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School of Occupational Therapy

Program Development and Advocacy for Addressing Sex and Intimacy with Cancer Survivors

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Abstract

Objective: The purpose of this project was to educate cancer survivors, their partners, and healthcare professionals about the benefits of occupational therapy, specifically regarding sex and intimacy. A secondary objective was to advocate for the use of occupational therapy in community cancer care.

Methods: Diagnosis-specific education sessions about occupational therapy and sex and intimacy were provided during existing support groups to survivors. Additionally, one education session was provided to partners of individuals living with cancer, and one to healthcare professionals. Formative and summative assessments in the form of pre- and post-surveys were used to measure knowledge of occupational therapy and success of the program.

Results: The total sample size was 32 participants (N = 32). After the group sessions, 93% of participants (n = 13) stated they did understand occupational therapy's role in cancer care. When partners and healthcare professionals if they understood the role of occupational therapy on the post-survey, 100% (n = 1) of partners and 100% (n = 2) of healthcare professionals stated that they did. When asked if the session met participants' expectations for group sessions 71% (n = 10) said yes. When asking the partner group and the healthcare professional group the same question, 0% (n = 0) and 100% (n = 2) said yes, respectively.

Conclusion: Patient, partner, and provider education on occupational therapy and sex and intimacy is needed in cancer care. Survivors, partners, and providers found this education program to be beneficial overall.

Program Development and Advocacy for Addressing Sex and Intimacy with Cancer Survivors

Introduction

This doctoral capstone experience (DCE) and project was completed at Cancer Support Community of Central Indiana (CSC), a non-profit organization in Indianapolis that provides free services to all individuals affected by cancer. During a needs assessment with Lora Hays, the executive vice president of CSC, it was clear that there was a need for a sex and intimacy program for individuals with cancer. Lora Hays expressed a vision for population-specific education on sex and intimacy due to the differences between diagnoses. Because occupational therapy (OT) places a large emphasis on client-centeredness, this author decided to do program planning for population-specific education sessions regarding sex and intimacy at CSC. The diagnoses that CSC serves includes 45 percent breast cancer survivors, eight percent colon cancer survivors, eight percent lung cancer survivors, eight percent prostate survivors, four percent ovarian cancer survivors, four percent pancreas cancer survivors, and four percent blood cancer survivors. I had the opportunity to participate in advocacy at CSC due to the topic for this DCE. An education session was tailored to healthcare providers and emphasized facilitating discussions about sex and intimacy more frequently. This author also advocated for CSC to provide educational information and resources on sex and intimacy to their population.

This paper will contain background information on sex and intimacy as it relates to cancer survivorship, the theory and model that was the basis for this DCE, the project design and implementation, project outcomes, and implications for future practice.

Background

According to the National Cancer Institute (2020), there were about 16.9 million cancer survivors in the United States at the beginning of 2019, with an estimated 22.2 million by 2030. The number of cancer survivors in the United States is increasing, and healthcare professionals should focus on reducing their functional deficits and improving their quality of life. Cancer has many side effects that can affect one's quality of life and ability to participate in occupations. Galbraith et al. (2012) stated that the most impactful side effect that cancer survivors reported was sexual dysfunction. Sex is an activity of daily living (ADL) that OT should address. Although sexual dysfunction is a largely reported issue among cancer survivors, it is often overlooked by healthcare professionals including therapists.

The aims of this project were to educate cancer survivors on how cancer and treatment can affect sex and intimacy for different populations, educate cancer survivors on techniques to manage side effects to participate in sex and intimacy, and educate healthcare providers on the importance of OT in cancer care and the importance of addressing sex and intimacy with cancer survivors. In the past CSC has provided general information on sex and intimacy to a wide population. Stakeholders at CSC made it clear that there was a need for population-specific education because of the differences in experiences and side effects between gender and diagnosis. Not only did the stakeholders at CSC agree that there was a need for this type of program, but the literature supported the program.

