

Additional Material

Table A1. Group comparison matrix of all categories' medians

	Current health	Quality of life		Burdens	Satisfaction	Resources	Helpful practices	Resilience	Social support	General satisfaction
	↓ isCorEB	↓ For patients: QOLEB	↓ For relatives: EB-BoD	↑ ResILL-EB Burden scale	↑ ResILL-EB Satisfaction scale	↑ ResILL-EB Resources scale	↑ ResILL-EB Helpful practices	↑ BRS	↑ F-SozU	↑ SWLS
Gender	$p=.014^{*1}$	$p=.029$	$p=.008$	$p=.025^{*1}$	No significant differences	$p=.001^{*2}$	$p=.008$	No significant differences	$p=.005$	$p=.045^{*2}$
Female	MD=2.53	MD=1.71	MD=0.89	MD=3.98		MD=2.60	MD=2.00		MD=4.67	MD=5.80
Male	MD=0.93	MD=1.29	MD=1.94	MD=1.38		MD=2.00	MD=1.83		MD=4.00	MD=5.00
EB-Form	$p<.001$	No significant differences	No significant differences	$p=.004$	$p=.001$	$p=.006$	No significant differences	No significant differences	No significant differences	$p=.046$
EBS	MD=1.20			MD=2.00	MD=8.67	MD=2.73				MD=5.80
DEB	MD=2.53			MD=3.65	MD=6.94	MD=2.35				MD=5.30
JEB	MD=3.27			MD=5.43	MD=5.00	MD=2.00				MD=3.80
Severity	$p<.001$	$p=.022$	$p=.005$	$p=.001$	$p=.025$	No significant differences	No significant differences	No significant differences	No significant differences	No significant differences
Mild	MD=1.20	MD=1.35	MD=0.64	MD=2.20	MD=8.44					
Moderate/severe	MD=2.83	MD=1.71	MD=1.94	MD=4.45	MD=6.78					
Visibility	$p=.034$	No significant differences	No significant differences	$p=.011$	No significant differences	No significant differences	No significant differences	No significant differences	No significant differences	No significant differences
Hardly	MD=1.20			MD=1.15						
Somewhat	MD=2.53			MD=2.80						
Very	MD=2.53			MD=4.50						
Acute EB phase	$p=.005$	$p=.023$	No significant differences	$p=.014$	$p=.001$	$p=.033$	No significant differences	$p=.033$	$p=.030^{*2}$	No significant differences
Yes	MD=3.33	MD=2.09		MD=4.50	MD=5.50	MD=2.15		MD=3.00	MD=3.50	
No	MD=2.00	MD=1.53		MD=2.45	MD=7.89	MD=2.60		MD=3.75	MD=4.58	
Limited mobility	$p=.006$	No significant differences	No significant differences	No significant differences	No significant differences	$p=.046$	No significant differences	No significant differences	No significant differences	No significant differences
Yes	MD=2.53					MD=2.15				
no	MD=1.60					MD=2.45				
Overall support	$p<.001$	No significant differences	No significant differences	$p=.021$	No significant differences	No significant differences	No significant differences	No significant differences	No significant differences	No significant differences
Frequently	MD=3.73			MD=5.05						
No support	MD=2.00			MD=2.35						
Psychologic/therapeutic support	$p=.003$	No significant differences	No significant differences	$p=.035$	No significant differences	No significant differences	$p=.037$	No significant differences	No significant differences	No significant differences
Frequently:	MD=2.93			MD=4.50			MD=2.03			
Not/once	MD=2.00			MD=2.30			MD=1.82			
Financial burden	$p<.001$	No significant differences	No significant differences	No significant differences	$p=.014$	$p<.001$	No significant differences	No significant differences	$p=.009$	$p=.001$
Burdened	MD=3.40				MD=6.67	MD=2.00			MD=4.00	MD=4.00
Not/rather not	MD=1.73				MD=7.67	MD=2.70			MD=4.58	MD=5.80
Financial satisfaction	$p<.001$	No significant differences	No significant differences	$p=.004$	No significant differences	$p=.002$	No significant differences	No significant differences	$p=.012$	$p=.004$
Satisfied	MD=1.60			MD=2.20		MD=2.70			MD=4.67	MD=5.80
Not/rather not	MD=3.20			MD=4.50		MD=2.05			MD=3.83	MD=3.80
Mood	No significant differences	No significant differences	No significant differences	$p=.007$	$p=.002$	$p=.008$	$p=.038$	No significant differences	$p=.037$	No significant differences
Happy				MD=2.20	MD=7.56	MD=2.60	MD=2.00		MD=4.50	
Unhappy				MD=4.50	MD=6.00	MD=2.05	MD=1.76		MD=4.00	
Burden due to feelings	$p=.004$	No significant differences	No significant differences	No significant differences	$p=.005$	$p=.041$	No significant differences	No significant differences	No significant differences	No significant differences
Burdened	MD=2.53				MD=6.78	MD=2.15				
Not/hardly	MD=1.67				MD=8.11	MD=2.50				
Burden due to worries and fears	$p<.001$	No significant differences	No significant differences	No significant differences	$p<.001$	$p<.001$	$p=.009$	$p=.017$	$p=.033$	$p=.002$
Burdened	MD=3.40				MD=6.56	MD=2.00	MD=1.76	MD=3.33	MD=4.00	MD=4.40
Not/hardly	MD=1.60				MD=8.44	MD=2.70	MD=2.03	MD=3.83	MD=4.50	MD=5.80

