

# Chemotherapy-Related Cognitive Impairment: The Breast Cancer Experience

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**C**ognitive changes, a commonly reported toxicity of breast cancer treatment, have been referred to as chemotherapy-related cognitive impairment (CRCI) in the literature and chemobrain by the lay public. Up to 83% of breast cancer survivors who have received chemotherapy report some degree of cognitive dysfunction (Jenkins et al., 2006; O'Shaughnessy, 2003). Cognitive changes can have a significant effect on cancer survivors' quality of life, and lack of information regarding the potential risk prevents patients from granting full informed consent prior to initiation of therapy.

The body of literature supporting the occurrence of CRCI is growing, although causal mechanisms have yet to be determined conclusively (Ahles et al., 2002; Brezden, Phillips, Abdolell, Bunston, & Tannock, 2000; Schagen et al., 1999; Von Ah et al., 2009; Wefel, Lenzi, Theriault, Davis, & Meyers, 2004; Wieneke & Dienst, 1995). A few qualitative studies have described patients' experience with CRCI, including the experience related to breast cancer treatment (Boykoff, Moieni, & Subramanian, 2009; Mulrooney, 2007; Downie, Mar Fan, Houede-Tchen, Yi, & Tannock, 2006; Fitch, Gray, Godel, & Labrecque, 2008; Thielen, 2008; Wagner, Sweet, Butt, Lai, & Cella, 2009). Fitch et al. (2008) interviewed 32 cancer survivors to study the effect of cognitive changes on daily living, as well as survivors' coping strategies. In addition, Boykoff et al. (2009) interviewed 74 Caucasian and African American breast cancer survivors to describe the psychosocial ramifications of CRCI. Study results included descriptions of the general psychosocial influence of cognitive changes, effect on interactions with healthcare providers, and consequences for social networks and work performance.

A common complaint of participants in those studies, as well as in unpublished work by Thielen (2008), was the lack of acknowledgment or education about the potential for cognitive changes by healthcare providers.

**Purpose/Objectives:** To provide an in-depth description of the experience of chemotherapy-related cognitive impairment (CRCI) for women with breast cancer and identify related information that women would find useful prior to chemotherapy and at the onset of cognitive changes.

**Research Approach:** Qualitative, descriptive design.

**Setting:** Academic breast cancer survivorship center in Kansas City, KS.

**Participants:** 18 breast cancer survivors within 6–12 months of having completed chemotherapy who self-reported changes in cognitive function.

**Methodologic Approach:** Data were collected with a demographic questionnaire, semistructured interviews, and a focus group. Qualitative content analysis was performed.

**Findings:** Study themes were Life With Chemobrain, How I Changed, How I Cope, and How to Teach Me. Participants described difficulty with short-term memory, focusing, word finding, reading, and driving. Issues with fatigue, trouble sleeping, neuropathy, balance, and coordination also were of concern. Coping strategies included writing things down, depending on others, focusing on one task at a time, and giving oneself permission to make mistakes. Participants described exercise and getting enough rest to be helpful and recommended activities to stimulate the mind. Participants wanted information about the potential for CRCI prior to initiating chemotherapy and desired an individualized approach to education. Specific recommendations for education were provided.

**Conclusions:** The study results provide a framework for understanding the experience of CRCI that can be used to guide development of patient and family education and generate questions for additional research.

**Interpretation:** Application of the study results will enhance informed consent, validate the experience of CRCI, and contribute to patient satisfaction.

Few educational tools are available, and oncology nurses have acknowledged lack of access to appropriate patient and family educational materials (Myers & Teel, 2008). The purpose of this qualitative, descriptive study was to

provide an in-depth view of the experience of CRCI for women with breast cancer and to identify related information that women would find useful prior to chemotherapy and at the onset of cognitive changes.

## Methods

### Design, Setting, and Sample

The current study was designed to answer the following research questions. How do women who have received chemotherapy for breast cancer describe the experience of CRCI? What information about CRCI would those women have found helpful prior to initiation of treatment? Finally, what information about CRCI would women with breast cancer have found helpful once changes in cognition were experienced?

A qualitative, descriptive design was selected because that methodology is suited to obtaining straightforward answers of interest to practitioners (Sandelowski, 2000). Data were collected through the use of a demographic questionnaire, semistructured interviews, and a focus group. Peer review, expert review, and data triangulation between the interviews and focus group transcripts enhanced study credibility.

Participants were recruited from the University of Kansas Breast Cancer Survivorship Center in Kansas City and by members of the Greater Kansas City Chapter of the Oncology Nursing Society. Purposive sampling was used to recruit adult women (aged 18 years or older) diagnosed with any stage of breast cancer, who were within 6–12 months of having completed chemotherapy and self-reported changes in cognitive function, such as mental foggy, difficulty concentrating, trouble with memory, inability to multitask or do mathematic calculations, and decreased sense of direction when driving. Any standard-dose regimen of chemotherapy and current or past hormonal therapy were accepted. Sampling continued until no new information was obtained during the in-depth semistructured interviews.

### Procedures

**Safety:** Human subjects committee approval was granted by the University of Kansas Medical Center, and informed consent was obtained. The consent form included an option to be contacted by the investigator to participate in a focus group following the completion of the interviews and initial data analysis. Interview participants' information was deidentified, and only first names were used in the focus group to maintain as much confidentiality as possible.

