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Intimacy with Cancer: Program Development and Evaluation Addressing Sexual Health and Intimacy with Cancer Survivors

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A capstone project submitted in partial fulfillment for the requirements of the Doctor of Occupational Therapy degree from the University of Indianapolis, School of Occupational Therapy.

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A Capstone Project Entitled

Intimacy with Cancer: Program Development and Evaluation Addressing Sexual Health and Intimacy with Cancer Survivors

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By

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OTS

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Abstract

The purpose of this Doctoral Capstone Experience (DCE) was to develop and implement a program to address cancer survivors' sexual health and intimacy concerns at Cancer Support Community of Central Indiana. Program development consisted of a thorough literature review, needs assessments from staff and survivors, and tracking measured outcomes for informed changes. Needs assessments from various stakeholders were completed until saturation was met, followed by thematic analysis to generate key themes to incorporate in each sessions' topic. Key themes that emerged from staff and survivors that were addressed in this program included communication, loss of libido/sexual interest, defining intimacy, normalizing the topic of sexual health concerns, the importance of sex and intimacy, wanting to address sex and intimacy in a therapeutic setting, difficulty getting and maintaining an erection, activity modifications for intimate and sexual activity, adaptive devices and equipment for intimate and sexual activity, and the desire for partners to be included when addressing the topic. Eight participants, including survivors and spouses, attended one or more of the three sessions created for this program. Results indicated participants' scores regarding their sexual health concerns increased, with an average increase of 0.74 for performance and an average increase of 0.98 for satisfaction, as measured by the Occupational Performance Index of Sexuality and Intimacy (OPISI). All three group sessions' formative evaluations displayed an increase in knowledge from pre-survey to post-survey scores. Overall, this program has promise to effectively address sexual health concerns for survivors and will be continued at this community setting.

MeSH Terms: Occupational Therapy, Survivorship, Cancer Survivors, Sexuality, Intimacy, Sexual Health, and Community Setting

Intimacy with Cancer: Program Development and Evaluation Addressing Sexual Health and Intimacy with Cancer Survivors

For the year 2018, in the United States (US), an estimated 1,735,350 new cases of cancer were diagnosed and approximately 65% of the estimated individual's with new cancer diagnoses will survive beyond their first year (National Cancer Institute, 2018). In the year 2015, there was an estimated 15.5 million cancer survivors in the US, which is expected to increase to 20.3 million by the year 2026 (National Cancer Institute, 2018). The National Cancer Institute (2018) notes that approximately 38% of men and women will be diagnosed with cancer during their lifetime, and as the US population continues to age, the cancer rates will also continue to increase with age. The decrease in cancer related deaths and increase in cancer survivors is likely due to the vast medical advances for detecting cancer sooner, as well as more effective treatment options (Johnson, 2015). For the purpose of this paper, a cancer survivor is defined as an individual from the point of diagnosis until the end of life (National Cancer Institute, 2014).

As the number of cancer survivors continues to increase, so does knowledge on the common side effects survivors face due to cancer and the corresponding treatments. Sexual dysfunction is a common side effect of cancer and cancer treatment that is frequently observed with survivors of various types of cancer and in both men and women (Brotto et al., 2012). In addition to having physically related sexual concerns (sexual dysfunction), survivors are likely to experience negative self-view and body image, increased anxiety and depression, and trouble maintaining previous roles and routines in relation to sexuality and intimacy (Walker, Barnes, et al., 2018; Woods, Hevey, Ryall, & O'Keefee, 2018). For the purpose of this paper, sexuality is defined as an intrinsic human experience of daily living which can impact a survivor's self-esteem, self-expression, attitudes, emotions, quality of life, and overall well-being (Walker,

Barnes, et al., 2018). Sexuality and intimacy can include, but are not limited to, sexual activity, meal preparation for intimate dinning, communication, meaningful touch, redefining pre-existing roles, and use of adaptive devices/equipment. It is important to note that sexuality and intimacy are not simply the act of sexual activity. Communication of feelings and emotions, personal values, roles and routines, as well as other Activities of Daily Living (ADLs) that help maintain a relationship are all aspects of sexuality and intimacy (Sellwood, Raghavendra, & Jewell, 2017; Walker, Barnes, et al., 2018).

As stated above, sexual dysfunction, sexuality, and intimacy concerns are common areas of difficulty for survivors due to the illness and side effects of treatment (Brotto et al., 2012; Walker, Barnes, et al., 2018). Researchers in oncology and other practice areas have found that not addressing sexual health concerns can lead to decreased sexual quality of life, decreased overall quality of life, and decreased overall well-being (Barsky Reese et al., 2014; Eglseder, Webb, & Rennie, 2018; Walker, Barnes, et al., 2018). Polo and colleagues (2018) found, while investigating interventions utilized to address side effects of cancer and cancer treatments within the field of occupational therapy (OT), that across all of the survivorship side effects listed, sexual activity was the ADL that was addressed the least. This is troubling given that sexual activity is an occupation within the scope of OT practice and is a common concern for survivors within their first year after treatment (American Occupational Therapy Association [AOTA], 2014; Hwang et al., 2015). Walker, Barnes, and colleagues (2018) note occupational therapists (OTs) have the expertise to address occupational deficits with sexual health, including sexual knowledge, self-view, sexual interest, sexual responses, sexual behavior, sex/sexual activity, and family planning as it relates to fertility and contraception. OTs can use their expertise in areas of adaptations, modifications, and relaxation and stress reduction techniques to address the ADL of

sexual activity and the ADL of personal device care for contraception and sexual devices, as well as the sexuality and intimacy aspect of social participation to increase quality of life for cancer survivors (AOTA, 2014; Newman 2011).

The effects of cancer and its treatments do not only affect survivors during treatment, but can impact survivors more than 20 years after treatment (Koppelmans et al., 2012). Due to survivors living longer and dealing with these side effects for longer periods of time after treatment, care for survivors should not solely be provided during the acute phase (Polo et al., 2018). Polo and colleagues (2018) discuss this gap in practice settings and time of care provided for survivors, emphasizing Polo and Smith's (2017) call for OTs to address these concerns in the community setting.

