



Cognitive Changes Related to Cancer Treatment

EXECUTIVE SUMMARY

Cognitive Changes Related to Cancer Treatment, an online survey developed by Hurricane Voices Breast Cancer Foundation was conducted between January 26, and May 15, 2007. 471 respondents—men and women, diagnosed with any type of cancer, currently in treatment or having completed treatment, participated in the survey. The goal was to garner information directly from cancer patients about their experiences with cognitive changes after cancer treatment—often referred to as ‘chemo brain.’

Of the 10.5 million cancer survivors in the United States an estimated 14–45% have had some level of cognitive dysfunction. Through this survey Hurricane Voices has created a collective representation of what millions of individuals experience as a result of their cancer and its treatment.

Key findings from the survey included:

> **Many cancer patients experience a ‘loss of self’ as a result of cancer treatment related to cognitive dysfunction.**

Cognitive impairments experienced by cancer patients alter the psyche. Patients no longer identify with the person they were prior to treatment. Contributing to the ‘loss of self’ is the loss of credibility, respect of others, self-esteem, and employment.

Respondents’ comments

“Mainly [affecting] my confidence in my abilities and [I think] others such as my husband may doubt them, too. This results in my postponing, delaying or canceling some tasks or activities which I would normally have done without a second thought.”

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

“My mind is not as sharp as it was, the total effect of all the symptoms is a real loss of confidence in myself... I am not myself anymore.”

“Inability to sequence numbers—i.e. telephone numbers, social security numbers. Since my job depended on those skills and others... I took an early retirement.”



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> **The impact cognitive changes have on cancer patients' lives are extensive and have critical consequences at home and work.**

Cognitive changes after cancer treatment impacted patients at home—62%, and at work—62%. Respondents report an inability to maintain pre-treatment levels of tasks and responsibilities both at home and at work. Results range from shifting familial relationships to loss of employment.

Respondents' comments

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

"I wasn't able to do daily chores, shopping, paying bills, helping with homework. I had to develop "tricks" to help me remember, stay organized, etc. My daughter (11 years-old) was forced to take on adult responsibilities too soon."

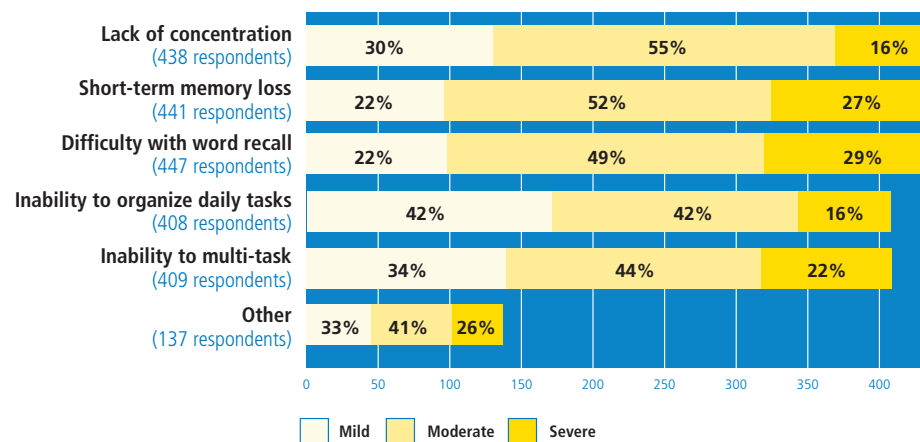
"I now work 30 rather than 40 hours and struggle constantly to do even that much. I'm a software engineer and sometimes can't put 2 thoughts together to solve the puzzles that are the main part of my job."

"I have had to give up my job as a customer-facing call center technical representative because adhering to the requirements to multitask and keep track of tremendous amounts of information was not possible. I was offered a paperwork job for 15% less money."

"Took early retirement because I could no longer track multiple projects; would get easily distracted with minor interruptions and couldn't complete assignments."

> **Deficits are experienced across the spectrum of cognitive functioning.**

Respondents rated their symptoms from mild to severe in all categories:



At least 50% of respondents rated their symptoms as moderate to severe in each of the categories.

Additional areas of impact included the ability to learn and/or retain new information and duties, intolerance to external stimuli, and issues with transposition/dyslexia.



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> **Short-term memory loss and word recall are the areas most impacted by cancer treatment.**

Patients rated these areas of deficit as severe 27% and 29% respectively.

Respondents' comments

"My forgetfulness and inability to come up with a word, etc., makes me feel I'm aging faster than I should, and my family members and spouse are becoming condescending or patronizing to the woman who says/does stupid stuff or forgets that things have happened."

"I often cannot remember things and conversations I've had. My short term memory is shot."

"[I] get very frustrated because I can't remember the name of things, i.e. saucepan, or other things I use daily..."



> **The cognitive deficits experienced by cancer patients can persist for an extended length of time.**

Of the 102 respondents 5 or more years out from treatment 92% were still impacted by cognitive changes—61% at the same level they first experienced following treatment. Only 8% reported that their symptoms had completely 'gone away.'

> **Medical professionals generally do not offer constructive information and assistance needed to help their patients cope with cognitive changes.**

63% of patients confer with their doctors/care providers, but only 10% felt they were provided information and support to help manage these changes. Written comments indicate that the experiences of 'chemo brain' are often underestimated and trivialized by caregivers and oncologists, leading to feelings of frustration for the patient.

Respondents' comments

"[My doctor] tries to listen but really doesn't get it, and keeps wanting to put me on antidepressants, NOT helpful, made me feel like I was lazy or not trying."

"Understanding, but not helpful—'yes, I have heard that from other patients.'"

"While my physician is understanding, he offers no solutions and tells me I need to find creative ways of staying focused."

"Some doctors do not recognize this at all, others acknowledge the problem but have no solutions."



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> **Opportunity exists to further educate the oncology, psycho-oncology, and nursing communities about the pervasiveness and subsequent impact of cognitive changes in the cancer patient population.**

55% of patients were unsatisfied with the response received when consulting with their medical professional about these changes. Written comments illustrate a disconnect between oncology teams and their patients regarding this important quality of life (QoL) issue.

Respondents' comments

"My oncologist is in general very warm and concerned but fundamentally does not really seem concerned about what she considers minor issues. After all, aren't I in a life saving course."

"My oncologist first noticed it during an appt. but told me brain function would return within 3 months of stopping treatment. That was 6 years ago. On follow ups when I mentioned it, was told studies were inconclusive."

"Both oncologists I have had insist 'there is no such thing as 'chemo brain'.'"

"Whilst understanding they cannot provide any help. "I guess you have to be thankful to be alive" is a phrase I have heard. Whilst true it is still distressing."

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 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.



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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.

For further *Cognitive Changes Related to Cancer Treatment* survey results visit: hurricanevoices.org/today/cognition.

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