

Optimization of multiprofessional care for young colorectal cancer patients: a qualitative Study

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Abstract

Background: The incidence of colorectal carcinoma (CRC) in patients ≤50 (early-onset-CRC, EOCRC) years is increasing. Given their different phase of life, younger individuals may face specific challenges in terms of body image, professional life, and psychosocial support. However, tailored programs for EOCRC patients are lacking in Germany. JUMP-START, a prospective study at the National Center for Tumor Diseases (NCT) Heidelberg in collaboration with the AIO (Arbeitsgemeinschaft internistische Onkologie) and the foundation for young adults with cancer in Germany aims to identify the specific needs of EOCRC patients and improve multiprofessional care.

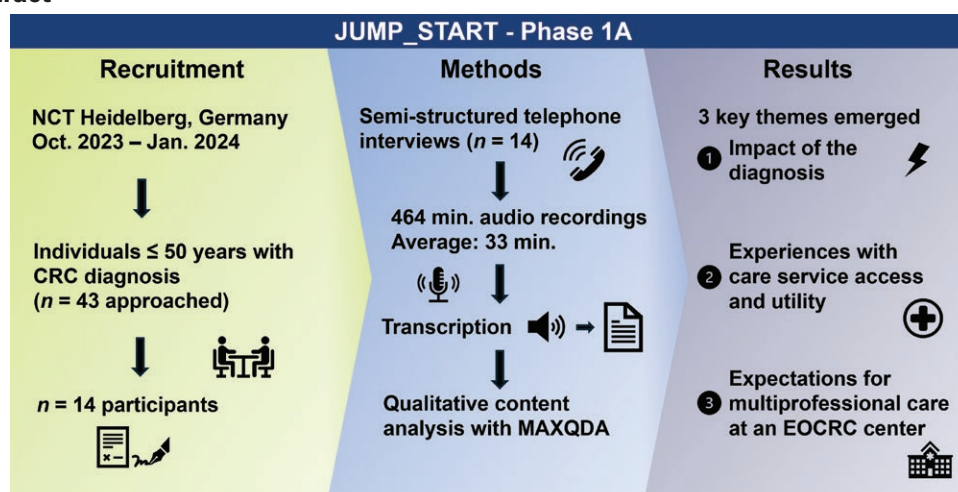
Materials and Methods: Semi-structured interviews were conducted until content saturation, based on an interview guide focused on challenges related to diagnosis, utilization of support programs, and unmet needs. The interview guide was developed in an expert and patient panelist discussion. Qualitative analysis was performed with MAXQDA, using a content structuring qualitative content analysis according to Kuckartz.

Results: Forty-three EOCRC patients were screened, and 14 participants were interviewed at NCT Heidelberg between October 2023 and January 2024. Three main themes emerged: (1) The impact of CRC diagnosis at an early age on psychological and physical health, daily routine, and future perspectives, (2) Experiences with care service access and utility, and (3) Expectations for a multiprofessional care at a dedicated EOCRC center.

Conclusions: EOCRC patients highlighted various age-group-specific challenges related to diagnosis and treatment. Tailored multiprofessional programs may optimize care for EOCRC patients.

Key words: early-onset colorectal cancer; young adults; prospective study; qualitative interview study; multiprofessional care; psychosocial oncology.

Graphical Abstract



Implications for Practice

Early-onset colorectal cancer (EOCRC) patients face various age-specific challenges related to diagnosis and treatment, including mental health, social and working situations, infertility, and future perspectives. However, dedicated programs addressing these needs are lacking in the German cancer care system. This study conducted in-depth interviews to explore EOCRC patients' experiences with supportive care services and their expectations for an EOCRC center, identifying critical gaps in the current system. The findings support the urgent need for early, proactive navigation services and tailored, multiprofessional counseling to address the multifaceted challenges faced by EOCRC patients.

Introduction

The global incidence of colorectal cancer (CRC) in patients diagnosed under the age of 50, early-onset colorectal cancer (EOCRC), has been rising in many countries and EOCRC cases are predicted to double by 2030 compared to 2010.^{1,2} EOCRC patients often present with more advanced disease compared to average age CRC patients and receive more intensive treatment.³ Especially, patients who received multimodal treatment are more frequently having unmet counseling needs.⁴ The underlying cause of a rise in EOCRC incidence is considered to be multifactorial. Healthcare systems have not yet adapted to the challenges and needs of this vulnerable patient group. Given these challenges, it is crucial to better understand the age-group-specific needs to provide more effective support for EOCRC patients.

