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Identifying the supportive care needs of men and women affected by chemotherapy-induced alopecia? A systematic review.

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Title: Identifying the supportive care needs of men and women affected by chemotherapy induced alopecia? A systematic review

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Abstract

Purpose: To systematically evaluate evidence regarding the unmet supportive care needs of men and women affected by chemotherapy induced alopecia (CIA) to inform clinical practice guidelines.

Methods: We performed a review of CINAHL, MEDLINE, PsychINFO, Scopus, the Cochrane Library (CCRT and CDSR) controlled trials databases and clinicaltrials.gov from January 1990 to June 2019 according to the Preferred Reporting Items for Systematic Review and Meta-analysis (PRISMA) statement. Twenty-seven publications were selected for inclusion in this analysis.

Results: Included reports used qualitative (ten) and quantitative (seventeen) studies. Across these studies men and women reported the major impact that CIA had on their psychological well-being, quality of life and body image. Hair loss had a negative impact irrespective of gender, which resulted in feelings of vulnerability and visibility of being a “cancer patient”. Men and women described negative feelings, often similar, related to CIA with a range of unmet supportive care needs.

Conclusions: Some patients are not well prepared for alopecia due to a lack of information and resources to reduce the psychological burden associated with CIA. Hair loss will affect each patient and their family differently, therefore intervention and support must be tailored at an individual level of need to optimise psychological and physical well-being and recovery.

Implications for Cancer Survivors: People affected by CIA may experience a range of unmet supportive care needs and oncology doctors and nurses are urged to use these findings in their everyday consultations to ensure effective, person-centred care and timely intervention to minimise the sequalae associated with CIA.

Key words: chemotherapy; induced alopecia; cancer; unmet needs; supportive care; systematic review; evidence synthesis.

Introduction

Cancer represents a significant global burden with an estimated 18.1 million people diagnosed in 2018 [1]. Supportive care has been defined as a person-centred approach to the provision of the necessary services for those living with or affected by cancer to meet their informational, spiritual, emotional, social, or physical needs during diagnosis, treatment, or follow-up phases, including issues of health promotion and prevention, survivorship, palliation, and bereavement [2]. A series of recent systematic reviews have identified a range of unmet supportive care needs in 21st century healthcare for people affected by prostate [2], bowel [3], gynaecological [4], bladder [5], lung [6], thyroid [7] and breast cancer [8], including mixed older cancer populations [9]. Generally, important areas for quality care include supported self-management, timely and informative information, continuity of care, good communication, and a therapeutic relationship with healthcare professionals.

One of the mainstay treatments for cancer worldwide is chemotherapy. Hair loss can be a concerning and distressing side-effect of chemotherapy for patients [10-14]. The likelihood of patients experiencing severe alopecia largely depends on several important clinical factors related to the type, frequency, dose and method of the administration of the cytotoxic agent [15]. Historically in clinical practice, alopecia is often assumed to be an unavoidable and a transient side-effect that can be dealt with using head covers or wigs [16]. To date, there have been several systematic reviews which have explored the impact of chemotherapy induced alopecia (CIA) on psycho-social outcomes [16-18]. There are, however, several limitations of these reviews worthy of comment. Firstly, some of these reviews lacked transparency in their review methodology, for example the absence of the Preferred Reporting for Systematic Reviews (PRISMA) guidelines [19]. Secondly, the scope of one of the reviews was gender and tumour specific [16], which limits our understanding of the experience and needs of men affected by CIA [20] and other tumour groups. Thirdly, since these reviews [16-18] clinicians are beginning to implement proactive strategies in clinical practice, such as improved scalp cooling technologies [15, 21-23] which will impact upon patients experience and quality of life (QoL) outcomes. Undoubtedly, CIA has been cited as one of the most disturbing side-effects among women [13], but largely the experience of men have been ignored with hardly any attention from a clinical and research perspective [20]. One study identified that young men appeared to have similar distressing experiences related to CIA as women [24]. Across many different cultures internationally the symbolism of hair continues to be a powerful individual and group identity

[25]. Some men articulated concerns related to their masculinity, particularly about being perceived as child-like with associated psychological distress from losing their hair from all body surfaces including: arms, pubic area, upper body surface, legs, toes, facial and head [20]. On the contrary, women did not comment on any hair loss below their eyes, suggesting gender differences in the experiences of CIA [16]. In a study elsewhere, men reported a worse self-image than women and the authors concluded healthcare professionals should provide men with supportive care interventions to cope with the distress of CIA as women [26]. Therefore, there is a clinical need to take stock of existing evidence to understand the unmet supportive care needs of both men and women affected by CIA to inform clinical practice guidelines and models of supportive care. This review addressed the following clinically focussed research questions:

1. What are the different domains of unmet supportive care needs of men and women affected by CIA?
2. What are the most frequently reported individual domains of unmet need of men and women affected by CIA?

