

## A Coordinated Clinical Center for Young Onset Colorectal Cancer

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*Disclosures of potential conflicts of interest may be found at the end of this article.*

**Key Words.** Colon cancer • Implementation • Program evaluation • Young onset colorectal cancer

The incidence of young onset colorectal cancer (YO-CRC), which includes adults diagnosed at 20–49 years of age, is increasing at an alarming rate for unclear reasons. In fact, the rates of colon and rectal cancer in young adults have been rising by 1%–2% annually since the mid-1990s [1, 2], and models project that 25% of rectal cancer cases will be in patients <50 years of age by 2030 [3]. Similar trends have also been found in several other countries, raising concern worldwide [4].

The cause of rising CRC incidence in younger patients is unknown, and it is unclear if YO-CRC has distinct biology from CRC arising in patients >50 years (i.e., average onset CRC). Prior studies have suggested that YO-CRC may be associated with more aggressive disease biology, with recent study results indicating patients with YO-CRC are significantly more likely to present with stage III or IV disease and more left-sided tumors compared with patients with average onset CRC [5–9]. However, interpretation of these data is complicated by the fact that adults <50 years of age have not traditionally been screened for CRC [1, 10] under U.S. Preventative Services Task Force guidelines [11], which are based on the median age of CRC diagnosis of 67 years [12]. The rise is in sporadic CRC and not due to a known genetic predisposition [13].

The increasing incidence of YO-CRC has led to calls for action to improve the understanding of risk factors, clinical behavior, and genetic characteristics of these patients [10, 14–20]. In addition, patients with YO-CRC face unique challenges and care needs compared with those with average onset CRC and of those in younger age groups for whom major centers have established adolescent and young adult (AYA) programs. These factors spurred the development of the Memorial Sloan Kettering Cancer Center (MSK) Center for Young Onset Colorectal Cancer, the first and largest center worldwide solely dedicated to the needs of patients diagnosed with CRC who are younger than 50 years of age. Here, we describe our 2-year experience with the Center, including

the rationale and methods for developing the program, as well as the specific services incorporated to address the unique challenges that affect patients with YO-CRC. In addition, we highlight the development and lessons from the first 2 years of a YO-CRC program at a cancer center.

### DEVELOPING A YOUNG ONSET COLORECTAL PROGRAM

The Center is designed with a dual purpose to address clinical and investigational objectives. The primary goal of the Center is to provide coordinated and systematic clinical care to comprehensively address the unique needs of patients with YO-CRC (Fig. 1). The secondary goal is to establish a research infrastructure to study the etiology of YO-CRC and ultimately improve outcomes. Initially the Center drew upon the pre-existing multidisciplinary support service infrastructure at MSK, with specific services selected based upon patient and caregiver survey data from the Colorectal Cancer Alliance [20] and our experience with treating this population. We included patients under the age of 50 as this is the population of people with colorectal cancer in whom, until very recently, routine screening colonoscopies were not recommended. The survey highlighted how the psychosocial needs and priorities of YO-CRC patients differ considerably from those of patients with average onset disease and younger patients who meet criteria for enrollment in AYA programs. A significant challenge for patients with YO-CRC is the impact of the illness on their families. In the recent Alliance survey of patients with YO-CRC, 80% of respondents had dependents younger than age 18 years when diagnosed [20]. Among patients with YO-CRC, 62% reported financial hardship, and 64% reported taking a leave of absence or terminating a job or schooling because of their diagnosis [20], which can have long-term consequences on career development and/or education trajectory. Additional financial challenges stem from the lack of standardized health insurance

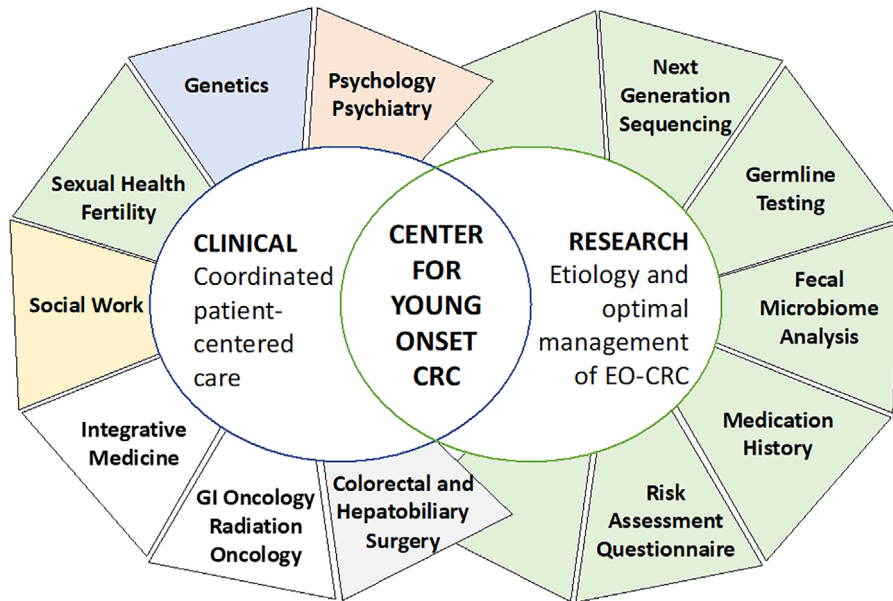
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coverage in the U.S. and the many expenses associated with a cancer diagnosis [21]. The physical and emotional consequences of CRC and its treatment may persist for many decades and can significantly impact patients [22–27].

