

Resource Utilization Among Patients with Epidermolysis Bullosa: Preliminary Findings from Seven European Countries

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OBJECTIVES

This study is part of the BUR-EB project, which aims to assess the social and economic consequences of epidermolysis bullosa (EB), a rare genetic skin disease, across seven European countries. The present analysis focuses on resource utilization among EB patients

METHODS

Study design: cross-sectional survey conducted in 2024 in seven european countries: Austria, Bulgaria, France, Germany, Hungary, Italy, Spain

Participants: patients suffering from EB without age restrictions

Data collection:

- Socio-demographics
- Disease characteristics such as EB type: simplex, dystrophic, other (junctional + kindler)
- Resource utilization due to EB: patients were asked whether they used the following resources at least once within the study's recall period:
 - Direct medical: medicines, health materials, medical visits, medical examinations, hospitalization, healthcare transport
 - Direct non-medical: social services, professional carer, non-healthcare transport, informal care

Statistical analysis:

- Descriptive methods to assess sample characteristics and resource utilization
- Chi-squared test to assess subgroup differences

Ethical approval was obtained from Medical Research Council, Hungary (BM/26385-3/2023).

CONCLUSIONS

This preliminary analysis provides baseline information on EB patients' resource use patterns, which appeared to be mainly dominated by healthcare-related needs and associated with patients' age and disease type. Our results draw clinicians' attention to patient needs and support healthcare professionals responsible for resource allocation decisions.

RESULTS

- All in all, N=347 patients (53% female) were involved from the seven countries, including N=206 adults (57% female) and N=141 children (48% female)
- Figure 1 and Figure shows patients resource use by age category and disease type, respectively

