'Chemo Brain': Research Findings Indicate the Need for Caution

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ABSTRACT

The article sets insights provided by haematology patients who have been through chemotherapy treatments on their attitudes, beliefs and experiences with regards to the notion of 'chemo brain' within the context of the available research literature on the topic. The qualitative methodology for the study involved open-ended exploration through in-depth interviews and a focus group. The data was audio-recorded, transcribed verbatim, coded and thematically analysed. The findings highlight the need for caution with regards to asserting the conclusiveness of the notion of 'chemo brain' to haematology patients. This conclusion is reinforced by the evidence of confusion, inconclusiveness and lack of understanding of both the concept and causation presently noted in the literature. Honesty in information giving about the present doubts and inconsistencies with regards the notion of 'chemo brain' that are recognised in the literature can ensure that the term does not unnecessarily increase the anxieties of patients. Such informed discussion can be accompanied by a compassionate response to those experiencing cognitive difficulties that affirms, normalises and provides referrals to expert psychological assistance.

Keywords: *'Chemo brain', haematology, cancer patients, supportive care, qualitative research.*

'CHEMO BRAIN': RESEARCH FINDINGS INDICATE THE NEED FOR CAUTION

The notion that cognitive changes are a likely consequence of oncology treatments has been documented in the literature from as early as the 1980s.[1,2] In recent years, the research attention focusing on the exploration of the association between chemotherapy and cognitive impairment has escalated, producing a burgeoning literature.[3,4] However, although the science of the phenomenon colloquially known as 'chemo brain' is in its infancy,[5] with many details of the concept still controversial,[6] the existence of chemo brain has become almost universally accepted.[6] Many of the assumptions

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about 'chemo brain', albeit often unfounded, are now entering clinical and supportive care practice.

Recent research on survivorship issues funded by the Leukaemia Foundation of Queensland provided the opportunity to explore haematology patients' thoughts, beliefs and experience with regards to 'chemo brain' and the possible impact of the use of the term on the individual's approach to and ability to cope with treatment. This article sets the findings on 'chemo brain' from the study in the context of a review of the literature on the topic. The findings highlight the need for caution with regards to asserting the conclusiveness of the notion of 'chemo brain' to haematology patients. This conclusion is reinforced by the evidence of confusion, inconclusiveness and lack of understanding of both the concept and causation presently noted in a review of the literature.

THE RESEARCH

The research project is a collaborative initiative of the Leukaemia Foundation of Queensland (LFQ) and the International Program of Psycho-Social Health Research (IPP-SHR). The aim of the research was to document and explore issues associated with the experience of survivorship for haematology patients supported by LFQ. The haematology patients' experiences with cognitive difficulties known as 'chemo brain' was one of the issues explored through the research. The study provides practical insights on how to effectively engage with and support individuals coping with a range of psycho-social issues associated with haematology diagnosis and treatment.

Research design

A qualitative design based on a series of open-ended interviews and one focus group was utilised for the research to explore and document the experience of survivorship from the perspective of adult patients diagnosed with a haematological malignancy. For the purpose of this research, a 'survivor' was defined as an adult individual with a haematological malignancy who was at least one year post diagnosis. A list of topic areas to explore during the interviews was developed from consultation with LFQ, published research and anecdotal comment. However, in accordance with the iterative principle of qualitative research the issues being explored evolved with the study with early insights informing the discussions in subsequent interviews. The focus group was used as a forum to return the findings to a separate group of haematology survivors to affirm or extend the conclusions reached.