Some previous studies have investigated the experiences and challenges of EOCRC patient's journey from diagnosis, during therapy and for long-term survivors.⁵⁻⁸ In a multi-national study, various barriers to timely diagnosis of EOCRC were reported.⁹ While the needs across all age groups diagnosed with CRC have been investigated in previous studies^{10,11} and first indications of differing care needs for EOCRC patients have been reported, the specific challenges of this age group, such as fertility preservation, career interference, as well as financial and insurance issues, were often not fully addressed in the clinical setting.^{7,8,12} Given the lack of international age-specific guidelines for providing EOCRC patients with multiprofessional care, in-depth analyses of the currently potentially inadequately addressed needs are required.⁴

Therefore, our study aims to address the existing gaps and gain a comprehensive understanding of the needs of EOCRC patients. JUMP_START is a prospective study at the National Center for Tumor Diseases (NCT) Heidelberg

and is associated with the Quality of Life/Patient Reported Outcomes Working Group of the Working Group for Internal Oncology of the German Cancer Society (AIO-LQ-0323ass). The study consists of 3 phases. Here, we report on phase 1A, which focuses on exploring the diagnosis and treatment-related experiences of EOCRC patients and gaining insights into their expectations for a specialized EOCRC center.

Materials and methods

The interview procedure and data analysis are in line with the "Consolidation Criteria for Reporting Qualitative Studies" (COREQ) checklist.¹³

Study setting and recruitment

JUMP_START (ClinicalTrials.gov ID: NCT06621277) is a prospective cohort study consisting of 3 parts: 1A) semi-structured interviews with EOCRC patients, 1B) social network analyses of EOCRC patients in comparison to average age CRC patients, and (2) Development of a multiprofessional care program for EOCRC patients and establishment of an EOCRC center. In parallel to phases 1A and 1B, the EORTC QLQ-C30 and QLQ-C29 surveys are used to assess and compare the quality of life for EOCRC patients compared to average onset CRC. The presented work reports on phase 1A of the project in which semi-structured qualitative interviews have been conducted.

Patients with CRC (ICD-codes C18-C20) at or before the age of 50 presenting at the department of Medical Oncology at the National Center for Tumor Diseases, Heidelberg University Hospital, were contacted in person at the clinic or by phone after their appointments and received the study information and consent form either in print or via email. The patients were informed about the background and aims of the study, and

participation in the study was voluntary. There was no prior relationship between the interviewer and the participants.

Semi-structured telephone interviews were conducted between November 2023 and January 2024 by a female final-year medical student at the Heidelberg University Hospital, under the supervision of experienced researchers from the study team. The interviews were audio-recorded in German. Data saturation was expected to be reached between 12 and 17 interviews.^{14,15} Recruitment stopped once content saturation was achieved. Before the interviews, participants were asked to complete a questionnaire that collected sociodemographic information, as presented in [Table 1](#).

Interview structure

Before conducting interviews, an interview guide was developed based on the following: (1) literature research, (2) discussions with EOCRC-affected individuals, and (3) multiprofessional expert panel involving specialists in psycho-oncology, social services, ethics, and medical oncology.

The interview guide included 29 questions addressing various challenging topics, experiences with counseling services, as well as the wishes and needs of EOCRC patients to enhance multiprofessional support ([Supplementary Material](#)).

Data analysis

Interview content was transcribed using Microsoft Word (Microsoft, Washington, USA) and manually checked for accuracy after transcription. The transcripts were then imported into MAXQDA (version 2024, VERBI Software GmbH, Berlin, Germany) for qualitative content analysis, which were performed using an inductive-deductive, data-driven approach based on Kuckartz’s method.¹⁶ Transcripts were thoroughly read before coding to ensure familiarity with the content. Codes were independently generated by 2 investigators from the study team (KX and CF). Inconsistencies between the coders were solved via discussion. Main categories and subcategories were identified and discussed within the study team. Categories were iteratively revised and refined through constant comparison with the data during the coding process.

Quotes from participants that supported the identified themes were translated into English using DeepL (DeepL SE, Cologne, Germany). To ensure that the original subtext was maintained, the quotes were then translated back into German. The content was thoroughly reviewed and edited after translation to enhance accuracy and clarity.

Ethics statement

This study is in accordance with applicable regulations including the Declaration of Helsinki and was approved by the ethics committee of the University of Heidelberg, Germany (Reference number: S-545/2023). All study participants provided written informed consent to participate in the study.

The study is associated with the Working Group for Medical Oncology (Arbeitsgemeinschaft Internistische Onkologie, AIO number: AIO-LQ-0323ass) and a collaboration with patient research partners from the German Foundation for Young Adults with Cancer (Deutsche Stiftung für junge Erwachsene mit Krebs).

Results

Fourteen out of forty-three approached EOCRC patients participated in the study. The interviews resulted in 464 minutes of audio (duration: 17-66 minutes, average duration: 33 minutes).

The demographic characteristics of the participants are shown in [Table 1](#).

Various topics related to the experience of participants after diagnosis were discussed in the interviews. Three main themes emerged:

- (1) Impact of the diagnosis on psychological and physical health, daily routine, and future perspectives.
- (2) Experiences with care service access and utility.
- (3) Expectations for multiprofessional care at a dedicated EOCRC center.

The main themes are divided into various subthemes, as shown in [Figure 1](#).

