



The Open Journal of Occupational Therapy

Volume 8
Issue 1 *Winter 2020*

Article 7

January 2020

A Personal Perspective on Daily Occupations to Counteract Cancer Related Fatigue: A Case Study

Sheila M. Longpre'

Gannon University, Ruskin, longpre001@gannon.edu

Katie M. Polo

University of Indianapolis, polok@uindy.edu

Mary F. Baxter

Texas Woman's University, mbaxter@twu.edu

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Recommended Citation

Longpre', S. M., Polo, K. M., & Baxter, M. F. (2020). A Personal Perspective on Daily Occupations to Counteract Cancer Related Fatigue: A Case Study. *The Open Journal of Occupational Therapy*, 8(1), 1-10. <https://doi.org/10.15453/2168-6408.1607>

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A Personal Perspective on Daily Occupations to Counteract Cancer Related Fatigue: A Case Study

Abstract

Background: This case study aimed to identify and describe meaningful physical occupations used by a cancer survivor to increase or maintain levels of participation during active chemotherapy and subsequent cancer related fatigue.

Method: A case study approach was used to develop an in-depth description and analysis based on one participant's experience with breast cancer and associated treatments. A semi-structured interview was conducted. The data were analyzed through description of the case, categories, and themes. It also included categorical aggregation in efforts to seek a collection of instances from the data to explore any issue-relevant meanings.

Results: Following data analysis, one overarching theme, return to normalcy, was identified with three subthemes: (a) prioritization of meaningful activities, (b) modifications to activities or routines, (c) lack of referral for immediate needs.

Conclusion: Personal knowledge of occupational therapy practice provided support for enhancing engagement in daily meaningful occupations. Lessons learned from this experience could be applied to clients experiencing cancer related side effects to improve engagement in daily occupations.

Comments

The authors report that they have no conflicts of interest to disclose.

Keywords

oncology, engagement, meaningful activities, occupational performance, case study

Credentials Display

Sheila M. Longpré, PhD, MOT, OTR/L; Katie M. Polo, DHS, OTR, CLT-LANA; Mary Frances Baxter, PhD, OT, FAOTA

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DOI: 10.15453/2168-6408.1607

Cancer, its symptoms, and the subsequent side effects of treatments create multiple physical and psychological challenges that can have devastating effects on a person's everyday life (Burg et al., 2015; National Comprehensive Cancer Network [NCCN], 2015; Pergolotti, Cutchin, & Muss, 2015). Many patients with cancer report changes in their physical activities, such as self-care and engagement in work and leisure, during cancer treatment and in its aftermath (Fleischer & Howell, 2017; Pergolotti, Deal, Lavery, Reeve, & Muss, 2015). Research provides support that physical activity helps patients to overcome cancer-related fatigue (CRF) (Buffart et al., 2017; Fuller, Hartland, Maloney, & Davison, 2018; Hunter, Gibson, Arbesman, & D'Amico, 2017; Repka & Howard, 2018; Thorsen et al., 2017). However, qualitative research that explores the extent to which cancer survivors use meaningful daily occupations to overcome fatigue is lacking. The current study uses a case study format to describe the purposeful use of meaningful occupations to overcome CRF.

The use of and reengagement in meaningful occupations is a vital foundation for occupational therapy (OT) interventions. Meaningful occupations are defined as "activities that bring meaning to the daily lives of individuals" (American Occupational Therapy Association [AOTA], 2017, p. 1), and it is the individual who defines what is meaningful to him or her. The philosophical base of OT practice is that engagement in meaningful occupations promotes health and well-being. The occupational therapist uses his or her knowledge of engagement in occupations as well as activity analysis to support clients in the engagement of meaningful occupations, both as an intervention strategy and as an outcome of therapy (AOTA, 2017; Buckland & Mackenzie, 2017; Rijpkema, Van Hartingsveldt, & Stuiver, 2018; Trombly, 1995).

Cancer survivors report fatigue as one of the most common adverse effects of cancer and cancer treatment (Bower, 2014; Burg et al., 2015; National Cancer Institute [NCI], 2018; NCCN, 2015). Indeed, CRF might persist for years after treatment completion in otherwise healthy survivors. CRF is known to disrupt all aspects of quality of life, including engagement in meaningful occupations (Abrahams et al., 2017; Baxter, Newman, Longpré, & Polo, 2017; Buckland & Mackenzie, 2017; Burg et al., 2015; Hwang, Lokietz, Lozano, & Parke, 2015).