Purposive sample of participants

Participants were purposively sampled from a database of patients maintained by LFQ. The participants were enrolled through two IPP-SHR project officers who were under contract with the University and independent of LFQ. Potential participants received a letter from LFQ informing them of the study and stating that if the person did not want to participate in the study they could contact LFQ to opt out. Any individual not wanting to be involved in the research was deleted from the list. At this stage the database of patient and carer contacts, excluding the details of those who chose to withdraw from the study, was provided to the external Project Officers for the selection of participants. Thus, the actual identity of those who did participate remained confidential as LFQ was not provided with any detail on the actual selection. Potential participants were provided with a written project description and consent form and an initial telephone call inviting participation in the research. Prior to interviewing, participants were again informed of their ethical rights (e.g. informed consent, confidentiality, right to withdraw) and individual consent obtained. The University Human Research Ethics Committee approved the study.

All participants had to meet the criteria for survivorship in that they were an adult individual with a haematological malignancy who was at least one year post diagnosis. One hundred and eighteen potential participants were contacted to participate in the research with 14 declining to participate and 54 being un-contactable (due to change in contact details). In total there were 50 participants (n = 26 male; n= 24 female) which represented the major haematological diagnostic groups: Multiple Myeloma (n = 15), Lymphoma (n = 14), Leukaemia (n = 17) and Other (n = 4). Of the overall cohort, 11 participants had a Bone Marrow Transplant and 15 had a Stem Cell Transplant (allogeneic and autologous transplants). Due to the unique geography, population and services provision patterns of Queensland Australia, a custom regional classification system was designed and used to ensure the purposive sample include participants that had varying levels of access to haematological services based upon their home address. The sample also ensured a representation of ages across the adult life span. At the completion of the data

collection the findings were provided to a group of seven focus group participant for comment.

Project management and collaboration was managed using the online qualitative collaboration software, Quadrant.

Interviews and focus group

The exploration of the experience of survivorship from the consumers' perspective was conducted through an iterative, qualitative research methodology using open-ended interviews conducted by speaker-phone at the time and location chosen by each participant. The interviews were initiated with the following focus question: 'Could you please talk about your experience of surviving a haematogical malignancy?' The interviews were also informed by present insights in the literature as well as the experience of the LFQ supportive care staff. They proceeded at the pace and direction of the interviewee and included techniques of probing, clarification, paraphrasing and summarising to explore each participant's experience. In accordance with the 'iterative' principle of qualitative research any significant issues arising in early interviews were introduced as 'prompt questions' during later interviews. The interviews lasted for approximately one hour and were audio-recorded and transcribed verbatim. The focus group participants were presented with a Power Point summary of the findings from the interviews and encourage to comment, by expressing agreement or disagreement and further thoughts on the issues. The focus group was recorded and transcribed verbatim. The focus groups findings were in complete agreement with the individual participant findings.

Analysis

The language texts were then entered into a computer aided qualitative data analysis program and analysed thematically. All of the participants' comments were coded into 'free nodes' which are category files that have not been pre-organised but are 'freely' created from the data. The list of codes was then transported to a Word Computer Program (Word 2007) and organized under thematic headings. The coding was established by an experienced qualitative researcher and completed by a project officer who has extensive experience with coding qualitative data. There was complete agreement on the coding and emergent themes created from the transcriptions.

Five of the codes related to the participants' experience with 'Chemo brain'. It is the analysis of that data that forms the basis for the findings presented in this article.

FINDINGS AND DISCUSSION

The de-identified information on participant statements provided in parenthesis refers to the diagnostic group, geographical location defined by regional classification system (MP: Metropolitan Primary; RR: Rural and Remote; Remote), gender (M: male; F: female), age and whether they underwent a transplant (SC Trans: Stem Cell Transplant; BMT: Bone Marrow Transplant).

