Psychometric Testing of the ICECAP-A in Patients with Coeliac Disease: a Comparative Analysis with EQ-5D-5L

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INTRODUCTION

Coeliac disease (CD) is a food-related autoimmune condition that primarily affects the small intestine with a global prevalence of 1%. Due to various symptoms and the strict gluten-free diet (GFD), the deterioration in patients' health-related quality of life (HRQoL) is well-documented.

OBJECTIVE

This study aims to assess the psychometric properties of the ICEpop CAPability measure for Adults (ICECAP-A) in patients with CD and compare its performance with the EQ-5D-5L.

METHODS

An online cross-sectional survey was conducted among 312 adult CD patients in Hungary, who completed both the ICECAP-A and EQ-5D-5L. The following psychometric properties were assessed: ceiling, convergent validity with the Gastrointestinal Symptom Rating Scale (GSRS) and Satisfaction with Life Scale (SWLS) and known-group validity. Mean ICECAP-A and EQ-5D-5L index values were computed using the Hungarian value sets [1,2]. To allow for comparison with the Hungarian population norms [3-4], ICECAP-A index values were also calculated using the UK value set [5], as this was used in the Hungarian population norm study.

RESULTS

Mean age was 36 years (range 18-80), and 70% were female. On the ICECAP-A, 51% (attachment) to 81% (stability) reported limitations in their capabilities. In comparison, 2% (self-care) to 41% (pain/discomfort) of patients reported problems on the EQ-5D-5L. No ceiling effect was observed on the ICECAP-A (7%), in contrast with a high ceiling effect on the EQ-5D-5L (39%).

Mean index values of ICECAP-A were lower than the EQ-5D-5L (0.85 vs. 0.92).

ICECAP-A correlated strongly with SWLS (r_s=0.685), moderately with EQ-5D-5L (r_s=0.485) and weakly with GSRS (r_s=-0.314).

The ICECAP-A differentiated between known groups by general health status and symptoms with large effect sizes (0.189-0.379), while GSRS tertiles and comorbidities with moderate effect size (0.065-0.073). The EQ-5D-5L showed larger effect sizes for health-related and clinical variables, as well as gender.
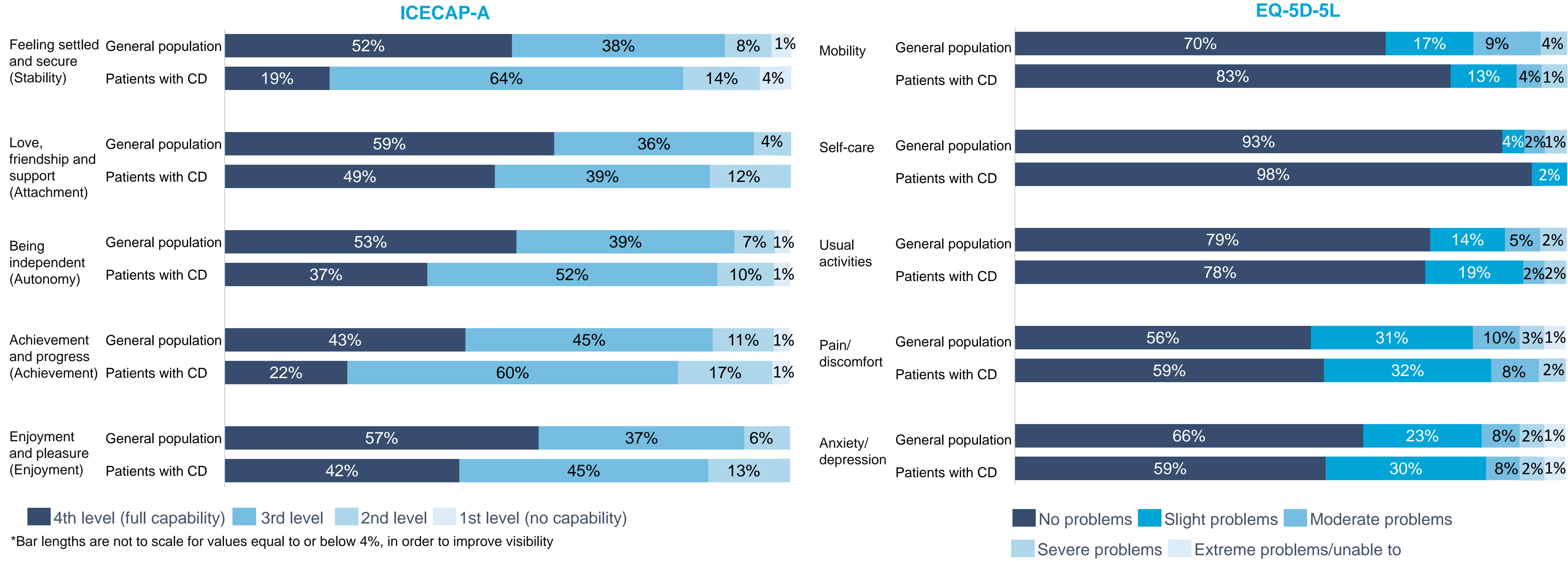
More limitations were reported among CD patients in multiple ICECAP-A items than the general population, particularly in stability (81% vs. 48%) and achievement (78% vs. 57%). Patients reported worse capability well-being across almost all age groups compared to the general population (mean ICECAP-A index: 0.76-0.86 vs. 0.84-0.92).