Methods

The review has been reported according to the PRISMA guidelines [19]. The priori systematic review protocol was registered on the International Register of Systematic Reviews available from: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42019139870

Eligibility criteria

Types of studies

- Studies investigating unmet supportive care needs of men and women affected by CIA.
- Qualitative and quantitative methods irrespective of research design.
- Relevant systematic reviews were scrutinised for potential studies for screening.

Exclusion

- Case reports, commentaries, editorials, and studies where unmet supportive care needs were not explicitly reported.

Types of participants

- Men and women (>18 years old) affected by CIA irrespective of cancer type or stage.

Types of outcomes measures

The primary outcome of the review was related to unmet supportive care needs. Individual supportive care needs are classified into eleven primary domains of need [27]. Specifically, physical, psychological/emotional, family-related, social, interpersonal/intimacy, practical, daily living, spiritual, health system/information, patient-clinician communication, and cognitive needs. The classification of supportive care needs domains are informed by the Supportive Care Needs Framework [28]. See **Table 1** for supportive care needs classification.

Literature search

The CINAHL, MEDLINE, PsychINFO, Scopus, and Cochrane (CCTR and CDSR) controlled trials databases and clinicaltrials.gov were searched for all relevant publications (data cut off January 1990 – June 2019, English language studies only, exclusion of case reports, reviews, commentaries, editorials, or studies with no clear data on unmet supportive care needs). Relevant systematic reviews were scrutinised for potentially relevant studies for screening.

The search architecture was designed by an expert systematic review librarian and the management of citations throughout the review process was conducted using Endnote^{x9}. The search used a wide range of keywords and free text items to increase the sensitivity and inclusiveness of the searches, see **Supplementary Table 1**.

Selection of studies

Following de-duplication, two review authors independently screened the titles and abstracts of identified records for eligibility. The full text of all potentially eligible records was retrieved and screened independently by two review authors, linking together multiple records of the same study in the process. Any disagreements were resolved by discussion. The study selection process was described using the PRISMA flow diagram [29].

Data extraction and management

Two review authors independently extracted outcome data and then compared for accuracy. Any disagreements were resolved by discussion. Data extracted included in the characteristics of the included studies table are author and year, purpose, sample size, participants, sampling, response rate, design, time points, data collection, and evidence of unmet supportive care needs.

Assessment of risk of bias in included studies

Methodological quality evaluation was conducted using two quality appraisal tools and have been used in a similar systematic review [27]. The quantitative appraisal tool assessed a range of designs including the following: randomized controlled trials (RCT), non-RCT, cohort, case-control, other observational studies which were classified as low risk, unclear risk and high risk of bias according to the criteria specific to each study design. The quantitative appraisal tool consisted of 17 items. Some items in the quantitative assessment tool are only relevant to RCT's; therefore a "non-applicable" item option was available for other research designs. The qualitative appraisal tool had 15 items and three levels of risk using the same risk of bias convention scoring as the quantitative appraisal tool.

Data synthesis

The review used a narrative synthesis and tabulation of primary research studies to generate broad findings and conclusions, because there were no usable data to perform a meta-analysis. More specifically, the narrative synthesis involved data reduction (sub-group classification based on levels of evidence and the review questions), narrative data comparison (iterative process of making comparisons and identifying relationships) and finally, drawing conclusions [30].

Results

Of the 5285 publications retrieved from the search 5193 were excluded following the application of the inclusion/exclusion criteria, see **Figure 1**. The remaining 92 publications retrieved in full, and 65 articles were excluded with reasons because they did not meet the inclusion criteria. In total 27 studies were included in this systematic review, 10 qualitative studies and 17 quantitative. There were a range of study designs which included cross-sectional survey [13, 24, 31-37], qualitative study [12, 20, 38-46], mixed methods [47, 48], prospective longitudinal survey [49-51], case-control study [52] and cohort study [53]. The methodological quality assessment of the retained studies was performed in parallel with the data extraction see **Table 2**. The studies were conducted in a range of countries which included: Netherlands (n=2), Sweden (n=1), Turkey (n=3), Malaysia (n=1), Korea (n=2), United Kingdom (n=3), United States of America (n=3), Germany (n=2), France (n=2), Brazil (n=2), Ireland (n=1), India (n=1), Australia (n=2), Belgium (n=1) and Denmark (n=1). The sample size varied from n=5 to n=676 with a total sample size of n=3394. The majority of the studies included women affected by breast cancer and only five studies [20, 24, 31, 32, 37] recruited men affected by CIA, see **Table 3**.

