

CANCER- AND CHEMOTHERAPY-RELATED COGNITIVE CHANGES: THE PATIENT EXPERIENCE

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OBJECTIVES: *To summarize the results of qualitative research conducted to describe patients' experience with cognitive changes attributed to cancer and chemotherapy.*

DATA SOURCES: *Peer reviewed journals and texts.*

CONCLUSION: *Patient experiences were consistent across tumor types and gender. Patients' desire to be informed about the potential for cognitive changes was a common theme, as was the desire for recognition, assessment, and validation by the health care team. Cognitive changes significantly impact quality of life, self-confidence, and independence.*

IMPLICATIONS FOR NURSING PRACTICE: *Understanding the patients' perspective is important to provide appropriate education and emotional support. Ongoing and future research is crucial to investigate interventions to prevent, mitigate, and treat the cognitive sequelae of cancer and chemotherapy.*

KEY WORDS: *Cancer, chemotherapy, cognition, cognitive changes, chemobrain*

THE body of knowledge for cancer and cancer-related cognitive changes continues to grow. Cancer survivors' complaints of cognitive changes during

and following chemotherapy have led to increased recognition of this phenomenon by health care professionals. Numerous studies have been designed to investigate the incidence, causal

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mechanisms, and interventions to prevent or mitigate the impact of cancer and chemotherapy on cognition. Fewer studies have been conducted to describe the lived experience of cancer-related cognitive changes from the patients' perspective. However, the qualitative work that has been done has yielded remarkably similar results and has been used to inform the development of self-report instruments such as the Functional Assessment of Cancer Therapy- Cognition.¹ The purpose of this article is to summarize the results of qualitative research conducted to describe patients' experience with cognitive changes attributed to cancer and chemotherapy.

The use of qualitative research methodologies (such as in-depth interviews and focus groups) is well-suited to garnering information about patients' experiences outside of information that can be gleaned from a quantitative approach.^{2,3} Qualitative research design provides a mechanism for gleaning first-hand accounts of the perception of cognitive changes and subsequent impact on daily functioning and quality of life.⁴ Patients' self-report of changes in cognitive function provide valuable insight into a clinically relevant understanding of the phenomenon and the patients' perspective of the experience.⁴⁻⁶

A review of the literature yielded 17 publications that included results for qualitative works designed to investigate cognitive changes associated with cancer and chemotherapy (see Table 1).^{1,4,5,7-20} Ten studies and one case description were comprised solely of participants who were survivors of breast cancer.^{4,5,7-14,20} Two studies included individuals with breast cancer as well as other tumor types (lung, esophageal, liver, prostate, colorectal, gynecologic, hematologic, and pancreatic).^{1,15} Two studies were designed to investigate the experiences of patients with testicular cancer¹⁶ and myeloma.¹⁷ Specific cancer diagnoses were not iterated for two studies.^{18,19} Regardless of the type of cancer represented in these studies, the results were consistent for types of cognitive complaints and the description of the patients' experiences.

DESCRIPTION OF THE EXPERIENCE

Study participants consistently described difficulties with attention, concentration, and short-term memory (see Table 2).^{1,4,5,7-15} Examples of these concerns included complaints

of "walking into a room and forgetting what they were doing there," misplacing items such as cell phones and keys, not being able to remember names and numbers, trouble with word finding, and the inability to multitask.^{5,7,9,10,12-14,16,17,19,20} The term "chemobrain" commonly was used to label these concerns.^{4,12,15,19} Participants related difficulties with reading comprehension and the ability to stay absorbed with a book.^{4,10,12,13,15,17,18} Concentration impairment and memory issues made driving difficult for many participants. Complaints also included trouble remembering where they were going, problems with directions, the fear of getting lost, and safety issues with awareness of other drivers and traffic signals.^{5,12,13,18,20}

Tasks were described as taking more effort and a longer time to accomplish.^{1,4,5,10,13,16,17} Participants noted complaints of repeating themselves, feeling foggy or spacey, and experiencing decreased self-confidence at work and in social settings due to issues with memory.^{8,10,12-14,18} Many described feeling their performance at work or school suffered because of their cognitive changes.^{1,4,8,11-13,17} Retaining new information or learning new concepts was difficult, as was communicating with others, particularly in settings involving multiple people and/or distractions.^{4,8-10,12,18}

