Vitaloni *et al. BMC Gastroenterology* (2025) 25:378
https://doi.org/10.1186/s12876-025-03976-y

BMC Gastroenterology

RESEARCH **Open Access**

Clinical challenges and patient experiences in early-onset colorectal cancer: insights from seven European countries

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Abstract

Background The incidence of early-onset colorectal cancer (eoCRC), defined as CRC diagnosed in individuals under 50, is rising globally. Younger patients often face diagnostic delays and receive care pathways designed for older populations. These gaps highlight the need for tailored approaches to diagnosis, treatment, and support.

Objective This study aimed to explore the lived experiences and challenges of eoCRC patients across seven European countries to inform public health strategies and improve patient-centered care.

Methods We conducted qualitative focus groups with 47 eoCRC patients and survivors from France, Ireland, Italy, the Netherlands, Romania, Spain, and the United Kingdom. Discussions were analyzed using a thematic approach, focusing on three stages of the patient journey: pre-diagnosis, diagnosis, and post-diagnosis.

Results Participants highlighted several key challenges, including low awareness of CRC symptoms among younger populations, diagnostic delays linked to age and gender biases, and limited access to age-appropriate support services. Many participants reported significant quality-of-life (QoL) impacts related to disrupted careers, intimacy issues, and challenges managing family responsibilities during treatment. Psychological support, physiotherapy, and nutritional counseling were inconsistently available, with significant disparities across public and private healthcare systems.

Conclusions The findings underscore the urgent need for targeted public health campaigns to raise awareness of eoCRC, improved training for healthcare providers to reduce diagnostic delays, and expanded access to tailored support services. Addressing these gaps is critical to mitigating the growing burden of eoCRC and improving outcomes for younger patients.

Keywords Early-onset colorectal cancer, Health disparities, Young adults, Quality of life, Patient-centered care, Healthcare inequities

Background

Each year, around half a million new cases of colorectal cancer (CRC) are diagnosed in Europe [1]. While most diagnoses are in people aged over 50, there has been an alarming increase in early-onset CRC (eoCRC), defined as CRC diagnosed in people under 50. This increase is most pronounced in adults aged 20–39 [2], a trend that raises important public health concerns given the lack of

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systematic screening and awareness for this younger population. Emerging evidence shows not only an increase in incidence but also that eoCRC often presents with more aggressive tumor biology and distinct molecular features compared to CRC in older adults [3–5]. These factors contribute to poorer outcomes and later-stage diagnoses at the time of presentation.

The reasons for the rise in eoCRC are likely multifactorial, influenced by complex determinants of health such as lifestyle factors (diet, physical inactivity, and obesity), environmental exposures, and alterations in gut microbiota [6, 7]. Psychosocial factors such as chronic stress, sleep disturbances, and socio-economic stressors have also been proposed as potential contributors [8, 9]. These factors interact with systemic barriers, including lack of healthcare provider awareness and diagnostic delays, meaning young adults are often diagnosed at advanced stages, after facing significant barriers to timely detection and treatment [10, 11].

The impacts of eoCRC extend beyond the physical disease, affecting multiple QoL factors, including psychological wellbeing, family dynamics, fertility, and career aspirations. Unlike older patients, young adults with eoCRC must navigate the dual burden of managing a life-threatening illness while contending with life stage-specific responsibilities, such as starting and managing a family or advancing their careers [11, 12]. In addition to immediate health challenges, eoCRC patients are faced with long-term consequences that can profoundly affect their ability to contribute to society. Many of these patients are expected to survive for 30–40 years post-diagnosis, yet they often face barriers to employment, caregiving, and social participation. The inability to work or care for family members can exacerbate financial instability, leading to long-term economic costs both for the patients and for society as a whole. Addressing these challenges through better healthcare support and public health strategies is not only ethically imperative but also economically prudent in the long term [13].

This study was conducted by Digestive Cancers Europe (DiCE), a non-profit umbrella organization representing patient advocacy groups from across Europe. DiCE aims to amplify the voices of patients and survivors of digestive cancers, raise awareness, and improve equitable access to high-quality care. In partnership with national patient organizations, DiCE organized focus groups to explore the lived experiences of eoCRC patients and survivors, examining their journeys from symptom onset to diagnosis, treatment, and post-treatment care.

The focus groups offered valuable insights into the determinants of health that shape the experiences of eoCRC patients. They highlighted critical gaps in awareness, diagnostic pathways, and tailored support systems. This study emphasizes the importance of integrated, people-centered health services that consider not only the clinical aspects of cancer care but also the broader social, emotional, and economic factors that impact health outcomes for younger patients. By centering the voices of eoCRC patients, this research aims to inform public health strategies and policies that address the unique needs of this growing population.

Methods

Focus group rationale and setting

In 2023 and early 2024, members of DiCE hosted a series of online focus groups with eoCRC patients and survivors, using the Zoom platform. The focus groups took place in seven European countries: France, Ireland, Italy, the Netherlands, Romania, Spain, and the UK. The focus group format was chosen for its ability to foster interactive discussions and explore shared and divergent patient experiences in depth. This method also allowed participants to reflect on and respond to each other's perspectives, generating rich insights into their care journeys. The online format allowed for greater flexibility and accessibility for participants across various European countries, facilitating inclusivity and enabling a broader range of participants to share their experiences.

