

HEALTH EXPECTATIONS AND COSTS OF PEOPLE WITH AUTISM AND THEIR FAMILIES

Trixler B¹, Boncz I², Szabó L³, Dinnyés KJ⁴, Pusztafalvi H¹

¹University of Pécs, Pécs, Hungary, ²University of Pécs, BUDAPEST, PE, Hungary, ³University of Pécs, Pécs, BA, Hungary, ⁴University of Pécs, Pécs, Hungary, Hungary

OBJECTIVES

Autism Spectrum Disorder is a neurodevelopmental disorder of a pervasive nature that results in atypical manifestations of reciprocal social interactions and communication, with stereotyped, repetitive activity, interest and behavior. As these factors can have a significant impact on daily living and activities, the aim of this research is to explore families’ expectations, expenditures and barriers to accessing health care.

METHODS

The quantitative cross-sectional online own editing questionnaire survey based on 125 Respondents’ answers. The data were collected between 30.04.2022 and 01.12.2023. In addition to descriptive statistics, we performed Mann-Whitney test, Kruskal-Wallis test and Chi-square test at 95% probability level (p<0.05), and data were analysed by SPSS 23.0 statistical software.

RESULTS

The gender distribution of autistic people in the questionnaire was 22.4% female and 77.6% male. The mean age was 16.03 years (SD: ± 3.804). Medication costs were associated with 84.0%. 33.6% of respondents spent for prevention. 55.2% had no savings. According to the sample, with the right help, the three most significant changes that could occur in their lives would be: 80% indicated less stress/anxiety, 70.4% indicated financial savings, 35.2% indicated less time spent organising daily life. The most ideal way of providing care for people with autism would be to designate autism-friendly care places in 80% of cases, 47.2% would also consider providing home health care. Those with moderate/severe condition had a higher proportion of monthly health expenditure on the child (p=0.001). Families earning over 350,000 HUF the caregiver scored significantly (p=0.01) higher on the Hungarian version of the Adult Hope Scale.

CONCLUSIONS

Despite the significant results, the findings refer to the sample only. Furthermore, the high heterogeneity of the condition and symptoms makes it difficult to generalize. However, through our study we would like to encourage further autism research.

TYPE OF COMORBID CONDITIONS	PERCENTAGE
No comorbidities	36.8%
Eating disorders	20%
Movement disorders	13.6%
Attention deficit hyperactivity disorder	12.8%

Table 1.
Distribution of the most common comorbidities in the research sample
(more response options in the questionnaire)

