

Occupational Therapy Practice Opportunities when Working with Mothers with Breast
Cancer: A Pilot Study

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Abstract

The purpose of this study was to identify current and ideal occupational therapy practice for mothers with breast cancer, from the perspective of the occupational therapist, in order to describe strategies for effective occupational therapy practice with this population. A grounded theory approach was used to analyze two interviews from occupational therapists working with mothers with breast cancer. Three themes emerged from the interviews, identifying effective treatment strategies: giving a voice, preventing loss of motherhood, and collaborating with multiple disciplines. These themes identified opportunities for occupational therapists to maintain the occupational performance and feelings of success in mothers with breast cancer, as well as support interactions with their children. Therefore, occupational therapists, should advocate to be able to support the role of mothers receiving treatment for breast cancer

Occupational Therapy Practice Opportunities when Working with Mothers with Breast Cancer

Motherhood varies as each relationship between mother and child is unique, but the stages in which mother and child depend on each other follow a pattern over the course of the child's development. After birth, the role of mothers is interactive as they immerse themselves in their child's needs (Francis-Connolly, 1999). Then with age, the child no longer requires constant care, yet mothers still remain invested by providing emotional and instrumental support (Francis-Connolly, 1999). A mother's chronic illness, such as breast cancer, however, may interrupt this reciprocal relationship.

More than 200,000 women are diagnosed with breast cancer each year (Clemmens, 2009). In 2008, it was estimated that out of 125 million women, 3.5 million would be mothers with children under the age of 18 (Breast Cancer Moms, 2008). These women undergo potentially physically and psychologically exhausting intensive invasive treatment (Ogce & Ozkan, 2008). Therefore, the occupations of many families may be affected due to the diagnosis of breast cancer (Clemmens, 2009), and the routines of children tend to be disrupted.

A study observing the effects of breast cancer in 220 families, found that 33% of children displayed various behaviors, such as emotional distress, refusal to help around the home, avoidance of any topics related to cancer, or becoming overly attached to their mother (Walsh, Manuel, & Avis, 2005). Mothers' attempt to retain normalcy, in efforts to prevent further distress, including, shielding children from the situation and maintaining routines, habits, and rituals as it was before their diagnosis (Billhult & Segesten, 2003). Breast cancer and its treatment, challenge these attempts. Mothers may

have difficulty balancing care for their children as they have to increase care for themselves (Billhult and Segesten, 2003 and Ogce & Ozkan, 2008). Help with, managing demands of activities and changes in routine to care for children, can be addressed by occupational therapy (OT) treatment, as the OT practitioner promotes participation in valued roles.

The Occupational Therapy Practice Framework-2 (OTPF-2) (AOTA, 2008) identifies areas of motherhood where OT may be applied. Client factors detail a mother's beliefs and values in what motherhood should be, and the physiological functions of the body and its structure affected by the presence of breast cancer. Performance skills describes a mother's actions used to participate in caregiving tasks, such as bending and reaching to pick her child up in order to respond its emotions. Performance patterns refer to habits, routines, rituals, and roles; this may describe a morning routine of a mother with a young child, in order to fulfill the perceived expectations of a mother. These are areas where OT interventions can enhance the participation of mothers while undergoing breast cancer treatment.

Current research examining the application of OT to motherhood with breast cancer is minimal. There is a high focuses on OT lymphedema treatment and relaxation methods, providing little knowledge about the disease and its effects on the role of motherhood (Cohen, 2005). So, to help answer how OT practitioners can provide for mothers with breast cancer, it is important to first determine the challenging tasks of this population.

Background

Motherhood. Motherhood is a biological role, defined by caring for children, helping them grow, keeping them safe, and passing on family values (Elmberger, Bolund, & Lutzen, 2005). Akerjordet and Severinsson (2010) interviewed 10 mothers of newborns two to three days post-delivery, to understand the experience of assuming a mother's responsibilities. Findings show that these women were critical of themselves as they prioritized responsibilities to create an image of a picture perfect mother based on personal experiences and parental modeling. Women then realized they were no longer just wives or career women, but now had a greater role in life by taking care of another individual (Akerjordet and Severinsson, 2010). All in all, motherhood involves changes in mentality in addition to providing care.

The role of motherhood continues to be defined over the course of the child's development. Francis-Connolly (1999) conducted 40 individual, semi-structured interviews to identify the tasks mothers engage in with children from preschool age to young adulthood. Tasks of mothers were organized in stages: motherhood immersion – demanding of the mother's time due to dependency of infants; enfolding activity – greater interaction with the child as they can endure play; young adult stage mothers – when the child becomes independent but may still require their mother's emotional and instrumental support, such as with finances; invested participant – when a mother is the home base for when the child needs advice, emotional and instrumental support, and may also look to mothers for enjoyment in their company. A "help exchange" between mother and child can also occur, when the mother begins to seek emotional support from

her child. A mother's role of providing for her child appears to continue periodically throughout the child's life, even when children are at a stage of independence.