Table: ICECAP-A, EQ-5D-5L index value, and EQ VAS scores by sociodemographic and clinical characteristics

Characteristics of the patient population			ICECAP-A index value*		P value	Effect size	EQ-5D-5L index value		P value	Effect size	EQ VAS**		P value	Effect size
Variables	N	%	Mean	SD			Mean	SD			Mean	SD		
Total	312		0.85	0.16			0.92	0.13			79.69	18.52		
Gender														
Female	219	70.19%	0.85	0.17	0.540	0.076	0.92	0.14	0.071	0.225	77.87	19.91	0.002	0.334
Male	93	29.81%	0.86	0.15			0.94	0.10			83.99	13.94		
Age (years)														
18-24	59	18.91%	0.87	0.15			0.94	0.11			83.80	14.24		
25-34	98	31.41%	0.87	0.15			0.93	0.12			81.47	16.33		
35-44	73	23.40%	0.85	0.17	0.167	0.021	0.93	0.11	0.070	0.028	81.41	14.96	<0.001	0.068
45-54	68	21.79%	0.82	0.18			0.90	0.15			75.41	23.50		
55+	14	4.49%	0.77	0.17			0.85	0.20			61.79	25.86		
Number of comorbidities														
0	33	10.58%	0.88	0.13			0.98	0.03			89.48	10.77		
1	74	23.72%	0.91	0.09	<0.001	0.073	0.97	0.05	<0.001	0.120	85.58	9.64	<0.001	0.159
2-3	101	32.37%	0.85	0.16			0.93	0.13			82.51	13.66		
4+	104	33.33%	0.79	0.19			0.87	0.16			69.65	24.24		
General health status														
Poor & very poor health	75	24.04%	0.73	0.22			0.82	0.20			61.97	23.80		
Fair health	141	45.19%	0.87	0.13	<0.001	0.189	0.94	0.08	<0.001	0.215	81.19	12.84	<0.001	0.353
Good health	76	24.36%	0.91	0.09			0.97	0.04			89.87	6.95		
Excellent health	20	6.41%	0.92	0.12			1.00	0.01			96.90	4.80		
Symptoms during last week														
No symptoms	90	28.85%	0.89	0.13	0.001	0.379	0.97	0.11	<0.001	0.496	87.67	12.04	<0.001	0.628
Symptoms	222	71.15%	0.83	0.17			0.91	0.13			76.46	19.70		
GSRS* tertiles**														
<= 21	111	35.58%	0.90	0.12			0.97	0.08			86.86	14.01		
22 - 30	99	31.73%	0.85	0.15	<0.001	0.065	0.94	0.06	<0.001	0.134	81.21	13.01	<0.001	0.138
31+	102	32.69%	0.80	0.20			0.92	0.18			70.41	23.08		

*ICECAP-A calculated with the Hungarian value set [3] **Visual Analog Scale, ***Gastrointestinal Symptom Rating Scale
Effect size was calculated using Cohen's d for binary comparisons (e.g. gender) and eta-squared (η^2) for multi-group comparisons (e.g. age groups).

Figure: Comparison of EQ-5D-5L and ICECAP-A dimension responses between patients with coeliac disease and the general population*

Legend ICECAP-A: 4th level (full capability), 3rd level, 2nd level, 1st level (no capability)
*Bar lengths are not to scale for values equal to or below 4%, in order to improve visibility

Legend EQ-5D-5L: No problems, Slight problems, Moderate problems, Severe problems, Extreme problems/unable to

CONCLUSIONS

This is the first study to validate the ICECAP-A in patients with CD. The ICECAP-A is a valid measure in this population, sensitive to specific symptoms and health status. The ICECAP-A effectively highlights the well-being impact of CD, showing the limitations faced by patients compared to the general population.

CONTACT

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