

MESTRADO EM PSICOLOGIA
PSICOLOGIA CLÍNICA E DA SAÚDE

Sexual health needs and concerns after colorectal cancer

Bruna Carvalho Carneiro

M

2022



Universidade do Porto
Faculdade de Psicologia e de Ciências da Educação

**SEXUAL HEALTH CONCERNS AND NEEDS AFTER
COLORECTAL CANCER**

Bruna Carvalho Carneiro

Outubro de 2022

Dissertação apresentada no âmbito do Mestrado Integrado em Psicologia, área de Psicologia Clínica e da Saúde, Faculdade de Psicologia e de Ciências da Educação da Universidade do Porto, orientada pela Doutora *Ana Luísa de Matos Dias Quinta Gomes* (FPCEUP).

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Resumo

O cancro colorretal é um dos cancros mais comuns em todo o mundo. Os seus tratamentos afetam significativamente a saúde sexual de pacientes e sobreviventes. Embora as evidências salientem a importância de identificar e satisfazer as necessidades sexuais destes pacientes, as discussões acerca da sexualidade continuam a ser limitadas, e os estudos que procuram identificar estas necessidades são ainda insuficientes. O objetivo deste estudo foi explorar as preocupações e necessidades de informação de saúde sexual após o cancro colorretal. Para este efeito, foi realizado um estudo quantitativo de natureza exploratória. Neste estudo, participaram 52 pacientes e sobreviventes com mais de 55 anos de idade, que responderam a um conjunto de instrumentos de avaliação. Os resultados mostraram que uma percentagem significativa de pacientes identificou necessidades de saúde sexual, refletindo preocupações com níveis mais elevados acerca das mudanças físicas decorrentes do cancro e tratamentos, mudanças no funcionamento sexual, capacidade de ter prazer sexual, e a capacidade de satisfazer o parceiro. Foram também relatadas necessidades de informação, mesmo em pacientes que demonstraram baixos níveis de preocupação e de necessidades de saúde sexual. Este estudo salienta a importância de identificar as preocupações e necessidades de saúde sexual de pacientes e sobreviventes de CRC mais velhos, e a necessidade de os profissionais de saúde abordarem esta temática. Estes resultados podem ser importantes para o desenvolvimento de programas de saúde sexual personalizados que atendam as preocupações e necessidades não satisfeitas destes pacientes, e contribuam para uma melhor qualidade de vida.

Palavras-chave: Preocupações de saúde sexual, Necessidades não satisfeitas de cuidados, Necessidades de informação de saúde sexual, Cancro colorretal, Pacientes com cancro, Sobreviventes de cancro

Abstract

Colorectal cancer is one of the most common cancers worldwide. Its treatments significantly affect the sexual health of patients and survivors. Although evidence underscores the importance of identifying and meeting the sexual health needs of these patients, discussions about sexuality remain limited, and studies seeking to identify these needs are still insufficient. The objective of this study was to explore sexual health concerns and sexual information needs after colorectal cancer. For this purpose, a quantitative study of exploratory nature was conducted. In this study, participated 52 patients and survivors over 55 years of age, who responded to a set of assessment instruments. The results showed that a significant percentage of patients identified sexual health needs, reflecting higher levels of concerns about physical changes related to cancer and treatments, changes in sexual functioning, ability to have sexual pleasure, and the ability to satisfy the partner. Information needs were also reported, even by patients who demonstrated low levels of sexual health concerns and needs. This study highlights the importance of identifying and addressing the sexual health concerns and needs of older CRC patients and survivors, and the need for healthcare providers to address this topic. These results may be important for the development of personalized sexual health programs that address the unmet concerns and needs of these patients and contribute to a better quality of life.

Keywords: Sexual health concerns, Unmet care needs, Sexual health information needs, Colorectal cancer, Cancer patients, Cancer survivors

Introduction

1. Sexual health and cancer

The World Health Organization (WHO, 1975) first defined sexual health in 1975 as "*the integration of the somatic, emotional, intellectual and social aspects of sexual being in order to enrich and strengthen personality, communication and love*". Sexual health is the state of physical, emotional, mental, and social well-being in relation to sexuality, and does not translate into the mere absence of disease, dysfunction, or infirmity (WHO, 2015).

However, sexual health may be related to the process of recovery and/or adaptation to various diseases and health conditions (Julien et al., 2010). In this sense, cancer is one of the most frequently diagnosed diseases worldwide in people of all ages, and it can hinder or affect a person's sexual and intimate life throughout the different stages of the disease.

Sexual health is affected by all aspects of cancer, including the processes of cancer growth and metastasis, the effects of cancer treatments, and the psychological and emotional changes that result from the cancer experience (Marrs & Krebs, 2006). Although cancer is a highly prevalent disease, people are living longer after treatments, which has drawn attention to the importance of the quality of life and sexuality of cancer survivors. As patients strive to improve their quality of life after treatments, they begin to focus on restoring their sexual health (Julien et al., 2010), which is an integral part of overall well-being and quality of life.

The prevalence of sexual health difficulties associated with cancer and its treatments is impressive (Traa et al., 2012). Sexual dysfunction is one of the most common consequences of cancer treatment (Bober & Varela, 2012; Flynn et al., 2010) and therefore is a concern throughout the course of the disease and its treatment (Flynn et al., 2010).

Sexual satisfaction has also been shown to be affected by cancer. Previous evidence showed that men and women with cancer diagnoses were less satisfied with their sex life (Den Oudsten et al., 2012; Jackson et al., 2016; Sutsunbuloglu & Vural, 2018; Traa et al., 2015) and engaged less frequently in sexual activities (Almont et al., 2018; Chokshi et al., 2022; Den Oudsten et al., 2012; Ussher et al., 2015). A study using a sample of older adults (≥ 50 years old) aimed to explore differences in sexual activity, function, and concerns between cancer survivors and cancer-free controls, found that men and women with cancer diagnosis reported lower levels of sexual satisfaction than controls (Jackson et al., 2016). Based on these findings and those from other studies comparing cancer survivors to the

general population (Den Oudsten et al., 2012), there is still a need to develop interventions aimed to address and improve sexual health of men and women, particularly for those in older age.

Even though sexual health problems can arise and develop at any time during the course of the disease, including from diagnosis to post-treatment follow-up (McKee & Schover, 2001), many survivors feel unprepared for such sexual changes and lack of proper support to deal with sexual problems (Bober & Varela, 2012).

2. Sexual health in colorectal cancer (CRC) patients and survivors

Colorectal cancer (CRC) is one of the most common cancers worldwide (Hultcrantz, 2020). In 2018, more than 1.8 million new cases of colorectal cancer and 881,000 deaths were estimated to occur across the globe (Bray et al., 2018). Despite improvements in various treatment modalities that have contributed to increased survival rates, about 40% of patients still die from the disease (Hultcrantz, 2020).

Most cases of CRC are sporadic, meaning that they are not related to inherited genes, and less than 5% of cases are associated with genetic mutations (Hultcrantz, 2020). Besides family history, there are other risk factors for CRC, particularly associated with individuals' lifestyles (e.g., poor diet, obesity, low physical activity, and active and passive smoking) (Lewandowska et al., 2022).

Generally, CRC appears after the age of 50, and is more common in men than in women (Hultcrantz, 2020). Although the standard conventional treatments for CRC are surgery, chemotherapy, and radiation therapy, new treatment alternatives such as cancer immunotherapy have been emerging recently (Johdi & Sukor, 2020). The types of treatments used for colorectal cancer depend on the location and severity of the cancer (Chokshi et al., 2022), and a combination of different treatments may be used. Surgery remains the only treatment that offers a chance of cure (Traa et al., 2012). Given that surgery may include surgical resection of the bowel, or rectum, and adjacent lymph nodes (Chokshi et al., 2022), sometimes a temporary or permanent stoma may be required, increasing the burden to the patient.

Colorectal cancer and its treatments, including surgery, radiotherapy, and chemotherapy, significantly affect patients' overall dimensions of sexual health (Bober & Varela, 2012; Donovan et al., 2010; Flynn et al., 2010; Marijnen et al., 2005; Traa et al., 2012). The literature available comparing patients' level of sexual functioning before and

immediately after treatment for CRC (Donovan et al., 2010), on the prevalence of sexual dysfunction (Stulz et al., 2020; Tenfelde et al., 2017) and its association to treatments (Traa et al., 2012), comparing treatment modalities (Marijnen et al., 2005), and assessing the importance attributed to sexuality before and immediately after treatment for CRC (Reese & Haythornthwaite, 2016), have been indicating that treatment for this type of cancer negatively influence the sexual health of patients and survivors.

In addition to the significant alterations in sexual response/function, other important components of patients' sexual experiences have been shown to be negatively affected. Patients with CRC also exhibit less involvement in sexual activities (Almont et al., 2018; Den Oudsten et al., 2012; Stulz et al., 2020; Ussher et al., 2015) and decreased sexual pleasure and sexual satisfaction (Den Oudsten et al., 2012; Stulz et al., 2020; Sutsunbuloglu & Vural, 2018). In a recent systematic review conducted by Chokshi and colleagues (2022) on sexual health of colorectal cancer patients, patients' sexual satisfaction and frequency of sexual activity was shown to decrease significantly over the course of the disease.

Regarding the prevalence of sexual dysfunction in CRC survivors, from the results found in a systematic review by Traa and collaborators (2012), it was found that a significant number of men and women experience sexual dysfunction postoperatively. The most common were erectile dysfunction, ejaculatory dysfunction and decreased sexual desire in men, and dyspareunia and absence and/or decrease of vaginal lubrication in women. These results are in line with the results found in other studies (Den Oudsten et al., 2012; Stulz et al., 2020).

A study conducted in Portugal by Cotrim and Pereira (2008) aimed to identify and assess the impact of CRC on patients and their families, showed that, compared to non-ostomized CRC patients, ostomized patients presented a greater decrease in functionality, more symptoms, a worse health status (overall) and quality of life. In addition, significant differences were found in terms of sexual functioning between these two groups, with a greater decline in sexual activity in ostomized patients. According to these findings, and those from other studies (Tenfelde et al., 2017), CRC deeply affected patients' sexuality, namely patients submitted to a colostomy.

In fact, the experience of sexuality by ostomized patients is influenced by physiological aspects, resulting from the surgical procedure in which the structures adjacent to the genital organs may be compromised (Cotrim & Pereira, 2008; Tenfelde et al., 2017). For example, radical procedures such as abdominoperineal resections can damage the nerves that are essential for the genitals and consequently for the sexual response, leading to the

appearance of sexual difficulties or dysfunctions (e.g., erectile dysfunction and ejaculation disorders in men, and dyspareunia and decreased vaginal lubrication in women) (Tenfelde et al., 2017). The results of a study by Sutsunbuloglu and Vural (2018), indicated that stoma patients experience high levels of sexual dissatisfaction and dysfunction; namely older women and those with a permanent stoma. According to the authors, the dissatisfaction with body image due to age-related physiological changes, in addition to the presence of a stoma, can lead to worse sexual problems in ostomized patients.

That said, the challenges after CRC treatments are not only physical, since the recovery of sexual functioning often becomes a long and slow process, experienced with enormous suffering and anguish by the CRC survivors. The presence of CRC in an individual's life can seriously affect their mental health and psychological well-being, leading, in many cases, to anxiety and depression (Cotrim & Pereira, 2008).

In a study conducted by Flynn and collaborators (2010) it was found that, for participants who lost erectile function (e.g., patients with CRC), the embarrassment raised by the inability to initiate and/or maintain an erection of the penis and to perform sexual activities lead to isolation and influenced relationships. In the same study, there were reports of ostomized patients indicating significant problems with their body image and interference of the ostomy bag during sexual activity (e.g., reduced frequency of the partner's touching for fear of damaging the bag) (Flynn et al., 2010). In addition, ostomized patients may have additional concerns, especially about odor, emptying, and elimination of gas and feces during sexual activity (Mohamed et al., 2020). The bag can be embarrassing and can make them feel less feminine/masculine, sexually attractive, and self-confident (Chokshi et al., 2022). Cancer patients may have concerns about their ability to satisfy their partners (Crowley et al., 2015), and especially ostomized women, as a result, may not achieve orgasm or find sexual activity satisfying (Sutsunbuloglu & Vural, 2018). In addition, women also worry about their sexual partners' reaction to the stoma and its potential rejection (Tripaldi, 2019). In this sense, all the issues described can cause much distress and further exacerbate the sexual difficulties of CRC patients, particularly those with a stoma.

