THE PAYERS' AND CLINICIANS' APPROACH TO BURDEN OF DISEASE AND UNMET HEALTH NEED IN A RARE DISEASE IN POLAND, GREECE AND THE CZECH REPUBLIC

- SIMILARITIES AND DIFFERENCES

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OBJECTIVES

Our analysis aimed to examine the payers' and clinicians' approaches unmet need for new treatments and the clinical and economic burden of rare disease. study also concerned the clinical value and financing of treatment for a rare disease.

METHODS

Nine in-depth interviews with clinicians and representatives of the payer in Poland, Greece and the Czech Republic were conducted. The interviews concerned the clinical and economic burden of the disease, current treatment, financing, and the need for new therapies for an exemplary rare disease. The background of this disease with current treatment options was presented to the respondents. To assess the clinical and economic burden the 10-point scale was used, where 1 meant very low burden and 10 – very high burden. The 5-point scale was used for unmet needs, where 1 meant no need, 2 – little, 3 – some, 4 – strong, and 5 – urgent need. The study did not concern any specific product.

RESULTS

The differences were two-level; between responders and between countries (Table 1).

The greatest differences between the payers and the clinicians in the approach to rare diseases were observed in Poland and Greece. The main differences were related to the clinical burden: Polish clinicians assessed it with 8-9 points, whereas one payer rated it at 3-4 points. Similar, the Greek payer indicated a moderate clinical burden (5-6 points), and KOL rated this disease at 10 points. On the other hand, for the second Greek payer, the clinical burden of the presented disease was rather on a high level (8-9 points). The perception of the economic burden differed particularly between KOL and payer representatives – KOLs seemed to assess the disease as causing a high burden for the public payer and society. Such differences may suggest that clinicians who have daily contact with patients assess the disease based on the patient's health status, quality of life and socio-economic consequences of functioning as a heavy burden. On the other hand, the payer representatives not only look at this disease, but also compare it with other rare diseases or, for example, cancers. This approach results in a lower score for the clinical and economic burden of this disease.

There were also some cross-countries differences. The respondents from the Czech Republic assessed unmet need as a "little need" or "some need", while most respondents from Greece and Poland assessed it as a "strong need". Especially Polish payer representative indicated that the existence of older drugs on the market or even using drugs off-label gave patients good treatment options, therefore there was no urgent need for newer treatment.

Table 1. Clincial and economic burden of rare disease, and unmet need - approach of clinicians and payer representatives

Country/ Responder	The Czech Republic			Greece			Poland		
	Payer 1	Payer 2	KOL	Payer 1	Payer 2	KOL	Payer 1	Payer 2	KOL
Clinical burden of disease 10-point Scale: 1 - very low burden, 10 - very high burden	6-7	7-8	7	5-6	8-9	10	3-4	7	8-9
Economic burden of disease 10-point Scale: 1 - very low burden, 10 - very high burden	3-4	3	7	7-8	8-9	8	3-4	6	8-9
Unmet need 5-point Scale: 1 - no need, 5 - urgent need	2	3	3	4	4	4	2-3	4	4

CONCLUSION

The perception of the clinical and economic burden of rare disease differs especially between clinicians and payer representatives. The approach to the need for new therapies in rare disease also varies between countries. The observed situation indicates the need for a better dialogue between clinicians and the payer, especially in Greece and Poland. Among the analysed countries, Polish payers seem to be the most sceptical about financing new therapies for rare diseases.

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