	1	18 (32.1%)
	2	9 (16.1%)
	3	6 (10.7%)
7. Involvement in sports	0	6 (10.7%)
	1	24 (42.9%)
	2	15 (26.8%)
	3	11 (19.6%)
8. Feeling frustrated	0	11 (19.6%)
	1	26 (46.4%)
	2	15 (26.8%)
	3	4 (7.1%)
9. Ability to move around outside house	0	16 (28.6%)

	1	21 (37.5%)
	2	12 (21.4%)
	3	7 (12.5%)
10. Relationship with family members	0	27 (48.2%)
	1	17 (30.4%)
	2	8 (14.3%)
	3	4 (7.1%)
11. Feeling embarrassed	0	14 (25.0%)
	1	25 (44.6%)
	2	12 (21.4%)
	3	5 (8.9%)
12. Need for home modifications	0	38 (67.9%)
	1	11 (19.6%)
	2	2 (3.6%)
	3	5 (8.9%)
13. Relationships with friends	0	20 (35.7%)
	1	25 (44.6%)
	2	8 (14.3%)
	3	3 (5.4%)
14. Feeling anxious or worried	0	12 (21.4%)
	1	25 (44.6%)
	2	13 (23.2%)
	3	6 (10.7%)
15. Family financial impact	0	9 (16.1%)
	1	23 (41.1%)
	2	20 (35.7%)
	3	4 (7.1%)
16. Feeling depressed	0	22 (39.3%)
	1	21 (37.5%)
	2	10 (17.9%)
	3	3 (5.4%)
17. Made feeling uncomfortable by others (e.g. teasing/staring)	0	17 (30.4%)
	1	20 (35.7%)
	2	18 (32.1%)
	3	1 (1.8%)