Fertility and sexual health are also major concerns; however, 64% of survey participants indicated that a

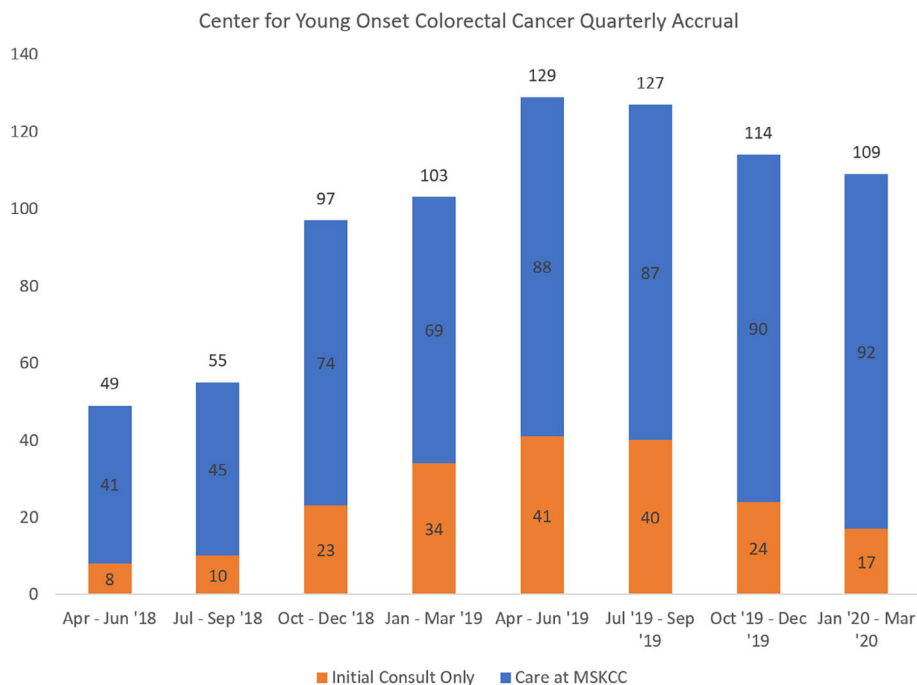
medical professional did not talk to them about fertility preservation during diagnosis or treatment [20]. Sexual dysfunction has been reported to be one of the most common long-term effects of CRC treatment [28] and may be of particular concern for young adult patients [29]. Based on these data, we identified psychosocial services,



**Figure 1.** The Memorial Sloan Kettering Center for Young Onset Colorectal Cancer’s coordinated clinical program involves gastrointestinal oncology, colorectal surgery, hepatobiliary surgery, radiation oncology, and gastroenterology, as well as support services, such as social work, fertility, sexual health, genetics, nutrition, integrative medicine, and psychology/psychiatry. In addition to these clinical services, patients are also approached for enrollment in research protocols involving tumor profiling, germline testing, and stool collection for microbiome analysis.

Abbreviations: GI, gastrointestinal; CRC, colorectal cancer; EO-CRC, early onset colorectal cancer.

[Correction added after online publication, June 19, 2021: Figure 1 was replaced.]



**Figure 2.** Quarterly accrual from April 2018 through March 2020. Abbreviation: MSKCC, Memorial Sloan Kettering Cancer Center.

**Table 1.** Patient demographic and clinical characteristics from April 2018 through March 2020

Characteristics	n (%)
Total no. of patients	751
Age, yr	
<20	3 (0.4)
20–29	42 (5.6)
30–39	232 (30.9)
40–49	474 (63.1)
Median age at diagnosis (range), yr	42.8 (37.1–46.7)
Sex	
Male	417 (55.5)
Female	334 (44.5)
Stage	
I	41 (5.5)
II	109 (14.5)
III	270 (36.0)
IV	331 (44.0)
Diagnosis	
Colon	399 (51.1)
Rectal	352 (46.9)
Race	
White	561 (74.7)
Black	64 (8.5)
Asian	80 (10.7)
Native American	1 (0.1)
Other	31 (4.1)
Unknown	14 (1.9)
Ethnicity	
Hispanic or Latino	8 (1.1)
Non-Hispanic or Latino	743 (98.9)

fertility, and sexual health as the key clinical programmatic elements.