Given the consequences of treatments for CRC, it becomes important to understand how patients adapt to these changes, and whether the adoption of specific coping strategies or the presence of certain beliefs may help or hinder the adaptive adjustment of these patients (Reese & Haythornthwaite, 2016). One such belief is the importance that patients with CRC place on sexuality. The results of a study conducted by Reese and Haythornthwaite (2016) showed that, for patients with CRC, the importance assigned to sexuality before cancer was

greater than the "current" importance; on the other hand, a greater importance of "current" sexuality was associated with marital status, the absence of metastatic disease, and not being on treatment; moreover, the current state of sexual functioning significantly predicted the "current" importance assigned to sexuality. These results suggest that the importance attributed to sexuality may decrease as a result of CRC and its associated sexual problems, and that patients may attribute less importance to sexuality as they perceive changes in their ability to engage in sexual activities (Reese & Haythornthwaite, 2016).

In summary, colorectal cancer (CRC) and its treatments have a profound impact on overall patients and survivors' lives, namely on their sexual health, particularly in ostomized patients (Benedict et al., 2015; Cotrim & Pereira, 2008; Den Oudsten et al., 2012; Donovan et al., 2010; Frankland et al., 2020; Tiranda et al., 2019; Traa et al., 2012). Given the significant impact of CRC on patients' sexual health and well-being, it is of great importance that healthcare professionals address these aspects throughout the course of the disease and the survivorship period.

3. Communication about the sexual health of colorectal cancer (CRC) patients and survivors

Communication between healthcare professionals and patients about sexuality is extremely important, however, studies suggest that information about the consequences of cancer and its treatment is still lacking in a consistent basis in clinical settings. Moreover, there is evidence showing that such information has not been properly addressed or communicated to patients (Flynn et al., 2011; Mohamed et al., 2020; Sutsunbuloglu & Vural, 2018), and that patients do not receive a complete sexual health assessment in a regular basis (Julien et al., 2010). The results of a study conducted by Sutsunbuloglu and Vural (2018), indicated that 79% of stoma patients had not been informed about any sexual problems that could occur in the postoperative period, and 83% of patients stated that they had not received any information about available treatments for sexual problems.

According to Reese and Haythornthwaite (2016), it is critical that healthcare professionals provide information to all patients with CRC about the potential side effects of cancer and related treatments on sexual functioning and assess patients' level of distress and interest in seeking help (e.g., for decision-making regarding various treatment modalities or possible further evaluation). However, open communication can be difficult, particularly, when talking about intimate topics (Flynn et al., 2011). Although several studies have

identified barriers to communication between patients and health professionals, particularly in oncology (Flynn et al., 2011; Julien et al., 2010; Traa et al., 2013), and highlighted the importance of identifying, assessing, and meeting patients' sexual health needs, (Cotrim & Pereira, 2008; Crowley et al., 2015; Flynn et al., 2011; Frankland et al., 2020; Reese & Haythornthwaite, 2016; Santin et al., 2015; Tiranda et al., 2019; Traa et al., 2012; Traa et al., 2013; Ussher et al., 2015), the discussions with the patients regarding their sexuality remain limited and/or insufficient.

Several barriers to communication have been identified, such as lack of time of the healthcare providers, insufficient knowledge on sexuality issues or training, as well as discomfort in addressing sexual issues with the patients (Bober et al., 2009; Park et al., 2009). In addition, there is evidence showing that patients feel reluctance and shame when addressing issues related to their sexuality (Traa et al., 2013) and anticipate that the healthcare professional will take the initiative to address the topic if it is considered important (Flynn et al., 2011). In this sense, if it is the health care professional who initiates the discussion, this may provide an opening for patients to discuss these issues (Traa et al., 2012).

The lack of communication between health professionals and patients about cancer treatment and sexuality may contribute to the reinforcement of patients several erroneous assumptions regarding sexuality. For example, in the absence of answers, survivors often assume that sexual problems and/or dysfunctions are a treatment-related inevitability that has no solution and, therefore, must be accepted and supported; or that sexuality is not an important topic (Bober & Varela, 2012).

According to Bober and Varela (2012), the provision of information about sexuality is optimized when it is not only relative to the physical needs of the survivor, taking into consideration each survivor's relational framework, their perceived self-efficacy, and their cultural context. For example, after cancer treatments, the quality of the intimate relationship between couples may be compromised, particularly in aspects related to their sexual life, such as the appearance of sexual dysfunctions or difficulties in adjusting to the sexual changes caused by the presence of a stoma (He et al., 2021; Mohamed et al., 2020; Traa et al., 2015). However, the lack of information and silence that survivors experience in medical and health care settings regarding this topic results in several difficulties in explaining sexual sequelae to their partners (Bober & Varela, 2012) and often leads to partners disregarding their own sexual needs (Traa et al., 2013).

A study by Flynn and colleagues (2011), assessed patients' experiences with oncology health professionals (OHP) regarding communication about sexual issues during and after cancer treatment. In this study, 78% of the participants reported that it was important to communicate with the OHP about any sexual problems, and more than half of the patients (64%) said that including partners in discussions about sexual health could be very helpful. Regarding "unmet" information needs, more than half of the participants (55%) reported that they had not received information about how cancer and its treatments could affect their sexual health. Regarding asking questions about sexual problems, participants who asked for help (29%) had more problems with sexual functioning than those who did not ask; some participants mentioned that it was important for OHPs to initiate discussions about sexual problems; and, another participant, who was a OHP, stated, "*[as a oncology professional], I can say that I don't often ask [about sex] unless it comes up. Now that I've been through [cancer], I'm think that I'll definitely ask that question. It's something that is definitely important as part of the quality of life.*".

In summary, although treating cancer and achieving a cure is the main clinical goal, it is essential to ensure the best possible quality of life during and after treatments. Sexuality and intimacy are important aspects of quality of life (Flynn et al., 2010; Flynn et al., 2011; Sutsunbuloglu & Vural, 2018). The side effects of treatment, such as lower levels of sexual functioning and/or sexual satisfaction, can negatively affect the quality of life and well-being of patients and their partners (Chokshi et al., 2022). Although experiencing a pleasurable and fulfilling sex life is a key component of quality of life, it still remains one of the "unmet" needs frequently reported by cancer survivors (Jackson et al., 2016; Traa et al., 2013).

4. The sexual health care needs of colorectal cancer (CRC) patients and survivors

Despite the evidence showing the extend of sexual health problems experienced by colorectal cancer (CRC) patients and survivors (Benedict et al., 2015; Bober & Varela, 2012; Cotrim & Pereira, 2008; Den Oudsten et al., 2012; Donovan et al., 2010; Flynn et al, 2010; Jackson et al., 2016; Marijnen et al., 2005; Reese & Haythornthwaite, 2016; Traa et al, 2012), to date, there is a scarce body of research that has focused on identifying (Flynn et al., 2011; Traa et al., 2013) and assessing (Reese & Haythornthwaite, 2016; Reese et al., 2012; Reese et al., 2014) the sexual health needs of these patients.

Santin and collaborators (2015) investigated the prevalence and nature of "unmet" needs of CRC survivors, along with the relationship between needs and quality of life, using

a quantitative approach. Findings indicated that 40% of participants reported one or more "unmet" health care needs, with 8% reporting needs related to body image and 12% highlighting the need to receive support and counseling regarding sexual health problems (Santin et al., 2015); furthermore, a relationship was found between the presence of "unmet" needs and poorer quality of life. Regarding ostomized CRC patients, the results of a recent study (Mohamed et al., 2020) showed that patients and their spouses, or intimate partners, reported unmet sexual health needs, particularly unmet needs related to sexual problems, interference of the stoma during sexual activities, and changes in the intimate relationship.

A qualitative study by Traa and collaborators (2013) sought to identify the sexual health care needs after CRC treatment, according to the reports of patients, partners, and healthcare professionals (HCPs). Regarding sexual health care needs, CRC patients and their partners emphasized the importance of receiving this type of care and the need to be informed about treatment options and the possible emergence of sexual problems; however, in clinical consultations, patients and their partners reported that they did not feel able to address the issue of sexual health, as they saw it as a secondary issue in relation to the main focus of the consultations: survival (Traa et al., 2013). In this study, health care providers indicated similar concerns regarding the appropriateness of discussing issues and concerns related to survivors' sexuality, as survivorship was the primary concern; they reported that they were hesitant to ask questions for fear of making patients and their partners uncomfortable; and, in some cases, they felt that discussing survivors' sex lives would be irrelevant, particularly if patients were older, female, or unmarried (Traa et al., 2013).

Another study conducted by Dau and collaborators (2020), indicated specific information needs according to the treatment status of CRC patients. The authors highlighted a greater need to help meet the information needs of patients undergoing active treatment for CRC. According to Almont and colleagues (2018), although healthcare professionals often assume that patients undergoing treatment are not interested in sexuality, the results of their study show that even when the prognosis is uncertain and the treatment intensive, most patients are concerned about sexuality during the treatment. Out of a total of 36 patients with colorectal cancer, 47% patients stated that they would use sexual health care if it were available. In a more recent study (Lee et al., 2021) investigating cancer patients over 65 years of age, including 100 patients with cancer of the colon, rectum or anus (43%), it was found that sexual health needs can also differ by age, showing higher levels of needs in older patients.

Taking into consideration the findings of the presented studies, there is a growing awareness regarding cancer patients and survivors sexual health care needs (Almont et al., 2018; Crowley et al., 2015; Lee et al., 2021; Mohamed et al., 2020; Park et al., 2009; Preyde et al., 2020; Santin et al., 2015; Traa et al., 2013), as well as information needs regarding sexuality (Crowley et al., 2015; Dau et al., 2020; Flynn et al., 2011; Lee et al., 2021; Santin et al., 2015). However, evidence suggests that such sexual care needs are not being adequately addressed in a regular basis (Julien et al., 2010; Traa et al., 2013). Therefore, it is extremely important to develop studies that allow us to identify which concerns and needs this vulnerable group identifies as relevant to the experience of a healthy and gratifying sexuality. In this way, it will be possible to develop and implement specific interventions with a positive impact on the sexual health and quality of life of these patients, which will also lead to a significant improvement in their satisfaction and their adjustment to the disease.

5. Objectives

According to the literature, to date, studies seeking to identify (Flynn et al., 2011; Traa et al., 2013) and assess the sexual health needs of CRC patients (Reese & Haythornthwaite, 2016; Reese et al., 2012; Reese et al., 2014) are scarce. Although the evidence highlights the importance of identifying, assessing, and meeting the sexual health needs of this patients, discussions about their sexuality also remain limited and/or insufficient, and the access to sexual care is still limited.

In view of the challenges faced throughout the course of the disease, it is unfortunate that the sexual health care needs of many patients and survivors are unknown, underestimated and disregarded by institutions, services, and healthcare professionals, particularly in oncology. In fact, according to Flynn and collaborators (2011), sexual health has not yet been properly integrated into cancer treatment.

In this regard, the aim of the present study is to explore the sexual health concerns and needs in a sample of colorectal cancer patients and survivors. Thus, this study sought to answer the following research question: "*What are the sexual health concerns and needs identified by colorectal cancer patients and survivors?*". To do so, we sought to describe and analyze (a) the sexual health concerns and (b) the sexual health needs identified by CRC patients and survivors, and (c) the experiences of communication about sexuality of this

patients with healthcare professionals. Given the exploratory nature of this investigation, no research hypotheses were formulated.

With this study, we hope to raise awareness among health care professionals about the necessity of addressing the topic of sexuality with colorectal cancer patients and identify potential sexual health concerns and needs. In this way, professionals will be able to develop and implement sexual health programs/interventions that address the specific concerns and needs of these population.

Method

1. Participants

Participants in this study were recruited directly at the Portuguese Institute of Oncology of Porto (IPO-Porto) and via online. Men and women with a diagnosis or history of colorectal cancer were invited to participate, regardless of their sexual orientation, gender identity and relational situation.

Individuals who met the following inclusion criteria were included: (1) being 55 years of age or older, (2) having a diagnosis or history of CRC, (3) being able to speak and write in Portuguese, and (4) having the physical and mental capacity to answer the questionnaire and to give informed consent. Exclusion criteria included: (1) being unable to give informed consent, and (2) current moderate or severe psychiatric illness or cognitive deficits (e.g., severe depression, psychotic disorders, dementia). To this end, in the face-to-face sessions, clinical interviews were conducted to screen for psychopathology, memory impairments, and comorbid conditions.

Out of a total of 102 people invited to participate in the study (83 at IPO and 19 who accessed the study online), 64 participants consented to participate in this study. 12 questionnaires were excluded from the sample due to presence of another oncologic condition other than CRC (n=1), age below than 55 years (n=2), missing data (e.g., no indication of age) or substantially incomplete questionnaire (n=9). The final sample was composed of 52 participants (48 completed the paper and pencil questionnaire and 4 the online version; completion rate of 51%); 13 participants identified as women and 39 as men, ranging from 55 to 86 years old ($M=66$; $SD=7.6$). At the time of the study, most of the

participants were married (81%), retired (65%), and had a completed Basic Education or below (69%). The characteristics of the final sample are presented in Table 1.

