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Experiences of Women with Breast Cancer Disclosing Cancer-Related Cognitive Impairment Symptoms to Health Professionals: A Systematic Review and Meta-Synthesis

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This thesis is submitted in partial fulfilment of the degree of

Master of Psychology (Health)

School of Psychology University of Adelaide

2023

Word Count: 6160

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Declaration

This report contains no material which has been accepted for the award of any other degree or diploma in any University, and, to the best of my knowledge, this report contains no materials previously published except where due reference is made. I give permission for the digital version of my thesis to be made available on the web, via the University's digital research repository, the Library Search and also through web search engines, unless permission has been granted by the School to restrict access for a period of time.

Susan Hamilton

April 2023

Contribution Statement

I conceived the original idea for the research topic, and my research supervisor and I refined the research aims and study design. I created the search grids utilised to gather the data for this study with the assistance of my research supervisor, and a research librarian helped to further refine search terms and syntax for each database. Together, my research supervisor and I conducted the database searches and completed title and abstract screening; then, I completed the full text screening independently. Quality appraisal was completed by myself, my research supervisor and a third researcher. With guidance from my research supervisor, I completed data extraction and analysis and developed evidence-based guidelines which my supervisor refined. I wrote up all components of the thesis.

Experiences of Women with Breast Cancer Disclosing Cancer-Related Cognitive Impairment Symptoms to Health Professionals: A Systematic Review and Meta-Synthesis

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<u>Author Note</u>: This article is intended for submission to 'Psycho-Oncology' which requires the article to be no more than 6000 words excluding references, all in-text references to be numbered consecutively in order of appearance and for the reference list to use Vancouver referencing style. The article has been written to satisfy the Master of Psychology (Health) thesis requirement of 6,000-8,000 words, which aligns with the journal word limits; however, the formatting and referencing adhere to the requirements of the chosen journal. Figures and Tables are included in the relevant location within the body of the text for the examiner's convenience.

Abstract

Objective: Cancer-related cognitive impairment involves changes in a range of cognitive domains and executive functions in people diagnosed with cancer. This study aimed to explore the impacts of cancer-related cognitive impairment on women with breast cancer, their experiences disclosing symptoms to health professionals, and methods of coping with cognitive impairment symptoms.

Methods: A systematic review and meta-synthesis was conducted utilising meta-aggregative strategies to create synthesised findings from existing literature. Six databases were searched from inception until mid-October 2022, with eligible studies appraised using the QualSyst Quality Assessment Checklist.

Results: Three synthesised findings were created from a sample of 8 included studies. Findings highlight that women primarily initiated cognitive impairment disclosure conversations and experienced dismissal or minimisation of their symptoms. Women rarely received information about cancer-related cognitive impairment symptoms before treatment commencement, which impacted their ability to adjust to symptoms. Positive interactions with health professionals often primarily involved the validation of symptoms. Women often utilised coping strategies shared by other women and reported that health professionals could be more involved in managing cognitive impairment symptoms.

Conclusion: This meta-synthesis highlights the importance of health professionals informing women of potential cognitive impairment symptoms before treatment and discussing, validating and follow up on cognitive impairment symptoms.

Keywords: cancer; oncology; breast cancer; cancer-related cognitive impairment; health professionals; review

Background

Breast cancer is the most commonly diagnosed cancer in women globally, with approximately 2.3 million new diagnoses annually [1]. Due to advances in screening, diagnosis and treatment, breast cancer survivorship has improved significantly in many countries, including the United States and Australia, with the five-year survival rate increasing from 70% in the 1980s to over 90% in 2022 [2, 3]. This increase in survivorship has led to research investigating the long-term adverse effects of cancer treatment on people's post-treatment life. One such adverse effect that has received attention is cancer-related cognitive impairment.

Cancer-related cognitive impairment, also commonly referred to as 'chemotherapyrelated cognitive impairment', 'chemobrain', or 'chemofog' [4] involves changes in higher-order executive functioning domains, including attention, information and processing speed, problemsolving and planning abilities and memory retrieval [5, 6]. The estimated prevalence of cancerrelated cognitive impairment varies greatly in the literature, between 10-70% in all cancer populations [7, 8], and between 12-82% of women with breast cancer as a result of their treatment regime [9]. More recent findings suggest that one in three women with breast cancer may experience clinically significant cognitive impairment symptoms [10].

Researchers have proposed numerous mechanisms for cancer-related cognitive impairment, particularly focused on neurobiological changes that occur due to the effects of toxic chemotherapeutic agents, especially in high-dose cases [11]. These neurobiological changes include the production of pro-inflammatory cytokines in the brain [12], vascular injuries, oxidative damage, autoimmune responses, and the presence of apolipoprotein Ee4 (APOEe4) allele [13, 14].

Changes in hormone levels, including low oestrogen and progesterone, during chemotherapy or other anticancer hormonal treatments have also been hypothesised to impact cognitive performance [15, 16]. However, as cognitive impairment symptoms have been reported to arise before chemotherapy, it is difficult to determine which mechanisms are specifically due to chemotherapy rather than cancer itself [6, 17, 18].

Individual factors, including genetics, age, education, and treatment-induced menopause, may also influence the presentation and severity of cognitive impairment symptoms [19]. In addition, psychological factors that occur after cancer diagnosis and treatment, such as anxiety or depression, can significantly influence cognitive functioning [17, 20]. Finally, physical changes common due to cancer and treatment, including pain, fatigue and sleeping difficulties, may also significantly impact cognitive functioning [21, 22].

The type and severity of cognitive deficit people with cancer experience varies significantly. For example, Wagner et al. [23] found that 63% of people after cancer treatment reported problems with concentration and attention, 50% reported problems with memory and 38% reported problems with abstract reasoning. Further studies found cognitive impairments related to memory loss and attention [17], concentration, visuospatial abilities and motor function [18].

Cancer-related cognitive impairment symptoms influence women's emotions and impact their sense of self, roles and social relationships. Women with breast cancer have reported a range of emotions alongside cognitive impairment symptoms, including frustration [24, 25] and feeling upset or frightened by problems processing information [24, 26]. Some women have reported reduced self-esteem and self-confidence, feeling misunderstood or embarrassed, and

that their symptoms cause distress when completing daily living tasks, such as paying bills or driving [25, 27, 28]. Family support varies; some women have reported that their families provide considerable understanding and support [27], while others reported that family members lacked awareness or showed apathy [24, 28].