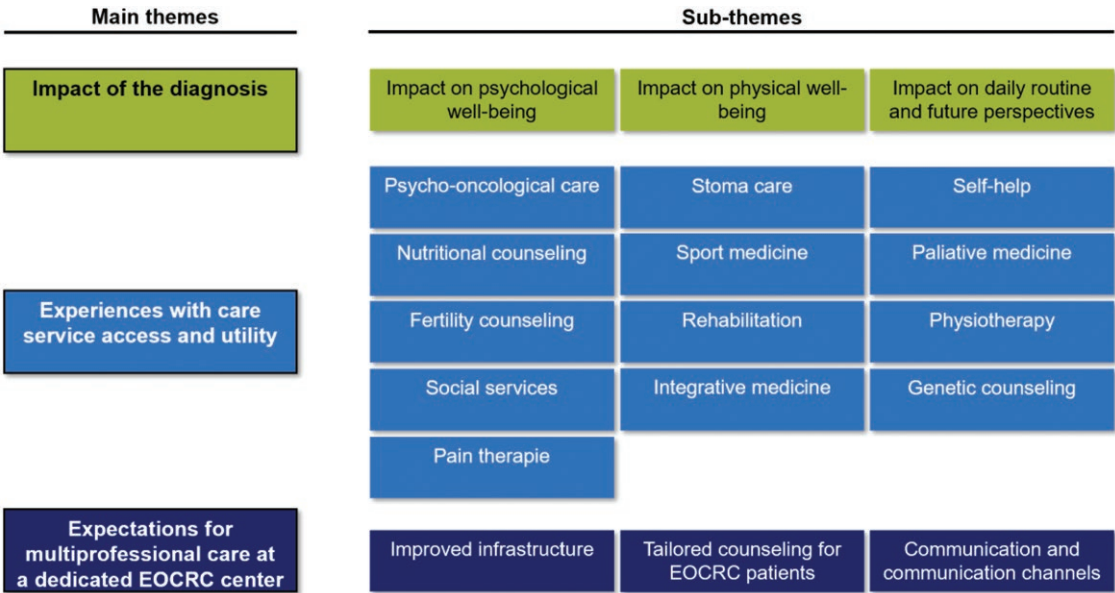


Figure 1. Representation of main themes and subthemes.

Table 1: Demographic characteristics of participants.

Characteristics	Mean	n	%
Nationality			
German		14	100%
Other		0	0%
Gender			
Female		5	36%
Male		9	64%
Age at interview	42 (34-50)		
Age at diagnosis	39 (34-50)		
Monthly net income ¹			
1500€-2000€		2	14%
2000€-3000€		5	36%
3000€-4000€		2	14%
4000€-5000€		1	7%
N/A		4	29%
Marital status			
Married		7	50%
In a relationship		5	36%
Single		2	14%
Employment status			
Full-time		4	29%
Part-time		1	7%
Currently not working		9	64%
Education			
Lower secondary school		2	14%
Middle school		5	36%
University entrance qualification		6	43%
Other/none applies		1	7%
Vocational education			
Apprenticeship		12	86%
Studies		2	14%

¹Average net monthly earnings of a one-person household in Germany: 2264€¹⁷.

Theme 1: impact of the diagnosis

Three subthemes related to the impact of the diagnosis are summarized in [Tables 2–4](#).

Impact on psychological well-being

All participants experienced psychological distress after their diagnosis, which was not only a severe emotional burden for themselves but also affected their families (T2: Qt 1). Receiving a cancer diagnosis at a younger age led to adaptation challenges, as the diagnosis was fundamentally unexpected and profoundly conflicting with the current life stage (T2: Qt 2). Additionally, symptoms might be misinterpreted due to young age contributing to delayed diagnosis and emotional distress (T2: Qt 3).

Accepting a new role as a patient also proved challenging, especially for participants with children. Additionally, fear of recurrence or progression further affected the psychological well-being (T2: Qt 4). Participants frequently reported increased anxieties and symptoms associated with depression including loss of interest in hobbies, impaired concentration, and feelings of reduced motivation and energy (T2: Qt 5).

Impact on physical well-being

In addition, the participants faced challenges regarding their physical health due to the disease or side effects of treatments.

Various gastrointestinal symptoms were reported by the participants. The symptoms included weight loss during the treatment, reduced appetite, frequent bowel movements, diarrhea, nausea and vomiting, obstipation, ileus, digestive difficulties, and stomach discomfort (T2: Qt 6). Many participants also had to change their dietary habits due to the stoma (T2: Qt 7). Especially frequent bowel movements and incontinence have been experienced as very challenging and restrictive to daily life and social interactions (T2: Qt 8).

