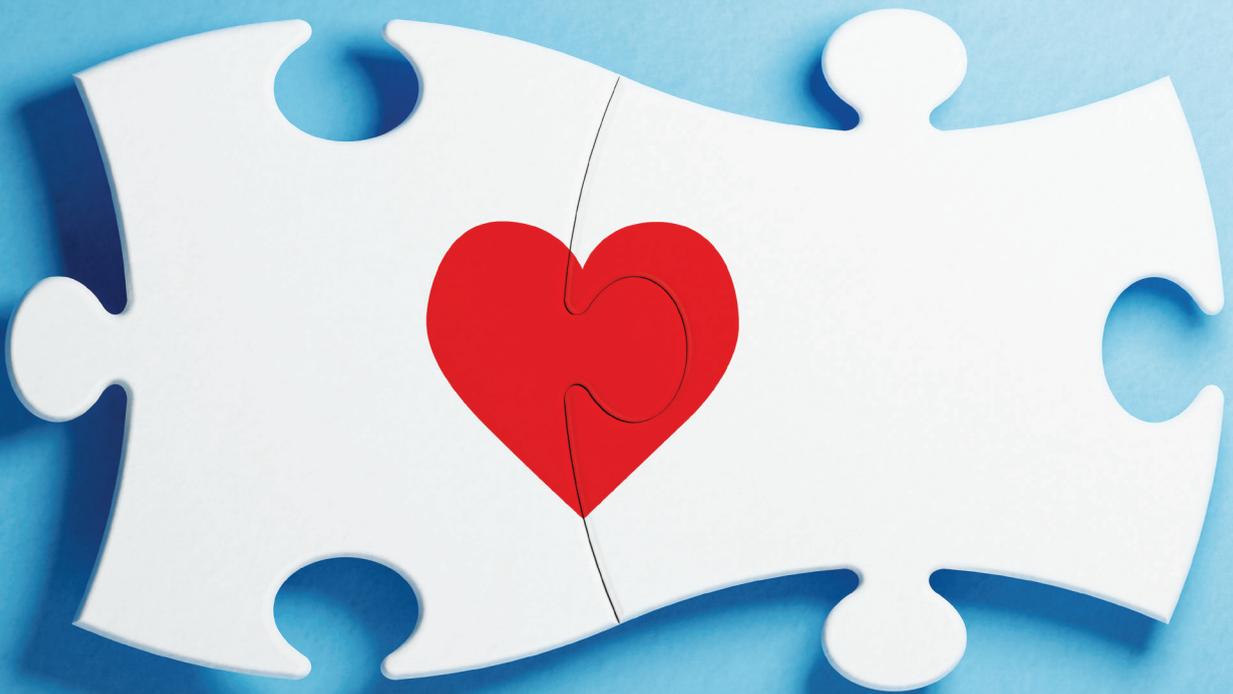


All of Me



Bridging the sexual health communication gap in cancer care

Cancer and its treatment impact patients in many ways, beginning before a diagnosis and lasting long through survivorship. One, often overlooked, side effect of cancer—whether it be from surgical, medical, or radiation treatment—relates to patients’ sexual health. Cancer can impact a person’s physical anatomy, hormonal status, emotional and psychosocial well-being, and intimate relationships. Addressing these concerns is a field of medicine called oncosexuality, including minimizing the negative effects of anti-cancer treatment on patients’ sexual function and pleasure and assisting patients with sexual impairments that result from their treatment. Further, patient-provider discussions on cancer’s sexual health impact(s) are critical and must happen before treatment plans are finalized. The American Society of Clinical Oncology recommends having these conversations and prescribing related treatments, and the National Comprehensive Cancer Network includes sexual health-care in its survivorship guidelines.^{1,2} Despite this national guidance, the sexual health communication gap between providers and patients persists.

Clinical Rational

Veronika Kolder, MD, is an associate professor emeritus and former medical director of the Menopause and Sexual Health Clinic, Department of Obstetrics and Gynecology at the University of Iowa Hospitals and Clinics. She explains that in addition to the domains of sexual health impacts listed above, a web of interrelated changes can overwhelm patients. Figure 1, page 35, illustrates the various impacts that cancer and its treatment can have on an individual’s sexual health.

It is critical that patients with cancer be educated early about cancer’s relation to their sexual health and referred appropriately to address any concerns that come up throughout their treatment.