Cognitive impairment symptoms also adversely impact employment. For example, Wagner et al. [23] found that 75% of people diagnosed with cancer reported their symptoms as having detrimental consequences on their work performance, 58% utilised compensatory strategies to complete work, and 50% experienced increased frustration while completing work tasks. Furthermore, feelings of stress, fear, worry, frustration, insecurity and low-spiritedness influence many women's decision to return to work after breast cancer treatment [29]. These findings highlight that women can experience significant challenges when deciding to return to work, and, subsequently, in performing their work tasks [29].

Despite the significant impact cancer-related cognitive impairment can have on a person's quality of life, previous findings have highlighted issues in communication between women and healthcare professionals regarding the experience of cancer-related cognitive impairment symptoms. Women often receive limited information about the potential for cognitive changes after cancer diagnosis and treatment [30, 31]. Additionally, women have reported that their medical team have dismissed their concerns [24] and that they have not received any post-treatment assessment for cognitive changes [28]. Conversely, women experiencing symptoms may also not discuss their cancer-related cognitive impairment symptoms with their healthcare team. For example, Cheung et al. [27] found that among

oncologists, nurses practising throughout Asia, half the oncologists stated that patients rarely discussed the issue of cognitive impairment symptoms.

Recent research exploring the perspectives of health professionals working with people with cancer found that how each professional responds to cognitive impairment symptoms depends on their years of cancer-related clinical experience and their prior understanding of cancer-related cognitive impairment [32]. The health professional's discipline determined the kind of support provided to patients, with oncology nurses providing reassurance and basic strategies to assist with memory, and oncologists validating the person's symptoms [32]. Furthermore, He et al. [32] found that many health professionals lack clarity about the proposed hypotheses and mechanisms underlying cancer-related cognitive impairment, leading to a reluctance to discuss this with people with cancer. Medical oncologists noted that a lack of clinical practice guidelines for managing cancer-related cognitive impairment symptoms is a barrier, which also builds reluctance to discuss cognitive impairment symptoms when gaining informed consent before commencing chemotherapy [33]. Other barriers to conversations about cancer-related cognitive impairment symptoms identified by health professionals included financial constraints within public hospital systems to establish clinics or have health professionals specifically address cognitive impairment and the limited time during follow-up appointments to ask questions about cognitive impairment [33].

The Current Study

Despite cancer-related cognitive impairment significantly impacting women with breast cancer, health professionals may be reluctant to discuss these symptoms, as screening tools and practical guidelines for managing cognitive impairment symptoms are absent. In addition, more

needs to be understood regarding women and health professionals' interactions when discussing cancer-related cognitive impairment symptoms. The current study aims to identify, appraise and summarise existing studies that have examined women with breast cancer's experiences of disclosing cancer-related cognitive impairment to health professionals and their perceptions of health professionals' responses to such disclosure to generate recommendations that can inform healthcare practice. This study specifically aims to explore (i) the impacts of cancer-related cognitive impairment symptoms on women with breast cancer, (ii) women's experiences disclosing cancer-related cognitive impairment symptoms to health professionals and (iii) women's coping strategies and intervention preferences.

Methods

Design

In accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [34], a systematic review with meta-synthesis was utilised to address this study's research aims. Data were synthesised via a meta-aggregative approach to amalgamate findings from existing qualitative studies [35]. Meta-aggregation aims to synthesise the meaning of human experience captured in independent research studies focusing on a related topic [36]. Meta-aggregative approaches do not reinterpret data from primary studies but instead aim to accurately interpret the combined findings across the included studies [36].

A key strength of the meta-aggregative approach is that it allows researchers to synthesise qualitative research in a way that maintains the original context and sensitivity of individual qualitative research studies and is comparable to the rigorous processes applied to meta-analyses of quantitative studies [36]. A meta-aggregative approach is well-suited to

addressing questions about healthcare practice [37] as it can inform evidence-based healthcare by synthesising existing qualitative research [38] to generate recommendations to guide health professionals and policy-makers [39]. A deductive approach was initially employed to examine data according to the study's three research aims. However, as the authors had no pre-conceived ideas about what women would express, an inductive approach was utilised when developing categories and sub-categories to organise the data and generate synthesised findings. Ethics approval was not required as the current study is a systematic review and meta-synthesis of pre-existing data. This review was pre-registered on PROSPERO (CRD42022375403).

Search Strategy and Data Collection

Six online databases (CINAHL, Embase, Medline, PsychINFO, PubMed and Web of Science) were searched from database inception until mid-October, 2022 and imported into EndNote to identify qualitative studies that have examined women who have been diagnosed with breast cancer's experiences of disclosing cancer-related cognitive impairment symptoms to health professionals. A search strategy using individual search terms and controlled vocabulary was customised to suit each database, including terms such as "chemotherapy-related cognitive impairment", "chemobrain", "chemofog", "breast cancer", "breast cancer survivor", "health professional", "health practitioner", "qualitative" and other variants deemed appropriate. A research librarian was also consulted to optimise the search strategy. Alerts were created to ensure studies published after the initial search were examined for possible inclusion. Additionally, the reference lists of included articles were manually searched, and citation searching was undertaken using Scopus to identify any other relevant studies not found in the original database searches.

Selection Criteria

Studies were included if they (i) investigated women diagnosed with breast cancer's experiences of disclosing cancer-related cognitive impairment to a health professional, (ii) presented qualitative data (mixed methods papers were eligible if qualitative data was reported separately and in sufficient detail), and (iii) were published in English in a peer-reviewed journal. Data were considered qualitative if collected via qualitative data collection methods (i.e., interviews, focus groups) or analysed using qualitative research methods (i.e., thematic analysis). Studies were excluded if they (i) were quantitative, (ii) were not published in English in a peer-reviewed journal, (iii) did not report primary data (e.g., opinion pieces, book reviews), or (iv) did not report full data (e.g., conference abstracts, brief reports).