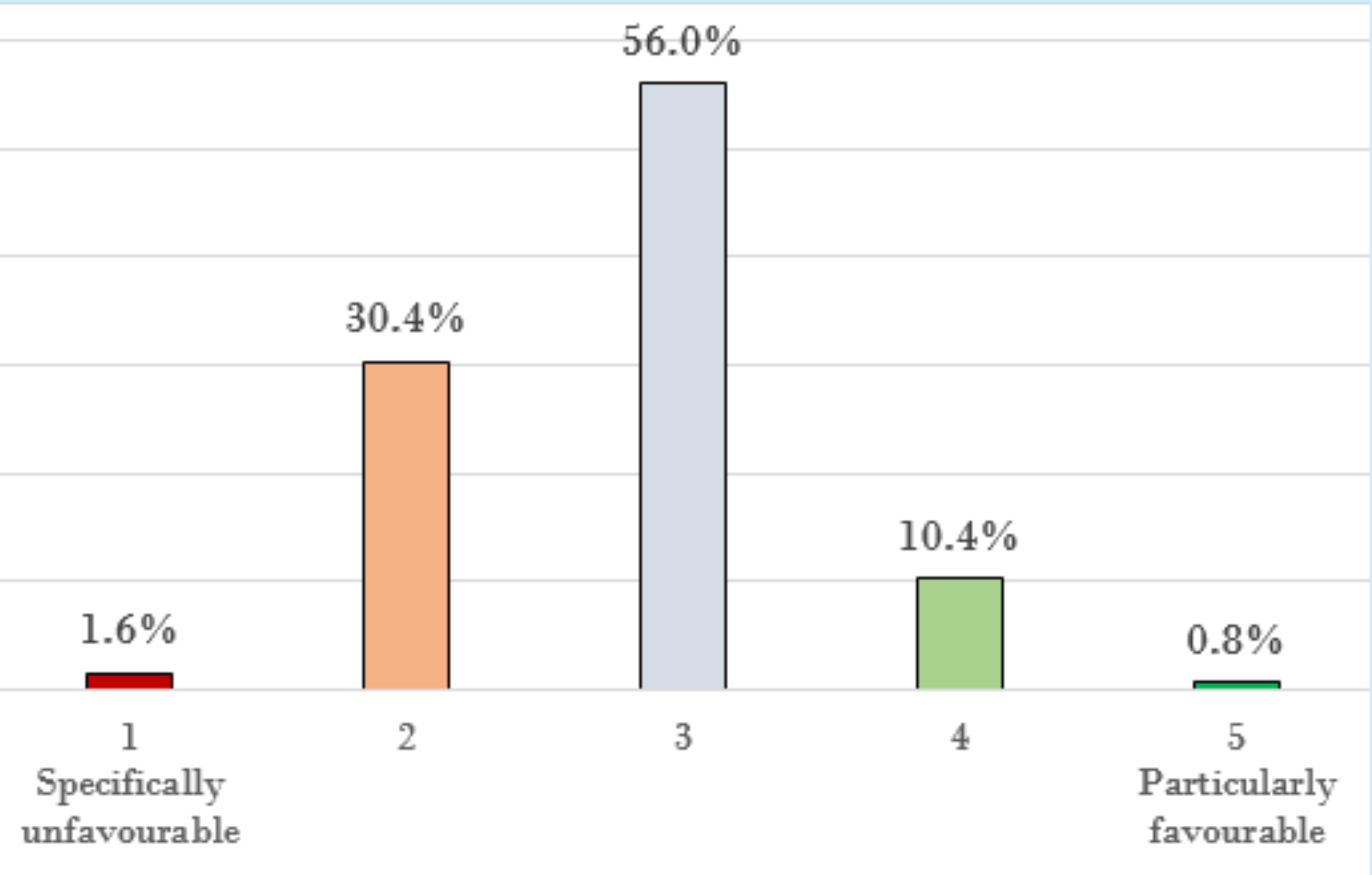


Figure 1.
Percentage distribution of families' living standards on a 5-point scale (N=125)

TYPE OF RIGHT VIOLATIONS	PERCENTAGE
Human dignity	37.6%
Right to healthcare	32.8%
Right to information	12.8%
Self-determination	8.8%
Right to refuse medical treatment	6.4%

Table 2.
Most common rights violations related to healthcare
(more response options in the questionnaire)

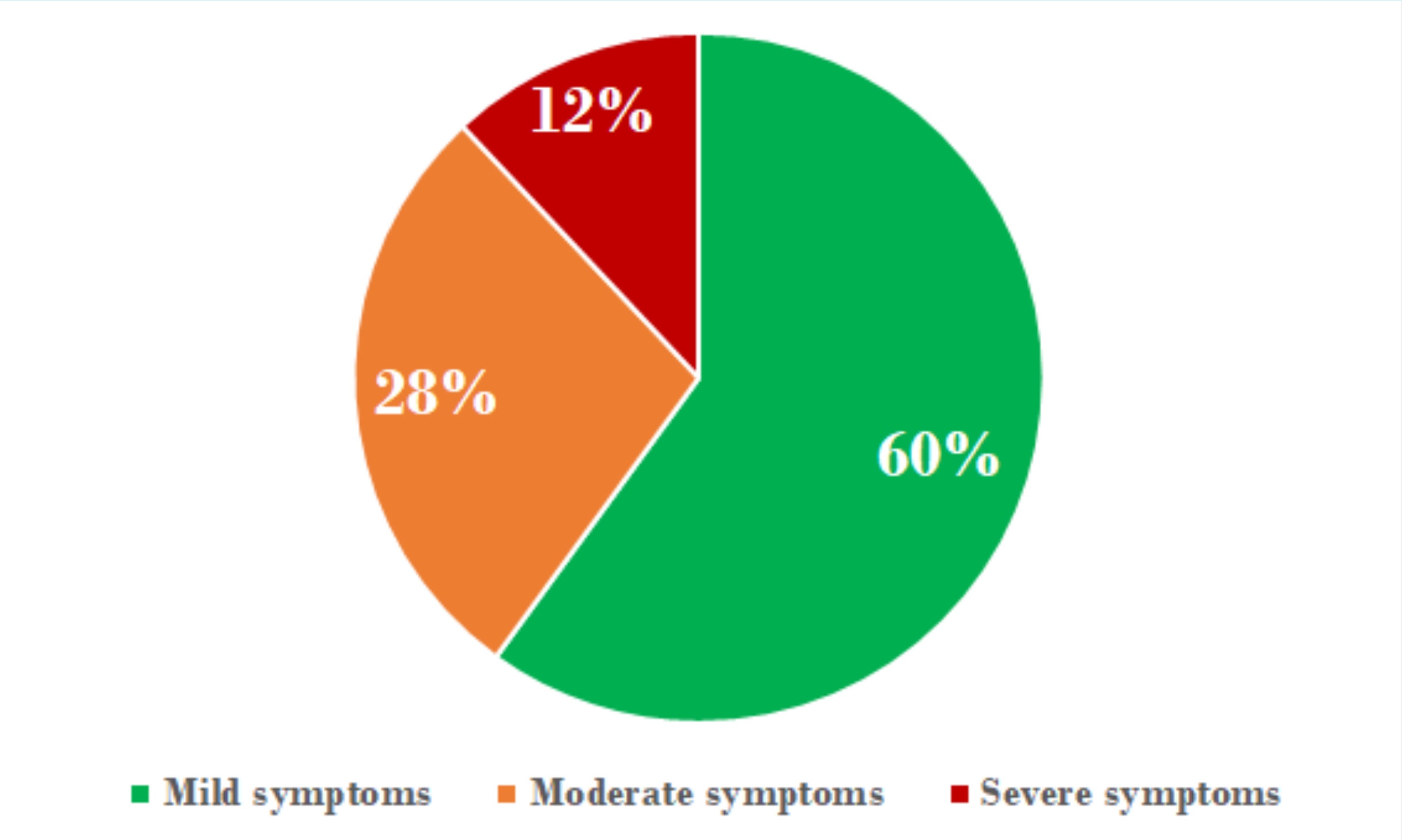


Figure 2.
Distribution of autism severity in research (N=125)



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Corresponding author:
Dr. Imre BONCZ, MD, MSc, PhD, Habil
University of Pécs, Faculty of Health Sciences, Hungary
Institute for Health Insurance
E-mail: imre.boncz@etk.pte.hu