Given the information presented above, the aim of this Doctoral Capstone Experience (DCE) was to develop a program to address sexual health and intimacy concerns of cancer survivors in the community setting. In addition to evidence from the literature mentioned previously, as well as guidance from the Sexual Assessment Framework (SAF) and the PLISSIT model described in detail below, this program was designed to provide group education and one-on-one consultations to address the physical and psychological side effects that negatively impact the overall quality of life of survivors. Therefore, the purpose of this DCE was to increase cancer survivors' quality of life by addressing their sexuality and intimacy concerns.

Theoretical Framework

PLISSIT Model

For the development of this program, the PLISSIT model was used to help guide the design of the group sessions and one-on-one consultations. Walker, Barnes, and colleagues (2018) note that the PLISSIT model was developed to address the sensitive topic of sexuality

during therapy and education. The PLISSIT Model and SAF are illustrated with specific references to this program in Appendix A. The levels, or stages, of information provided within this model include permission, limited information, specific suggestions, and intensive therapy (Kokesh, 2016; McBride & Rines, 2000). The healthcare provider works from the bottom to the top of the diagram and all levels might not be reached if they are deemed unnecessary (Kokesh, 2016). For example, if an individual is satisfied with the information gained in the limited information stage, he or she does not need to be guided through the specific suggestions stage.

To further explain this model, the first level is P, for permission. The purpose is to gain permission from the individual to further discuss the sensitive topic, as well as to give the individual permission to bring up the topic (Kokesh, 2016; McBride & Rines, 2000). The second level is LI, for limited information. This is when general education and basic knowledge are provided, not completely unique to an individual's given situation (Kokesh, 2016; McBride & Rines, 2000). The unique information for the individual's specific situation is provided during the third level, SS, standing for specific suggestions (Kokesh, 2016; McBride & Rines, 2000). For the SS stage of this model, individualized information and education are provided based on the individual's unique situation and concerns (Kokesh, 2016; McBride & Rines, 2000). The final level or stage of this model is the IT level, short for intensive therapy (Kokesh, 2016; McBride & Rines, 2000). During the IT level, information or concerns are out of the healthcare professional's scope of practice and therefore, referrals are made to other professionals who have greater expertise in that given area (Kokesh, 2016; McBride & Rines, 2000).

Sexual Assessment Framework

As stated above, the theory that was used to help guide the development and implementation of this program is the SAF. The visual representation of this framework within

the PLISSIT model can be found in Appendix A. The SAF was utilized with the PLISSIT model because Walker, Barnes, and colleagues (2018) state that even though the PLISSIT model can be exceptionally useful for guiding practitioners addressing this topic, it does not provide specific instructions for an all-inclusive assessment and intervention. Walker, Barnes, and colleagues (2018) found that the SAF, "provided an effective format for which to explore the occupational nature of sexuality" (p. 3). Even though the SAF was originally designed as a framework for the nursing profession, it has been useful for OTs who are addressing the topic of sexuality (Kokesh, 2016; McBride & Rines, 2000).

The SAF describes the seven key components that make up sexual health, which are sexual knowledge, sexual behavior, sexual self-view, sexual interest, sexual response, fertility and contraception, and sexual activity (Kokesh, 2016; McBride & Rines, 2000).

The first of the seven parts of sexual health listed above is sexual knowledge, which is composed of the individual's values and beliefs about their sexual activity and sexuality (Kokesh, 2016; McBride & Rines, 2000). The sexual behavior component is how the individual is creating and maintaining relationships (Kokesh, 2016; McBride & Rines, 2000). Sexual self-view is focused on the individual's body image and self-concept (Kokesh, 2016; McBride & Rines, 2000). The drive behind an individual's sexual activity and 'libido' is termed sexual interest (Kokesh, 2016; McBride & Rines, 2000). Sexual response describes the physical response and arousal experienced during sexual activities (Kokesh, 2016; McBride & Rines, 2000). Activities such as family planning, education of safe sex, and various types of birth control are all within the fertility and contraception portion of sexual health (Kokesh, 2016; McBride & Rines, 2000). Finally, McBride and Rines (2000) describe sexual activity as being focused on skills such as gross and fine motor functioning, strength, dressing and undressing,

management of bowels, management of bladder, affectionate activities, and transferring. These seven components of sexual health will be useful supplements for the limited information and specific suggestion levels of the PLISSIT model.

Needs Assessments

Needs assessments are a critical part of program development. A needs assessment is defined by Cole (2012) as being an organized set of methods used to help identify and define areas of need for a selected population. AOTA (2015) notes that needs assessments can lead to clearly defined goals and objectives for a group or program. Needs assessments should include gathering background information from literature reviews, collaboration with participants, interviews with potential participants, and interviews with individuals who come into regular contact with potential participants (key informants) (AOTA, 2015). After this has been completed, the data collected should be analyzed to assist with program development (AOTA, 2015).

As the literature review was completed and summarized above, this section will focus on the remaining components of the needs assessment, specifically interviews with potential participants and key informants. In order to analyze the collected data from both sets of interviews, thematic analysis was utilized because it is a flexible method of identifying and reporting rich and detailed themes within a set of data (Braun & Clarke, 2006).

Staff Needs Assessment

In research methodology, one key purpose for using survey research is to help guide planning of health care services within the community (Stein, 2013). Stein (2013) found when it comes to community health planning, survey research is vital. Therefore, a seven-question survey was utilized when completing a staff needs assessment at the community site, which can

be found in Appendix B. Questions were created after completion of the literature review in order to elicit information on concerns survivors have brought up with other group facilitators, counselors, and other staff at Cancer Support Community (CSC), as well as provide opportunities for staff to list recommendations for topics and suggestions for program development. Staff needs assessments were gathered until saturation was met, meaning when no new concepts or themes emerged from staff answers to the questions (Corbin & Strauss, 2015).

