



Cognitive Changes Related to Cancer Treatment

SURVEY RESULTS

Researchers from varied disciplines have conducted and published studies which focus on identifying causal relationships between cancer treatment and cognitive dysfunction.

In addition to the many unanswered questions still to be addressed by these medical studies, there is a persistent lack of understanding of this treatment side-effect from the patients' perspective—how cognitive deficits impact the daily lives of the millions of men and women coping with changes in memory, thinking, attention span, and concentration.

Hurricane Voices Breast Cancer Foundation developed *Cognitive Changes Related to Cancer Treatment*, an online survey conducted between January 26, and May 15, 2007. The goal was to garner information directly from cancer patients about cognitive impairment after cancer treatment—often referred to as 'chemo brain.' The results expand upon the singular anecdotal story and present a collective voice that illuminates the patient experience.

471 self-selected respondents participated in the survey, which was open to men and women, diagnosed with any type of cancer, currently in treatment or having completed treatment. A recap, assessment and analysis of the results follow.

QUESTION 1

Have you experienced changes in your thinking, memory, or attention during or after cancer treatment?

Yes: 453

No: 9

Note: 9 respondents did not answer this question.

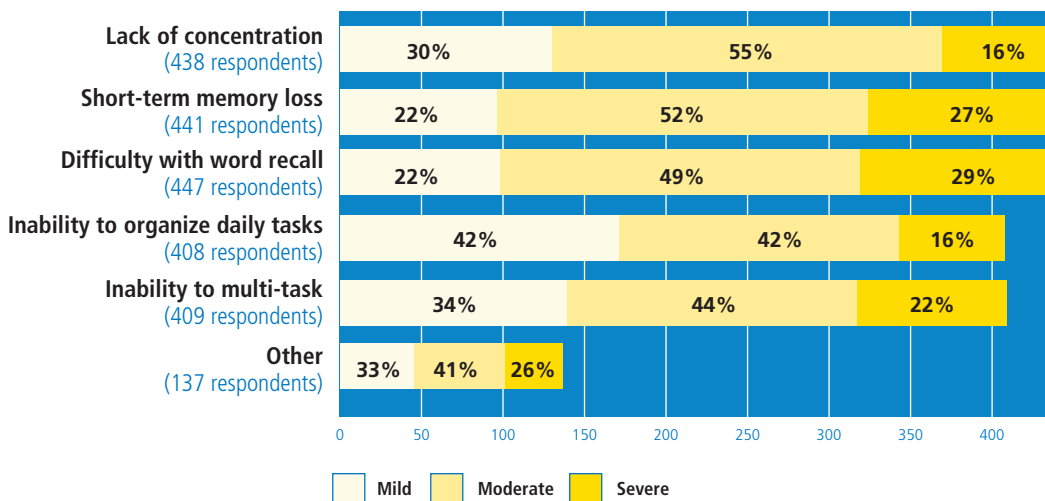


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QUESTION 2

How would you describe and rate your symptoms?



Respondents experienced changes across the board. In all areas more than 50% of participants had moderate-to-severe symptoms. Patients reported having the most difficulty with short-term memory loss and word recall—the areas having the highest ‘moderate’ and ‘severe’ ratings. Lack of concentration is also a critical area.

The most common ‘other’ responses as reported by 137 respondents:

- :: Issues with transposition/dyslexia.
- :: Intolerance to external environment, i.e. interruptions, commotion, confusion.
- :: Foggiess—mental cloud.
- :: Inability to follow-through.
- :: Difficulty learning and retaining new information and duties.

Some survey-takers also annotated their ratings by adding comments to the ‘other’ field. Common themes emerged, including frustration with the cognitive changes and resultant inability to function at work/home at pre-treatment level.

QUESTION 3

When did you notice these symptoms?

The majority of survey respondents (85%) noticed changes in cognitive function after starting treatment (not immediately upon treatment), or at the end of treatment. Just over 2% identified changes prior to treatment.