Due to anatomical changes from surgery to treat cancer, certain parts of the body may need to be removed to improve a patient’s chance of cure or remission. This is true for many types of cancer, such as uterine or bladder cancers, among others. Specific to ovarian cancer, pre-menopausal patients whose ovaries are removed as a part of their cancer treatment will experience induced menopause post-operation. These patients will have dramatic hormonal changes that they may not be prepared to address. Hormones are important for bone, cardiovascular, and sexual health, but the surgical removal of the ovaries in females or the prostate in males for treating cancer may be necessary. “It would be naive of us to believe that cancer treatments would not affect sexual health,” explains Amy Pearlman, MD, a urologist, clinical assistant professor, and director of the Men’s Health Program at the University of Iowa Hospitals and Clinics. “It has some to do with surgical technique, but it also has to do with anatomy and the anatomy in the pelvis that’s responsible for sexual health.”



Dr. Veronika Kolder (left) and Erin Sullivan-Wagner (right).

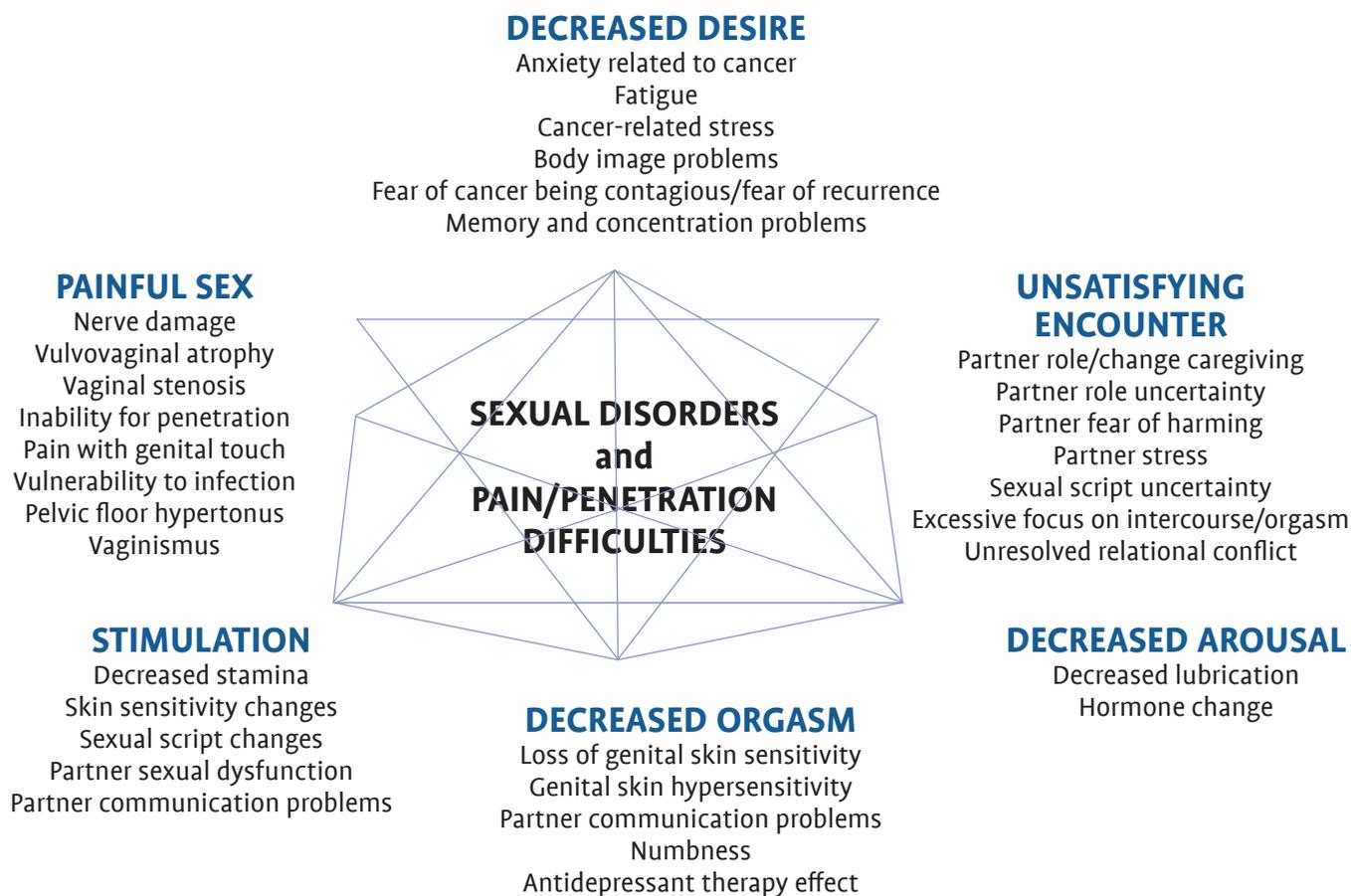
Additionally, chemotherapy, radiation, and hormone therapy often have a direct impact on patients' sexual health. Dr. Kolder explains that radiation therapy as a treatment for cancer affects the tissues in the body that are being targeted. "Unfortunately, when the vagina is irradiated, it becomes raw, more scarred, and smaller," she says. "In combination with reaching menopause, either naturally or through radiation or chemotherapy, it is a setup for significant pain problems related to penetration." The same goes for men. If radiation treatment targets any area in the pelvis, patients may have sexual health concerns.