*1 only for patients significant differences, *2 only for relatives significant differences, ↑ = Higher values indicate higher expression in the targeted construct, ↓ = Lower values indicate higher expression in the targeted construct

	Current health ↓	Quality of life ↓		Burdens ↑	Satisfaction with EB ↑	Resources ↑	Helpful strategies ↑	Resilience ↑	Social support ↑	Overall satisfaction ↑
	IscoREB	For patients: QOLIEB	For relatives: EB-BoD	ResILL-EB Burden scale	ResILL-EB Satisfaction scale	ResILL-EB Resources scale	ResILL-EB Helpful strategies	BRS	F-SozU	SWLS
Gender	$p^{*1}=.014$	$p=.029$	$p=.008$	$p=.025^{*1}$		$p^{*2}=.001^{*2}$	$p=.008$		$p=.005$	$p^{*2}=.045$
Female	MD=2.53	MD=1.71	MD=0.89	MD=4.98	-	MD=2.60	MD=2.00	-	MD=4.67	MD=5.80
Male	MD=0.93	MD=1.29	MD=1.94	MD=2.38		MD=2.00	MD=1.83		MD=4.00	MD=5.00
EB-Form	$p<.001$			$p=.004$	$p=.001$	$p=.006$				$p=.046$
EBS	MD=1.20	-	-	MD=3.00	MD=9.67	MD=2.73	-	-	-	MD=5.80
DEB	MD=2.53			MD=4.65	MD=7.94	MD=2.35				MD=5.30
JEB	MD=3.27			MD=6.43	MD=6.00	MD=2.00				MD=3.80
Severity	$p<.001$	$p=.022$	$p=.005$	$p=.001$	$p=.025$					
Mild	MD=1.20	MD=1.35	MD=0.64	MD=3.20	MD=9.44	-	-	-	-	-
Moderate/severe	MD=2.83	MD=1.71	MD=1.94	MD=5.45	MD=7.78					
Visibility	$p=.034$			$p=.011$						
Hardly	MD=1.20	-	-	MD=2.15	-	-	-	-	-	-
Somewhat	MD=2.53			MD=3.80						
Very	MD=2.53			MD=5.50						
Acute EB phase	$p=.005$	$p=.023$		$p=.014$	$p=.001$	$p=.033$		$p=.033$	$p^{*2}=.030$	
Yes	MD=3.33	MD=2.09	-	MD=5.50	MD=6.50	MD=2.15	-	MD=3.00	MD=3.50	-
No	MD=2.00	MD=1.53		MD=3.45	MD=8.89	MD=2.60		MD=3.75	MD=4.58	
Limited mobility	$p=.006$					$p=.046$				
Yes	MD=2.53	-	-	-	-	MD=2.15	-	-	-	-
no	MD=1.60					MD=2.45				
Overall support	$p<.001$			$p=.021$						
Frequently	MD=3.73	-	-	MD=6.05	-	-	-	-	-	-
No support	MD=2.00			MD=3.35						
Psychologic/ therapeutic support	$p=.003$			$p=.035$			$p=.037$			
Frequently:	MD=2.93	-	-	MD=5.50			MD=2.03			
Not/once	MD=2.00			MD=3.30			MD=1.82			
Financial burden	$p<.001$				$p=.014$	$p<.001$			$p=.009$	$p=.001$
Burdened	MD=3.40	-	-	-	MD=7.67	MD=2.00	-	-	MD=4.00	MD=4.00
Not/rather not	MD=1.73				MD=8.67	MD=2.70			MD=4.58	MD=5.80
Financial satisfaction	$p<.001$			$p=.004$		$p=.002$			$p=.012$	$p=.004$
Satisfied	MD=1.60	-	-	MD=3.20		MD=2.70	-	-	MD=4.67	MD=5.80
Not/rather not	MD=3.20			MD=5.50		MD=2.05			MD=3.83	MD=3.80
Mood				$p=.007$	$p=.002$	$p=.008$	$p=.038$		$p=.037$	
Happy	-	-	-	MD=3.20	MD=8.56	MD=2.60	MD=2.00	-	MD=4.50	-
Unhappy				MD=5.50	MD=7.00	MD=2.05	MD=1.76		MD=4.00	
Burden due to feelings	$p=.004$				$p=.005$	$p=.041$				
Burdened	MD=2.53	-	-	-	MD=7.78	MD=2.15	-	-	-	-
Not/hardly	MD=1.67				MD=9.11	MD=2.50				
Burden due to worries and fears	$p<.001$				$p<.001$	$p<.001$	$p=.009$	$p=.017$	$p=.033$	$p=.002$
Burdened	MD=3.40	-	-	-	MD=7.56	MD=2.00	MD=1.76	MD=3.33	MD=4.00	MD=4.40
Not/hardly	MD=1.60				MD=9.44	MD=2.70	MD=2.03	MD=3.83	MD=4.50	MD=5.80