Cognitive problems attributed to 'Chemo brain'

As detailed in Table 1, some of the participants talked about a range of cognitive problems that they had during treatment or were presently experiencing. Some directly and emphatically attributed the cognitive problems to the phenomenon popularly known as 'chemo brain', for example:

- (MM_RR_M_68yrs_SCTrans) *I tell you what, chemo brain without a shadow of a doubt.*

Others attributed the cognitive problems to other issues such as old age, for example:

- (MDSAML_RR_F_59yrs) (When discussing forgetfulness) *…. It is only old age.*

The descriptions of cognitive problems listed in Table 1, associated by many with 'chemo brain', reflect Kibiger and associates'[3] notion that lay definitions are fairly non-specific and subjective, with most individuals using expressions such as 'mind does not seem to be clear'. However, even though subjective, the list of cognitive problems in Table 1 does resonate with the changes in cognitive function detailed in the literature on 'chemo brain' which includes forgetfulness, absentmindedness, an inability to focus when performing a variety of daily tasks and problems with memory, attention, concentration, language, motor skills, multitasking and ability to organise information.[5,7,8,9,10,11,12] Taillibert[6] emphasises the subtlety and range of cognitive complaints often attributed to 'chemo brain' in the following comprehensive description:

The manifestations of chemo brain also named chemo fog are

often subtle. Cancer survivors may complain of fatigue, lack of focus, mental confusion, inability to concentrate, inability to organise daily activities, loss of memory and memory lapses, decreased mental clarity, trouble concentrating and maintaining attention, trouble remembering details, names and common words, trouble multi-tasking and finishing certain tasks, trouble learning new skills and slower thinking and processing (Taillibert, 2010:87)

Table 1: Cognitive Problems Associated with 'Chemo Brain'

Cognitive Problem	Participants' statements
Difficulty concentrating	(LymHL_RR_F_21yrs_SCTrans) Concentration is a bit hard, yeah not so much for memory, I'm okay with my memory but the concentration levels are not very good (laughs).
Problem with mathematics	(LymBCell_RR_F_65yrs_SCTrans) It's affected me badly. The last lymphoma newsletter it mentioned how people are having trouble with mathematics and I noticed that in the puzzles in the paper that I normally whip through in five minutes flat I was struggling with.
Difficulties with managing finances	(LymBCell_RR_F_65yrs_SCTrans) … even working out finances and things now I'm finding difficult which normally was right up my alley.
Poor memory	(LymNHLComorbidity_RR_M_52yrs) Yeah I have trouble remembering (cannot remember names of people they've known for years).
Problems sequencing the alphabet and numbers	(LymHL_MP_F_29yrs) Someone will give me a phone number. I'll write it down back to front or like they'll give me a number and I'll start writing the third number before I write the first and second number and go back and write them in and then do the others.
Confused routine associations: have to think through everyday processes	(LymHL_MP_F_29yrs) It's really weird and when I was going through it and my mum would put stuff in the fridge and I'd go through the cupboards. (MDS_M_M_68yrs_SCTrans) But when it's affecting you pretty much there is no things that you do in automatic pilot where your brain just knows what to do, your body knows what to do. You've got to think about it and formulate what you're going to do before you attempt to do it and at times I just don't want to drive a car because I could drive alright but I don't trust myself, don't think I'm doing a good enough job. You know you look at a glass or a cup of coffee on a table and you look down and you see coffee cups so you know it's that in your brain and you acknowledge you're going to move your arm out, then you acknowledge you're going [to] pick up. You know you go through a process, can't have a conversation and put your hand down unknowingly and pick it up.
Loss of vocabulary	(LymHL_RR_F_23yrs) Then the year with having treatment and stuff my vocabulary was shocking. It was the first year uni course I was doing and then to that and to uni and I found there were certain words that I knew what I wanted to say but I couldn't.
Inability to maintain the flow of conversation	(LymNHL_MP_M_38yrs_BMTandSCTrans) … just funny little things that I forget what I'm even talking about in mid-sentence. (MM_RR_F_76yrs_SCTrans) My head; my brain wasn't my brain, it was all scrambled. You know people would talk to me and… I'd say a couple of words and then stop and forget what I was talking about and stuff like that.
Confusion	(MM_Remote_F_70yrs) I get things mixed up and I wonder whether I'm not as on the ball as I used to be.
Disorientation	(LeukCML_Remote_M_45yrs) … and getting disorientated.