On the other hand, chemotherapy can affect brain signaling and make patients feel tired. "It's a normal response to not want to have sex if you're exhausted from work or treatment," explains Dr. Pearlman. "You have this sort of compounded effect. None of the therapies that we use to treat cancer are going to improve sexual function, and a lot of patients are getting one or multiple of these therapies." Finally, hormone therapy—especially con-

sidering its use for prostate cancer treatment—decreases testosterone levels, which is an important hormone for optimal sexual health in males.

Furthermore, any patient in active treatment or survivorship may experience emotional and relationship effects because of their cancer. If a patient with cancer was previously working full time and solely providing for their family, their partner may then be required to financially support the family and take on the caregiver role during active treatment. Patients with sexual partners may also have their connection(s) tested because of cancer. "The unspoken look that one partner gives another, a little hug and squeeze, or bringing coffee in the morning, those little messages and the touch that are your love languages with your partner get eroded and have to be rethought and reinvented after things change sexually," says Erin Sullivan-Wagner, a survivor of anal cancer. Patients may experience worsening body image, self-esteem, and stamina, which can further impact relationships. Therefore,

Figure 1. The Web of Sexual Problems for Patients with Cancer*



*Image recreated with permission from Sarah Shaffer, DO, obstetrician gynecologist and clinical assistant professor, Obstetrics and Gynecology at the University of Iowa Hospitals and Clinics.

it is critical that patients with cancer be educated early about cancer’s relation to their sexual health and referred appropriately to address any concerns that come up throughout their treatment.

Enter Erin

Sullivan-Wagner is a wife, mother, and cancer survivor. She was diagnosed with anal cancer in 2008 and was treated with chemotherapy and radiation therapy at the University of Iowa Hospitals and Clinics. “I was told I wouldn’t have sexual health side effects as a result of my radiation therapy because I was young, healthy, and sexually active,” she says.

Sullivan-Wagner’s treatment was successful, and she was cancer free in just two months. Like millions of patients who survive their cancer diagnosis, she now lives with the sexual dysfunction caused by her cancer and treatment. “My husband was extremely supportive throughout treatment and accompanied me at every

appointment,” she explains. “At the first follow-up appointment six weeks after my last radiation treatment, we were given the green light to resume sexual activity, specifically intercourse. We were told to go slow and use plenty of lubricant. We did, but the pain was immediate and severe. It felt like he was tearing through my skin. We tried repeatedly over the next month and had the same results: every attempt at penetration ended with me unable to stand the pain.”

Sullivan-Wagner reported her concerns to her oncologist at her next follow-up appointment and was referred to the cancer program’s radiation team for evaluation, who then referred her to a gynecologist. By this time, Sullivan-Wagner was six months into survivorship. In August 2008, a pelvic exam revealed a web of scar tissue inside her vagina, and she was diagnosed with vaginal stenosis. After minor surgery in September to open her vagina, Sullivan-Wagner was told to “use it or lose it.” For the first time since she was diagnosed, Sullivan-Wagner was given

Despite national guidance, healthcare providers are not educating patients on the relationship between sexual health and cancer, nor are patients being appropriately referred to allied professionals when necessary.

dilation tools, vaginal estrogen, skin protectants, and burn cream to treat her sexual health side effects. Despite months of treatment adherence, Sullivan-Wagner states, “All attempts at intercourse ended the same way: severe pain almost immediately and sometimes blood on the bed sheets.” Pelvic rehabilitation therapy for the vagina’s muscles, lidocaine to deaden the pain, and anti-anxiety prescriptions did not resolve the problem. Sullivan-Wagner’s search for answers lasted years with no success.