Quality Appraisal

The author (SH) and two other researchers (MO, YS) independently appraised the reporting quality of each eligible study using the QualSyst Quality Assessment Checklist [40]. This appraisal tool considers the methodological rigour and quality of studies across 10 items considered important to a qualitative study's internal validity. Each study was appraised as to whether it met each of the 10 specific criteria ("Yes" = 2, "Partial" = 1. "No" = 0). A summary score was calculated for each study, which involved summing the score obtained for each item and dividing by the total possible score (20), yielding a score between 0-1, where higher scores indicate higher quality. Variation in quality assessment was resolved through discussion between the three researchers. Kmet et al. [40] report a liberal cut-off score of .55 and a more conservative score of .75. In this meta-synthesis, the liberal cut-off was chosen to avoid giving a

restricted summary of the limited research in this area. However, seven studies scored above the conservative cut-off score of .75, and the remaining study scored .70.

Data Extraction and Synthesis

The 21-item Enhancing Transparency in Reporting the Synthesis of Qualitative Research guidelines (ENTREQ; [41]; See Supplementary Table 1) was utilised when reporting this metasynthesis. A study-specific data extraction sheet was used to gather study characteristics and relevant findings from the included studies. Data extracted from each study included (i) sample characteristics (e.g., sample size, age), (ii) study characteristics (e.g., aim, location, research design, recruitment source, analysis methodology), (iii) breast cancer characteristics (e.g., age at diagnosis, stage of treatment) and (iv) cancer-related cognitive impairment characteristics (e.g., impacts, experiences of disclosure, coping strategies).

Following extraction, relevant original findings from each of the included studies were identified and extracted verbatim in the form of categories or themes, along with illustrative extracts/quotes. For studies without author-identified themes, definitive statements made by the authors were extracted from the narrative. All extracted findings were then grouped into categories based on shared meaning, and then these categories were combined into a series of synthesised findings to address the research aims [42]. All researchers agreed the final synthesised findings.

Reflexivity

It is important to consider the impact of researchers' characteristics and previous experiences when conducting, interpreting or reviewing qualitative research to minimise the effect of researcher bias [43, 44]. The author (SH) is a young, Caucasian female that has not previously been diagnosed with breast cancer, or undergone chemotherapy. The author has also

not experienced cognitive impairment symptoms due to any medical treatments. The author has previously worked with a large cancer charity organisation in a role that involves interacting with people affected by cancer. To minimise researcher bias when integrating the synthesised findings, the author engaged in regular discussion with the research team to ensure that findings from the included studies were not being re-interpreted or taken out of the original context.

Results

Study Selection

The initial search resulted in 168 results (See Figure 1). After removing 62 duplicates, 106 studies were screened by title and abstract. After applying the inclusion/exclusion criteria, 76 studies were excluded, leaving 30 studies for full-text screening. The author (SH) and a second researcher (MO) co-screened all 106 records to reduce data-selection bias. Interrater agreement was high (96%, K = .90, p < .05), with any discrepancies resolved by consensus discussion. During the full text review, 22 studies were excluded, resulting in eight studies eligible for inclusion that were subsequently assessed for methodological quality. After quality appraisal, all eight studies were of sufficient quality to be included in the meta-synthesis.

Figure 1:

PRISMA flow chart illustrating the article selection and screening process



Study Characteristics

Table 1 summarises the key characteristics of the eight included studies. The studies were published between 2009 and 2018, with most studies originating from the United States of America ($N_{studies} = 4$). Qualitative data were collected predominantly through interviews ($N_{studies} = 7$). Researchers used thematic analysis ($N_{studies} = 4$) to analyse data in half of the studies and content analysis ($N_{studies} = 4$) for the remaining half.

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Table 1:

Summary of Included Studies

Lead Author (Date)	Country	Sample Size (N = 225)	Recruitment Strategy	Data Collection	Data Analysis	Quality Score
Bolton (2018)	Australia	50	Email to members of the BCNA	One-on-one telephone interviews	Qualitative description framework (thematic analysis)	.75
Boykoff (2009)	USA	74	Flyers in multiple cancer wellness centres, doctor's offices and support group meeting sites	Focus groups and individual interviews	Ethnographic content analysis	.85
Crouch (2017)	USA	13	Flyers in a breast cancer treatment centre	One-on-one telephone interviews	Content analysis	.85
Munir (2010)	UK	13	Two local support groups affiliated with a national cancer support charity	Focus groups	Template analysis (thematic analysis)	.85
Munir (2011)	UK	31	An NHS hospital breast cancer clinic	Interviews (face-to-face or telephone)	Content analysis	.85
Player (2014)	Australia	9	Email to members of the BCNA	Interviews (face-to-face or telephone)	Thematic analysis	.85
Rosedale (2010)	USA	13	Volunteer list from a cancer survivor network	Interviews	Thematic analysis	.70
Von Ah (2013)	USA	22	Mailed eligible participants from an Institutional Review Board-approved registry	Interviews	Content analysis	.85

Note. UK = United Kingdom; USA = United States of America; BCNA = Breast Cancer Network Australia; NHS = National Health

Service

Reporting Quality of Included Studies

Figure 2 summarises the reporting quality results of all included studies, as assessed using the QualSyst Quality Assessment Checklist [40] as shown in Figure 2 (for a detailed assessment of each study refer Supplementary Table 2). All studies fully met five of the 10 criteria. For example, all studies described the study design and context, connected the study to a wider theoretical framework, reported data analysis methods and described conclusions supported by the results (*Items* 2-4, 7 and 9; 100% fulfilled). In addition, most studies fully met criteria concerning a clear statement of the study's research question/s and/or objectives, a description of data collection procedures, and employed verification procedures to help establish credibility (*Items* 1, 6, 8; 87.5% fulfilled). However, most studies only partially met the criteria for clearly describing and justifying their sampling strategy (*Item* 5; 37.5% fulfilled), and no researchers explicitly assessed the impact of their characteristics and experiences on the research process through a reflexivity statement (*Item* 10; 0% fulfilled).