Many individuals with cancer have issues related to sexual dysfunction. McLeod and Hamilton (2013) stated that roughly half of cancer survivors in their study of case examples report sexual dysfunction. Similarly, in a study done by Galbraith et al. (2012), survivors of prostate cancer reported that sexual dysfunction impacted them more than any other side-effect related to their cancer. These two studies show a need for addressing sex and intimacy with cancer survivors. During the development of this program, it was important to know what side effects cancer survivors reported interfering with their ability to participate in sex and intimacy. Cancer survivors have reported many sexual issues, including hot flashes, vaginal dryness, atrophic vaginitis, negative body image, fatigue, sleep difficulty, pain, loss of range of motion (ROM), short-term memory loss, difficulty with concentration and motivation, decreased libido, and more (Dizon et al., 2014; Kessing et al., 2016; Paterson et al., 2016). Additionally, it was important to understand that side effects, experiences, and concerns varied by population in terms of diagnosis. For example, Crowley et al. (2015) reported that prostate cancer survivors were concerned with physical changes to their body and their ability to give and receive pleasure, whereas breast cancer survivors were concerned with if they were attractive, if their bodies would still work sexually, concerned with pain during intercourse, and if they would be able to experience pleasure (Crowley et al., 2015). A survey was sent to participants of each education session prior to the session date to help understand specific problems and questions that each group had in order to remain client-centered.

Along with physical challenges, cancer survivors can experience barriers related to mental health. Sporn et al. (2015) reported that patients in their study experienced high rates of depression (65%) and anxiety (59%), which research has shown affects sexual satisfaction. Likewise, Baxter et al. (2017) reported that anxiety and depression impact a survivor's ability to engage in occupations such as sex. Therefore it is important to include information about mental health in population-specific education sessions.

Occupational therapists address functional deficits to enable clients to engage in ADLs, instrumental activities of daily living, rest and sleep, work, education, play, leisure, and social participation. Although occupational therapists can address functional deficits and improve quality of life, they are frequently underutilized in cancer care (Polo & Smith, 2017). Hwang et al. (2015) discovered that within their study, only four and a half percent of participants received OT during their first-year post-treatment, resulting in lowered quality of life. Occupational therapists can address functional deficits that cancer survivors experience and improve their quality of life, however, they are not given an opportunity to do so. Sex and intimacy are frequently unaddressed in healthcare settings despite many survivors reporting sexual dysfunction and the impact this ADL has on quality of life (Bober et al., 2019; McLeod & Hamilton, 2013; Vermeer et al., 2015).

Because sex is an ADL, occupational therapists are uniquely qualified to address it with individuals who experience illness or disability that decreases their participation in it. In a survey by Sporn et al. (2015), 41 percent of patients reported that they wanted their oncologist to ask about sexual health and 58 percent reported wanting their primary care physician (PCP) to ask about sexual health. However, over 90 percent of participants in the survey reported that their oncologist hardly ever initiated a discussion about sexual health and concerns (Sporn et al., 2015). Quality of life for cancer survivors can be greatly impacted when OT services are underutilized and the topic sex and sexual dysfunction is avoided by healthcare professionals. One education session was targeted at healthcare providers to educate them on OT's role in cancer care and the importance of addressing sex with patients. The survey sent to participants prior to the session date also asked participants if they have ever received OT services and if a healthcare provider had ever discussed sex and sexual side effects of cancer and treatment with them. This information helps to understand if OT is truly being underutilized in cancer care and if healthcare providers are addressing sex with their patients.

Theory and Model

The KAWA model guided this DCE project (Lim & Iwama, 2011). In this model, life flows like a river. There can be impediments in the flow of the river that is life, and it is an occupational therapist's job to remove the impediments and restore function."Rocks" are things that limit one's life flow (Cole & Tufano, 2008). For the population at CSC, "rocks" might included side effects from treatment, the stigma surrounding sex and intimacy, and poor quality of life. "Driftwood" refers to the attributes and resources of the client that can either be helpful or obstructive (Cole & Tufano, 2008). Examples of "driftwood" of individuals at CSC might include fear of asking about sex and intimacy, personal values, knowledge, personality, and confidence. By using my program to remove "rocks" and use "driftwood" to my advantage, I can work to address sex and intimacy with cancer survivors at CSC and improve their quality of life.

