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Cancer Support Community Program Development: Health Promotion and Wellness Education

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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

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Abstract

Literature findings showed that there was a need for occupational therapy with cancer survivors due to chronic symptoms from cancer treatment. The purpose of the Doctoral Capstone Project at Cancer Support Community was to increase awareness of occupational therapy, provide health promotion and wellness education to cancer survivors, and obtain grant funding for an occupational therapy program at Cancer Support Community. A needs assessment was filled out by thirteen cancer survivors. Advertisements were distributed to obtain a caseload for individual and group sessions. An occupational profile and the Canadian Occupational Performance Measure were used for evaluation in individual sessions. Most goals were met in individual sessions showing increased occupational performance and satisfaction with performance as a result of health promotion and wellness education. Formative and summative evaluations were used for group sessions to measure increased knowledge and workshop quality. The Goal Attainment Scale measured outcomes for the Health Promotion and Wellness Education Program and showed that individuals could benefit from services with a part-time caseload. Increased knowledge was a result of the educational workshops. A grant application was submitted to a grant to sustain an occupational therapy program for these cancer survivors. Occupational therapists must continue to meet the needs of underserved populations like the cancer survivorship population.

Literature Review

Those who have had cancer treatment are living longer, which is increasing the need for occupational therapy services due to lasting effects from treatment as well as physical impairments from cancer and comorbidities (Hunter, Gibson, Arbesman, & D'Amico, 2017). The U.S. had approximately 14.5 million survivors of cancer in 2014, and that number is expected to increase to 18 million by the year 2022 (Hunter et al., 2017). Cancer can interrupt daily routines, work, leisure, social activities, and self-care (Hunter et al., 2017). Evidence shows that therapy services can benefit individuals before as well as after treatment while suggesting a multidisciplinary approach (Hunter et al., 2017). A multidisciplinary approach should include occupational therapy in important decisions in respect to population care for the betterment of this underserved population (Polo & Smith, 2017).

There is a major lack of referrals for rehabilitation with the cancer population as well as obtaining the appropriate services needed for their condition (Hunter, Gibson, Arbesman, & D'Amico, 2017). The young adult cancer population report a lack of services in the areas of emotional functioning, quality of life (QOL), work, and school (Sleight & Duker, 2016). The young adults expressed unmet needs within the areas of occupational therapy (OT), social support, physical therapy, and mental health (Sleight & Duker, 2016). Unmet needs for older adults include psychological distress and QOL (Sleight & Duker, 2016), which are areas where occupational therapists can help through meaningful occupational engagement. Cancer can also cause decreased activity participation and limitations within activity performance, in which occupational therapists can be of service (Hunter et al., 2017).

Cancer survivorship is considered the time of diagnosis until the person is no longer living (Baxter, Newman, Longpre, & Polo, 2017). There is not only a lack of rehabilitation for

survivors in treatment but also those in remission, which can exacerbate physical, emotional, and cognitive symptoms while limiting participation in meaningful activities (Baxter et al., 2017). Survivor's, in turn, lose independence and self-efficacy (Baxter et al., 2017). Occupational therapy practitioners can incorporate physical activity into daily routines to increase wellness, QOL, and overall health (Hunter et al., 2017). Physical exercise can also decrease fatigue, increase functional performance, and improve sleep (Hunter et al., 2017). Occupational therapists should include symptom management strategies through occupation-based interventions including education, energy conservation, and problem solving (Hunter et al., 2017). More research is needed that goes beyond exercising and physical functioning to include occupational participation and meaningful activities (Hunter et al., 2017).

OT's main role within the cancer population is ultimately increasing QOL through occupational engagement (Hunter et al., 2017). Cancer treatment targets the cancer tissue; however, the surrounding arteries, muscles, and nerves end up being collateral damage (Baxter et al., 2017). Given that individuals often have chronic symptoms and disabilities from cancer and cancer treatment, returning to one's previous vocation can also be difficult, and caregiver burden occurs if return to work is not an option due to chronic disabilities being a barrier (Baxter et al., 2017). Returning to work can be beneficial with recovery while having a sense of identity/purpose (Baxter et al., 2017). Cancer survivors, whether in treatment or in remission, are more likely to need assistance with Instrumental Activities of Daily Living (IADLs) and Basic Activities of Daily Living (BADLs) due to the symptoms they experience (Polo & Smith, 2017). Practitioners are responsible for providing health promotion and wellness services within cancer survivorship community settings to increase social participation, activity engagement, role productivity, and QOL (Polo & Smith, 2017). The action plan for occupational therapists

includes bringing awareness to the survivorship population and the population need, using supportive documentation for OT's unique role in this survivorship setting, advocating for a larger OT role within this setting, and providing supportive documentation of intervention efficacy within health promotion and wellness programs (Polo & Smith, 2017).