IMPACT OF THE EXPERIENCE

Commonalities in emotional responses to cognitive changes included feelings of distress, anxiety, depression, irritation, frustration, and embarrassment (see Table 2).^{1,4,7,8,13-15,19} Participants described feeling stupid, out of control, cuckoo, or as if they were going crazy or out of their head.^{7,13,19} Many related fears of being at risk for dementia or Alzheimer's disease.^{10-12,18,19} Family tensions and frustrations resulted from participants' inability to remember things and frequently repeating themselves.^{4,7,12,13,20}

The impact of cognitive changes resulted in many participants withdrawing from social activities.^{4,5,10,13,15} A number of work-related changes were described including losing jobs, changing jobs, early retirement, or being unable to return to work once treatment was completed.^{12,13,17} Some survivors noted being passed over for promotion or looking for jobs with a lighter work load.⁴ Others described feelings of decreased

TABLE 1.
Qualitative Research Summary

Author	Methods	Sample	Eligibility
Downie et al, 2006 ⁵	I	Breast (21)	Receiving adjuvant chemotherapy
Mitchell, 2007 ¹⁸	I, D	Not described (19)	Men and women about to receive chemotherapy
Capiello et al, 2007 ⁷	I	Breast (20)	Completed three or more chemotherapy cycles within previous 6 months
Fitch et al, 2008 ¹⁵	I	Breast (15) Colorectal (8) GYN (3) HEM (4) Lung (1) Pancreas (1)	Employed at Dx. Started chemotherapy a minimum of 6 months previously
Mulrooney, 2008 ⁹	I	Breast (15)	Self-report of cognitive changes after chemotherapy
Wagner et al, 2009 ¹	I,F	Breast (10) Lung (4) Esophageal (2) Liver (1) Prostate (1) Myeloma (1)	Completed three or more cycles of chemotherapy within previous 6 months
Boykoff et al, 2009 ⁴	I,F	Breast (74) Caucasian (38) African American (36)	At least 1 year post chemotherapy
Portrata et al, 2009 ¹⁷	I	Myeloma (15) Caucasian (10) Asian (3) African (1)	Took part in larger study of symptom experiences; 1 to 5 years after at least one tx. Majority had stem cell transplant
Munir et al, 2010 ¹⁰	F	Breast (13)	Completed primary and/or adjuvant chemotherapy within 5 years
Raffa and Martin, 2010 ²⁰	I	Breast (1)	Case description; 15 years post-chemotherapy. Hx of BMT
Mitchell and Turton, 2011 ¹⁹	I	Breast (1) Other types not described	Due to start chemotherapy with curative intent
Munir et al, 2011 ¹¹	I	Breast (31)	4 months after completion of chemotherapy
Skoogh et al, 2012 ¹⁶	I	Testicular (40)	Swedish men treated for testicular cancer within previous 26 years. Mean Dx within 11 years, range 3 to 26 years
Von Ah et al, 2012 ¹³	I	Breast (22)	Self-reported cognitive changes; 1 year post-chemotherapy
Chuang et al, 2012 ⁸	F	Breast (43)	Receiving or completed chemotherapy. Multiethnic sample, primarily Chinese. Receiving tx (10); within 3 to 6 months of tx (6); within 12 months of tx (18); >12 months after tx (9)
Myers, 2012 ¹²	I,F	Breast (18)	Self-report of cognitive changes within 6 to 12 months of chemotherapy
Rust and Davis, 2013 ¹⁴	F	Breast (24)	Medically underserved African American ≥12 months after tx.

Abbreviations: I, interviews; D, diaries; F, focus groups; Dx, diagnosis; GYN, gynecology; HEM, hematology; tx, treatment, Hx, History; BMT, bone marrow transplant.

confidence and relying more on co-workers to double check their work.^{8,13,18} The difficulties with driving described earlier resulted in complaints of loss of independence.⁴

Participants acknowledged that cognitive changes were exacerbated by fatigue and stress.^{1,12} The most varied descriptions from the studies reviewed involved the timing for when participants began to notice cognitive changes and whether or not they noted improvement

over time. Responses ranged from some awareness of cognitive changes before therapy¹⁵ to not noticing changes until chemotherapy was completed and most other side effects had subsided.¹³ Many noted cognitive changes within the first one to two cycles of chemotherapy.^{10,12,15} Likewise, a great deal of variety was seen across study results for improvement in cognitive function. Improvements were noted between chemotherapy cycles for some patients,¹¹ while others