Akerjordet and Severinsson (2010), and Elmberger et al. (2005) interviewed mothers who reported striving to be their image of the ideal mother. A grounded theory method was used to extract main concepts. The epitome of motherhood was highlighted as fulfilling tasks and providing resources beyond what is expected (Elmberger et al., 2005). This explained why mothers delved into their child's activities and participated as much as possible (Elmberger et al., 2005). When mothers, however, are unable to carry out what is beyond their perceived tasks, Elmberger et al. (2005) indicated that feelings of guilt and self-blame arise. The complexity of motherhood appears to not only be framed by the responsibilities in place, but set to what may be an unrealistic standard of perfection.

Motherhood and Chronic Illness. The physical impact an illness and its treatment process has, limits the interaction between mother and child (Farber, 2000; Vallido, Wilkes, Carter, & Jackson, 2010). In interviews, mothers who had cerebral palsy, Parkinsonism, multiple sclerosis, fibromyalgia, retinitis pigmentosa, and diabetes recounted experiences that were both different from and similar to those of mothers without an illness (Farber, 2000). The experience that differed was the decrease in active participation of mothers with an illness. One participant described how she felt unable to protect her child in a harmful situation, and multiple mothers said they were more likely to refuse participation in family activities due to fatigue and lack of endurance. These chronic illnesses withdrew mothers from social participation with their children, family, and community, due to the physical impacts of their diagnosis.

The change in amount of mother-child interaction due to a medical diagnosis was also related to how mothers perceived their role as a caregiver (Farber, 2000; Vallido et al., 2010). Vallido et al. (2010) identified overarching themes from 13 studies of mothers' experiences when affected by an illness. The themes were disruption of mothering, restructuring the role of a mother, feelings of guilt, preventing children from suffering, medical experiences, and mother's endurance to live. Supporting a mother's statement in Elmberger et al. (2005), all mothers from the studies analyzed in Vallido et al. (2010), expressed feelings of guilt and shame because they were unable to maintain ideal care for their children. Sense of identity and purpose (Elmberger et al., 2005) was undermined, as they were unable to sufficiently fulfill their maternal duty (Vallido et al., 2010). Three of the 13 studies analyzed in Vallido et al. (2010) pertained specifically to cancer. Cancer of the breast is the most prevalent cancer for mothers (Billhult & Segesten, 2003) as it is diagnosed in 1 in 4 women in the U. S. (American Cancer Society, 2009). Therefore, mothers with breast cancer can be assumed to be a sizable population that endures changes in motherhood as treatment progresses.

Motherhood and breast cancer. Breasts are a sign of maturity and a feature of women's sexuality; however, they are also a symbol of maternalism (Langellier & Sullivan, 1998). Biologically, breasts are the means by which infants receive nourishment and overall exemplify the care and affection mothers provide for their children (Langellier & Sullivan, 1998). A majority of breast cancer cases involve surgery to remove the tumor in a part of or in the entire breast, followed by weeks of radiation or accompanied by chemotherapy, hormone therapy, or other forms of invasive treatment (American Cancer Society, 2009). Based on the studies observing the influence of

chronic illnesses and motherhood, it may be assumed that when the physical manifestation of breasts is affected, the identity of being a mother is not only challenged, but the representation of motherhood is reduced physically and figuratively, and rightly or wrongly may call into question whether mothers are fulfilling their role.

Side-effects of breast cancer treatment affect mothers both physically and psychologically. Ogce and Ozkan (2008) assessed the function of women diagnosed with breast cancer in a longitudinal descriptive study, during two rounds of chemotherapy. Results identified a significant change between pre and post chemotherapy treatment. Some physical effects were anorexia, fatigue, groin and back pain, lack of energy, nausea, vomiting, insomnia, indigestion, lack of concentration, shortness of breath, hair loss, and dry mouth (Ogce & Ozkan, 2008). Some psychological effects were depression, nervousness, hopelessness, tension, and fear. Ogce and Ozkan (2008) also suggested that these psychological effects are most common and are unavoidable. These major symptoms require mothers to focus their energy on themselves causing them to withdraw from family activities and fall behind on household care (Ogce & Ozkan, 2008). These constant symptoms often disrupt motherhood and make it difficult to maintain the energy to provide the consistent care children need.

Mothers diagnosed with breast cancer are aware of how their symptoms affect their care giving, and in response selectively choose how they spend their time (Billhult & Segesten, 2003; Coyne & Borbasi, 2007; Elmberger et al., 2008). In response to breast cancer and its various treatments, mothers who were interviewed in Coyne and Borbasi (2007), Billhult and Segesten (2003), and Elmberger et al. (2008) voiced the need to budget their priorities. Mothers banked the little energy they had into interacting with

their children and providing a “normal” life, for example, continuing to attend sporting events (Billhult & Segesten, 2003), cooking meals, and helping with school work (Elmberger et al., 2008). Ten women explained that maintaining a routine was aimed to prevent the disease and its treatments from interfering in their child’s life (Billhult & Segesten, 2003). Coyne and Borbasi (2007) and Elmberger et al. (2008) also surveyed women who scheduled breast cancer treatments when their child was not home or in the evenings.

Although mothers attempted to prevent their children from being affected by their diagnosis, children were still highly aware of the presence of breast cancer in the home. Forrest, Plumb, Ziebland, and Stein (2006) explored how children in three age groups: 6-10 years, 11-15 years, and 16-18 years old perceived their mother’s recent breast cancer diagnosis and treatment. Elementary aged children (6-10 years) appeared to make connections from what they have seen and heard through the media and/or school to recognize that breast cancer may lead to death. They were highly aware of the physical changes their mothers endured, such as their loss of hair during chemotherapy. It was found that all age groups developed fear and anxiety in response to the presence of breast cancer (Forrest, Plumb, Ziebland, & Stein, 2006).