Participants were recruited through multiple channels, including national and regional patient advocacy organizations, social media platforms, and referrals from healthcare professionals (primarily oncologists). This mixed recruitment strategy was designed to ensure geographic and experiential diversity, while also engaging patients outside traditional institutional pathways. To ensure diversity in experiences, purposive sampling was used to include participants of different ages, genders, and stages of diagnosis, thus ensuring that the study included a diverse range of experiences related to eoCRC. Participants were eligible if they were over 18 and had been diagnosed with CRC before the age of 50, regardless of cancer stage or treatment status. The final sample included individuals across a range of disease stages (from stage II to metastatic), although most were diagnosed at stage III or IV. The study aimed to capture a diversity of clinical trajectories, but data were not stratified by stage or treatment status. Focus groups were conducted in the national languages of France, Ireland, Italy, Spain, and the UK, while sessions in Romania and the Netherlands were conducted in English. Groups comprised of five to nine participants, ensuring manageability while allowing diverse perspectives to emerge.

As an initial step, all participants engaged in a 30-min one-on-one call with a researcher to review the study's aims and objectives, address any concerns, and provide informed consent. This call also served to establish rapport and prepare participants for the focus group discussions. Participants received a pre-meeting questionnaire to collect demographic data and to confirm their age at diagnosis and stage of their tumor at diagnosis. They were also familiarized with the session agenda and discussion guidelines. All participants provided written informed consent and participated voluntarily. No clinical data, medical procedures, or interventions were involved, and the research posed minimal risk to participants. In accordance with applicable national regulations for non-interventional social research, and consistent with published ethical frameworks for participant-led health research, this study did not require formal approval by an institutional ethics committee [14, 15].

The project was conducted by a non-profit patient organization and was reviewed internally by its scientific board and a patient advisory committee. All procedures were carried out in line with the principles of the Declaration of Helsinki and adhered to recognized standards of research ethics, including respect for autonomy, privacy, informed consent, and data confidentiality.

DiCE researchers developed a questionnaire to guide the focus group meeting with the support of three expert CRC patients and a nurse. The three expert CRC patients, who had lived experiences with eoCRC, and a nurse with clinical expertise, collaborated with DiCE researchers to ensure that the questionnaire was relevant, patient-centered, and aligned with the needs of the study population. The questionnaire was used as the basis for discussion for each focus group and was translated into the four languages of the project (see Supplementary data 1). Six out of the seven focus groups (conducted in English, Italian, Spanish, Romanian, Dutch, and Irish contexts) were moderated by the same lead researcher, fluent in English, Spanish and Italian and experienced in qualitative health research. The French-language focus group was facilitated by a second trained researcher who had previously observed several sessions and was thoroughly briefed on the study methodology. This moderator used the same discussion guide and mirrored the facilitation approach to ensure alignment. Sessions lasted approximately 90 min and were audio-recorded with participants' consent. Recordings were transcribed using Turboscript, with manual correction during analysis. The transcriptions from France, Italy and Spain were translated into English by a translation company and verified for accuracy by the session moderators from DiCE.

Participants

A total of 47 individuals participated in the study, distributed across seven European countries: France (*n* = 6), Ireland (*n* = 7), Italy (*n* = 5), the Netherlands (*n* = 6), Romania (*n* = 9), Spain (*n* = 5), and the United Kingdom (*n* = 9). The sample included 20 men and 27 women. Educational attainment was generally high, with 42 participants having completed a university degree or higher, and five reporting secondary education or lower.

The average age at diagnosis was 40.5 years, ranging from 29 to 49 years. Participants under the age of 30 were underrepresented, with most falling between 35 and 49 years of age. This age distribution reflects both recruitment challenges and existing epidemiological data, which show that the majority of early-onset colorectal cancer (eoCRC) cases occur in the 40–49 age group [16].

Regarding clinical stage at diagnosis, 23 participants were diagnosed with stage IV/metastatic disease, 20 with stage III, and 4 with stage II. For analytical purposes, seven cases were considered early-stage (stage I–II) and 40 as late-stage (stage III–IV). A full overview of participant characteristics by country is presented in Table 1.

Data analysis

All focus group discussions were recorded, transcribed verbatim, anonymized to protect participant identities, and verified by the DiCE members who had moderated the sessions. A researcher conducted an inductive thematic analysis, reviewing transcripts iteratively to identify recurring themes and patterns. Inductive thematic analysis was used to allow themes to emerge naturally from the data, rather than being imposed by pre-existing theoretical frameworks, ensuring that the analysis accurately reflected participants' lived experiences. Initial codes were refined through subsequent transcript reviews by a second researcher, resulting in the identification of eight overarching themes categorized under three stages of the patient journey: pre-diagnosis (with three connected themes of awareness + family history, lifestyle + risk factors and signs + symptoms), diagnosis (with three themes of delays in diagnosis, gender specific delays and biomarker detection), and post-diagnosis (with two themes of impact on QoL and support system). Sub-themes were selected where appropriate to focus on specific aspects of an overarching theme (See Fig. 1 for more detail). Thematic coding and the conceptual map were reviewed and refined by both researchers to ensure clarity and consistency. Findings were validated by the DiCE members who had moderated the sessions. Given the cultural diversity of the participants, the analysis also considered potential cultural differences in the expression of experiences. We conducted a systematic cross-country analysis to explore both shared and divergent experiences among the seven countries included.