Figure 2:

Reporting Quality of Included Studies Using the QualSyst Quality Assessment Checklist [40]



% of Included Studies

Participant Characteristics

The sample comprised 225 women diagnosed with breast cancer who experienced cancer-related cognitive impairment ($N_{studies} = 8$). Participants were aged 30-80 years, based on 212 participants ($N_{studies} = 7$), with a mean age of 49.82 years (SD = 3.76), based on 88 participants ($N_{studies} = 5$). Most studies did not report participants' ethnicity ($N_{studies} = 5$; n = 118, 52.44%); where ethnicity was reported ($N_{studies} = 3$), 65 participants were Caucasian (28.89%), 40 were African American (17.78%), and 2 were unspecified (0.89%). Fifty-five participants ($N_{studies} = 4$) were married (24.44%), 47 participants were divorced or single (20.89%), and 14

participants reported other circumstances (e.g., widowed, living with a partner but not married) (6.2%). The average age at the time of breast cancer diagnosis was 44.23 years (SD = 7.43), based on 22 participants ($N_{studies} = 2$). Stage of diagnosis varied, with data reported for 30 participants ($N_{studies} = 2$), indicating participants were primarily diagnosed with Stage II breast cancer (n = 18, 8%), while 6 participants were diagnosed with Stage 1 (2.67%), and 6 with Stage III breast cancer (2.67%).

Surgical treatment was common, with 119 participants ($N_{studies} = 3$) undergoing surgery (52.89%) for breast cancer. Participants also underwent chemotherapy (n = 70, 31.11%), radiotherapy (n = 68, 30.22%), and hormone therapy (n = 60, 26.67%) ($N_{studies} = 3$). Eighteen participants (8%) had completed their cancer treatments less than four years before participating in the included study, while 12 participants (5.33%) had completed their cancer treatments more than four years before participating in the research ($N_{studies} = 2$). Post-treatment care length ranged between 4-36 months (M = 19 months), based on 13 participants ($N_{studies} = 1$).

Synthesised Findings

Applying a meta-aggregative approach, 35 findings reported in the included studies were combined into a total of 19 categories, which were then formed into three synthesised findings (overarching descriptions of the categorised findings) relating to the three research aims. Findings related to the first research aim regarding the impacts of cancer-related cognitive impairment symptoms on women with breast cancer comprised six categories: (i) Women experience symptoms in multiple areas of executive functioning; (ii) Symptoms impact women's sense of self, resulting in lower self-esteem and self-confidence; (iii) Social interactions and relationships were significantly impacted for some women due to their symptoms; (iv) Social withdrawal and avoidance behaviours were common reactions for women adjusting to

symptoms; (v) Symptoms have potentially severe implications for returning to work posttreatment; (vi) Most women tend to notice cognitive impairment during chemotherapy, but symptoms became a higher priority after cancer treatment had ended. Seven categories summarised findings for the second research aim exploring women's experiences disclosing cancer-related cognitive impairment symptoms to health professionals: (i) Women were not informed about cognitive impairment symptoms prior to chemotherapy treatment; (ii) Women were primarily the ones to initiate conversations that disclosed symptom experiences; (iii) Limited support was offered after disclosure; (iv) Health professionals' responses after disclosure varied; (v) For women who had frequent changes within the healthcare team, it was harder to initiate conversations about symptoms; (vi) Women perceived their concerns as trivial to doctors, contributing to hesitancy to discuss symptoms during appointments; (vii) Positive experiences that women had with their healthcare team involved validation and understanding of symptoms, examples of self-management strategies and regularly checking on symptoms at follow-up appointments. Finally, findings related to the third research aim exploring how health professionals can support women experiencing symptoms comprised six categories: (i) Women tended to rely on a range of self-management strategies to cope with symptoms; (ii) Strategies can be helpful, but can also succumb to cognitive impairment symptoms; (iii) Some women resigned to perceived limitations; (iv) A range of resources were utilised by women to form selfmanagement strategies; (v) Women preferred to not engage in pharmacological treatment of symptoms; (vi) When developing coping strategies, women suggested health professionals could be more involved in providing resources and monitoring

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Table 2:

Synthesised Findings and Component Categories of Experiences of Cancer-Related Cognitive Impairment Among Women Diagnosed

with Breast Cancer

Experiences of Cancer-Related Cognitive Impairment: Cancer-related cognitive impairment affects multiple areas of executive functioning, where symptoms, often noticed during chemotherapy, that impact sense of self, social interactions and relationships, lead to withdrawal and work-related challenges, becoming the highest health priority after cancer treatment

- Women experience symptoms in multiple areas of executive functioning
- Symptoms impact women's sense of self, resulting in lower self-esteem and self-confidence
- Social interactions and relationships were significantly impacted for some women due to their symptoms.
- Social withdrawal and avoidance behaviours were common reactions for women adjusting to symptoms.
- Symptoms have potentially severe implications when returning to work post-treatment
- Most women tend to notice cognitive impairment during chemotherapy, but symptoms became a higher priority after cancer treatment had ended

Experiences of Disclosing Cancer-Related Cognitive Impairment to Health Professionals: Women, often uninformed about cancer-related cognitive impairment before chemotherapy, were primarily the one's to initiate conversations with their health professionals, which was challenging in the context of frequent changes in the healthcare team. Upon disclosure, women received mixed responses and limited support, which contributed to hesitancy to discuss symptoms, although some health professionals were supportive, leading to a positive doctor-patient relationship

- Women were not informed about cognitive impairment symptoms prior to chemotherapy treatment
 - For women who received information before treatment, it was through non-specific brochures/leaflets provided by cancer support groups or clinics

- Women were primarily the ones to initiate conversations that disclosed symptom experiences
- Limited support was offered after disclosure
- Health professionals' responses after disclosure varied
 - o Lack of understanding or dismissal of symptoms
 - o Acknowledgement of symptoms but no follow-up or formal assessment
- For women who had frequent changes within the healthcare team it was harder to initiate conversations about symptoms
- Women perceived their concerns as trivial to doctors, contributing to hesitancy to discuss symptoms during appointments
- Positive experiences that women had with their healthcare team involved validation and understanding of symptoms, examples of self-management strategies and regularly checking on symptoms at follow-up appointments

Coping Strategies and Intervention Preferences: Women employed a range of self-management strategies which they learnt about from a range of sources, preferring not to use pharmacological treatment but noted that strategies can succumb to cognitive impairment symptoms, with some women resigned to perceived limitations and others wanting health professionals to be more involved in management.

