

# Patients' experiences with cognitive changes after chemotherapy

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## Abstract

*Being diagnosed with cancer and undergoing treatment can be a daunting experience. The side effects of treatment often influence a person's quality of life. One side effect that has been identified more recently is known as "chemobrain." Although attempts have been made to quantify and measure cognitive changes, little attention has been paid to describing the changes from the patient's viewpoint.*

*This investigation was undertaken to understand the impact of cognitive changes on daily living and to identify the strategies patients used to cope with "chemobrain." Thirty-two individuals provided in-depth interviews about their experiences living with cognitive changes. Their descriptions provided clear evidence that the changes could affect daily living, social and work-related activities. About a quarter of the individuals expected the changes to be temporary while the rest were uncertain or expected the change to be permanent. The emotional distress people experienced was linked to whether or not the cognitive changes interfered with their doing something that was of importance to them. Overall, participants used a variety of strategies to cope with the changes. The most frequently identified strategy was "writing everything down." When asked what nurses could do to assist them in managing this side effect, participants emphasized how important it is for them to have information about the potential for cognitive change at the beginning of their treatment.*

Being diagnosed with cancer and undergoing treatment can be a daunting experience. In addition to dealing with the insults of the disease and the therapy, patients must confront a range of psychosocial, economic and spiritual challenges (Fitch, 2000).

Side effects of cancer treatments can often have a significant impact on quality of life, both during and after the treatment process. Nausea, vomiting, fatigue, hair loss and increased susceptibility to infections have been reported frequently (Harden et al., 2002). Patients describe changes in self-esteem, body image, social roles, faith, life meaning, despair and emotional distress, as they attempted to cope with such symptoms over the course of their cancer journey. Recently, cancer patients undergoing chemotherapy treatment have reported experiencing changes in their thinking, ability to concentrate, and recall. They often refer to these cognitive changes as "chemobrain" or "chemo-fog" (Anderson-Hanley, Sherman, Riggs, Agocha, & Compas, 2003). Since adequate cognitive functioning is imperative for patients to continue with their daily lives, this phenomenon has the potential to disrupt and decrease the quality of the patients' lives.

## Background literature

As the cadre of survivors increases, a growing number of publications report cognitive impairment after cancer treatment. The phenomenon of "chemo-fog" is now almost universally accepted and has been observed in those treated for breast cancer (Wefel et

al., 2004; Johnson, 2006), central nervous system (CNS) tumours (Raffa et al., 2006), solid tumours (Minisini et al., 2004) and lymphoma (Correa et al., 2004). It is considered multifactorial and its etiology is not fully understood (Tannock, Ahles, Ganz, & van Dam, 2004). The aspects of cognitive functioning that have been investigated include: executive function (brain's supervisory or regulatory function), verbal or working memory, visual memory, attention, language information processing speed, visuospatial ability, and motor function (Anderson-Hanley et al., 2003). Variations in effect have also been noted for different types of regimens. For example, the addition of tamoxifen may lead to more widespread memory loss (Bender, Paraska, Sereika, Ryan, & Berga, 2001). However, there are challenges in measurement that make the categorization of impairment inconsistent across studies and, hence, the true nature and extent of the impairment unclear (Shilling, Jenkins, & Trapala, 2006). Different measurement tools are utilized and many question the appropriateness of using tools developed for other populations with the cancer population. Concern has been expressed that these tools do not capture some of the subtle changes cancer patients' experience.

Despite the measurement challenges, several investigations have used neuropsychological tests with patients to quantify and evaluate cognitive functioning. Statistically significant differences have been reported between healthy individuals and the breast cancer patients receiving adjuvant chemotherapy (Brezden, Phillips, Abdoell, Bunston, & Tannock, 2000; Bender et al., 2001; Tchen et al., 2003; van Dam et al., 1998; Wieneke & Dienst, 2004; Shilling et al., 2006). Statistically significant differences have also been reported between breast cancer patients who did or did not receive chemotherapeutic agents (Schagen, 1999; Ahles et al., 2002). The incidence of impairment is reported to range from 32% to 75%. While the results were varied regarding the specific cognitive capacity where impairment was identified, the most commonly reported areas for changes in these studies were memory and concentration. Other areas where changes were noted included attention, language, and visual motor functioning (Jansen et al., 2005).

