Cognitive complaints in women with breast cancer: cross-cultural considerations

Research on cognitive changes following adjuvant breast cancer therapy has evolved considerably over the past decades. Earlier studies focused mainly on chemotherapy-related cognitive deficits [1], whereas more recent research has examined the potential etiological role of adjuvant endocrine therapies [2]. In most studies, cognitive function was measured with standardized neuropsychological tests [3]. If subjective cognitive complaints were assessed, various validated self-report questionnaires, ‘self-developed’ nonvalidated questionnaires, and/or semistructured interviews were used [4]. The prevalence rates of cognitive dysfunction in women with breast cancer vary between 19% and 78% [5] based on results obtained by objective testing and between 21% and 90% when self-reported [4]. This wide range may be explained by the variety of neuropsychological test or self-report measures applied, differences in designs (i.e. cross versus longitudinal), or inconsistencies in cutoffs used to classify the level of impairment. Current research focus is directed toward animal and imaging studies, to clarify the mechanisms by which chemotherapies impact brain structure, function, and consequential behavior in patients with cancer [5]. Additional results are now available on the long-term impact of chemotherapy on cognitive performance in breast cancer survivors, more than 20 years after chemotherapy, suggesting that cognitive deficits, following breast cancer diagnosis and subsequent chemotherapy, can be long lasting [6].

This emerging research on the cognitive effects of chemotherapy has coined the term ‘chemobrain’, referring to mental cloudiness or foggy thinking. Specific cognitive complaints reported by women with breast cancer cover memory lapses, troubles with concentrating, mental slowing, difficulties with decision making, and the inability to multitask. However, this term has been questioned because it does not impact their everyday lives, and how they cope to deal with
problems related to these changes. Information on these three topics was collected by conducting eight focus groups, four held in English and four in Chinese. Forty-three participants were recruited from the National Cancer Centre in Singapore and included when they had a diagnosis of breast cancer and were currently receiving or had recently completed chemotherapy treatment.

An intriguing result of Cheung’s study [9] was that the participants were unfamiliar with and averse to accept the term ‘chemobrain’, regardless whether they were presented the English term or its equivalent in Chinese. A common misconception among the participants was that ‘chemobrain’ referred to brain metastases or to a risk factor for dementia. It seems that ‘chemobrain’ is a phenomenon which is not easily understandable and accessible for women with Asian origin. Two questions become apparent when taking into account that the view or values of illness, attitudes toward treatment, and caregiving can differ between patients having a different cultural background [10]. Is ‘chemobrain’ a term with unique cultural attribution, i.e. a ‘Western-world’ concept? And if yes, can results from existing studies on cognitive dysfunctions be transferred across cultures?

Considering the fact that the vast majority of available studies on cognitive function in women with breast cancer were conducted in Europe, i.e. in the Netherlands, Germany, UK, Denmark, or in the United States, Canada, or Australia with predominately Caucasian women constituting the study population, these are reasonable questions to ask. Of the very few studies that described their study population by ethnicity, there was only one in which a substantial proportion of the participating women were from Asian origin [11]. In contrast to studies available on the incidence rates of breast cancer diagnosis, treatment, and survival in Asian women in the United States (e.g. [12, 13]), little is known about psychosocial factors in this minority population. In a recent systematic review and meta-analysis on psychological morbidity and quality of life of ethnic minority patients with cancer [14], only one of the 21 studies reviewed included a substantial proportion of Asian women with breast cancer.

In Cheung et al. [9] study the participants describe their specific cognitive complaints as problems with memory and verbal ability and as difficulties with concentration, learning and decision making. All these cognitive complaints match those commonly reported as chemotherapy-related cognitive deficits known from previous (Western-countries) studies [5] indicating that even if the term ‘chemobrain’ was not familiar to those women, their cognitive complaints do not differ from those of Caucasian women. As possible causes for their cognitive changes participants mentioned age, adverse physical effects associated with chemotherapy, fatigue, mood, or they even stated multi-factorial causes or had a holistic view by attributing cognitive changes to a misbalance of body, mind, and spirit. These responses reflect results from many studies that found a relationship between subjective cognitive function and psychological distress [4]. In addition, the participants’ awareness of multiple potential etiologies for cognitive changes after chemotherapy accentuates the request to replace the term ‘chemobrain’ by ‘cancer- or cancer-therapy associated cognitive change’ as suggested by Hurria [7] a few years ago.

A further topic addressed by Cheung et al. [9] that is quite neglected by research so far concerns the impact of cognitive changes on breast cancer survivors everyday life. The focus groups’ discussions revealed that all participants received sufficient psychosocial support and patience from their family members. However, there were also wishes that their husbands would be more appreciative for their current condition, and blame on themselves for having difficulties to fulfill their responsibilities as wives and mothers. They reported limitations in their work capabilities due to their loss of confidence in their abilities or difficulties in making decisions as a consequence of memory and concentration problems. Strong emotional reactions occurred including fear, frustration, and embarrassment when interacting with colleagues and friends, when they recognized changes in their cognitive abilities.