- Women tended to rely on a range of self-management strategies to cope with symptoms
- Strategies can be helpful, but can also succumb to cognitive impairment symptoms
- Some women were resigned to perceived limitations
- A range of resources were utilised by women to form self-management strategies
- Women preferred to not engage in pharmacological treatment of symptoms
- When developing coping strategies, women suggested health professionals could be more involved in providing resources and monitoring

Experiences of cancer-related cognitive impairment. The meta-synthesis of women's experiences of cancer-related cognitive impairment was derived from seven studies that were grouped into six categories (Table 2) to provide the overall synthesised finding: *'Cancer-related cognitive impairment affects multiple areas of executive functioning, where symptoms, often noticed during chemotherapy, that impact sense of self, social interactions and relationships, leading to withdrawal and work-related challenges, becoming the highest priority for health after cancer treatment'.*

Women reported experiencing significant deficits in a range of executive functions, including attention and concentration, memory, language, processing speed and problem-solving [26, 28, 31, 45, 46, 47]. Common complaints included 'going blank' [45, 47], lack of clear thinking or feeling 'foggy' [26, 28], increased difficulty in multitasking and maintaining conversations with multiple people at once [26, 45], repeating oneself in conversation [45], an inability to cope with stressful situations [46], difficulty learning new skills [45], losing things [45], and experiencing greater fatigue due to engaging in compensatory strategies [46].

Women experiencing cancer-related cognitive impairment also commonly reported difficulties with verbal tasks and word recall [24, 28, 45, 46]. Greater attention and concentration were required to understand book and magazine content, making it more difficult to read for enjoyment [24, 28], and women experienced greater difficulty completing paperwork and medical forms [46]. Some women also experienced greater spelling and word recall difficulties, as described by one woman: *"I will lose a word and not be able to come up with it for hours or sometimes days."* [28, p.238].

Some women reported experiencing cancer-related cognitive impairment symptoms severe enough to interfere with daily living activities, including paying bills, remembering passwords or pin numbers, and grocery shopping [24, 26, 28, 45, 46]. Additionally, women commonly reported difficulties with driving, including planning routes and coordinating driving movements [24, 28, 45, 46]. The inability to concentrate while driving became dangerous in some situations, leading to driving avoidance, as one woman highlighted: *"I was at an intersection and I just didn't see it [the other car] …I decided that was enough for me"* [46, p. 235].

Cancer-related cognitive impairment strongly impacted women's sense of self, with some women describing feeling as though they were no longer themselves [28]: "*I'm just not the person I used to be and it gets very frustrating*" [28, p. 239]. In addition, many other women reported feeling 'frustrated' by their symptoms [24, 26, 28, 45, 46], as they lost their role and identity (Player et al., 2014), were unable to function at their previous pace [26], and noticed a reduction in their ability to learn new things [24]. Other common emotional reactions included feeling disheartened and disconcerted [28], embarrassed [28, 46], and upset or fearful [24, 46]. In addition, many women reported experiencing a loss of self-confidence and self-esteem [24, 26, 28, 45, 46] and were overwhelmed by stressful situations [26, 45, 46], as articulated by one woman: "...*before treatment I used to have quite a high stress level, I can't deal with too much stress anymore*" [26, p. 1366].

Women expressed that their cancer-related cognitive impairment significantly impacted their relationships with family and friends. Family and friends' reactions to symptoms ranged from apathetic to supportive [24]. Women who experienced adverse impacts reported that their family and friends were 'confused' by or misunderstood their symptoms [24, 28] and that family

members likened their symptoms to dementia: *"I repeat myself many times and my husband says 'Have you got Alzheimer's?'"* [26, p.1366]. Women reported feeling disconnected from their families due to missing important events and family role changes [46]. Some women experienced their friends feeling afraid for them when interacting at a time when their cognitive impairment symptoms were severe [24].

Cancer-related cognitive impairment also significantly impacted women's employment. Some women reported being keen to return to work for a sense of normality and that their workplace was supportive, which helped to build confidence [26]. However, women reported that work tasks were often more difficult to perform [28] due to an inability to maintain concentration, multitask, or tolerate noise [26]: "I remember going back to work and thinking: 'Oh I just want to get out of here, I can't stand this, all the noise and everything" [26, p. 1367]. Some women's cognitive impairment was such that they reduced their hours, changed work roles, left their jobs or retired early, significantly impacting their finances [24, 26, 28], as one woman shared: "I went into retirement because of the cancer, simply because I could not maintain the level of work that I was used to ... " [24, p. 229]. Some women were hesitant to discuss their cognitive impairment with their employers [26] and reported an increase in work stress and a reduction in confidence to handle work-related stress [24, 26, 31, 46], as one woman explained: "I'm worried I'll have to go down a grade at work, because I can't keep up cognitively with the job I have at the moment" [46, p. 235]. Symptoms also impacted women seeking employment, who noted increased stress about participating in job interviews and finding suitable employment [24]: "I feel I can't go out and look for other work because I don't know how I would physically fit into a work environment because of looking utterly stupid. I've worked since I was 16 and now, I have to apply for unemployment benefits." [45, p. 1268].

Women first noticed cancer-related cognitive impairment during their chemotherapy treatment but it was not a primary concern at that time: "... when I was receiving chemotherapy, I was so caught up in all of the other physical aspects of the chemo... that I didn't pay particular attention to my memory function" [28, p. 238]. However, cognitive impairment persisted for many women, lasting a year or longer [31], with symptoms being inconsistent and unpredictable [46]: "You know, I never felt like, neurologically, I really returned to my pre-cancer state. I kept thinking it would get better but it never did" [47, p. E30]. As women's symptoms lingered after chemotherapy ceased, they became increasingly concerned about their cognitive functioning and its impact on their lives: "...When I became concerned and noted it as something I perceived as a problem was when chemotherapy was over and I was physically feeling better and I felt like I was back in life, and then I just couldn't do what I had done before, and I didn't understand why." [28, p.238].

Experiences of disclosing cancer-related cognitive impairment to health

professionals. The meta-synthesis of experiences of disclosing cancer-related cognitive impairment symptoms to health professionals was derived from eight studies that were grouped into six categories and three subcategories (Table 2) to provide the overall synthesised finding: 'Women, often uninformed about cancer-related cognitive impairment before chemotherapy, were primarily the one's to initiate conversations with their health professionals, which was challenging in the context of frequent changes in the healthcare team. Upon disclosure, women received mixed responses and limited support, which contributed to hesitancy to discuss symptoms, although some health professionals were supportive, leading to a positive doctorpatient relationship'.

