

Questions	EB simplex n=29 n (%)	Junctional EB n=8 n (%)	Dominant dystrophic EB n=13 n (%)	Recessive dystrophic EB n=5 n (%)	All n=55 n (%)
1. Does your EB affect your ability to move around at home?					
Not at all	16 (55)	3 (38)	7 (54)	2 (40)	28 (51)
A little	12 (41)	3 (38)	6 (46)	2 (40)	23 (42)
A lot	1 (3)	2 (25)	0 (0)	1 (20)	4 (7)
Severely	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
2. Does your EB affect your ability to bath or shower?					
No, no impact	27 (93)	6 (75)	10 (77)	2 (40)	45 (82)
Yes, I sometimes need assistance	1 (3)	1 (13)	3 (23)	1 (20)	6 (11)
Yes, need assistance most of the time	1 (3)	1 (13)	0 (0)	0 (0)	2 (4)
Yes, I need assistance every time I bath/shower	0 (0)	0 (0)	0 (0)	2 (40)	2 (4)
3. Does your EB cause you physical pain?					
No pain	4 (14)	1 (13)	4 (31)	0 (0)	9 (16)
Occasional pain	19 (66)	2 (25)	2 (15)	3 (60)	26 (47)
Frequent pain	5 (17)	4 (50)	6 (46)	0 (0)	15 (27)
Constant pain	1 (3)	1 (13)	1 (7)	2 (40)	5 (9)
4. How does your EB affect your ability to write?					
It does not interfere with writing	26 (90)	6 (75)	12 (92)	2 (40)	46 (84)
I find it difficult to grip the pen	0 (0)	1 (13)	0 (0)	0 (0)	1 (2)
I find it easier to type than write	3 (10)	1 (13)	1 (7)	3 (60)	8 (15)
I cannot write due to my EB	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
5. Does your EB affect your ability to eat?					
No, I eat normally	27 (93)	4 (50)	11 (85)	2 (40)	44 (80)
A little	2 (7)	4 (50)	2 (15)	2 (40)	10 (18)
A lot	0 (0)	0 (0)	0 (0)	1 (20)	1 (2)
I rely on my gastrostomy tube for nutrition	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
6. Does your EB affect your ability to go shopping?					
No, not at all	18 (62)	5 (63)	9 (69)	1 (20)	33 (60)
A little	10 (34)	1 (13)	4 (31)	2 (40)	17 (31)
A lot	1 (3)	2 (25)	0 (0)	0 (0)	3 (5)
I need assistance all the time	0 (0)	0 (0)	0 (0)	2 (40)	2 (4)
7. How does EB affect your involvement in sport?					
No impact	2 (7)	0 (0)	1 (7)	0 (0)	3 (5)
I need to be cautious in sports	8 (28)	0 (0)	8 (62)	2 (40)	18 (33)
I need to avoid some sports	16 (55)	2 (25)	4 (31)	2 (40)	24 (44)
I need to avoid all sports	3 (10)	6 (75)	0 (0)	1 (20)	10 (18)
8. How frustrated do you feel about your EB?					
No frustration	9 (31)	0 (0)	5 (38)	2 (40)	16 (29)
A little	18 (62)	8 (100)	8 (62)	2 (40)	36 (65)
A lot	1 (3)	0 (0)	0 (0)	1 (20)	2 (4)
So frustrated that I am angry most of the time	1 (3)	0 (0)	0 (0)	0 (0)	1 (2)
9. Does your EB affect your ability to move around outside of your home?					
Not at all	4 (14)	0 (0)	6 (46)	1 (20)	11 (20)
A little	21 (72)	5 (63)	7 (54)	2 (40)	35 (64)
A lot	4 (14)	2 (25)	0 (0)	2 (40)	8 (15)
Severely	0 (0)	1 (13)	0 (0)	0 (0)	1 (2)
10. How does your EB affect your relationships with family members?					
No impact at all	24 (83)	5 (63)	9 (69)	3 (60)	41 (75)
A small impact	5 (17)	3 (38)	4 (31)	1 (20)	13 (24)
A large impact	0 (0)	0 (0)	0 (0)	1 (20)	1 (2)
A very large impact	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
11. How embarrassed do people make you feel about your EB?					
No embarrassment	24 (83)	2 (25)	7 (54)	2 (40)	35 (64)
A little	4 (14)	6 (75)	5 (38)	3 (60)	18 (33)
A lot	1 (3)	0 (0)	1 (7)	0 (0)	2 (4)
Extremely	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
12. Have you needed to, or do you need to modify your home (installing ramps etc.) due to your EB?					
No, not at all	25 (86)	4 (50)	13 (100)	3 (60)	45 (82)
A few	2 (7)	3 (38)	0 (0)	1 (20)	6 (11)
A lot	2 (7)	1 (13)	0 (0)	1 (20)	4 (7)
Extensive	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
13. Does your EB affect your relationships with friends?					
No, not at all	21 (72)	4 (50)	10 (77)	3 (60)	38 (69)
A little	8 (28)	4 (50)	3 (23)	1 (20)	16 (29)
A lot	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
It severely restricts my social interaction	0 (0)	0 (0)	0 (0)	1 (20)	1 (2)
14. How worried or anxious do you feel because of your EB?					
Not anxious at all	15 (52)	3 (38)	7 (54)	2 (40)	27 (49)
A little	13 (45)	3 (38)	6 (46)	2 (40)	24 (44)
A lot	1 (3)	2 (25)	0 (0)	1 (20)	4 (7)
Extremely	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
15. How are you or your family affected financially by your EB?					
No financial impact	22 (76)	3 (38)	10 (77)	2 (40)	37 (67)
Slightly affected	5 (17)	2 (25)	3 (23)	2 (40)	12 (22)
Greatly affected	2 (7)	2 (25)	0 (0)	1 (20)	5 (9)
Severely affected	0 (0)	1 (13)	0 (0)	0 (0)	1 (2)
16. How depressed do you feel because of your EB?					
Not depressed at all	23 (79)	3 (38)	10 (77)	2 (40)	38 (69)
A little	6 (21)	5 (63)	3 (23)	3 (60)	17 (31)
A lot	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Constantly very depressed	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
17. How uncomfortable are you made to feel by others (e.g. teasing or staring) because of your EB?					
Not at all	25 (86)	3 (38)	9 (69)	3 (60)	40 (73)
A little	3 (10)	5 (63)	4 (31)	2 (40)	14 (25)
A lot	1 (3)	0 (0)	0 (0)	0 (0)	1 (2)
So much that I don't go out socially	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)