**Data collection:** Demographic information was collected with a questionnaire, and a semistructured interview guide was used to elicit information from participants through the use of open-ended questions. The guide consisted of four primary questions and a series

of related probes used to enhance participant response if needed. The primary questions were as follows.

- How would you describe your experience with changes in thinking or memory during chemotherapy?
- What information would you have found helpful prior to starting chemotherapy?
- What information would you have found helpful once you began to notice changes in your thinking or memory?
- Is there anything else you would like to share about your experience?

The interview guide was piloted with two key informants who met all eligibility criteria, except being within 6–12 months of completing therapy. No revisions to the guide were deemed necessary.

In-depth interviews (about 60 minutes in length) were conducted at locations mutually agreeable to the participants and the investigator. The interviews were tape-recorded and transcribed verbatim. Field notes were used to supplement study transcripts. The notes facilitated the inclusion of manifest and latent content for analysis.

On completion of the interviews and initial data analysis, consenting participants were invited to take part in a focus group. The purpose of the focus group was to provide the opportunity for member checking (participant feedback and validation) to ensure that study results and interpretations from the data collected during the interviews were an accurate reflection of participants' experience of CRCI and recommendations for education. Four women attended the focus group, and their feedback was used to further refine the description of the experience of CRCI, related educational needs, and specific suggestions for educational content. The focus group session was tape-recorded and transcribed verbatim. Peer review was conducted with the focus group scribe (a nursing colleague) as data from the interviews were analyzed. Expert review was conducted with members of the university faculty who had expertise in qualitative content analysis.

Data collection procedures were supplemented by regular journaling of thoughts, feelings, observations, and insights by the investigator. Journal notes were used to provide an audit trail during data analysis as decisions were made related to identification of categories and themes from participants' descriptions of the experience of CRCI and desired timing and content of related education. The process served to identify biases prior to the start of the research. The investigator made a conscious effort to separate herself from those biases to be open to the information shared by participants. In particular, the investigator noted preconceived ideas about the timing of cognitive changes and women's preferences related to receipt of education about CRCI.

**Data analysis:** Data were simultaneously collected and analyzed in an iterative process (Sandelowski,

2000). Qualitative content analysis of the study transcripts was performed, and inductive analysis procedures were used to prepare, organize, and report the data (Elo & Kyngas, 2007). Transcripts were organized into meaning units (such as words, phrases, sentences, or paragraphs that conveyed similar content deemed important to understanding the participant experience). The meaning units were coded and grouped into categories. NVivo 8 qualitative software was used for the organization and coding of the transcripts. The abstraction process continued until primary themes were identified (Elo & Kyngas, 2007). Participants' direct quotes were used to provide an in-depth description of the experience of CRCI and recommendations for education.

## Results

Life With Chemobrain was identified as the overarching theme for the study. Three subthemes (How I Changed, How I Cope, and How to Teach Me) encompassed the participants' descriptions of their CRCI experience, the coping strategies they employed, and the method and content of education they would have liked to have received.

### Sample Description

Demographic information for the 18 participants is reported in Table 1. No changes in marital status occurred since participants were diagnosed with breast cancer. One woman changed employment status to part-time during treatment, and two attributed loss of employment to cognitive changes.

The primary chemotherapy regimen was doxorubicin and cyclophosphamide, followed by paclitaxel ( $n = 12$ ) or docetaxel ( $n = 5$ ). Five received trastuzumab in addition to the primary regimen. Two also received bevacizumab. Other regimen components included capecitabine ( $n = 1$ ) and paclitaxel protein-bound particles for injectable suspension ( $n = 1$ ). Treatment duration ranged from four to eight months.

### How I Changed

Participants provided poignant descriptions of the many changes in their lives resulting from CRCI. Descriptions of those changes were coded into the following seven categories.

**Deficits in short-term memory:** Nine participants acknowledged a significant change in their short-term memory. Deficits included difficulty retaining information in a variety of settings such as casual conversation with friends or family, work- or school-related activities, and reading or films. One young mother described the deficit as follows.

Yeah . . . not so much long-term, but more recent . . . short-term . . . So even to the kids, like . . . did you

**Table 1. Demographic Characteristics**

Characteristic	n
<b>Age (years)</b>	
25–30	3
31–35	1
36–40	3
41–45	3
46–50	1
51–55	5
56–65	2
<b>Job status<sup>a</sup></b>	
Full-time	11
Part-time	2
Not working	3
Homemaker	2
Lost job	2
<b>Marital status</b>	
Married	16
Divorced	2
<b>Ethnicity</b>	
Caucasian	15
African American	3
<b>Education level</b>	
High school	1
College	11
Graduate school	6
<b>Stage at diagnosis</b>	
I	4
II	8
III	3
IV	1
Not sure	2
<b>Menopausal status pretreatment</b>	
Pre	12
Post	5
Peri	1
<b>Menopausal symptoms<sup>a</sup></b>	
Hot flashes	6
Trouble sleeping	8
Weight gain	5
Feeling irritable	2
<b>Hormonal therapy</b>	
Yes	10
No	8
<b>Menopausal status post-treatment</b>	
Pre	4
Post	12
Peri	1
Not sure	1
<b>Other symptoms<sup>a</sup></b>	
Anxiety	7
Depression	6
Fatigue	10

N = 18

<sup>a</sup> Participants could select more than one response.

brush your teeth? And you know, two minutes later, did you brush your teeth? Like I couldn't remember, did you say? You know, and my kids would say, "I answered you five times!" And I'm like . . . so sorry, I do not remember hearing you . . . I don't remember asking and I don't remember hearing you answer [chuckling].