Women commonly expressed receiving insufficient information and preparation for cancer-related cognitive impairment before treatment [24, 26, 28, 45, 47, 48]. No verbal information was reported to be provided by health professionals, with a minority of women receiving general information from brochures inside clinics or provided by breast cancer support groups [26, 28]. The lack of information increased distress for women, as their symptoms led them to question their judgement [47]. Information regarding cancer-related cognitive impairment before treatment was expressed to be beneficial in assisting women in understanding and adjusting to cognitive changes, especially regarding returning to work [26]. It was also viewed as important for women to receive this information directly from their health professional: "*[...] I wish that whether it's a doctor or patient care coordinator… would talk to them [and say] 'You know, you may not get it, but these are some of the things that happen…just be aware, so that you don't get frightened that you are losing it or aren't meeting everybody's expectations'"* [24, p.227-228].

Conversations disclosing cancer-related cognitive impairment to health professionals occurred due to women initiating them rather than resulting from routine screening by the healthcare team during or after treatment [28. 48]. For women who experienced frequent changes in their healthcare team (e.g., seeing a surgeon, oncologist and general practitioner in different locations), it was difficult to form a trusting relationship with health professionals, leading to a greater reluctance to disclose cancer-related cognitive impairment and formulate an intervention plan [46]. One woman described a desire to continue having contact with Breast Care Nurses who were part of her healthcare team: "*Breast Care Nurses were absolutely wonderful but I had no contact with them once I moved from surgeon to medical oncologist. I would have liked contact with them for the remainder of treatment.*" [45, p. 1269].

Furthermore, support and investigation after disclosure of cancer-related cognitive impairment were limited, with health professionals not offering further assessment or treatment options [28, 45, 46, 48]. Responses varied but were limited; some women were prescribed antidepressants and vitamins [48] or referred to a psychiatrist [45]. However, no women were referred to allied health professionals, such as psychologists or occupational therapists [46].

Overall, most women did not receive adequate support for their cancer-related cognitive impairment, which may have arisen from a perceived lack of understanding from health professionals after symptom disclosure. Women frequently reported experiencing frustration after their healthcare professional minimised their cognitive concerns [28], attributed their symptoms to other factors, including other cancer symptoms [28], or their age [24]. In addition, some women experienced dismissal of their symptoms when they raised them with their healthcare team: "*when I discussed it with my oncologist, he dismissed it as nonsense.*" [45, p. 1269].

Women's perceptions about their healthcare team's reactions to the disclosure of cancerrelated cognitive impairment contributed to greater hesitancy to discuss symptoms for fear of damaging the doctor-patient relationship [47]. Women reported feeling that their concerns were unimportant to their busy doctors, who were more focused on treating the physical symptoms of cancer [46], or that their concerns were exaggerated or unreasonable [47], as described by one woman: "*They don't know what to do [to fix it]*. *More of an approach of solve the life/death and then mop up everything else afterwards*" [45, p. 1269].

Some women reported positive experiences after disclosing cancer-related cognitive impairment to health professionals. Validation of symptoms and reassurance that the cognitive changes were common were fundamental to a positive reaction from women after symptom

disclosure [28, 46, 48]. Acknowledgement and validation of symptoms provided a sense of relief for women [28], alongside the reassurance that other women commonly experienced similar symptoms [48]. Also, women appreciated when health professionals accepted and valued their concerns about cognitive impairment symptoms: *"I have to say that none of my doctors have taken any sort of cognitive or psychological or emotional issues lightly"* [45, 2018, p.1269].

Coping strategies and preferences for intervention. The meta-synthesis of coping strategies and preferences for intervention was derived from four studies that were grouped into six categories (Table 2) to provide the overall synthesised finding: *'Women employed a range of self-management strategies which they learnt about from a range of sources, preferring not to use pharmacological treatment but noted that strategies can succumb to cognitive impairment symptoms, with some women resigned to perceived limitations and others wanting health professionals to be more involved in management'.*

Women utilised a range of coping strategies to counteract cancer-related cognitive impairment. A combination of organisational and preventative strategies assisted with daily living tasks and routines, including using calendars, journals and lists to remember appointments and tasks for completion [24, 46], placing post-it notes with reminders throughout the house (e.g., to turn off the gas, lock the door) [24, 46], or training oneself to place items in specific locations (e.g., placing keys by the front door) [24]. However, these common strategies sometimes became susceptible to cognitive impairment symptoms, so women received support from family, as one woman explained: *"My husband calls me to remind me of the things I need to do"* [48, p.85].

To challenge cognitive impairment symptoms, women frequently engaged in activities involving mental stimulation, such as completing puzzles, word-based or mathematical-based

problem-solving activities, or computer-based brain training games [24, 46, 48]. In addition, some women utilised activities that focused on specific symptoms such as word recall, as highlighted by one woman: *"I do word and name association-type activities so that I will be less likely to forget words and names"* [48, p.85].

These coping strategies were initiated by women experiencing cancer-related cognitive impairment. Women did not report receiving professional assistance from an allied health professional specifically for their cognitive impairment symptoms [46] but reported that suggestions for activities occasionally came from their healthcare team [48] or were shared by other women with breast cancer within support groups [46].

Women used diverse coping strategies to alleviate complex emotions that coincided with cancer-related cognitive impairment, including adjusting expectations of themselves, humour, and receiving support from family and friends [48]. Women also received support from other women undergoing breast cancer treatment or attending cancer support groups [46]. They described discussions with other women experiencing similar symptoms as positive and validating: *"Knowing there are others out there that are struggling with this, it's not good news, but it makes me feel better that I am not crazy. It validates that this is real."* [48, p.85].

Women articulated that they preferred not to receive pharmacological treatments for cognitive impairment symptoms, as summarised by one woman: *"I am leery of taking any medication at this point."* [48, p.86]. Women also highlighted that health professionals should be more involved in providing information about cancer-related cognitive impairment to women diagnosed with breast cancer, as well as their families and employers [31], and assist in developing and monitoring coping strategies at follow-up appointments [45].