Participant Needs Assessment

Within the scope of OT, there are currently no formal assessment tools to address sexual health and intimacy concerns with any population. Therefore, Walker, Otte, and colleagues' (2018) Occupational Performance Index of Sexuality and Intimacy (OPISI) was utilized for the participant needs assessment and summative program evaluation. This tool, designed through the lens of the SAF, was selected because of its significance given the topic and framework selected to guide this project (Walker, Otte et al, 2018). Due to the novelty of this assessment tool and the unestablished psychometric properties of the tool, the OPISI was utilized after permission was granted from Walker. The initial screen of the OPISI, which can be found with the complete tool in Appendix C, was utilized during the needs assessments until saturation was reached.

Needs Assessment Results

Nine staff members completed the needs assessment questionnaire. Key themes that emerged during thematic analysis of the staff needs assessments included communication, changes in relationship dynamics, body image/self-esteem, loss of libido/sexual interest, defining intimacy, and normalizing the topic of sexual health concerns. Forty-four percent of staff members noted communication as important, with communication appearing multiple times in

each individual survey. Approximately 44% percent of individuals noted changes related to relationship dynamics as key. Approximately 33% of staff members listed body image/self-esteem as a major concern. Defining intimacy and loss of libido/sexual interest were both listed in approximately 33% of surveys. Finally, normalizing the topic of sexual health and concerns around the topic of sexuality and intimacy was present in approximately 22% of completed surveys.

Two staff members suggested activity modifications and adaptive devices/equipment for addressing some of the above concerns. These suggestions included sensate focused techniques, stress reduction for performance anxiety, vacuum pumps, penis rings, mutual masturbation, non-intercourse sex, oral, and erotic literature and films.

Four participants completed the OPISI initial screen, two survivors and two spouses. Key themes included the importance of sex and intimacy, discussing the subject and receiving handouts/brochures, wanting to address this topic in a therapeutic setting, and the desire for partners to be included when addressing the topic. The two survivors both noted self-view/body image, getting/keeping an erection, and medications, including Viagra, as key concerns. Two participants, a spouse and a survivor, noted that stigma and normalizing the topic were a very important part of what has kept them from addressing their intimacy concerns.

Community Versus Acute Care Setting

Sexual health is one concern survivors continue to face stigma with throughout the majority of OT practice settings. With this in mind, these needs assessments would likely be beneficial to utilize in both the community and acute care settings. As mentioned previously, sexual activity is a common concern within the first-year post treatment (Hwang et al., 2015), and therefore should be addressed within the acute care setting as well. However, the timing is

not always appropriate given that changes related to sexuality and intimacy might not present until after treatment. Furthermore, it was more appropriate to complete this project and needs assessment in the community setting because in acute care survivors are more focused on survival and treatment, as opposed to sexual activity. Once survivors have completed treatment, transitioned to less frequent doctors' appointments, and begin returning to regular life activities, these concerns become more evident. McCabe and colleagues (2013) note that a majority of survivors obtain continuing care within the community setting. This is a primary reason why Polo and Smith (2017) have called for OTs to recognize their potential roles within the community setting to help survivors with promotion of health and wellness, which should include sexual health and intimacy.

Implementation

The program created and implemented during this DCE was a three-part series of educational group sessions with optional one-on-one consultations to address sexual health and intimacy concerns with survivors and their spouses. Participants were provided with educational material during the first portion of each group session, followed by group discussion, which was open to anonymously written or verbally asked questions. During each session, participants were given a note card to write down any questions they were not comfortable asking aloud. These questions were then collected and addressed during the discussion portion of the session. At the end of each session, participants were also given the opportunity to sign up for individual consultations.

Group one of this series addressed communication and defining sexuality and intimacy. During this session, sexuality and intimacy were explained beyond the act of intercourse. Other daily activities that could be included in sexuality and intimacy were also discussed, including

meal preparation for intimate dinning, meaningful touch, and hand holding. The importance of communication, tips on how to communicate with healthcare providers, and how to communicate with a partner were also discussed during the first session. Participants were given the opportunity to complete the five love languages quiz to better understand their love language, with the intention of increasing effective communication.

The second session of this three-part series was focused on activity modifications. During this group session education was provided on everyday activities included with intimacy, as well as energy conservation techniques that could assist with these activities. Activity modifications and energy conservation for the act of intercourse/sexual activity were discussed, in addition to common concerns that survivors face due to cancer and cancer treatment that impact sexual activity. Strategies and topics further discussed, following the introduction of these common concerns, included increased/routine masturbation and stimulation, an optional month-long masturbation challenge, positioning for pain and fatigue during sexual activity, non-intercourse alternatives for sexual activity, and sensate focused techniques.

Finally, the third and final session in this series discussed adaptive devices and equipment to address common concerns survivors face with sexual activity and intimacy. During this session, barriers and stigmas associated with the use of adaptive devices were discussed, such as age-related stereotypes and participants' perceptions of these devices. Devices, and the purposes of those devices, were introduced to the group, including positioning devices, harnesses, vibrators, dildos, fleshlights/mood pleasers, masturbation gloves, prostate stimulators, anal devices, sensitivity devices, lubricants, and hygiene products. Caution was given for use with some of these devices due to potential adverse reactions and sensitivity concerns. Websites that sell these devices, sell other devices not discussed, and provide sexual education articles, as well

as provide discrete billing and shipping were also provided to participants during this final session.

During each of these sessions, participants completed pre-/post surveys, created utilizing evidence-based literature, needs assessment results, and group materials provided in the sessions. These pre-/post surveys were utilized as formative evaluations to measure the effectiveness of each individual session. Prior to the first session and after completion of the last session, participants completed the OPISI in its entirety. The fully completed OPISI was utilized as a summative evaluation to measure the effectiveness of the overall program for participants.

Leadership Skills

Skills of an effective leader, as defined by AOTA (2013), include being goal oriented, respectful, effective with communication and planning, and motivating and challenging others. During this program, these skills of an effective leader were utilized through creating and facilitating each group session.