Duration over time

The group of individuals who described symptoms associated with 'chemo brain' reported differences in whether the symptoms were limited to the period of treatment or persisted over time. As can be seen by the following examples, some indicated that the cognitive problems were experienced during the time of treatment:

- (LymHL_MP_F_29 yrs) … *when I was going through it* (treatment).
- (MM_RR_N_68yrs_SCTrans) *Well it does pass. But I mean when you're getting that poison* (chemotherapy drug)…
- (LymHL_RR_F_23yrs) *Then the year with having treatment and my vocabulary was shocking.*

Some indicated the cognitive problems were acute when on specific drugs during treatment such as Thalidomide, for example:

- (MDS_RR_M_68yrs_SCTrans) *And particularly when you get into those drugs like Thalidomide.*
- (MM_RR_F_76yrs_SCTrans) …*put me on thalidomide and steroids – I hated side effects, my brain wasn't my brain, it was all scrambled.*

Others indicated the symptoms lasted for some time after treatment as demonstrated by many of the statements about ongoing cognitive problems in Table 1.

The research literature demonstrates similar confusion with studies focusing on a range of periods both during and following chemotherapy. The data on duration is not clear and there is, as yet, no consensus on when and how long 'chemo brain' exerts its influence.[8,13] Some studies suggest short-term symptoms during and following treatment and other studies document the persistence of cognitive problems for years after treatment.[5,11] Similarly, there is no consensus as to whether 'chemo brain' is a transient phenomenon or a permanent disability. Although some evidence suggests that it might be transient (recovery is documented at four years post-treatment),[11] in a small minority of patients, 'chemo brain' is described as still perceptible 10 years after treatment.[5,14,15] According to Taillibert,[6] more recent longitudinal and follow-up studies generally suggest that the disturbances resolve over time. Further controversy exists over whether the patient can return to pre-treatment levels of function and whether the actual duration of treatment is a factor conferring risk of 'chemo brain'.[5,16,17]

Evidence of lack of cognitive problems and related disbelief in 'chemo brain'

In contradiction to the evidence in Table 1, there were many individuals in the study who strongly stated the case that they did not have any cognitive problems as an outcome of treatment and consequently did not believe in 'chemo brain'. This is exemplified by the following comments:

- (MantlecellLym_RR_M_61yrs) *No. Not at all. [Interviewer: So there's been no impact at all on your thinking whatever?] Not at all, no.*
- (MPD-ET_RR_F_53yrs) *[Interviewer: Do you have any cognitive problems similar to the descriptions of 'chemo brain'?] No, no.*
- (MM_RR_M_63yrs_BMT) *No, it is not an issue. I still enjoy doing my crosswords and my jigsaw puzzles and reading news papers. No I don't think so. I mean, I'm still learning, have access and all that sort of thing on the computer. No.*
- (CML_MP_F_27yrs_BMTrans) *I don't think there's anything wrong with my memory that's for sure.*

These participants spoke of having good memory, the ability to do academic study, guitar playing, the ability to problem solve and the enjoyment of newspapers, crosswords and puzzles. There is legitimacy to their negation of 'chemo brain' because, to date, the phenomenon is only a construct that is poorly understood and controversial. As Raffa[10] sums up the recent research literature on the topic:

Unfortunately, clinical studies designed to test for the extent of these deficits are hampered by inherent or methodological difficulties and leave uncertainty regarding not only the magnitude of the problem, but even its existence. [emphasis added] (Raffa, 2010:1)

