Access to healthcare, experiences with care coordination, patients‘ needs, and expectations: the rare cancer patients‘ perspective

L. Oestreich[1], M. Boukovala[1], T. Fey[2], V. Heinemann[1,2], J. Hinneburg[3], V. Kratzer[2], J. Lühnen[4], F. Mumm[1,2], T. Pichler[1,2], A. P. Schön[1], A. Steckelberg[3], M. von Bergwelt-Baildon[1], C. B. Westphalen[1,2], S. Zacher[3], D. Zhang[1], K. Berger-Thürmel[1]. On behalf of the TARGET-study group.

[1] Department of Medicine III, LMU University Hospital Munich, Munich
[2] Comprehensive Cancer Center (CCC Munich LMU), LMU University Hospital Munich, Munich
[3] Institute for Health and Nursing Science, Interdisciplinary Centre for Health Sciences, Medical Faculty, Martin Luther University Halle-Wittenberg, Halle (Saale)
[4] Institute of Clinical Nursing Science, Charité – Universitätsmedizin Berlin, corporate member of Freie Universität Berlin and Humboldt Universität zu Berlin, Berlin

INTRODUCTION

Patient orientation is crucial in order to continue to meet the many new challenges in the changing German healthcare system and to adapt the system accordingly. For cancer patients an important part of the healthcare experience is the journey from first symptoms until diagnosis and treatment[1]. Therefore, information on patients‘ needs, expectations, and experiences regarding the access to the healthcare system is needed. However, evidence on these aspects is still scarce in Germany – especially for rare cancer patients.

OBJECTIVE

This study aims to explore the patients‘ perspective on access to healthcare, care coordination, and patient information needs.

METHODS

- Anonymous online survey (LimeSurvey®) for cancer patients
- Survey based on 10 explorative, semi-structured interviews, and pilot-tested
- Ethics waiver obtained from the Ethics Committee of the LMU Munich Hospital (reference number 23-0795 KB)
- Investigated categories: patient and cancer characteristics, patients‘ experiences with access to healthcare, participation preferences, patient satisfaction, information needs, and the Care Coordination Instrument (CCI)[2]
- Subggroup of study: rare cancer patients
- Distribution channels: social media (instragram/LinkedIn), CCC Munich, outpatient practices, pharmacies, and cancer support groups in Bavaria

RESULTS

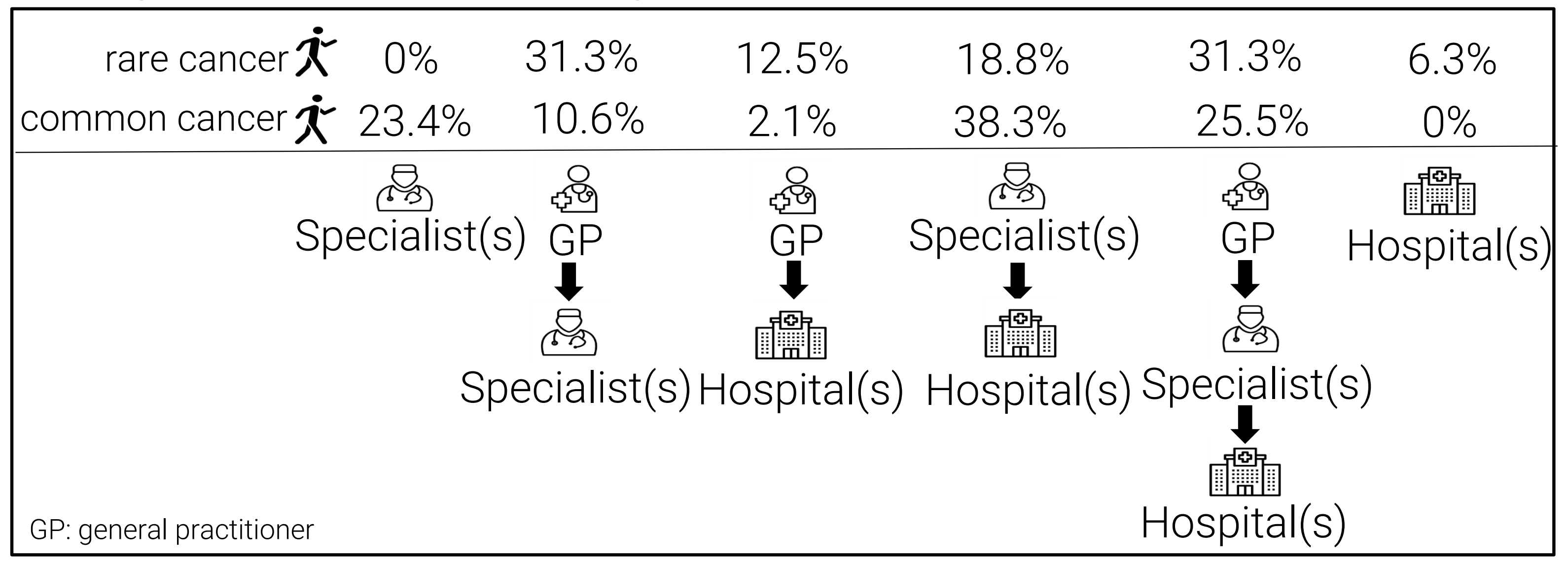
- 87 patients participated (study still ongoing)
- 20 patients with rare cancers (incidence <6/100,000)
- 86.7% female, mean age 47.7 years (SD: 13.0 years)

