The individual journey of chronically ill Ukrainian refugee patients as the mirror of the Czech health care system

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Abstract: The ongoing war in Ukraine continues to lead to a significant flow of refugees into Europe, and the Czech Republic remains one of the countries with the highest number of Ukrainian refugees (UR) per capita. Refugees continue to face multiple challenges in European countries, including unemployment, lack of housing and limited access to education, healthcare and mental health support. A significant number of UR who are staying in the Czech Republic for a long time suffer from severe chronic health problems that require constant medical and social care. Their most common long-term serious illnesses are primarily cancer diagnoses.

The aim of our research was to:

- Obtain more detailed information about the specific obstacles that UR patients have to overcome and the causes of these obstacles.
- Identify healthcare barriers from patients' perspective and their strategies to overcome them while recognising opportunities to improve the current system.
- Explore how chronically ill UR patients engaged with non-profit and patient organisations during their healthcare journey and their experiences with these "touchpoints."

Healthcare quality is based on three fundamental pillars: clinical effectiveness, patient safety, and patient experience. Patient experience is a crucial aspect of care quality, and one approach that concentrates care around the patient is mapping the patient's journey through the healthcare system. This method helps to understand barriers, facilitators, experiences, interactions with services, and care outcomes for individuals and their caregivers while navigating the system.

We used two methods for data collection in the mixed research. The quantitative phase comprised the questionnaire survey with 81 respondents - experts operating in various settings focused on providing health and social care services to UR, including state and public administration representatives and other patient support bodies. We based the qualitative part on the exploratory case study focusing on the patient pathway of chronically ill UR and examined their interactions with the healthcare system across three phases: prediagnosis, the acute phase of illness, and ongoing care. We collected those data through in-depth semi-structured interviews. Our sample included 13 beneficiaries of the project "MHPSS for disabled refugees and refugees with an oncological diagnosis from Ukraine - a pilot programme."

UR entered the system at various stages of illness, with some diagnosed in Ukraine and others after arrival in the Czech Republic. Thanks to emergency legislation introduced following the 2022 war in Ukraine, refugees were entitled to publicly funded healthcare services from the moment they entered the Czech Republic. The findings point to gaps in service provision and communication that affect the overall quality of care and integration of refugees, including language and system knowledge barriers, primary care access, long waiting times, coordination challenges, health inequalities, community support and long-term integration, health professionals' lack of knowledge about refugees' needs and the ability to communicate with patients from culturally different backgrounds. On the other hand, UR valued informal assistance from the community and support from various organisations during the patient's journey through the healthcare system.

These findings suggest the need for improved systemic support to facilitate the integration of UR into the Czech healthcare and social system, mainly through intercultural work and better communication strategies.