Evidence of unmet supportive care need by domain

Physical needs

Nineteen of the included studies describe the physical needs of people affected by CIA [12, 20, 24, 31-34, 36, 37, 41-50]. Across the majority of the studies the participants ranked hair loss as one of the most distressing side-effects of chemotherapy [31, 36, 41, 42, 49] which resulted in decreased physical well-being [13, 24, 33, 34]. CIA was a physical consequence of treatment which was most confronting when both young men and women experienced clumps of hair on their pillow or losing handfuls of hair during washing [20]. The physical symptoms caused by CIA included: soreness and pain on the scalp, skin and eye irritation and dryness inside of the nose [12, 45, 50]. Patients also described the experience of wearing a wig as a physical burden [12, 48] which was difficult and exhausting due to trying on multiple wigs [48]. Some women wore protective glasses while outside to prevent debris entering their eyes due to the loss of their eye lashes [45]. The experience of re-growth of eyelashes was associated with pruritis [45].

Psychological needs

Emotional needs were consistently reported across 25 of the included studies. Women ranked hair loss as the second most distressing symptom where as men ranked hair loss as the third most distressing symptom [31]. Younger men appeared to have as much difficulty adjusting to CIA and to other people's reactions towards their hair loss as women did [20]. In particular, some women articulated that CIA was psychologically very painful and ranked this more upsetting than losing a breast following mastectomy [38, 46]. Psychological well-being scores were consistently lower in both men and women for those affected by partial or complete hair loss [24, 33]. One study observed that after adjusting for clinical and demographic variables, body image, psychological well-being and depression were statistically associated with severe CIA distress ($p<0.001$) [13]. One study explored the needs of children with mothers who were affected by CIA [39]. Children expressed distress at observing the side effects of chemotherapy, and seeing their mothers losing their hair was particularly upsetting for them [39].

For many patients it was important that the headwear did not look like a "cancer hat" [20, 47] to reduce the associated stigma [50]. For many, CIA became a psychological acknowledgement that they were unwell [12, 20]. CIA invoked a range of negative feelings which included: shame, guilt, reduced confidence, uncertainty, hopelessness, vulnerability, anxiety, depression, sadness, stress, reduced self-esteem, fearfulness, loss of control, and some described CIA as the most painful experience beyond their imagination [12, 34-36, 40, 41, 45, 48, 50, 52]. Even following hair re-growth people affected by CIA continued to experience difficulties with confidence, self-esteem and anxiety [41]. Noteworthy, interventions including scalp cooling to prevent hair loss was associated with improved quality of life domain scores for some women [53].

Cognitive needs

Women affected by severe CIA induced distress reported reduced cognitive functioning ($p<0.001$) [13]. Women expressed cognitive needs around madarosis [45] and being hyper vigilant around hair care behaviours [44]. Interestingly, some women found benefit in CIA because they perceived that their hair loss was evidence that chemotherapy was working to cure them of cancer [46]. Women used different cognitive strategies to conceal their hair loss [12].

Patient-Clinician Informational Needs

For the most part people receiving chemotherapy were very well informed about the potential side-effect of CIA. However, some people expressed a lack of preparedness and information about potential coping strategies and practical support available to self-manage CIA [12]. Others would have valued advice and information from their healthcare professional on self-care strategies that they could use to minimise their hair loss by access to interventions, such as scalp-cooling [44]. Some patients articulated that they only found out about scalp-cooling through other patients rather than direct information provided to them from their cancer care team. Moreover, patients reported a lack of information from their clinician about how scalp-cooling worked, because women falsely believed that scalp cooling would prevent madarosis [45]. Women also expressed the need for information to be available to them to provide to their hairdressers about hair care [44]. Importantly, from the child's perspective they felt excluded from the nurse or doctor caring for their mother, and young people wanted more information about cancer and therapy regimes [39].

Health System Needs

Across the studies it was apparent that people affected by CIA wanted more information from their hospitals about how to self-manage hair loss [12, 20, 32, 41, 43, 45] and how to source correct fitting headwear [47]. Women did not receive information about where to purchase wigs or headwear from their hospital but rather accessed information ad hoc from the Internet. Women wanted to have information available to empower them to plan their coping strategies to conceal CIA before they experienced it [12]. Furthermore, some women felt unprepared about how to approach the difficult conversation with their children about CIA and would have benefited from guidance from a healthcare professional [39]. Importantly, some patients expressed disappointment that scalp cooling was not offered to them as part of their decision-making process [44].

Spiritual Needs

The spiritual needs were rarely explored across the included studies. However, for some people they conceptualised their baldness as being sick, with re-growth of hair represented hope and renewed life [12]. Others expressed that CIA invoked feelings of hopelessness, but they used spirituality as a coping mechanism [40].