Adolescents, however, displayed different behaviors in response to breast cancer in their home. Clemmens (2009) conducted qualitative interviews with adolescents, to determine how they responded to having a mother with breast cancer. Clemmens (2009) found that these children would lose concentration in school and during extra-curricular activities, and took on a more independent role in the home to relieve their mothers from the responsibility of taking care of everything for them. Adolescents of this study also

strove for normalcy. Surveyed mothers, however, did not realize that their children were making these changes (Clemmens, 2009). Clemmens (2009) suggested that symptoms, from the mothers' breast cancer diagnosis and treatment drew focus away from their children, so that mothers could take time for themselves. This shift of mothers' attention supports earlier suggestions made by Billhult and Segesten (2003).

While some adolescent children are changing their routines to accommodate their mothers' needs, mothers are attempting to do the same. According to Clemmens (2009), Coyne and Borbasi (2007), Billhult and Segesten (2003), and Elmberger et al. (2008) mothers with breast cancer strive to maintain normalcy for their children. Some mothers would also attempt to ignore their symptoms in order to participate in their children's activities as much as possible (Billhult & Segesten, 2003; Elmberger et al., 2008). These research findings suggest, that in attempt to preserve normalcy in habits and routines, mothers attempt to reinforce their caregiver role by attempting to provide extra care for children while adolescents may try to reduce their care needed. Thus the behavior of mother and child are at odds as each one's goal challenges what the other is doing.

OT and motherhood. Roles are designated by society and cultural expectations likewise, but ultimately determined by the individual (AOTA, 2008). As mentioned earlier, mothers have preconceptions as to what a mother should be and provide, which determines how mothers perform their day to day life. The perceived role of motherhood constructs part of their identity which supports their values and beliefs in how mothers expect themselves to perform (AOTA, 2008). Breast cancer is a highly invasive disease infecting mothers' performance in care giving functions; thus affecting her beliefs and overall identity.

Within the range of treatments given to mothers with breast cancer, physical rehabilitation is not a part of their standard area of care (Schmitz, Stout, Andrews, Binkly, & Smith, 2012). As previously stated, mothers undergo through a series of physical changes, so physical rehabilitation would be assumed beneficial. Clients diagnosed with breast cancer however, only receive rehabilitative care when referred by their primary care physician (Schmitz et al., 2012). Recently a prospective surveillance model (PSM) for rehabilitation was proposed for clients with breast cancer (Gerber, Stout, Schmitz, & Stricker, 2012). PSM promotes early identification and intervention for physical impairments, which would allow a multidisciplinary team to collaborate to promote overall wellness for this population (Schmitz et al., 2012). Within a model such as this, the profession of occupational therapy could begin to identify a role within the standard area of practice for mothers with breast cancer.

Occupational therapy should be considered a part of the PSM to not only address physiological deficits but also the role of motherhood impacted by the diagnosis. A mother's routine is stressed by the diagnosis of a physical disability, such as, breast cancer, as it forces mothers to attend more to their own health as they attempt to maintain normal routines for their children (Billhult & Segesten, 2003; Coyne & Borbasi, 2007; Elmberger et al., 2008). The literature tends to focus on mothers with children who have a disability, leaving minimal research to examine OT treatment for mothers with a physical disability.

A case study by Grant (2001), explored the experience of four mothers with arthritis and the experiences gained during OT treatment. Mothers identified a range of OT interventions: pain management, joint protection, relaxation training, activity analysis

to break tasks into simpler components, worksheets to recognize pain and energy levels, problem solving techniques, social support from peers and occupational therapists, information of other services and benefits, splints, and equipment to aid in routine tasks. One mother reported turning down equipment because she felt, that it was not something she needed from her OT treatment (Grant, 2001). Mothers of the study noted their continued inability to maintain their role as a mother without family and friends taking over (Grant, 2001). This suggests that the occupational therapists tended to focus on mothers' physical deficits and indicates the need for OT practitioners to increase attention to the occupations affecting the role of motherhood. These chronic diagnoses are similar to breast cancer in how they affect mothers' ability to function, which implies that occupational therapists can provide care in a similar way.

Current research on OT practice for clients with breast cancer identified the following areas as commonly addressed during treatment: controlling lymphedema, coping with the anxiety, providing energy conservation strategies, and teaching adaptive techniques (Cohen, 2005). Vockins (2004) surveyed occupational therapists working with clients diagnosed with breast cancer, and found that therapists spent 26% of their total intervention time on treatment and the remaining 74% is spent on documenting, teaming, and referrals. Unfortunately no literature has been found detailing OT treatment specifically for mothers diagnosed with breast cancer and its effectiveness. Therefore the purpose of this study is to identify current and ideal occupational therapy practice for mothers with breast cancer, in order to describe strategies for effective occupational therapy practice with this population.