Other authors also highlight the wide range of conceptual and methodological problems that challenge the legitimacy of the notion. As Tallibert[6] argues, the term may be inaccurate as little is known about 'chemo brain' mechanism, cause, type, severity and episode

length. An important concern is that in most studies cognitive dysfunction is not rigorously defined and there is no current standard for measurement or assessment of cognitive function in patients with cancer.[6,8] Instruments validated for assessment of cognitive function in other settings (e.g. Alzheimer disease) may not be sensitive to the subtle changes experienced as a result of cancer treatment.[8,18] As Kibiger and associates[3] highlight, the inherent problem with assessing 'chemo brain' is that while the perception of cognitive impairment is common in cancer patients, there are difficulties interpreting the nature of these complaints and separating them from depressive preoccupation. More than 80 different instruments are used to assess attributes of cognitive function in cancer patients, with major inconsistencies in the use of instruments to measure specific cognitive domains.[8] Staat and Segatore[5] argue that not only are the instruments inconsistent, but reliability and validity of instruments is not addressed and statistical analysis often ambitious given sample sizes.

Not only test instrument, but also test setting is an important factor impacting on the reliability of results on cognitive function for cancer patients. As Schagen and associates[4] explain, the optimum circumstances in which neuropsychological testing takes place compared to the real-life situation in which much more distractions are experienced may distort findings in this area. Compounding the assessment problem is the fact that there is a higher sensitivity of self-perception to detect mild cognitive changes compared with neuropsychological measures.[4] Indeed, the literature shows no correlation between self-reported cognitive change and formal assessments of cognitive function among cancer patients.[4,8,12,19,20] It is of interest in relation to the present findings that research indicates that the group of patients with detectable cognitive impairment does not per definition coincide with the patient group that expresses cognitive complains.[4]

The difficult question of causation

The participants in the present study provided a range of ideas on the causation of 'chemo brain' with some factors confirming a link with chemotherapy and other factors pointing to non-treatment factors, including:

- the anaesthetic associated with surgery;
- ageing;
- overtiredness;
- chemotherapy drugs like thalidomide; and
- steroids.

A prerequisite for validation of the concept of 'chemo brain' is the need to link the cause of cognitive problems with the impact of chemotherapy treatment. As Hess and Insel[8] explain, this is highly problematic:

> *Because patients experience many physiologic and psychosocial changes following cancer diagnosis, a variety of factors may contribute to changes in cognitive function in patients with cancer. Because of the confounded nature of the problem (e.g., often co-occurring factors), determining the precise cause of possible cognitive decline may be difficult* (Hess & Insel, 2007:981).

By way of example, some of the possible mediating and moderating factors that need to be controlled for assessment of cognitive impairment from chemotherapy include changes in haemoglobin levels, anxiety, use of anti-depressants and pain medication, depression, distress, high dose chemo versus standard-dose, tamoxifen, androgen deprivation, oestradiol decline, radiation therapy, age, education, gender and intelligence quotient.[8] Taillibert[6] highlights the complexity of the concept presently known as 'chemo brain' and posits a range of factors that may be involved including individual vulnerability, surgery and anaesthesia, hormonal therapy, treatment-induced menopause, stress, anxiety, depression, fatigue, supportive care medication, genetic predisposition, comorbid medical conditions and paraneoplastic syndromes.

As with all other issues associated with 'chemo brain', the literature on the topic of causation is inconclusive and does not unequivocally establish a direct causal relationship between cancer patient cognitive difficulties or changes with chemotherapy.[10,11] Even given the possibility that chemotherapy is causative, the mechanism by which chemotherapy drugs produce cognitive dysfunction is unclear.[5] As Hess and Insel[8] argue, cognitive function may be altered along two quite different but interacting pathways: the cancer diagnosis, which can lead to anxiety, stress, distress, and depression, and the direct physiologic effects of cancer treatment. Indeed, the literature is quite divided on whether the cause may be psychosocial or disease/treatment related or an interaction between both aspects of the cancer experience.[8] The relationship is not yet clear and may not be linear.[8]

A range of physiological factors have been implicated including chemotherapy dose and duration,[19,21] organic factors (e.g. metastases to the central nervous system, effects of nerotoxic medications, and effects of radiation therapy) and or effects of neurotoxic medications.[3] Although less information is available on the issue,

authors such as Raffa and associates[11] suggest the cognitive changes might be biochemical aberrations of cancer itself , or the impact of serious illness, rather than chemotherapy being the actual cause.

