

Occupational therapy health and wellness programming for a client living with cancer

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Cancer and cancer treatments can poorly affect performance of daily activities and quality of life during and after treatment for persons living with and beyond cancer (Neo et al., 2017). Authors of a systematic review found that 36.7% to 54.6% of persons living with and beyond cancer reported having disabilities related to performance in basic ADLs and IADLs after cancer treatments (Neo et al., 2017). Some of the common cancer-related side effects that present barriers to performance are cancer-related fatigue, sleep disturbances, cancer-related cognitive impairments, and stress (Baxter et al., 2017).

Further, specific social determinants of health can create disparities in health care access and delivery such as socioeconomic status, ethnicity, race, and gender have a particular impact on cancer care (Patel et al., 2020). These determinants contribute to poor outcomes in cancer care because they affect access to appropriate prevention and treatment, and therefore contribute to potential negative functional outcomes of survivors (Patel et al., 2020). Because of limited access to quality care, disparities in health care delivery can exaggerate any cancer side effects that impact performance of ADLs and well-being (Baxter et al., 2017). Occupational therapy programming that targets the side effects of cancer and improving performance in daily activities is beneficial to those living with and beyond cancer (Newman et al., 2019; Petruseviciene et al., 2018).

One occupational therapy intervention, the Occupational Therapy Health and Wellness Program (OT-HAWP) focuses on return to participation while managing the common side effects of cancer treatment for clients with various types of cancer (Polo et al., 2021). Participants in the original study received the community-based program in group format one time per week for 4 weeks, with 1.5-hour modules focused on sleep hygiene, fatigue management, cancer-related cognitive impairments, and stress management. Each week's education module focused on each of the side effects, their prevalence, how to identify the signs and symptoms, the possible impact on occupational participation, and environmental and task modifications that improve the performance of daily activities. Group members then engaged in action planning to identify strategies for improved individual occupational performance and practiced these at home for a week. Thirty-four participants with various cancer diagnoses completed patient-reported measures of occupational performance and satisfaction (Canadian Occupational Performance Measure [COPM]; Law et al., 2019), global health-related quality of life (Patient-Reported Outcomes Measurement Information System-Global Health; Hays et al., 2009), sleep quality (Pittsburgh Sleep Quality Index; Buysse et al., 1989), and the effect of fatigue on activities (Multidimensional Assessment of Fatigue; Belza, 1990). For all outcomes, there was a statistically significant improvement after participation in the 4-week program (Polo et al., 2021). Feedback from participants included the need for updating language in simpler terms for the educational scripted workbook for easy understanding and readability (Polo et al., 2021).

In this article, we describe how an occupational therapist (OT) modified and implemented the OT-HAWP in a hospital for low-income, underserved, and underinsured clients in an urban Midwest city. Relying on feedback from previous participants in the original study (Polo et al., 2021), and recognizing the low health literacy levels of the clients at her facility, the OT recognized a need to update the OT-HAWP workbook to adjust for the low health literacy levels. Additionally, recognizing her client population profile, she identified a need to offer the OT-HAWP as individual sessions in the infusion clinic instead of as group sessions. Therefore, the OT-HAWP was tailored to be at the recommended reading level of fifth to sixth grade to ensure understanding and improve access. The OT took the following steps to improve readability and health literacy access of the OT-HAWP:

- Step 1: The OT-HAWP was placed into a content and readability analyzer—Analyze My Writing—as recommended by the Agency for Healthcare Research and Quality's Health Literacy Universal Precautions Toolkit (Brega et al., 2015).
- Step 2: The initial reading level was evaluated based on the Flesch-Kincaid formula, the Simple Measure of Gobbledygook Index, and Fry formula for each page of the OT-HAWP workbook.
- Step 3: The OT-HAWP was revised by reducing sentence length and replacing medical

terminology with fifth or sixth grade layman's terms. The workbook was then reevaluated for readability. This process was repeated as needed until a sixth grade reading level was achieved.