TABLE 2.
The Experience of Cognitive Changes

Author	Deficits Noted	Impact	Other Concerns
Downie et al, ⁵ 2006	Short-term memory Forget names, words, places, appointments Concentration Verbal fluency Mental fluency Processing speed Planning Misplace items Multitasking Sense of direction Coordination Distance judgment	Anxiety Decreased confidence	
Mitchell, ¹⁸ 2007	Thinking Retrieving thoughts Concentration Repeating self Memory Reading comprehension Driving Communication with others	Anxiety Decreased confidence	"Feel cuckoo"
Capiello et al, ⁷ 2007	Memory Concentration Multitasking	Distress	Need information on persistent treatment effects Symptoms persist throughout first year post treatment
Fitch et al, ¹⁵ 2008	Memory Forget names, numbers, event details Word finding Concentration Walk into a room and forget why they are there Reading comprehension Movie comprehension Decision making Planning Completion of activities Requiring attention to detail Work performance	Distress Irritable Resignation	Wanted information at the beginning of treatment Wanted information about coping strategies
Mulrooney, ⁹ 2008	Memory Concentration Multitasking Forget names Overwhelmed by multiple stimuli Word finding		Most with complaints had high stress occupations
Wagner et al, ¹ 2009	Word finding Forgetfulness Lack of mental clarity Attention Memory Abstract reasoning Psychomotor slowing Verbal comprehension Mental calculations	Frustration Depression Distress	Exacerbated by stress Feel fuzzy or foggy

(Continued)

TABLE 2.
(Continued)

Author	Deficits Noted	Impact	Other Concerns
Boykoff et al, ⁴ 2009	Tangential speech Slowed rate of speech Work performance Driving Retention Digest new information Memory for numbers, names, places, Directions Reading technical or Philosophical texts Job performance Focusing Slowed performance Easily distracted Changed jobs	Decreased QOL and daily functioning Comparison to attention deficit disorder Frustration Decreased independence Confused family and friends Decreased chance of promotion for lighter workload Early retirement Resignation Negative impact on job interviews and school performance Unable to return to work	Wanted upfront information about cognitive changes Wanted validation and advice Exacerbated by stress
Portrata et al, ¹⁷ 2009	Recall Short-term memory Concentration Remembering the research and prearranged meetings Word finding Reading Walk into a room and forget what they were doing Misplace items Longer time to complete tasks		
Munir et al, ¹⁰ 2010	Concentration Confusion Clear thinking Multitasking Communication with more than one person at a time Decision making Repeating self Work performance Thinking quickly Reading comprehension	Frustration Family tension Decreased self-confidence	Symptoms lasted 1 year or longer Noticed changes when chemotherapy started Feel like "going out of my head" Comparisons to Alzheimer's and dementia Insufficient information from oncology team
Raffa and Martin, ²⁰ 2010	Misplace items (clothes in freezer) Reading Walk into a room and forget what was doing Driving Fear of getting lost	Frustration	Estimates 20% cognitive loss
Mitchell and Turton, ¹⁹ 2011	Reading Word finding Misplace items Short-term memory for names, numbers Multitasking	Anxiety Frustration Feeling out of control	Comparison to Alzheimer's Exacerbation by fatigue Feared risk of dementia

(Continued)

TABLE 2.
(Continued)

Author	Deficits Noted	Impact	Other Concerns
Munir et al, ¹¹ 2011	Remembering tasks at work Memory Attention Focusing	Decreased confidence at work	Requested information and support Thought "going senile" Wanted information for friends, family, colleagues and boss Wanted assessment prior to and at end of chemotherapy
Skoogh et al, ¹⁶ 2012	Word finding Dependent on notes Misplace items Slow thinking		
Von Ah et al, ¹³ 2013	Memory for names, events, appointments Walk into a room and forget what they are doing Word finding Slower processing and completing tasks Reading Calculations Directions/Driving Work performance	Frustration Decreased self-confidence Embarrassment Frustrated family	Most prominent complaints after treatment complete Most stated no improvement over time Wanted validation from HCP so know "not going crazy" Feeling "foggy or spacey" Feeling "stupid" Needed information before treatment
Cheung et al, ⁸ 2012	Memory Decision making Speech Learning new concepts Work capabilities	Frustration Anxiety Frightened Embarrassed Lost confidence when returned to work	Were not "warned" Acknowledge minor deficit before treatment Fatigue as significant contributor
Myers, ¹² 2012	Short-term memory Retain information during conversation Reading comprehension Movie comprehension Walk into a room and forget what they are doing Misplace items Word finding Driving Coordination/balance Focusing Concentration Planning Work and school performance Slower to complete tasks	Lost jobs (2) Trouble with school Lost photographic memory	Wanted information prior to chemotherapy Felt like "going crazy" Analogies to being pregnant, drunk, on allergy medicine, Alzheimer's Exacerbated by fatigue Most experienced some improvement over time Wanted support and validation Wanted regular assessment Younger women wanted age-matched support
Rust and Davios, ¹⁴ 2013	Memory Walk into a room and forget why there Misplace items Driving/directions Multitasking Slower to accomplish tasks Work performance	Frustration Aggravation Disruption of daily lives	Feeling "foggy", "going blank" Concern about being perceived as mentally Lack of information from HCP