Table 1 Sociodemographic and clinical characteristics of participants by country

	France (*n* = 8)	Ireland (*n* = 7)[a]	Italy (*n* = 5)	Netherlands (*n* = 6)	Romania (*n* = 9)	Spain (*n* = 5)	United Kingdom (*n* = 7)	Total (*n* = 47)
Sex								
Male	2	1	3	3	4	3	3	19
Female	6	6	2	3	5	2	4	28
Educational level[a]								
Secondary education or lower	0	1	1	2	0	0	0	4
Degree or higher	8	4	4	4	9	5	7	41
Average age at diagnosis	41	40.3	41	39	39	43	38	40.5
Age range at diagnosis	31–49	34–49	31–48	30–46	32–47	37–45	29–46	29–49
CRC Stage at diagnosis								
Early stage (I–II)		0	1	0	1	1	1	4
Late stage (III–IV)	8	7	4	6	8	4	6	43

The table summarizes key characteristics of the 47 participants in the study, disaggregated by country. Variables include sex, educational level, average age at diagnosis, age range, and cancer stage at diagnosis (Stage II, III, IV/metastatic). For interpretative purposes, early-stage refers to Stage I–II and late-stage to Stage III–IV/mCRC. Most participants were diagnosed at a late stage, consistent with existing literature on early-onset colorectal cancer. The country-level breakdown allows for contextual understanding of sample composition but is not intended for comparative statistical analysis due to small group sizes and qualitative design

Early stage includes stage I–II; late stage includes stage III–IV/metastatic CRC. Participants ranged in age from 29 to 49 years; individuals in their 20 s were underrepresented

[a] 5 of 7 participants in Ireland provided educational information

Results

Several topics emerged within three overarching themes mapping the stages of the patient journey: pre-diagnosis, diagnosis and post-diagnosis. Although themes are presented according to patient journey phases (pre-diagnosis, diagnosis, and post-diagnosis), several issues emerged as cross-cutting across these stages. In particular, participants consistently described communication challenges with healthcare providers, emotional and psychological strain, and the need for self-advocacy as persistent experiences that shaped their trajectory from symptom onset to survivorship.

Pre-diagnosis

CRC screening programs typically start after the age of 50, which means that diagnosis in younger patients often depends on the awareness of symptoms by individuals and HCPs. As a result, raising awareness about CRC, particularly its increasing incidence among younger populations, is crucial for timely diagnosis.

Awareness and family history

Awareness of CRC risks among focus group participants was generally low. Most did not initially associate their symptoms with cancer due to their age, reflecting a lack of public health messaging targeting younger populations. Participants with a family history of cancer were often unaware of this history before their diagnosis, highlighting potential cultural barriers to discussing family health.

> *Once you say you have been diagnosed, there's someone who then says: 'But your grandmother, she died of intestinal obstruction,' or 'Ah, but your grandfather had stomach cancer.'*
> *–Patient, France*

In addition to low awareness, several participants mentioned the stigma or taboo surrounding discussions about bowel health. This reluctance to discuss symptoms delayed some individuals from seeking medical attention.

Lifestyle and risk factors

Although CRC is heavily associated with certain lifestyle factors, including a high intake of processed meats and low intake of fruits and vegetables, sedentary lifestyle, obesity, smoking, and excessive alcohol consumption [17], most participants stated they led healthy lifestyles before their diagnosis, which points to a need for reevaluating traditional risk factor models for younger patients. Many expressed frustration with societal stereotypes linking cancer to lifestyle choices. Participants also