Brezden et al. (2000) and Ahles et al. (2002) reported a lessening of impairment following chemotherapy treatment, but lingering nonetheless one year to five or more years later. Bender et al. (2001) found that women who were already post-menopausal before commencement of treatment showed less pronounced cognitive deficits. Wefel et al. (2004) reported 36% of breast cancer patients undergoing chemotherapy who exhibited impairment had already been impaired prior to the start of their chemotherapy

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treatment, suggesting the impairment could have been due, at least in part, to the anxiety and stress of having been diagnosed with cancer. This would imply the need for baseline assessment of cognitive status prior to treatment. Schagen and van Dam (1998) report 32% of breast cancer patients who received high-dose chemotherapy were cognitively impaired in comparison to 16% who received standard dose chemotherapy and Schagen et al. (1999) concluded a chemotherapy group of breast cancer patients exhibited heightened levels of impairment in the areas of concentration, memory, attention, and verbal function in contrast to a surgically treated group. An extensive review of studies (n=57 with 3,424 patients) of cognitive functioning after chemotherapy in adult patients concluded there were similar effects for those treated with chemotherapy as those treated with cranial irradiation. In the 28 trials reporting quantitative data on patients with cognitive deficits after treatment, 44.1% (range 18%–75%) of 451 patients in the chemotherapy group, 44% (range 29%–83%) of 320 patients in the radiotherapy group, and 64.5% (range 30%–100%) of 229 patients in the combined irradiation and chemotherapy group had deficits.

Clearly, the evidence is growing that cognitive change occurs for cancer patients. Unfortunately, the available literature's sole focus has been on quantifying the phenomenon of cognitive impairment or "chemobrain". Study of the patient perspectives and experiences in living with cognitive impairment after treatment has not been undertaken. Health care professionals know the incidence and nature of side effects, but they also need to understand the impact the side effect has from the patient's perspective and how to assist patients in coping with subsequent changes.

## Purpose

The purpose of this exploratory study was to understand and document cancer patients' experiences with changes in cognitive functioning following cancer treatment. Gaining insight into patients' perspectives about the impact of these cognitive changes on daily living and the strategies they have found to be useful in coping with the respective changes was seen as valuable in guiding the development of future informational and support interventions for patients who are at risk for, or have experienced cognitive changes (i.e., "chemo brain"), and for their family members.

## Methods

This exploratory qualitative study used in-depth interviews with cancer patients receiving treatment for their disease. Following ethical review by the Hospital Research Ethics Committee a purposive sample was accrued from a comprehensive cancer program. Nurses caring for the patients told them that the study was being conducted if they met the following criteria: 18 years of age or older, English-speaking, no history of mental illness within the last six months, no use of medication (antidepressants, narcotics) in the last six months, started chemotherapy treatment a minimum of six months ago, received a definitive diagnosis of breast, gastrointestinal, genitourinary, gynecological, hematological, skin or lung cancer, and reported experiencing mental "fogginess", difficulty remembering or concentrating since start of chemotherapy. If the patient was interested in hearing about the study, the nurse contacted the research assistant (RA) who informed the patient about the details of the study purpose and participation. Those who wanted to participate signed a written consent form. Participation involved one interview regarding the person's experiences with cognitive changes that had occurred since receiving treatment, the impact of these changes, and what strategies the person has used to deal with the changes. The interviews took between 30 and 60 minutes, depending on how much detail the patient wished to share.

The open-ended questions used in the interview were designed to encourage exploration of the patient's own perspectives about the cognitive changes they were experiencing. Once several demographic questions had been asked (i.e., age, work status, marital status, educational status, cancer type, date of diagnosis) participants were asked in an open-ended manner to describe the events surrounding the diagnosis and treatment of their cancer. This was followed by queries about what cognitive changes they had noticed, what impact the changes had, what they had done to deal with the changes, what they found helpful, and what the cancer centre might do to assist patients with this type of experience. Probes were only used to encourage elaboration (i.e., tell me more about) or to seek clarification (e.g., did that happen before or after the treatment?).