The Theory of Andragogy also guided this DCE project (Knowles, 1978). This theory helped plan and implement my program because it focuses on adult learning, and my program focused on education for individuals with cancer, all of which were adults. The Theory of Andragogy states that adult learners retain information relevant to them (Knowles, 1978). For this reason, I offered the program to all participants at CSC and invited those who were interested to attend. By doing this, only those who found the information relevant to themselves, attended sessions, likely leading to better outcomes. I also asked what questions individuals had prior to their session so that I could tailor the information to their personal experiences. By tailoring the information provided in my sessions, I was able to ensure that the information provided was relevant and meaningful for the individuals attending the session.

Project Description

Project Design

This project was developed to help meet the needs of cancer survivors at CSC and partnering hospitals. There is a gap in care due to healthcare providers not referring their patients to OT and not addressing sex and intimacy with their patient, despite the impact this ADL has on quality of life. This program aimed to educate cancer survivors about how sex and intimacy can be affected by cancer and cancer treatment, ways to continue participating in sex and intimacy, and ways to advocate for themselves by requesting a referral to OT or another appropriate provider to address sex and intimacy. The literature indicated that many cancer survivors experience sexual dysfunction, and it is not addressed, thus affecting their quality of life (Bober et al., 2019; McLeod & Hamilton, 2013; Vermeer et al., 2015).

In conjunction with the stakeholders at CSC, this author chose to offer diagnosis-specific education sessions during the time of already established support groups at CSC. One education session each was offered to the Women's Group, Breast Group, Men's Group, and Pink Youth Group during that group's pre-established meeting time. This ensured that diagnosis-specific information on sex and intimacy was being shared with the correct group. Meeting during the support group increased the likelihood of individuals attending the sessions because they likely already had this time set aside. Additionally, a group was created for partners of individuals with cancer and healthcare workers. The partner group was created because the literature indicates that partners of cancer survivors experience changes in participation in sex and should also be included in therapy (Ghizzani et al., 2018). The healthcare provider group was created to advocate for OT's role in cancer care, and the importance of discussing sex and intimacy with cancer survivors. Marketing strategies included distributing flyers to individuals at CSC via

email, support group leaders distributing flyers to their group, and counseling interns and other group leaders recommending the education sessions to any client they believed might benefit.

To measure the success of the program, I used formative assessments in the form of selfcreated pre- and post-surveys to measure knowledge of OT. I also use summative assessments to measure the success of the program during the DCE. Pre- and post-surveys were created for group sessions, the partner session, and the healthcare professional session. No standardized assessments were used due to the limited availability of tools that align with this specific program.

Implementation

There were four group sessions: Women's Group, Breast Group, Men's Group, and Pink Youth. Women's Group was a group for women of any age with any type of cancer, Breast Group was for older breast cancer survivors, Men's Group was for men of all ages with any type of cancer, and Pink Youth was for young adult women, ages 18 to 40, with breast cancer. Participants' diagnoses included breast cancer, prostate cancer, lymphoma, colorectal cancer, and ovarian cancer. Additionally, one group for partners of cancer survivors and one group for healthcare professionals were held. Group sessions were held virtually during each group's designated support group time. If an individual was not part of a support group, they were invited to attend the group that best fit their diagnosis. Each session lasted between 30-45 minutes and questions were accepted at the end. Pre-surveys were distributed to interested participants two days prior to the session in an introductory email. Post-surveys were distributed one day after the session to those who attended. Getting people to attend sessions was difficult due to the sensitive nature of the topic and stigma surrounding it. The sessions were marketed through support groups, counselors, and other group leaders. Creating and implementing this program during the COVID-19 pandemic also presented itself as a challenge because many people do not like to meet on a virtual platform and/or do not understand how to use the virtual platform.

Project Outcomes

I used formative assessments in the form of pre- and post-surveys to measure knowledge of OT and success of the program during the DCE. Pre- and post-surveys were created for support group sessions, the partner session, and the healthcare professional session. It was necessary to create three different pre- and post- surveys because the target population was different for support groups, the partner group, and the healthcare provider group, therefore the information provided and gathered differed. The use of pre- and post-surveys enabled me to see a clear change in participants' knowledge of OT and how cancer and treatment can affect sex and intimacy. Summative assessments were used for all groups to allow me to analyze feedback and make continuous quality improvements throughout the program.