Individuals with cancer or undergoing cancer treatment and experiencing the resultant fatigue often encounter a disruption in the engagement of meaningful occupations (Burg et al., 2015; DeSanto-Madeya, Bauer-Wu, & Gross, 2007; Fleischer & Howell, 2017; Hwang et al., 2015). Demands on performance for each occupation may require individuals to choose systematically which occupations he or she will engage in for the day. DeSanto-Madeya, Bauer-Wu, and Gross (2007) identified six themes that encompassed the variety of activities in which an individual with breast cancer may engage, including the impact of cancer on daily activities, interactions with others, home and work responsibilities, personal well-being and care, communication, and slowing down and pacing. They also identified both changes in normal activities and evidence of pronounced limitations, as well as the importance of maintaining as much normalcy in daily activities as possible (DeSanto-Madeya et al., 2007). These findings are consistent with other research reporting that many women with breast cancer experience limitations in physical functioning, including engagement in work and leisure activities (Fleischer & Howell, 2017; Hwang et al., 2015; Pergolotti, Cutchin, et al., 2015).

Caspersen, Powell, and Christenson (1985) describe physical activity as a complex behavior that can include engagement in leisure time, occupational activities, and household activities that are performed by everyone. The amount of engagement is subject to personal choice and varies considerably from person to person (Caspersen, Powell, & Christenson, 1985). Exercise is defined as

physical activity that is planned, structured, repetitive, and with an end result of improvement or maintenance of one's physical fitness (Caspersen et al., 1985). There is a growing body of literature that shows that physical activity, specifically tailored exercise programs, help alleviate CRF (Maltser, Cristian, Silver, Morris, & Stout, 2017; Thorsen et al., 2017). Evidence suggests moderate-intensity exercise for this population, and survivors interviewed after chemotherapy indicated preference to performing low to moderate intensity programs (Maltser et al., 2017; Thorsen et al., 2017). In addition, prescribed home programs can improve CRF over time (McMillan & Newhouse, 2011; Wirtz & Baumann, 2018); yet, the energy levels of cancer survivors affect their participation levels before the benefits of exercise are manifested (Polo & Smith, 2017).

As stated, physical activity is often defined as exercise, yet also includes engagement in leisure time, occupational activities, and household activities (De Vreede, Samson, Van Meeteren, Duursma, & Verhaar, 2005; Lacourt et al., 2018; Smith, Ng, & Popkin, 2014). The measurement for physical activity is energy expenditure, which is commonly measured using Metabolic Equivalent of Task, known as MET level. MET level is the estimated amount of energy used during physical activity, with 1 MET the equivalent of the amount of energy used at rest. MET levels are used to guide recovery of and re-engagement in physical activities, including activities of daily living during cardiac rehabilitation, ensuring a safe and gradual increase in energy expenditure (Ainsworth et al., 2011; Lacourt, et al., 2018; Rijpkema et al., 2018; Smith et al., 2014). In the literature, physical activity and exercise are synonymous. Walking at a moderate pace and yoga are considered a moderate MET of about three. Yet, a moderate MET level (3-4) also includes daily activities, such as showering while standing up, standing up to do the dishes, making beds, doing the laundry, light gardening, and standing up to complete crafts, such as cutting fabric or painting (Ainsworth et al., 2011; NCI, 2018).

Using MET guidelines, and following guidelines developed in the literature, engagement or re-engagement in physical activities can be used to address CRF (De Vreede et al, 2005; Rijpkema et al., 2018; Smith et al., 2014). Smith, Ng, and Popkin (2014) found that patterns of activities associated with housework, caregiving, and leisure were effectively used for increasing overall physical activity levels in sedentary adults, thereby meeting the physical activity recommendations. As a consequence, understanding the MET levels for activities of daily living, leisure occupations, and household tasks could guide the occupational therapist in facilitating participation in meaningful occupations that could systematically address CRF and other impairments that affect engagement in daily routines. There is a paucity of literature exploring the use of meaningful occupations to meet physical activity recommendations for cancer survivors. The purpose of this case study was to collect perceptions on engagement in daily occupations as a replacement for recommended rote physical exercise to combat CRF.