Fertility was also an important issue for participants who had not completed their family planning before the diagnosis (T2: Qt 9). Additionally, participants reported that their physical performance was impacted. Those with stoma found it difficult to exercise. Limited endurance, pain, muscle weakness, polyneuropathy, and fatigue led to decreased physical activity (T2: Qt 10 and Qt 11). Pain was frequently reported as a symptom that affected participants' quality of life. The pain was caused by metastasis and therapy side effects. Especially back pain interfered with daily activities (T2: Qt 12).

Table 2. Impact of the diagnosis (theme 1).

Subthemes	Participants' quotes
<i>Impact on psychological well-being</i>	
Emotional burden for patients and their families	Qt1 "[...] So in the beginning it was an extreme emotional burden. So it was the same for me as it was for my family" (P10)
Shock after diagnosis	Qt2 "[...] because I had lived a healthy life up until then, it was a bit of a hit to get a diagnosis like that, because we also lived a vegan lifestyle, yes, we did a lot of sport, we didn't drink alcohol [...], and from that point of view it was a bit of a hard blow all of a sudden." (P1)
Misdiagnosis causes mental health issues	Qt3 "I go to a psychologist every 4 weeks because my complaints and symptoms were all attributed to my mental health and my general practitioner and my psychologist didn't recognize that it was colon cancer." (P14)
Distress due to recurrence	Qt4 "[...] and then three and a half years in between, you've actually tended to almost put it behind you and then there's a setback and then, of course, it's mentally challenging." (P8)
Anxiety and depressive symptoms	Qt5 "I somehow don't do anything anymore. My head doesn't really work anymore and it's not much fun anymore." (P5)
<i>Impact on physical well-being</i>	
Gastrointestinal symptoms	Qt6 "I can't eat large amounts; I can only eat very limitedly. I eat little and don't take much pleasure in eating anymore." (P11)
Impairments due to stoma	Qt7 "I've had a stoma twice [...] you have certain dietary restrictions and it's best not to eat raw food and things like that [...] But I'm finding it difficult because vegetarian food is actually always so rich in beans, lentils [...] so my diet has been restricted a bit, yes." (P7)
Incontinence/frequent bowel movements	Qt8 "[...] because I don't have a rectum, I have difficulties or problems with going to the toilet and controlling bowel movements. [...] and that's why it affects my everyday life [...] I always have to think about whether I can go out now or not. I need to listen to my body and be cautious." (P10)
Challenges with fertility	Qt9 "[...] because technically, I'm fertile, but with certain limitations." (P8)
Decreased physical activity	Qt10 "I can only get things done very slowly; I quickly reach the limits of my strength and become exhausted very quickly." (P11) Qt11 "Then no more Zumba or anything like that. So also due to the polyneuropathy in my feet and my coordination, I can't do that anymore." (P7)
Pain	Qt12 "I still have pain in the surgical area. When standing and sitting for longer periods. It was very, very bad in the first year." (P12)
<i>Impact on the daily routine and future perspectives</i>	
Changes in daily routine	Qt13 "And then I couldn't do much at home either, with a lot of lying around and pain. And it's been a while now and I've been able to mobilize more and more and now my daily routine is less active than before the illness because I don't have as much energy, but I'm actually almost back to normal." (P11)
Loss of independence/freedom of movement/autonomy	Qt14 "But now I realize what a problem it is when you're not allowed to drive a car. And I'm really more dependent on friends and family." (P2)
Changes in work activity	Qt15 "So exactly, the professional activity, that's gone to 0, so I've given it up, so to speak." (P1)
Challenges in making long-term decisions	Qt16 "Above all, I don't dare do anything anymore. As far as investments or future plans are concerned [...]. I actually live in a 2-month rhythm." (P8)
Financial burden	Qt17 "Well, it has to work somehow. We just can't afford anything except what we definitely need, because I'm the main earner." (P14)
Impact on family planning	Qt18 "But yes, I was just a bit blindsided, and I didn't have time to think about it [fertility preservation]. It was said, like from one day to the next, yes or no." (P10)
Changes in leisure activities	Qt19 "I just don't have as much energy as before. I always have to think about how much I can handle the day, what I can manage. [...]. So, my activities have significantly, significantly reduced in terms of leisure activities." (P11)
Changes in the social situation	Qt20 "I haven't been out much with friends or anything. I'm mostly at home; occasionally, someone calls, but I also try not to have too many people over because I'm afraid of catching something. Whether it's COVID, the flu, or anything else." (P4)

Impact on the daily routine and future perspectives

All participants reported an impact on their daily routines after diagnosis. These changes were caused by the disease and the treatment, such as extended hospital stays after surgery, side effects of multimodal therapies, and restrictions due to physical limitations (T2: Qt 13). Some participants have experienced increased dependence on support from other people (T2: Qt 14).

Most participants experienced changes in their work situations after diagnosis, such as taking sick leave, changing

jobs due to physical health issues, or reducing their working hours (T2: Qt 15). When self-employed, concerns about planning and making long-term decisions were expressed (T2: Qt 16). A worsened financial situation due to the disease, causing restrictions in their daily lives, was also reported (T2: Qt 17). Fertility not only emerged as an important aspect within the subtheme of physical impacts but also affected future perspectives, revealing connections between the different subthemes. Those who had not completed their family planning faced stress related to fertility. In some cases, the desire to

Table 3. Experiences with care service access and utility (theme 2).