Throughout follow-up and additional treatments, Sullivan-Wagner’s husband became disappointed, frustrated, and concerned, thinking that he was hurting his wife at every attempt of intercourse. Because Sullivan-Wagner’s oncologist told her not to expect sexual health problems from her anti-cancer treatment, she and her husband were surprised when they immediately had issues and every suggested treatment failed. When she was prescribed anti-anxiety medication, it was then that her husband wondered whether her care team thought the problem was all in her head. “I see now that my husband and I needed counseling, but I didn’t realize it at the time,” she says. “Instead, we gradually spent less time doing activities that used to lead to sex and eventually stopped going on vacations and spending time alone together.” She notes that she and her husband continued the routines of their daily lives, such as attending their children’s activities, eating dinner together, and sleeping in the same bed. But both noticed that they were no longer connected in the same way they had been before her cancer. “Gradually, my obsession with finding a solution to the sexual pain gave way to fatigue and defeat,” explains Sullivan-Wagner. “My husband started questioning my desire and love for him. We grew apart.” As shown by Sullivan-Wagner, couples dealing with cancer often have their sexual scripts tested or diminished to a point that they need to be reworked or rewritten. These sexual scripts can be an unspoken look that one partner gives another, a kiss or squeeze, or anything that causes a non-sexual situation to become sexual. These small messages are a part of a couple’s love language and can get eroded throughout the course of cancer treatment. As such, Sullivan-Wagner’s story is no exception. In 2016, she and her husband separated and spent three and a half years living apart.

Though it took eight years (2008 to 2016), Sullivan-Wagner eventually received closure. “I remember the appointment where the specialist held my hand and told me in a soft, consoling voice

that too much time had passed between the end of my cancer treatment and the evaluation and treatment to address my radiation and menopausal damage,” she recalls. “They said, ‘You waited too long. I am sorry.’” An examination showed that it was not the vaginal stenosis that was the main problem; instead, it was tissue scarring at the hymenal ring. The dilator size Sullivan-Wagner could tolerate did not stretch the opening of her vagina enough to comfortably accommodate penetration, as her skin was repeatedly torn open during intercourse. “The elasticity at my vaginal entrance was gone and no amount of estrogen was going to help me,” she says. “My problem was irreversible. I needed to grieve and finally had been given permission to move on.”

The Problem

As a life coach for cancer survivors, Sullivan-Wagner learned that most of her clients had sexual health concerns after their cancer treatment that were not being addressed. “It wasn’t that they were being told something wrong,” says Sullivan-Wagner. “They just weren’t being told anything at all and were missing the opportunity to prevent, address, and resolve their issues.” Both Sullivan-Wagner and Dr. Kolder agree that sexual health is a quality-of-life concern. Furthermore, both state that these conversations should be brought up during patient-provider discussions on the side effects of anti-cancer treatment (e.g., bladder or bowel symptoms) or impacts on patients’ quality of life. These conversations are necessary to empower those impacted by cancer to maintain agency over their sexual health, which is essential for health, quality of life, and personhood, especially when losses in function and pleasure are likely.³

Though Sullivan-Wagner brought her sexual health concerns to her providers’ attention, she notes that often patients who are in survivorship and have sexual health concerns are reluctant to go back to their care team with questions. “They may be invested in being the ‘good patient.’ The one who does well, is grateful, and does not complain,” she explains. “Patients often are not sexually active during active radiation and chemotherapy and are unaware that they have issues until they are in survivorship, and that may be too late. Or they may not know where to start and lack the medical vocabulary to describe their experiences.” Healthcare providers cannot assume that patients will bring up their sexual health concerns at their medical appointments. Therefore, these conversations need to be normalized for patients and providers alike, so expectations can be set and patients know where to turn to for help.