Some studies have indicated that a much larger percentage, approximately 30% of patients experience changes before starting treatment. There are several possibilities for this disparity including the difference between self-reporting and formal testing,

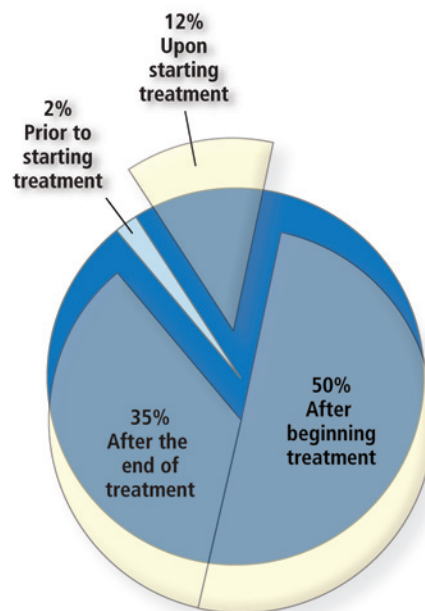


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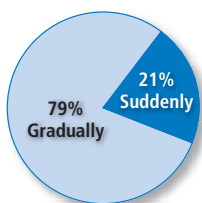
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as well as retrospective data gathering vs. testing concurrent with diagnosis/treatment. Patients may also be more apt to notice changes after the initial whirlwind of appointments, procedures and treatment has shifted to a less frenetic schedule.

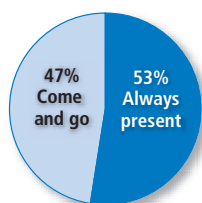
The discrepancy between our survey and research employing objective tests points to the importance of incorporating baseline testing in future studies of cognition and cancer treatment, with a goal of pinpointing the onset timing of cognitive changes. Zeroing in on the timing of changes will help researchers identify various mechanisms which contribute to cognitive impairment.



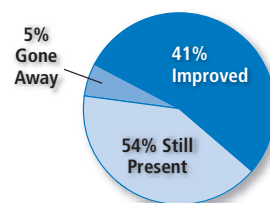
Did You Notice the Symptoms...



Are (were) they, or do (did) they...



Have they, or are they...



Overall, changes tended to come on, or be noticed gradually (79%). Approximately one-half of the respondents experienced these changes constantly, while the other half noticed them intermittently.

While 40% feel their cognitive functioning has improved somewhat, only 5% report that the symptoms have 'gone away' completely. More than 50% of the respondents report that the changes are still present at the same level.

Patients are often told, and some studies indicate, that the effects of 'chemo brain' are ameliorated within several months. While this is true for some patients, many others have to cope with long-term cognitive impact of treatment. 92% of survey respondents who are five or more years out from treatment are still experiencing deficits on some level.

Recent studies have substantiated patient's reports of prolonged effects—some as long as 10 years after treatment, but the scope of the impact in the patient population is uncertain. Studies designed to follow a large number of patients over many years will help determine the percentage of survivors experiencing long-term cognitive impairment.



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QUESTION 4

Have these changes impacted your functioning and/or relationships at home?**Yes: 286****No: 173**

The majority of respondents indicated that changes in how their brain works impacted their functioning and relationships at home (62%), and in employment outside the home (62%).

The effects range from taking longer to do ordinary jobs around the house and no longer being able to do household/financial tasks, to having to change/downsize job function, change careers, or stop work completely.

At home respondents report:

- :: Being teased, criticized, or 'supervised' by family members.
- :: Children prematurely taking on increased responsibility.
- :: Spouses who feel the cancer patient is acting irresponsibly.
- :: Respondents won't go to social functions due to embarrassment.
- :: Inability to maintain personal responsibility for household or financial tasks.

Frustration is a common theme—with one's self and/or frustration exhibited by family members at the changes in the cancer patient. This point is illustrated by one woman's note that her *"family members don't believe in 'chemo brain' and are intolerant."*

Other common themes which emerged were making copious notes—at times on one's body; lapses during conversations; difficulty communicating due to lack of word recall; and losing one's train of thought.