Subthemes	Participants' quotes
Psycho-oncological counseling	Qt21 "Yes, in the hospital itself, a psycho-oncologist came to see me in bed from time to time, and I found that very helpful." (P11) Qt22 "I then realized that it benefited me more to talk to people I know, that means reaching out to friends, family, and having such exchanges." (P10).
Nutritional counseling	Qt23 "I just have to change my diet properly. The nutritional counseling was also very helpful in that case." (P1). Qt24 "[...] in the hospital, it was discussed verbally by the doctors. So, the information I received there was relatively limited. After I hardly dared to eat anything myself and visibly lost about 5 kilograms within a short period, I then turned to the hospital again." (P11).
Fertility counseling	Qt25 "That there's a possibility that I might not be able to have children anymore. But I haven't received any further information about this from the hospital." (P10).
Social services	Qt26 "Especially in the beginning, when I became ill, the social services were a great help because I was overwhelmed by all the new problems [...] they helped me apply for my severely disabled person's pass and, yes, answered questions about my employment and so on." (P2).
Stoma care	Qt27 "A stoma therapist came, and he looked after me and showed me how to put the bag on, how to take it off, how to measure the hole and how to care for the stoma, he informed me about it." (P5).
Rehabilitation/physiotherapy/sports for cancer patients	Qt28 "[...] I was in rehab and there were various sports programs, of course. Very easy things that I did, which was a bit frustrating because it's not age appropriate." (P7).
Self-help	Qt29 "[...] because of the children, we also went to the hospice association. It sounds intense, but it was a very good and pleasant conversation." (P7). Qt30 "I think that helps the patients. I also noticed that in this Facebook group I was in, which helped all of us who were in the group." (P10).
Pain therapy	Qt31 "It was partly recommended, especially with pain therapy [...] and we simply tried it out. And it was all actually helpful. I must say, it's a great thing." (P1).
Palliative medicine/Integrative medicine/genetic counseling	Qt32 "And I had a palliative care service that visited me and took care of my needs. That was really good." (P11).

have children remained unfulfilled due to the disease, or quick decisions had to be made (T2: Qt 18).

Many participants also described changes in their leisure activities. Sports and other activities had to be given up or adapted to less demanding alternatives (T2: Qt 19). Furthermore, the diagnosis led to changes in the social situation. Being in the focus and adapting to the new role as a patient was a challenging new experience. Additionally, social activities have been reduced due to limited energy, stoma leakage, and concerns about infections (T2: Qt 20).

Theme 2: experiences with care service access and utility

Almost all participants used interdisciplinary care services or consultations at the NCT Heidelberg or other clinics to manage the symptoms caused by the disease or its treatment (Figure 1 and Table 3). Although the participants were recruited at NCT Heidelberg, the experiences shared are not solely related to the counseling services at NCT Heidelberg, they also reflect the services accessed at other clinics during cancer treatment, as presented in Table 3.

EOCRC patients received information on care services during appointments, through proactive contact by providers, or via flyers. However, some participants did not receive sufficient information and informed themselves through various sources such as flyers or the Internet.

The reasons for using multiprofessional care services included the need for more information to understand the implications of the disease, dealing with emotional distress, managing symptoms, or because the service was proactively offered.

Reasons for not using care services included insufficient information about the services, long travel distances to

appointments and the resulting costs of travel, and either a recent diagnosis or no need due to mild symptoms or other personal coping strategies. Apart from care services, support from family and friends, such as assistance with the household or driving to appointments, also helped EOCRC patients cope with the challenges.

Although additional information on support services was considered helpful, experiences with the different support services varied, especially regarding psycho-oncological support, nutritional counseling, and fertility counseling.

Psycho-oncological counseling

Some EOCRC patients found professional psychological / psycho-oncological support very helpful, while others preferred only interactions and support from their families or other EOCRC patients (T3: Qt 21 and Qt 22).

Nutritional counseling

Lack of information provided on adjustments of dietary habits after surgery, dealing with weight loss, and loss of appetite after chemotherapy were the main reasons for seeking additional nutritional support. Although nutritional counseling was helpful in most cases, following a strict diet sometimes negatively affected the quality of life of EOCRC patients, as food they enjoyed needed to be avoided due to stoma care or digestive difficulties (T3: Qt 23 and Qt 24).

Fertility counseling

Participants reported different experiences with fertility counseling. While information on fertility preservation was generally considered helpful and important, not all received adequate information, and time pressure or additional costs sometimes restricted the effective use of these services (T3: Qt 25).

Social services

All participants who received support from social services found the assistance on social and legal matters, including rehabilitation application, severely disabled person's pass, employment, and information on cancer support groups, very valuable (T3: Qt 26).