Table 1
Sociodemographic characteristics of the total sample (N=52)

Variable	Women (n=13) N (%)	Men (n=39) N (%)	All (N=52) N (%)
Marital Status			
Cohabiting/cohabiting	-	2 (5.1)	2 (3.8)
Married	11 (84.6)	31 (79.5)	42 (80.8)
Divorced	-	4 (10.3)	4 (7.7)
Widowed	2 (15.4)	2 (5.1)	4 (7.7)
Professional Status			
Employed	2 (15.4)	13 (33.3)	15 (28.8)
Unemployed	1 (7.7)	2 (5.1)	3 (5.8)
Retired	10 (76.9)	24 (61.5)	34 (65.4)
Education			
1st Cycle	4 (30.8)	17 (43.6)	21 (40.4)
2nd Cycle	1 (7.7)	4 (10.3)	5 (9.6)
3rd Cycle	3 (23.1)	7 (17.9)	10 (19.2)
High School	2 (15.4)	4 (10.3)	6 (11.5)
Higher Education	3 (23.1)	7 (17.9)	10 (19.2)
Age (in years)			
Mean (SD)	66.85 (7.11)	65.74 (7.84)	66.02 (7.61)
Range	56-76	55-86	55-86

2. Procedures

2.1. Study Design

The present study was part of a larger research project intitled "*ANATHEMA: Technology for ageless sexual health*", developed in partnership with the Research Group in Human Sexuality (SexLab) of the Faculty of Psychology and Educational Sciences of Porto University and Fraunhofer Portugal AICOS, a German research company, based in Portugal. The Anathema project aims to develop and implement a digital program to promote the sexual health in older adults (55+) and people with chronic diseases such as colorectal cancer (CRC) survivors and stroke survivors. Considering the uniqueness of each user, as well as their specific needs, the present study integrated the first phase of the Anathema project, which consisted in exploring sexual health unmet care needs of CRC patients to further inform the content development of the program. The project received ethical approval by the Ethical Board of the Portuguese Institute of Oncology of Porto (IPO-Porto) and the Ethical Board of Faculty of Psychology and Education Sciences of the University of Porto.

2.2. Ethical Approval and Informed Consent

In order to collect the data for this study, permission was obtained from the Ethics Committee of the University of Porto (CEUP) and the Portuguese Institute of Oncology of Porto (IPO-Porto). Before any assessments and specific study procedures were conducted, the objectives of the research project were explained to the participants. Information was also provided about the anonymity and confidentiality of their responses, as well as the protection of the collected data. Participants who agreed to participate in the study signed two Study Information Forms and Informed Consent Forms (ICF) (Appendix A) in the presence of the researchers and a copy was provided to them. Subsequently, the participants were asked to answer a set of assessment instruments (Appendix B). Once filled in, the questionnaires were returned directly to the researcher in a sealed envelope. Participants were also informed about the possibility of withdrawing from the study at any time, if they wished to.

2.3. Data Collection

To collect the necessary data for this study, several meetings were conducted in February of 2022 at the Portuguese Institute of Oncology of Porto (IPO-Porto) and at the Association of Support to Digestive Cancer Patients (Europacolón Portugal). The main purpose of these meetings was to present the Anathema project and the various studies to be implemented – including this one –, to negotiate and define the conditions of the participant recruitment process, as well as to clarify doubts and ask relevant questions. These contacts were important moments for the presentation of the members of the research team and the associated organizations.

Between March and August of 2022, two members of the research team recruited participants who were being followed at the Digestive Pathology Clinic of the Portuguese Institute of Oncology of Porto (IPO-Porto). In parallel, participants were invited to participate in this study online, through the dissemination of the study and the online questionnaire in the main social networks of the Association Europacolón Portugal, the Faculty of Psychology and Education Sciences of the University of Porto (FPCEUP) and the Research Group in Human Sexuality (SexLab). The completion of the questionnaire in person and online took approximately 30 to 60 minutes. No monetary compensation or other incentives were offered to participants for their participation.

At the IPO-Porto, two offices were used for the individual administration of the questionnaire, ensuring patient privacy. Although the research team members suggested that the questionnaire should be completed privately and autonomously, some participants chose to answer the questions in the presence of the person accompanying them (e.g., a family member, a partner). The researchers provided help in completing the questionnaires whenever requested.

3. Measures

3.1. Sociodemographic questionnaire

The sociodemographic questionnaire provided a reliable characterization of the following sociodemographic variables: sex, gender, age, professional status, marital status, and academic qualifications.

3.2. Clinical questionnaire

A clinical questionnaire was designed to collect information regarding cancer-related characteristics, including the type of cancer, the stage of cancer, the type(s) of treatment(s) received, the date of diagnosis, the date of the last treatment performed and the type of intestinal stoma (in case the patient had undergone a colostomy surgery). In addition, information was also collected regarding the presence/absence of mental disorders, the type of medication being taken, and the participants' perception regarding their physical and mental health status.

3.3. Sexual Health Questionnaire

The Sexual Health Questionnaire was designed to collect information regarding different aspects of sexuality, such as sexual orientation, relationship status, duration of relationship, current sexual partners, frequency of certain sexual behaviors, need for communication with health professionals about sexual intimacy problems, experiences communicating about sexuality with health professionals and barriers to this communication. Explicit definitions of the following concepts were provided at the beginning of the questionnaire to ensure uniformity: sexual activity, sexual intercourse and sexual stimulation.

3.4. Information on Sexual Health: Your Needs after Cancer (InSYNC)

The InSYNC was developed by Crowley and collaborators (2015) and consists of a self-assessment questionnaire that evaluates sexual health concerns and information needs after cancer diagnosis. This questionnaire includes 12 items related to multiple dimensions of sexual health (e.g., sexual function, self-perception, and sexual relationships) and important psychosocial aspects of sexual health (e.g., initiating new relationships, confidence as a sexual partner) (Tounkel et al., 2022). The respondent rates each item on a scale of 0 to 5, with a higher score indicating higher levels of concern (Crowley et al., 2015). This questionnaire also integrates an additional question for each yes/no response item to assess the patient's need for further information (Crowley et al., 2015); this option is unique to the InSYNC (Tounkel et al., 2022).

The InSYNC uses non-gender-specific terminology, eliminating heterosexual bias (Tounkel et al., 2022). The questionnaire is brief and user-friendly; is considered a clinically useful tool for identifying the sexual health care needs of cancer survivors and can be used by institutions, services, and health care professionals to identify cancer survivors who need counseling and/or additional information (Crowley et al., 2015).

The validation study for this questionnaire was completed in 2016 using a population of breast and prostate cancer survivors (Tounkel et al., 2022). Although face validity has been established, the instrument has not undergone extensive psychometric testing (Crowley et al., 2015; Tounkel et al., 2022).

The psychometric validation of the Portuguese version of the scale is under study and show good psychometric indicators. An Exploratory Factor Analysis was performed through a Principal Components Analysis on the 12 items of the questionnaire identified one factor (sexual care needs) explaining approximately 57% of total variance (KMO = .80 and Bartlett's test $p < 0.05$). The InSYNC questionnaire also showed good internal consistency (Cronbach's $\alpha = .93$).

In the present study the items from the InSYNC questionnaire were used to characterize the sexual health concerns and information needs of a sample of colorectal cancer patients and survivors.

4. Analysis

The present study was conducted using the 27th version of the IBM SPSS Statistics. The sociodemographic and clinical characteristics of the sample, as well as the data obtained from the InSYNC and Sexual Health questionnaires were presented using descriptive statistics (means, standard deviations and range) and frequency analysis (numbers and percentages). Considering the small sample size and the distribution of data across the InSYNC response options, all questionnaire items were dichotomized into high (4-5) and low (1-3) levels of concern to facilitate analysis (Crowley et al., 2015; Preyde et al., 2020). The content analysis method (Bardin, 1977) was used to analyze the responses to the open-ended questions of both questionnaires. After a floating reading of the participants' responses, the content was coded and organized according to common opinions and experiences, and then classified into major themes and sub-themes. Subsequently, each theme was assigned a code to allow statistical analysis. These results were presented with the number and percentages of participants who mentioned each theme and sub-theme.

Results

1. Clinical characteristics of the sample

Regarding cancer characteristics, 23 participants indicated that they had received a diagnosis of colon cancer (44%), 10 indicated rectal cancer (19%), and 19 indicated both (37%). Approximately 19% of participants received the diagnosis of cancer at stage I (n=10), 12% at stage III (n=6), 4% at stage IV (n=2), and the remaining 65% did not know the stage of cancer (n=34). The year they got their diagnosis ranged from 1997 to 2022.

Regarding the treatment for CRC, 96% of participants underwent surgery (n=50), 33% reported have received chemotherapy (n=17), 27% have received combination therapy (e.g., chemotherapy and radiation therapy) (n=14), and 8% have received radiation therapy (n=4). At the time of the study, 44 participants had finished their last treatment (85%) and reported the year of the last treatment ranging from 1999 to 2022.

Twenty men (51%) and 4 women (31%) underwent colostomy surgery. Of a total of 24 participants (46%), 23% had a permanent stoma (n=12), 15% had a temporary stoma

(n=8), and the remaining 8% had in the past (n=4). The results regarding the participants' CRC characteristics are presented in Table 2.

Information was requested regarding the presence or absence of a diagnosis of mental disorders. Nineteen participants indicated a previous diagnosis of at least one mental disorder (37%). Depression was the primary mental condition indicated by participants (21%; n=11), followed by anxiety (19%; n=10). 64% of participants indicated that they had never received a mental disorder diagnosis (n=33). Most participants indicated they were taking medications at the time of the study (75%; n=39), with antihypertensives being the most reported (42%; n=22). Other types of medication (e.g., cholesterol and diabetes medication) were indicated by twenty-seven participants (52%). Most participants rated their psychological and physical health status as good or excellent at the time of the study (75% and 54%, respectively). These results are present in Table 3.

Table 2.
CRC characteristics (N=52)

Variable	Women (n=13) N (%)	Men (n=39) N (%)	All (N=52) N (%)
CRC Type			
Colon	7 (53.8)	16 (41)	23 (44.2)
Rectal	3 (23.1)	7 (17.9)	10 (19.2)
Both Sites	3 (23.1)	16 (41)	19 (36.5)
CRC Stage			
Stage I	1 (7.7)	9 (23.1)	10 (19.2)
Stage III	1 (7.7)	5 (12.8)	6 (11.5)
Stage IV	2 (15)	-	2 (3.8)
Unknown	9 (69.2)	25 (64.1)	34 (65.4)
Treatment Type			
Surgery	13 (100)	37 (94.9)	50 (96.2)
Chemotherapy	9 (69.2)	8 (20.5)	17 (32.7)
Radiotherapy	3 (23.1)	1 (2.6)	4 (7.7)
Combination Therapy	2 (15.4)	12 (30.8)	14 (26.9)
End of Treatment for CRC			
Yes	11 (84.6)	33 (84.6)	44 (84.6)
No	2 (15.4)	6 (15.4)	8 (15.4)
Colostomy surgery			
Yes	4 (30.8)	20 (51.3)	24 (46.2)
No	9 (69.2)	19 (48.7)	28 (53.8)
Stoma Type (n=24)			
Had in the past	-	4 (10.3)	4 (7.7)
Permanent stoma	2 (15.4)	10 (25.6)	12 (23.1)
Temporary stoma	2 (15.4)	6 (15.4)	8 (15.4)
Date (range)			
Diagnosis	1997-2021	1999-2022	1997-2022
Last treatment	1999-2021	2000-2022	1999-2022

Table 3.
Clinic characteristics of the sample (N=52)

Variable	Women (n=13) N (%)	Men (n=39) N (%)	All (N=52) N (%)
History of Mental Disorder			
Yes	10 (76.9)	9 (23.1)	19 (36.5)
No	3 (23.1)	30 (76.9)	33 (63.5)
Types of Mental Disorder			
Depression	5 (38.5)	6 (15.4)	11 (21.2)
Anxiety	6 (46.2)	4 (10.3)	10 (19.2)
Other (e.g., insomnia)	1 (7.7)	-	1 (1.9)
Taking Medication			
Yes	11 (84.6)	28 (71.8)	39 (75)
No	2 (15.4)	11 (28.2)	13 (25)
Type of Medication			
Antidepressants	4 (30.8)	4 (10.3)	8 (15.4)
Anxiolytics	5 (38.5)	3 (7.7)	8 (15.4)
Mood stabilizers	-	1 (2.6)	1 (1.9)
Antihypertensives	4 (39.8)	18 (46.2)	22 (42.3)
Other (e.g., diabetes)	8 (61.5)	19 (48.7)	27 (51.9)
Mental health status			
Poor/bad	2 (15.4)	1 (2.6)	3 (5.8)
Neither good nor bad	3 (23.1)	7 (17.9)	10 (19.2)
Good/excellent	8 (61.5)	31 (79.5)	39 (75)
Physical health status			
Poor/bad	3 (23.1)	2 (5.1)	5 (9.6)
Neither good nor bad	4 (30.8)	15 (38.5)	19 (36.5)
Good/excellent	6 (46.2)	22 (56.4)	28 (53.8)

2. Sexual behavior characterization

All participants in this study reported an exclusively heterosexual orientation (N=52). Most of the participants were in an intimate relationship with a partner (94%; n=49) and approximately 89% (n=46) reported engaging in sexual activity in the context of that exclusive relationship. The average duration of participants' relationships was 38 years ($SD=13$) (Table 4).