Discussion

This study explored the impacts of cancer-related cognitive impairment symptoms among women diagnosed with breast cancer, their experiences disclosing their symptoms to health professionals, and women's coping strategies and intervention preferences. Consistent with previous findings, this study found that cancer-related cognitive impairment affects multiple areas of executive functioning [5, 6, 17], which subsequently impacts wellbeing and functioning.

Synonymous with earlier findings [23, 25, 27, 29], this study also highlighted the significant impact cancer-related cognitive impairment symptoms can have on women's sense of self, social relationships and difficulties associated with returning to work. Frustration, which arose due to deficits in multiple areas of cognitive functioning, was the most commonly expressed emotion reported by women reported in the included studies [24, 26, 28, 45, 46]. Increased frustration was reported as women encountered greater difficulty completing daily living tasks (i.e., reading, driving or paying bills) and tasks in the workplace, leading to increased work-related stress [26, 31, 46], which contributed to a reduction in work hours, a change in roles, or retirement for some women, and was consistent with previous findings [29]. This study highlighted the diverse presentation of symptoms that can occur in women experiencing cancerrelated cognitive impairment and that significant psychological, social and employment impacts can occur for women. Given these findings, health professionals should explore these impacts further after disclosure of cancer-related cognitive impairment symptoms to determine symptom severity and provide guidance on managing such symptoms.

Previous research investigating health professionals' perspectives in discussing and managing cancer-related cognitive impairment symptoms, like the present study, found that women were primarily the initiators of discussion about cognitive impairment symptoms [27,

32]. He et al. [32] explored symptom disclosure to health professionals of varying disciplines, with medical oncologists reporting a minority of women disclosed symptoms and clinical psychologists reporting that they had not received referrals for cognitive impairment but had women report cognitive impairment symptoms as a secondary concern. Common barriers to discussing cognitive impairment symptoms include limited time during appointments, lack of valid screening and assessment tools, lack of clinical management guidelines, and the perception that if symptoms were distressing, women would raise them [32, 33].

This study also highlighted that the lack of information before treatment increased distress for women experiencing symptoms, with many women questioning their judgement [47]. Information provided before treatment delivered by a health professional was viewed as an important step in preparing and adjusting to cognitive changes after treatment by women [24, 26].

While there are currently no clinical management guidelines for cancer-related cognitive impairment, women viewed validation of symptoms from their health professionals as very important [28, 46, 48]. Women also described employing a range of coping strategies, such as brain-stimulating activities and creating routines, which could be suggested to other women by health professionals or cancer support charities [26]. Health professionals may also be involved in monitoring coping strategies, as findings highlighted that common coping strategies can also be susceptible to cancer-related cognitive impairment symptoms [46]. Overall, this study demonstrated the importance of health professionals being proactive in discussing cancer-related cognitive impairment, providing opportunities for symptom disclosure, and following up symptom experiences during appointments if symptoms have been disclosed.

Study Limitations

Rigorous research methods were used; however, this review is limited by containing a relatively small number of included studies, published in English, that only explored women diagnosed with breast cancer's experiences of cognitive impairment and disclosure of cognitive impairment symptoms. Therefore, the study does not consider the views of women with breast cancer and cancer-related cognitive impairment who may have participated in research published in other languages or the perspectives of individuals with other cancers in which cancer-related cognitive impairment has been reported, such as colorectal cancer [49] and lung cancer [50]. Additionally, the included studies were conducted in high-income countries, and their samples comprised adult women of primarily Caucasian descent, meaning gaps remain in knowledge about cancer-related cognitive impairment in women with breast cancer from lower socioeconomic groups and diverse cultural backgrounds. The authors of the included studies also did not report symptom duration or explore changes in symptoms over time, so it is unknown whether women were recalling current or past symptoms and their impacts. Finally, recruitment for the included studies was primarily through support groups or cancer support charities, meaning participants' experiences may not be representative of all women with breast cancer who experience cancer-related cognitive impairment.

Clinical Implications and Conclusion

This review contributes to the growing literature exploring cancer survivorship and the impacts of cognitive impairment symptoms on post-cancer quality of life. The synthesised findings provide valuable information for health professionals working with women diagnosed with breast cancer about the impact of cancer-related cognitive impairment, with recommendations for practice summarised in Table 3. In the absence of formal clinical

guidelines for assessing and managing cancer-related cognitive impairment, the evidenceinformed recommendations for practice provided in this article aim to assist health professionals in supporting women with breast cancer experiencing cancer-related cognitive impairment. Future research should continue to investigate methods to assess the presence and severity of cancer-related cognitive impairment symptoms and explore strategies to manage symptoms and reduce distress.

Table 3:

Recommendations for Practice

- Health professionals should ensure they maintain up-to-date knowledge about cancerrelated cognitive impairment, including prevalence, symptom presentation and effective management strategies
- 2. Provide information before treatment commencement, as part of seeking informed consent, to women about the potential for cancer-related cognitive impairment symptoms
- 3. Develop a strong, empathetic, collaborative relationship throughout treatment to create a safe space to discuss cancer-related cognitive impairment symptoms
- 4. When supporting people with cancer, consider proactively asking about cancer-related cognitive impairment symptoms as part of standard care
- 5. Provide validation and emotional support after cancer-related cognitive impairment symptom disclosure, especially if women are distressed by their experiences
- 6. Routinely and thoroughly investigate cancer-related cognitive impairment symptoms after disclosure has been made
- 7. Consider providing information/support/basic coping strategies where appropriate, as opposed to using pharmacological interventions for cognitive impairment symptoms
- 8. Consider referral to an allied health professional (e.g., occupational therapist, psychologist) for women experiencing significant distress or difficulty adjusting to cognitive impairment symptoms
- 9. Provide information/resources to family, carers and employers to enable increased awareness and support for women in multiple environments
- 10. Regularly follow up on the use of coping strategies during post-treatment appointments
- 11. Consider cognitive impairment symptoms as separate from ageing/other factors

Conflict of Interest: The author/s have no conflicts to declare.

Acknowledgements: The author/s would like to acknowledge Research Librarian, Ms

, for her assistance with the search grids. No funding was received for the conduct of this research.

