

Understanding of Metastatic Colorectal Cancer in the Real World: Initial Results from a European Survey on the Unmet Needs of Patients Living with Metastatic Colorectal Cancer

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Background

- EuropaColon, a European colorectal cancer (CRC) patient organisation, planned and carried out an international survey on the unmet needs of patients living with metastatic colorectal cancer (mCRC).
- The aim of the survey was to better understand the challenges and needs of those living with mCRC as well as to better understand their health-related quality of life in 1,000 patients in 13 countries, including Austria, Belgium, Cyprus, Germany, Hungary, Italy, the Netherlands, Poland, Portugal, Serbia, Spain, Turkey and the UK.
- Data processing in Hungary, Poland, Serbia, and Spain is complete.
- The objective was to describe basic demographics and responses regarding understanding of the disease in the four countries.

About EuropaColon

- EuropaColon is a not-for-profit European organisation that was established in 2004 with the aim to unite patients, caregivers, healthcare professionals, politicians, the media, and the public in the fight against digestive cancers. The organisation works with 43 partner groups in 32 European countries and has been recognised as the voice for colorectal cancer patients in Europe.



Methods

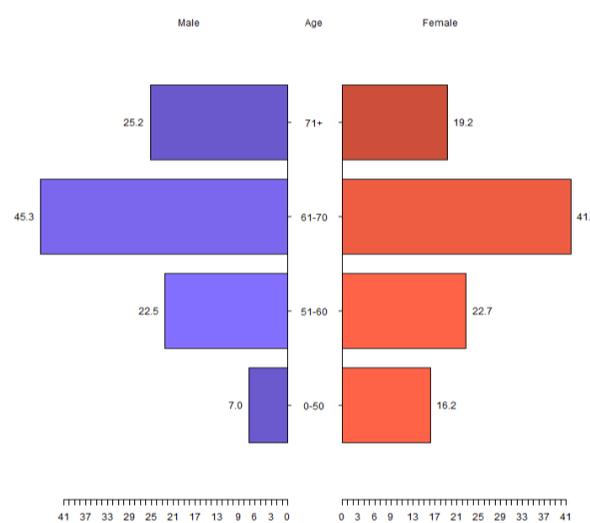
- Institutional review board (IRB) approval was sought for the survey, where needed. Nurses and clinicians volunteering for the survey, and partner organizations of EuropaColon, recruited patients.
- The survey included sections on demographics and the disease - discovery of the disease, diagnosis, treatment and support, and included the European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Core 30 (QLQ-C30) and Core 29 (C29) questionnaires on health-related quality of life.
- The section on discovery was comprised of 16 questions, including reasons for contacting physicians, symptoms experience, the lag between first symptoms and seeking clinical help, and misdiagnosis.
- Patients could complete the survey on-line or fill in a paper-based survey. Single data entry from paper surveys was executed by EuropaColon. Descriptive analysis of the data was carried out in Microsoft Excel®.

Results

Profiles

- Altogether, 548 surveys were collected and analysed, most surveys were received in paper form (80%). The majority of surveys came from Serbia (170), Poland (163), Spain (112) and Hungary (103).
- Completion rates varied across responses, but in general were high.
- The elapsed time from diagnosis to completing the survey was 2 years on average.
- Average age of patients across these countries was 63.59, ranging from 62.1 years in Hungary to 65.33 in Serbia.
- The sample included 56.5% men and 43.5 % women.
- In terms of education, 66% of the patients had a primary or secondary school as their highest degree and 29% reported college or university education. In terms of employment status, 65% were retired.

Figure 1. Demographical Graph—Age vs. Male/Female



Illness Discovery

- Fifty percent of patients had discovered something was wrong on a routine exam or due to symptoms not related to CRC while only 4% were diagnosed through screening programs. When it comes to attitude toward screening – 56% of patients answered they would have participated in the screening had they been invited. It shows, that most of the patients did not discover their illness via screening programs, mostly during routine examination or - in a worst-case scenario – through emergency hospitalization. Although their attitude after their diagnoses shows a completely different approach.
- CRC symptom awareness in the analysed sample was very low – only 26% of patients knew before what symptoms may have been associated with CRC, though in Serbia 39% of the patients were aware of the relating symptoms.
- Although 35% of patients waited less than a month from observing symptoms, 33% waited 1-3 months, 14% waited 3-6 months and the rest even longer. Similar time distribution was observed for diagnosis.