Participants described frequently finding themselves in a room and not remembering their purpose for being there. Several women noted frequently misplacing items such as cash, keys, and cellular phones. Participants were unable to remember appointments, tasks they needed to do, or items from conversations without writing things down. Prior to chemotherapy, one woman indicated she never needed to write down appointments. She said she could remember her own, as well as her mother's and her children's appointments, without difficulty. However, on the day of her scheduled interview for the current study, she admitted to having no recollection of scheduling the appointment and was not dressed or expecting anyone to come by.

**Trouble with word finding (verbal memory):** Difficulty with word finding was noted by all of the women. Participants described "forgetting names, not completing sentences," and "not being able think of the word."

And that's part of memory. I mean, you've got your vocabulary stored, but if you can't . . . I've noticed myself saying in the last few weeks when I'm on tours, I can't think of the word I wanted to use. And I'll say . . . we'll stop and be like . . . uuuhh, like tongue-tied kind of . . . fumbling for a word, and then I'll figure it out. And I'll feel kind of stupid, cause I'm not that way, I haven't been that way. But when I was going through chemo, we had a joke, I'd always say, chemobrain, chemobrain today. Don't trust what I'm saying because it's chemobrain. I'm a very verbal person and to not be able to come up with the word is very frustrating and it feels awkward.

One young woman described having an extensive vocabulary and reported significant frustration at not being able to think of the words she wanted to use in expressing herself. She and other participants in the study described the use of word substitution to maintain a conversation.

**Lack of focus and inability to concentrate:** Nine participants described being unable to focus or concentrate, contributing to issues such as maintaining their train of thought in conversation and reading comprehension.

I've always been a reader. And I used to like be able to read even, you know, like thrillers or mysteries and stuff . . . and [I] always used to enjoy books on tape, or CD or whatever . . . but I did ONLY those probably for a year because I couldn't concentrate or focus on reading a book, you know, I couldn't sit down with even, like, a simple little romance novel and focus on reading it. I couldn't do it.

Difficulty focusing and concentrating hampered women's ability to plan and execute various tasks

(decreased executive function), such as the inability to follow a recipe when cooking. One woman's husband had taken over handling the bills (the process of writing the checks, stamping, and mailing). She described herself as "not trustworthy enough to do it" and that her husband "wasn't sure where the bills would end up." Several women mentioned losing the ability to multitask or focus on one thing at a time.

Six participants described lapses in focus while driving familiar routes and in other various aspects of driving, such as coming to a complete stop at intersections, correctly responding to traffic signals, and the necessary steps to refuel the vehicle.

Sometimes I'm driving and then I'll . . . I won't remember . . . oh, I already went through that intersection or, you know, there's like a blank moment of . . . where am I going? [laughing] You know . . . oh right . . . that's what I'm doing . . . you know. It's not like you're completely unsafe in the car, it's not that, it's just you may be . . . it's the same process of where you might be running upstairs or downstairs and then all of the sudden you can't remember what it was that I was doing and . . . it's sort of the same thing, but you do notice it in the car . . . which I would never have done before.

**Decreased performance:** Two participants indicated that cognitive changes contributed to loss of employment. One woman had worked more than 60 hours per week as a company comptroller and was the go-to team member for problem resolution because of her organizational skills and ability to balance multiple activities. At the time of study, she described looking at the job descriptions in the newspaper and struggling to find the type of employment where she would have a one-focus job. The other participant worked in a retail position as a personal shopper. Subsequent to her changes in cognition, she described being unable to remember her clients' preferences, sizes, or previous requests for merchandise.

A young woman working on her master's degree described herself as having a photographic memory prior to chemotherapy. She related previously never having to read something more than once. However, she had to drop a class during chemotherapy treatment because of her inability to retain information from reading and class work. Participants noted that overall performance was slowed because of the need to read things several times and decreased processing speed.

**Analogies:** Participants described the experience of cognitive changes to be analogous to being pregnant, drinking too much, or taking potent allergy medicine. Comparisons were made to aging, as well as Alzheimer disease. Participants reported feeling like one's grandmother or someone's "daffy old aunt." One participant described a strong family history of Alzheimer disease



and expressed the fear that the cognitive changes she was experiencing now would predispose her to an earlier onset of Alzheimer disease in the future. Another participant related her experience to the female protagonist in the film *Mr. and Mrs. Bridge*, in which the character is seen sitting in the car in the garage without a clear notion of what to do next. The participant described pulling up to the gas station to refuel her vehicle and having no idea how to release the gas cap. She sat in the car for 15 minutes before she was able to remember the steps involved. She said this happened to her on two occasions. She referred to the experience as “pulling a Mrs. Bridge.”

**Other physical factors:** As participants described the experience of CRCI, several other physical factors were discussed consistently. Most women ( $n = 13$ ) discussed experiences with fatigue during and after treatment, and 10 reported ongoing issues with fatigue. Participants acknowledged that cognitive issues were more pronounced when they were tired and noted some improvement in mental clarity after napping or “getting enough rest.”