Dr. Kolder also shares that medical communication has only become a formal part of medical education in recent decades. When she was in medical school, a single one-hour lecture addressed sexual history, sexual orientation, and gender expression. Many programs today, such as the Carver College of Medicine at the University of Iowa, require small group workshops with facilitators and simulated patient actors to allow students to practice having these difficult conversations with patients. “Communicating about sex and breaking bad news are two of the most challenging conversations medical professionals will



All of Me presenters with conference attendees in Mason City, Iowa.

have with patients,” she says. “In the oncology setting, specifically when providing anticipatory guidance about the sexual health impacts of cancer, medical professionals need to be comfortable doing both.”

A New Idea

In 2010, Sullivan-Wagner immersed herself in patient advocacy. “I got certified as a life coach and founded a patient advocacy business: After Cancer, Solutions for Sexual Health,” she explains. “I coached patients, joined survivor groups, and presented my story at conferences.” Looking to make a difference in patients’ lives on a larger scale, Sullivan-Wagner joined the Iowa Cancer Consortium and co-chaired its Quality of Life Implementation Group. She then applied for its grant funding to develop sexual health educational materials for healthcare professionals. After being turned down, Sullivan-Wagner continued to look at how she could help others just like her. She knew she needed collab-

orators and, in 2014, approached Dr. Kolder, who immediately understood and related to Sullivan-Wagner’s passion for addressing the sexual health communication gap in cancer care. In 2016, the two collaborated with their supporters on writing their first successful grant application to the Iowa Cancer Consortium. This grant was the first of five approved by the consortium for the *All of Me Iowa* project—a project that bridges the communication gap between healthcare providers and patients on the intersection of sexual health and cancer via education, resources, workshops, and conference presentations.

As Dr. Kolder brought expertise on the female side of sexual health, both women knew they needed to also consider and address men’s health. They invited Bradley Erickson, MD, a urologist at the University of Iowa Hospitals and Clinics who specializes in the surgical treatment of erectile dysfunction, to join them in developing a presentation to bring awareness to the oncology nursing community. Due to competing priorities, Dr.

Erickson eventually took a step back from the project and introduced the *All of Me* team to Dr. Pearlman, who is now a key collaborator and representative of men's health.

All of Me

Sullivan-Wagner and Dr. Kolder co-founded *All of Me* in reaction to Sullivan-Wagner's cancer experience. And her story corroborates many persisting truths in oncology, including:

- Patient access to oncologists is limited, especially in rural states like Iowa.⁴
- Increasing access to sexual healthcare for people impacted by cancer has been slow, particularly for women.^{5,6}
- Oncology nurses and advanced practice providers are increasingly providing survivorship care that includes sexual healthcare.⁷
- Long-term survivors of cancer want information about sexual health.⁸
- Sex therapists and treatments may be under-recommended.⁹
- Education improves providers' perceptions of having enough knowledge and training to provide sexual healthcare.¹⁰

Despite national guidance, healthcare providers are not educating patients on the relationship between sexual health and cancer, nor are patients being appropriately referred to allied professionals (e.g., mental health and sex therapists, urologists, gynecologists, etc.) when necessary. "No time and no privacy are the barriers that we kept hearing about during our awareness-raising lectures and focus groups," explains Dr. Kolder. "It was the same as in the literature. If we were going to make a difference on implementation, at a minimum, we would have to overcome those two barriers."

Sullivan-Wagner and Dr. Kolder chose to name the project *All of Me* to underscore that sexual healthcare is a part of comprehensive cancer care, and their work quickly began through communication workshops, conferences, and pilot studies across Iowa. They brought formal education to oncology care teams, including advanced practice providers, nurses, social workers, radiation and physical therapists, nurse navigators, and mental health professionals. "In Iowa, most oncologists were too busy, too uncomfortable, or both to take on sexual health," says Dr. Kolder. "We needed to focus on the professionals who were most likely to embrace this care." The program has since expanded to encompass anyone who has a relationship with oncology patients at any point of the cancer care continuum.

All of Me is not the first to address sexual healthcare in oncology, but it is the first statewide, non-profit education program focusing on this concern. And as its collaborators continued to refine the program with workshop and conference participants' feedback, it has become an expert-driven and accessible resource for medical care teams across many disciplines. Treating sexual health problems has always involved multiple specialties that need to coordinate care across departmental silos, says Dr. Kolder. Therefore, it is vital that conversations around sexual health be normalized within medicine and between patients and providers.