Occupational therapists are certified to provide valuable services to the cancer survivor population; however, occupational therapy is not seen in this community setting (Polo & Smith, 2017). A major reason why occupational therapy goes unrecognized is due to the majority of individuals who do not have a clear understanding of OT's role and the profession's valuable services (Polo & Smith, 2017). Many services that are related to health promotion and wellness at Cancer Support Community (CSC) are already in place, which makes the value of occupational therapy decrease (Polo & Smith, 2017). Occupational therapists can do a broad range of interventions with individuals; this causes confusion of what OT's distinct role is (Polo & Smith, 2017). For example, CSC has a program involving a 12 week "Moving Beyond" survivorship program dedicated to helping individuals with managing symptoms, so they can achieve IADL completion. Occupational therapists did not create this program, nor are they a part of the team for this program; however, they are qualified for this specific type of program and would bring value to the team.

A need exists for increased awareness for OT services and service reimbursement for survivors of cancer to increase occupational performance and QOL (Baxter et al., 2017). Occupational therapists must advocate for interventions related to self-management for acute and chronic conditions secondary to cancer and cancer treatment (Baxter et al., 2017). There are currently no OT services at CSC. Thus, the purpose of my Doctoral Capstone Project is to increase awareness of occupational therapy, provide health promotion and wellness education to

the members of CSC, and obtain grant funding for an OT program to provide program sustainability.

Specific Interventions

Effective OT interventions specific to the cancer population include energy conservation, problem solving, monitoring lymphedema, pain management, sleep hygiene, yoga, expressive writing, mindfulness techniques, increasing range of motion and strength, work simplification, sex, and body image (Braveman, Hunter, Nicholson, Arbesman, & Lieberman 2017). Greater than 30% of individuals with a new cancer diagnosis experience cancer-related fatigue within the first 12 months, 75% experience cognitive deficits while receiving treatment, 38% experience peripheral neuropathy from multiple treatment agents, 33-50% experience pain, 80% develop lymphedema post-surgery in 3 years or less, and 60% experience psychological issues (i.e. distress and stress) (Baxter et al., 2017). Currently, OT is an emerging practice area in cancer survivorship; however, OT has been shown to be effective in this practice area through applying adaptation, remediation, restoration, and compensatory approaches within interventions (Sleight & Duker, 2016). The implication for occupational therapists at a community site should include a health promotion and wellness approach to promote meaningful exercise and activity so that chronic symptoms are managed and prevented (Hunter et al., 2017). Occupational therapists need to make sure they are also addressing mental health, occupational participation, social engagement, QOL, and symptom management so that all aspects of individuals are being met (Hunter et al., 2017).

Hunter et al. (2017) looked at more specific interventions within this practice area. One finding was related to the cognitive rehabilitation approach which proved to increase overall attention and QOL (2017). There was also strong evidence supporting psychosocial interventions

including stress management, expressive groups, life review, cognitive-behavioral interventions, mindfulness techniques, problem-solving, and education to decrease depression and anxiety (2017). Moderate evidence supports life reviews, expressive writing, self-management training, and stress management as interventions to increase QOL and provide psychosocial adjustments (2017). Moderate evidence found that sex was the preferred form of exercise; however, high-intensity exercise is also supported- such as interval, home-based, and resistance exercises- for increasing functional performance in preparation of completing any activity that individuals need or want to do (Hunter et al., 2017).

Theory

The Model of Human Occupation (MOHO) uses a holistic approach to the OT process looking at the body and mind connection in relation to motivation through meaningful occupations (Cole & Tufano, 2008). This model encompasses a wide variety of illnesses and considers all ages of individuals (Cole & Tufano, 2008). The MOHO identifies what is meaningful to the individual through establishing the person's personal causation, interests, and values (Cole & Tufano, 2008). Interventions are individualized and relate to occupational performance, which may include modifications and adaptations (Cole & Tufano, 2008). Natural environments are ideal for interventions- especially those related to roles and habits (Cole & Tufano, 2008). The use of MOHO is supported within the community setting and is noted to positively challenge occupational therapists' perspectives on different beliefs and ideas (Wimpenny, Forsyth, Jones, Matheson, & Colley, 2010). The MOHO may be challenging to incorporate into practice given its complexity, but the model has lasting and tangible benefits (Wimpenny et al., 2010).

Lifestyle Redesign enacts and develops customized routines that promote health and include meaningful activities (Dieterle, 2014). Lifestyle includes ADLs, routines, IADLs, health status, mood, and habits (Dieterle, 2014). This is a client-centered theory focused on individuals or a group setting goals and creating an action plan so that the goals are attainable (Dieterle, 2009). Individuals become their own advocates for health promotion through identifying aspects of their routines and occupations that need altered for health-related goals (Dieterle, 2014). This can be as simple as drinking water instead of caffeinated beverages or deep breathing to relax (Dieterle, 2014).