The words "cognitive changes" were used in talking with patients about this work during our interviews. However, our experience with the pilot interviews revealed that we needed to add examples of cognitive changes for clarification purposes (i.e., we told patients that cognitive changes include things such as not remembering names and numbers). The word cognitive did not have meaning for individuals in our pilot work. During the initial testing of the interview guide, we also identified the need to ask each patient about each type of cognitive change. Patients struggled in describing the full range of changes they had experienced. Therefore, in the interview, we first asked an open-ended question (i.e., what type of cognitive changes have you experienced?) and let each person mention the ones he or she wanted to mention and talk about those in detail. We then followed up with a specific question about any cognitive changes that had not been mentioned by the patients (e.g., have you noticed changes in doing calculations?). Our "checklist" of cognitive changes was created after reading the literature on potential for cognitive change following chemotherapy. In the end, the interview became somewhat more structured than we had originally intended. All of the interviews were conducted by the RA and audiotaped for future transcription. At the end of the interview, general information about cognitive changes was provided and the offer of support or referral extended to each patient.

All interview tapes were transcribed verbatim and identifying features removed. A content analysis was performed (Speziale & Carpenter, 1999) using all interviews, including our pilot interviews. All team members independently read each transcript in its entirety and made marginal notes about the content. The team members then discussed their impressions of the interview content and, working collaboratively, designed an overall categorization scheme (set of categories) for the subsequent analysis. All interviews were then coded on the basis of this agreed-upon scheme by one team member (MF). The content within each category was then reviewed in-depth and summarized, and the key ideas were identified. These key ideas are reported below as they concern patients' experiences with cognitive changes following cancer treatment.

## Findings

### Sample

A total of 32 cancer patients participated in this study. The seven men and 25 women ranged in age from 20 to 72 years (average 57.2). Twenty-four were married or living with a partner and eight were continuing to work during their treatment. A cross-section of cancer types was included (See Table One). Twelve were living with metastatic disease. Allocation of numbers by two different research assistants resulted in numbers assigned for 33 and 35.

### Context of the interviews

The participants in this study described the shock and dismay they felt when their cancer was diagnosed and the initial treatment decisions were made. They were keenly aware of the disruptions

cancer and its treatment brought to their lives. All were able to describe cognitive changes that had occurred (see Table Two) and pinpoint when those changes became evident. A few indicated they had experienced some forgetfulness prior to the cancer diagnosis that they had thought was a result of aging (n=7) or menopause (n=2). The majority of the participants (n=26) attributed the 'new' cognitive changes they experienced primarily to the chemotherapy they had received.

For about a quarter of the participants, the changes were most noticeable in the few days following a dose of chemotherapy. They would notice an easing in the intensity of the changes four or five days after the chemotherapy treatment. The alterations would become evident again with their next dose of chemotherapy. Those who had chemotherapy during their initial diagnosis had actually noticed the cognitive changes eased substantially once their treatment stopped, but returned as the treatment for their recurrent disease started. Approximately a quarter of the sample held the idea that, ultimately, the changes were transitory and expected that things would return to normal after treatment stopped. This was clearly the context in which they were dealing with the cognitive changes they experienced.

*Sometimes I'm frustrated. But I'm thinking it's a temporary thing and it's all going to go away. Once my system gets back to normal, I'll be okay. Once I get back to work and be active... once I start to think and do things, then maybe my brain will start working a bit better. (31)*

However, about a half of the participants in this study indicated that once the changes occurred, they remained (i.e., were ongoing) with little alteration. Some with recurrent disease had not noticed any easing or alteration in the cognitive changes even during their period of remission. From their perspective, the changes were permanent.

*It's very frustrating... I thought that, you know, once all the chemo drugs were out of your system, you might have it for a few more months. But I'm sure it's exactly the same now... has just never returned. (P1)*

### Describing the changes

These participants experienced a range of cognitive changes with varying degrees of intensity. Nine described experiencing one change, while eight described two, seven described three, seven described four, and one described five. The extent of the descriptions varied widely with some participants providing rich descriptions about the cognitive changes and the impact of those changes in their lives.