With this need identified, *All of Me* was created to address three key care components:

1. Normalizing conversations around sexual healthcare
2. Setting patient expectations regarding the sexual health impacts of their disease and treatment
3. Referring patients to allied professionals via defined pathways.

In developing the education and tools needed for these three components, Sullivan-Wagner and Dr. Kolder partnered with experts from their original target group. This dynamic program now includes a turnkey, half-day, accredited workshop that is hosted within a cancer program or practice and an eight-week, module-based educational program, including videos, teaching aids, and other resources. Among other disciplines, *All of Me's* workshops have featured:

- Local sex therapists
- An ear, nose, and throat surgeon who has human papilloma virus expertise
- An expert on systemic racism in healthcare
- A Veterans Administration sexual trauma researcher
- Cancer program administrators
- Financial navigators.

Getting the Message Right

The first and arguably the most important component of the *All of Me* program is normalizing conversations on sexual health and helping staff create their own 30-second message that allows them to appropriately inform patients without having to get into any details of their sexual history. "Here was a universal message about the impact of cancer on sexual health," says Sullivan-Wagner. "It was short, simple, generic, and 'vanilla.'" Medical professionals can use this message within any area patients are seen (e.g., clinic room, hallway, reception area, infusion suite) and with whomever may accompany them (e.g., caregiver, child, parent). Sullivan-Wagner explains that the *All of Me* 30-second message is not meant to start an in-depth conversation with patients but to make them aware that there is a relationship between cancer and sexual health.

By acknowledging to patients with cancer that sexual health issues are common, expected, and an important quality-of-life concern for most people, the issue is normalized. Patients need to know that sexual health problems are healthcare problems—that it is appropriate to bring these issues up to their healthcare providers. Furthermore, patients may not care at the time of their diagnosis, but it can matter later during or after their treatment. Addressing sexual health ensures patients know where to bring their questions and can prevent or reduce long-lasting effects.

Next, the program's collaborators needed to ensure that oncology professionals are educated on the timing of this message. Medical professionals should tack sexual health onto any discussions regarding the short- and long-lasting effects of cancer treatment, as well as whenever quality of life is discussed with patients. Dr. Kolder emphasizes, "Along with urinary and bowel

side effects, the impact of treatment on sexual health has to be brought up each time side effects of treatment or quality of life are discussed.”

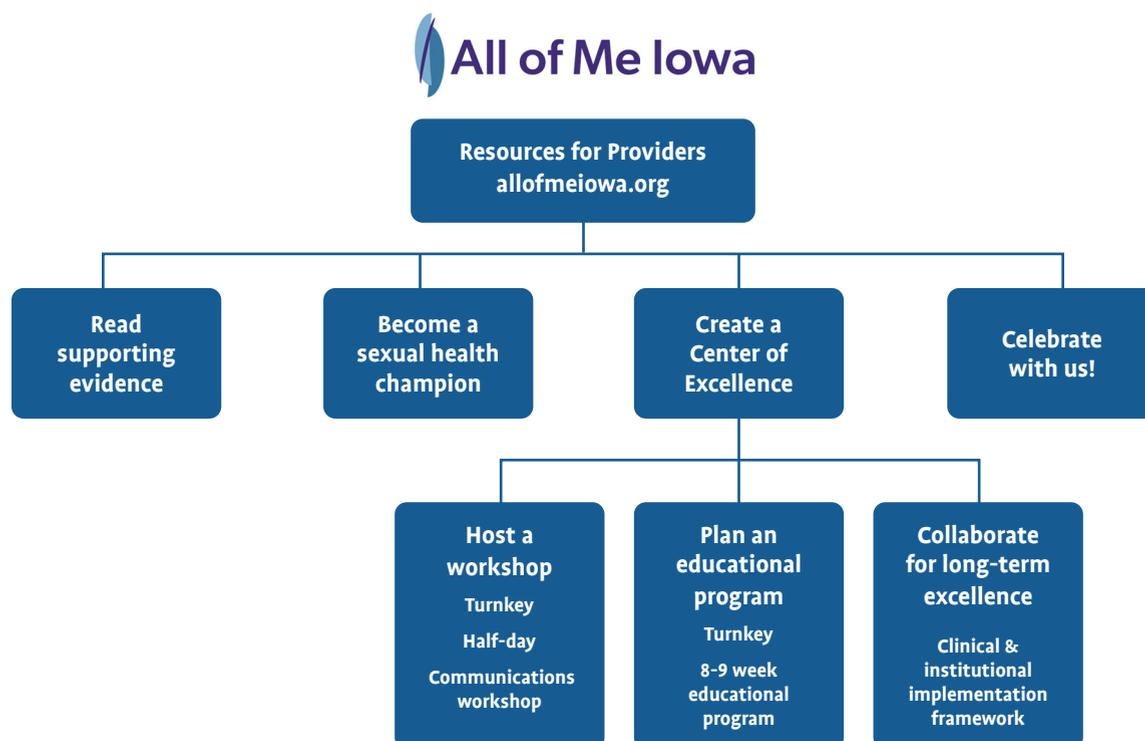
Unique to the *All of Me* project, program participants learn what their 30-second message needs to include, write it in their own words, and practice it in a safe setting with a facilitator and simulated patient actor. During these practice rounds, more challenging scenarios are identified and acted out to ensure that program participants are prepared for patients’ reactions or concerns.