Prior to the sessions, effective planning was completed to ensure all topics and materials were researched, organized, and suitable for each session topic. At the beginning of the sessions participants were reminded that the group was a safe, respectful, and judgment free zone. To increase effective communication, the opportunity for anonymous or verbally asked questions was presented. Finally, the leadership skill of motivating and challenging others was developed through the creation of this program as a whole because by advertising a program to address these sexual health and intimacy concerns, participants were motivated and challenged to begin the process of addressing their sexual health concerns.

Staff Development

Staff development occurred through advocating for OT as a profession, as well as for OT within the community setting. Throughout the duration of time spent at CSC, staff members were educated during staff meetings on the role of OTs with survivors, within the community setting, and with addressing sexual health concerns. Staff development was observed after these encounters through interns of other disciplines noting increased awareness of OT as a profession, as well as other staff members reporting their increased awareness of how OTs can help with sexual health concerns. Finally, another example of observed staff development following these meetings, was an increase in referrals to this program from other staff members and interns.

Program Outcomes

Throughout the entirety of the program there were a total of eight participants, including survivors and spouses, as well as three CSC interns that attended sessions. Of the total eight participants, two participants attended all three intimacy sessions. Four participants were educated on the topics from sessions one and two. The remaining two participants only attended and received education on topics from session one. Of the eight participants, three completed the OPISI prior to the first session and following the final session. Two of the three participants who completed the OPISI were not present for the final session, therefore they completed their reassessment over the phone following the final session. The three participants' assessment results for summative evaluations will be explained in more detail below and can be found in Appendix D (table 1D and 2D). Of the total eight participants, six were over the age of 65 years old, resulting in 75% of the group population being older adults.

For the summative evaluation of the entire program, the OPISI was utilized prior to the first session and following the final session. The groups' initial performance average in their

listed problem areas around sexual health and intimacy was 2.13 out of 10 and their group initial satisfaction average was 2.02 out of 10. The group reassessment average for performance was 2.87 out of 10 and their group reassessment satisfaction average was 3.00 out of 10. This indicates a group increase in performance by 0.74 and an increase in group satisfaction by 0.98; which shows increased perception of satisfaction and performance by participants with their sexual health problem areas.

Formative evaluations of each session were completed through pre-/post-surveys, which can be found in Appendix E (session one), Appendix F (session two), and Appendix G (session three). Participants and interns completed these surveys prior to starting each session and following the discussion portion of each session. These formative evaluations were used to evaluate and measure individuals' increased knowledge and education on the sexuality and intimacy topics presented. Results of the formative evaluations can be further seen and found in Appendix D (table 3D) with the summative evaluation results. For the first session, with a total number of six participants, the groups' pre-survey average was a three out of five (60%) and the post-survey average was a 4.75 out of five (95%); indicating an increase in knowledge of 1.75 points. The groups' average pre-survey score for the second session, with a total of nine participants, was 1.7 out of five (34.2%) and their post-survey average was 3.86 out of five (77.2%); demonstrating an increase in knowledge of 2.16 points. Finally, the third session groups' average pre-survey score was 3.33 out of seven (47.5%) and post-survey average score was 5.67 out of seven (81%); indicating an increase in knowledge of 2.34 points.

The three program outcome goals developed at the beginning of this DCE included increasing survivors' education on sexuality and sexual dysfunction concerns, increasing survivors' comfort with discussing their sexuality/sexual health concerns and being more

comfortable seeking help for their sexual health concerns, as well as increasing satisfaction and participation in sexual activity and intimacy for survivors. The results from the formative assessments show that survivors and other participants of the sessions had increased knowledge and education of the topics discussed, as demonstrated by increased scores from the pre-survey to the post-survey. Results from the OPISI indicate that survivors had an average increase in participation (performance) and satisfaction with their sexual activity and intimacy, as evidenced by increased performance and satisfaction scores. Finally, through increased discussions during each session, there was observed increased comfort when discussing sexual health concerns and seeking help for those concerns among session participants, as demonstrated by increased conversations with survivors during the discussion portions of each session.

Personal and professional outcome goals set at the beginning of this DCE included creating and implementing a program for survivors to address cancer and treatment related sexuality concerns, applying critical thinking and utilizing evidence-based practice principles to influence program development, using leadership and advocacy skills to demonstrate the value of OT with survivors and OTs role with sexuality and intimacy, using advocacy skills to demonstrate the value of OT in the community setting, and demonstrating professional development and continuing competence through increased confidence and ability to discuss sexual activity and intimacy with survivors. These goals have been met exceeding previously set standards through communication with staff and participants, evidence-based literature on sexual health, program development, and program implementation with survivors.

Ongoing Quality Improvement

Batalden and Davidoff (2007) defined quality improvement as a combined, collaborative effort from everyone involved to help make changes for better patient/client health outcomes,

better system performance, and better professional development. The collaborative approach utilized for this DCE involved the needs assessments and feedback from staff and survivors, as well as insight from literature and sexual health experts in order to create a program that was best fit for survivors' needs at this community site. Ongoing changes were applied to individual sessions following participants' feedback after each session to help increase patient/client outcomes. Professional development occurred through reflection on suggestions from staff and participants on how to better develop and implement educational materials and facilitate discussion during sessions.

Batalden and Davidoff (2007) mention the five knowledge systems for improvement, including generalizable scientific evidence, specific context awareness, performance measurement and analysis of patterns, plans for change, and execution of planned changes. The systems of generalizable scientific evidence and specific context awareness were utilized during this DCE through literature review and evidence-based practice for each session. In addition, specific context awareness also was utilized while completing the staff needs assessments. Performance measurements and analysis of patterns were completed through the formative and summative evaluations, as well as the thematic analysis of the needs assessments. Finally, plans for change were completed through the implementation of anonymous suggestions made by participants at the end of each session so that effective changes could be applied to the following sessions. Through these methods, quality improvement was continuously applied throughout each of the three sessions and will continue to be applied as the program remains at CSC.