Lifestyle Redesign Theory also applies to the cancer population with a focus on leading a healthier lifestyle over time (Dieterle, 2009). Another focus of this theory would be on stress management and participating in meaningful activities to increase QOL (Dieterle, 2009). One main activity would be healthy eating, which will be incorporated with referrals to the cooking group with the other Doctorate of Occupational Therapy (OTD) student at CSC (Dieterle, 2009). Other considerations within this theory include pain management, ergonomics, energy conservation, organization, exercise, time management, and prevention (Dieterle, 2009). Lifestyle choices have been proven to have a strong effect on cancer, such as diet, exercise, hormone changes, smoking, sunlight exposure, etc. (Lee & Loh, 2013). Out of those lifestyle habits previously listed, physical activity is the main contributor to cancer control and QOL which can be done through meaningful occupational engagement; however, one must participate in all types of exercise for the greatest cancer-related outcomes (Lee & Loh, 2013).

Screening and Evaluation

Preplanning

The OTD student and the vice president of CSC, Lora Hays, had a meeting one year prior to the DCE. Lora and the OTD student discussed many options for how OT could benefit the CSC population. Literature was well researched to identify aspects of the cancer survivorship population where occupational therapists could contribute within a community setting. All the literature found is listed in the literature review and validates the need for the occupational therapy profession practicing within a cancer survivorship community setting. CSC decided to take on two occupational therapy students, and the students discussed the similarities and differences in their roles before starting the Doctoral Capstone Experience (DCE).

Needs Assessment

Population health is considered the outcomes related to health within and distributed across a defined group of individuals (Braveman, 2016). Occupational therapists must analyze aspects of the population to determine needs related to occupational performance, and this can be done through a needs assessment evaluating the population level first and then the individual level or vice versa (Braveman, 2016). For group occupational therapy health promotion and wellness education sessions, individuals filled out a needs assessment in the form of a questionnaire at the first two educational workshops titled “Cancer-Related Fatigue” and “How OT can Help Cancer Survivors”. Not all attendees chose to complete the needs assessment, so those who attended Supper Club were also asked to fill the questionnaire. A total of twelve individuals completed the form. This needs assessment provided information related to needs found in the literature as well as feedback gathered from CSC stakeholders (i.e. vice president, president, and program and outreach coordinator) to provide themes of the overall needs specific

to the cancer survivor population. Identifying the needs of this population helped determine what programs and information were needed for this population. Lastly, a distress screener that contained questions related to the OT's scope of practice were used to identify needs for multiple individuals as well as justify the need for grant funding an OT program.

According to all the stakeholders involved at CSC and the evidence previously noted in the literature review, the CSC population needs OT services in the form of meeting physical, emotional, and psychological needs through occupational performance. Many individuals stated an interest in gardening; this will become available for the CSC members before the end of the DCE. The main theme among the needs assessments included a desire for increased occupational performance and participation. This looked different for every individual considering everyone's habits, values, and interests vary (see Appendix A). The Goal Attainment Scale (GAS) outcomes are to be determined at the end of the DCE, and the Canadian Occupational Performance Measure (COPM) was supported throughout literature which justified its use during one-on-one sessions.

GAS vs. COPM

The GAS was used to measure overall progress in the Health Promotion and Wellness Program and the grant funding process for the OT program. The GAS is used at a population level whereas the COPM is used at the individual level (Doig, Fleming, Kuipers, & Cornweli, 2010). The GAS is more objective whereas the COPM is more subjective (Doig et al., 2010). Both tools effectively show progress with occupational performance and participation levels, which relate to community-based goals (Doig et al., 2010). Both have good responsiveness and sensitivity to any change as well as good ecological validity for real-life functioning (Doig et al.,

2010). Using both tools has proven to result in significant improvements with client-centered goals (Doig et al., 2010).

The COPM is designed to prioritize and identify any problems with occupational changes that may occur over time; this is beneficial for chronic effects of cancer and cancer treatment (Nieuwenhuizen, de Groot, Janssen, Van Der Maas, & Becherman, 2014). The COPM identifies how satisfied individuals are with their occupational performance and which occupations are most meaningful (Nieuwenhuizen et al., 2014). A cancer-related community program called Camp Discovery had great success using the COPM to measure progress in satisfaction with occupational performance (Maher & Mendonca, 2018). The COPM is holistic and can be used for re-evaluation to measure progress throughout treatment from the perspective of the client (Nieuwenhuizen et al., 2014). This was beneficial for the doctoral project since the focus was on education with follow-up sessions discussing the implementation of strategies into everyday activities. The COPM also allowed the OTD student to take client reports and translate that information into measurable scores that could be used for goal setting.

The goals within the GAS focus on program development, advocacy, and educational components of the doctoral experience (Koski & Richards, 2015). The GAS is appropriate for the doctoral capstone and other non-classroom experiences due to its method of quantitative measurements for assessing competence within the student's individualized project goals (Koski & Richards, 2015). The GAS can also be used in a wide range of settings and has good sensitivity, test-retest reliability, and content validity (Koski & Richards, 2015).

Individual and Group Sessions

For individual sessions, the screening included education to individuals about OT-related services. Then, the individuals sought out services if they felt there were deficits within their

occupational performance due to chronic cancer-related side effects. Clients were evaluated using the COPM and an occupational profile questionnaire, which provided a holistic view of the unique needs of the individual clients. The occupational profile was based off the AOTA occupational profile template. Individual sessions allowed for individualized treatment to target occupational barriers specific to every individual. Necessary supervision was given to the OTD students for the COPM evaluation until competency was reached.

