The issue is... the occupational therapist’s role in addressing the silent sequelae associated with cancer-related cognitive dysfunction among survivors of cancer

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THE ISSUE IS... THE OCCUPATIONAL THERAPIST’S ROLE IN ADDRESSING THE SILENT SEQUELAE ASSOCIATED WITH CANCER-RELATED COGNITIVE DYSFUNCTION AMONG SURVIVORS OF CANCER

by

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ABSTRACT

The National Comprehensive Cancer Network identified occupational therapy as a first line of intervention for the treatment of cancer-related cognitive dysfunction (CRCD) (National Comprehensive Cancer Network [NCCN], 2016). Thus, occupational therapists have an opportunity to develop interventions that facilitate participation in meaningful occupations for survivors of cancer living with CRCD. In this article, we argue for occupational therapists to create occupation- and evidence-based, client-centered interventions for survivors of cancer with CRCD that address the multidimensional presentation of CRCD. One survivor’s story illustrates the affect of CRCD on occupational performance and the features to consider when developing interventions to meet the unique needs of survivors of cancer with CRCD. We recommend that interventions can be provided through self-paced home programming, community settings, or delivered through modes such as tele-rehabilitation to reach the growing population of survivors of cancer.
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Introduction

For the past 30 years, the incidence of breast cancer has increased, partly because of early detection, more frequent screening through breast self-examinations, and the utility of mammography (DeSantis, Ma, Bryan, & Jemal, 2014). Despite the increase in incidence, mortality due to breast cancer has decreased in combination with earlier detection and effective systemic treatments (Edwards et al., 2014; Ulloa et al., 2015). With increased detection, the age of cancer onset is also declining with nearly 20% of breast cancer cases diagnosed in women younger than 50 years (Edwards et. al, 2014).

Prior to a diagnosis of cancer, women are fulfilling roles and responsibilities expected by the people situated within their sociocultural lives. They are daughters, mothers, spouses, sisters, workers, and friends to the people in their social worlds. In survivorship, most patients, especially women of a younger age, will be expected to return to these pre-cancer roles.

Throughout the cancer continuum, especially in survivorship, there is a persistent underutilization of rehabilitation therapy services despite a high prevalence of impairments that are responsive to intervention (Cheville, Kornblith, & Basford, 2011; Alfano et al., 2014). Research has documented that certain impairments such as psychosocial dysfunction, and cognitive impairment related to cancer often go undetected and/or untreated. Cancer-related cognitive dysfunction (CRCD) may affect learning and memory, executive function, and processing speed (Wefel, Saleeba, Buzdar, & Meyers 2010). More specifically, CRCD may impact word finding and language processing, multitasking and attention of a survivor (Wefel, Kesler, Noll, & Schagen, 2015). In
addition to persistent cognitive challenges, women who have survived breast cancer report ongoing challenges with pain, fatigue, sleep disturbances, and psychosocial distress (Desantis et al., 2014). These challenges may result in greater functional disability and decreased quality of life, which are also undertreated (Silver, Baima, & Mayer, 2013).

The National Comprehensive Cancer Network (NCCN) has identified occupational therapy as a first line of intervention for the treatment of CRCD (NCCN, 2016). Currently, there are a lack of occupation- and evidence-based, client-centered interventions that facilitate participation in meaningful occupations for individuals living with CRCD. While society attributes high standards of health and positivity to survivorship, individuals who have survived cancer juggle ongoing symptoms, such as CRCD, and expectations to return to daily activities (Kaiser, 2008). There is an inherent tension between viewing oneself as cured that is at odds with persistent problems that interfere with returning to one’s former self. One survivor’s story illustrates the impacts of CRCD on occupational performance and the features to be considered when developing interventions to meet the unique needs of survivors of cancer living with CRCD.

The Impact of CRCD on Daily Life

Nicole*, a 39-year-old survivor of breast cancer, was referred by a physician to outpatient occupational therapy, in a Midwestern suburban hospital in the United States, to address upper extremity dysfunction secondary to breast cancer treatment. Nicole received chemotherapy, radiation, a mastectomy and hormonal therapy to treat Stage III
breast cancer. After her diagnosis of cancer, Nicole was also diagnosed with depression and prescribed medication to manage her difficulty sleeping. Upon completion of her outpatient occupational therapy, Nicole was referred by her therapist to an occupation-based, self-management program for survivors of breast cancer with late cognitive effects of treatment. During the initial interview for the self-management program, Nicole reported and described her past medical history, including cognitive impairments and strategies she currently used to manage the impact of cognitive difficulties on daily life. She completed the Canadian Occupational Performance Measure (COPM) and the Functional Assessment of Cancer Therapy-Cognitive Function (FACT-Cog) (Law, Baptiste, Carswell, McColl, Polatajko, & Pollack, 1990; Wagner, Sweet, Butt, Lai, & Cella, 2009). The FACT-Cog is a self-report questionnaire used in clinical practice to evaluate a patient's cognitive function before, during, and after chemotherapy (Wagner et al., 2009). This initial interview provided the program’s occupational therapist with insight into Nicole’s perception of her performance and satisfaction in daily activities.