Participants reported having difficulty with external stimuli—they find coping with sounds and distractions distressing, confusing, and anxiety provoking.

On a lighter note, one positive aspect appeared—decreased ability to hold a grudge when one can't remember conversations, arguments or rules violation.

Productivity at home is severely diminished:

- :: Inability to organize daily tasks, such as:
 - fixing lunches,
 - paying bills,
 - feeding pets.
- :: Inability to cook:
 - difficulty following recipes,
 - leaving things cooking on the stovetop and burning meals.

There is also a loss of credibility with their partners, spouses, and children. Since you're wrong some of the time, you must be wrong all of the time.

"My husband doesn't trust my memory anymore, even when I am actually right!"

"Mainly [affecting] my confidence in my abilities, and [I think] others such as my husband, may doubt them, too."



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Changes in family dynamics also include:

- :: Shift in responsibilities (onto partner or child).
- :: Children worrying about the parent.
- :: Person with cognitive impairment is relegated to a marginalized role.
- :: Family members can become abusive, condescending, or patronizing.
- :: Partner dynamics shift:
 - exhibiting frustration and intolerance,
 - becoming more supportive and assuming additional responsibilities.
- :: Divorce or separation.

Patients report a “loss of self”—they no longer can function as the person they were before cancer.

“I have had to let go of the ‘smart’ person I once was.”

“[I am] unable to contribute to household income, and depression and reduced self-esteem have occurred as a result.”

Have these changes impacted your functioning and/or relationships at work?**Yes: 275****No: 166**

Although 38% indicated that they were not impacted at work, we were able to identify 10 instances where respondents had to leave jobs, or were terminated from jobs—thus experiencing the ultimate ‘impact’ in their work lives.

(The survey did not reveal if others who indicated they were not working, left their jobs due to their cancer treatment.)

An additional ten respondents, who answered ‘no’ were, in fact, impacted, based on their written comments. These participants felt ‘stupid’ at work, and/or had to work differently to compensate and to cover-up changes in thinking.

Of the 62% who indicated that their work life has been effected. An overriding theme is that work requires greater effort and concentration—working harder at the same job as before. The greatest impact was experienced 1–5 years out from treatment (52% of respondents).

Their experiences fell into several categories:

- :: Having to shift or relinquish employment:
 - inability to function in a work environment,
 - going on disability,
 - premature retirement,
 - downsizing to a job with fewer responsibilities and less pay.
- :: Being overwhelmed by tasks assigned, unable to multi-task, or organize daily work load.



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- :: Issues with memory force a heavy reliance on extreme note-taking, memo posting, calendar notices, etc.
- :: Issues of word recall severely hamper writing abilities and effective professional communication.
- :: Difficulty with focusing and concentration.
- :: Need for re-training on familiar responsibilities.
- :: Difficulty learning new tasks, understanding new concepts, retaining new skills sets.
- :: Coping with lack of understanding and frustration exhibited by managers and co-workers.
- :: Loss of self-confidence and feelings of inadequacy in the workplace.

As reflected in the responses to question #4 the challenges these patients are dealing with in the workplace contribute to the overall loss of self-esteem and confidence, leading to a 'loss of self.'

QUESTION 5

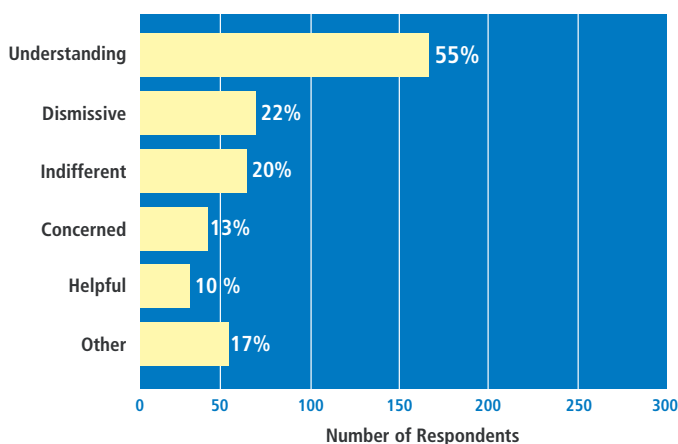
Have you spoken to your oncologist and/or another doctor about this?