Programming Changes and Sustainability to Meet Societal Needs

Reflecting on the outcomes of the ongoing quality improvement mentioned above, changes to this program will include interprofessional approaches with licensed mental health

therapists at CSC, moving all three sessions to the open studio, and incorporating more discussion throughout the sessions. Plans are in place for a licensed mental health therapist to incorporate a mental health aspect in the first session of this program to address psychosocial concerns, such as decreased body image and self-esteem. This plan was put into place based on observations during the discussion portion of the first session and after suggestions from participants of the program. After reflecting on feedback from participants on the environments provided for each session, future sessions for this program will be held in the open studio instead of the closed off support group rooms at CSC. This decision was made after multiple participants stated they felt more comfortable in the open studio during the last session than in the support group room during sessions one and two. Finally, also reflecting on feedback from participants, more discussion will be incorporated throughout each session to help meet participants' needs and desires to discuss their own concerns more openly in the group setting.

For sustainability purposes, future volunteers can use the binder created and provided to the Vice President at CSC to run this program again with the recommended changes mentioned above. This binder, created with the intention of increasing sustainability, was divided into three sections, one for each session of the program. Each section of the binder included the created flyer for the session, all handouts provided to participants during the session, the pre-/post surveys utilized for formative evaluations, the PowerPoint that was utilized and distributed to participants during each session, and finally a handout to provide for sessions one and two to remind participants of the remaining sessions' dates, times, and topics. The only item utilized during the program that was not provided in the binder was the OPISI. This summative assessment tool was purposively left out of the binder due to further edits being made by Walker, Otte, and colleagues (2018) for a formal final assessment tool. At this time, the plan discussed

by this student and the Vice President at CSC is for this student to return to reimplement the program during the fall of 2019 or the spring of 2020. This change in seasonal time the program will be offered is to promote increased participation due to better weather conditions. Additionally, while the plan for this student to reimplement this program is in place, having this binder will be beneficial if these plans are no longer achievable and another volunteer is needed to run the program.

The societal needs of survivors were met by this DCE through the implementation of this three-part program to address sexual dysfunction, sexual health, and intimacy concerns. This DCE further met the abovementioned needs by providing services within the community setting, the ideal environment when survivors are re-entering the community and returning to their everyday occupational activities that might not have been focused on during active treatment in the acute setting. Furthermore, the aforementioned changes and this student's plan to volunteer as the program leader in the future are also ways that this program will continue to meet these societal needs with survivors in this community setting.

Overall Learning

Overall learning in the areas of program development and implementation comprised of increased knowledge with advertising strategies, contacting survivors and CSC staff for needs assessments, professional emailing with staff and participants, calling/contacting participants for reminders for next sessions, navigating opportunities for advocacy of the OT profession, and many other examples of communication with participants, staff, and interns during this DCE. Advocacy for the OT profession was completed in many ways, as discussed above, however the best exposure to navigating opportunities for advocacy was having the chance to go in front of the board of directors for CSC to explain the details of this program, provide a specific example

of how this program was impacting survivors at CSC, discuss the role of OT with sexual health, and discuss the role of OT with survivors in the community setting. Communication with staff, through verbal communication and emailing, was helpful during this DCE for completing needs assessments, gathering information about potential participants, and resolving conflicts or concerns following sessions. Through this experience, confidence was gained with professional communication with staff and clients. Overall, communication was effective and professional, as well as timely and respectful. Areas for future improvement include increased creative involvement in advertising strategies and increased exposure to other groups offered at CSC for recruitment purposes. While other groups were educated on the upcoming sessions, this could have been expanded upon more in the beginning of this DCE.

As previously stated, effective skills of a leader include being goal oriented, respectful, effective with communication, effective with planning, and motivating and challenging others (AOTA, 2013). Through this DCE these skills grew, especially effective planning and being goal oriented. Effective leadership can additionally be observed through the efforts mentioned above for advocating to staff and other interns on the role of OT with survivorship, in the community setting, and with sexual health concerns.

Conclusion

This DCE established a three-part program for addressing sexual health concerns with cancer survivors at CSC. Results indicated this program had successful outcomes in terms of improving participants' perceived satisfaction and performance with sexual health and intimacy, as well as increased knowledge on topics discussed. Education and discussion-based programs within the community, such as the one created during this DCE, are important for addressing these common sexual health concerns faced by survivors that are continuing to become more

apparent as survivors are living longer after cancer treatment. Furthermore, cancer is also now recognized as a chronic condition and an emerging area of practice for OT (Baxter, Newman, Longpré & Polo, 2017), which is another reason it is important to create programs to address these common concerns survivors are continuing to face. Research and program development such as this, focusing on both sexual health of survivors and the community setting, will continue to fill the gaps in practice trends and literature around this critical concern for this population.