Method

Design

This qualitative study used a grounded theory approach to identify themes in current and ideal OT practice for mothers with breast cancer. Two semi-structured interviews were conducted with occupational therapists who work with mothers with breast cancer. A focus group with these occupational therapists was initially planned, but was changed due to the low number of volunteers. Responses shared by each practitioner, provided information regarding therapeutic practice for mothers with breast cancer. Findings from both interviews facilitated the development of themes reflecting OT practice for this population (Glasser & Strauss, 1967; Strauss & Corbin, 1994).

Rigor was obtained for this qualitative study in several ways. Credibility was maintained through a substantial literature review that provided background on the current topic (Glasser & Strauss, 1967). Themes that emerged from the results were also supported by quotes and examples drawn directly from transcripts (Glasser & Strauss, 1967). Peer-review and member-checking were conducted throughout the data analysis process to inquire about themes drawn from the data (Kidd & Parshall, 2000).

Procedures

Recruitment began after the study's approval by the university Institutional Review Board (IRB). To recruit participants, the research advisor of this study contacted an alumnus from the university's OT program, who specialized in lymphedema treatment, to be an intermediary support. The alumnus helped volunteer recruitment by distributing recruitment fliers that contained the research contact information (see Appendix A).

Prospective occupational therapists volunteered their participation via e-mail. An informed consent was then sent via postage mail, with a demographic survey to identify how often the prospective occupational therapists work with women and mothers with breast cancer (See Appendix B). The two therapists who volunteered were selected to participate. An interview guide was created based on the literature reviewed for this study and feedback from the research committee. Questions sought insight into current OT practice used for the population of mothers with breast cancer who have young and adolescent children, whether these treatments were perceived as effective, and what the ideal treatment would be for this population (See Appendix C).

A mock interview was conducted prior to the actual interviews, with a peer reviewer at her site of employment. The peer reviewer was an occupational therapist and a mother diagnosed with breast cancer. During the mock interview, audio and video recordings were taken for later review. The experience provided the researcher with practice and tips on interviewing. Content provided by the occupational therapist and feedback on the interview questions also helped to strengthen the interview guide. For example, inquiring practitioners about the cost and benefits of suggested ideal OT interventions, such as, social groups and creating schedules for mothers with breast cancer. Changes to the interview guide were made accordingly.

Participants were e-mailed the date and time for the focus group, but due to personal commitments, the scheduled time conflicted with both occupational therapists. Two interviews were then scheduled according to each therapist's availability. The first interview took place at a university, determined by the researcher in collaboration with the therapist. The second interview was conducted via Skype, to accommodate the

occupational therapist's schedule. An e-mail was sent one week prior confirming the details of each interview.

Each participant interview began with a brief introduction and description of the study's purpose. Guiding questions facilitated the content of the interview. Probing questions were then posed to clarify the researcher's understanding of the current and ideal practice used for mothers with breast cancer and the effectiveness perceived by the practitioner. The first half the discussion pertained to treatment of mothers with young children and the second half to treatment of mothers with adolescent children. At the end of the interview, each participant agreed to participate in member-checking throughout the data collection process. The duration of each interview was approximately 60 minutes.

Audio recordings from the two interviews were transferred to the researcher's computer, and secured by a password. Recordings were kept on the researcher's computer as a back-up. Copies of each recording were sent electronically to a paid transcriptionist who transcribed them verbatim.

Participants

Two occupational therapists met the inclusion criteria: occupational therapists treating only women with breast cancer, with approximately half being mothers with young children and/or adolescents. Both were practicing in the same western Washington State area in an out-patient lymphedema clinic. Commitment was given for two months of member-checking. Permission was also provided for actual names to be used.

Cathy has worked as an occupational therapist for 27 years, with 13 years dedicated to lymphedema care. Approximately 50–60% of her clients are mothers with breast cancer. Cathy is a survivor of breast cancer, which has enhanced her ability to motivate the women that receive her care.

Laura has practiced OT for 10 years and has specialized in lymphedema care for seven of them. She noted the increasing number of mothers with breast cancer who are beginning to receive OT care. Laura's mother was diagnosed with breast cancer when she was 13 years old. She uses this experience to relate to the children of mothers who come in for lymphedema care.

Data Analysis

Three apriori codes helped develop the main focus of the study: commonalities between current and ideal OT practice, unique traits to current OT practice, and unique traits to ideal OT practice for mothers with breast cancer. These were developed from the primary researcher's synthesis of the literature reviewed. Using these codes, the primary researcher took notes while listening to each audio recording twice and each transcription was read through twice. Each transcription was then color-coded by hand according to responses that applied. Webs were drawn to combine the responses from both participants. A continuous journal was kept detailing the researcher's process in method development, data analysis, and to document any biases.

Aposteriori codes that emerged from the data addressed strategies used for effective OT practice for mothers with breast cancer. These strategies were identified from memos based on patterns within each discussion and further analysis of current and

ideal practice. These findings were continually refined throughout data analysis. This was done by consistent exploration of the data, peer-reviews, and member-checking.

Peer reviews and member-checking occurred throughout the data analysis process to increase triangulation. Peer-reviews were performed by the research committee, two occupational therapists with PhD's and backgrounds in qualitative research. Member-checking was done through two group e-mails. Participants responded with feedback on the interpretation of the data and emerging themes. They provided additional research references about PSM. Coding proceeded until saturation occurred, which means that no additional themes were found (Glasser & Strauss, 1967, pp. 61).