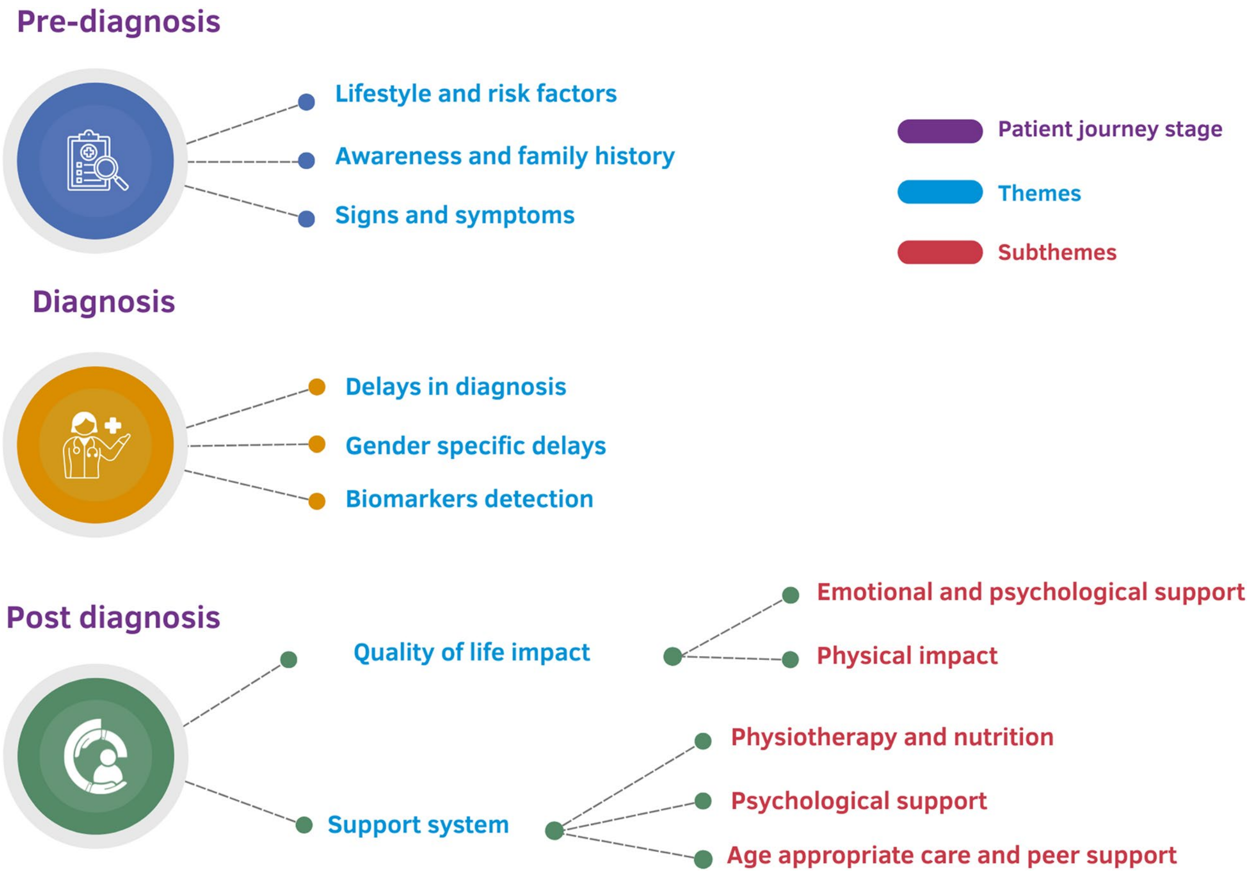

Fig. 1 Thematic map of patient experiences across the care continuum

The figure illustrates the main themes and subthemes that emerged from the analysis, organized along three stages of the patient journey: pre-diagnosis, diagnosis, and post-diagnosis. Themes include lifestyle and risk factors, awareness and family history, signs and symptoms, delays in diagnosis, the impact of age and gender on care, biomarker testing, psychological and peer support, physical consequences, and access to age-appropriate services. Each theme is positioned according to the stage at which it was most commonly discussed by participants, though several themes (e.g., psychological support) were crosscutting. This figure reflects aggregated themes across all countries. Country-specific differences are discussed in Sect. "Country comparison"

frequently mentioned stress as a potential contributing factor, which warrants further investigation.

> *We need to break the stereotypes that people who have this disease have done something wrong. I don't smoke, I don't drink, I've been a rugby player, an athlete, training three times a week. Maybe we should rethink it.*
> *–Patient, Spain*
> *I do believe stress is a massive factor. For me, I worked really hard. Since I've been diagnosed, I've tried to reduce stress and learn how to not be stressed.*
> *–Patient, Ireland*

Signs and symptoms

Participants reported a range of early signs and symptoms that complicated timely diagnosis. Commonly reported visible signs included rectal bleeding, while subjective symptoms included abdominal pain, fatigue, and iron deficiency anemia. Fatigue was a strikingly prevalent early symptom, even among those with no other notable signs, highlighting the need for broader symptom awareness among HCPs. Participants emphasized the profound impact of fatigue, often underestimated in its severity. Non-specific symptoms like fatigue complicate timely diagnosis.

> *I didn't really have many symptoms, no bleeding or anything visible like that. I just felt really tired. I just thought it might be COVID and kept thinking, 'Why am I so tired?'*
> *–Patient, UK*

Diagnosis

Delays in diagnosis

Participants frequently described experiencing diagnostic delays, with symptoms dismissed as benign or attributed to conditions like hemorrhoids. Younger patients often face skepticism from HCPs due to their age, delaying critical diagnostic procedures.

Several participants said they ignored signs and symptoms for some time, assuming they were nothing to worry about. A lack of awareness about the condition and its growing prevalence in younger adults was cited as a barrier to seeking help.

> *When I started losing more and more blood, I went to see my GP (General Practitioner) again, but she pushed back saying that I was too young and saying, 'No, it's fine.'*
> *–Patient, Netherlands*
> *I went to my doctor, and he said 'No, look, it must be hemorrhoids.' But it became increasingly debilitating, so I went back and said, 'Let me see a proctologist - he'll be the judge.'*
> *–Patient, Italy*

Gender-specific delays

Gender-specific delays were highlighted by female participants, whose symptoms were often attributed to gynecological issues such as heavy periods or hormonal imbalances. This highlights the need for gender-sensitive approaches in diagnosing young adults. These findings underscore the urgent need for targeted education and training programs for HCPs to raise awareness of eoCRC, particularly its presentation in younger women, to reduce diagnostic delays and address disparities in care.