In assisting medical providers in closing out these conversations, project collaborators designed an education aid—available in English and Spanish—for oncology staff to share with patients as they end their sexual health conversations. This aid provides further information for patients to read on their own time. It directs them to the *All of Me* website (allofmeiowa.org) and other resources. “Having something in your hand takes the eye contact away from each other on this awkward topic that I may be feeling uncomfortable about,” says Sullivan-Wagner. “It’s easy to say, ‘Take this home. Read it. If you have any questions, please bring them back to us. This is something that we expect that you might care about, and we care about it, too.’”

Addressing Patients’ Concerns

After sharing *All of Me*’s 30-second message and brochure, patients may immediately ask for more information. Dr. Kolder explains that this is especially likely if more information on sexual health could influence patient-provider discussions on treatment plans. These patients should be scheduled for an immediate appointment with an internal expert. Other patients who request more information at a later date should be scheduled for an appointment with an identified expert or have their oncologist refer them to an appropriate allied professional. “Because counseling about what to expect is more complicated and needs to be personalized to patients’ circumstances, staff should set patient expectations—also known as providing anticipatory guidance—within a private setting where one can ask about their sexual health information,” says Dr. Kolder. She notes that staff do not need to tease out patients’ sexual orientation or complicated relationship statuses. Instead, they should simply ask whether patients are sexually active and, if so, whether they are with men, women, or both. This will inform the referrals needed to meet patients’ needs, such as determining whether an LGBTQ+ welcoming professional would be more appropriate.

Figure 2. *All of Me* Provider Resources Website Flowchart



When addressing patients' sexual health concerns, Dr. Kolder also emphasizes the need for chunking and checking. *All of Me* program participants are taught how to break these conversations into bite-sized chunks for patients to easily digest and how to check in to ensure that patients understand the information that is being shared.

Referring Patients to Appropriate Resources

The third and final key to implementing sexual healthcare is referring patients as needed. According to Dr. Kolder, "One of the unexpected bonuses of conducting our early workshops and piloting the educational program was the personal connections participants made with each other, often within their own institution. Just a few hours together helped providers connect with like-minded colleagues, learning what type of referrals they welcome."

By hosting workshops across Iowa, Sullivan-Wagner and Dr. Kolder learned that *All of Me* needed additional resources to further support oncology staff. Therefore, they created a roadmap for referrals worksheet that included a template and instructions, along with sample emails, for soliciting information from internal, community, and area-based providers. Mental health professionals, social workers, physical therapists, ostomy specialists, occupational therapists, speech therapists, pharmacists, urologists, urogynecologists, gynecologists, spiritual services, and support groups who welcome individuals or couples impacted by cancer and sexual problems are included as part of this tool, and it is customized to each cancer practice or program.

Further, *All of Me* has broadened its referral template to include introductory videos of local mental health professionals, sex therapists, and social workers, who share their experiences in working with people impacted by cancer. By splicing these videos together, *All of Me* gives local oncology professionals an easy way to meet other community-based specialists.