The results regarding the frequency with which participants engaged in a set of sexual behaviors in the past 6 months are presented in Table 5. At the time of the study, most participants reported never or rarely have engaged in the following sexual behaviors in the past 6 months: performing oral sex (77%; n=40); receiving oral sex (75%; n=39); performing vaginal penetration (58%; n=30); performing anal penetration (90%; n=47); and masturbation (64%; n=33). Regarding the exchange of caresses, such as kissing, hugging, holding hands, while 29% of the participants reported a low frequency of these behaviors, approximately 42% of the participants (6 women and 16 men) indicated exchanging caresses often or always, and 29% occasionally.

Table 4.
Sexual characteristics (N=52)

Variable	Women (n=13) N (%)	Men (n=39) N (%)	All (N=52) N (%)
Sexual orientation or preference			
Exclusively heterosexual	13 (25)	39 (75)	52 (100)
Relational status			
No relationship	2 (15.4)	-	2 (3.8)
Intimate relationship with multiple partners	-	1 (2.6)	1 (1.9)
Intimate relationship with one partner	11 (84.6)	38 (97.4)	49 (94.2)
Current sexual partners			
Sex with a partner, in the context of my exclusive relationship with him/her	11 (84.6)	35 (89.7)	46 (88.5)
Casual sex with a partner	-	3 (7.7)	3 (5.8)
Casual sex with several partners	-	1 (2.6)	1 (1.9)
No sexual partner	2 (15.4)	-	2 (3.8)
Relationship duration (in years)			
Mean (SD)	41.8 (8.1)	36.92 (13.9)	38.0 (13.0)
Range	29-56	1-62	1-62

Table 5.
Participants' sexual behaviors (N=52)

Variable	Women (n=13) N (%)	Men (n=39) N (%)	All (N=52) N (%)
Exchanging caresses			
Never/rarely	5 (38.5)	10 (25.6)	15 (28.8)
Occasionally	2 (15.4)	13 (33.3)	15 (28.8)
Frequently/always	6 (46.2)	16 (41.0)	22 (42.3)
Performing oral sex			
Never/rarely	10 (76.9)	22 (56.4)	40 (76.9)
Occasionally	1 (7.7)	6 (15.4)	7 (13.5)
Frequently/always	1 (7.7)	4 (10.3)	5 (9.6)
Receiving oral sex			
Never/rarely	12 (92.3)	29 (74.4)	39 (75.0)
Occasionally	-	8 (20.5)	8 (15.4)
Frequently/always	1 (7.7)	4 (10.3)	5 (9.5)
Vaginal penetration			
Never/rarely	10 (76.9)	20 (51.3)	30 (57.7)
Occasionally	1 (7.7)	11 (28.2)	12 (23.1)
Frequently/always	2 (15.4)	8 (20.5)	10 (19.2)
Anal penetration			
Never/rarely	12 (92.3)	35 (89.7)	47 (90.4)
Occasionally	-	3 (7.7)	3 (5.8)
Frequently/always	1 (7.7)	1 (2.6)	2 (3.8)
Masturbation			
Never/rarely	11 (84.6)	22 (56.4)	33 (63.5)
Occasionally	1 (7.7)	13 (33.3)	14 (26.9)
Frequently/always	1 (7.7)	4 (10.3)	5 (9.6)

Note. Range 0-5. "Never/rarely" corresponds to the questionnaire options "Never" (1) and "A few times" (2); "Occasionally" matches the option "Sometimes" (3); "Frequently/always" corresponds to the options "Often" (4) and "Almost always/always" (5).

The Sexual Health questionnaire includes a set of four open questions regarding communication with health professionals about sexuality. In the answers provided by the participants it was possible to identify some main themes and sub-themes (See Table 7 in Appendix C).

Most participants never addressed the topic of sexuality with a healthcare professional (64%; n=33) and reported never felt the need to do so (69%; n=36) (Table 6). The participants indicated some aspects that prevented them from approaching the theme, such as: no need (50%; n=26), feeling afraid or ashamed (4%; n=2), feeling that it was not worthwhile (4%; n=2), among other reasons (6%; n=3). Although most of the participants did not address the topic of sexuality, 19 participants (37%), including 6 women and 13 men, indicated that they had addressed the issue with health professionals. Some participants made comments regarding the evaluation of the experience, with approximately 15% (n=8) evaluating it positively, and 4% (n=2) negatively. Some participants also talked about who had taken the initiative to communicate. Approximately 19% of the participants (n=10) indicated that it was their own, and 8% (n=4) reported that it came from professionals. Regarding the reason or context that led to this experience, 21% of the participants (3 women and 8 men) reported bringing up the topic of sexuality because of the presence of sexual difficulties/problems, and 12% (n=6) reported asking or answering questions about sexuality.

The preferred health professionals to address the topic of sexuality were the Family or General Practitioner (17%; n=9), followed by IPO Professionals (8%; n=4), and Psychologist (4%; n=2). Most participants (52%; n=27) indicated no preference, and 17% (n=9) did not provide an answer (e.g., due to lack of need). Finally, the participants were asked about the stage of the disease/treatment course that they consider important to address the topic of sexuality. Approximately 39% (n=20) of the participants indicated it was important to address at an early stage, 6% (n=3) during treatment, 12% (n=6) after treatment, and 10% (n=5) at all stages of the disease course. 6% reported no preference and 29% (n=15) did not answer the question.

Table 6.
Communication with healthcare professionals about sexuality (N=52)

Variable	Women (n=13) N (%)	Men (n=39) N (%)	All (N=52) N (%)
Since being diagnosed with cancer, have you ever felt the need to talk to a health professional (e.g., doctor, psychologist) about problems related to sexual intimacy?			
Yes	3 (23.1)	13 (33.3)	16 (30.8)
No	10 (76.9)	26 (66.7)	36 (69.2)
During this period, have you ever broached the subject of sexuality with health professionals?			
Yes	6 (46.2)	13 (33.3)	19 (36.5)
No	7 (53.8)	26 (66.7)	33 (63.5)

3. Sexual health and information needs after colorectal cancer (CRC)

Participants in this study reported sexual health concerns and additional information needs on the InSYNC questionnaire. High levels of concern were found in several items of the InSYNC questionnaire (Table 8), with at least 25% of participants reporting high levels of concern in 4 of the 12 questionnaire items, and 20% indicating the same in another 4 items. The most concerning items pertained to physical changes after cancer and treatments (33%; n=17), the ability to sexually satisfy the partner (33%; n=17), the ability to have sexual pleasure (31%; n=16), and changes in the way the body works sexually (27%; n=14). Among the highly concerned, the percentage of participants who would like more information on the subject ranged from approximately 82% to 100% across all items (except for the item "Ability to have children"). Two questionnaire items showed the lowest results of high levels of concern, and the highest number of responses in the N/A (not applicable) option. The results on the item "Initiating new intimate relationships" were probably due to the fact that 81% of the sample was married. Regarding the item "Ability to have children", the results probably reflect the participants' older average age ($M=66$; $SD=7.6$). The average points obtained on the 12 items of the InSYNC questionnaire are presented in Table 9.

Although only the information needs among the most concerned participants were considered, it was found that some participants with low levels of concern also indicated willing to have more information on most items.

Several themes and sub-themes were identified in the participants' responses to the two open-response questions at the end of the InSYNC questionnaire (See Table 10 in Appendix D). Most of the participants (77%; n=40) indicated that they had no additional

concerns or issues about sexual intimacy or health that they would like to address. On the other hand, some participants indicated additional concerns related to their sexual difficulties (12%; n=6), partners' sexual problems (2%; n=1), ability to satisfy their partner sexually (4%; n=2), lack of communication with their partner (2%; n=1), and sexual health information needs (4%; n=3). Regarding the participants' perceptions about what they would need to have a healthy and happy/gratifying sex life, approximately 40% (n=21) indicated having no needs.

Among the responses of the participants who reported having needs, it was possible to identify four types of needs. The most common needs, reported by 19% (n=10) of the participants, are related to partners (e.g., need for more emotional closeness to the partner, greater sexual compatibility, better communication, better health status of the partner, having a partner or a new one, and the need for the partner to receive help for her/his sexual difficulties). Approximately 17% (n=9) of participants reported needs related to their overall health status (e.g., better health status), 15% (n=8) regarding their sexual health (e.g., treat sexual difficulties, improve sexual functioning, increase frequency of sexual activity), 4% (n=2) related to age (e.g., desire to be younger), and one participant indicated the need for more free time and fewer work hours.

Table 8.
Sexual health concerns and information needs (N=52)

Variable	Women (n=13) N (%)	Men (n=39) N (%)	All (N=52) N (%)	% Wanting more information**
Physical changes				
Highly concern	3 (23.1)	14 (35.9)	17 (32.7*)	
Low or not concern	8 (61.5)	23 (59.0)	31 (59.6)	94.1%
N/A	1 (7.7)	2 (5.1)	3 (5.8)	
Missing	1 (7.7)	-	1 (1.9)	
Satisfy partner sexually				
Highly concern	3 (23.1)	14 (35.9)	17 (32.7*)	
Low or not concern	7 (53.8)	22 (56.4)	29 (55.8)	82.4%
N/A	2 (15.4)	2 (5.1)	4 (7.7)	
Missing	1 (7.7)	1 (2.6)	2 (3.8)	
Ability to have sexual pleasure				
Highly concern	2 (15.4)	14 (35.9)	16 (30.8*)	
Low or not concern	6 (46.2)	23 (59.0)	29 (55.8)	93.8%
N/A	4 (30.8)	2 (5.1)	6 (11.5)	
Missing	1 (7.7)	-	1 (1.9)	
Changes in body works sexually				
Highly concern	2 (15.4)	12 (30.8)	14 (26.9*)	
Low or not concern	8 (61.5)	25 (64.1)	33 (63.5)	100%
N/A	2 (15.4)	2 (5.1)	4 (7.7)	
Missing	1 (7.7)	-	1 (1.9)	

Physically attractive					
Highly concern	2 (15.4)	10 (25.6)	12 (23.1*)		
Low or not concern	9 (69.2)	27 (69.2)	36 (69.2)	91.7%	
N/A	1 (7.7)	2 (5.1)	3 (5.8)		
Missing	1 (7.7)	-	1 (1.9)		
Effect on overall sexual relationship					
Highly concern	2 (15.4)	9 (23.1)	11 (21.2*)		
Low or not concern	7 (53.8)	28 (71.8)	35 (67.3)	100%	
N/A	3 (23.1)	2 (5.1)	5 (9.6)		
Missing	1 (7.7)	-	1 (1.9)		
Changes in orgasm experience					
Highly concern	2 (15.4)	9 (23.1)	11 (21.2*)		
Low or not concern	6 (46.2)	27 (69.2)	33 (63.5)	90.9%	
N/A	4 (30.8)	3 (7.7)	7 (13.5)		
Missing	1 (7.7)	-	1 (1.9)		
Losing confidence as sexual partner					
Highly concern	2 (15.4)	9 (23.1)	11 (21.2*)		
Low or not concern	7 (53.8)	28 (71.8)	35 (67.3)	100%	
N/A	3 (23.1)	2 (5.1)	5 (9.6)		
Missing	1 (7.7)	-	1 (1.9)		
Coping with sexual changes					
Highly concern	2 (15.4)	6 (15.4)	8 (15.4*)		
Low or not concern	7 (53.8)	31 (79.5)	38 (73.1)	100%	
N/A	3 (23.1)	2 (5.1)	5 (9.6)		
Missing	1 (7.7)	-	1 (1.9)		
Pain with intercourse					
Highly concern	2 (15.4)	1 (2.6)	3 (5.8*)		
Low or not concern	6 (46.2)	29 (74.4)	35 (67.3)	100%	
N/A	4 (30.8)	9 (23.1)	13 (25.0)		
Missing	1 (7.7)	-	1 (1.9)		
Starting new intimate relationships					
Highly concern	-	1 (2.6)	1 (1.9*)		
Low or not concern	3 (23.1)	16 (41.0)	19 (36.5)	100%	
N/A	10 (76.9)	22 (56.4)	32 (61.5)		
Ability to have children					
Highly concern	1 (7.7)	-	1 (1.9*)		
Low or not concern	1 (7.7)	6 (15.4)	7 (13.5)	-	
N/A	11 (84.6)	33 (84.6)	44 (84.6)		