Clumsiness and decreased balance were issues for five participants. Descriptions included no longer being able to stand on one leg to put on a sock, losing their balance going down a slope, dropping things, and stumbling more than they used to do. Participants experienced neuropathy in their feet ( $n = 2$ ), toes ( $n = 4$ ), fingers ( $n = 4$ ), or fingers and toes ( $n = 2$ ), and five still had some residual numbness. However, only two participants with residual neuropathy reported clumsiness or balance issues.

**Trajectory of cognitive changes:** Participants’ perceptions of when they began to experience cognitive changes varied. Most noticed changes during chemotherapy after one to two months of treatment. One woman described noticing changes immediately after receiving her first treatment. Three participants did not notice changes until after therapy. One of those women described experiencing changes four to five months after completing chemotherapy, and one did not notice changes until several months later.

Most participants described perceiving some improvement in their cognition over time. Some women mentioned beginning to notice improvement one to two months following the completion of chemotherapy. However, word finding appeared to be the primary residual deficit, with all participants reporting that problem at the time of the interviews. Five participants noted that improvement may have been hampered by recovery from subsequent surgeries after chemotherapy related to breast reconstruction and the effects of general anesthesia.

## How I Cope

Primary coping strategies included writing things down, the importance of support and validation, helping others, depending on others, focusing on one task

at a time, not rushing, and giving oneself permission to make mistakes. Participants also described attempts at intervention for CRCI, including exercise, getting enough rest, and mind stimulation.

**Writing things down:** The most common strategy described for coping with changes in memory and thinking was writing things down. Participants varied slightly in the method they selected, such as the use of phone calendars, day planners, notebooks, lists, and sticky notes. However, 16 women described the need to make note of things they wanted to remember shortly after receiving information because of their difficulties with short-term memory loss.

**Importance of support and validation:** Fifteen participants expressed frustration at the lack of communication and validation by healthcare providers, and most acknowledged the importance of the support of family, friends, and coworkers. In general, participants described others reacting to their cognitive changes with patience and understanding. However, a few women shared that family members (e.g., husbands, children) expressed frustration at having to repeat themselves frequently because of the participant’s inability to retain information.

Younger participants reported very different issues than most of the women they encountered in the infusion room and, therefore, requested a different type of support. For example, women aged 20–35 expressed a desire for being matched with someone their own age as a support mechanism (age-matched support) because of concerns about fertility and finding a mate. Those issues were not a concern for older survivors and contributed to a lack of connection and support from other survivors.

**Helping others:** Nine participants indicated a strong desire to help others through their chemotherapy experience. Some wanted to volunteer in infusion rooms to provide inspiration to those just starting treatment. Others wanted to start a support group in their area or develop a mechanism to provide meals to newly diagnosed women receiving treatment. Participants described the desire to “give back” and to “make something positive” out of their breast cancer experience.

**Depending on others:** Seven participants described depending on their spouse, children, or coworkers to help them remember certain things. One participant reported the need to tell coworkers what she had accomplished at the end of the day.

We had a joke in the office that I needed to tell them things in case I got hit by a bus on the way home, but I think really what I was doing was I needed to tell somebody else what I had done so I could say to her, did I do that?

**Exercise:** Eleven participants reported that exercise was an important interventional strategy. However, only five were able to exercise during treatment. Those who

described returning to exercise following treatment indicated a perception of benefit to cognitive function. Others acknowledged that the reduction in fatigue that allowed resumption of exercise may have contributed to cognitive improvement. One participant described the benefits of leaving the work setting to “work out for 30–60 minutes,” allowing her to return to her job with more mental clarity.

**Getting enough rest:** Association between cognitive changes and fatigue was mentioned frequently. Participants described the need to get enough rest or take short naps during the day to sharpen their mental acuity. One participant shared that she was thankful she worked from home. The autonomy allowed her the flexibility to rest for 30 minutes when she needed to “sharpen her focus.” Another woman described the need to “power nap” during the day, as she would become so fatigued during social interactions that she would “hit a wall” and need to rest because of mental “foginess.”

**Mind stimulation:** Many participants recommended initiating efforts to “stimulate their mind” such as Sudoku, crossword puzzles, or other “brain teaser” activities. Despite difficulties with reading, participants recommended trying to read each day as a way to “work their brain.”

## How to Teach Me

Six participants were told about the potential for cognitive changes during or following chemotherapy by members of their healthcare team prior to receiving therapy. Participants were adamant about the need to know about this potential side effect up front and expressed frustration at the lack of information provided. Women described “feeling like they were going crazy” when cognitive changes began to occur for which they were unprepared.

The primary basis for participants’ recommendations about education related to CRCI was the need for individualized care. Variation was seen in the extent of desired information, as well as the delivery method. Participants were divided between wanting extensive information as early as possible so they could make appropriate plans and begin to assimilate the information versus those who preferred brief, general information. Five participants described being overwhelmed by the volume of written information provided about chemotherapy and side effects prior to treatment. One woman described her experience in receiving a bag of booklets and pamphlets from her surgeon, medical oncologist, and radiation oncologist. As a result, she read little of the information that had been provided. Eight participants expressed the desire to have someone sit down with them and assess how they preferred to learn, as well as their readiness to learn.