Results

Interviews conducted with Cathy and Laura provided a basic understanding of what is occurring in occupational therapy practice with mothers with breast cancer, and what occupational therapists could work toward to provide effective care for these mothers. Their responses were developed into three strategies: giving a voice, preventing loss of motherhood, and collaborating with multiple disciplines.

Preventing Loss of Motherhood: Addressing Client Factors

Current practice for mothers with breast cancer utilizes a biomechanical approach, which includes various physical activities and education. These address the onset of the debilitating symptoms that may occur due to, axilla cording, lymphedema, scar tissue adhesions, and cancer-related fatigue. Physical issues limit mothers' range of motion, endurance, strength, and energy, all of which are used to perform caregiving tasks, such as, interacting with children and performing household activities. Occupational therapy

lymphedema specialists, Cathy and Laura, identified a “hands-on approach” to address these physiological impairments.

“So my goal is patient will have enough endurance to complete an 8-hour workday without needing three days to recover. But within that goal is she needs to be able to have enough energy by doing that to be able to go on a hike with her son for three hours and not spend two days in bed.”

Laura described her sessions as “manual treatment”, she performed myofascial release to break up scar tissue and increase mobilization of the upper extremities. Stretching and strengthening exercises were used to increase range of motion, muscle power, and endurance. In the presence of lymphedema, care included manual lymph drainage, compression garments to reduce the swelling, and constant skin care to maintain skin integrity. Additionally, occupational therapists recommended a light physical activity, like walking, to maintain endurance.

OT provided education, and served as a resource for mothers throughout breast cancer treatment. One of the main goals of education was to help mothers understand their diagnosis and how caregiving and self-care function could be impacted. This promoted awareness and prevented body functions from worsening. Topics addressed fatigue management, pain management, risk factors of breast cancer treatment, lymphedema signs and symptoms, and energy conservation. Fatigue and pain management included recognizing limitations to their physical functions. Cathy also described how she educated on topics that could be discussed with other health professionals and how to address these medical discussions. Furthermore, Cathy and Laura helped to interpret medical documents, so that mothers understood how

physiological and physical changes, during treatment would affect their performance in daily tasks.

Ideal practice promoted early intervention, consisting of the treatments described as biomechanical and education. Early OT intervention however, requires more advocacies from occupational therapists. Laura suggested that assessment of early deficits and education be performed around seven days post-surgery, after the mothers' lymph drains are removed. Intervention involved baseline measurements and assessment for early signs of physical deficits. Mothers would then be seen every six to eight weeks after, unless greater physical impairments have been detected, then biomechanical interventions noted earlier would be implemented. Both Cathy and Laura expressed that it is crucial to promote and maintain the occupations of motherhood. Through education, mothers increased their awareness of their body function during breast cancer treatment to prevent further physical deficits from affecting their occupations of motherhood.

Giving a Voice: Addressing Performance Skills through Consultation

Occupational therapists consult with mothers on a variety of habits and routines concerning their role as a mother. This includes motivating mothers to continue their participation in valued activities, promoting children's understanding of breast cancer to better the interactions with their mothers, and collaborating with mothers to alter the demands of valued activities to increase performance success. In current practice, occupational therapists integrate time into their treatment sessions, to listen and empathize with mothers' experiences, in order to accommodate to their needs. Mothers tended to voice frustration with their physical ability. They were unable to match the expectations they had for themselves with what others had for them. Many women found

an emotional release during occupational therapy treatment. Cathy and Laura both described their therapeutic environment as comfortable. As Cathy stated, it was “intimate”,

“My lights are low. I’ve got music on. It’s a very, kind of intimate time. They look forward to coming to see us because it feels good and it feels safe. And many of them, up to that point everything has been kind of invasive...”

This allowed mothers to relax and build rapport with the therapist, by sharing personal concerns about their diagnosis and home environment. Laura applied her therapeutic-use-of self, by showing empathy, listening, and even allowing mothers to cry.

“The biggest thing that I do is tell them you are right. You are tired. You have a reason to be, you know? That, you know, it’s normal to have this gradual recovery period. And everybody is different.”

Words of encouragement were used to help mothers know that it was okay to feel the impact of their symptoms and have concerns about their role as a mother. These words of confirmation indicated to mothers that what they felt was normal and they should not overexert themselves.

Occupational therapists also take time to hear the concerns of children. Young children tended to be confused and scared about their mother’s situation. They, too, required a “safe environment” to express thoughts and feelings. Cathy described how occupational therapists can address children’s confusion,

“...providing them with some education regarding what is happening to their mother in a way that is developmentally appropriate for the child.”

OT practitioners help families accommodate and cope with the presence of breast cancer in the home. By opening the channel of communication, children’s knowledge about

breast cancer increases. Children's understanding about breast cancer contributes to identifying ways they could interact with their mothers. Cathy described,

“...there was conflict between the two. So I actually ended up meeting with the daughter separately and the two of us talked about it— and I've actually had breast cancer myself. So a few— you know, it was like, I can understand your mom. You know? Wanting to do all of these things. And she really wants to do this in order to be— to remain here with you, you know? That's kind of her goal. And trying to help her maybe focus on maybe the underlying motivation of her mom so that they would be more able to talk without anger.”