*Note. Range 0-5. Items rated 1 to 3 correspond to “Low or not concern”, and 4 to 5 indicate “High or Highly concern”. N/A (not applicable) equals 0. *Percentage of participants who rated the items with 4 or 5, indicating high levels of concern. **Among highly concerned, percentage of participants who would like to receive more information.*

Table 9.
Mean and standard deviations of InSYNC scores by gender (N=52)

Variable	Women (n=13)	Men (n=39)	All (N=52)
InSYNC (Total score)	1.94 (1.27)	2.13 (1.29)	2.11 (1.31)
InSYNC (Items score)			
Physical changes	2.17 (1.70)	2.57 (1.76)	2.52 (1.71)
Satisfy partner sexually	1.88 (1.64)	2.61 (1.81)	2.50 (1.80)
Ability to have sexual pleasure	1.25 (1.60)	2.57 (1.86)	2.44 (1.83)
Changes in body works sexually	1.70 (1.49)	2.30 (1.78)	2.17 (1.72)
Changes in orgasm experience	2.13 (1.64)	2.14 (1.69)	2.14 (1.66)
Effect on overall sexual relationship	1.78 (1.56)	2.16 (1.68)	2.09 (1.64)
Losing confidence as sexual partner	1.89 (1.76)	2.08 (1.55)	2.04 (1.58)
Physically attractive	1.82 (1.47)	2.05 (1.68)	2.00 (1.62)
Coping with sexual changes	1.78 (1.56)	1.81 (1.39)	1.80 (1.41)
Ability to have children	3.00 (2.83)	1.00 (.000)	1.50 (1.41) *
Pain with intercourse	2.25 (1.83)	1.23 (.817)	1.45 (1.16)
Starting new intimate relationships	1.00 (.000)	1.24 (.970)	1.20 (.894) *

*Note. Range 1-5. For the calculation of the averages and standard deviations, the items rated with 0, which correspond to the N/A option, were not considered. * Only six participants (2 women and 6 men) responded to the item "Ability to have children", only twenty participants (3 women and 17 men) responded to the item "Starting new intimate relationships".*

Discussion

The purpose of this study was to explore sexual health concerns and needs in a sample of patients with a diagnosis or history of colorectal cancer. Despite evidence demonstrating the extent of sexual health problems experienced by CRC patients and survivors, this important component of quality of life remains one of the commonly reported "unmet" needs following CRC (Jackson et al., 2016; Traa et al., 2013), and studies that have sought to identify (Flynn et al., 2011; Traa et al., 2013) these needs remains insufficient.

Regarding the sexual health concerns identified by InSYNC, the results showed that a significant percentage of the participants in our sample reported having sexual health concerns. Higher levels of concerns were indicated regarding physical changes caused by cancer and treatments, changes in the body's sexual functioning, ability to have sexual pleasure, and the ability to satisfy their partners. These results did not differ significantly from other studies conducted with other oncological populations (Crowley et al., 2015;

Preyde et al., 2020), and can be explained by the well-known impact of colorectal cancer and its treatments on patients' and survivors' physical and sexual health (Almont et al., 2018; Den Oudsten et al. 2012; Donovan et al., 2010; Flynn et al., 2010; Sutsunbuloglu & Vural, 2018; Traa et al., 2012; Ussher et al., 2015). Furthermore, considering that couples' intimate relationships are significantly affected by cancer, particularly regarding sexual intimacy (He et al., 2021; Mohamed et al., 2020; Traa et al., 2015), it is common for patients to reveal additional concerns about their ability to satisfy their partners (Crowley et al., 2015; Sutsunbuloglu & Vural, 2018).

Regarding the participants' responses to the two open-ended questions in the InSYNC questionnaire, these not only allowed to collect additional information about their concerns (e.g., related to their intimate relationships with their partners, sexual health information needs), but also helped to have access to more detailed information about the concerns identified in the questionnaire items (e.g., related to sexual changes and difficulties experienced after cancer and its treatments). The results of this questionnaire also revealed that patients with sexual health concerns would also like to receive more information about the issues and the possible ways to address them.

Yet, it should be noted that a significant number of participants in this study reported low levels of sexual health concerns and no sexual health needs. Considering the participants' comments, these results seem to be due to the perception of a currently satisfactory sexual life, the adoption of a conformist/normalized position towards sexual changes resulting from cancer and the aging process, and the lack of importance attributed to sexual life. Regarding the last aspect, these findings are consistent with previous research results indicating that the importance attributed to sexuality may decrease after experiencing health problems (Gott & Hinchliff, 2003), such as a diagnosis of colorectal cancer (Reese & Haythornthwaite, 2016). In fact, it has been shown that after cancer, patients and their partners may re-prioritize sex as less important, especially if they are older, when comparing it to other aspects considered more valuable in a relationship (Ussher et al., 2015). Furthermore, factors associated with being older, being in a long-term relationship, or having the expectation that sexual changes come naturally with the aging process, were perceived to facilitate the coping when sexual activity becomes less frequent or has stopped completely (Gott & Hinchliff, 2003). It is also important to mention that stereotypical assumptions about sexuality in older adults with cancer disease (Traa et al., 2013), may also explain the low levels of sexual health concerns and needs reported by the participants. Moreover, social desirability, as well as the presence of companions when the questionnaires were being administered, may have conditioned

participants' responses, leading them to minimize the importance of sexuality or imply that they do not think much about this topic.

In this study, the sexual behavior of the participants was also characterized, and it was found that the majority did not engage, or rarely engaged, in a set of penetrative and non-penetrative sexual practices in the past six months. However, exchanging caresses was reported to be the sexual behavior that patients most frequently performed. These results support previous studies (Ussher et al., 2015), suggesting that after cancer some couples may renegotiate their sexual practices or intimacy by engaging more frequently in caress exchanges. In a study conducted by Ussher and colleagues (2013), it was found that sexual renegotiation after cancer may center on redefining sex outside the coital imperative (i.e., penis-vagina intercourse within a heterosexual matrix), by positioning non-coital genital practices as sex, and positioning intimacy (e.g., exchange of caresses, kissing, non-sexual touches, massages, time spent together, affection, or conversations) as more important than sex, without affecting pleasure or satisfaction. That said, although genital sexual practices are less frequent among the participants in this study, greater engagement in other forms of intimacy, through the exchange of caresses, appears to be contributing to the perception of a currently satisfying sex life and, therefore, a reduced number of sexual health concerns and needs. However, these results should be interpreted with caution, since self-reported satisfaction with one's sex life, less importance given to sexuality, and absence of sexual concerns may not mean that participants do not experience changes in their sexual health or even sexual difficulties. It is known that the decreased importance attributed to sexuality may act as a coping strategy to deal with the psychological distress triggered by sexual changes, including the onset of sexual difficulties or dysfunctions (Barsky et al., 2006), which are often seen by patients as inevitable and unsolvable, due to lack of information and communication with healthcare professionals (Bober & Varela, 2012).

In this regard and considering that many patients and partners dealing with colorectal cancer have unmet sexual health concerns and needs, communication about sexuality between patients and healthcare professionals is of great importance. In this study, more than half of the participants reported never having discussed the topic in health care settings, suggesting that patient sexuality remains a rarely discussed component of quality of life. However, despite participants reported having no needs, when discussing their experiences of communication with professionals, they emphasized the importance of addressing this topic, particularly early in the course of the illness (e.g., at diagnosis), as well as the need to include partners in discussions to promote greater understanding and better adjustment. The

unmet information needs about sexual health was indicated by participants as problematic, since it did not give them or their partners the opportunity to prepare for the changes on their sexual lives. It turned out to be a shock for some couples, preventing them from experiencing a healthy and satisfying adjustment with less suffering. Once again, these findings seem to note some inconsistency in the participants' discourses regarding the presence/absence of sexual needs, suggesting that there may be an attempt, albeit hesitant, to devalue these needs.

The results of this study not only show that patients with a diagnosis or history of colorectal cancer have sexual health concerns and needs, but also highlight the importance of discussions about sexuality with health professionals as a way to identify and meet them. Thus, it is important that health care professionals, particularly in oncology, receive adequate training to develop essential communication and counseling skills related to patients' sexual health (Julien et al., 2010; Traa et al., 2013). Regardless of whether or not patients raise questions on the subject, health professionals should take responsibility for the first approach to the topic, providing patients with all the information regarding the side effects of cancer and treatments on sexual health (Flynn et al., 2011), as well as the opportunities for rehabilitation interventions or sexual counseling that are available, and guiding them in this direction. To this end, it is essential to assess the importance and meaning of sexual rehabilitation for patients to evaluate their ability and motivation to implement the recommendations given by health professionals (Bobe & Varela, 2010).

Since many patients share their lives and their sexuality, and sexual partners are also affected by sexual alterations resulting from cancer and treatments, it is essential that the partners also participate in the information and guidance consultations to be equally informed and prepared for the potential sexual changes. This will promote a better understanding between the partners, a greater understanding of the unexpected effects, and the desired cooperation on the way forward, leading to a better adaptation and recovery. These discussions should begin early in the course of the disease, so that, from the time of diagnosis of CRC and knowledge of the procedures to be carried out, the patients and their partners can be prepared, and have in their possession the knowledge and information necessary to face the consequences of the disease and its treatments, and avoid being unexpectedly surprised.

Although patients may feel some reluctance, or even embarrassment, to address issues related to their sexuality (Traa et al., 2013), in this study several participants made positive statements about the possibility of sharing their experiences with the research team members responsible for the direct data collection at the IPO. Some patients mentioned that

they were positively surprised by the approach to the topic, and that their participation in this study was a valuable opportunity to talk about issues that had never been addressed with them before and which they consider important. It was possible to verify that the open questions promoted a higher level of openness from the patients in sharing more in-depth information. The inclusion of qualitative data in this study allowed a deeper exploration of patients' sexual health concerns and needs, as well as their experiences communicating with healthcare professionals. To our knowledge, the present study was the first to directly explore and describe sexual health concerns and needs after colorectal cancer in an older Portuguese population sample, contributing to the current state of knowledge about an important but still understudied field of research. However, the following limitations of this study should be considered. First, the small sample size, mostly collected from a single oncology institute, as well as the lack of diversity in terms of age, gender, sexual orientation, intimate relationship status and disease status (e.g., patients in treatment vs. survivors), compromised a better representativeness of this population, the generalization of findings and the analysis of differences by groups. Second, social desirability, as well as the reluctance and/or discomfort perceived in some patients in approaching their sexuality, and the presence of some companions at the time of completing the questionnaires, constituted factors that may have influenced these results and responses to the questionnaires. Finally, the third limitation of this study is related to the use of a questionnaire (InSYNC) that is still under psychometric validation for the Portuguese population.

This study highlights the importance of identifying and addressing the sexual health concerns and needs of older CRC patients and survivors, and the need for healthcare providers to address sexuality in healthcare settings. Despite limitations, we believe that the findings may be valuable to clinical practitioners who intend to develop and implement personalized sexual health programs/interventions to address the unmet concerns and needs of these patients and promote the experience of a healthy and fulfilling sexuality.

Finally, we believe that future research regarding sexual health concerns and needs of CRC patients and survivors needs to be developed with larger and more diverse samples, in order to analyze potential differences according to age, gender, intimate relationship status, disease state, or stoma status. This will enable better exploration and understanding of the specific concerns and needs of this population and therefore the development of personalized sexual health programs that promote this important component of quality of life. We believe that investment in rehabilitation and/or optimization of sexual health after CRC should become a key element in the care provided to these patients.

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Appendix A.



INFORMAÇÃO A PARTICIPANTE

ANATHEMA – TECHNOLOGY FOR AGELESS SEXUAL HEALTH (ANATHEMA: TECNOLOGIA PARA A SAÚDE SEXUAL SEM IDADE)

NOME DO ESTUDO: Estudo de caracterização de atitudes e necessidades de suporte não satisfeitas no domínio da saúde sexual (Estudo 1 – Parte 1)

ENTIDADES RESPONSÁVEIS: Fraunhofer Portugal AICOS (Coordenador); Faculdade de Psicologia e Ciências da Educação da Universidade do Porto (Portugal); INSTAHELP (Áustria); SPRIGS (Holanda); KBO-PCOB (Holanda).

EQUIPA DE INVESTIGAÇÃO: Ana Correia de Barros (Investigadora Principal), Ana Quinta Gomes, Anna Fuchs, Bernadette Frech, Cristina Mendes Santos, Jan Brinkers, Joan de Boer, Joana Couto, Kerstin Jäger, Kreshnik Hasanaj, Miradije Zeqiri, Nora Ramadani, Pedro Nobre, Priscila Vasconcelos, Raquel Pereira.