Participants did not identify any one person on the healthcare team whom they felt was the best suited to provide the information. However, they described wanting someone who was not rushed with whom they could

spend enough time to gain comfort in asking sensitive questions. One participant suggested that education specialists should be used to accommodate variation in adult learning styles. Focus group participants stated a cancer survivor would be ideal to fill this role, so that the person providing the information would have first-hand knowledge of the experience and would approach the topic with great sensitivity. Participants also recommended that the person should be assigned at the beginning of treatment and maintain the relationship throughout treatment and subsequent follow-up. The benefit of a consistent relationship with an individual who “knew them” and was skilled in education was noted to be of great value.

Participants shared their beliefs on the educational content and style they would have found beneficial. Suggestions included providing a simple one-page handout with large font and no medical jargon. A compilation of pertinent statements from participants for the description of CRCI to women preparing to start chemotherapy was validated by the focus group and is summarized in Figure 1.

### Suggested Statements to Describe CRCI

- Some women have experienced memory changes during and after receiving chemotherapy.
- Those changes have been compared to the type of memory changes experienced during pregnancy or when taking allergy medicine.
- Some women describe feeling as if they were in a fog. Not all women have this experience, but those who do describe issues with short-term memory and difficulty finding the right word.
- Others have described difficulty with driving and sense of direction, following written instructions (e.g., recipes), or maintaining focus when reading.
- Many women experience improvements in memory and thinking over time.

### Recommendations for Educational Content

- Choose a method of writing down important things or activities you want to remember such as in a notebook, day planner, or cellular phone that you keep with you at all times.
- Get enough sleep to feel rested (this may include naps).
- Start or maintain activities to stimulate your mind, such as word or crossword puzzles, Sudoku, or word-finding games.
- Give yourself permission to focus on one thing at a time.
- Use a GPS (global positioning system) unit if you have trouble with driving directions.
- Choose only activities that are important to you and allow yourself plenty of time to complete tasks to reduce stress.
- Consider use of relaxation techniques such as meditation or yoga.
- Maintain some form of regular exercise (this does not need to be strenuous).
- Do not criticize yourself for not remembering things like you used to be able to do before chemotherapy.
- Tell your family and friends you may need help remembering things and ask for their patience and support.
- Be aware that your reading retention may change during and after chemotherapy. This may affect your study habits or test-taking ability.

**Figure 1. Patient Education About Chemotherapy-Related Cognitive Impairment (CRCI)**

Participants wanted a description of likely cognitive changes, such as trouble with short-term memory and word finding. They also wanted to know what was meant by cognitive changes. As one participant joked, “Does it mean that I’ll roll over in bed one morning and not recognize my husband? What does it really mean?”

Information for spouses and children was desired. Many participants discussed the lack of information geared toward describing CRCI for their family members and felt that education was important for the family to anticipate and understand CRCI.

When asked what information they would have liked to have received once they began to experience cognitive changes, participants acknowledged the desire for “someone regularly to ask them” whether they were experiencing any difficulty with memory as a “part of the assessment.” Participants suggested that the educational content described previously could be reinforced throughout treatment. They also wanted reassurance that CRCI would resolve. Focus group participants noted that CRCI might not resolve and agreed that educational content should be designed carefully so as not to mislead. The recommendation was to include a statement such as “Many women experience improvement in memory and thinking over time.” Participants also wanted to be kept informed about any information on effective interventions.

## Exemplars

Exemplars were developed from two interviews that yielded a complete description of the experience of CRCI as both participants volunteered information about almost all of the components of CRCI identified during the study (see Figures 2 and 3). Pseudonyms were used to maintain confidentiality. Information provided in the exemplars highlights issues with word finding, attention or concentration, memory, and difficulty driving, as well as the coping strategies of writing things down and taking naps during the day to refresh mental clarity. Participants’ quotes demonstrate some of the difficulties with verbal expression and social interaction. The additional effort needed to accomplish day-to-day tasks is evident.

## Discussion

The study results provide further evidence for self-report of changes in cognitive function across many domains, including attention and concentration, short-term memory, verbal memory, and motor function. Participants’ reports of lack of focus and inability to concentrate are examples of changes in the attention and concentration domain. Decreased ability to focus and concentrate also contributed to impaired executive function, as shown by reports of difficulty with planning and executing multistep activities such as following a recipe or paying bills.

Prior to her breast cancer diagnosis, Rachel, a woman in her 40s, left bedside nursing to become a full-time homemaker and do the book-keeping for her family business. During chemotherapy, she described her frustration at not remembering her rationale for data entry. She noted that she experienced similar issues when she was pregnant.

Rachel also described significant difficulty remembering names and maintaining social relationships. When introduced to a director of music candidate for her church, she told the candidate and his wife up-front that she would not be able to remember their names. Later she felt she had been rude, but did not want to expend the social energy to explain her situation that early in the relationship.

Rachel said that the cognitive changes were exacerbated by fatigue. She was surprised by how draining social interaction could be because of difficulties with word finding and trouble focusing on verbal and nonverbal cues to respond appropriately.

### Decreased Performance

I do the family business book work, and I like to be able to go down there and understand what I’m doing and be able to come back a week later and understand what I had done the week before.