Implementing the OT-HAWP

Given the outpatient infusion clinic setting, it was difficult to administer the OT-HAWP in a group format due to participants having limited access to transportation outside of their treatment time and different treatment dates and times. Therefore, the OT-HAWP was modified to individualized sessions and implemented during cancer treatments. The OT met the clients individually, while they were waiting for infusion, to screen for inclusion in the OT-HAWP. The screening included asking clients whether they were experiencing fatigue, sleep disturbances, cognitive impairments, or stress, which are topics discussed in the OT-HAWP. If a client stated that they were experiencing these side effects, they were considered candidates for the OT-HAWP, and the OT would educate them on the program, including the benefits as well as the necessary time and commitment.

Each of the four weekly modules in the OT-HAWP focuses on the common side effects of cancer survivorship that impact occupational performance: sleep disturbance, fatigue, cognitive impairments, and distress. Each module includes interactive education for each side effect on the prevalence, how to identify the signs and symptoms, the possible impact on occupational performance, and environmental and task modifications that improve the performance of daily activities. Self-management approaches in the program include goal setting, action planning for identifying strategies, and problem solving. One strategy includes recommending and trying mobile apps that could be used to facilitate management of the side effects. Examples of mobile apps that are present in OT-HAWP can be found in the online version of this article.

Case Example

Sam was a 69-year-old African American male who enjoyed cooking for family and friends, playing with his grandchildren, and going to professional football games. He was diagnosed with stage 3 multiple myeloma 1 year ago and stage 2 prostate cancer 2 years ago. He began receiving chemotherapy 8 months ago for both cancers. His treatments were delayed because he had only recently been able to afford medical treatment. Sam's individual chemotherapy sessions lasted 3 hours and were scheduled every 2 weeks. On the weeks Sam did not receive chemotherapy, he had radiation therapy.

Sam lived with his son for convenience and safety as he went through chemotherapy. Sam

reported fatigue, poor sleep, and stress while on active chemotherapy. He also reported that he was struggling to engage in his meaningful activities because of the side effects of the cancer and cancer treatments. Sam was experiencing episodes of depression due to the difficulties related to participation in his favorite activities as well as fulfilling his role as a grandfather. Further, he reported that he often disengaged from the family, not wanting to be a burden.

Assessment

After hearing about the OT-HAWP, Sam expressed interest in learning how to cope with his side effects, find ways to improve his role as a family member and grandfather, and improve participation in some of his favorite activities. The OT met Sam in a private exam room to screen him for participation in OT-HAWP. Through screening questions, Sam indicated experiencing difficulties with fatigue, cognition, and sleep or stress that impacted his daily life. He also indicated feelings of depression that were related to the other side effects. Sam indicated that if he could be more independent and less “reliant on others,” he might be less depressed. After identifying Sam as a good candidate for the OT-HAWP, the OT performed an occupational profile and collaboratively completed the COPM with Sam. After analyzing the data, the OT worked with Sam on creating goals using the COPM. She further described the layout of future sessions and provided him with the interactive OT-HAWP workbook. Goals identified by Sam as meaningful during the COPM were being independent in cooking, medication management, tailgating at football games, playing with grandchildren, and bowling.

Intervention

The OT-HAWP was implemented to align with Sam’s visits to the cancer clinic when he received chemotherapy infusions. Some mobile apps were recommended for Sam, who had a cell phone and was comfortable using it. The OT reviewed and vetted each app for appropriate functions and features before recommendation. Because of Sam’s financial constraints, the OT decided to use free mobile apps throughout the modules to keep costs minimal.

During the first session (Module 1: sleep hygiene), Sam complained of poor sleep due to his stress levels; therefore, the OT recommended the free version of Calm®, a mobile app to assist him with preparing his body for sleep. This app highlighted for Sam the importance of sleep and its impact on his daily activities. Sam and the therapist recognized that sleep difficulties were a result of his unmanaged stress levels. Stress management was addressed in a subsequent module.

During the second session (Module 2: fatigue management), Sam was instructed in how to use energy conservation strategies during daily performance of activities for fatigue management.