INSTITUIÇÕES A COLABORAR NO ESTUDO: Instituto Português de Oncologia do Porto, Francisco Gentil, EPE (IPO-Porto); EuropaColon Portugal.

Convidamo-la(o) a participar no projeto de investigação designado ANATHEMA, que tem por objetivo desenvolver um programa digital de promoção da saúde sexual de **homens e mulheres com mais de 55 anos de idade, sobreviventes de cancro colorectal**. De modo a informar o desenvolvimento do programa e garantir que este responde às reais necessidades dos seus utilizadores finais, o projeto utilizará diferentes métodos (e.g., questionários, grupos de discussão focal, entrevistas, sessões de co-design, testes de usabilidade e estudos piloto controlados e randomizados) que serão aplicados em estudos distintos. Este projeto inclui os seguintes estudos:

- 1) **Estudo de caracterização de atitudes e necessidades de suporte não satisfeitas no domínio da saúde sexual (Estudo 1 – Parte 1)**
- 2) Estudo de identificação de requisitos para o desenvolvimento de um programa de promoção da saúde sexual (Estudo 1 – Parte 2)
- 3) Estudo de co-desenvolvimento de um programa de promoção da saúde sexual (Estudo 2 – Parte 1)
- 4) Estudo de usabilidade de um programa de promoção da saúde sexual (Estudo 2 – Parte 2)
- 5) Estudo de avaliação da exequibilidade e eficácia de um programa de promoção da saúde sexual (Estudo 3).

A sua participação neste projeto é **voluntária** e a **participação em um destes estudos não obriga à participação nos restantes** sendo, no entanto, possível participar em mais do que um estudo se for essa a sua vontade.

O **Estudo 1 – Parte 1**, a que este documento diz respeito e para o qual está a ser convidada(o) a participar, tem como objetivo **conhecer as necessidades e atitudes de sobreviventes de cancro colorectal** face à utilização de tal programa.

A participação neste estudo **implica o preenchimento de um conjunto de questionários** destinados a avaliar dimensões psicológicas, cognitivas e psicossociais. A sua participação poderá contribuir para o conhecimento das necessidades destes grupos, bem como da adequabilidade e adesão a uma intervenção digital para a promoção da saúde sexual. **A resposta ao questionário demora cerca de 30 minutos. Não estão previstos quaisquer pagamentos/remunerações relacionadas com a sua participação.** Serão garantidas justificações de ausência de trabalho sempre que necessite, no decurso da sua participação neste estudo.

Os dados recolhidos no âmbito desta investigação são **confidenciais** e serão **codificados**, isto é, toda a informação recolhida irá sofrer um processo de transformação, com recurso a um algoritmo/cifra, de modo a impossibilitar a sua leitura a todos exceto aqueles que possuam uma identificação particular/senha de acesso. Apenas um número restrito

de investigadores (os responsáveis pela análise dos dados e condução do estudo) terá acesso a esta senha de acesso. Todos os elementos da equipa de investigação com acesso aos dados pessoais e clínicos dos participantes estão obrigados ao sigilo profissional. Para além disso, todos os participantes receberão um código de participação no estudo, pelo que a sua identidade não será nunca utilizada para efeitos de gestão, tratamento ou publicação de dados. Os dados recolhidos durante esta investigação poderão ser publicados em relatórios, artigos científicos, conferências científicas ou teses académicas desde que nunca revelando informação que permita a identificação de participantes. Os resultados da presente investigação estarão também disponíveis para consulta pelos participantes no estudo no website do projeto: www.anathemaproject.eu

Os dados recolhidos serão arquivados e mantidos durante pelo menos 5 anos e até um máximo de 25 anos, servindo apenas para os fins da presente investigação. A chave utilizada para produzir o código que permite a identificação indireta dos participantes será eliminada 5 anos após o fim do estudo (que termina em Março de 2023), tal como mandatado pela Deliberação n.º 1704/2015 da Comissão Nacional de Protecção de Dados aplicável ao tratamento de dados pessoais efetuados no âmbito de Investigação Clínica.

Não estão previstos riscos resultantes da sua participação neste estudo, mas, na eventualidade de surgir algum tipo de incómodo, poderá contactar a equipa de investigação com o intuito de abordar e discutir questões relacionadas com a sua experiência. No caso de as suas preocupações não serem devidamente atendidas poderá apresentar uma reclamação junto das seguintes entidades:

Instituição	Entidade	Contactos
IPO-Porto	Gabinete de Apoio ao Doente	225084000
EuropaColon Portugal	Direção (Eng.º Vítor Neves)	225400441

Outras entidades que poderá contactar no exercício dos seus direitos à privacidade e protecção de dados surgem em baixo identificadas:

Instituição	Entidade	Contactos
IPO-Porto	Encarregado de Protecção de Dados	dpo@ipoporto.min-saude.pt
Comissão Nacional de Protecção de Dados	Comissão Nacional de Protecção de Dados	geral@cnpd.pt/213928400

Este estudo foi aprovado pela Comissão de Ética do IPO-Porto, de modo a garantir a protecção dos direitos, segurança e bem-estar de todas as pessoas participantes e garantir prova pública dessa protecção. Não se verifica qualquer tipo de conflito de interesses dos profissionais que promovem o estudo e participantes.

Depois de compreender o estudo e ter esclarecido todas as suas dúvidas junto da equipa de investigação de forma satisfatória, terá a liberdade de decidir participar ou não. Caso queira participar, ser-lhe-á solicitado que assine e date o formulário chamado "Consentimento Informado".

A sua participação no estudo é voluntária, podendo em qualquer altura cessá-la sem qualquer tipo de consequência.

Obrigada pela sua disponibilidade para ler este folheto e considerar participar no projeto ANATHEMA.

CONSENTIMENTO INFORMADO
ANATHEMA: TECHNOLOGY FOR AGELESS SEXUAL HEALTH
(ANATHEMA: TECNOLOGIA PARA A SAÚDE SEXUAL SEM IDADE)

Estudo de caracterização de atitudes e necessidades de suporte não satisfeitos no domínio da saúde sexual (Estudo 1 - Parte 1)

Considerando a "Declaração de Helsínquia", da Associação Médica Mundial

(Helsínquia 1964; Tóquio 1975; Hong Kong 1989; Somerset West 1996; Edimburgo 2000; Washington 2002; Tóquio 2004, Seoul, 2008 e Fortaleza 2013)

Eu, que abaixo assino (nome completo de doente maior de idade ou persona voluntária sã),

recebi o texto de *Informação a Participante* relativo ao procedimento que concordei em efetuar. Compreendi a explicação que me foi fornecida pela investigadora que assina este documento. Foi-me ainda dada a oportunidade de fazer perguntas que julguei necessárias, e de todas obtive resposta satisfatória.

Tomei conhecimento de que, de acordo com as recomendações da Declaração de Helsínquia, a informação ou explicação que me foi prestada versou os objetivos, os métodos, os benefícios previstos, os riscos potenciais e o eventual desconforto. Além disso, foi-me afirmado que tenho o direito de anular a todo o tempo a minha participação no estudo, sem que isso possa ter como efeito qualquer prejuízo na assistência que me é prestada.

Por isso, consinto que me sejam aplicados os questionários propostos pelo(a) investigador(a).

Assinatura de doente ou pessoa voluntária sã:

_____ Data: __/__/202__

Nome da Investigadora responsável: Ana Maria Vieira Rebelo Correia de Barros

Assinatura da Investigadora responsável: _____ Data: __/__/202__

Anulação do Consentimento Informado

Declaro que recebi a *Informação a Participante* relativa ao estudo/projeto de investigação em questão, que me foi proposto pela investigadora que assina este documento e **pretendo anular** o consentimento dado na data __/__/202__

Assinatura de doente ou pessoa voluntária sã:

_____ Data: __/__/202__

Assinatura da Investigadora responsável:

_____ Data: __/__/202__

Nota: Fornecimento obrigatório de cópia a participante

CONTACTOS DA INVESTIGADORA RESPONSÁVEL: Ana Correia de Barros (Fraunhofer Portugal AICOS)

T: (+351) 220430306

E-mail: ana.barros@fraunhofer.pt

Comissão de Ética Para a Saúde do Instituto Português de Oncologia do Porto Francisco Gentil E.P.E. (Doc. CES-IPOP 03)

Appendix B.



I - Código de Identificação _____

1. Sexo atribuído à nascença: Mulher Homem Outro _____

2. Género com o qual se identifica (identidade de género): Feminino Masculino Outro _____

3. Idade: _____

4. Situação profissional: Empregado/a Desempregado/a Reformado/a

5. Estado Civil: Solteiro/a Em união de facto/coabitação Casado/a Divorciado/a Viúvo/a

6. Habilitações Literárias:

1º ciclo (até ao 4º ano) 2º ciclo (até ao 6º ano) 3º ciclo (até ao 9º ano)

Secundário (até ao 12º ano) Licenciatura/Mestrado Integrado Doutoramento

7. Professa alguma religião?

Sim, sou crente e praticante Sim, sou crente mas não praticante Não sou crente

Outro _____

8. Em que medida se considera religioso/a?

Nada religioso/a	Um pouco religioso/a	Moderadamente religioso/a	Muito religioso/a	Extremamente religioso/a
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<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
--------------------------	--------------------------	--------------------------	--------------------------	--------------------------

9. Alguma vez lhe foi diagnosticado/a por algum/a médico/a ou psicólogo/a:

Depressão Doença Bipolar Ansiedade Perturbação Obsessivo-Compulsiva

Esquizofrenia (ou outra doença psicótica) Anorexia Bulimia Hiperatividade

Jogo Patológico Personalidade Borderline Dependência de Drogas Alcoolismo Nenhuma

Outro _____

10. Atualmente toma algum tipo de medicação?

Nenhuma Antidepressivos Ansiolíticos Antipsicóticos Estabilizadores de humor

Sedativos Anti hipertensores Outro _____

11.1. Como classifica o seu estado de saúde mental/psicológica?

Péssima	Má	Nem boa nem má	Boa	Excelente
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

11.2. Como classifica o seu estado de saúde física?

Péssima	Má	Nem boa nem má	Boa	Excelente
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

12. Por favor, indique o tipo de cancro com o qual foi diagnosticado/a:

Intestinal Retal Ambos (intestinal e retal)

12.1. Quando obteve o diagnóstico? (ex. Março de 2016): _____

12.2. Qual o estágio do cancro? Estadio I Estadio II Estadio III Estadio IV

12.3. Por favor, indique que tipo de tratamentos realizou ou que se encontra a realizar:

Cirurgia Imunoterapia Quimioterapia Radioterapia

Terapia combinada (ex. quimioterapia e radioterapia) Terapia dirigida (ex. anticorpos, moléculas ou inibidores)

12.4. Já terminou o seu último tratamento? Não Sim

12.4.1. Se sim, indique quando terminou o último tratamento (ex. Junho 2020): _____

12.5. Foi submetido/a cirurgia de colostomia? Não Sim

12.5.1. Se sim, encontra-se atualmente com o estoma intestinal?

Não, mas já tive Sim, com estoma temporário Sim, com estoma definitivo

13. Indique se alguma vez foi diagnosticado/a com alguma das patologias apresentadas a seguir:

13.1. Enfarte do miocárdio:

Indique se já teve um enfarte do miocárdio ou se apresenta alterações no ECG.

Não Sim

13.2. Insuficiência cardíaca congestiva:

Não Sim

13.3. Doença vascular periférica:

Indique se tem bypass para insuficiência arterial crónica, história de gangrena ou insuficiência arterial aguda.

Não Sim

13.4. Doença cerebrovascular:

Indique se já teve um acidente vascular cerebral (AVC).

- Não Sim

13.5. Demência:

Indique se apresenta défice cognitivo significativo.

- Não Sim

13.6. Doença pulmonar obstrutiva crónica (DPOC):

- Não Sim

13.7. Conjuntivite ou doença do conjuntivo:

- Não Sim

13.8. Úlcera péptica:

Indique se alguma vez teve qualquer histórico de tratamento para úlcera ou sangramento de úlcera.