### Analogies

When I was pregnant, just like when I was in chemotherapy, at the end of the year when I’m going through the books again I’m like, why did I do this? Why did I put that and enter it this way? I have no clue! And it was the same thing going through the book work this year.

### Other Physical Factors

When I’m tired it gets worse. The fatigue . . . just yesterday I was at a friend’s house and . . . I have to take a power nap, in the middle of the day . . . and I didn’t get that. And in trying to talk to her, one thing that I realized is that the energy required in interpersonal relationships is a whole lot more than I ever imagined.

### Lack of Focus and Trouble With Word Finding

So talking, I can function at home, but to get out with people where I am required to read their emotions or read . . . you know just that whole . . . I don’t think we realize how much energy we put into interpersonal relationships and when all of your energy is put into trying keep up with the conversation and making sure you’re acting appropriately? It’s like I’m exhausted.

So after talking with somebody for a while, I start losing words. I can’t finish my thought. And I’m a fairly verbal person. . . . Sometimes the words just don’t come.

## Figure 2. Case Exemplar: Rachel

Short-term memory deficits included the inability to remember the content of conversations or various tasks to be performed and frequently losing objects, such as keys and cellular phones. Decreased verbal memory was described as the inability to remember individuals’ names and pervasive difficulty with word finding. Finally, motor function was impaired for some participants who reported changes in coordination and balance.

Information gleaned from the interviews about the experience of CRCI supported results from previous qualitative research (Boykoff et al. 2009; Downie et al., 2006; Thielen, 2008). Participants acknowledged the importance of validation of CRCI by healthcare providers as well as family members. The need for validation may be congruent with the phenomenon of



Emily was distressed over the residual effects on cognition. She was only 26 years old and felt like she had lost four months of her life during chemotherapy. She continues to experience issues with short-term memory, word finding, lack of focus, and inability to concentrate.

#### **Lack of Focus and Inability to Concentrate**

After chemo, everything is sort of foggy. I keep making the joke to my husband that this is a whole new experience for me, spring in this city, because I slept through last spring. And I really do not remember much of those four months. It's very foggy. Since then, I don't think I realized how much of a fog I was walking around in.

A lot of that's starting to clear, but I do find that it's extremely hard to concentrate for very long at all. I can concentrate in short bursts of 20 to 30 minutes tops. And then I'm just thinking about a million things, sort of have drifted, and I find it's a lot harder to be as efficient at work as I was before.

#### **Decreased Performance and Deficits in Short-Term Memory**

I was always very organized and worked very efficiently, and I have a hard time being that way now. I have to write things down in three or four places because I'll forget it and can't remember where I wrote it down.

#### **Analogies**

I get lost a lot easier driving. I have two GPS [global positioning system] units and I typically take printed directions with me now also, and I could not find where I was going to a meeting this morning. Forty-five minutes later, I finally figured out where I was supposed to be. And at that point, I had missed the meeting. I find that I get sort of confused about what word I'm trying to use. I sort of feel like my grandmother who has Alzheimer's.

#### **Trouble With Word Finding**

I sit there and have a conversation and neither one of us can find the correct word. So you know, I just find that everything is a little more of a struggle to remember and to focus and to concentrate in general. I have to concentrate a lot harder to accomplish what I used to be able to do sort of easily.

### **Figure 3. Case Exemplar: Emily**

participants' self-report of cognitive changes being more accurate than the results of current objective measures of cognitive function (Saykin et al., 2006; Wagner et al., 2009). Participants expressed frustration at the lack of validation of cognitive changes by family members, but acknowledged that the changes might not be noticeable to others. This finding is consistent with that of Jacobs, Jacobsen, Booth-Jones, Wagner, and Anasetti (2007), who noted subjective measures may be sensitive to smaller effect sizes than those of available objective measures. Support from family, friends, and coworkers was noted to be important to successful coping and included assistance with memory, as well as patience and understanding concerning cognitive changes. Age-matched support was desired by younger participants because of the differences in issues they faced as a result of cancer and chemotherapy, such as fertility and finding a mate.

Of note, 17 of 18 participants reported one or more symptoms in addition to CRCI. Twelve participants reported experiencing fatigue during chemotherapy, and

10 continued to experience residual fatigue at the time of the interviews. Similarly, eight women acknowledged trouble sleeping. Fatigue and sleep disturbance are two of the most commonly reported symptoms for cancer survivors (Beck, Dudley, & Barsevick, 2005), and sleep disturbance is a common menopausal symptom. Eight women also noted neuropathy during treatment, and five mentioned residual effects. Neuropathy is experienced commonly by survivors who receive a taxane as a component of chemotherapy (e.g., paclitaxel, docetaxel). Seventeen participants received a taxane, one of whom received paclitaxel and docetaxel.

The reports of concurrent symptoms are congruent with the results of a secondary analysis of a data set for women with ovarian cancer conducted to explore the potential relationship between receiving chemotherapy and complaints of memory problems (Myers, Sousa, & Donovan, 2010). Women with ovarian cancer who had received chemotherapy ( $n = 638$ ) were statistically significantly more likely ( $t[82.7] = -3.12, p < 0.01, \bar{X}$  difference =  $-1.04$ , 95% confidence interval  $[-1.7, -0.38]$ ) to complain of memory problems than those who had not received chemotherapy ( $n = 68$ ). Regression analysis demonstrated that fatigue ( $\beta = 0.18, p < 0.01$ ), neuropathy ( $\beta = 0.07, p < 0.05$ ), and sleep disturbance ( $\beta = 0.16, p < 0.01$ ) were significant predictors for complaints of memory problems in addition to mood swings ( $\beta = 0.23, p < 0.01$ ).