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*Denotes references included in review

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Running head: DISCLOSING CANCER-RELATED COGNITIVE IMPAIRMENT

Supplementary Table 1:

ENTREQ Checklist

Item	Item Guide and Description			
		Number		
Aim	State the research question the synthesis addresses.	12		
Synthesis	Identify the synthesis methodology or theoretical framework which underpins the	12		
Methodology	synthesis and describe the rationale for choice of methodology (e.g.,			
	metaethnography, thematic synthesis, critical interpretive synthesis, grounded theory			
	synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis).			
Approach to	Indicate whether the search was pre-planned (comprehensive search strategies to	13		
Searching	seek all available studies) or iterative (to seek all available concepts until theoretical			
	saturation is achieved).			
Inclusion Criteria	Specify the inclusion/exclusion criteria (e.g., in terms of population, language, year	14		
	limits, type of publication, study type).			
Data Sources	Describe the information sources used (e.g., electronic databases (MEDLINE,	13		
	EMBASE, CINAHL, psychINFO, Econlit), grey literature databases (digital thesis,			
	policy reports), relevant organisational websites, experts, information specialists,			
	generic web searches (Google Scholar), hand searching, reference lists) and when			
	the searches were conducted; provide the rationale for using the data sources.			
Electronic Search	Describe the literature search (e.g., provide electronic search strategies with	13		
Strategy	population terms, clinical or health topic terms, experiential or social phenomena			
	related terms, filters for qualitative research and search limits).			
Study Screening	Describe the process of study screening and sifting (e.g., title, abstract and full text	14, 16		
Methods	review, number of independent reviewers who screened studies.			
Study	Present the characteristics of the included studies (e.g., year of publication, country,	18		
Characteristics	population, number of participants, data collection, methodology, analysis, research			
	questions).			
Study Selection	Identify the number of studies screened and provide reasons for study exclusion	17		
Results	(e.g., for comprehensive searching, provide numbers of studies screened and reasons			

	for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications to the research question and/or contribution to theory development).	
Rationale for Appraisal	Describe the rationale and approach used to appraise the included studies or selected findings (e.g. assessment of conduct (validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings).	14, 20
Appraisal Items	State the tools, frameworks and criteria used to appraise the studies or selected findings (e.g. Existing tools: CASP, QARI, COREQ, Mays and Pope [25]; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting).	14
Appraisal Process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.	14
Appraisal Results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale.	20, 21
Data Extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies? (e.g. all text under the headings "results /conclusions" were extracted electronically and entered into a computer software).	15
Software	State the computer software used, if any.	N/A
Number of Reviewers	Identify who was involved in coding and analysis.	15
Coding	Describe the process for coding of data (e.g. line by line coding to search for concepts).	15
Study Comparison	Describe how were comparisons made within and across studies (e.g. subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary).	15
Derivation of Themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.	13
Quotations	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations or the author's interpretation.	26-33
Synthesis Output	Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct).	22-24, 38

Supplementary Table 2:

Qualsyst Evaluation of Methodological Quality of Included Studies

Lead Author (Date)	Question/ Objective	Study Design	Context	Theoretical Framework	Sampling Strategy	Data Collection	Data Analysis	Verification Procedure	Conclusion	Reflexivity	TOTAL
Bolton (2018)	٠	٠	٠	٠	(•	٠	0	•	0	.75
Boykoff (2009)	(•	•	•	•	•	•	•	•	0	.85
Crouch (2017)	•	•	•	•	•	•	•	•	•	0	.85
Munir (2010)	•	•	•	•	(•	•	•	•	0	.85
Munir (2011)	•	•	•	•	•	•	•	•	•	0	.85
Player (2014)	•	٠	•	•	•	•	•	•	•	0	.85
Rosedale (2010)	•	(•	٠	•	0	•	•	•	0	.70
Von Ah (2013)	•	•	•	٠	•	•	•	•	•	0	.85

Qualsyst Criteria

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Appendix A: Psycho-Oncology Instructions to Authors

Sections

- **1. Submission**
- 2. Aims and Scope
- **3. Manuscript Categories and Requirements**
- 4. Preparing Your Submission
- **5. Editorial Policies and Ethical Considerations**
- **6. Author Licensing**
- 7. Publication Process After Acceptance
- **8. Post Publication**
- 9. Editorial Office Contact Details

1. SUBMISSION

Thank you for your interest in *Psycho-Oncology*. Note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium.

New submissions should be made via the <u>Research Exchange submission portal</u>. For technical help with the submission system, please review our FAQs or contact

@wiley.com.

For help with submissions, please contact

We look forward to your submission.

Data Protection and Privacy

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Psycho-Oncology is concerned with the psychological, social, behavioral, and ethical aspects of cancer. This sub-speciality addresses the two major psychological dimensions of cancer: the psychological responses of patients to cancer at all stages of the disease, and that of their families and caretakers; and the psychological, behavioral and social factors that may influence the disease process. Psycho-oncology is an area of multi-disciplinary interest and has boundaries with the major specialities in oncology: the clinical disciplines (surgery, medicine, pediatrics, radiotherapy), epidemiology, immunology, endocrinology, biology, pathology, bioethics, palliative care, rehabilitation medicine, clinical trials research and decision making, as well as psychiatry and psychology.

This international journal is published twelve times a year and will consider contributions to research of clinical and theoretical interest. Topics covered are wide-ranging and relate to the psychosocial aspects of cancer and AIDS-related tumors, including: epidemiology, quality of life, palliative and supportive care, psychiatry, psychology, sociology, social work, nursing and educational issues.

Special reviews are offered from time to time. Summary proceedings of important national and international symposia falling within the aims of the journal are presented.

Manuscripts should be confined to work relating to cancer and AIDS-related tumors. The criteria for publication are originality, high scholarly quality as determined by peer review, interest to a wide audience of those concerned with psycho-oncology.

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Journal Article

1. Wood WG, Eckert GP, Igbavboa U, Muller WE. Statins and neuroprotection: a prescription to move the field forward. Ann N Y Acad Sci 2010; 1199:69-76.

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2. Hoppert, M. Microscopic techniques in biotechnology. Weinheim: Wiley-VCH; 2003. *Electronic Material*

 Cancer-Pain.org [homepage on the internet]. New York: Association of Cancer Online Resources, Inc.; c2000–01 [Cited 2015 May 11]. Available from: <u>http://www.cancer-pain.org/</u>. *Tables*

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