Abbreviations: QOL, quality of life; HCP, health care professional.

TABLE 3.
Coping Strategies

Author	Coping Strategies
Downie et al, 2006 ⁵	Writing things down Avoid social activities
Fitch et al, 2008 ¹⁵	Avoid substantive social interactions Write things down Keep items in the same place Mind stimulating activities Don't try to do too much Humor
Mulrooney, 2008 ⁹	Ask others for help Put things in the same place Writing things down Ask others for help Mind stimulating activities Exercise
Wagner et al, 2009 ¹	Over-concentrating Repetition
Boykoff et al, 2009 ⁴	Writing things down (eg, turn off gas, shut door) Keep things in same place Mind stimulating activities Curtail work and social activities
Portrata et al, 2009 ¹⁷	Writing things down Change to reading newspaper, children's books, magazines or use of short audiobooks
Von Ah et al, 2013 ¹³	Withdraw from social situations Leave employment
Cheung et al, 2012 ⁸	Mind stimulation activities Exercise Family support
Myers, 2012 ¹²	Writing things down Give self permission to make mistakes Exercise Mind stimulation activities Getting enough rest Depend on others for help Focus on one thing at a time Not rushing
Rust and Davis, 2013 ¹⁴	Humor Social support Spirituality

described improvements 6 to 12 months after completion of therapy.^{7,10,12} Some participants had seen no improvements at the time the research was conducted (6 to 12 months post-treatment).¹⁵

STRATEGIES FOR COPING WITH THE EXPERIENCE

Coping strategies were consistent across the studies (see Table 3). Survivors described the need to write things down, make lists, and a dependency on notes to remember deadlines, tasks to

be done, appointments, and even very simple things such as the need to remember to turn off the gas or shut the door as they left their home.^{1,4,5,9,12,15,17} Many noted the need to be very consistent in where they kept items such as their car keys or their cell phones in order not to misplace them.^{4,9,15} Participants described using strategies to mitigate cognitive changes such as exercise, getting enough rest, reading simpler books or magazines, and attempting mind stimulating activities like crossword puzzles or Sudoku.^{12,15,17} Participants related giving themselves permission to make mistakes, focusing on one thing at a time, and not rushing.¹²

Survivors consistently shared their desire for information about the potential for cognitive changes to be provided before receiving chemotherapy.^{4,7,12-15} They wanted information to be shared with their family, co-workers, and friends.^{10,12} Acknowledgement of the existence of cognitive changes as a result of cancer and chemotherapy was very important to participants.^{4,12-14} On-going support and assessment of cognitive concerns also was desired.^{11,12,15}

CONCLUSION

Consistent results from qualitative research designed to investigate the patient experience of cancer- and chemotherapy-related changes in cognition lend support to the commonalities of the phenomenon across tumor types and gender. The results gleaned from these qualitative studies provide valuable information to health care professionals about the impact cognitive changes have on patients' quality of life and day-to-day function. Understanding the experience of cognitive changes from the patients' perspective is important to oncology nurses as education and emotional support are provided.

Patients' desire to be informed about the potential for cognitive changes before receiving chemotherapy is a common theme throughout the literature, as is the desire to have the phenomenon recognized, assessed, and validated by the health care team. The significant impact cognitive changes have on quality of life, patients' self-confidence, and independence highlights the importance of on-going and future research to investigate interventions to prevent, mitigate, and treat the cognitive sequelae of cancer and chemotherapy.

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