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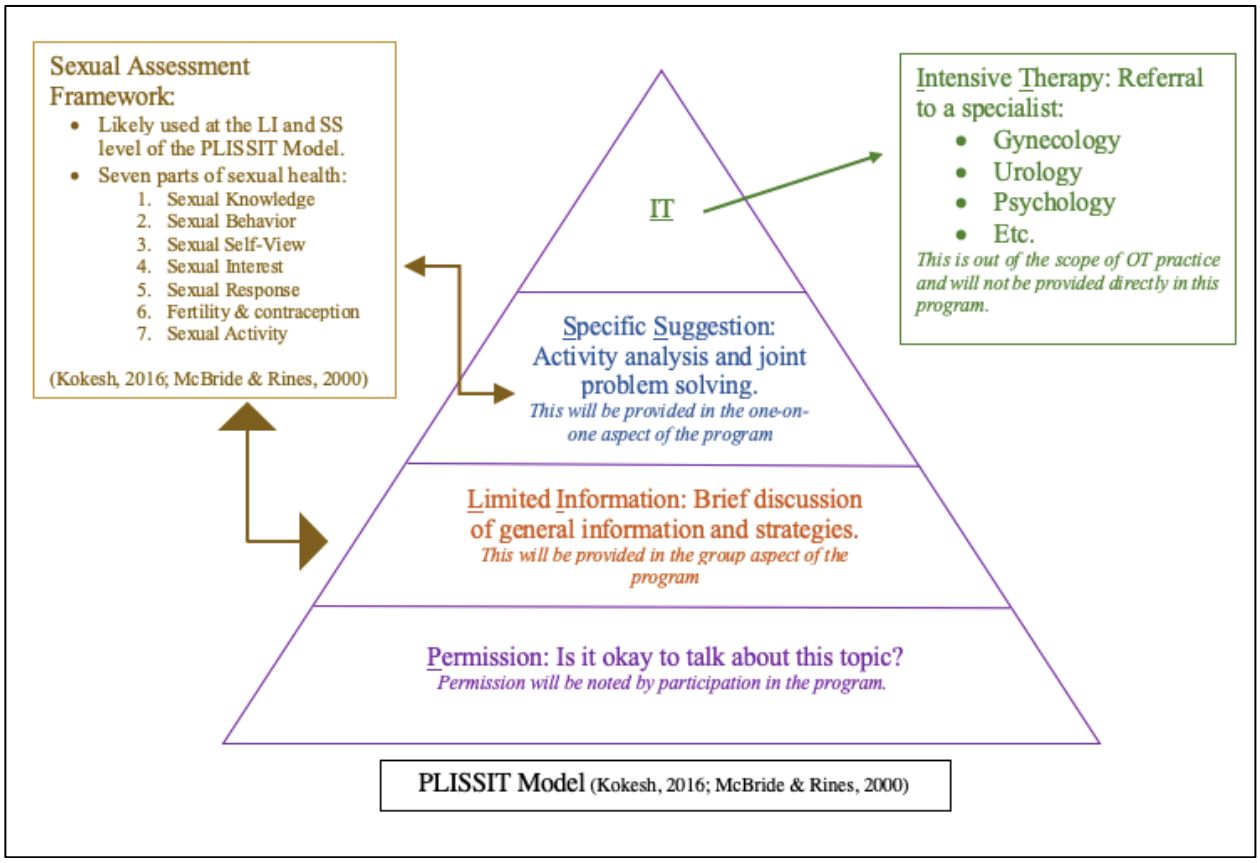
Appendix A

Figure of Theoretical Frameworks

Figure 1

Sexual Assessment Framework and PLISSIT Model



Note: Visual representation of theory and model and how they are used to guide this program.

Appendix B

Questionnaire for Staff Needs Assessment

Key Definition:

Sexuality/Intimacy: An intrinsic human experience of daily living that can impact self-esteem, self-expression, quality of life, and general well-being (Walker et al., 2018). This could include, but not limited to: sexual activity, meal preparation for intimate dinning, communication, meaningful touch, redefining stereotypical gender roles, and use of adaptive equipment.

1. Have you had any survivors note concerns with sexuality and/or intimacy?

2. Have you heard other staff mention survivors with sexuality and/or intimacy concerns?

3. If yes to either, what are some common concerns noted by survivors?

4. Have you noticed any common threads/concerns around sexuality and or intimacy with survivors in groups you've facilitated?

5. Have any of your networking sites mentioned sexuality and/or intimacy as an area of concern?

6. What are some topics/threads you think would be helpful to include in this programming?

7. Is there anything else you feel is important to note going forward while developing this program?

Appendix C

Occupational Performance Index for Sexuality and Intimacy

Occupational Performance Inventory of Sexuality and Intimacy (OPISI)

Authors:
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2018

The Occupational Performance Inventory of Sexuality and Intimacy (OPISI) includes an individualized self-screen and an in-depth self-assessment for clients of occupational therapy followed by an individualized measure for use by occupational therapists to detect self-perceived change in occupational performance problems associated with sexuality and intimacy over time.

Client Name:
Date of Screen:
Date of Full Assessment:
Date of Reassessment:
Occupational Therapist:

It is normal to have questions about how your illness, injury, disability, or life stage may impact sexuality and intimacy. Many individuals would like more information regarding this topic, but do not know who to ask or what to ask. Occupational therapists work with individuals of all ages to improve their ability to perform activities of daily living. Sex and intimacy are considered activities of daily living. Although you may be apprehensive to discuss the topic or complete the questionnaire, your occupational therapist can use the following information to help you in this area or make a referral for specialized services if needed. ***Below are a number of statements regarding concerns you may have as it relates to sexuality and intimacy. Please read each one and select the items that apply to you.***

Initial Screen	
Sexual Knowledge: Includes your values and beliefs regarding sexuality and intimacy and serves as a guide to determine what information you need in order to increase your understanding of changes to sexuality and intimacy as a result of your illness, injury, disability, or life stage.	**Check all that apply**
According to my values and beliefs regarding sexuality and intimacy:	
Sex and Intimacy are important to me	
I would prefer to only receive handouts or brochures about this subject	
I would prefer to talk about this subject and receive handouts or brochures about this subject	
I am not sure who to ask when I experience difficulties with sexuality and intimacy	
I want to address this topic in therapy	
I want my partner to be included when addressing the topic in therapy	
I wish I knew other individuals with similar conditions to discuss aspects of sexuality and intimacy	
I need more information regarding the overall impact my illness, injury, disability, or life stage has on:	
My *sexual self-view*, sexual identity, self-esteem, and body image (p3)	
My *sexual interest* or desire to participate in sexual activities (p4)	
My body's *sexual response*: ability to achieve penile erection, vaginal lubrication, ejaculation, or orgasm (p5)	
My ability to initiate or maintain intimate/sexual relationship(s) or *sexual behavior* (p6)	
My ability to engage in *sexual activity* (p7)	
My ability to practice safe sex for *sexual health* (p8)	
My ability to manage aspects of fertility and *family planning* (p8)	
Additional Comments or Concerns:	

Below are a number of statements regarding concerns you may have as it relates to Sexual Self-View. Please read each one and select the items that apply to you.