To promote a better mother-child relationship, occupational therapists used their therapeutic-use-of-self to help children and mothers understand each other. Cathy, who was a breast cancer survivor, was able to share with a frustrated daughter the mother's perspective. In a developmentally appropriate manner, Cathy explained to the goal of treatment and how the mother was working toward an increase in function so that she could maintain her expected roles as a mother. Laura, who was a daughter of a woman with breast cancer, connected with the children. She could share with mothers who had breast cancer about their children's concerns. Some of which revolved around the decline in their mother's ability to perform the caregiving tasks she once used to. So, by addressing children's knowledge about the skills mothers are able to do, they could better understand breast cancer and cope with the change in their mother's role in the home.

In addition to addressing the communication between mother and child, Cathy and Laura, assisted in providing interaction between mother and children. Both occupational therapists allowed the children to be a part of the therapeutic activity. For example, Cathy would have a mother's young daughter help rub lotion on her mother's arm. The social interaction informs children that mothers are still okay to participate in

activities and vice versa. This would especially apply to the ideal OT practice provided for mothers planning end-of-life care.

To identify appropriate activities for mothers to engage in, task analyses were performed in collaboration with mothers based on their concerns. With OT, mothers were able to conduct activity analyses identify effective ways to adjust the processes in which mothers performed activities and modified the demands of various tasks to meet their available function. Thus, occupational therapists focus on the success of performance skills to bridge the gap in communication, social interaction, and the performance of mothers' to meet their expectations within their role of motherhood.

Collaborating with Multiple Disciplines: Addressing Advocacy

During interviews with OT practitioners, the area of ideal practice that was emphasized, was advocating for an OT role in breast cancer treatment. One way of doing this would be to collaborate with various disciplines. An area that a multidisciplinary approach could be taken is for mothers with psychosocial needs. Cathy and Laura indicated that occupational therapists have some knowledge to address psychosocial issues. Other resources and guidance from other disciplines however, are still required to help cope with the effects of breast cancer.

Social groups, especially for young mothers, were suggested to be beneficial. Groups could be run by psychologists, who bring in speakers in areas such as OT, PT, nutritionists, social workers, plastic surgeons, and more. The additional knowledge would provide mothers with various ways to adapt and modify their lifestyles, so that they could better resume the role of motherhood, while being able to care for themselves. In addition, Laura commented on informing other professionals as to how occupational

therapists provided care for mothers with breast cancer and could better contribute to their healing process.

Social groups for children were suggested to provide effective coping strategies for their emotional needs. As suggested by Cathy and Laura, other professionals such as social workers and psychologists could provide more psychological and environmental modifications to address children's concerns. This could help children to better accommodate and modify their routines in response to their mother's change in performance and role within the home.

Discussion

This study identifies potential treatment strategies for OT practice opportunities for the role of motherhood when it is disrupted by breast cancer. Some of these may be seen as emerging practice areas, but are consistent with the centennial vision, to advocate for the profession (AOTA, 2012). Breast cancer is considered a chronic illness that interferes with the stages of motherhood (Francis-Connolly, 1999). Physical deficits may restrict mothers from providing care for all areas of need for infants and young children; and psychological stressors may prevent mothers from providing adolescents with the instrumental and emotional support they need (Ogce & Ozkan, 2008). Mothers affected by these changes voiced dissatisfaction and experienced shame and guilt, as they were unable to meet the expectations they have for themselves, in order to fulfill their perceived role of motherhood (Elmberger, 2005). Occupational therapists help mothers maintain their values of motherhood and may re-shape their beliefs in how their role as mothers provides care. OT practitioners help mothers establish new habits and routines

related to the priorities set by mothers, and match mothers' physical capabilities to valued activities.

Mothers tend to have difficulty managing their routines while undergoing breast cancer treatment. Without OT treatment, mothers forego their own health to continue usual routines, so that they may remain a participant in their child's life (Billhult & Segesten, 2003). In collaboration with occupational therapists, mothers identify activities and priorities they wish to remain a part of. Occupational therapists also use their therapeutic-use-of-self, to listen and help identify activities that are most important to mothers. Based on Cathy and Laura's descriptions of OT treatment, sessions become a "sanctuary" where mothers feel safe and are able to express themselves, and occupational therapists provide empathy to validate their emotions. Cathy described, "Some sessions we don't do anything physical. All we do is talk." Indicating that by allowing mothers to express their thoughts, feelings, and concerns in an emotional way is therapeutic in itself. This also allows occupational therapists, to provide words of encouragement to motivate mothers during her treatment and throughout the recovery of such an invasive diagnosis, and alleviate frustrations that interfere with the interactions with their children.

In addressing beliefs about motherhood, occupational therapists can also help children cope with the change in their mothers' ability to provide care. Children attending their mothers' treatment sessions may be experiencing fear and anxiety about what may happen to their mother or uncertain in how to interact with her. In support of Forrest, Plumb, and Ziebland (2006), older children are seen with greater frustration and anger toward their mother, usually due to the change in their mother's ability to engage in the occupations of motherhood she once used to. Hence, by sharing the concerns of

children during OT treatment and identifying strategies to help cope and alleviate feelings of anxiety and fear, occupational therapists can address the psychosocial issues that occur in children.