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	iscorEB	For patients: QOLEB	For relatives: EB-BoD	ResILL-EB Burden scale	ResILL-EB Satisfaction scale	ResILL-EB Resources scale	ResILL-EB Helpful strategies	BRS	F-SozU	SWLS
Gender	$p^{*1}=.014$	$p=.029$	$p=.008$	$p=.025^{*1}$		$p^{*2}=.001^{*2}$	$p=.008$		$p=.005$	$p^{*2}=.045$
Female	MD=2.53	MD=1.71	MD=0.89	MD=4.98	-	MD=2.60	MD=2.00	-	MD=4.67	MD=5.80
Male	MD=0.93	MD=1.29	MD=1.94	MD=2.38		MD=2.00	MD=1.83		MD=4.00	MD=5.00
EB-Form	$p<.001$			$p=.004$	$p=.001$	$p=.006$				$p=.046$
EBS	MD=1.20			MD=3.00	MD=9.67	MD=2.73				MD=5.80
DEB	MD=2.53			MD=4.65	MD=7.94	MD=2.35				MD=5.30
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Severity	$p<.001$	$p=.022$	$p=.005$	$p=.001$	$p=.025$					
Mild	MD=1.20	MD=1.35	MD=0.64	MD=3.20	MD=9.44	-	-	-	-	-
Moderate/severe	MD=2.83	MD=1.71	MD=1.94	MD=5.45	MD=7.78					
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Acute EB phase	$p=.005$	$p=.023$		$p=.014$	$p=.001$	$p=.033$		$p=.033$	$p^{*2}=.030$	
Yes	MD=3.33	MD=2.09	-	MD=5.50	MD=6.50	MD=2.15	-	MD=3.00	MD=3.50	-
No	MD=2.00	MD=1.53		MD=3.45	MD=8.89	MD=2.60		MD=3.75	MD=4.58	
Limited mobility	$p=.006$					$p=.046$				
Yes	MD=2.53	-	-	-	-	MD=2.15	-	-	-	-
no	MD=1.60					MD=2.45				
Overall support	$p<.001$			$p=.021$						
Frequently	MD=3.73	-	-	MD=6.05	-	-	-	-	-	-
No support	MD=2.00			MD=3.35						
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Burdened	MD=3.40	-	-	-	MD=7.67	MD=2.00	-	-	MD=4.00	MD=4.00
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Satisfied	MD=1.60	-	-	MD=3.20		MD=2.70	-	-	MD=4.67	MD=5.80
Not/rather not	MD=3.20			MD=5.50		MD=2.05			MD=3.83	MD=3.80
Mood				$p=.007$	$p=.002$	$p=.008$	$p=.038$		$p=.037$	
Happy	-	-	-	MD=3.20	MD=8.56	MD=2.60	MD=2.00	-	MD=4.50	-
Unhappy				MD=5.50	MD=7.00	MD=2.05	MD=1.76		MD=4.00	
Burden due to feelings	$p=.004$				$p=.005$	$p=.041$				
Burdened	MD=2.53	-	-	-	MD=7.78	MD=2.15	-	-	-	-
Not/hardly	MD=1.67				MD=9.11	MD=2.50				
Burden due to worries and fears	$p<.001$				$p<.001$	$p<.001$	$p=.009$	$p=.017$	$p=.033$	$p=.002$
Burdened	MD=3.40	-	-	-	MD=7.56	MD=2.00	MD=1.76	MD=3.33	MD=4.00	MD=4.40
Not/hardly	MD=1.60				MD=9.44	MD=2.70	MD=2.03	MD=3.83	MD=4.50	MD=5.80

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