Further exploration of the potential relationships among fatigue, neuropathy, sleep disturbance, and CRCI is warranted. Given the potential predictive nature of fatigue, neuropathy, and sleep disturbance for reports of memory problems, residual side effects may be predictive of long-term CRCI. Fatigue is a potential confounding variable for CRCI (Nail, 2006), yet studies in which confounding variables have been controlled still yielded the independent presence of cognitive changes (Ahles et al., 2002). Results from the secondary analysis described previously in conjunction with results from the current study support the need for further examination of a moderator effect of fatigue on CRCI.

Clumsiness and issues with balance and coordination were reported by five women. A comparison was made between the participants who experienced neuropathy ( $n = 8$ ) and those who reported balance and coordination issues ( $n = 5$ ). Only two participants were common to both groups. This result was surprising because neuropathies can contribute to decreases in motor coordination (e.g., dropping items) or issues with gait (complaints of tripping or stumbling). The lack of commonality between the two groups may indicate the presence of an unidentified factor that contributes to balance and coordination issues. Additional investigation may be warranted in this area.

Other confounding factors mentioned in the literature include anxiety and depression. Participants were asked to report whether they were currently experiencing either



of those states on the demographic questionnaire. Seven participants documented anxiety, six reported depression, and five noted anxiety and depression. Fatigue accompanied anxiety and depression for three participants, and four noted depression and fatigue. Trouble sleeping was reported by eight women and occurred in conjunction with depression ( $n = 3$ ), anxiety ( $n = 3$ ), and fatigue ( $n = 5$ ). Finally, two patients reported all four symptoms. In the current study, anxiety, depression, and trouble sleeping were reported less frequently than fatigue. Some overlap among the four symptoms was noted, providing support for additional analysis of the relationships among concurrent symptoms.

Most participants were employed full-time and did not report a change in work status since diagnosis of breast cancer. However, two participants related loss of employment to cognitive changes, and one described significant changes in school performance during and after chemotherapy. Focus group participants validated reports of slower time frames to complete work-related tasks because of decreases in processing speed and difficulties with reading and comprehension. The results are consistent with a qualitative study by Munir, Burrows, Yarker, Kalawsky, and Bains (2010) in which women reported that poor concentration, memory problems, difficulties in thinking quickly, and issues with reading comprehension affected their work performance. However, participants in the study by Munir et al. (2010) felt cognitive effects were independent of fatigue.

Most participants acknowledged the importance of receiving information about CRCI prior to receiving chemotherapy (when they received information about other potential side effects), thus reinforcing the need for education about this potential side effect as a component of providing informed consent. Six participants were informed about CRCI prior to therapy by a healthcare provider, and three noted they received information about CRCI from their oncologist. Additional improvement in providing education about CRCI is needed to meet women's needs.

Two study themes, How I Changed and How I Cope, reflected the consequences of CRCI on health-related quality of life and alterations to functional ability. The

third theme, How to Teach Me, supported the desire of women with breast cancer to be provided with information about the phenomenon of CRCI. Theme content provides a framework for enhanced understanding of CRCI and can be used to educate healthcare providers about the phenomenon. The framework can be used to guide content to include information about the experience of CRCI, common coping strategies, and information important for inclusion in the development of an approach to patient and family education.

## Limitations

Coding was performed by a single investigator and, therefore, was subject to the biases and interpretations of one individual. However, the limitation was mediated by expert review and advice from School of Nursing faculty at the University of Kansas.

## Conclusions and Implications for Nursing Practice

This study's results provide an in-depth description of the experience of CRCI and specific recommendations for the development of an individualized educational approach and pertinent educational materials for women with breast cancer who will be receiving chemotherapy, as well as their families. Practical application of the study results will enhance the process of informed consent, validate the experience of CRCI for women with breast cancer, and contribute to patient satisfaction with the delivery of care. In addition, the results may contribute to further development of self-report instruments to include items related to difficulties with reading or driving. Oncology nurses should use these findings to support additional nursing research in the area of CRCI.

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## References

- Ahles, T.A., Saykin, A.J., Furstenberg, C.T., Cole, B., Mott, L.A., Skalla, K., . . . Silberfarb, P.M. (2002). Neuropsychologic impact of standard-dose systemic chemotherapy in long-term survivors of breast cancer and lymphoma. *Journal of Clinical Oncology*, 20, 485-493.
- Beck, S., Dudley, W.N., & Barsevick, A.M. (2005). Pain, sleep disturbance, and fatigue in patients with cancer: Using a mediation model to test a symptom cluster [Online exclusive]. *Oncology Nursing Forum*, 32, E48-E55. doi:10.1188/05.ONFE48-E55
- Boykoff, N., Moieni, M., & Subramanian, S.K. (2009). Confronting chemobrain: An in-depth look at survivors' reports of impact on work, social networks, and health care response. *Journal of Cancer Survivorship*, 3, 223-232. doi:10.1007/s11764-009-0098-x
- Brezden, C.B., Phillips, K.A., Abdolell, M., Bunston, T., & Tannock, I.F. (2000). Cognitive function in breast cancer patients receiving adjuvant chemotherapy. *Journal of Clinical Oncology*, 18, 2695-2701.
- Downie, F.P., Mar Fan, H.G., Houede-Tchen, N., Yi, Q.L., & Tannock, I.F. (2006). Cognitive function, fatigue, and menopausal symptoms in breast cancer patients receiving adjuvant chemotherapy: Evaluation with patient interview after formal assessment. *Psycho-Oncology*, 15, 921-930. doi:10.1002/pon.1035
- Elo, S., & Kyngas, H. (2007). The qualitative content analysis process. *Journal of Advanced Nursing*, 6, 107-115.
- Fitch, M.L., Gray, R.E., Godel, R., & Labrecque, M. (2008). Young women's experiences with breast cancer: An imperative for tailored