Group sessions were held in addition to individual sessions to address overarching cancer-related topics supported through evidence-based practice. The group sessions involved a formative and summative assessment for each educational session. The formative assessment was a pre-post Likert Scale survey which included questions to demonstrate increased knowledge after implementation of the educational workshops. The summative survey included questions about their satisfaction with the educational content and included open-ended questions asking what went well and what could have been improved. This was meant to improve the Health Promotion and Wellness Education Program as well as provide future occupational therapists with resources for continual improvement.

Occupational Performance and Participation

As the amount of cancer survivors continues to grow exponentially, activity performance, QOL, and participation in life roles are failing to be addressed whereas psychological and physical aspects of the individual are the focus (Hwang, Lokietz, Lozano, & Parke, 2015). This is important on the population and individual level in making sure all aspects of persons are being analyzed and synthesized during evaluation and throughout the OT process (Hwang et al., 2015). Some common psychosocial issues reported in the cancer survivorship community includes living with a constant caregiver shadow and fear that cancer will return (Hwang et al.,

2015). This is important for occupational therapy evaluation because these psychosocial issues result in decreased participation in meaningful activities including work and education (Hwang et al., 2015). Decreased QOL can be seen through the COPM evaluation and tends to be more severe in early survivorship (Hwang et al., 2015).

The population, individual, and organizational levels of CSC need to be educated on the role of OT in the cancer survivorship community setting. The knowledge on how occupational therapists can help cancer survivors will justify the need for occupational therapists practicing in this setting (Polo & Smith, 2017). Some areas where occupational therapists are valuable include accommodations for chemobrain, fatigue, and emotional needs (Polo & Smith, 2017). These are occupational barriers in activity performance to look for during screening and evaluation (Polo & Smith, 2017). About half of cancer survivors report that their occupational performance and social participation were lowered overall due to fatigue (Polo & Smith, 2017). Also, meeting emotional needs will increase self-efficacy and overall QOL (Polo & Smith, 2017). Lastly, cancer-related cognitive deficits can interfere with functioning and thought processes within one's normal daily routines/roles and can be managed with the help of an occupational therapist (Polo & Smith, 2017).

Community Setting vs. Other Practice Areas

As previously stated in the literature review, there is a great lack of referrals for occupational therapy in community-based settings for cancer survivors. OT implications for community-based settings focus on advocating for the needs of the community population being served and advocating for access to services through supportive documentation (Polo & Smith, 2017). Advocating for OT services and the cancer survivorship population will close the gap and allow equal access among individuals where services are not readily available in community

settings (Polo & Smith, 2017). When developing health promotion and wellness programs, the occupational therapist must be cognizant of state laws for planning interventions within the scope of practice as well as billing appropriate services under appropriate codes (Scaffa & Reitz, 2014). Within community settings, however, there is a serious concern with how OT services will be reimbursed (Polo & Smith, 2017).

According to Reilly (1971) (as cited in Scaffa & Reitz, 2014), the occupational therapist's role should transition from medical settings to the community with a focus on developing programs and experiences in an individual's natural community-based environment to increase adaptive competencies. Occupational therapists' main roles within a community setting include increasing QOL by increasing independence with ADLs, meeting psychosocial and emotional needs, managing chronic symptoms/disabilities, and promoting healthy lifestyles and overall well-being (Polo & Smith, 2017). The focus of health promotion programs involves enabling individuals to gain increased control over their health with a strong preventative component for overall wellness (Scaffa & Reitz, 2014). According to Finn (1972) (as cited in Scaffa & Reitz, 2014), the occupational therapist's role needs to expand in the community setting to assume roles such as a health agent, community organizer, advocate, program developer, and consultant. This was originally stated in the 1971 Eleanor Clarke Slagle Lecture and still reigns true in present day (Scaffa & Reitz, 2014). Taking on these roles beyond the therapist role at CSC will help the OTD student achieve the overall program goals.

Implementation Phase

Prior to the implementation of the program, a plethora of advertising methods for "Health Promotion and Wellness Education" services were used. The method that worked best was calling individuals from a roster of members that attended the cancer survivorship presentations

last year presented by the University of Indianapolis students. During the initial session, interventions were provided via education near the end of the session if there was time after the evaluation. Individuals were encouraged to attend follow-up appointments that involved more hands-on interventions or discuss education in further detail. The OTD student demonstrated competency in evaluation and implementation of education under supervision of a licensed occupational therapist. All resources used to educate individuals were supported through research.

According to the Indiana State Practice Law, OT students cannot provide OT services without supervision unless competency is demonstrated. Thus, the foundation of the health promotion and wellness program focused on educating individuals through a self-management approach. Educational handouts were created in relation to evidence found in research with compensatory strategies, stress management, energy conservation, peripheral neuropathy, and chemo brain for this population. Each member signed an agreement to demonstrate understanding that they were meeting with students who were not licensed occupational therapists. This agreement also included consent to educational intervention from the students with knowledge of the Indiana State Law criteria (see Appendix B).