▸ Table 1: Access to healthcare

	All patients (n=75)
Patient interval[1] (first symptom to first visit), mean (median)	155.8 (70) days
Diagnostic interval[1] (first visit to diagnosis), mean (median)	68.0 (20) days
Treatment interval[1] (diagnosis to treatment), mean (median)	23.1 (14) days
Health care centers visited until diagnosis, mean (SD)	2.4 (1.1)

- When choosing a hospital, 62.6% choose a hospital specialised in their cancer, 29.3% a hospital nearby, 18% a well-known hospital, and 17.3% a certified hospital.

▸ Figure 1: Routes to diagnosis and treatment



GP: general practitioner

- 47.5% of patients would change their route to treatment in retroperspective (mainly visiting a specialist sooner and searching for a specialised hospital).

Information needs:

- 49.3% of all patients wish for more information (mainly on treatment alternatives, side effects, clinical study options, aftercare, and social and psychological aftereffects).

▸ Table 2: Care coordination

	Max	Survey (n=56)	Werner et al. (2024)[3]
Total score CCI, mean (SD)	87	49.5 (11.8)	49.4 (11.2)
Communication/information score, mean (SD)	48	31.2 (8.4)	30.1 (8.9)
Need-based inter-professional navigation score, mean (SD)	51	26.1 (6.5)	24.0 (8.4)

DISCUSSION

- Routes to diagnosis seem to differ between rare and common cancer patients
  - First contact with GP important for rare cancer patients, specialists important for common cancer patients.
- More engagement for shared-decision making and better care coordination needed
- 76% recruited via social media (potential bias)
- Study still ongoing, link to study:
  https://www.ccc-muenchen.de/forschung/projekte-des-ccc-munchen/target/6775567545306859
- Further analyses regarding cancer types, age and regional patterns planned

CONCLUSION

- Patients‘ experiences and needs are important for discussions on optimizing healthcare structures.
- Several patients have unmet information needs.
- Outpatient practices are important during patient journeys until cancer diagnosis.
- Further studies on patients‘ experiences and needs are warranted for describing and analyzing the healthcare situation of patients with rare cancers.

The project on which this publication is based was funded by the Innovation Committee of the Joint Federal Committee under the funding code 01NVF20012.

Sources

[1] Scott SE, et.al. The model of pathways to treatment: conceptualization and integration with existing theory. Br J Health Psychol.2013;18(1):45-65.
[2] Okado,I. et al. Development and psychometric evaluation of a questionnaire to measure cancer patients' perception of care coordination. BMC Health Serv Res,2020.20(1):52.
[3] Werner et al. Care Coordination Questionnaire for Cancer Patients: Translation, adaptation, and validation of the questionnaire on care coordinatin for cancer patients.2024 [in preparation].