The most commonly identified cognitive change concerned memory (n=29) (see Table Two). The capacity to remember names, numbers, and details about events or situations was decreased.

*My short-term memory is gone. Shot. It slides at times. Usually for the first three or four days only. Then I'm right back. I'm sharp as a tack. Calculations are hard. I find calculations hard. And sometimes I just zone out... it's like blanking out for a bit... New information? I just can't keep it in, not like the old days... I have to go over it a couple of times to retain it. I take it in, but I can't remember it. (2)*

*...short term memory and inability to find my way through my thought process. If I'm telling a story, I go off topic and I cannot call out the word that I need to use... all of a sudden the name and the place that I'm referring to leaves me. It's so frustrating. (35)*

*Well, when I got out the door, and I've got five things to remember, sometimes I'll have to go back four times to get what I thought I had in the car, that kind of thing. (19)*

The second most commonly identified cognitive change was concentration (n=17) and the third, comprehension (n=10). Often, the changes were intertwined. Participants found they were easily

distracted, or had a decreased attention span, and found it hard to take in new information or recall it when they did.

*I find I have to re-read paragraphs in books. I really don't absorb what is there. And I can't concentrate for very long when I am reading... I'd say I was "sharper" before the chemo. Now, I do forget little things. Like, I'll go into a room and say, "I knew I came here for something, but now what was it?" I move along a little more slowly, just not thinking as fast as I used to. (1)*

*I'm more irritable than I used to be. So you know, I maybe get bored with something quicker than I used to... that's what I would say... especially if something really isn't interesting. (11)*

*I was just in a fog. I just felt really spacey, I felt that I couldn't react quickly enough. (29)*

### Impact of the changes on daily life

The impact of the cognitive changes was often described in terms of what the person could no longer easily do either in terms of daily living, work, or leisure activities. For some, the changes and the subsequent impacts were not clearly evident to others. Recognizing the change had occurred and finding ways to handle the situation could become a challenge for both patients and family members.

*Well, it was quite, I wouldn't say irritating, but just a bit, uh, frustrating... I'd have to ask my family and friends to repeat things or I'd forget things and then they wouldn't understand that I'm not trying to deliberately forget things. I actually can't remember what I've been told and what was said five minutes ago. So, it was kind of difficult for them, really. And more difficult for me... 'cause they [family] didn't understand what I was going through and then I had to come to grips with that I can't do things like I used to... before. So it was quite difficult. (8)*

**Table One. Selected demographics (N=32)**

Gender:	Male	7
	Female	25
Age:	Average	57.2
	Range	20–72
Marital Status:	Married/Common Law	24
	Single/Divorced/Widowed	8
Work Status:	Employed (working)	8
	On leave	9
	Retired	11
	Other	4
Education Status (Highest Level Completed):	Grade School	2
	High School	8
	College/University	18
	Post University	4
Type of Cancer:	Breast	15
	Colorectal	8
	Gyne	3
	Hematology	4
	Lung	1
	Pancreas	1

The basic impact on daily living was described in terms of feeling the need to be organized in order to get things done. Past organizational patterns were no longer working. Decision-making, problem solving, concentrating, and keeping track of information were not as easy as they had been in the past.

*...I'm doing a lot less and I have more time to do it... I'm not working... my kids are grown. Whatever I have to do in the house, it takes me so much longer to do it. And just making the decision to go out, for example, if I've got to go shopping, it'll take me two or three hours to get up and do it... it takes me a while to get myself organized mentally, physically, to go out to go shopping. (5)*

*During chemo, I found it... very difficult to concentrate... my concentration was less than average... I felt quite scattered doing tasks... I just had to get a grip and get organized. I am an organized person, so it was not my typical behaviour. (25)*

*I think planning things, thinking things through, reading [are different]. Forgetting exactly what I was doing or where I put things. I still haven't found some things I put away (laughs)... I'd totally forget what it was that I read or what it meant or what day it was... It's like reading it, understanding it... just sort of disappears. (21)*

*...you hear people talk about how they go to the video store and they keep watching the same film. Well, I'm sort of in that category now. I go and I look at the back [of the video case] and it sounds pretty good and I bring it home. My husband said, "Well, yeah, you liked it because we already saw it" ...when I go to the video store now I can't go without my cell phone so I can phone him and say, "Okay, I'm looking at this, this and this. Have I seen any of these?" (1)*

Completing activities at home that demanded attention to detail could sometimes be overwhelming. In addition, as a person first noticed the changes, it could be frightening or, at best, worrisome.