Method

A case study approach was used to develop an in-depth description and analysis based on one individual's experience with breast cancer and associated treatments (Creswell, 2013). A semi-structured interview was conducted in addition to the review of documents that provide additional trustworthiness to the data regarding daily engagement in meaningful occupations. Consultation with three university's institutional review boards determined that IRB review and approval was not required for a case study approach.

Participant

The participant for this case study was a 60-year-old female who, at the time of the interview, was a 1-year breast cancer survivor. She was diagnosed with stage 2B, Tumor 2 (T2 Nodes 1 (N1), Metastases 0 (M0) breast cancer in October 2016. In other words, her tumor was 2.5 cm in size and had some lymph node involvement but had not yet metastasized to other organs. She completed multiple rounds of chemotherapy with four rounds of doxorubicin and cyclophosphamide combined, followed by 12 rounds of tamoxifen. In June 2017, she underwent a lumpectomy with sentinel axillary node dissection, followed by 6 weeks of daily radiation to the right breast and axillary area. The participant is an occupational therapist who is employed as a university faculty member. In addition to her position at the university, she participates in a myriad of indoor and outdoor occupations, including fiber arts, gardening, and assisting her husband in ranch work.

Procedures

The semi-structured interview was conducted using GoToMeeting, which is a virtual platform for video conferencing (see Table 1). The semi-structured interview questions were designed to explore the participant's survivorship journey. During the interview, additional questions were asked based on the participant's response that reflected her knowledge of OT. The interview was recorded and field notes were taken during the interview. The audio recording was then transcribed verbatim. The data were analyzed through description of the case, as well as development of categories and themes (Creswell, 2013). The process of analysis included categorical aggregation to seek a collection of instances from the data and to explore any issue-relevant meanings. In addition, patterns were established to explore correspondence between two or more categories (Creswell, 2013). Naturalistic generalization was conducted through the data analysis to detect any generalizable information that people could learn from the case study. In naturalistic generalization, a process of reflection on the details and description occurs guiding the reader to deeper insight. Lastly, a detailed view about the facts of the case was used. During analysis, categories and themes were developed and compared to present a detailed description of the case study (Creswell, 2013). A peer review process resulted in agreement of categories and themes by the two researchers. Member checking was completed with the participant reviewing the categories and themes to ensure accuracy of data interpretation. This triangulation process of peer review and member checking was used to increase rigor and trustworthiness of the results.

Table 1

List of Semi-Structured Interview Questions

1. What was a "typical" day like for you prior to treatment?
 - a. During treatment?
 - b. Post treatment?
 2. What specific activities/occupations did you engage in during your course of treatment?
 3. What specific activities/occupations did you engage in before treatment?
 4. What specific activities/occupations do you engage in now?
 5. How do you determine which activities/occupations you will engage on a daily basis?
 6. Were there any factors that limited your occupational engagement? If so, how did they limit your engagement?
 - a. Did you have any formal restrictions imposed on you by the health care team during your treatment for cancer?
 - b. How did you prioritize what you would engage in for the day?
 - c. Have these factors changed over time? And if so, how?
 7. Were you offered OT during or post treatment? Do you think that would have been beneficial? Why? If you would have been offered that, what types of services do you feel OT could have provided to you?
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8. How do you think your formal preparation as an occupational therapist prepared you for this process (helped you during your survivorship), if at all?
 9. How was your energy level during treatment?
 - a. How is your energy level now?
 10. Did you keep track of your occupational performance during the time of treatment? How did you keep track?
 11. Do you keep track of your occupational performance post treatment? How did you keep track?
 - a. Are there any changes from prior to diagnosis (changes in what you did, or how long you could tolerate)?
 12. Did you require any adaptations for successful occupational engagement during treatment?
 13. Did you continue paid employment during treatment? If so, were you able to maintain full-time employment? Were there any barriers to employment? If so, what were some strategies you used?
 14. Did you continue to engage in social activities? Did you notice a change? If so, what were they? What strategies did you use to promote/continue engagement?
 15. What advice, if any, would you provide to other individuals who may be going through treatment for cancer?
 16. What advice would you provide to occupational therapists who may be working with individuals that have cancer that are currently receiving treatment?
 - a. Would the advice differ for those who are status post treatment?
 - b. What advice, if any, would you provide to health care workers in general?
 17. Is there anything not covered in the questions today that you would like to add?
-