There were four participants present for Women's Group, eight for Breast Group, eight for Men's Group, and two for Pink Youth. There were also five participants present for the partner group and five for the healthcare professional group. The total sample size of participants that attended one of my sessions was 32 participants (N = 32). Pre- and post-surveys were sent to all participants but, despite email reminders, not all participants completed one or both surveys. The total sample size for the group sessions was 22 participants (n = 22), however only 14 of the 22 (63%) participants completed the post-survey. There were five participants present for the partner group (n = 5), all of which completed the pre-survey, however only one completed the post-survey. There were five participants present for the healthcare group (n = 5), all of which completed the pre-survey, however only two completed the post-survey. When analyzing the pre-survey for group sessions, it was clear to me that many participants did not understand OT's role in cancer care and almost no one had ever been asked about sex and intimacy from a healthcare professional. In fact, only 32% of participants (n = 7) stated that they did understand OT's role in cancer care and 77% (n = 17) had never been asked about sex and intimacy by a healthcare professional. These numbers support Polo and Smith's (2017) statement that OT is underutilized in cancer care and the idea that healthcare professionals are not addressing sex and intimacy as they should (Bober et al., 2019; McLeod & Hamilton, 2013; Vermeer et al., 2015). After the group sessions, 93% of participants (n = 13) stated they did understand OT's role in cancer care, showing that my program was beneficial in improving knowledge of OT. When asked if partners and healthcare professionals understood the role of OT on the pre-survey, 40% (n = 2) and 60% (n = 3) of participants stated that they did, respectively. When asked the same question on the post-survey, 100% (n = 1) of partners and 100% (n = 2) of healthcare professionals stated that they did understand the role of OT.

The post-survey used multiple choice and short answer questions to explore participants' satisfaction with the session. When asked if the session met participants' expectations for group sessions 71% (n = 10) said yes. When asking the partner group and the healthcare professional group the same question, 0% (n = 0) and 100% (n = 2) said yes, respectively. Participants from the group sessions reported that the most beneficial parts of their sessions included the speaker being open and frank, talking about emotional effects of cancer, discussing advocating for oneself, the conversational nature of the session, and normalizing the topic of sex. Participants from the partner group reported that they found the most beneficial part of the group to be getting to hear about what OT can do for this issue. Healthcare professionals reported that the most beneficial part of the group to be information on how OT can address sex and intimacy.

Suggestions for change from the group sessions included keeping in mind that not everyone has a partner, explaining how biochemistry is changed with hormone therapy and how that affects sex, more discussion of body image, more detailed information on the use of assistive devices, and including more information about specific medications and their side effects. Because I collected this information after each session throughout my program, I was able to make immediate changes to the sessions prior to the next session based on feedback. For example, after the Breast Group session, many participants reported that they felt I assumed they all had a partner, which was not the case. Consequently, for the Men's Group, I made sure to talk about sex and intimacy for a single man, as well as those who were dating or in relationships. Suggestions for change from the partner session included having a doctor co-speak to explain sexual dysfunction in more detail. Suggestions for change from the healthcare provider session included providing more information on how to refer a patient to OT and where a patient should be referred to. Because I only ran these sessions once, I can make note of these suggestions for any future sessions. When asked if they would recommend the sessions to a friend, 57% (n = 8) of group participants said yes, 100% (n = 1) of partner group participants said yes, and 100% (n= 2) of healthcare professional group participants said yes. All of the information collected throughout this program has enabled me to make needed changes and improvements, as well as provided me with the information to improve the program should it continue.

Summary

The number of individuals affected by cancer in the United States is growing every year, affecting the functional abilities and quality of life for those living with cancer (National Cancer Institute, 2020). Occupational therapists are trained to address functional deficits, therefore improving quality of life, however they are underutilized in cancer care (Polo & Smith, 2017).

Despite sex being an ADL and sexual dysfunction affecting many cancer survivors and their quality of life, healthcare providers tend to leave sex and intimacy unaddressed when working with cancer survivors (Bober et al., 2019; McLeod & Hamilton, 2013; Vermeer et al., 2015). This statement was supported by the results of my pre-survey in which 77% (n = 17) of participants stated that they had never been asked about sex and intimacy by a healthcare professional.