Leadership Skills

Organizational skills were demonstrated through planning for group and individual sessions with members of CSC. Educational handouts were developed over specific cancer-related topics in preparation for members who would potentially benefit from them. An organized schedule was created by the OTD student to include the grant writing process, individual/group sessions, gardening program, and various other duties to manage time efficiently throughout the DCE. Professional communication and marketing skills were also

demonstrated by advocating for services through the companion (i.e. magazine calendar), flyers, phone calls, and word of mouth. Advertisements included examples of symptoms that have been researched within this population as well as a description of what occupational therapy is as a profession and what "Health Promotion and Wellness Education" services included. Individuals were made aware that services are being delivered by OTD students and that anything outside of education will be supervised by a licensed therapist prior to setting up the initial appointments. If individual needs were related to more traditional settings (i.e. outpatient) beyond health promotion and wellness services, then individuals were given a recommendation to obtain a doctor's referral for those services. For example, an individual may need a physician's referral and order for the TENS machine for pain management due to chronic neuropathy pain.

Other leadership skills included the ability to build rapport with individuals on a group and individual basis. Interpersonal and professional communication skills were needed when talking to the staff and CSC members. Confidence was shown when providing education to those who attended Health Promotion and Wellness education sessions. For individual and group sessions, accountability and punctuality was needed for appointments. Lastly, delegating responsibilities was demonstrated amongst staff members with different tasks.

Staff Development

Caseload was divided between two students for individual sessions. There were four individuals- not including the student- who were on the grant writing team and had extensive experience within grant writing. With this amount of people on staff, effective implementation was seen for the program as well as development of an occupational therapy program for sustainability purposes. Since students do not have enough competencies to provide interventions outside of education without supervision, the grant will be an excellent way to bring registered

occupational therapists to CSC to expand upon the service availability for individuals as needed and to promote occupational justice. One of the GAS goals measured staff requirements based on the number of individuals on caseload to represent the number of hours the occupational therapist would need to fulfill.

Discontinuation and Outcome Phase

Formative and summative evaluations were used to measure increased knowledge and satisfaction with the group educational sessions. Almost all formative surveys indicated increased knowledge after the presentations using a pre-post Likert Scale measure. Most of the group sessions indicated improvements needed in making the information more generalized based on the summative surveys. For example, the cancer-related fatigue presentation included information mostly related to chemotherapy and radiation treatment; however, the neuroendocrine and carcinoid group of individuals indicated that their fatigue comes from a different type of medicine that most of them take for cancer treatment. Group sessions are now designed to be as generalized as possible whereas individual sessions are specific to the individual.

Considering most of the “Health Promotion and Wellness” services were educational, quality of services was dependent upon the quality of evidence-based practice available. Substantial research goes into providing individuals with the newest and most consistent information so that participants can apply that information within daily life. The OTD students compiled all educational resources in a binder for future occupational therapists to utilize at this site. This will also add to sustainability of the occupational therapy program as well as improve the quality of services through patient feedback in the formative and summative surveys.

Grant Funding and Distress Screener

A grant will provide sustainability for the occupational therapy program at CSC. For the grant writing process, steps were taken to achieve outcomes based on the GAS criteria. Developing a skeleton proposal and cover letter were the beginning stages of funding an OT program at this site. Justification for funding an OT program at this community setting was included in the skeleton proposal in addition to the distress screener data collection to demonstrate the need for services at this site (see Appendix C). The target grant was decided on among the CSC and University of Indianapolis grant teams from a list of potential grants that the OTD student compiled. Most grants were found through the Infoed SPIN database, which is a global database with the largest selection of funding opportunities and uses a specific transmittal service to find the most accurate grants to fund specific needs. The submission letter was created after the grant meeting by the OTD student under the supervision of the grant teams. The skeleton proposal was reviewed by the University of Indianapolis and CSC grant writing teams to provide feedback for the final draft. After all materials for the grant application were finalized, they were submitted to the target grant that was chosen during the grant meeting. The grant will promote the emergence of occupational therapy at this setting to work on health promotion and wellness with the cancer survivors. The lack in OT services for cancer survivors occurs when there is a lack of awareness of OT and the benefits of OT services. Bringing in licensed occupational therapists and funding services through the grant will bring services to CSC beyond education to its members.

Multiple grants were chosen as target grants to apply for funding for staff hours and the COPM assessment tool. The target grants included the Walmart Community Grant and the Firestarter Award. Both of these grants are looking to fund community-based programs and grant

a max of $5,000 each. The Walmart Community Grant is focused on increasing quality of life within the community. The Firestarter award is looking for community-university partnerships to increase health equity, social health, and overall health.

Vision 2025

Society is changing with an increased population growth of cancer survivors. This is increasing the need for occupational therapy services as noted in the literature review. Part of the Vision 2025 includes building OT programs for accessible services that are customized and culturally responsive (AOTA, 2016). Having OT emerge in this cancer survivorship community setting will promote equal access to services for an underserved population. To bring awareness to the need for OT services in cancer survivorship community settings, the OTD student will attempt to submit an article to an occupational therapy journal. This will ensure ongoing client-centered evidence for vision 2025 as well (AOTA, 2016).