> *I was always told it was heavy periods. Whether it was tiredness, being really bloated, or polycystic ovaries, all of my symptoms were constantly pushed down to my irregular periods, and I was never ever taken seriously.*
> *–Patient, Ireland*
> *If it's a woman, blood must mean a period. They don't think of anything else. I don't know if they would react the same to a man.*
> *–Patient, France*

Biomarker detection

Microsatellite instability (MSI) testing and Lynch syndrome screening are recommended at diagnosis for all CRC patients, particularly younger adults, while KRAS, BRAF and other treatment-oriented biomarkers are typically tested in metastatic (stage IV) disease [18]. However, many participants said they were not clearly informed whether biomarker testing had or would be performed, or had to explicitly ask for results and explanations. This highlights gaps in communication and inconsistency in how biomarker testing is implemented. In Romania, access was especially limited and dependent on the initiative of individual doctors, with no standardized national protocol for MSI or Lynch syndrome testing. Patients often had to pay out of pocket or pursue testing independently, and most only received KRAS and BRAF results. In contrast, participants in other countries generally reported that Lynch syndrome testing was conducted, although not always explained, and in some cases only after patients requested it.

> *My doctors didn't tell me anything about this. I found out about these tests from other patients. Even my family doctor didn't know what to tell me.*
> *–Patient, Romania*
> *And then he said to me, 'But you have a rarer one. It's called BRAF. Don't Google it,' and then he left me sitting there. What am I meant to do with that information?*
> *–Patient, Ireland*

Post diagnosis

QoL impact

The diagnosis and treatment of CRC have been shown to negatively impact QoL, with ongoing psychological, physical, social, and functional impacts [19]. However, the type of support required by younger adult patients may differ significantly from older patients [20] including disruptions to careers, relationships, and family planning. This was reflected in the feedback.

> *I had an ascending trajectory within the company, I was part of the management team with good prospects for professional development. Now, the approach seems to be 'Let's find you something a little sidelined to feel useful working.'*
> *–Patient, Spain*

Several focus group participants commented that their relationships had suffered because of their CRC, in particular intimacy and sex life. Participants mentioned the lack of support around this topic; that it was rarely talked about, and there was a lack of information around how to regain intimacy. The lack of support for partners was also discussed.

> *Sex for me is non-existent at this moment. I can't even think about it.*
> *–Patient, Netherlands*

Some participants who had children spoke about the extra challenges that living with CRC brought – from the challenge of running a busy household when unwell and tired, to the difficulties of explaining the situation to children and managing their emotional response. A few noticed the emotional impact on their children manifested itself in terms of physical symptoms. Participants spoke about the need for more support in this area to understand how to help children through their parent's cancer journey.

> *My daughter started getting anxiety that was presenting itself as tummy ache.*
> *–Patient, UK*

Participants emphasized the need for support tailored to the unique family and professional challenges faced by younger patients.

Emotional and psychological impact Many of the focus group participants talked about the significant emotional distress caused by their diagnosis and treatments. A common theme was that while many of the physical aspects of cancer could be dealt with, the mental side of it was much harder to manage. Many participants were diagnosed with Stage IV. These individuals shared profound reflections on living with an advanced diagnosis, expressing feelings of fear and resilience. Participants shared that beyond physical symptoms, the emotional and psychological toll of a Stage IV diagnosis at a young age can be profound. The severity of the emotional distress was apparent in many comments, with several participants describing feelings of anxiety, stress, trauma and post-traumatic stress disorder (PTSD).

> *I couldn't think straight or really process anything, you know? And then I thought maybe it's kind of some kind of PTSD or anxiety or something.*
> *–Patient, UK*

Several participants commented that they felt very much isolated and alone – even when surrounded by friends, family and HCP. The theme of survivor's guilt was discussed in some of the focus groups. It is a feeling often closely associated with PTSD.

> *I feel what they call 'survivor's guilt', because I realized that I was lucky in how things went for me. At any step of the way, things could have gone worse. Mental health is an ongoing struggle.*
> *–Patient, Romania*

Physical impact Commonly mentioned physical impacts of cancer and treatment in the focus groups included fatigue, hair loss, surgical scars and pain. The challenges of adapting to and living with a stoma bag were frequently mentioned, including the stress of worrying about it leaking during social situations.

> *Now, one year post-surgery, and my quality of life is extremely low. I need some treatments every day to get through the day. I have a lot of problems with my stoma, requiring more surgery. And I feel extremely tired by all the surgeries and treatments and my concentration level is much lower.*
> *–Patient, Netherlands*

Several women in the focus groups talked about undergoing early menopause due to chemotherapy or radiotherapy, and the significant impact this had on their lives. The long-term health consequences of early menopause were noted, such as increased risk of osteoporosis and cardiovascular diseases, which have a lasting impact on physical health. The psychological impact of early menopause was also emphasized, as it added to the emotional strain many women already faced. One woman had been going through IVF (in vitro fertilization) when she was informed that she would be entering menopause.

> *The doctor told me, 'By the way, you're going to be in menopause.' I was 40. My last IVF was three months prior to this, and we were thinking about doing one more treatment. I think for me, that was the most difficult part of my diagnosis.*
> *–Patient, Netherlands*

Another woman was informed that she could have her eggs frozen, but it would delay treatment.