CSC offers support services to cancer survivors free of charge and because if does not have a regular sex and intimacy program or group, this made it a great place for this program. Providing diagnosis-specific education to already established support groups at CSC made it easier to get relevant information about sex and intimacy to those who wanted it. Because CSC had support groups for women with cancer, men with cancer, breast cancer, and young adults with breast cancer, I targeted these groups and provided them with education about what OT does, how sex and intimacy can be impaired, how OT can address sex and intimacy, and how to advocate for oneself. There is a need to include partners in therapy; therefore, I also offered a partner group to educate individuals about how their relationships might change when their partner has cancer (Kessing et al., 2016). Providing a healthcare professional session served to not only educate healthcare professionals on the role of OT in cancer care, but also advocate for referring to OT and addressing sex and intimacy with patients.

Overall, this program was a success with improvements in knowledge across all groups and high satisfaction across all groups. Future suggestions to improve the program included, adding more content about dating and communicating with potential partners, more detailed discussion on body image changes and how to manage them, and more detailed information on the use of assistive devices. To improve this program in the future, the person implementing the

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program should add more information, such as exercises to improve body image, create a list of adaptive devices and prices, create a list of suppliers for adaptive devices, and do more research on dating with cancer. Additionally, the future person implementing this program should personally reach out to support group leaders about inviting their participants, consider requesting a list of support group members to contact personally, make presentations more interactive, and add activities and exercises to presentations. This program can be sustained even after my leaving CSC by encouraging CSC to continue taking DCE students and suggesting a sex and intimacy program for their project. By leaving all of the materials I have developed, research, outcomes, and my scholarly report in a binder with CSC before I leave, others at CSC could replicate or improve my program.

Conclusions

Throughout this project, I have improved my skills in program development and advocacy. Through experience, I learned about developing and utilizing surveys to measure change and gather feedback. Cancer survivors at CSC reported many sexual side effects of treatment and were happy that they were being given an opportunity to learn about those effects and how to manage them. Healthcare professionals that attended my session were overall happy with the information and learned more detailed information about what OT can do in cancer care.

CSC benefited from my program because I was able to provide an education service to their population that they did not already have. There was a gap in CSC's services that I was able to help fill. Because of the information I provided during my education sessions, cancer survivors at CSC are more knowledgeable about how OT can help them, more understanding of the sexual side effects they might experience and how OT can address them, and how to advocate for themselves. The program and its results were presented to the Vice President and Program Director of CSC at the conclusion of the program. Both individuals were happy with the program and program results and look forward to offering similar services in the future. The leadership at CSC understands the importance of addressing sex and intimacy with their participants and will continue to take opportunities to do so in the future.

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Appendix A

DCE Weekly Planning Guide

This table is a weekly planning guide that I developed at the start of my project to help guide me from week to week. I followed this weekly planning guide and made some adjustments as needed.

Week	DCE Stage (orientation, screening/evaluation, implementation, discontinuation, dissemination)	Weekly Goal	Objectives	Tasks	Date complete
1	Orientation Screening/Evaluation	1) Complete orientation by the end of the week. 2)Complete needs assessment with site mentors by the end of the week. 3)Review literature to understand need for education/program.	Meet with site mentors to discuss schedule and project. Complete orientation of the building. Discuss virtual work days (3 days/week). Review literature	Confirm orientation dates. Complete orientation of building Finalize and confirm MOU. Develop questions to ask mentors. Set up recurring meetings with faculty mentor. Begin working on project materials.	1/10 1/12 1/12 1/10 1/12 1/10

2	Screening/Evaluation	 Continue to review literature. Continue working on project materials (education presentations). 	Complete breast cancer and partner presentations. Review literature of program evaluation.	Review literature related to sex and intimacy and breast cancer.
		3)Start developing evaluation tools for project.		Review literature discussing sex and intimacy for partners of individuals with cancer. Review evaluation literature. Choose type of evaluation. Develop outcome measures.