COPM Findings

Discontinuation officially took place when the DCE was over; however, individualized sessions required goals to be set in hopes that all individuals would meet their goals before that time. The individuals were encouraged to meet those goals and attend an average of three to four sessions total. Each individual had a long-term goal to increase their COPM performance or satisfaction scores by 2 points. Progress was measured at the final session by administering a reassessment with the COPM and comparing initial and final scores. Individuals were given strategies to help promote occupational performance, and the COPM scores were meant to provide evidence that these strategies helped increase their satisfaction with their increased occupational performance. The COPM score changes were not high enough to meet the long-term goal but individuals did make progress towards their long-term goal (see Appendix D). The

low scores for the COPM were due to the fact that caseload started picking up later in the program giving the participants less time to show improvements. Earlier recruitment will be beneficial when trying to build a larger caseload and give individuals the time to show improvement for future practice.

GAS Midterm Scores

The GAS outcomes at midterm included a score of -1 (i.e. somewhat less than expected) for the goal of effective advertisement as evidenced by the number of individuals on caseload. The second goal included progress seen in individuals as a result of the health promotion and wellness education program, which has a score of 0 (i.e. expected level of outcome) at midterm. Lastly, the grant funding goal has a score of -1 (i.e. somewhat less than expected) meaning that a rough draft of the skeleton proposal is the only thing completed at the point of midterm. The scores were predicted to increase by the end of the DCE. See Appendix E for GAS midterm results.

GAS Final Scores

The GAS outcomes at the end of the program showed significant progress for the overall Health Promotion and Wellness goals. The GAS outcomes included a score of -1 (i.e. somewhat less than expected) for the goal of effective advertisement as evidenced by the number of individuals on caseload. There ended up being five individuals on caseload by the end of the DCE. The second goal included progress seen in individuals as a result of the health promotion and wellness education program, which has a score of +1 (i.e. somewhat more than expected). Most individuals only met their short-term goals. Lastly, the grant funding goal has a score of +2 (i.e. much more than expected) meaning that the grants were decided on among the grant writing

teams and final draft skeleton proposals were submitted to the two target grants. See Appendix E for GAS results.

Overall Learning

Effective communication was used when recruiting clients over the phone or at different events. Communicating what occupational therapists do was difficult at a setting that does not have occupational therapy in addition to summarizing a broad profession. Also, the student's role at CSC was communicated in a way where individuals understood what was being offered with the health promotion and wellness education. Family was communicated with on occasion when referring their family member to our services if they felt that person could benefit from individual sessions. There were no other health providers at this site; however, referring individuals to art therapy or individual counseling as needed was expected. Quality interactive discussions were held at the different workshops with small groups of cancer survivors and critical reasoning skills were needed to sort through the problems discussed with different topics that were mentioned. Lastly, professional communication was used when communicating needs to different staff at CSC. There were times of uncertainty in knowing how to word something professionally, so building those communication skills was good for future practice.

The overall learned experience at this site was understanding how much work goes into starting a new program at a community setting where OT is needed. For example, grant writing will be a beneficial skill to have for future practice if that is needed. Starting a program involves a lot of continuous quality improvement as well, which will be beneficial with future practice with eliminating waste and improving quality of services. Learned experiences from mentors involved knowing different laws and ethics at a non-traditional setting where rules and regulations may not necessarily be set in place yet. Also, with a nonprofit organization it takes

the entire staff to work together in preparing different rooms for support groups or working different phone shifts at the front desk. So even though the main responsibilities of the student were related to occupational therapy, other responsibilities were expected when working at a non-profit community setting.

Leadership and Advocacy

As a leader, there were specific professional skills needed when starting an OT program at CSC. Flexibility is needed at a non-traditional setting when helping other staff members suddenly. For example, giving a stress management and mindfulness presentation to a support group with a two-day notice. Also, discussing different grants at meetings takes communication skills beyond the entry-level. To gain clients on caseload or encourage them to openly discuss their occupational issues in a group and individual session, a leader must make sure they are portraying non-verbal and verbal communication that deems the occupational therapist approachable. Lastly, listening to client needs is a very important leadership skill when providing client-centered health promotion and wellness education.

The majority of CSC staff and cancer survivors were unsure of what occupational therapists do; however, they would ask if occupational therapy was similar to physical therapy. The OTD student was constantly advocating for occupational therapy as a profession as well as for health promotion and wellness education. Individuals needed to understand what services were being offered to find appeal in participating in health promotion and wellness education for their benefit. Advocating for the cancer survivors' needs was done by advocating for OT services at this site as well as obtaining grant funding. The skeleton proposal included this justification.