According to Clemmens (2009), participation in school and extra-curricular activities are disrupted by children's emotional response to their mothers' diagnosis of breast cancer. By addressing the psychological effects of children, they may better function throughout their daily activities. Collaborating with child life specialists, the occupational therapist may help educate young children in a developmentally appropriate manner, to de-mystify the effects of breast cancer seen in the media (Forrest, Plumb, Ziebland, & Stein, 2006). OT practitioners, also identifies activities mothers and children can perform together. Cathy described how a daughter would paint her mother's nails during therapy, which transferred to an activity also done at home to share time with one another. In essence, occupational therapists validate and promote an understanding of how mothers are able to participate with their children, while enduring breast cancer treatment, reducing the strain on the mother-child relationship; thus supporting the psychosocial health of both mother and child.

Furthermore, by listening to the concerns of mothers and children, occupational therapists, may increase their understanding of the expectations placed upon mothers with breast cancer in the continuum of motherhood. Cathy describes, "Support them with the things they really want to do. Like what do you really want to do? If you have limited time and you kind of know that how do you want to spend it?" Giving time to be empathetic toward mothers during treatment sessions, allows mothers a chance to contribute to their own therapy. Collaboration may occur between OT and mothers to

implement task analyses, to address mothers' participation with their children and take care of themselves, so they may feel successful in their role as a caregiver.

OT practitioners can help mothers to re-evaluate their high standards of what they believe mothers should be, and adjust that definition using task analyses, to find success in their performance as a mother. Task analyses, assesses tasks to modify and adapt activities so that mothers can also remain a valued participant in their children's daily routine. This appears particularly helpful for infants and young children, as mothers attend to multiple caregiving tasks at once (Francis-Connolly, 1999). Without OT treatment, it was observed that mothers attempted to keep normal routines for their children, so that children would not experience the impact of the diagnosis (Billhult & Segesten, 2003 and Elmberger et al., 2009). However, it was noted that,

“Sometimes women who get cancer realize, wow, you know, life is limited. And I want to refocus my life. And I want to have more energy for my kids so I am going to cut back work.”

Mothers realize that they must prioritize activities to effectively budget their energy.

With occupational therapists, mothers make adjustments to their routine and performance skills and patterns, in order to prioritize and schedule activities to fulfill their occupations of motherhood and attend to their personal care. Thus, mothers can better match the demands of motherhood to their available functions, which may increase their understanding of their physical limitations. Furthermore, modifying activities assist mothers' in monitoring their activities in order to prevent them from overworking and experiencing a burn out.

Early intervention can provide further education on appropriate care and physical management during other invasive treatment procedures. This strives to keep mothers as

an active participant in their children's daily activities. An increase in knowledge at the beginning of breast cancer treatment has potential to increase awareness of the signs and symptoms indicating the on-set of possible risk factors that may occur during treatment. Thus, through early prevention of exercise management and education mothers will be able to perform their modified routines to support participation with their children.

The need for early intervention promotes the prospective surveillance model (PSM) and identifies the need for the unique role of OT. PSM contributes to the holistic approach occupational therapists take, observing the interaction between person, occupation, and environment for optimal occupational performance. OT practitioners inform mothers about their occupational performance in relation to their medical condition. They however, are unable to effectively address all the needs of mothers with breast cancer. Therefore, utilizing a multi-disciplinary team emphasized in the PSM can address these various areas of concern.

Multiple professions can contribute their knowledge to help mothers adjust to their change in physical ability and suggest methods modify the demands of the task or the environment. Collaboration with psychologists and social workers addresses the psychosocial factors that occur in mothers and children, as mothers are less able to engage in care and interaction with their children. Other suggested areas of practice, that can collaborate with occupational therapists to address the routines and role of a mother are, nutritionists and physical therapists.

For all that has been discussed to continue and increase future OT practice for mothers with breast cancer, occupational therapists need to advocate more for a role within the area of care for this population. The American Occupational Therapy

Association (AOTA) centennial vision highlights advocacy for the OT profession (AOTA, 2012). By increasing the understanding of OT in the general public, especially mothers with breast cancer, and other medical professionals, occupational therapy can be widely recognized as a valuable part of treatment, helping mothers maintain their role of motherhood when disrupted by breast cancer (AOTA, 2012). Only recently, however, mothers are being referred to OT by oncologists or primary care physicians for the physical impairments that occur in reaction to ongoing breast cancer treatment. The biomechanical approach however, is emphasized in other rehabilitative disciplines, which does little to set OT apart from other professions such as physical therapy.

To advocate for OT, as emphasized in the AOTA centennial vision, collaborative care during early intervention should be emphasized. Occupational therapists can further educate other professionals about the role of OT for mothers with breast cancer.

Occupational therapists address the important activities within a mother's day, by performing task analyses and altering the demands of the task, in order to maintain successful participation in her role of motherhood. OT addresses the state of mothers outside of the hospital, and in all other contexts they participate in. These unique characteristics of OT fill in the areas other medical professionals are unable to attend to, suggesting the need for occupational therapy in the care of mothers with breast cancer.

Limitations

The current research findings were enhanced through, thorough descriptions of participants' response and providing supporting quotes (McDaniel & Bach, 1996), however reproducibility of the study was weakened by the number of participants (Kreuger & Casey, 2000). The low number of participants and lack of in-depth

conversation from multiple perspective and experiences limit the scope of current and ideal practice for mothers with breast cancer. The participants were employed at the same facility during the time of the interviews. It could be assumed that both have similar approaches to treatment due to their shared therapeutic setting. The facility in which they work was also a lymphedema outpatient clinic, with an emphasis on a biomechanical approach to treatment. For these reasons, the current research provides a beginning perspective on current and ideal practice occurring in OT treatment, and best strategies may differ for overall treatment of mothers with breast cancer.