3	Screening/Evaluation	 Develop men's group presentation by the end of the week. Develop Pink Youth presentation by the end of the week. Continue to develop outcome measures. 	Work on men's group presentation on Monday and Tuesday. Work on Pink Youth presentation on Wednesday and Thursday. Finalize outcome measures on Friday.	Create PowerPoint s for groups. Wrap up outcome measure and get it approved by mentor. Determine outcome measure format (phone call, paper, online).	
4	Implementation Screening/Evaluation	 Complete women's group session on Thursday 2/3) Email all women participating in group to administer survey and collect information. Distribute evaluation measure to participants. 	Get a list of women interested in participating in group. Contact all interested participants and gather necessary information. Follow up with participants after session.	Talk to site mentor about obtaining participant list.Implement education session.Follow up with participant s.Log all informatio n into necessary spreadsheet s.	

5	Implementation Screening/Evaluation	 Complete breast cancer group session on Saturday 2/12) Email all women participating in group to administer survey and collect information. Distribute evaluation measure to participants. 	Get a list of women interested in participating in group. Contact all interested participants and gather necessary information. Follow up with participants after session.	Obtain participant list. Implement education session. Follow up with participant s. Log all informatio n into necessary spreadsheet s.
6	Screening/Evaluation	 Begin analyzing data. Continue to review literature for new information. Develop education post for Facebook page. 	Ensure all data has been entered into necessary spreadsheets. Meet with faculty mentor to discuss data and a plan for analyzing/interpretin g it. Review new literature.	Double- check spreadsheet s. Enter any missing data. Set up meeting with faculty mentor to discuss plan for data. Continue to read literature. Incorporat e facts and figures into infographic for Facebook.

7	Implementation Screening/Evaluation	 Complete men's group session on Thursday 2/24) Email all men participating in group to administer survey and collect information. Distribute evaluation measure to participants. 	Get a list of men interested in participating in group. Contact all interested participants and gather necessary information. Follow up with participants after session.	Obtain participant list. Implement education session. Follow up with participant s. Log all informatio n into necessary spreadsheet s.
8	Screening/Evaluation	 Continue analyzing data. Add new data to spreadsheets. Continue to review literature for new information. Create education post for Facebook page. 	Ensure all data has been entered into necessary spreadsheets. Meet with faculty mentor to discuss data and a plan for analyzing/interpretin g it.	Double- check spreadsheet s. Enter any missing data. Set up meeting with faculty mentor to discuss plan for data. Continue to read literature. Incorporat e facts and figures into infographic for Facebook.

9	Implementation Screening/Evaluation	 Complete partner group session on Saturday 3/12) Email all partners participating in group to administer survey and collect information. Distribute evaluation measure to participants. 	Get a list of partners interested in participating in group. Contact all interested participants and gather necessary information. Follow up with participants after session.	Obtain participant list. Implement education session. Follow up with participant s. Log all informatio n into necessary spreadsheet s.	
10	Screening/Evaluation	 Continue analyzing data. Add new data to spreadsheets. Continue to review literature for new information. Create education post for Facebook page. 	Ensure all data has been entered into necessary spreadsheets. Meet with faculty mentor to discuss data and a plan for analyzing/interpretin g it.	Double- check spreadsheet s. Enter any missing data. Set up meeting with faculty mentor to discuss plan for data. Continue to read literature. Incorporat e facts and figures into infographic for Facebook.	

11	Implementation Screening/Evaluation Discontinuation	 Complete Pink Youth group session on Saturday 3/12) Email all young women participating in group to administer survey and collect information. Distribute evaluation measure to participants. 	Get a list of young women interested in participating in group. Contact all interested participants and gather necessary information. Follow up with participants after session.	Obtain participant list. Implement education session. Follow up with participant s. Log all informatio n into necessary spreadsheet s.
12	Dissemination	1)Work on DCE VoiceThread. 2)Work on DCE paper. 3)Work on DCE poster.	Complete first draft of DCE paper. Complete first draft of DCE VoiceThread. Complete first draft of DCE poster.	Combine all drafted sections for paper. Record VoiceThrea d. Pull informatio n from paper to add to DCE poster.

13	Dissemination	1)Complete final draft of DCE paper, poster, and VoiceThread.	Review changes to final materials.	Make suggested changes. Meet with faculty mentor. Meet with site mentor. Confirm final disseminati on date.
14	Dissemination	1)Present DCE project to board at CSC on Tuesday 4/12.	Confirm date with site mentor. Confirm meeting place for dissemination.	Meet with site mentor. Decide on in-person or virtual format.