Another argument against chemotherapy as the cause is that some people report having these symptoms even before they start treatment or have first chemotherapy exposure.[6,22] There are findings in other medical settings[23,24,25] that suggest patients' subjective reports of loss of cognitive function is related to psychological distress and not to the effects of treatment. The psychological factor of depression has been linked with cognitive impairment in cancer patients.[11,26] However, it is still unknown whether and how the impact of decline in specific attributes of cognitive function through the physiologic pathway differs from that of the psychosocial pathway.[8]

Caution: The problem of certainty

As can be seen by the following participant vignette, the notion of 'chemo brain' can be problematic and there is the potential for the term to have a negative impact on the haematology patient's anxiety and belief in their own abilities:

- *(LeukAML_MP_M_64yrs_BMT) I'd seen a poster in the hospital in the corridor that was current research and they'd done some research on people being treated with chemo and they had something like 80% of patients have been badly affected in... their brain capacity. Anyway* ***that thing about the 'chemo brain' had me worried because my biggest asset has been my ability to think*** *and read. I decided that I'd do my own independent check, I should get something like Microsoft Flight Simulator which has a module in it that trains you how to fly aeroplanes and so I put myself through that module; I bought the game and I put myself through it and I found I was able to control the speed of the plane and height and direction and a whole lot. I was getting back to the stage of something like a 30 year old's ability to control my plane. So having done that I then was not always having to think to myself 'have I lost it?' And I just wrote that off with a tick and said, 'okay pass that one'. So that gave me a lot of confidence having done that* ***because if I hadn't been able to do a test and had it private to myself I don't think I would have had a lot of confidence to do things.***

Such data highlights the need for caution in the use of the term, especially in this early stage of exploration of the concept through research. The use of the term 'chemo brain' has the negative potential to undermine patients' confidence, create doubts about undergoing treatment and generate fears about possible sequelae to treatment that may not be founded in fact. As demonstrated by the preceding discussion, the literature is contradictory and inconclusive about the concept of 'chemo brain' with strong reservations about methodological issues associated with definitions, assessments, sampling and analysis. Indeed, some studies suggest that the evidence for 'chemo brain' does not exist[10] and there certainly is a profound lack of understanding of what causes the condition if it does exist.[5,6] In short, in view of the present lack of knowledge on the subject it is not ethically appropriate to use the term in a clinical context where it can heighten anxiety and worry about possible outcomes.

In the literature several problems are associated with using the term 'chemo brain' before the research actually establishes with certainty that it does in fact exist. Firstly, as Hess and Insel[8] argue, there are currently no treatments available for patients who present with cognitive complaints associated with 'chemo brain'. Secondly, as Raffa[10] states, there are problems with decisions being made on the assumption that chemotherapy is a fault when this is not yet proven. Thirdly, and importantly, there is extensive research in social psychology that shows that the presentation of a concept or stereotype (such as in this case, 'patients who have chemotherapy have cognitive complaints') can exercise a non-conscious, powerful influence on perceptions and behaviour.[4,27] Recent studies indicate that patients who had pre-existing knowledge about chemotherapy-associated cognitive complaints reported higher levels of cognitive complaints regardless of whether they had first-hand chemotherapy experiences.[4] Such priming effects become stronger with repeated exposure and complaint reporting can thus increase with media publicity and information provided by cancer societies or other sources of external information.[4,28] In short, there is the power for the concept to, in part, drive behaviour and experience. Raffa and associates[11] highlighted the problem associated with such priming effects, with reports that some patients chose to discontinue chemotherapy when made aware of purported negative effects on cognition.