Stoma care

Stoma care with practical advice on how to manage the stoma after surgery was found to be helpful. However, additional outpatient stoma care would also be useful for addressing any new questions or issues such as leaking and skin irritation (T3: Qt 27).

Rehabilitation/physiotherapy/sports for cancer patients

Participants reported that rehabilitation, physiotherapy, and sports programs for cancer patients helped improve their physical activity and manage the side effects of surgery. However, it was noted that the sports programs in rehabilitation were not specifically tailored for EOCRC patients (T3: Qt 28).

Self-help

Due to the limited information on counseling services for parents with cancer and their children, visiting a hospice association was considered as an alternative (T3: Qt 29). EOCRC patients emphasized the importance of cancer support groups and exchanging experiences with other EOCRC patients, for example through social media. However, in some cases, it was challenging to connect with others of similar age or with a CRC diagnosis (T3: Qt 30).

Pain therapy

Participants who received pain therapy for managing cancer- or cancer treatment-related pain from a specialized team stated that it significantly improved their quality of life by enhancing mobility and emotional well-being (T3: Qt 31).

Palliative medicine/integrative medicine/genetic counseling

Palliative medicine, integrative medicine, and genetic counseling were considered helpful (T3: Qt 32). However, it has been reported that integrative medicine is not always available locally.

Theme 3: expectations for multiprofessional care at a dedicated EOCRC center

To improve multiprofessional care and establish a dedicated program for EOCRC patients, participants were asked about their suggestions for an EOCRC center. The identified sub-themes are presented in [Table 4](#).

Improved infrastructure for accessing multiprofessional care

A key theme identified was the need to improve the infrastructure within clinics and among local support service providers to enhance access to care services. Participants reported gaps in obtaining general information about multiprofessional supportive services, which led to a delay in utilizing counseling services such as social services or nutritional support. Improved navigation for accessing information about care programs and dedicated guides for early, comprehensive consultation was considered helpful (T4: Qt 33).

Furthermore, participants reported the challenge of getting appointments with local care providers, such as

psycho-oncologists or physiotherapists (T4: Qt 34). Referrals to these local care providers or additional support from a dedicated EOCRC center would be helpful. Participants also wished for better and more effective communication between different clinics and their general practitioners to avoid delays in sharing information.

Tailored counseling for EOCRC patients

Although many multiprofessional supportive services are established for cancer patients, participants identified several unmet needs for tailored care services dedicated to the younger age group apart from the supportive services at the NCT Heidelberg or other cancer centers in Germany presented in [Figure 1](#).

More support for managing the side effects of cancer treatment was considered important (T4: Qt 35). Participants also emphasized the critical need for intensified psycho-oncological support for EOCRC patients (T4: Qt 36).

Participants, who had not completed family planning or were experiencing difficulties, highlighted the need for early fertility counseling before starting therapies. A more sensitive way with greater empathy of discussing fertility has been wished (T4: Qt 37).

Additionally, a lack of counseling services for parents with cancer and their children has also been reported. Participants with children wished their doctors had proactively addressed this topic earlier and provided more information and support (T4: Qt 38).

Participants highlighted the importance of social services and the need for more information regarding social and legal matters, and financial support for young families was expressed (T4: Qt 39).

Another unmet need identified is the lack of age-appropriate rehabilitation and suitable sports programs after rehabilitation (T4: Qt 40). Participants also emphasized the need for peer support and interaction with other EOCRC-affected individuals (T4: Qt 41). Earlier screening programs were also identified as an unmet need to detect EOCRC in an early stadium to avoid delays in diagnosis and treatment (T4: Qt 42). Additionally, more and up-to-date information on available studies was mentioned by participants (T4: Qt 43).

Communication and communication channels

When asked about their preferred communication channels for receiving information about care services and their preferences for the format of care services, participants generally suggested using a combination of different communication channels. An initial contact in person or via telephone was often preferred as it was easier to initiate and provided the opportunity to ask questions about care services directly. Additionally, providing information through email or on a website for flexible access to resources was recommended.

Regarding the format of supportive services, video meetings were frequently suggested for higher flexibility, which helps to avoid long trips to the cancer center (T4: Qt 44). This would also enable access to care services that may not be available locally such as integrative medicine (T4: Qt 45).

Furthermore, participants emphasized the importance of effective and appropriate doctor-patient communication and unmet information needs were experienced as a factor causing additional emotional distress (T4: Qt 46). Additionally, participants wished more shared decision-making and considered

Table 4. Expectations for multiprofessional care at a dedicated EOCRC center (theme 3).