Nicole is married, African American, and the mother of two children. Nicole described herself as a homemaker, soccer coach, and the family “problem-solver.” When asked about her biggest challenges, Nicole responded:

My biggest thing is that I can’t find words…or figure out how to express myself. It takes me a minute. Multitasking and stuff, I can still somewhat do some of that. I do get waylaid at times, so it’s easy to distract me but I kind of, I don’t know, I just, I’m just really mellow about stuff now. When you were asking me does it affect my life, I’m like no, not really. I get a little frustrated that I can’t remember words at times, but eh…

These cognitive concerns affected Nicole’s daily routine in different ways and at different times. As Nicole explained, the CRCD impacted her ability to initiate and manage her
household chores:

I sit there…and stare at the house and say, ‘I should really clean up, but I don’t’…I’m supposed to do this and I don’t do this and I beat myself up about it but I’ve learned now, whatever, I’m a little more easygoing.

Nicole described how the CRCD affected her ability to cope with challenging tasks. Her cognitive difficulties resulted in the loss of her role as a soccer coach and contributed to social isolation from other parents on her son’s soccer team and school district. Nicole shared that her self-reported anxiety about passing a test interfered with her ability to be her son’s soccer coach:

I can’t have a day [when] I’m freaking out. I’m the coach for my son’s soccer team…and [for the coaching requirements] you need to take a test and everything, and I had a meltdown…You’ve got to take the test…[I’m] freaking out and I’m like ‘you have to read…how many did you get wrong?’

Ongoing cognitive deficits not only diminished her role as a coach, but disconnected Nicole from the community of fellow parents which were apart of her social environment. Nicole explained further that CRCD impacted her ability to socialize with parents in her children’s school and maintain family relationships, leading to increased social isolation. As the “problem-solver” and caregiver for multiple members of her family, Nicole had to manage both the impact of cancer on herself, and the impact on her family.

I’m a [freaking] wreck because I can’t express myself to [my family]. I’m holding it in…And so the stress of that feeling ‘cuz [my mom] puts it on my that I need to take care of everybody. I have to make everything right…But I refuse to let anything get to me.

It took me just now to get back on track mentally…[My sister] complains, ‘you’ve become so mean since you got breast cancer.’

Following the initial interview, Nicole withdrew from the self-management program,
citing child-care issues as the primary reason she was unable to participate in the intervention.

**Presentation of Self as Healthy – CRCD is Incongruent with Survivorship**

Nicole’s story revealed two important considerations to inform the development of occupation- and evidenced-based, client-centered interventions. First, we learn how cognitive challenges impact performance of daily activities. Nicole’s challenges with social relationships and instrumental activities of daily living, such as cleaning the house, are similar to those reported by the participants in a study of survivors of breast cancer with CRCD conducted by Player and colleagues (2014). Nicole reported that CRCD affected her ability to take care of her children, maintain and create social relationships, and be involved in her children’s school programs, which interfered with her occupational roles and responsibilities and contributed to social isolation.

Second, Nicole’s presentation of self in the interview was at odds with her self-reported performance of activities on the standardized assessments, the COPM and the FACT-Cog. For example, on the COPM Nicole identified cleaning (Performance: 3; Satisfaction: 1) and making herself a priority (Performance: 2; Satisfaction: 1) as two of six occupational areas that she would like to improve. Despite Nicole’s low COPM scores, she claims in the general interview that her decreased occupational performance does NOT affect her life. This discrepancy in Nicole’s presentation of self is consistent with literature about survivors of breast cancer. In order to move beyond the identity of a “cancer patient” a survivor may strive to present themselves as recovered, without ongoing occupational performance challenges (Kaiser, 2008). Because acknowledging
CRCD would perpetuate an illness narrative, survivors of cancer may avoid reporting ongoing symptoms. Even minor changes in a survivor’s cognition may be hidden or suppressed in order for the survivor to return to their former self (Pertl, Quigley, & Hevey, 2014). As reflected in Nicole’s FACT-Cog assessment, Nicole reported that cognitive impairments affected her multiple times a day, yet in the interview she reported that these same symptoms had no impact on her quality of life. Pertl and colleagues (2014) note that survivors of breast cancer may feel a moral obligation “to act and be healthy” (p.148). To project an image of well-being, Nicole reported that ongoing symptoms did “not really” affect her life, yet when the occupational therapist probed, Nicole recalled numerous on-going cognitive challenges.