*I couldn't remember... and I was so upset. I could not remember what was a pound and what was a cup... it was for a recipe... I had not heard about chemobrain... I got it and I was frightened... well I was upset... I was so relieved when I learned about it... it's the little things, the numbers, the names, the little daily things and I'll get upset with myself to the point of crying. (19)*

*I was like an electronic whiz before... show me how to do something with a machine and I could grasp it and learn it and then do it. But I'm finding that really, really difficult. We have a home theatre and... I've had to have the people from Bay-Bloor come up*

*about four times and go through everything with me. And I write it down when they are here... and then I try to do everything and I get confused... I'm 46 years old and I feel like I'm 86. (1)*

The individuals who continued to work noticed cognitive changes as they performed their work-related activities. They had a clear picture of the differences in what they could do before and after the treatment.

*...sometimes I've got to be figuring out numbers for the businesses and stuff like that, or my stocks... so. if I can't figure out something over the phone, it bothers me. Because sometimes I have to do fast calculations... Well I can't do it, you know, figure out the percentages. And that bothers me. (2)*

*At work I've noticed a few times... starting to tell somebody a story about a student that they would need to hear, say for example a guidance counsellor, and then recognizing in their eyes, 'oh I guess I've told them already'. (22)*

*...if I had to review big documents, it would be much harder to absorb it all. I'd have to go through it more times than I normally would... I remember my boss coming to me with a binder two inches thick and I sort of looked at her and said, "You've got to be kidding, it isn't going to happen." (14)*

Participants described social changes they had noticed and thought were related to the cognitive changes. Being in a social situation was a challenge for some who had experienced changes in their capacity to concentrate on what others were saying and take in information.

*I don't get into heavy conversations and I get tired out easily. Even just talking to somebody for a long time, it just tires me out. I'd rather just listen. (5)*

*Forgetfulness, something I call tracking. Following a conversation, I needed more staying power. I just had trouble, not just with general conversation, but tracking something that required moving from point A to B. Sometimes I'd forget the in-between stuff. (22)*

Some participants noticed the cognitive changes had an impact on their enjoyment of leisure activities.

*I used to read a lot... write poetry and I don't do that anymore because I can't concentrate. Like, I'll start something and I'll just like drift... my brain gets foggy, things just seem blank. Reading is very hard for me right now. I can read say a, maybe a short essay or something. Or I can read the newspaper, or maybe even a couple of paragraphs. But I can't read a book. (8)*

*I was quite a film buff. I'd go to five films a day for all 10 of the Film Festival days... I could remember all the names and the plots and things. Now, I still go and I still love it; I'm doing two or three films a day because four or five just, they muddle together so much now... a day later, even if I really loved it at the time, I would have a hard time remembering the details... so, film was a pretty big hobby of mine. So that's something that's very disappointing to me that has changed. (1)*

### Emotional response to the changes

As the participants discussed the cognitive changes they experienced, they often described their personal feelings about the changes and the impact on their lives. Feelings ranged from dismissal or resignation to irritation and frustration. Whether or not the person found the changes to be problematic could be evidenced in the intensity of these feelings.