- information and support. *Canadian Oncology Nursing Journal*, 18, 74–86.
- Jacobs, S.R., Jacobsen, P.B., Booth-Jones, M., Wagner, L., & Anasetti, C. (2007). Evaluation of the functional assessment of cancer therapy cognitive scale with hematopoietic stem cell transplant patients. *Journal of Pain and Symptom Management*, 33, 13–23. doi:10.1016/j.jpainsymman.2006.06.011
- Jenkins, V., Shilling, V., Deutsch, G., Bloomfield, D., Allan, S., Bishop, H., . . . Winstanley, J. (2006). A 3-year prospective study of the effects of adjuvant treatments on cognition in women with early stage breast cancer. *British Journal of Cancer*, 94, 828–834. doi:10.1038/sj.bjc.6603029
- Mulrooney, T. (2007). *The lived experience of cognitive impairment in women treated with chemotherapy for breast cancer* (Unpublished doctoral dissertation). University of Utah, Salt Lake City, UT.
- Munir, F., Burrows, J., Yarker, J., Kalawsky, K., & Bains, M. (2010). Women's perceptions of chemotherapy-induced cognitive side effects on work ability: A focus group study. *Journal of Clinical Nursing*, 19, 1362–1370. doi:10.1111/j.1365-2702.2009.03006.x
- Myers, J.S., Sousa, V.D., & Donovan, H.S. (2010). Predictors of self-reported memory problems in patients with ovarian cancer who have received chemotherapy. *Oncology Nursing Forum*, 37, 596–603. doi:10.1188/10.ONF.596-603
- Myers, J.S., & Teel, C. (2008). Oncology nurses' awareness of cognitive impairment secondary to chemotherapy. *Clinical Journal of Oncology Nursing*, 12, 725–729. doi:10.1188/08.CJON.725-729
- Nail, L.M. (2006). Cognitive changes in cancer survivors. *American Journal of Nursing*, 106(3, Suppl.), 48–54.
- O'Shaughnessy, J. (2003). Chemotherapy-related cognitive dysfunction in breast cancer. *Seminars in Oncology Nursing*, 19(4, Suppl. 2), 17–24. doi:10.1053/j.soncn.2003.09.002
- Sandelowski, M. (2000). Focus on research methods: Whatever happened to qualitative description? *Research in Nursing Health*, 23, 334–340. doi:10.1002/1098-240X(200008)23:4<334::AID-NUR9>3.0.CO;2-G
- Saykin, A.J., Wishart, H.A., Rabin, L.A., Santulli, R.B., Flashman, L.A., West, J.D., . . . Mamourian, A.C. (2006). Older adults with cognitive complaints show brain atrophy similar to that of amnesic MCI. *Neurology*, 67, 834–842. doi:10.1212/01.wnl.0000234032.77541.a2
- Schagen, S.B., van Dam, F.S., Muller, M.J., Boogerd, W., Lindeboom, J., & Bruning, P.F. (1999). Cognitive deficits after postoperative adjuvant chemotherapy for breast carcinoma. *Cancer*, 85, 640–650.
- Thielen, J. (2008). *The experience of neurocognitive changes in women undergoing chemotherapy for breast cancer* (Unpublished doctoral dissertation). University of Connecticut, Storrs, CT.
- Von Ah, D., Harvison, K.W., Monahan, P.O., Moser, L.R., Zhao, Q., Carpenter, J.S., . . . Unverzagt, F.W. (2009). Cognitive function in breast cancer survivors compared to healthy age- and education-matched women. *The Clinical Neuropsychologist*, 23, 661–674. doi:10.1080/13854040802541439
- Wagner, L., Sweet, J., Butt, Z., Lai, J., & Cella, D. (2009). Measuring patient self-reported cognitive function: Development of the Functional Assessment of Cancer Therapy–Cognitive Function instrument. *Journal of Supportive Oncology*, 7, W32–W39.
- Wefel, J.S., Lenzi, R., Theriault, R.L., Davis, R.N., & Meyers, C.A. (2004). The cognitive sequelae of standard-dose adjuvant chemotherapy in women with breast carcinoma: Results of a prospective, randomized, longitudinal trial. *Cancer*, 100, 2292–2299. doi:10.1002/cncr.20272
- Wieneke, M.H., & Dienst, E.R. (1995). Neuropsychological assessment of cognitive functioning following chemotherapy for breast cancer. *Psycho-Oncology*, 4, 61–66. doi:10.1002/pon.2960040108