Results

Following data analysis, one overarching theme, a journey of the return to normalcy, was identified with three subthemes of (a) prioritization of meaningful activities, (b) modifications to activities or routines, and (c) a lack of referral for immediate needs.

Overarching Theme: A Journey of the Return to Normalcy

During the interview, the participant identified the salient overarching theme of the return to normalcy throughout the cancer survivorship journey. The theme of a journey of the return to normalcy was chosen because it reflects the words and ideas that the participant used in the interview. She described this survivorship journey and her return to normalcy as a roller coaster, stating:

But it was a roller coaster. It was an up and it was down. You would sort of start evening off and then you'd get whammed with the next round of chemo. And those chemos were every 3 weeks and then weekly. So, by the time I kinda got back up to normal it was time for another chemo.

She also stated, "So, you'd feel bad on a Saturday and Sunday and then you know you'd start to climb back up and you never quite got back up to normal."

A pattern found in the data was that of a downward trajectory of occupational performance during times of active cancer treatment, particularly during her chemotherapy treatments. When describing the meaningful activity of gardening, she elaborated on this downward trajectory during treatment and her return to normalcy during her survivorship journey:

I'm almost back to normal. I can go out; I've been to the garden for about two hours now, it took me a couple of months to get to that point. I'd go out for about half an hour and that's all I could tolerate and I'm back up to about two hours which is what I would do before.

When analyzing the data further with these downward trajectories of occupational performance, three subthemes emerged.

Subtheme 1: Prioritization of meaningful activities. The first subtheme in a journey of the return to normalcy theme was prioritization of meaningful activities. The participant described the

importance of prioritizing her meaningful activities for continued engagement over other activities, such as exercise:

Cause I knew that if I exercised I wouldn't have energy to do anything else. And it was more important for me to, to try to keep the house partly clean and to make sure that we had clean laundry and, you know, and I do like to get outside and enjoy the sunshine and the breezes and stuff but I'm not going to go out and run for half an hour just for that sake. I want to do things that in the end have a meaning for me.

In addition, in this subtheme the participant described prioritizing her meaningful activities for three different reasons: (a) to balance activities that she needed and wanted to do, (b) to counterbalance the side effects of her cancer treatment, and (c) to meet certain MET levels.

The participant described prioritizing her meaningful activities by balancing what she needed and what she wanted to do in a day:

Or family members that I had to take care of, I would choose to take care of them at the cost of something else that maybe I wanted to do. You know, cooking a meal for family rather than sewing or getting into work rather than going out to lunch with friends. You know, just certain things you prioritize knowing that it was going to take your energy and that you would have to rest afterwards. Sort of that balance of what you need to do with what you want to do.

When receiving chemotherapy, the participant described prioritizing meaningful activities to counterbalance the side effects:

I knew that I wanted to keep my hands active because . . . and I don't know that there's any research to support this, but I was hoping that by keeping my hands active it would stave off some of the neuropathy. And so, I knit and I do needlework, quilting, needlepoint and other kinds of things. Knitting required my hands to be up and active and it required some thinking because there was a lot of manipulation of the yarn and the needles. And so, there were days when I could do that very well when I couldn't stand or sit at the sewing machine. So, I would sit and try to knit. So between those three issues I kept going back and forth between these three art forms, if you will, to try to counteract the cognition, the neuropathy, and the fatigue.

The participant also described prioritizing meaningful activities given their MET levels:

So, part of my training as an OT was in cardiac rehab and I was aware of the MET levels, which is a way of grading activity, for the amount of exertion and the amount of energy expenditure. So, you know, going back to the example that I used of a shower. I knew that a shower takes three to four MET levels depending upon whether you're standing or . . . how much you move around and whether you wash your hair or not. And of course, at that point (smiles and laughs) I didn't have any hair to wash. But still I would choose to do that instead of walking around the block. That was my choice of physical activity.