In conclusion, cancer survivors often have residual symptoms years after cancer treatment. Occupational therapy as a profession is going unnoticed by primary care physicians

and the public, which is resulting in lack of referrals for the cancer survivor community. Obtaining grant funding at this cancer survivorship community setting will not only meet the needs of the cancer survivors but also provide opportunities for higher education by sustaining a partnership with the University of Indianapolis. The students will have a therapist mentor to guide them through the OT process in a non-traditional setting. Therapists must continue to advocate for OT services in emerging practice areas for underserved populations to promote occupational justice and QOL. Also, evidence needs to be expanded in the area of community practice with cancer survivors to increasingly show that a need exists for occupational therapy.

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Appendix A

Needs Assessment

1. **What do you consider to be meaningful activities to you even if you have trouble doing them?**
2. **What cancer-related symptoms do you experience?**
3. **What activities do you find difficult doing related to self-care if any?**
4. **What are some values and interests of yours?**
5. **What roles do you play (i.e. mother, caregiver, etc.) and what barriers are making those roles difficult?**
6. **How have your performance in daily activities/occupations changed over time?**

Appendix B

Participant Name:_____

Doctor of Occupational Therapy Student:_____

I understand that if I participate in any programs sponsored by Cancer Support Community Central Indiana (CSC-CI), I am responsible for ascertaining my physical and emotional ability to participate. I waive any claims that I may have against CSC-CI by virtue of participation in this program and any other programs offered to me in the future. I also authorize the use any photos taken during this program to be used by CSC-CI for future advertising and marketing of the program.

I understand that all individual health promotion and wellness education is completed by occupational therapy doctoral student interns and are supervised by a licensed occupational therapy practitioner.

Cancer Support Community (CSC) offers health promotion and wellness education to explore ways to optimize health through appropriate routine and participation in meaningful occupation. Educational sessions are available to members of CSC.

We ask that each participant for health promotion and wellness education is aware of the following:

1. CSC and University of Indianapolis doctoral students do not provide medical advice or assistance
2. We make every effort to begin and end sessions on time as scheduled
3. The staff members who provide this service keep all information confidential with the following exceptions mandated under Indiana State Law:
    a. Serious threats of violence toward another individual
    b. Suspected abuse or neglect of children, the elderly, or an individual with a disability
    c. Serious indication of harming one's self
    d. Legal requests from a court of law
4. Each participant accepting this education must sign this form

I have read and understand the above information.

_____ _____

Signature of Participant Date

Appendix C

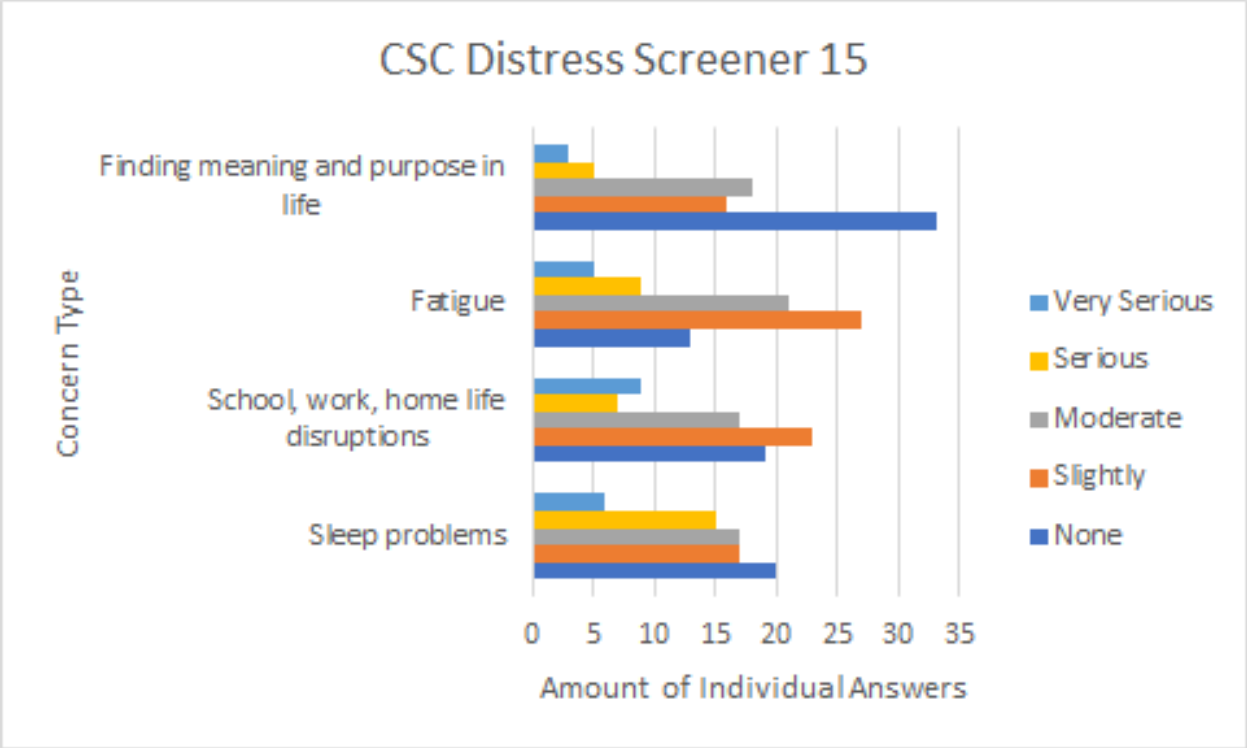

Figure 1C. Cancer Support Community Distress Screener 15 Data. This data is out of 75 individuals who completed the Distress Screener 15. The different legends represent the ratings of concern on a Likert Scale for four different questions related to occupational therapy's scope of practice with cancer survivors at CSC. Answering none means there is no concern in the four different areas of life, and answering very serious indicates severe concern. The data collection represents the surveys taken from 01/01/2017 to 03/08/2018. Approximately 56% of individuals answered with greater severity of overall concern, indicating a need for occupational therapy services.