Yes: 299
No: 165

63% of respondents felt compelled to discuss their impairments with a medical professional. However, their concerns were met with mixed reactions.

If yes, what has been his/her response?

Survey-takers were given the opportunity to choose multiple responses to this question. By far, oncologists were understanding about their patients' cognitive impairment, but few patients (10%) felt that they were offered assistance to deal with these challenges. Participants described their doctors' response as dismissive and/or indifferent 42% of the time.



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The 51 'other' responses were either exclusive of, or in addition to a rating. The majority describe doctors who were unhelpful and/or dismissive. The comments range from doctors saying that there is no proof that 'chemo brain' exists, to not believing cognitive changes are due to the cancer or treatment—changes are ascribed to aging, stress, hormones, etc. Several notes were made about doctors being focused on only keeping patients alive.

One inference from this survey question is that some medical practitioners clearly understand that patients' brain functioning is impacted and want to offer help—however, currently there is very little known about what *can* help.

An additional conclusion is that doctors and other healthcare practitioners don't focus on cognitive issues due to a variety of reasons: it isn't central to their work as oncologists, they don't believe in it, they don't know enough about it, etc.

Were you satisfied with his/her response?

55% of the respondents answering this question were not satisfied with their oncologists/medical team's response. In the answers and comments provided, it is clear that although doctors can understand that their patients are experiencing difficulties with cognition, at the same time they can be dismissive, and/or unhelpful.

Oncologists should be acquainted with issues related to cognitive changes and able to refer the patient to the appropriate team member for follow-up. Demonstrating empathy for patients' cognitive impairments, and understanding that in addition to the trauma of 'fighting for their lives,' they are also experiencing a loss of self, will enhance the patient/physician relationship.

A broad-based need for education within the medical community about cognitive impairment associated with cancer treatment is indicated by survey responses and written comments. These illustrate the misunderstanding of this crucial quality of life (QoL) issue, which grows more urgent as cancer patients are living longer.

An opportunity exists to reach out to oncologists, nurses, social workers, etc. informing them of the latest scientific research on cognitive functioning related to cancer and its treatment—and complementing that research with patient-reported experiences.

Yes: 133

No: 164

QUESTION 6

Have you had neuropsychological testing?

Yes: 21

No: 442

If yes, did you feel the test results accurately matched your experiences?

Yes: 10

No: 18



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QUESTION 7

Did you have interventions to try to improve your cognitive function?

Yes: 36
No: 408

If yes, did your cognitive function improve significantly?

Yes: 17
No: 38

Very few patients are referred for neuropsychological testing and subsequent intervention strategies. However, where interventions were utilized patients gained improvement in their cognitive functioning.

There were discrepancies in the numbers and answers for questions 6 and 7, indicating misunderstanding and misinterpretation by respondents on this section of the survey. However, of the 36 who said they had intervention to improve cognitive function, 17 (about 47%) did experience some improvement.

A recently published pilot study with breast cancer patients showed improvement in cognitive functioning after using Memory and Attention Adaptation Training (MAAT). The results indicate the positive potential for cognitive-behavioral intervention in treating patients experiencing cognitive impairment from cancer treatment.¹

QUESTION 8

What type of cancer were you diagnosed with?

Although the survey was open to people who have had any/all types of cancers, the survey was disseminated to, and was answered predominately by women diagnosed with breast cancer (91%).

Women diagnosed with breast cancer, represent the single largest group of cancer survivors. They have typically been vocal advocates around ‘chemo brain’ often pressing the issue with their doctors and medical teams, and taking an active role in this area of research.