> *I didn't know what I was doing. I was so panicked. I just wanted to survive. They told me I had a 12-week window to get treatment, but freezing the eggs and fertility treatment would take weeks as well. And I just panicked. And I was like 'No, no, it's fine.'*
> *–Patient, Ireland*

Support systems

Access to support services varied significantly across participants and countries, revealing systemic disparities in care for young adults with CRC. Psychological, physiotherapy and nutritional support were frequently highlighted as critical yet inconsistently available. Participants who received these services reported significant benefits in managing their physical and emotional wellbeing. However, many noted that access depended on private healthcare options, with public systems often failing to provide such support or involving prohibitively long waiting times.

Physiotherapy and nutritional support Physiotherapy was identified as a vital yet underutilized resource, particularly for managing bowel function issues such as low anterior resection syndrome (LARS) after surgery. Many participants were unaware of its availability until actively seeking recommendations from peers or private practitioners. Nutritional counseling was also perceived as essential in navigating dietary adjustments during and after treatment, but it was rarely offered as part of standard care. Expanding access to these services within public healthcare systems could significantly improve QoL for younger patients.

> *Physiotherapy helped me, certainly. And no one had told me about it. My psychologist told me about it when I explained to him how I struggled for a year and a half, walking around with a diaper and having to rush to the bathroom. He said, 'Have you ever tried physiotherapy?'*
> *–Patient, Italy*

Psychological support Participants underscored the importance of psychological support in managing the emotional challenges of CRC. Those with access to timely, professional counseling described it as invaluable in addressing feelings of isolation, trauma, and anxiety. However, in some countries, such as Romania and Ireland, psychological support was only available through private healthcare or with long delays, limiting access for economically disadvantaged patients. In Romania, patients needed a referral from the GP before each psychotherapy session, a procedure that created a barrier to the support service. In other countries, such as Italy, the Netherlands and Spain, psychological support was available, but often only when requested. This inconsistency highlights the need for integrated mental health services within public healthcare systems, with support provided from the day of diagnosis, particularly for younger patients managing long-term cancer-related distress.

> *Neither psychological nor nutritional therapy was available, I did everything privately on my own. I looked for psychological support myself, but no one ever proposed it to me. Instead, they asked my wife, 'Are you sure your husband wants to do it, or is it you who's pushing him to do it?'*
> *–Patient, Italy*
> *You have to wait a lot for a psychologist, because there are only a few slots covered by the public insurance.*
> *–Patient, Romania*

Age-appropriate care and peer support Participants emphasized the importance of age-appropriate care tailored to the unique needs of younger adults. This included rehabilitation programs designed for physically active individuals and support groups with peers of a similar age. The opportunity to connect with other young adults facing similar challenges was particularly valued, with many expressing that peer support filled gaps left by formal healthcare systems. Structured peer support initiatives could complement professional services, fostering emotional resilience and reducing feelings of isolation.

> *I found as a younger patient, that I wanted a doctor that would be more aggressive. To be more investigative in terms of trials and what's going on in a whole new area of biomarkers and the new drugs and so on.*
> *–Patient, Ireland*
> *I can talk to my doctor, I can talk to my wife. But it's never on the same level as talking to people who actually experienced the same thing and are a similar age.*
> *–Patient, Netherlands*

Country comparison

While many challenges were universal among counties, such as delayed diagnosis due to age bias, psychological distress, and the need for greater patient initiative, our analysis revealed several notable differences in healthcare system functioning and patient experience.

Of the countries in the study, Romania had the most fragile healthcare system, with minimal access to biomarker testing, psychological or nutritional support, and a strong reliance on out-of-pocket payments. Patients often had to advocate for themselves or travel abroad to access adequate diagnostics.

In Italy and Spain, fragmented care pathways across public and private sectors were frequently described. While care was often of good quality, patients needed to push for referrals, support services, and clinical information—indicating a system dependent on individual initiative. Additionally, Italian participants reported variation in service access depending on the region, reflecting broader disparities in healthcare organization across the country.

France and the Netherlands offered a wider range of support services, but access was passive and poorly communicated. Patients frequently reported not being aware of services unless they actively inquired. In France, stigma surrounding CRC further delayed diagnosis and reduced visibility.

The UK and Ireland showed significant regional disparities in access to diagnostics, follow-up care, and psychological support. Despite having nationalized healthcare systems, experiences varied depending on the hospital, region, or provider.

> *After this, they said from the emergency room, okay, you have colon cancer, and that's it. You're dismissed. And basically, I had to find out what to do next because no one was telling me anything. I didn't know where to go.*
> *—Patient, Romania*
> *I now go to [another hospital] with my scan printed myself, because they might not have it on the system. It was me, the patient, that highlighted to my surgeon; 'Actually, that's grown by two centimeters,' because the two hospitals don't communicate whatsoever. I feel like I'm my own kind of PA or secretary.*
> *— Patient, Ireland*

Discussion

The rising incidence of eoCRC among young adults presents unique challenges that extend beyond traditional cancer care frameworks. This study highlights critical gaps in awareness, diagnostic processes, and access to tailored support systems. The findings emphasize the need for systemic reforms to improve care delivery, reduce disparities, and address the unique needs of this population, which has been left vulnerable by a lack of health system focus.