- Não Sim

13.9. Insuficiência hepática (fígado):

Leve = hepatite crónica ou cirrose sem hipertensão portal

Moderada = cirrose e hipertensão portal, mas sem história de sangramento por varizes

Grave = cirrose e hipertensão portal com história de sangramento por varizes

- Não Sim, leve Sim, moderada a grave

13.10. Diabetes:

- Não Sim, sem complicações Sim, com complicações

13.11. Hemiplegia (paralisia de metade do corpo) ou paraplegia:

- Não Sim

13.12. Insuficiência renal crónica moderada a grave:

Grave = em diálise, estado pós-transplante renal

- Não Sim



13.13. Tumor: Não Sim

13.14. Leucemia: Não Sim

13.15. Linfoma: Não Sim

13.16. Síndrome de imunodeficiência adquirida (SIDA): Não Sim

14. Para cada uma das questões seguintes, coloque uma cruz na opção que melhor descreve a sua situação atual:

14.1. Tem queixas acerca da sua memória?

Não Sim, mas sem importância Sim, com alguma importância Sim, com problemas

14.2. Já lhe disseram que o(a) acham esquecido(a)?

Não Sim, por vezes Sim, frequentemente

14.3. Esquece com frequência nomes de pessoas da família ou de amigos?

Não Sim, mas sem importância Sim, com alguma importância Sim, com problemas

14.4. Esquece-se frequentemente onde põe as coisas?

Não Sim, mas sem importância Sim, com alguma importância Sim, com problemas

14.5. Costuma tomar apontamentos para não se esquecer das coisas?

Não Sim, por vezes Sim, frequentemente

14.6. A conversar costuma ter dificuldades em encontrar as palavras?

Não Sim

14.7. Já alguma vez se perdeu perto de sua casa?

Não Sim

14.8. Acha que anda a pensar mais devagar do que antes?

Não Sim Sim, com problemas

14.9. Sente que as suas ideias por vezes ficam confusas (baralhadas)?

Não Sim Sim, com problemas

14.10. Tem tido dificuldades em concentrar-se?

Não Sim Sim, com problemas

Os itens seguintes abordam aspetos da sua vida sexual. Pedimos-lhe que responda às seguintes questões com base na sua experiência pessoal. Por favor, considere as seguintes definições:

Atividade sexual pode incluir carícias, preliminares, masturbação e penetração vaginal/anal.

Relação sexual é definida como penetração (entrada) na vagina/ânus.

Estimulação sexual inclui situações como preliminares com um/a ou vários parceiro/a(s), auto-estimulação (masturbação) ou fantasias sexuais.

15. Como definiria a sua orientação ou preferência sexual?

- Exclusivamente heterossexual (somente atraído/a por pessoas de outro sexo)
- Predominantemente heterossexual (mas também me sinto atraído/a por pessoas do mesmo sexo)
- Bissexual (atraído/a por pessoas de ambos os sexos)
- Predominantemente homossexual (mas também me sinto atraído/a por pessoas do outro sexo)
- Exclusivamente homossexual (somente atraído/a por pessoas do mesmo sexo)

16. Situação relacional:

- Sem relação
- Relação íntima com vários/as parceiros/as
- Relação íntima com um/a parceiro/a

17. Há quanto tempo dura a relação com o/a seu/sua parceiro/a (por favor especifique em anos)?

18. Parceiros sexuais atuais:

- Nenhum/a parceiro/a sexual
- Sexo com um/a parceiro/a, no contexto da minha relação exclusiva com ele/a
- Sexo com vários/as parceiros/as, no contexto da minha relação com eles/as
- Sexo casual com um/a parceiro/a
- Sexo casual com vários/as parceiros/as
- Outro _____

19. Considerando os últimos 6 meses, por favor indique a frequência com que se envolveu nos seguintes comportamentos sexuais (em cada uma das alíneas, faça uma cruz na opção que melhor descreve a frequência dos seus comportamentos sexuais):

	Nunca	Poucas vezes	Algumas vezes	Muitas vezes	Quase sempre/sempre
1. Troca de carícias (como, por exemplo, beijos, abraços, andar de mãos dadas)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Fazer sexo oral	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Receber sexo oral	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Penetração vaginal	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Penetração anal	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Masturbação	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

20. Desde que recebeu o diagnóstico de cancro, alguma vez sentiu necessidade de falar com um profissional de saúde (por exemplo, médico, psicólogo) sobre problemas ao nível da intimidade sexual?

Sim Não

21. Ao longo deste período, alguma vez abordou o tema da sexualidade com os profissionais de saúde?

Sim Não

21.1. Em caso afirmativo, como foi para si essa experiência?

21.2. Em caso negativo, o que o/a impediu de falar sobre sexualidade com o profissional de saúde?

21.3. Com quais profissionais de saúde gostaria de abordar o tema da sexualidade?

21.4. Em que fase do curso da doença/tratamento seria importante para si abordar o tema?

22. As questões seguintes são sobre as suas atitudes relativamente ao sexo. Por favor, marque uma cruz (x) no quadrado que corresponde à resposta que melhor descreve a sua reação a cada uma das seguintes afirmações.

	Concordo Muito	Concordo um pouco	Não concordo nem discordo	Discordo um pouco	Discordo Muito
	1	2	3	4	5
1. É errado uma pessoa casada ter relações sexuais com alguém que não é o/a seu/sua esposo/a.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. É errado ter sexo ocasional (<i>one night stand</i>).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Relações sexuais satisfatórias são essenciais para manter uma relação de longa duração.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. É aceitável ter relações sexuais sem amor.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Hoje em dia as pessoas sentem muita pressão para ter sexo.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Hoje em dia há demasiado sexo na comunicação social.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. A capacidade para ter sexo diminui quando a pessoa envelhece.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. As mudanças sexuais que ocorrem com a idade não são importantes para os idosos.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Ser sexualmente ativo é benéfico física e psicologicamente para os idosos.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

23. Por favor, indique em que medida concorda com as seguintes afirmações. Registe apenas uma resposta em cada linha.

23.1. No último ano, sentiu alguma das seguintes dificuldades sexuais? durante um período de 3 meses ou mais?

23.2. Se sim, em que medida esta dificuldade foi perturbadora para si?

			Nada perturbadora	Levemente perturbadora	Moderadamente perturbadora	Severamente perturbadora
	Sim	Não				
1. Falta de interesse sexual.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Falta de prazer durante o sexo.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Sentiu-se ansioso/a durante o sexo.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Sentiu dor física em consequência do sexo.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Não sentiu excitação ou ereção durante o sexo.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Não chegou ao orgasmo ou demorou muito tempo a atingi-lo (apesar de sentir excitação).	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Chegou ao orgasmo mais depressa do que desejava.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Se é mulher: secura vaginal desconfortável	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Se é homem: dificuldade em conseguir ou manter a ereção	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

23.3. Pensando na sua vida sexual no último ano, de um modo geral, qual o seu grau de satisfação com a sua vida sexual? (Indique uma resposta apenas)

Completamente insatisfeito/a	Insatisfeito/a	Nem satisfeito/a nem insatisfeito/a	Satisfeito/a	Completamente satisfeito/a
1	2	3	4	5
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

23.4. Quão satisfeito/a está com o nível atual de atividades sexuais na sua vida, de forma geral?

Completamente insatisfeito/a	Insatisfeito/a	Nem satisfeito/a nem insatisfeito/a	Satisfeito/a	Completamente satisfeito/a
1	2	3	4	5
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

23.5. Eu e o/a meu/minha parceiro/a beijamo-nos e acariciamo-nos (Indique uma resposta apenas, a que mais se adequa):

- Raramente
- Frequentemente

23.6. Nas últimas 4 semanas, com que frequência o/a seu/sua parceiro/a lhe tocou e acariciou? (Indique uma resposta apenas, a que mais se adequa)

- Nunca, 1 ou 2 vezes por semana
- 2-3 vezes por semana, quase diariamente ou diariamente

23.7. Por favor indique em que medida concorda com as seguintes afirmações, pensando no/a seu/sua esposo/a ou parceiro/a regular (Registe uma resposta em cada linha)

	Concordo Completamente	Concordo	Não concordo nem discordo	Discordo	Discordo completamente
	1	2	3	4	5
• O/a meu/minha parceiro/a e eu partilhamos o mesmo nível de interesse em ter relações sexuais	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• O/a meu/minha parceiro/a e eu partilhamos os mesmos gostos no sexo	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Sinto-me emocionalmente próximo/a do/a meu/minha parceiro/a quando fazemos sexo juntos	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

24. Gostaríamos de saber mais sobre as suas preocupações e necessidades de informações relacionadas à saúde sexual após o tratamento para o cancro. Não existem respostas certas ou erradas, sendo que pessoas diferentes podem ter sentimentos também eles muito diferentes sobre a sua situação. Apenas indique a resposta que melhor descreva as suas preocupações e a sua necessidade de informações sobre saúde sexual após o cancro. As suas respostas são anónimas.

Se existirem itens que não se aplicam ao seu caso, selecione a opção NA (não se aplica).

Quando pensa sobre a sua saúde sexual atualmente:

	Nada preocupado/a					Muito preocupado/a	Gostaria de ter mais informação	
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	NA <input type="checkbox"/>	Sim <input type="checkbox"/>	Não <input type="checkbox"/>
1. Está preocupado/a com as mudanças físicas decorrentes do cancro e do seu tratamento?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	NA <input type="checkbox"/>	Sim <input type="checkbox"/>	Não <input type="checkbox"/>
2. Está preocupado/a com as mudanças na forma como o seu corpo trabalha sexualmente?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	NA <input type="checkbox"/>	Sim <input type="checkbox"/>	Não <input type="checkbox"/>
3. Está preocupado/a com a capacidade para ter filhos/as?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	NA <input type="checkbox"/>	Sim <input type="checkbox"/>	Não <input type="checkbox"/>
4. Está preocupado/a em estar fisicamente atraente depois do cancro?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	NA <input type="checkbox"/>	Sim <input type="checkbox"/>	Não <input type="checkbox"/>
5. Está preocupado/a em estar capaz de satisfazer sexualmente o/a seu/sua parceiro/a?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	NA <input type="checkbox"/>	Sim <input type="checkbox"/>	Não <input type="checkbox"/>
6. Está preocupado/a em iniciar novas relações fisicamente íntimas?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	NA <input type="checkbox"/>	Sim <input type="checkbox"/>	Não <input type="checkbox"/>
7. Está preocupado/a com a sua capacidade para ter prazer sexual?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	NA <input type="checkbox"/>	Sim <input type="checkbox"/>	Não <input type="checkbox"/>
8. Está preocupado/a em sentir dor nas relações sexuais com penetração?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	NA <input type="checkbox"/>	Sim <input type="checkbox"/>	Não <input type="checkbox"/>
9. Está preocupado/a com as mudanças na forma como experienciar orgasmos?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	NA <input type="checkbox"/>	Sim <input type="checkbox"/>	Não <input type="checkbox"/>
10. Está preocupado/a em perder a sua confiança enquanto parceiro/a sexual?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	NA <input type="checkbox"/>	Sim <input type="checkbox"/>	Não <input type="checkbox"/>
11. Está preocupado/a em lidar com os sentimentos sobre as mudanças na sua vida sexual?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	NA <input type="checkbox"/>	Sim <input type="checkbox"/>	Não <input type="checkbox"/>
12. Está preocupado/a sobre como as suas relações sexuais em geral serão afetadas?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	NA <input type="checkbox"/>	Sim <input type="checkbox"/>	Não <input type="checkbox"/>

Tem alguma outra preocupação ou pergunta acerca da sua intimidade ou saúde sexual que gostasse de abordar?

Na sua opinião, do que é que necessitaria para ter uma vida sexual saudável e feliz/gratificante?

25. Por vezes, os/as pacientes com diagnóstico de cancro relatam mudanças ao nível da sua saúde sexual após a realização dos tratamentos.

Responda, por favor, a todas as afirmações abaixo, selecionando a opção que melhor se aplica a si.

Não há respostas “certas” ou “erradas”. As informações que irá fornecer permanecerão estritamente confidenciais. Por favor, tente responder a tantas perguntas quanto possível.

Durante as últimas 4 semanas:	Não, de forma nenhuma	Um pouco	Bastante	Muitíssimo	NA
1. Quão importante é para si uma vida sexual ativa?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Teve diminuição da libido?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Esteve satisfeito/a com o seu nível de desejo sexual?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. A atividade sexual foi agradável para si?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Esteve satisfeito/a com a sua capacidade para ter orgasmo?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Esteve preocupado/a em estar incontinente (urina/fezes)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. A fadiga ou falta de energia afetou a sua vida sexual?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. O tratamento afetou a atividade sexual?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Sentiu dor durante ou depois da atividade sexual?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Esteve preocupado/a que o sexo fosse doloroso?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Comunicou com profissionais de saúde sobre questões sexuais?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Esteve satisfeito/a com a comunicação sobre questões sexuais com o/a seu/sua parceiro/a?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Esteve preocupado/a que o/a seu/sua parceiro lhe causasse dor durante o contacto sexual?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Esteve satisfeito/a com o seu nível de intimidade?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Sentiu-se inseguro/a em relação à sua capacidade para satisfazer o/a seu/sua parceiro/a?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. Foi sexualmente ativo/a?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Em que medida sentiu prazer sexual?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. Esteve satisfeito/a com a sua vida sexual?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Apenas para os homens:					
19. Esteve confiante em obter ou manter a ereção quando teve relações sexuais?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Sentiu-se menos masculino como resultado da sua doença ou tratamento?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Apenas para as mulheres:					
21. Teve secreta vaginal durante a atividade sexual?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. Sentiu-se menos feminina como resultado da sua doença ou tratamento?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

26. Para cada uma das seguintes questões, selecione a opção que melhor se aplica a si.

26.1. Tem acesso à internet? Sim Não

26.2. Qual o tipo de conexão que usa habitualmente para ter acesso à internet?

- Não uso internet Conexão pessoal (conexão doméstica/dados móveis)
- Conexão privada (conexão da entidade empregadora/associações) Conexões públicas (ex. em livrarias, cafés, etc.)