Provider Impact

Over the last six years, *All of Me* has been shaped by feedback from completed workshops, conferences, and three pilot studies. The largest of these pilots was hosted by St. Anthony's Regional Hospital in Carroll, Iowa. Led by nursing leadership, St. Anthony participants completed a nine-week study of the *All of Me* education program. "The preliminary results suggested that when comparing pre- and post-pilot confidence, across all domains of sexual healthcare implementation that were evaluated, providers showed significant improvement," says Dr. Kolder. "We found that people were ready for this level of detail regarding treatment and referral because they were already convinced of the need for normalizing these conversations and the importance of sexual healthcare in oncology."

Though *All of Me*'s tools were originally created for oncology professionals, the program and its resources, including the 30-second message, are not limited to oncology. For example, Dr. Pearlman—an *All of Me* collaborator since 2019—brought the 30-second message to her colleagues at the University of Iowa Hospitals and Clinics' Department of Urology. In teaching her

colleagues the 30-second message, Dr. Pearlman increased referral rates to her clinic, ensuring that patients with cancer are being treated for their sexual health concerns. "A lot of these staff are seeing our oncology patients and are helping me in my clinic," says Dr. Pearlman. "So, there's an opportunity for them when they're checking patients in, getting their vitals, and talking with patients to bring sexual health up and provide resources."

In summarizing her role in the *All of Me* program and its impact on how she practices today, Dr. Pearlman states: "It's changed how I counsel patients and how I counsel other providers. I tell them that if they [providers] are treating someone with a pelvic cancer, it would be naive of us to believe that those cancer treatments would not affect sexual health. We must bring up these common concerns, but we don't have to be the ones to treat it [the concern], we just have to address it, and we can do that in 30 seconds and provide a brochure. Everyone wins."

Additionally, Dr. Kolder shares that two of the project's collaborators have gotten an advanced degree (an advanced registered nurse practitioner and a doctor of nursing practice), and others have conducted relevant research after being inspired by the project.

All of Me Today

Since its inception, *All of Me*'s collaborators have accumulated many teaching aids and created their own patient-facing materials. These materials were added to the *All of Me* website as they were developed, and, because of the COVID-19 pandemic, the program's collaborators were forced to reconfigure their workshops and educational materials for the virtual setting.

Since then, Sullivan-Wagner and Dr. Kolder have reformatted their materials, making the program's website design intuitive and easy to navigate. Provider resources are now better organized, so visitors can quickly access the content they need (Figure 2, page 39). The website also includes step-by-step instructions for hosting the *All of Me* accredited half-day workshop and eight-week education program. Website visitors can access the referrals roadmap worksheet, instructions for making a video to introduce local mental health and sex therapists to oncology professionals, clinical and institutional frameworks for sexual healthcare implementation, and recordings of past conference presentations.

Looking Ahead

As the program's website work and accreditation is finalized, Sullivan-Wagner and Dr. Kolder are continuing to explore how *All of Me* can ensure that patients are given much-needed information regarding the side effects their cancer and/or treatment may have on their sexual health and that medical professionals are setting expectations and referring to allied professionals when appropriate. As some cancer programs and practices address this topic in survivorship care, it can still be considered a new supportive care mission. Dr. Kolder emphasizes the need for addressing the impacts of cancer and its treatment on patients' sexual health at the time of their diagnosis, when treatment options are being discussed and preventive strategies can be put in place. "Sooner is better than later applies here, too," she says. "The erosion of

intimate relationships due to failing to address sexual health can affect marriages and children's well-being."

Sullivan-Wagner adds, "Our dream is to partner with a software developer to create an app for patients and healthcare providers about the sexual health impacts of cancer." This app would allow an individual to enter their basic information (i.e., sex, age, cancer, stage, treatment), consider their menopause status if applicable, and output a list of potential side effects related to their sex and intimacy, along with evidence-based treatments. "Such an app would go a long way toward addressing another challenge: the need for professionals from many different fields to have a host of oncosexuality information on-hand during patients' visits. This personalized information is needed to provide anticipatory guidance," says Sullivan-Wagner.

Since presenting to oncology professionals at conferences and workshops across Iowa, *All of Me* has gained interest among healthcare professionals across the United States. When asked whether she would consider expanding *All of Me* on a national scale, Sullivan-Wagner said that is her intention. "I hope to partner with national organizations that are interested in educational programs for their cancer centers, clinics, and practices. Our work will not be complete until addressing sexual health is standard practice in the cancer care setting, as national guidance recommends." 

Maddelynn Parker is associate editor, Oncology Issues, Rockville, Md.

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