These strategies included using a chair when cooking or grilling for rest breaks, and finding games to play with his grandchildren that require sitting like board games, puzzles, and painting. Additionally, the OT asked the ordering physician to write a note indicating Sam's active cancer diagnosis and that he was in active treatment, to qualify him for a community home cleaning resource. Sam qualified and the company came to clean his house once a month during his cancer treatment, which helped him to conserve his energy for other prioritized daily activities.

During the third session (Module 3: cancer-related cognitive impairment [CRCI]), specific tools and strategies were provided to Sam including planning his day and week. He used a travel sized calendar to assist with remembering his appointments and dates for his extracurricular activities, and it included a notes section to help him remember his cooking tasks for the week. Sam also downloaded the free mobile app from Luminosity© and used brain games to target cognitive skills. The therapist recommended pre-packaged pills to organize his medications and ensure accurate and independent dosing. The OT communicated this need to Sam's social worker, who contacted his national pharmacy, which provided this service free of charge. This strategy allowed Sam to maintain control over his medication while reducing the cognitive strain and stress of medication management.

During the fourth session (Module 4: stress management), Sam was instructed in how to use the previously recommended Calm© app to help manage stress through meditation, controlled breathing, and mindfulness. Because Sam was familiar with this app from the module on sleep hygiene, the OT, working with Sam, chose this streamlined approach rather than introducing a new app specific to stress management.

Each subsequent session with Sam included a discussion on the effectiveness of the practiced strategies and tools, opportunities to ask any questions, and the need for any further problem solving for effective solutions. After a strategy was identified as one that Sam could successfully implement at home, the OT reviewed scheduling and/or frequency of its use, as applicable. Last, the OT provided Sam with information about community resources and local services such as support groups, cooking classes, assistance with nutrition, house cleaning, and transportation to support continued engagement in his daily occupations. The OT also educated Sam about ongoing monitoring for the possible side effects of cancer and occupational performance limitations, and an action plan was identified for steps to take for referral to occupational therapy services for future issues.

Outcomes

The COPM was re-administered at week 5 after the 4 week OT-HAWP program but before completing chemotherapy and radiation. Sam’s scores indicated a clinically important change in all of his goal areas, with an overall improvement in performance of two points and an overall satisfaction improvement of five points (see Table 1). A COPM change of 2 or more points is considered clinically important.

Table 1. Sam’s Pre-Post Canadian Occupational Performance Measure Scores														
Occupational Performance Problem					Baseline Performance			Baseline Satisfaction		Post-Intervention Performance		Post-Intervention Satisfaction		
Cooking	3	3	7	8										
Medication Management					6	5	8	8						
Tailgating at Colts Game					4	3	7	9						
Playing with Grandchildren					3	2	7	9						
Bowling at Bowling Club					4	4	6	8						
Total Average Score					4	3.4	7	8.4						

Sam indicated in a post OT-HAWP survey that the information presented to him was clear, interesting, and easy to use during daily activities. He further indicated that he understood all the information presented in the program’s workbook and that there were no medical terms used that were hard to understand.

Discussion

In summary, the OT-HAWP has previously been found to be effective with clients who are living with and beyond cancer in a group format in the community (Polo et al., 2021). This case example shows how the OT-HAWP can be successfully modified and implemented on an individual level, for 4 weeks, in an infusion clinic. Overall, implementing this program to individuals in the infusion clinic allowed the OT to gain better access to clients while targeting specific occupational performance issues, developing an action plan for change, and following up with individuals to assure recommendations and strategies were successful. Implementing occupational therapy programming such as the OT-HAWP throughout the oncology care continuum may ultimately

programming such as the OT-HAWP throughout the oncology care continuum may ultimately improve clients' satisfaction and performance of daily activities. Such programs can be in groups or with individuals, as demonstrated by this case example. Additionally, any program implemented by OTs should be designed and reviewed for recommended reading levels for improved health literacy access. This case example highlights two outcomes—the process and value of ensuring clients' understanding through improving readability and health literacy access, and how the OT-HAWP, which is a program designed for cancer survivor groups, can be successfully modified and implemented for individuals undergoing cancer treatment.

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