However, this discussion in no way dismisses or seeks to deny the difficulties associated with cognitive decline often experienced by cancer patients. The available research indicates that cognitive deficits in cancer patients are mild to moderate with most deficits being subtle, but

most individuals with a cancer diagnosis who undergo treatment and experience cognitive decline continue to be assessed within the normal range of functioning.[5,8,12] Patients receiving chemotherapy perform only slightly lower on specific cognitive measures compared to age-matched, health counterparts.[8,18] However, for those with cognitive difficulties the experience can have a profound psychological impact with diminished quality of life which such patients can find disturbing and unacceptable.[3,5,13] Cognitive decline can become a serious detriment to multitasking, create stress and weaken performance when patients are challenged by high-level cognitive demands, including acquiring new skills, maintaining a career or academic performance.[5,15] It is important and appropriate to respond to the stress of such cognitive decline. However, the conflation of cognitive decline with the phenomenon of 'chemo brain' when the research literature has not yet affirmed with certainty the existence of such a syndrome is to move beyond the bounds of legitimate research evidence.

Cancer patients affected by cognitive decline need to hear the reassuring and normalising message that they are not alone in experiencing such difficulties. As Hess and Insel[8] indicate, appropriate interventions that can be used in clinics to improve mental functioning as well as patients' quality of life and overall well-being are required for cancer patients with cognitive difficulties. Empathic and intelligent responses to the distress of cognitive problems in cancer patients do not require a distortion of the present factual understanding (or more correctly, lack of understanding) of the concept and cause of 'chemo brain'. Patients undergoing stressful chemotherapies for cancer require honest, balanced information on the present research conclusions about the phenomenon colloquially know as 'chemo brain'. Such discussions can go hand in hand with the affirmation and understanding of any cognitive distress experienced by patients and referral to psychological assistance if required. Practical measures suggested to assist with managing cognitive decline include convenient arrangement of the home or work environment, memorization exercises, the use of mnemonic devices, notes and avoidance of distractions.[11,12]

The need for further research

The present literature on 'chemo brain' raises a myriad of questions to be answered and methodological issues to be addressed. This is an important area of research that has significant implications for patient quality of life and the provision of supportive care. The issue will assume greater significance as cancer survival improves.[5] As Raffa and Martin[29] suggest, if the condition does exist there will be some consolation in the knowledge that such cognitive decline has a name. However, it is still too early in the process of inquiry to be able to make, with certainty, the informative statements needed in response to patients' concerns about the relationship between treatment and cognitive functioning. Further research may eventually determine the link or clarify other causes of cognitive decline. The only certainty at present is that further research is required.

Hopefully, further research will not only provide information on causation but may also develop therapeutic strategies for avoiding cognitive decline. As Raffa and associates[11] point out, if certain drugs are found to be more responsible than others for cognitive impairment, in the short-term, clinical choices can be made on the basis of relative adverse effects on cognitive function and, in the long term, this potential adverse effect could be incorporated into drug-discovery screens, yielding future drugs producing less of a problem. Similarly, research progress may also be made in relation to the suggestion that erythropoietin may have some neuroprotective ability to reduce potential cognitive damage.[5]

There is much work to be done to clarify the many issues associated with the, as yet, controversial notion of 'chemo brain'. To properly understand the complexity of this issue will require a concerted effort by research from a broad range of disciplines and a variety of methodological approaches.

CONCLUSION

This article sets insights provided by haematology patients who have been through chemotherapy treatments on their attitudes, beliefs and experiences with regards to the notion of 'chemo brain' within the context of the available research literature on the topic. The findings indicate the need for caution in the way the literature is interpreted and presented to patients. Honesty in information-giving about the present research doubts and inconsistencies with regards to the notion of 'chemo brain' can ensure that the term does not unnecessarily increase the anxieties of patients. Such informed discussion can be accompanied by a compassionate response to those experiencing cognitive difficulties that affirms, normalises and provides referrals to expert psychological assistance.

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