Sexual Self-View: includes aspects of your sexual identity, gender identity, self-esteem, and/or body image	**Check all that apply**
In regards to my sexual self-view, I have the following concerns:	
My sex life is not ideal	
I do not feel attractive or appealing	
I am afraid of being rejected sexually	
My partner does not see me as sexually attractive	
I feel like a failure as a sexual partner	
My insecurities interfere with my ability to have a satisfying intimate/sexual relationship	
Poor datable self-esteem interferes with my ability to have a satisfying intimate/sexual relationship	
My partner's(s') guilt interferes in our ability to enjoy participation in sexual activity	
My guilt interferes in my ability to enjoy participation in sexual activity	
Depression interferes with my ability to express my sexuality	
Anxiety interferes in my ability to express my sexuality	
My sexual desires interfere with my religious/spiritual beliefs	
My illness/disability has affected my gender identity, sexual preference, or sexual orientation	
I do not feel that my sexual identity is accepted by people I interact with on a daily basis	
Expressing my sexuality/sexual identity is a challenge	
I am no longer comfortable expressing my sexual identity	
I do not feel that I am able to perform basic roles associated with my sexual identity	
Additional Comments or Concerns:	

Below are a number of statements regarding concerns you may have as it relates to Sexual Interest. Please read each one and select the items that apply to you.

Sexual Interest: includes your sexual interest, sex drive, libido, or desire to participate in sexual activities.	**Check all that apply**
In regards to sexual interest or the physical and psychological drive behind sexual activity engagement, I have the following concerns:	
My level of sexual interest (i.e. sex drive) has changed since the onset of illness/injury	
My condition interferes with feeling aroused or excited in preparation or during sexual activities	
I am dissatisfied with my desire to engage in sexual behavior with my partner(s)	
Limited energy interferes with my sex drive	
Limited motivation interferes with my sex drive	
My appearance interferes with my sex drive	
Fear interferes with my sex drive	
Depression interferes with my sex drive	
Anxiety interferes with my sex drive	
Lack of experience interferes with my sex drive	
My interest in sex is excessive and interferes with my sex drive	
Pain, or anticipation of pain, interferes with my sex drive	
Lack of sleep interferes with my sex drive	
Lack of spontaneity interferes with my sex drive	
Stress between myself and my partner(s) interferes with my sex drive	
Limited control of body movements interferes with my sex drive	
Anger and/or resentment interferes with my sex drive	
Lack of time to participate in sexual activities interferes with my sex drive	
Inability to take on a dominating or submissive role interferes with my interest in engaging in sexual activity	

I am concerned that my medications interfere with my interest in engaging in sexual activity	
Fear of pregnancy interferes with my interest in sex and intimacy	
Fear of sexually transmitted diseases interfere with my interest in sex and intimacy	
Additional Comments or Concerns:	

Below are a number of statements regarding concerns you may have as it relates to Sexual Response. Please read each one and select the items that apply to you.

Sexual Response: involves your body's physical response associated with sexual activity such as penile erection, vaginal lubrication, response to erogenous zones, nipple erection, ejaculation, and/or orgasm.	**Check all that apply**
In regards to sexual response I have the following concerns:	
I experience difficulty with arousal during sexual activity	
I experience difficulty with achieving orgasm during sexual activity	
I am unable to find other means of experiencing sexual satisfaction to compensate for lack of orgasm	
I am unable to feel satisfied with sexual activity due to lack of orgasm	
Loss of feeling or numbness in my genitals	
Erectile dysfunction or vaginal dryness	
Being aroused at appropriate times	
Age related changes interfere with my participation in sex and intimacy	
Inability to relax	
Change in physical response due to condition	
Side effects of medication interfering with my sexual response	
Additional Comments or Concerns:	

Below are a number of statements regarding concerns you may have as it relates to Sexual Behavior. Please read each one and select the items that apply to you.

Sexual Behavior: Involves your ability to initiate or maintain an intimate/sexual relationship	**Check all that apply**
In regards to my ability to initiate or maintain an intimate and/or sexual relationship, I have the following concerns:	
I do not have a partner, and this concerns me	
My ability to find persons to engage in sexual activities	
My ability to travel to meet partner(s)	
My ability to understand, access, and use social media platforms to develop relationships	
Due to my condition, I am unsatisfied with my sexual relationship(s)	
My condition limits my ability to fulfill my partner's(s') needs	
Limitations in my ability or my partner's ability to empathize with my condition interferes in our intimate/sexual relationship	
Difficulty regulating my mood or behavior interferes with my ability to adequately express sexual interest to my partner(s) or potential partner(s)	
I do not know how to discuss or explain aspects of sexuality and intimacy	
My ability to express my sexual interest and desires in a way that my partner(s) understands	
My partner's(s') ability to meet my sexual needs within our intimate/sexual relationship	
I am not comfortable discussing sexual needs with my partner(s)	
I feel that my partner's(s') limited understanding of my condition serves as a barrier to our intimate/sexual relationship	
Fear that my partner(s) will not respect my boundaries within the sexual relationship	
Fear that I will be taken advantage of in relationships	
My ability to initiate or end a relationship with a partner	
My partner is my caregiver, and I feel like this dynamic interferes with our sexual relationship	
My ability to attend to my appearance and hygiene in preparation for romantic encounters	

My ability to create romantic environment	
Additional Comments or Concerns:	

Below are a number of statements regarding concerns you may have as it relates to Sexual Activity. Please read each one and select the items that apply to you.