Appendix D

Table 1D.

COPM Scores at Initial Evaluation and Discharge

Client	Initial Assessment Score		Reassessment Score		Score Change	
	Performance	Satisfaction	Performance	Satisfaction	Performance	Satisfaction
1	5.8	7.2	6.4	7.2	0.6	0
2	5.2	3	7.4	8	2.2	5
3	5.8	4.8	7.4	6.4	1.6	1.6
4	6.6	6.2	7.2	7.6	0.6	1.4
5	6.8	4.6	NA	NA	`NA	NA
Average Score Change					1.25	2

Appendix E

Table E1.

Goals Toward Developing an Occupational Therapy Program at Midterm

Goal Attainment Scale			
	Goal 1: Health Promotion and Wellness Education services will be advocated for through flyers, social media, magazine advertisements, and word of mouth with success evidenced by amount on caseload by April 27th, 2018.	Goal 2: The Health Promotion and Wellness Education program will prove effective in group/individual sessions and will meet the criteria of medically necessary at this setting through progress seen in individuals and the majority of goals being met by April 27th, 2018.	Goal 3: The grant writing team will collaborate with the OTD student in writing and submitting a grant application/letter to fund an OT program at CSC by April 27th, 2018.
Much less -2 than expected	No members of CSC on caseload.	Members made no improvements.	This task did not get completed.
Somewhat less -1 than expected	**There are 0-5 members of CSC on caseload per week.**	Members made insignificant improvements.	**The skeleton grant proposal rough draft is written.**
Expected level 0 of outcome	There are 6-10 members of CSC on caseload per week.	**The majority of CSC members increased knowledge in group sessions but did not meet goals in individual sessions.**	The skeleton grant proposal final draft is written and approved through UIndy grants office and CSC grants office.
Somewhat more +1 than expected	There are 11-20 members of CSC on caseload per week.	The majority of CSC members increased knowledge in group sessions and only met STGs with individual sessions.	A target grant is identified among the grant writing team.
Much more +2 than expected	There are 21+ members of CSC on caseload per week.	The majority of CSC members increased knowledge in group sessions and met all goals in individual sessions.	A full grant proposal is written and submitted to targeted grant.

Comments:	There are currently six individuals on caseload. The best form of recruitment was calling through a phone roster from the Cancer Survivorship educational session attendees from last year.	All group sessions have shown increased knowledge. Individual sessions have not gotten to the point of intervention yet.	The skeleton proposal takes the longest amount of time in the grant funding process.

Table E2.

Goals Toward Developing an Occupational Therapy Program at Final

Goal Attainment Scale			
	Goal 1: Health Promotion and Wellness Education services will be advocated for through flyers social media, magazine advertisements, and attendance to various events with success evidenced by amount on caseload by April 27th, 2018.	Goal 2: The Health Promotion and Wellness Education program will prove effective in group/individual sessions and will meet the criteria of medically necessary at this setting through progress seen in individuals and the majority of goals being met by April 27th, 2018.	Goal 3: The grant writing team will collaborate with the OTD student in writing and submitting a grant application/letter to fund an OT program at CSC by April 27th, 2018.
Much less -2 than expected	No members of CSC on caseload.	Members made no improvements.	This task did not get completed.
Somewhat less -1 than expected	**There are 0-5 members of CSC on caseload per week.**	Members made insignificant improvements.	The skeleton grant proposal rough draft is written.
Expected level 0 of outcome	There are 6-10 members of CSC on caseload per week.	The majority of CSC members increased knowledge in group sessions but did not meet goals in individual sessions.	A target grant is identified among the grant writing team.

Somewhat more +1 than expected	There are 11-20 members of CSC on caseload per week.	**The majority of CSC members increased knowledge in group sessions and only met STGs with individual sessions.**	The skeleton grant proposal final draft is written and approved through UIndy grants office and CSC grants office.
Much more +2 than expected	There are 21+ members of CSC on caseload per week.	The majority of CSC members increased knowledge in group sessions and met all goals in individual sessions.	**A full grant proposal is written and submitted to targeted grant.**
Comments:	Individuals would set up appointments and would either not show up or not call back. Otherwise, the caseload would have been rated at about a zero.	The long-term goal included the 2-point increase in COPM scores, which individuals did not meet. There needs to be extended time for individuals to show that much progress.	The grant sources will contact us and let us know whether or not they will fund the occupational therapy program or not.