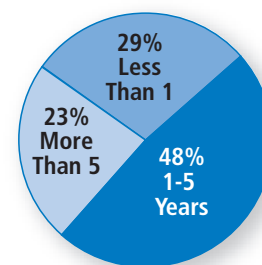
Recent studies related to cognition and cancer have been conducted with prostate, colorectal, and other cancer patients.

- 1 Bladder**
- 3 Lung**
- 430 Breast**
- 0 Melanoma**
- 4 Colon/Rectal**
- 2 Non-hodgkin’s lymphoma**
- 1 Endometrial**
- 6 Ovarian**
- 2 Leukemia**
- 0 Prostate**
- 17 Other**

QUESTION 9

How long ago did you complete chemotherapy?

71% of survey respondents are more than 1 year out of treatment—48% between 1 and 5 years, 23% more than 5 years.



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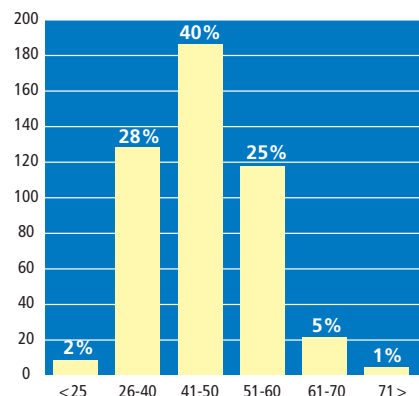
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QUESTION 10

How old were you when you received treatment?

Patients are impacted by cognitive impairment at every age. The majority of participants in our survey were 50 or younger (68%).

Although aging is often a scapegoat, growing older does not appear to be the primary factor in cognitive deficits related to cancer treatment.



QUESTION 11

What is Your Gender?

From a variety of studies conducted over the past several years, we know that cognitive changes cross the gender divide. However, due to distribution channels, the vast majority of the respondents were women. The men answering the survey experienced cognitive changes across the board, with similar issues of impact at home and at work.

Male: 9
Female: 455*

*461—6 additional records were able to be identified as female.

CONCLUSION

As graphically illustrated in this survey, cognitive impairment resulting from cancer treatment greatly diminishes quality of life (QoL) for cancer patients/survivors, and has far-reaching implications for the individual and society. The impact of ‘chemo brain’ goes far beyond an occasional lost word, or missed appointment. Often one’s “self” is no longer recognizable, employment can be lost, and familial relationships shift.

Despite the pervasive impact on patients’ lives, cognitive changes are not adequately acknowledged and addressed by healthcare providers. This could be a result of several factors:

- :: Oncology teams may not be familiar with current research presenting data that brain functioning is impacted by cancer treatment.
- :: Neuropsychological testing does not always confirm deficits as reported by cancer patients (some cognitive changes are too subtle for current testing methodologies).
- :: Effective intervention strategies are not currently available—medical professionals are left with few options to help patients cope with symptoms.

As the number of survivors continues to grow, cognitive deficits will become a critical QoL concern for millions of cancer patients. To ensure quality care, it is vital for



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oncology teams to be aware of current research and to incorporate cognitive changes in the array of side-effects discussed and monitored throughout and following treatment.

Additional studies are being conducted and are required in order to identify the mechanisms leading to cognitive changes, as well as prevention, intervention, and coping strategies.

The recent formation of the International Cognition and Cancer Task Force (ICCTF) will facilitate collaboration between institutions and disciplines, and will “advance understanding of cancer and cancer-related treatment on cognitive and behavioral functioning in adults with non-CNS [central nervous system] cancers.” The ICCTF also plans to develop a website as a resource for both the scientific community and general public interested in cognitive changes related to cancer and cancer treatment.

To read the *Cognitive Changes Related to Cancer Treatment* executive summary visit: hurricanevoices.org/today/cognition.

¹Ferguson R., Ahles T. et al: Cognitive-behavioral management of chemotherapy-related cognitive change. *Psycho-Oncology* 16-8: 772-777

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