How can we compare these problems to those reported by other ethnicities? Only a handful of predominantly qualitative studies investigated the impact of cognitive impairment after chemotherapy on everyday function in Caucasian or African American breast cancer survivors. Similar to Cheung’s study cognitive complaints of participants in those studies interfered with their work productivity, social role functioning, and community involvement [15, 16]. When looking at the ways how to deal with cognitive problems breast cancer survivors in general apply similar strategies including practical aids such as writing journals or post-its for the refrigerator. Keeping the mind active is also a strategy reported across ethnicities; yet, there are cultural disparities regarding specific activities. While women in the study by Boykoff [16] mentioned using workbooks from their children or even going back to school, Asian women in Cheung’s study engage in everyday tasks by consciously recalling each step involved in cooking or sewing or by chanting religious prayers. As in Singapore, the population is Chinese-dominated, coping strategies founded in the Chinese culture such as practicing Qigong or playing mahjong are popular among the participants. Qigong incorporates gentle repetitive movements combined with breathing techniques and meditation with the purpose to cleanse, strengthen, and circulate the life energy (qi). Mahjong is a game of skill, strategy and calculation, stimulating memory, fast reactions, and mind flexibility. In addition, the participants relied on walnut or gingko extracts used in traditional Chinese medicine to preserve their alertness and energy.

Cheung et al. [9] chose the qualitative method of focus groups to assess cognitive changes. Focus groups are group interviews conducted by a facilitator, with or without the assistance of an observer or recorder, which capitalize on discussions with a group of people (usually 6–10) on a specific topic from the perspective of their individual experience or opinion. This approach differs from most studies where subjective cognitive function was usually investigated by using self-report questionnaires or semistructured interviews. Self-report questionnaires measure typically the frequency and severity of different types of cognitive problems with or only a very limited number of questions concerning the impact of those problems on family and work life (e.g. FACT-Cog). Therefore, qualitative approaches such as group discussions are valuable alternatives to gain a comprehensive picture on the
consequences of cognitive impairments on survivor’s family life and work ability. Besides participating in the focus groups, women in Cheung’s study had to complete a short questionnaire on sociodemographic factors and their attitudes toward chemotherapy. Complementing this assessment with a validated self-report questionnaire would have been an opportunity to see whether the responses of Asian women differ from those of Caucasian women with breast cancer, even if some of the most commonly used questionnaires to assess subjective complaints in this population (e.g. Cognitive Failures Questionnaire) are not available in Chinese [3]. Nevertheless, there would have been alternatives: Chinese versions are available for the FACT-Cog or the EORTC QLQ-C30, a quality of life measure that at least includes a two-item subscale on cognitive function.

Information on subjective cognitive function is certainly useful to get some preliminary insight on potential disparities across cultures. However, the International Cognition and Cancer Task Force (ICCTF) does not recommend self-report questionnaires as a valid mean to measure cognitive function in patients with cancer, due to the research showing a stronger association between subjective cognitive complaints and psychological distress and fatigue than between subjective cognitive complaints and objective tests [17]. The ICCTF recommends a core set of objective cognitive tests, criteria for defining cognitive impairment and cognitive changes, and approaches to harmonize study methods to facilitate between study comparisons and meta-analyses but does not explicitly address the issue of cross-cultural comparability. Classical neuropsychological test batteries are mainly paper-and-pencil tests that depend strongly on culture and language. For instance, it has been shown that accessibility of episodic memory differs between Caucasians and Asians because of culture-specific perceptual processing [18]. As a consequence, to be able to compare results across cultures, there is a need for normative data on batteries of neuropsychological matching the study population ethnic origin. Such normative data on a set of neuropsychological tests, including some of those recommended by the ICCTF, were recently published for the Mandarin-speaking mainland Chinese population [19]. For the cross-cultural approach, a promising strategy may be the use of computerized test batteries, relying on culture-independent stimuli such as card games (e.g. Cogstate Ltd).

Cheung’s study is the first to address chemotherapy-related cognitive problems in a population of multiethnic Asian breast cancer survivors that gives insight on how women with a different (than Western) cultural background perceive and deal with cognitive complaints after chemotherapy. The study’s limitations are inherent to the qualitative nature of their study. Findings are not representative for breast cancer survivors with other Asian ethnicities (e.g. Japanese, Korean, or Filipinos), which may have their own culture-dependent modes of perception and coping styles. Nevertheless, it points out that potential differences across cultures need to be considered when dealing with cognitive problems related to the adjuvant treatment of breast cancer. In light of increasing breast cancer incidence trends among Asian Americans [12] or in China, where in the cohort of women aged 35–49 years in 2001 nearly 2.5 million breast cancer cases are projected by 2021 [20], it is important to know whether hypotheses, questions, methods, and outcomes of current research attempts within the field of cancer and cognition are transferable to Asian ethnicities, with scale validation research as one specific topic. Determining the role of cultural and societal factors is important in order to respond effectively to the concerns of women about their cognition during and after breast cancer treatment. Further research on the impact of cognitive changes during and after chemotherapy on women’s everyday lives and on coping strategies that are helpful to deal with cognitive problems is needed by considering approaches that allow comparisons across cultures.

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disclosure

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