Data from Nicole’s FACT-Cog revealed daily difficulty with initiating tasks. She reported to the occupational therapist that she no longer independently initiates morning routines, relying on her son to take over these responsibilities.

My son comes in the room…and he’s like ‘Mom, the alarm went off. Put the shower on’…I lay there and keep stalling and then he comes in and says mom it’s your turn [to shower now]. So that’s on a good morning.

Rather than attributing this change to a cognitive impairment secondary to cancer treatment, Nicole attributed decreased initiation to a personality shift: “I’ve learned now, whatever, I’m a little more easygoing”. The breast cancer literature states that the dominant image of a cancer survivor reflects exceptional health, strength in adversity, as well as triumphant behavior (Kaiser, 2008).

Frank (1995) notes that patients tell “restitution stories” to illustrate the dominant medical model of disease. That is, modern medicine can triumph or fight against disease
and return people to health. While Nicole attempts to embrace this restitution narrative, the data from her interview and assessments belie her story. When her story is viewed in relation to the assessment data, Nicole’s story reflects chaos and loss. Frank (1995) asserts that “chaos narratives” represent a life that is out of control because the person is still enmeshed in the sequelae of disease. Given the strength of the prevailing restitution narrative in our culture, Nicole avoids any discourse of ongoing concerns, and she presents herself as positive, easy going, and mellow. Changes in her cognition may be hidden or suppressed in order to return to her former self (Pertl, Quigley, & Hevey, 2014). However, in embracing the restitution narrative, the occupational therapy practitioner may miss the opportunity to understand evolving challenges to Nicole’s quality of life.

**Evaluation and Intervention Considerations**

As the profession creates occupation- and evidence-based, client-centered interventions to address the impact of CRCD on occupational performance, it will be important to recognize the multidimensional nature of CRCD. These dimensions include the psychosocial considerations related to societal expectations for survivors and the affect of pain, fatigue and sleep disturbances common among survivors of breast cancer (NCCN, 2016). Nicole’s story is unique and Player and colleagues’ research (2014) demonstrated that each women’s experience with cognitive changes following treatment of breast cancer is highly individualized. The occupational therapist listens to and validates the survivor’s personal narrative of the CRCD experience. Thus, it is crucial to evaluate which aspect(s) of cognition and other symptoms affect the occupational
performance of survivors of cancer. Nicole’s story highlights the need to elicit evaluation data through multiple methods including interview and standardized assessment. By carefully listening to patients’ stories and by reviewing a client’s cultural and personal context, social environment, role competence, performance patterns and process skills, the occupational therapist can analyze how cognitive abilities impact occupational performance (AOTA, 2014).

Survivors of cancer with lasting effects of cancer treatment, such as physical, psychological or cognitive concerns, may benefit from occupational therapy services that can be embedded in survivors’ daily routines. As they return to their pre-cancer identities, routines and responsibilities survivors may have less time and desire to return to the cancer center or hospital where they received treatment to eradicate the disease. Thus, we recommend that intervention(s) focus on self-management of symptoms and be provided in a variety of settings or modes such as tele-rehabilitation, or within community-based settings, such as outpatient clinics or local community centers.

**Conclusion**

Nicole’s story illustrates the complexity of survivorship and raises practical implications for occupational therapy’s role in the evaluation and intervention of CRCD. Occupational therapy practitioners can listen carefully for the often undetected and undertreated symptoms of CRCD through the use of multiple evaluation methods, including standardized assessment, client interview and observation of functional performance. These methods to understand clients’ needs can inform the creation of individualized intervention that address the multi-dimensional nature of survivorship.
Although Nicole’s story focuses on survivorship, occupational therapy practitioners can also play a role in supporting newly diagnosed individuals with breast cancer to develop strategies prior to cancer treatment to prepare for the possible cognitive, physical, psychosocial and emotional effects of treatment on occupational performance and participation in meaningful activities (Player et al., 2014).
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Vita