### COORDINATED CLINICAL CARE

Within the first 2 years of opening, 751 patients were enrolled into the Center (Fig. 2; Table 1). Because of the need for psychosocial support for patients with YO-CRC and caregivers established in the literature [20], one of the first major priorities of the Center was early connection to psychosocial resources. We hired a dedicated social worker and reserved new psychiatry appointments for patients with YO-CRC. Our social worker contacts all patients shortly after their initial visit. In the first 2 years, the social worker provided ongoing support to more than half of the patients and families, assisting them with their psychosocial needs and with the financial burdens associated with the diagnosis by connecting them to appropriate financial assistance programs at MSK and in the community.

A second key aim of the Center is to ensure that all patients with YO-CRC are screened for fertility needs. In order to reliably incorporate a discussion of patients'

**Table 2.** Ancillary service rationale

Ancillary service	Rationale
Social Work	Patients with YO-CRC have significant psychosocial needs atypical of the patient with average onset CRC, as well as needs outside of the typical AYA population. A dedicated social worker with a focus on patients with YO-CRC was hired to meet these needs.
Fertility	CCA data indicated that a majority of patients with YO-CRC did not speak to a fertility specialist before or during their treatment, even though patients reported infertility and/or early menopause resulting from treatment. Intentional, early intervention with fertility was deemed a key programmatic element.
Sexual Health	Sexual dysfunction has been reported as one of the most common long-term effects of CRC treatment. In consultation with our sexual medicine group, early education about sexual health services and early intervention when necessary are needed to reduce these effects.
Nutrition	A focus on early access to nutrition services was identified as a key component because of expected nutritional challenges that may result from multimodality treatment.
Integrative Medicine	Integrative medicine services were found to reduce side effects in some patients with CRC. Education about and referral to these services were included in the program.
Psychiatry and Psychology	Providers with a focus on treating this patient population reserved psychiatry visits for high acuity patients with YO-CRC.

Abbreviations: AYA, Adolescent and Young Adult; CCA, Colorectal Cancer Alliance; CRC, colorectal cancer; YO-CRC, young onset colorectal cancer.

**Table 3.** Patient-reported service utility

Ancillary service used	Positive service utility <sup>a</sup>
Social Work ( <i>n</i> = 49)	71%
Nutrition ( <i>n</i> = 52)	89%
Fertility ( <i>n</i> = 18)	78%
Sexual Health ( <i>n</i> = 16)	88%
Integrative Medicine ( <i>n</i> = 30)	70%
Psychology/Psychiatry ( <i>n</i> = 16)	88%

<sup>a</sup>Patient rating 4 or 5 (somewhat helpful or very helpful).

wishes regarding fertility into their initial visits, we counseled the primary oncologists' teams (physicians and nurses) about the importance of discussing fertility at diagnosis. Patients who wish to further discuss fertility-related issues are then referred to the Fertility Nurse Specialists in MSK's Cancer and Fertility Program. We also incorporated sexual health in the initial Center welcome packet, in which patients are introduced to the MSK Sexual Health Service, a team of doctors, nurses, social workers, and psychologists experienced in treating specific sexual health concerns triggered by cancer. Patients are also referred to the Nutrition and Integrative Medicine Services 4–6 weeks after the start

**Table 4.** Patient-reported preferred ancillary service timing

Ancillary service timing	Timing was appropriate	First visit	First treatment visit	1–2 months into treatment	2–4 months into treatment	4+ months into treatment	Barriers to access <sup>a</sup>
Social Work ( <i>n</i> = 55)	78%	0%	9%	9%	0%	4%	0%
Nutrition ( <i>n</i> = 66)	71%	12%	9%	2%	0%	3%	3%
Fertility ( <i>n</i> = 28)	64%	10%	11%	0%	0%	4%	11%
Sexual Health ( <i>n</i> = 36)	31%	13%	22%	17%	3%	14%	0%
Integrative Medicine ( <i>n</i> = 54)	56%	6%	13%	4%	7%	4%	11%
Psychology/Psychiatry ( <i>n</i> = 30)	40%	3%	20%	3%	0%	27%	7%

<sup>a</sup>Barriers mentioned include cost, insurance coverage issues and distance from clinic.

of treatment. Rationale behind inclusion of ancillary services to which the Center refers can be found in Table 2.

Given their complex psychosocial needs, Center patients are offered information on relevant psychosocial resources in the community and at MSK, including support groups and MSK's Patient and Caregiver Peer Support Program, which links long-term patients, survivors, and caregivers with new patients by age. In addition, we created an online community group specific to YO-CRC through MSK's online program, Connections, to address feelings of social isolation.