Subtheme 2: Modifications to activities or routines. While referring to prioritizing meaningful activities in her day, the participant described modifications to activities or routines that she would mindfully perform or problem-solve for better engagement. One such example describes modifications she performed during her chosen leisure activities:

So, the quilting needle is tiny and when my neuropathy was really bad I couldn't hold the needle and do an effective stitch. That's why I went to the larger needle for needlepoint and there were some days I couldn't hold that and I would go to the knitting needles that were quite a bit larger. I did find some gardening gloves that have like a silicone padding on them or covering on them, which means I didn't need as strong of a grip to pull the weeds out and to dig in the garden. I have a couple of raised beds and normally I would stand up and work them in standing and sometimes I would just sit on the side and kind of dig in while I was sitting down.

The participant also shared that modifications and energy conservation strategies were used to continue engagement in her daily routine. She stated:

If I was low level [energy], but not really down, then I knew that if I went I would find the energy to engage but I would keep it shorter than I normally would. I think time was a big modification.

In providing further explanation and details related to modifications in time, the participant talked about her engagement in quilting and sewing and related shorter times with more frequent rest breaks.

The participant also shared strategies of delegating tasks to others. She specifically spoke of driving. She explained that using energy to drive would not allow her to participate in the activity, such as church or quilt groups, when she arrived. She stated: "Sometimes I would have someone else drive me, or have someone pick me up. My husband was real good about dropping me off or picking me up later on."

In addition, she used modifications in her work activities, including scheduling of priorities and elimination of tasks, to continue work engagement. She indicated that work was a meaningful activity and it was important to engage in work activities to overcome fatigue. She stated:

I continued full time, but I had to back off [from] some of the things that I was involved with. So, for instance, we typically would have faculty meetings on Thursdays, and Thursday was the day I was getting chemo, so I worked it out with my supervisor that we'd keep me on full time and I'd do as much work from home as I could. So, I wasn't required to go into the office as often as I had been. I stepped off a major committee that I was on; I was the chair of Institutional Review Board, I stepped away from that. I was teaching one class on-line and one class face-to-face. So, I would go in the afternoon of the day before, I would teach my class, and I would be there in the afternoon to do student advising and other kinds of things that are required and I would go home Wednesday night, be ready for chemo on Thursday. Everything else I would do by phone or computer. I would join in the meetings that I could by phone.

Subtheme 3: Lack of referral for immediate needs. The final subtheme that was found during her survivorship journey and the return to normalcy was a lack of referral for immediate needs. The participant described that often she did not receive advice, education, or referral to appropriate professionals for changes that affected her engagement in daily activities. This lack of referral for immediate needs continued during her downward trajectories as she tried to return to some normalcy during her active cancer treatments. She elaborated:

When I had the surgery for the tumor, again, no information about, you know, they just said keep it clean and dry. There was no helpful advice on range of motion, activity limitations, nothing about wearing a bra, how to support yourself. Because the incision would pull on my skin and that would cause problems.

With this lack of referral for immediate needs, the participant gave credit to her OT knowledge and training in addressing these needs without a professional referral:

Well, I think my training as an occupational therapist and my ability to do an activity analysis certainly helped in making decisions . . . but definitely my OT training made a big difference in how I dealt with some of (my) immediate needs.

Although she possessed OT knowledge to assist with some of her immediate needs, sometimes this was not enough, and she had to stop meaningful tasks because of the effects of her cancer treatment causing issues with multitasking:

I'm involved with a sewing group at my church and they meet once a month and there were a couple of times when I would go to the meeting and we would be sewing, dialoging, planning, and interacting, and there were two or three times when I would say, "I can't do this" and would just leave. I can flip flop between all of that, but the fatigue or the concentration, I'm not sure which was the real problem with trying to work with that group or participate in that group. So that was quite shocking in a way to me that I couldn't deal with it because I can usually deal with that stuff pretty easily.

In summary, through an in-depth description and analysis of the participant's responses to the interview questions, major subthemes of prioritization of meaningful activities, modifications to activities or routines, and a lack of referral for immediate needs were identified. The participant's responses support an overarching theme of the return to normalcy during and after cancer treatments.