Subthemes	Participants' quotes
<i>Improved infrastructure for accessing multiprofessional care</i>	
Guides for counseling services / more information on counseling services	Qt33 "And that you simply have a point of contact. I also think that's important, and I would like it to be more like that. I've also read that several cancer patients have no real point of contact. If you have symptoms, you don't know who to turn to." (P11).
Referral to local counseling services	Qt34 "it's not that easy to get an appointment with a psycho-oncologist and it's difficult to get psychological support. I found that very frustrating." (P11).
<i>Tailored counseling for EOCRC patients</i>	
Stronger support for managing side effects	Qt35 "[...] a bit more support with all the side effects that occur during such an operation or in such a case. Yes, it's not just the cancer, but sometimes something else is also affected by the operation." (P12).
Intensified psycho-oncological support	Qt36 "Well, I think it's very important that young cancer patients receive much more psycho-oncological support [...] when you're old and you get cancer, you've got your life behind you. But when you're young and you get cancer, everything is called into question and normally you don't have to deal with thoughts of death or anything like that." (P11).
Early fertility counseling	Qt37 "I don't know whether the doctor would have approached me proactively, I don't know. [...] But it would always be an issue with young patients in any case." (P8).
Counseling service for parents and children	Qt38 "Well, they asked if family planning was pending or completed, but now, when someone is metastasized and family planning was already completed with children already here, there's also dealing with that aspect. How much support can one get in this situation? How do you explain it to the children and so on." (P7).
Counseling for social and legal questions	Qt39 "And nobody told me that in hospital either, what rights and obligations and the like I have." (P3).
Suitable sports programs for EOCRC patients	Qt40 "At home, I live in a small town. So that means what's on offer here is for normal people, sporty people. I can't really keep up with those kinds of activities. Then there's the gap between what you're told is good and what the actual offerings are." (P7).
Peer support and interaction with other EOCRC patients	Qt41 "[...] what I would find good is that you could perhaps now somehow exchange ideas with people of the same age, because now that I've been through chemo, I was usually always the youngest or one of the youngest." (P5).
Earlier cancer screening	Qt42 "Preventive screenings shouldn't start only at a certain age, like 50 or 60. Perhaps they should begin at 40 or even 30, because as I've experienced, cancer can affect people under 40 as well." (P10).
More information about studies	Qt43 "But accessing information about what else is available, what's coming next, how research is progressing, whether a new study is being launched. I can't access that as a patient." (P8).
<i>Communication and communication channels</i>	
Utilization of multiple communication channels / online counseling services	Qt44 "Yes, so basically, using flexibility and new technologies to save routes. It's also good for the environment, I think, not having to drive for each trip or appointment." (P1). Qt45 "I would like to have alternative treatment options. No one here [...] offers that to me. It's just difficult to travel all the way to Heidelberg." (P14).
More information about the disease and treatment	Qt46 "Actually, I have experienced a lot where you always had to get information yourself. You always had to talk to the doctors and ask and ask again." (P10).
Designated medical contacts	Qt47 "It's always good to have a [...] designated contact person [...]" (P1).

designated medical contacts as useful to ensure continuity of care (T4: Qt 47).

Discussion

The JUMP_START project aims to optimize the multiprofessional care of EOCRC patients. Here, we report on phase 1A of the study, which employed a qualitative approach to explore the challenges experienced by EOCRC patients due to the disease and treatments, utilization of supportive care services, and expectations for an EOCRC center. Participants reported various physical and psychological symptoms and diverse experiences with care services. Furthermore, this study provides a comprehensive insight into the specific needs of EOCRC patients, including improved infrastructure, tailored care services, and better communication. Although the participants were recruited from a single center, the findings primarily address the general needs of EOCRC patients and

might be applied to the overall journey of younger individuals affected with CRC.

The current study not only provides a more comprehensive overview of the challenges and treatment-related symptoms but also provides deeper insights into the experiences with different supportive programs and unmet needs of the EOCRC patients. It has been indicated that unmet needs were associated with lower quality of life in young adults with cancer.¹⁸ Compared to older CRC patients, younger individuals are more likely to report greater disruption of their general activities caused by a wide range of symptoms, such as fatigue, severe pain, increased emotional distress, and sexual dysfunction.¹⁹⁻²¹

Psychological distress is one of the most significant burdens experienced by EOCRC patients in our study, which is in line with previous studies.^{19,22,23} EOCRC patients are at higher risk to experience distress or develop depression compared to average onset CRC patients. Specifically, awareness challenges

regarding EOCRC might lead to misinterpretation of symptoms and result in diagnostic delays,^{6,9} which contribute to emotional distress. Additionally, they have higher anxiety levels, increased body image concerns, and embarrassment with bowel movements compared to older CRC patients.^{19,22,23}

For parents with cancer, the uncertainty of how to communicate with their children about the severity of the disease was reported as an additional emotional burden. Furthermore, managing changes in their parental role and balancing their own needs as both patients and parents can be very challenging. These challenges often influence treatment decisions, leading many patients to prefer life-extending treatments.^{24,25} Our study has identified a critical gap in addressing the mental health needs of EOCRC patients. Therefore, there is an urgent need for stronger professional psychological support for EOCRC patients and for proactively providing information on family-orientated psychological care, including addressing parental issues in the clinical setting.