We approach all patients to enroll in a young onset research protocol, which includes targeted next-generation sequencing–based tumor profiling, germline testing, stool collection for fecal microbiome analysis, and risk factor survey data. Patients with clinically significant germline variants are contacted by the Clinical Genetics Service, which provides counseling regarding additional screening needs and implications for family members. Since the opening of the Center, 83% (623/660) and 79% (594/660) of patients consented to tumor genomic and germline testing, respectively. Results from this comprehensive testing will be synthesized to help elucidate the etiology of YO-CRC. In addition to this established protocol, we are opening a prospective study to evaluate the effects of chemotherapy and chemoradiotherapy for early-stage disease on female and male hormone levels and to prospectively evaluate sexual health via several quality-of-life assessments.

#### EARLY PROGRAM LESSONS LEARNED

Following the opening of the Center in March 2018, we prospectively identified patients with YO-CRC based on intake records. Despite the clear needs established in the literature, there were mixed responses to our outreach services, which may be in part related to inherent bias in the Alliance survey leading to selection of services that do not apply to our population. However, we noted that one third of social work attempts to contact patients by phone were not answered and from this we learned that patient communication is an important challenge that may contribute to mixed responses to outreach. Younger patients are more likely to interact in the virtual setting and less likely to engage in phone calls and extensive counseling. The number of patients with YO-CRC enrolled in the online

MSK patient portal (97%, 728/751) is notably higher than the number of patients with average onset CRC (>50 years) enrolled during the same time period (69%, 3,415/4,949).

In order to better understand potential barriers to ancillary service use and further evaluate the optimal time to approach patients, we administered a patient satisfaction survey to existing patients (Tables 3, 4). We asked patients to rate utility of ancillary services through a Likert-type scale in the categories of not helpful at all, not very helpful, not sure, somewhat helpful, and very helpful. We also asked patients about intervention timing and barriers to access. Based on the completed surveys (*n* = 91), the majority of patients who used these ancillary services did find them helpful, which aligns with Colorectal Cancer Alliance data [20, 27]. Nutrition, sexual health, and psychology/psychiatry referrals were found to be most helpful.

Patient interest in these ancillary services may be affected by the timing of introduction. Our current model presents Center resources at the patient's initial consult. We acknowledge that this is a time when patients are inundated with information about their treatment options, extent of disease, and life expectancy, yet most patients still found current timing for social work, nutrition, and fertility services to be appropriate. Although 36% of patients indicated a preference for sexual health services before starting treatment, ideal timing for introduction of sexual health services remains unclear because of mixed responses. The same can be said of psychology/psychiatry services because responses were polarized, with 23% of respondents preferring services prior to treatment and 27% of respondents preferring services 4 or more months into treatment. As the Center continues to expand, we will further explore the appropriate timing for ancillary interventions.

#### FUTURE DIRECTIONS

Our program lessons learned have already offered us insight into this patient population. In mid-2020, we transitioned to online contact as the main method of communication with our patients. Although our survey data indicate that patients with YO-CRC find utility in ancillary services, additional information is still needed about optimal timing. It is also important to note that the racial and ethnic composition of our institution's patient population is not representative of those affected by CRC in the general

population, which limits extrapolation to other centers. The rate of young onset cancer is increasing for several other gastrointestinal tumors, particularly gastric, appendiceal, and pancreatic cancers [5, 30–32]. As such, we are seeing more young adult patients facing similar challenges to patients with YO-CRC, and we are expanding the Center to include patients with all gastrointestinal malignancies. We will continue to refine our program using patient and institutional stakeholder feedback to optimally address the unique needs of our patients. Our program has inspired the development of similar programs at other major cancer centers, which are critical to improve care of young adults with colorectal cancer.

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## ACKNOWLEDGMENTS

We thank The Society of Memorial Sloan Kettering for its philanthropic funding.

## DISCLOSURES

**Andrea Cercak:** Bayer, Incyte, GSK (C/A), Settle Genetics, RGenix, GSK (RF); **Robin Mendelsohn:** Exact Sciences (C/A); **Julio Garcia-Aguilar:** Intuitive Surgical, Medtronic, Ethicon (H); **Zsofia Stadler:** Adverum Biotechnologies, Allergan, Genentech/Roche, Novartis, Neurogene, Gyroscope Tx, Optos Plc, Regeneron, RegenexBio (C/A—immediate family member). The other authors indicated no financial relationships. (C/A) Consulting/advisory relationship; (RF) Research funding; (E) Employment; (ET) Expert testimony; (H) Honoraria received; (OI) Ownership interests; (IP) Intellectual property rights/inventor/patent holder; (SAB) Scientific advisory board