Sexual Activity: includes your ability to engage in intimate and sexual activities such as hugging, foreplay, masturbation, and intercourse	**Check all that apply**
In regards to engagement in sexual activity, I have the following concerns:	
My symptoms prevent me from enjoying or participating in sexual activities	
I experience pain during sexual activity	
I experience discomfort or pain with penetration	
I avoid participation in sexual activities that include penetration due to pain	
Ability to participate in oral sex	
Tremors or shaking in my hands or body	
My ability to position myself adequately or safely during sexual activities	
Inability to control bladder or urinary symptoms during sexual activity	
Catheters or other devices interfering with sexual activity	
Inability to control bowel	
Inability to control bowel during sexual activity	
Limited strength during sexual activity	
Limited energy or physical endurance during sexual activity	
Limited balance during sexual activity	
Limited control of body movements during sexual activity	
Limited flexibility during sexual activity	
Limited coordination during sexual activity	
Impaired vision during sexual activity	
Impaired hearing during sexual activity	
Impaired sense of touch and pressure during sexual activity	
Lack of privacy during sexual activity	

I don’t know how to use alternative methods of receiving pleasure, such as sexual toys, aides, or devices during sexual activity.	
Additional Comments or Concerns:	

Below are a number of statements regarding concerns you may have as it relates to Sexual Health and Family Planning. Please read each one and select the items that apply to you.

Sexual Health and Family Planning: involves your ability to develop, manage and maintain routines for sexual health and family planning; this includes practicing safe sex, identifying, understanding, selecting and use of contraception, and planning for parenthood.	**Check all that apply**
In regards to sexual health and family planning, I have the following concerns:	
Ability to safely engage in sexual activities	
Ability to protect myself from sexual assault or rape	
Ability to choose/use the right method of contraception to prevent pregnancy or STDs	
Ability to discuss safe sex practices with my partner(s)	
Ability to use contraception as intended	
Ability to conceive a child	
Ability to manage day to day tasks during pregnancy	
Ability to be manage day to day tasks associated with parenting	
Ability to provide care and supervision to support the developmental needs of a child	
Additional Comments or Concerns:	

Following a thorough review and discussion of the inventory, confirm with the client the 5 most important problem areas and record them below. Ask the client to rate each problem on performance and satisfaction with performance on a scale from 1-10, with 1 indicating very poor performance or satisfaction and 10 indicating very high performance or satisfaction. Total scores are calculated by adding together the performance or satisfaction scores for all problems and dividing by the number of problems. At reassessment, the client scores each problem again for performance and satisfaction. Calculate the new scores and the change score.

Occupational Performance Problem	Initial Assessment:		Reassessment:	
	Performance	Satisfaction	Performance	Satisfaction
1.				
2.				
3.				
4.				
5.				
Total performance or satisfaction scores				
Number of problems				
Total Score = Score/# of problems				
Change in performance = Performance Score 2 - Performance Score 1				
Change in satisfaction = Satisfaction Score 2 - Satisfaction Score 1				

Additional Concerns: **Beyond the 5 most important problem areas, please list any remaining concerns the client may have.**
Notes:

Based on the results of the OPISI and discussion with the client, a referral to the following services is also recommended:	Check all that apply
Attending Physician	
Sex Therapist	
Psychiatric Services	
Social Services	
Physical Therapy	
Other:	

Appendix D

Tables of Program Results

Table 1D

Summative Evaluation OPISI Performance Scores

	Initial Performance Score	Reassessment Performance Score	Change in Performance Score
Participant A	1.4	1.6	0.20
Participant B	4	6	2.00
Participant C	1	1	0
Group Averages	2.13	2.87	0.74

Note. Scores are based on a rating scale of one to 10, with a rate of one being little to no performance and a rate of 10 being no problems with performance.

Table 2D

Summative Evaluation OPISI Satisfaction Scores

	Initial Satisfaction Score	Reassessment Satisfaction Score	Change in Satisfaction Score
Participant A	1.4	2	0.60
Participant B	3.67	6	2.33
Participant C	1	1	0
Group Averages	2.02	3	0.98

Note. Scores are based on a rating scale of one to 10, with a rate of one being no satisfaction with current performance and a rate of 10 being completely satisfied with current performance.

Table 3D

Formative Evaluation of Knowledge Scores from Pre-/Post Surveys

	Pre-Survey Group Average Score	Post-Survey Group Average Score	Change in Group Average Score
Session One	3.00 (60%)	4.75 (95%)	+ 1.75 (+ 35%)
Session Two	1.71 (34.2%)	3.86 (77.2%)	+ 2.14 (+ 43%)
Session Three	3.33 (47.5%)	5.67 (81%)	+ 2.33 (+ 33.5%)

Note. Scores for session one and two are out of five possible points. Scores from session three are out of seven possible points.

Appendix E

Formative Evaluation Questions from Session One Pre-/Post Surveys

1. Is sexuality and intimacy just sexual activity?

2. Who is responsible for bringing up the topic of sexual health concerns with your healthcare team?

3. What is your love language?

4. True or false? Sexual health concerns are common among men and women who have had various types of cancer.

5. True or false? It is important to focus on societal views for traditional gender roles when trying to re-establish your new self after cancer and cancer treatment.

Appendix F

Formative Evaluation Questions from Session Two Pre-/Post Surveys

1. Circle the correct answer: When it comes to masturbation, (increasing or decreasing) masturbation can increase sensitivity during intercourse.

2. True or False: Sensate focused techniques are more about providing pleasure than the sensation of touch itself.

3. True or False: Increasing masturbation can help with sexual function and sleep quality.

4. What are 3 alternatives to intercourse sexual activity:
   1)

   2)

   3)

5. The 5 main strategies for conserving energy during everyday tasks include:
   1)

   2)

   3)

   4)

   5)

Appendix G

Formative Evaluation Questions from Session Three Pre-/Post Surveys

1) List 3 websites for purchasing sexual activity devices and/or equipment that offer discrete packaging.

    1.
    2.
    3.

2) True or false: Vibrators are for external stimulation and internal stimulation.

3) True or false: Vibrators decrease male's erectile function.

4) List 3 types of vibrators:

    1.
    2.
    3.

5) Prostate stimulators can be used:
    a. During oral sex
    b. During intercourse
    c. During masturbation
    d. All of the above
    e. A and B, but not C

6) Ben-Wa Balls can:
    a. Weaken vaginal walls
    b. Increase intensity of orgasm
    c. Help women reach orgasm quicker
    d. All of the above
    e. B and C, but not A

7) List 3 alternative everyday devices that can be used in similar ways as these sexual activity devices.

    1.
    2.
    3.