*It doesn't bother me, it's just part of life. I'm fighting for my life as it is, so memory would be the least of my worries. Death is my biggest worry. Actually, death and pain... but the loss of memory, because I'm not in business, I'm just at home. (2)*

*Sometimes I laugh. Everybody laughs about it. It's funny... I wasn't angry you know. When you're frustrated, that assumes that there was*

**Table Two. Frequency of cognitive change**

Item	Number of Participants (N=32)
Memory (forget names, numbers, details, etc.)	29
Comprehension (taking in new information)	10
Concentration (easily distracted, decreased attention span)	17
Trouble finding words or information when talking	6
Calculations hard to do	4
Feels like fading in and out ("in another zone")	2
Confused/cloudy/fuzzy ("dopey" thinking)	6
More emotionally reactive, fearful, irritable, not as open-minded	5
Feel disorganized	1

anger in there. There was no anger. I just felt stupid. You know, walking into a room with my keys, thinking, “I’m supposed to go somewhere, where am I supposed to go?” (laughing). (6)

*It was all so... extremely frustrating. Because I’m a very organized person. Very organized before, and I was always, have been always able to, in my mind, organize things, and not necessarily have to have lists to remember what I need to do. Not now. And that was tough for me.* (16)

Finding they were not able to do what they could easily in the past often left these participants thinking of themselves as stupid. In turn, this feeling had the potential influence on their self-esteem. Living with the situation often left them feeling a sense of fatigue and being overwhelmed with no end in sight.

*I can’t remember things. I find I doubt myself now... constantly rechecking.* (20)

*So you get frustrated because you forgot something, which eats up more of your energy, which makes you more tired... You have to redo what you already do...* (14)

*[It makes you feel] stupid... frustrated. You know, like you wanna be able to be healthy, and the way you used to be, and it’s just one more thing thrown on the pile, you know.* (13)

*I don’t know whether one comes to terms with it... if one defines themselves based on intellectual capabilities and then you find that it diminishes in any way, shape or form, there is a reactive depression that goes with that.* (10)

### Dealing with the changes and their impact

How participants were dealing with the cognitive changes seemed to vary based on whether they thought the changes were permanent or temporary, the degree of impact they felt from the changes, and their attitude about their situation (life philosophy). The notion of just having to accept the situation as part of the cancer experience was described frequently.

*...I don’t get upset because I know it’s not going to be permanent. I’m hoping once this [chemo] stops, it’ll stop happening. As long as it doesn’t get any worse, you know... I get annoyed with it, but I try not to let it upset me. I’ve tried to laugh at it.* (15)

*Someone told me it would take a year. You have to accept it like a lot of things with cancer.* (33)

*I’ve learned to accept it... always I think positive. That’s my attitude for everything in life, and hope for the best.* (P2)

*I don’t think there is any intervention that is going to change things. So I just have to accept it as part of the territory.* (10)

*They [cognitive changes] aren’t the big things that shut down your life, they’re the little stupid things that you do, you forget... names and people... it’s, well, embarrassing.* (25)

Table Three lists various strategies participants described to deal with the cognitive changes they experienced. By far the most frequently identified strategy involved writing things down, and included making a list, taking notes at meetings, and maintaining a calendar. People developed personal reminder systems for themselves and for their family members (e.g., post-it notes on the fridge, coloured stars on a calendar, leaving phone messages for themselves at home if they were away from home, etc.) and included telling others, enlisting help, making use of humour, and acknowledging the reality of the changes.

### Perspectives on how health care professionals could help

Participants talked a good deal about the need for information regarding the cognitive changes. When asked about the advice they would give to health care professionals, providing information was suggested most frequently.

*Tell us about it.* (1) *We need to know what to expect so we are not caught off-guard.* (2)

*...I think that if people know that they are not the only ones that feel this way, then they’ll be able to, not to be as frightened about it... I think it’s more frightening if you don’t know where you are.* (6)

Participants thought that the potential for cognitive change needed to be mentioned by health care providers initially before treatment was started.

*...it should be mentioned, just like all the other side effects... even if it only happens to a few people... there’s not much you can do about it and obviously, to save your life, you’re going to do all the traditional things that need to be done... it should be mentioned so that it’s not such a shock.* (21)

The situation regarding cognitive change should also be monitored during and after treatment. If cognitive changes occur, then sharing ideas about how to manage those changes would be welcomed by patients. Participants mentioned the value they saw in having a list of what patients and family could do about the changes and examples of what others had found useful (i.e., share Table Three).