Treatment-related infertility was an important issue addressed by the participants. EOCRC patients are more frequently treated with adjuvant, neoadjuvant therapy, surgery, and multi-agent systemic therapy.^{26,27} All CRC treatments, including radiation, surgery, or chemotherapy, can affect the fertility of EOCRC patients.²⁸ Participants reported several barriers to using specialized fertility counseling or preservation services. These included a lack of sufficient information on fertility preservation options, organizational difficulties due to time pressure to start therapy as quickly as possible, and costs.

Currently, there are gaps in fertility discussion in clinical practice. More than half of all rectal cancer survivors under 50 years reported that their doctors did not discuss potential fertility complications related to their therapy.²⁹

Our findings are consistent with previous studies which identify an unmet need for support in fertility and family planning.^{28,29} Additionally, our study also provides insights into the barriers of accessing fertility preservation services.

Our findings also highlight various stoma-related issues with impact different aspects of life, including stoma leakage, giving up physical activities, dietary adjustments, or reducing social activities. Many CRC patients need either a temporary or a permanent stoma during the treatment.³⁰ Especially in the younger age group, living with a stoma strongly affected physical activities, contrasting with a more active lifestyle they had before the stoma.³¹

Our report indicates that diagnosis at a younger age is associated with a stronger impact on the professional career and frequently leads to employment disruption, change of workplace, or financial decline, which is also in line with previous findings.³²⁻³⁴ Overall, these findings highlight the urgent need for support services addressing social and legal questions, as the lack of support on these topics has been identified as an unmet need.

Clinical implications

Our study is the first in Germany to explore the challenges faced by EOCRC patients, their utilization of supportive care services and experience with these services, as well as existing gaps in the current care. The qualitative approach allows a deeper understanding of the impact of CRC diagnosis on different aspects of life, including mental health, social and working situations, and future perspectives.

Our results demonstrate the importance of offering personalized guidance on supportive services as early as possible. In addition, referral to local support services or providing contact information is crucial, especially since many patients have long travel distances to reach the cancer center. We suggest that it is essential to offer comprehensive counseling that familiarizes patients with available resources. This should be provided in addition to regular appointments, preferably through a dedicated guide, such as a specialized nurse. It is important that healthcare providers proactively offer multi-professional supportive care services to help EOCRC patients manage the psychological, physical, and social challenges related to a cancer diagnosis and to address the current gaps in supportive care.

Limitations

The findings were based on the recall of the participants concerning their experiences with different support services, which might introduce recall bias. The data could also be influenced by interviewer and coder bias due to the qualitative approach. It is important to note that all interviews were conducted at a single center, potentially limiting the generalizability of our findings. However, participants shared a wide range of experiences, including insights related to previous counseling services at other clinics, enhancing the depth of our analysis. Furthermore, content saturation was achieved, which strengthens the reliability of our results despite these limitations.

Conclusion

The German cancer care system has not yet adapted to the rise of EOCRC, there is an urgent need for dedicated programs addressing the needs of the younger population affected by colorectal cancer. Our study unravels very specific needs and underlines the necessity for a tailored EOCRC program.

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Author contributions

Conception/design: K.X., C.F., J.W., E.C.W., T.J.B., and B.C.K.. Provision of study material or patients: K.X., C.F., K.K., N.S., C.B., J.R., K.M., A.Z., E.K., J.W., M.K., D.J., P.H.W., G.M.H., F.P., T.J.B., and B.C.K.. Collection and/or assembly of data: K.X., C.F., K.K., N.S., C.B., and P.H.W.. Data analysis and interpretation: K.X., C.F., K.K., N.S., C.B., K.M., A.Z., G.M.H., F.P., T.J.B., and B.C.K.. Manuscript writing: K.X., C.F., K.M., A.Z., G.M.H., T.J.B., and B.C.K.. Final approval of manuscript: All authors.

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Conflict of Interest

EK: Advisory Board Daiichi Sankyo Deutschland GmbH; Advisory Board IPSEN Pharma GmbH; Advisory Board

Novartis Pharma GmbH. Consulting or Advisory Role: Bristol-Myers Squibb; MSD Sharp & Dohme; Lilly; Novartis; Daiichi Sankyo, Servier; Pierre Fabre; Astra Zeneca; Abbvie, Honoraria: Servier; MSD Sharp & Dohme; Lilly; Bristol-Myers Squibb; Astra Zeneca; MCI Conventions, Swiss Cancer League, Astellas Research Funding: DKFZ Heidelberg, MSD Sharp & Dohme, Travel; Accommodations: Bristol-Myers Squibb; Lilly; Servier; MSD Sharp & Dohme, Daiichi Sankyo. The remaining authors have no conflicts of interest to declare.

Data Availability

The data underlying this article will be shared upon reasonable request to the corresponding author.

Supplementary material

Supplementary material is available at *The Oncologist* online.

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