Our study reinforces prior evidence indicating that younger adults with CRC often face significant diagnostic delays, with increased risk of presenting at an advanced stage of disease [21]. Participants frequently cited misattribution of symptoms such as rectal bleeding and fatigue to benign conditions, a challenge also documented by Sinicrope [22]. Diagnostic delays reflect systemic barriers to timely detection, as HCPs often dismiss CRC as unlikely in younger patients. Fritz et al. [23] recently outlined the importance of recognizing specific red-flag symptoms – namely abdominal pain, rectal bleeding, diarrhea, change in bowel habits, and iron deficiency anemia – to reduce these delays. Our study suggests that fatigue could potentially be added to this list. It was a strikingly prevalent early symptom among our cohort, even among those with no other notable signs.

Female participants frequently reported that their symptoms were attributed to gynecological issues, such as menstrual irregularities or polycystic ovary syndrome. While prior research, including by Siminoff et al. [24] has revealed that women were more likely to experience a missed diagnostic opportunity for CRC, our study shines a light on a relatively under-explored area, which suggests the need for gender-sensitive diagnostic training to reduce disparities in care.

As with symptoms, there is a similar need to reassess risk factors for patients with eoCRC. The absence of traditional CRC risk factors, such as obesity, smoking, and excessive alcohol consumption among many participants aligns with findings from the *Never Too Young Survey Report* [25], which suggests a growing role for genetic predisposition and non-traditional factors. It has been postulated that the rise in eoCRC may be linked to shifts in the composition of the human gut microbiome [26]. Emerging research also points to psychosocial stress as a potential contributing factor in eoCRC. Recent studies, including McCollum et al. [27] and Cao et al. [28], have demonstrated associations between stress and CRC development and progression, warranting further investigation into its role in eoCRC etiology.

In terms of support requirements, our study revealed an important need for age-appropriate care tailored to the unique needs of younger adults, such as rehabilitation programs designed for physically active individuals and support groups with peers the same age.

While challenges such as diagnostic delays, emotional distress, and gaps in support were common across countries, our cross-national approach also revealed significant systemic and cultural differences in patient experiences. In Romania, for example, access to CRC screening programs has been historically limited, with national initiatives only recently being piloted, leading patients to seek care abroad or forego testing altogether [29]. In contrast, patients in the UK and Ireland highlighted regional disparities within national health systems, particularly around diagnostic coordination and follow-up care, consistent with previous research on variation in cancer outcomes across NHS regions [30]. In Italy, participants described fragmented pathways and unequal access to services depending on the region—aligning with longstanding evidence of regional disparities in healthcare delivery and outcomes [31]. These country-specific findings underscore the importance of tailoring interventions not only to the unique needs of younger patients but also to the structural characteristics of each healthcare system. They also support ongoing calls for more integrated, equitable, and person-centered cancer care across Europe.

Public health implications

Improving awareness and education

The low awareness of CRC risks among younger populations, coupled with the dismissal of symptoms by HCPs, highlights an urgent need for targeted public health campaigns. These campaigns should focus on educating young adults about red-flag signs and symptoms and encouraging HCPs to consider CRC in younger patients presenting with gastrointestinal complaints. Prior successes in awareness campaigns for breast and cervical cancers provide a roadmap for similar initiatives in eoCRC [32, 33]. Our study also suggests that it may be beneficial to further explore fatigue as a potential red-flag symptom of eoCRC.

Integrating tailored support services

Participants' experiences revealed systemic gaps in access to psychological counseling, physiotherapy, and nutritional guidance. These disparities disproportionately affect younger CRC patients, who often face unique challenges related to their life stage, such as family planning, career development, and managing family responsibilities. Expanding access to these services through public healthcare systems is critical to ensuring equitable care and improving outcomes for all patients, regardless of socioeconomic status.

Prior research has demonstrated that integrating mental health and rehabilitation services into cancer care significantly improves patient outcomes and QoL [34]. Addressing these gaps through targeted policies and resource allocation could alleviate the physical and emotional burdens faced by younger CRC patients, fostering a more holistic and patient-centered approach to cancer care.

Promoting gender-sensitive diagnostic training

Gender-specific delays in diagnosis highlight the critical need for gender-sensitive diagnostic approaches. HCPs should be trained to recognize CRC symptoms in women without attributing them solely to gynecological conditions. Similar recommendations have been made in studies addressing gender biases in cancer care [35]. Incorporating gender-sensitive training into continuing medical education and cancer screening programs could help mitigate diagnostic delays and improve outcomes.

Exploring non-traditional risk factors

The potential role of psychosocial stress in eoCRC warrants further exploration. Traditional prevention strategies have focused on modifiable lifestyle factors, but incorporating psychosocial and environmental determinants into public health strategies could provide a more comprehensive approach to reducing eoCRC incidence.

Limitations and future research directions

This study has several limitations that should be acknowledged. The relatively small sample size and focus on seven European countries limit the generalizability of findings. The lack of quantitative data restricts the ability to assess the prevalence of specific issues raised by participants.

Additional limitations include the exclusive focus on patient and survivor perspectives, which limits insights into provider-level decision-making or structural health system constraints. As a result, the study can only report how participants interpreted their experiences, not the underlying causes of diagnostic delays or service fragmentation.

Moreover, although the study included participants from seven European countries, only one focus group was held per country, limiting within-country thematic saturation and the generalizability of any country-specific findings.