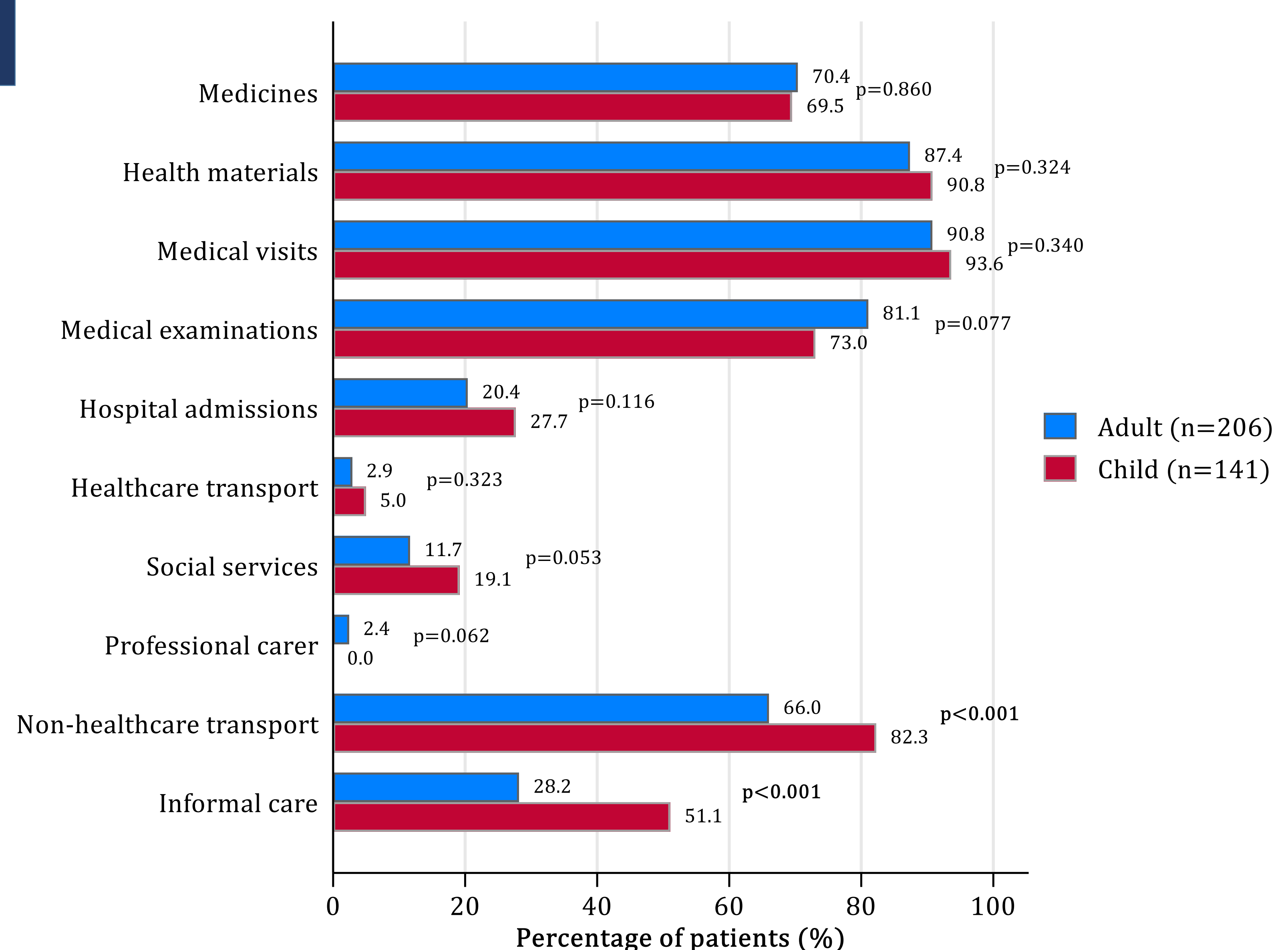


Figure 1. Resource utilization by age category

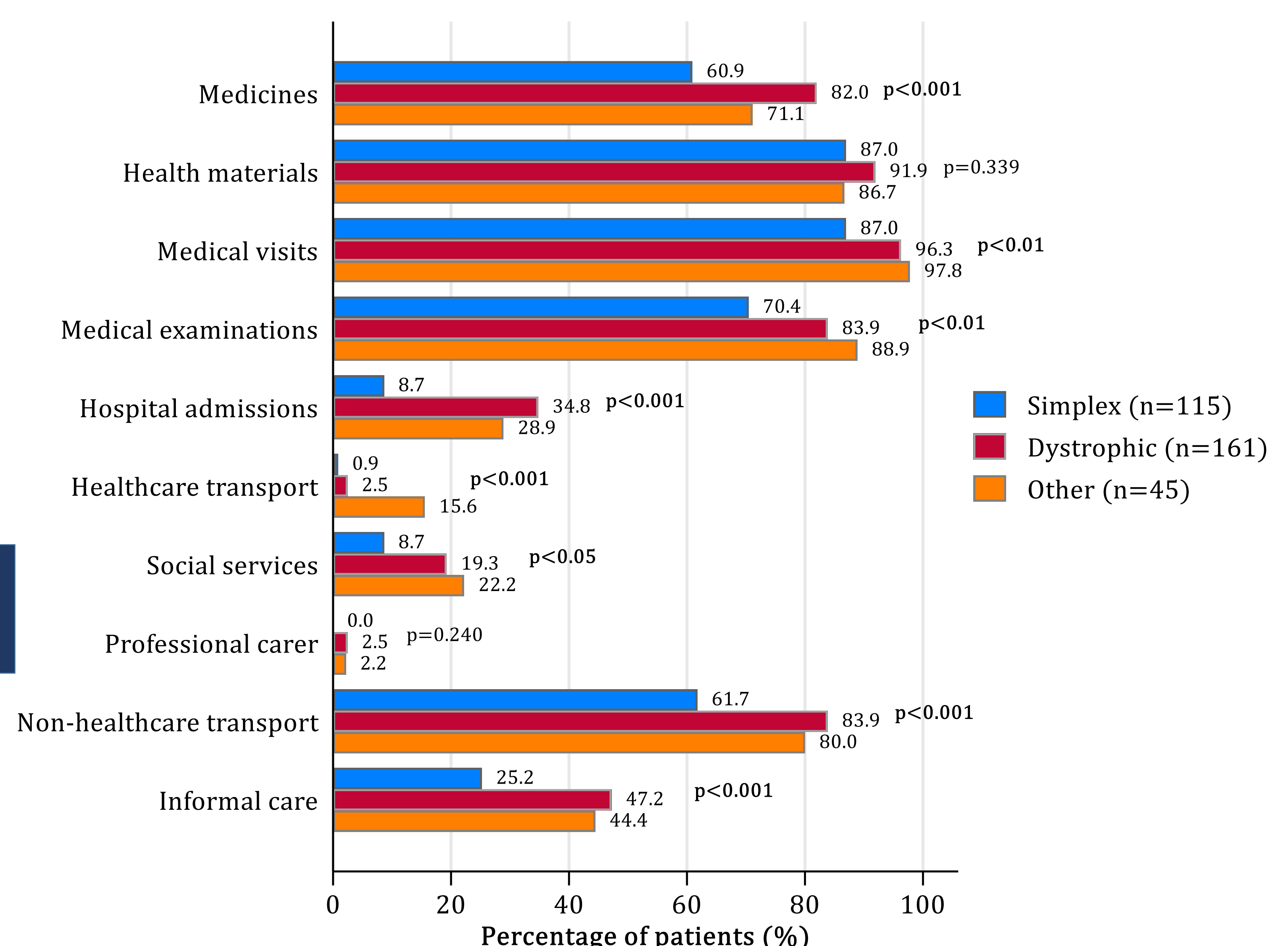


Figure 2. Resource utilization by disease type