26.3. Com que frequência utiliza internet?

- Não uso internet Uma vez por semana ou menos 2-3 vezes por semana Diariamente

26.4. Que tipo de dispositivo habitualmente usa para ter acesso à internet?

- Não uso internet Computador pessoal Dispositivos móveis (por exemplo, telemóvel, tablet)
- Computador ou dispositivos móveis de terceiros

26.5. Alguma vez utilizou internet para pesquisar sobre tópicos relacionados com a saúde?

- Sim Não

26.6. Se sim, fá-lo habitualmente sozinho/a ou tem o apoio de outras pessoas?

- Faço-o sozinho/a Peço apoio a outras pessoas (ex., família, amigos/as, cuidadores, etc.)
- Dispositivos móveis (ex. telemóvel, tablet) Computador ou dispositivos móveis de terceiros

26.7. Se sim, quais tópicos tem por costume pesquisar ou pesquisou no passado?

- Estilos de vida saudáveis
- Mudanças físicas e psicológicas associadas ao envelhecimento
- Informações sobre doenças específicas
- Informações relacionadas a condições clínicas com quais fui diagnosticado/a (por exemplo, sinais e sintomas, exames de diagnósticos, tratamentos)
- Condições de saúde mental
- Saúde sexual
- Mudanças ao nível da sexualidade associadas ao envelhecimento
- Dificuldades sexuais
- Condições de saúde mental
- Cuidados de saúde sexual/especialistas em saúde sexual
- Outros _____

26.8. Imagine que uma aplicação (por exemplo, para telemóvel, tablets) está a ser desenvolvida na qual as pessoas poderão encontrar informações sobre saúde sexual no cancro intestinal e colocar questões de forma anónima e discreta a um profissional. O que pensa sobre esta ideia?

26.9. Na sua opinião, em que medida isso seria interessante para pessoas com doença oncológica?

Nada interessante	Um pouco interessante	Razoavelmente interessante	Muito interessante	Extremamente interessante
1	2	3	4	5
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

26.9.1. Tendo em conta a sua resposta anterior, poderia explicar brevemente porquê?

26.10. Em que medida estaria interessado/a em utilizar uma aplicação anónima sobre saúde sexual?

Nada interessado/a	Um pouco interessado/a	Razoavelmente interessado/a	Muito interessado/a	Extremamente interessado/a
1	2	3	4	5
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

26.10.1. Se respondeu “nada interessado/a”, poderia explicar o porquê de não estar interessado/a em utilizar este tipo de aplicação?

26.11. Quais tópicos gostaria de ver abordados na aplicação?

- Estilos de vida saudáveis Saúde mental Saúde sexual e envelhecimento
 Saúde sexual e doenças (por exemplo, cancro ou AVC) Problemas na intimidade e sexualidade
 Problemas relacionais Outros:

TERMINOU O SEU QUESTIONÁRIO!

MUITO OBRIGADA PELA SUA COLABORAÇÃO NESTE ESTUDO.

Appendix C.

Table 7.

Content analysis of the participants' answers to the open-ended questions of the Sexual and Reproductive Health questionnaire (N=52)

If yes, how was this experience for you?					
Themes	Sub-themes	Women	Men	All	Quotations
Feedback	Positive	2 (15.4)	6 (15.4)	8 (15.4)	"I felt understood and enlightened." "It was a very good experience." "It was satisfactory. I talked to the family doctor two or three months after the surgery."
	Negative	-	2 (5.1)	2 (3.8)	"It was an unpleasant surprise, but life goes on." "I went to a urology consultation (...), but I didn't get specific information in the face of the issues I presented."
	Not evaluated	4 (30.8)	5 (12.8)	9 (17.3)	-
Initiative	Patient	4 (30.8)	6 (15.4)	10 (19.2)	"I talked to my psychologist about the difficulties I was having, because I lost all sexual appetite." "I broached the subject with a gynecologist doctor due to vaginal dryness issues." "After I had surgery, I talked to a doctor..."
	Professional	1 (7.7)	3 (7.7)	4 (7.7)	"Before I had surgery I was questioned regarding sexual activity, but I was not sexually active." "I was asked if I needed counseling, but I said no." "I didn't take the initiative, but I was talked to about sexual health early on in my illness."
Motive/context	Not mentioned	1 (7.7)	4 (10.3)	5 (9.6)	-
	Sexual difficulties/problems	3 (23.1)	8 (20.5)	11 (21.2)	"I was stitched in the anus and vagina area. I could not have intercourse... They informed me that vaginal penetration would not be possible." "I spoke out because I had erection difficulties and ejaculated little.... I was told there was no solution. It was the first and only time I broached the subject." "A treatment based on injections was suggested to me. Although I felt burned, the injections had an effect. I came close to ejaculation, but eventually gave up [the treatment]."
	Questions about sexuality	2 (15.4)	4 (10.3)	6 (11.5)	" I asked my family doctor some questions after (...) the surgery." "...I talked to a doctor to find out if I could continue to have an active sex life and if I could have anal sex." "A health professional approached the topic with the goal of knowing if everything was okay."
	Not mentioned	1 (7.7)	1 (2.6)	2 (3.8)	-

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Table 7. (Continued)

If not, what prevented you from discussing sexuality with the health professional?				
Themes	Women	Men	All	Quotations
No need	7 (53.8)	19 (48.7)	26 (50.0)	"I didn't feel the need or concern." "I didn't feel the need, because I don't have [sexual] difficulties." "I already had no sexual activity before the disease." "I don't really value [sexuality]."
Feeling afraid or ashamed	-	2 (5.1)	2 (3.8)	"I didn't address [the topic] out of shame/fear."
Feeling that it is not worth it	-	2 (5.1)	2 (3.8)	"I don't think it's worth it because they [health professionals] can't do anything." "I think the difficulties I experience [at the erection level] are unresolvable, so I've never broached the subject."
Other	-	3 (7.7)	3 (5.8)	"Considering my age and illness.... Besides, I don't want to take medication either." "As a matter of fact, I'm going to address it in this consultation I'm having next."
Not mentioned	-	2 (5.1)	2 (3.8)	
With which health professionals would you like to discuss sexuality?				
Themes	Women	Men	All	Quotations
No preference	7 (53.8)	20 (51.3)	27 (51.9)	"No preference, just a person who would advise me." "Any doctor, I have no preference."
Family or General Practitioner	2 (15.4)	7 (17.9)	9 (17.3)	"Maybe with my family doctor." "I would address it with a general practitioner."
IPO Professionals	-	4 (10.3)	4 (7.7)	"I would talk to the doctor at the IPO."
Psychologist	1 (7.7)	1 (2.6)	2 (3.8)	"With my psychologist..."
Other	-	1 (2.6)	1 (1.9)	"With a professional of the same gender as me [male]."
Not mentioned	3 (23.1)	6 (15.4)	9 (17.3)	"It doesn't make sense to me to talk, so I don't know." "I have no interest [in addressing the topic]." "I don't feel the need, so I don't comment [on the subject]." "I wouldn't like to talk to anyone about this."

(Continued on next page)

Table 7. (Continued)

At what stage in the course of your illness/treatment would it be important for you to address the topic?				
Themes	Women	Men	All	Quotations
At the beginning	6 (46.2)	14 (35.9)	20 (38.5)	"I didn't know that I wouldn't be able to have [sexual] relations. In this way, I think it would be important to address the topic at the very beginning..." "At the beginning. The earlier it is, the better! It's important to ask questions...so that the effects [of treatments] and changes are not a shock.... Beyond that, there should be follow-up..." "In the beginning, to be aware of the possible [sexual] changes...It is also important to inform the partner, so that there is more understanding... and better adaptation".
During Treatment	-	3 (7.7)	3 (5.8)	"During the treatments." "In the treatment phase."
After Treatment	2 (15.4)	4 (10.3)	6 (11.5)	"Right after the surgery, like the surgeon did with me when he operated on me for colorectal cancer...he warned me that my sexuality would diminish because the vaginal nerve had been cut." "...Especially after the operation."
In all stages	1 (7.7)	4 (10.3)	5 (9.6)	"In all phases of disease and treatment." "Throughout the whole course [of the disease]." "At the beginning, during, and after."
No preference	-	3 (7.7)	3 (5.8)	"It's always important [to address the topic] ...I have no preference." "I have no preference...in my case, they [the health professionals] didn't address the topic at the beginning."
Not mentioned	4 (30.8)	11 (28.2)	15 (28.8)	"It doesn't make sense to me to address [the topic]." "I don't think it is important to address the topic." "For me it was not necessary, so I don't know." "I think it is up to the person to determine the need to speak." "I don't think it's worth it."

Appendix D.

Table 10.

Content analysis of the participants' answers to the open-ended questions of the InSYNC questionnaire (n=52)

Do you have any other concerns or questions about your intimacy or sexual health that you would like to address?		Percentage of participants with specific concerns or questions about sexuality			Quotations
Major Themes		Women	Men	All	
No worries or questions		10 (76.9)	30 (76.9)	40 (76.9)	"I don't want to worry. If I were younger... But when we talk [among friends] I notice that even younger people feel these difficulties.... that's life."
Missing		1 (7.7)	3 (7.7)	4 (7.7)	
Major Themes	Sub-themes	Women	Men	All	Quotations
Concerns or questions	Related to sexual difficulties and problems.	1 (7.7)	5 (12.8)	6 (11.5)	"I would like to know more because I have trouble getting a full erection." "I worry about what I already mentioned, lack of interest, difficulties in ejaculation and erection."
	Related to sexual difficulties experienced by the partner.	-	1 (2.6)	1 (1.9)	"I am concerned about my wife who has breast cancer.... She has trouble getting pleasure and reaching orgasm.... The [ostomy] bag bothers her [during sexual activity] because it scrapes on her."
	Related to the ability to satisfy the partner.	1 (7.7)	1 (2.6)	2 (3.8)	"Two months ago, I started to feel pain during vaginal penetration.... In the last three weeks we stopped doing [vaginal penetration] ...I feel worried about satisfying my husband." "I worry about the difficulty in getting an erection and satisfying [sexually] my wife.... She tells me to take it easy."
	Related to communication with the partner.	-	1 (2.6)	1 (1.9)	"Besides the problems with ejaculation, I worry about the lack of communication with my wife."
	Related to sexual health information needs.	1 (7.7)	1 (2.6)	2 (3.8)	"Since I had my uterus and ovaries removed, I worry about my intimate hygiene...it may influence sexual activity." "I would like to get information about the treatments available [for sexual problems] so I can have a sex life again."

(Continued on next page)

Table 10. (Continued)

In your opinion, what would you need to have a healthy and happy/gratifying sex life?	Percentage of participants with specific needs regarding sex life			Quotations
	Women	Men	All	
Major Themes				
No needs	4 (30.8)	17 (43.6)	21 (40.4)	"Nothing. I just need the sex life I've been experiencing." "I already have everything to have a fulfilling sex life." "Nothing...The [sexual] changes are natural... I have adapted... It's a natural process of losing capacity." "For me sex life is not important."
Partner-related needs	4 (30.8)	6 (15.4)	10 (19.2)	"Having a closer relationship with my husband." "I would need my wife to share the same level of sexual interest as I do." "Help for my wife [to treat her sexual difficulties]." "I would need my husband not to be sick.... He had a stroke at 42." "If my husband was healthy.... right now, he is having prostate problems and is going to have surgery." "I would need to be married and in love." "Having another partner." "...improving communication with my wife."
Health-related needs	4 (30.8)	5 (12.8)	9 (17.3)	"I would like to get well physically and have the stoma removed." "I would need my health condition to be stable." "Having physical health." "Me getting back to being what I was, meaning healthy." "To be healthy... To feel no pain."
Sexual health-related needs	-	8 (20.5)	8 (15.4)	"Have sexual interest." "Regain the ability to have an erection." "Solve these [sexual] problems, namely with erection." "Improve erection and ejaculation..." "Regain sexual functioning." "Have more sexual activity." "I would need my [sexual] difficulties to be addressed."
Age-related needs	-	2 (5.1)	2 (3.8)	"I would need to be younger."
Other	1 (7.7)	-	1 (1.9)	"Having more leisure time.... Working less hours."