Future Research

To increase the scope of current and ideal OT practice with mothers with breast cancer, more occupational therapists who work these clients need to be approached to advocate for the profession. Noting the various places of work therapists may treat in, may relate differences that occur as the mission of various facilities differ. To follow-up, a focus group containing occupational therapists from various settings would provide a comparison of practice within different settings. To provide a different and important perspective, a focus group with only mothers with and without occupational therapists present, would provide better insight into the effectiveness of OT treatment strategies. Conducting quantitative studies with mothers with breast cancer undergoing OT treatment will also be informative. Results from these studies can identify significant effects on mothers' quality of life and participation in daily activities pre and post OT treatment. Further research will expand the knowledge of current OT strategies presented in this study or provide further revisions for effective OT practice. Furthermore, it can identify the importance in OT treatment from diagnosis to post-treatment.

Breast cancer is a diagnosis that impacts the whole family. Children are highly affected to the point that they change their routines to accommodate or react to their mothers' change in function. The role of fathers, are also assumed to change as mothers' function declines. Examining the role change in spouses and furthering the research on children affected by breast cancer will help identify more opportunities for occupational therapists to promote effective interactions within the family. Studies that also identify the effects of social support from other family members and friends, from the mothers and family members' perspective, will provide insight in to how social support affects the role of motherhood.

Conclusion

There is a role for occupational therapy, throughout the continuum of breast cancer treatment, to promote the skills mothers need in order to spend time and care for their children. As a result, mothers may find success within the role of motherhood. Participants of this study, helped identify current and ideal OT therapeutic interventions that address mothers' physical and emotional states throughout the course of breast cancer treatment. These traits range from utilizing a biomechanical approach, educating about possible physical deficits, using therapeutic-use-of self to address concerns within the role of motherhood, and advocating for mothers, children, and the OT profession. This gives rise to strategies for OT practice, for mothers with breast cancer: giving a voice to mothers and their children, preventing loss of motherhood, and collaborating with other disciplines to recognize the holistic perspective occupational therapists use to address mothers. Ceasing these opportunities helps maintain mothers' participation and sense of success in their role of motherhood, and promote a reciprocal relationship with

their children. Practice with this population will open avenues to advocate for the profession of occupational therapy.

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Appendix A: Demographic Survey

How many years have you practiced occupational therapy? _____

How many years have you practiced occupational therapy with women who have breast cancer? _____

Currently, how often do you treat women with breast cancer?

(Circle the answer that best fits)

Rarely	Sometimes	Often	All the time
(1 of 10 clients)	(4 of 10 clients)	(7 of 10 clients)	

Have you ever treated ONLY women with breast cancer? Y N

How many years have you practiced occupational therapy with ONLY women with breast cancer? _____

Among your clients with breast cancer, did they have young children (birth to elementary)? Y N

How often do you treat women with breast cancer who have young children?

(Circle the answer that best fits)

Rarely	Sometimes	Often	All the time
(1 of 10 clients)	(4 of 10 clients)	(7 of 10 clients)	

Among your clients with breast cancer, did they have adolescent children(middle school to high school)? Y N

How often do you treat women with breast cancer who have adolescent children?
(Circle the answer that best fits)

Rarely Sometimes Often All the time
(1 of 10 clients) (4 of 10 clients) (7 of 10 clients)

Availability

Please indicate the times you are usually available.

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Mornings (9am to 12 pm)							
Afternoons/ Evenings (12pm to 7pm)							

Appendix B: Interview Guide

Tell me about your experience in working with women with breast cancer.

Have you worked with a mom who has breast cancer and young child(ren) (birth to elementary age)?

If yes...

Describe times you worked with a mom who was diagnosed with breast cancer and has a young child.

Describe the goals for these mothers.

Describe OT treatment that addresses the physical concerns of these moms.

Describe OT treatment that addresses the role of these mothers.

How were the outcomes?

If no...

What do you think occupational therapy can do for mothers with young children?

Have you worked with a mom who has breast cancer and older child(ren) (middle school to young adult)?

If yes...

Describe times you worked with a mom who was diagnosed with breast cancer and has an older child.

Describe the goals for these mothers.

Describe OT treatment that addresses the physical concerns of these moms.

Describe OT treatment that addresses the role of these mothers.

How were the outcomes?

If no...

What do you think occupational therapy can do for mothers with older children?

Describe ideal occupational therapy treatments for moms with breast cancer.

I interviewed an occupational therapist who is also a mom with breast cancer, she mentioned making schedules for her and her time with her child. How would creating schedules for mothers with breast cancer be beneficial?

She also discussed constant fatigue. How would OT treatment address fatigue in women with breast cancer?

There is a lot of emotional impact from being diagnosed with breast cancer and undergoing its treatment, how can OT address this?

What do you think about performing OT therapeutic activities in a social group?

Anything else you would like to share about current or ideal OT treatment for mothers with breast cancer or how OT practice should change for this population?