Group dynamics and cultural norms may also have influenced participants' willingness to share sensitive topics—such as psychological distress, intimacy, or fertility concerns—despite efforts to create an open and respectful space. While six of the seven focus groups were moderated by the same lead researcher, minimizing variation in facilitation, some differences in tone or depth may still have occurred.

The sample also included patients at different cancer stages, although the majority were diagnosed at stage III or IV, which is consistent with the literature on eoCRC linking diagnosis at a younger age with more advanced disease [2, 5, 36]. While the qualitative analysis did not aim to stratify by stage, it is possible that clinical status shaped participants' priorities and emotional responses.

Lastly, recruiting through patient networks and healthcare providers may have introduced self-selection bias, as individuals who are more engaged or connected may be overrepresented, while more isolated voices may be missing.

Future research should:

- Explore stage- or age-specific subgroups (e.g., under-35 s, early-stage survivors) to tailor interventions more precisely.
- Investigate provider and system-level perspectives to better understand the roots of diagnostic delays and service fragmentation.
- Assess the impact of integrated psychological, nutritional, and rehabilitative care on long-term QoL and return to normalcy.
- Evaluate how cultural and health system factors influence awareness, access to care, and follow-up practices across countries.

- Examine ways to engage less-connected or underserved patient populations in qualitative research.

Conclusion

Given the growing incidence of CRC in those under 50, it is important to understand the experiences and challenges that younger adults face throughout their cancer journey.

This study reinforces prior evidence around diagnostic delays, the dismissal of CRC in younger patients, the frequent misattribution of symptoms, the absence of traditional CRC risk factors, and supports recent evidence around the potential association between stress and CRC.

The study also highlights relatively unexplored topics, including fatigue as a potential red flag symptom for CRC, the frequent misattribution of symptoms in women to gynecological issues, and the need for age-appropriate care tailored to the unique needs of younger adults. The study also reveals some of the structural and cultural differences that shape patient journeys in different countries.

In terms of priority policy actions, we believe there is a need for education campaigns highlighting the 'red flag' symptoms of eoCRC, gender-sensitive training for HCPs to avoid misattribution of symptoms, expanded access to age-appropriate tailored support services for eoCRC patients, and further research into non-traditional risk factors, including psychosocial stress. The ongoing discussion regarding lowering the age for screening could represent a steppingstone to ensuring early detection and better outcomes. The costs of implementing these measures should be weighed against the potential benefits, particularly the societal value of reintegrating survivors into the community, contributing both to individual well-being and societal productivity. By addressing these gaps, healthcare systems can ensure more equitable, patient-centered care for this vulnerable population.

Abbreviations

CRC	Colorectal cancer
DiCE	Digestive Cancers Europe
eoCRC	early-onset CRC
GP	General Practitioner
HCP	Health Care Professional
IVF	in vitro fertilization
LARS	low anterior resection syndrome
MSI	microsatellite instability
PTSD	post-traumatic stress disorder
QoL	quality of life

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12876-025-03976-y.

Supplementary Material 1.

Acknowledgements

We express our gratitude to all patients who participated in this study, the focus group participants and expert patients who contributed to the design and development of the project. Special thanks are extended to Lāsma Nikolaisone for her material revision and to Steve Rowley for providing his Facebook group as a platform to announce our project.
We acknowledge the invaluable support of the DiCE Member Organizations Mon Reseau Cancer Colorectal, Community Health Association, Stichting Darmkanker, and Bowel Cancer Ireland for their trust in and commitment to this project, investing their resources accordingly. Finally, we extend our thanks to Giulia Cavestro, Claudia Cardone, Mario Scartozzi, Ana Ruiz Casado, Maria Romero, and Iosune Baraibar Argota for their support and a shared belief in the significance and impact of patient involvement and patient organizations.

Authors' contributions

MV, ZM wrote the study protocol, MV coordinated the entire project, MV, KM conducted focus group meeting, MV, KM, AC, PS, VdJ recruited patients, MV, KM, RW analyzed the data, RW was a major contributor in writing the manuscript, MV, ZM, KM participated in writing the manuscript, AC, PS, VdJ revised the manuscript.

Funding

This study was supported by funds from Bayer, BMS and Daiichi Sankyo. The sponsors were not involved in the design, analysis, and interpretation of data in this study.

Data availability

The datasets generated and/or analysed during the current study are not publicly available due to confidentiality agreements with participants. However, anonymized excerpts or relevant data may be made available from the corresponding author on reasonable request and subject to ethical considerations.

Declarations

Ethics approval and consent to participate

This study was conducted by Digestive Cancers Europe, an independent patient organization. As a qualitative study based on voluntary interviews, with no medical interventions or collection of sensitive clinical data, it did not require approval from an institutional ethics committee. However, the study was reviewed and approved by our board and expert patient advisory committee. All participants received detailed information about the study objectives, the voluntary nature of their participation, and their right to withdraw at any time. Written informed consent was obtained from all participants before taking part in the study and the study was conducted in accordance with the ethical principles outlined in the Declaration of Helsinki.

Consent for publication

Not applicable. No identifiable personal data is included.

Competing interests

The authors declare no competing interests.

Received: 22 January 2025 Accepted: 6 May 2025

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