Discussion

This case study was designed to identify and describe how a cancer survivor used meaningful occupations that are physically demanding to increase or maintain various levels of participation during active chemotherapy and subsequent CRF. In the current literature, physical activity and/or exercise is described in detail. However, the results of this case study drew on the idea of prioritizing meaningful occupations that equate to MET levels 3-4, which is similar to current recommended physical activity engagement (Ainsworth et al., 2011; Lacourt, et al., 2018; Rijpkema, et al., 2018; Smith, et al., 2014). This innovative idea has not yet been defined and could be described as engagement in meaningful and physically engaging occupations. The case study provides insight into the occupations in which one cancer survivor chose to engage and highlights reasons for those choices, including meaningfulness and necessity. Prioritization of occupational engagement and modifications to tasks, routines, and processes were identified as key components in obtaining a return to normalcy. In addition, the participant identified a lack of referral to helpful resources, such as OT, as a potential impediment to the return to normalcy.

As demonstrated by this case study, the participant used her OT knowledge to promote participation through energy conservation techniques, modifications and adaptive techniques, and need-based strategies. The lack of referrals or information during cancer treatment required that the

participant establish her own way of completing daily physical activities, sometimes through trial and error. The participant used her OT training to determine the energy levels required to complete daily tasks, which led to the prioritization of meaningful and physically engaging occupations that could be completed in a day or a period of time. These results raise additional questions about the type of care being provided to individuals who are cancer survivors. Given the variety of training each health care provider has regarding oncology care, this study could be used to promote more comprehensive care to include the expertise of the occupational therapist across the cancer care continuum.

This case study approach was designed to address the specific findings as related to one individual; therefore, it is not generalizable. In addition, given the nature of case study research and the unique aspects of the participant being studied, this study cannot be replicated and is only applicable to the individual represented in the case study (Creswell, 2013). Additional research across cancer types exploring similarities and differences regarding engagement in physical occupations could be beneficial. Studies exploring dosing of MET level equivalent daily activities to develop guidelines for physical activity recommendations are warranted.

These results support the literature that indicates a need for and a lack of referral to OT for persons experiencing cancer and cancer treatments (Buckland & Mackenzie, 2017; Pergolotti, Cutchin, Weinberger, & Meyer, 2014; Pergolotti, Deal, et al., 2015; Stein Duker & Sleight, 2019). Yet, comprehensive care programs for cancer survivors across the cancer care continuum should include the expertise of the occupational therapist (Baxter et al., 2017; Pergolotti, Williams, Campbell, Munoz, & Muss, 2016). Occupational therapists can use knowledge of MET levels to guide reengagement in basic and instrumental activities of daily living. Knowledge and application of MET levels can contribute to ensuring a safe and gradual increase in energy expenditure (De Vreede et al., 2005; Lacourt et al., 2018; Rijpkema et al., 2018; Smith et al., 2014). Further, activity analysis and occupational profiles of engagement in leisure, personal care, and work occupations with equitable MET levels recommended for physical activity is warranted if person-centered care for cancer survivors is to occur. Of further note, expanding OT services for cancer survivors would necessarily require an increase in education for such. Educational and conference programs, as well as textbooks and literature related to OT in oncology care, are needed to advance practice in this area.

Conclusion

The results of this study provide evidence for the unique role that occupational therapists have in providing care to cancer survivors. Because of the limited research regarding the role of OT in oncology, this study was instrumental in providing the perspective of one individual receiving care across the cancer care continuum.

Overall, through personal knowledge in OT practice, personal choice, and the need to return to normalcy, the participant engaged in the occupations that she determined most meaningful. Since engagement in meaningful occupations is a core concept for OT practice, it seems that occupational therapists can be a vital component to the interprofessional health care team in an oncology setting.

Sheila M. Longpré, PhD, MOT, OTR/L; Gannon University, Ruskin

Katie M. Polo, DHS, OTR, CLT-LANA; University of Indianapolis, School of Occupational Therapy

Mary Frances Baxter, PhD, OT, FAOTA; Texas Woman's University, School of Occupational Therapy, Institute for Health Sciences- Houston

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