*...I’d say anything that I’ve gone through in treatment I just feel a whole lot better, no matter how awful it might feel, to know it’s normal. It’s when you get those wacky things that nobody’s ever had before or mentioned before that I find more upsetting. When you are warned, when you know it is a consequence, then I don’t get as stressed about it. I just make a plan.* (25)

Finally, the participants described how responses that health care professionals give when patients raise questions about side effects can be helpful or can create a barrier to further conversation about how to manage the changes. One patient’s comments illustrate how the professional’s response can be non-supportive:

*...talked with my oncologist and she sort of “pooh-poohed” the whole idea. She said there’s no such thing [as chemobrain]. Or there’s no proof. But I would be interested in talking to a couple of patients. I thought, well you know what? Just because it hasn’t been studied doesn’t mean that it doesn’t exist for various people.* (22)

## Discussion

This investigation was undertaken to learn more about the experiences cancer patients had with cognitive changes during and following treatment. Learning more about their experiences and how they managed any changes can help guide the development of educational programs. Clearly, the strategies that participants described in this study can be incorporated into educational written materials.

**Table Three. Patient-initiated strategies for coping with cognitive changes**

- Write everything down; keep lists and carry them with you
- Keep a journal (dates, times, conversations)
- Highlight different activities in different colours
- Use a chart board or white board in kitchen—develop a system of reminders
- Keep things in the same place; keep names and numbers all in one
- Don’t try to do too much at one time; right after chemo, don’t try to do too much
- Do crosswords; play games with your mind; keep your brain active
- Tell people about it; don’t hide it; learn about it
- Use a joke once in a while; laugh
- Get others to help you; carry a cell phone
- Stay positive; recognize it is part of your life now
- Consider doing something in a new way (e.g., write versus computer; magazines versus books)

The participants plainly illustrated that, for some, cognitive changes do occur and have significant personal impact. The changes may not be entirely evident or noticeable to others, or measured definitively on a standardized scale, but they are very real to the person. The changes have the potential to be frustrating, embarrassing, or humorous, depending on how they affect daily functioning and the individual's attitude about the effect. If they interfere with something the individual considers important, the resulting emotional reaction is heightened. Individuals respond in accordance to their perception of threat or harm associated with a particular event in their lives.

The proportion of patients who expected that the cognitive changes they were experiencing were temporary is noteworthy. Given the degree of permanent change other participants described, we could see this notion of temporary impact might be a source of future distress for patients. Cancer nurses need to be alert to patient expectations regarding the lessening of side effects. Future research needs to isolate the factors that create permanent cognitive change. In the meantime, this is an important piece of information to incorporate into educational programs with patients to help in setting realistic expectations.

The importance of providing information about cognitive changes and how to cope with them was a key finding in this investigation. Repeatedly, patients indicated they wanted to be warned ahead of time about potential difficulties. They did not want to be "caught off guard" or be worried about something being abnormal if they experienced a change. Additionally, they wanted ongoing monitoring and information about how to manage any changes that occurred.

Clearly, there is an onus on cancer nurses to "check in" with the patient and to provide information regarding cognitive changes throughout the cancer experience.

Finally, the investigative team was struck by the potential differences between what the patients experience, and choose to talk about, and what the health care professional care provider can observe during clinic visits. The descriptions participants shared during this study revealed uniquely personal consequences of cognitive change, much of which they had not shared with their care providers. The impact of cognitive change is very real to the person living through the experience, but the actual change may seem to be small or non-existent in the eyes of the care provider. The change has the potential to add burden to the suffering patient's experience. Whether the changes are normal, expected, and seemingly somewhat inconsequential to the health care professional, they can be profound to the person who is coping with them day by day. Cancer nurses need to be ever sensitive to the person's reality in living through the cancer experience. Learning about that reality requires use of open-ended questions by cancer nurses and the capacity to listen to the individual patient's story of daily coping with cancer's demands on their lives.

This study offered an initial exploration of the impact of cognitive changes that can accompany cancer treatment. The descriptions provided were rich and offered a poignant picture of the consequences some cancer patients experience. Future research is needed to enlarge our understanding of the consequences in other groups of patients and to identify effective interventions to help individuals cope with the cognitive changes they experience. ♣

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