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## BACKGROUND

- The growth of health care spending is a major concern for insurers and governments but also for patients whose health problems may result in costs beyond direct medical costs.
- It is particularly the case for ambulatory patients who require continuous care and support from their relatives.
- There is currently no standard instrument to measure patients' and their relatives' out-of-pocket costs.

## OBJECTIVE

- To develop a comprehensive tool to measure direct and indirect costs of a health condition for patients and their relatives. The Costs for Patients Questionnaire (CoPaQ) was constructed to be generalizable to various outpatient contexts.

## METHODS

- Online Delphi:** iterative process with multiple rounds with an expert panel. The process was online and anonymous.
- Pilot test-retest:** The CoPaQ was administered twice with a two-week delay but covering the same period.
- Participants:** There were 14 members of the Delphi panel (researchers=6 & patients=8) and 18 participants for the test-retest (criteria: utilization of health care services in the previous 6 months).
- Outcome Measures:** Items related to direct and indirect costs for patients or their families.

## RESULTS

- An initial list of 34 items was established from a systematic review.
- Each round of the Delphi panel incorporated feedback from the previous round until a strong consensus was achieved about the most important costs items and how the questions should be formulated.
- After four rounds of the Delphi to reach consensus on items to be included and wording, the questionnaire had a total of 32 cost items.

Table 1

Kappa statistics of CoPaQ

Items	Agreement	Expected agreement	Kappa value (k)	Std. Err.	Z	Prob>Z	Interpretation
Means of transportation	44.44%	29.01%	0.217	0.133	1.630	0.051	Fair
Parking fees	94.44%	62.35%	0.852	0.233	3.660	0.000	Almost perfect
Purchase of prescription drugs-related with the illness	100%	55.56%	1.000	0.236	4.240	0.000	Almost perfect
Purchase of non-prescription drugs in pharmacies	83.33%	67.28%	0.491	0.203	2.420	0.008	Moderate
Other expenses related to accessing health care services	100%	89.51%	1.000	0.236	4.240	0.000	Almost perfect
Other treatments	88.89%	50%	0.778	0.236	3.300	0.001	Substantial
Childcare or other services for children	100%	89.51%	1.000	0.236	4.240	0.000	Almost perfect
Other expenses related to childcare or other services for children	5.56%	10.19%	-0,052	0.030	-1.710	0.957	Poor
Loss of income	100%	52.47%	1.000	0.236	4.240	0.000	Almost perfect
Costs for informal caregivers or accompanying persons	94.12%	56.06%	0.866	0.240	3.600	0.000	Almost perfect
Training	100%	68%	1.000	0.447	2.240	0.013	Almost perfect
Other expenses related to informal caregivers	20%	28%	-0.111	0.199	-0.560	0.712	Poor

- For the test-retest, Kappa coefficients ranged from -0.11 to 1.00 (median=0.86)

Table 2

ICC statistics of CoPaQ

Items	ICC value	[95% Conf. Interval]	ICC interpretation
Travel costs	0.937	0.843 0.976	Excellent
Waiting time	0.381	-0.081 0.711	Slight
Time spent during traveling and consultation	0.415	-0.048 0.731	Acceptable to good
Time spent looking for a treatment or appointment	-0.022	-0.486 0.451	Slight
Loss of income	0.286	-0.478 0.822	Slight
Time spent traveling	0.998	0.985 0.999	Excellent
Help from an informal caregiver due to a limited capacity with domestic tasks	0.822	0.015 0.987	Excellent
Waiting time during the patient consultation	0.996	0.964 0.999	Excellent

- For the test-retest, ICC ranged from -0.02 to 0.99 (median=0.62)

## DISCUSSION

- Results allowed to develop a questionnaire measuring costs for patients (CoPaQ).
- This is one of the few studies about the development of a comprehensive tool to measure direct and indirect costs of a health condition for patients and their families to various outpatient contexts.
- The Costs for Patients Questionnaire (CoPaQ) may be used by researchers who wish to capture out-of-pocket costs of a condition for patients and their relatives and, in clinical practice to identify patients who are overwhelmed by the economic burden to begin conversations about their health-related costs.

## CONCLUSION

- A rigorous process of content and face validity development was implemented for the CoPaQ and this study allowed to set a list of cost elements to be considered from the patients' perspective.
- Additional research including a test-retest with a larger sample will be part of a subsequent validation strategy.

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