Figure 2. How long did patients wait between observing the first symptoms and consulting the clinician?

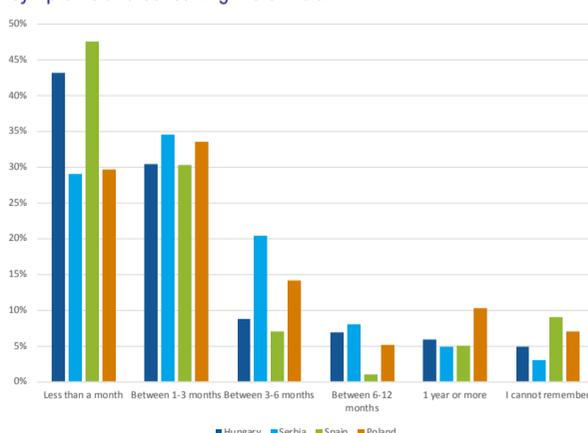


Figure 3. What were patients' attitudes toward screening?

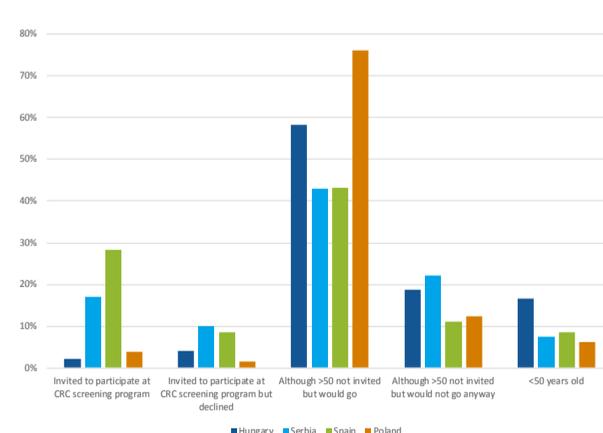
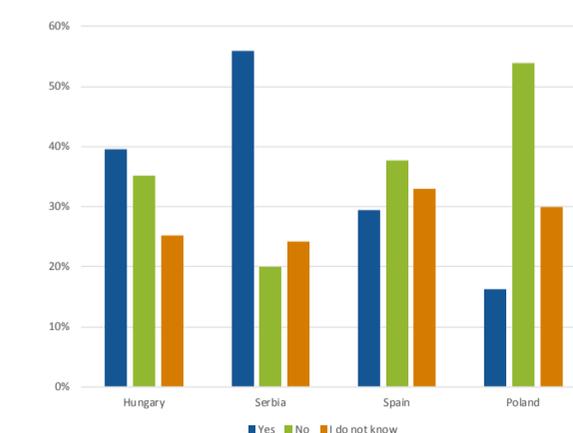


Figure 4. When patients were screened, did they perform FOBT?



Diagnosis

- Importantly, only 23% indicated that they were misdiagnosed and 47% of patients were very satisfied with the process of establishing a diagnosis on average, but there was large variation across countries, including 35% in Hungary who were not satisfied at all.
- When patients were screened, 37% performed foecal occult blood tests (FOBT), 36% did not, and the rest did not know if they had those tests. The connection with the results of awareness of FOBT performance and CRC-related symptoms shows that knowledge of CRC illness should be enhanced to draw attention to the necessary screening programs and disease or progressive disease prevention.

Conclusions

- Awareness of patients with CRC is low, with few respondents recognising symptoms and seeking help without delay. Misdiagnosis levels are still high.
- The attitude toward screening programs is positive among patients; despite the existence of various screening programs in these countries, awareness and compliance rates are low.
- The conditions of the discovery of CRC need to be improved both on the patient awareness and the clinical side.