Daily Living Needs

Daily living needs were found to be intrinsically linked to the need to conceal hair loss. Both men and women reported that CIA severely limited their daily activities [20, 41, 47] in the community and workplaces [12]. Daily living was restricted by being unable to go out in public, for example to get shopping, exercise, work, and going to childcare facilities [12, 39]. To try and overcome the barrier that CIA had on their daily lives almost all used camouflage strategies such as wigs, hats, scarves and other head wear [12, 24, 33, 46, 47]. However, there was a negative economic burden in the cost of purchasing headwear and the upkeep of them through washing and dying [12]. Others would have valued more detailed information and education when undergoing scalp-cooling on their daily lives [44].

Interpersonal/Intimacy Needs

Alopecia had a profound consequence on body image for both men and women [33]. Women expressed that they were afraid that the disease and its associated side effects would alter their sense of normality and core identity to that of a perpetual cancer patient [38]. Women felt a lack of connection with their appearance and were unable to associate with it or recognise their reflection in the mirror [45]. One study identified that there was no difference in body image scores between men and women for those affected by CIA [24]. Specifically, men expressed concerns that they looked less masculine as a result of CIA and this made them feel vulnerable [20]. The most prominent difference between men and women's experiences was that women did not speak about hair loss below their eyes, whereas men commented on hair loss from other parts of their bodies liked to their masculinity [20]. For both men and women hair was part of their identify and sexuality [41]. Young men found it difficult to start a new relationship due to alopecia [20], and a small number of people were scared that they would be rejected by their partners [34].

Practical Needs

Practical needs were related to the need to conceal/disguise their hair loss by wearing hats, scarves, and wigs [12, 20, 47]. Women found it helpful having a family member with them when trying on wigs to provide encouragement and feedback [48, 50]. Many women found practical strategies of using eyebrow pencils, eyeliners and eye shadow was helpful to cover up patchy hair loss or replicate eyebrows [45] but they were dissatisfied with the cosmetic result. For the most part women expressed the importance of taking their time when choosing their wig [41].

Family-Related Needs

The family unit was affected as a result of cancer and alopecia. Patients affected by CIA expressed concern for how alopecia would affect their loved ones [31]. Whereas, partners reported it was much more difficult for them to cope with the impact of cancer and its treatments than for the women themselves [38]. Children also found it distressing seeing their mothers with wigs because they no longer looked like their mother [39]. Women with young children also expressed the need to wear a wig at home due to fear that their children's friends might tease them because of their altered appearance and baldness [12]. Most of the participants across the studies relied on the support provided to them by their family [12, 40, 43, 50]. Women also found support groups helpful for emotional support because they were able to disclose feelings that they were unable to share with family members due to the fear of upsetting their loved ones [41].

Social Needs

Social well-being was negatively affected for both men and women [32]. Reduced social function was associated with CIA distress [13, 33]. Women valued headwear which helped them blend into society to help minimise stares and conceal their illness [47]. Both men and women voiced worries about being perceived as an aggressive person and being labelled as a skin head [20]. Due to the social impact that alopecia had on them publicly it forced them to confront that they had cancer [20]. This altered the way people affected by CIA socialised in the broader community and resulted in a decreased ability to communicate with others [45]. Many used avoidance coping strategies to stay home to prevent them experiencing sympathy from people in public [12, 45, 46]. Alopecia prevented people from enjoying a social life. Despite the negative feelings towards wearing a wig they endured it to be accepted into society [41, 43, 45].

Frequency of supportive care needs documented in the literature

In descending order of supportive care needs, the frequency reported across the included studies comprised of: psychological needs (25/27), physical needs (19/27), family related needs (12/27), interpersonal/intimacy needs (11/27), practical needs (10/27), social needs (9/27), health system needs (9/27), daily living needs (7/27), patient-clinician informational needs (6/27), cognitive needs (5/27) and spiritual needs (2/27), see **Table 5**. See **Supplementary Table 2** for unmet supportive care needs across the included studies.

Discussion

CIA presents a challenge to the patient and family during and following treatment and recovery. This comprehensive systematic review set out to identify the potential unmet supportive care needs of both men and women affected by CIA to identify the most frequently reported unmet needs in the literature to inform service delivery. Not all patients will experience high levels of distress as a consequences of CIA and this review has informed healthcare professionals about the different and complex needs which underscores the importance for person-centred supportive care. Hair-loss remains an important and distressing side-effect of chemotherapy for patients regardless of gender, and healthcare providers may underestimate its impact on patients [54]. Oncology doctors and nurses play a critical role in preparing for and coping with CIA for their patients. What is apparent from the existing evidence is that patients require additional support in assisting them with proactive individualised self-care strategies to manage CIA. A recent study identified that patients would have preferred more information about the process of scalp cooling, tolerability issues, hair care, and also information to give to their hairdresser about hair care [44].

Historically nurses and doctors have spent considerably less time assisting men in their adjustment to CIA, with limited, if any, offer of proactive interventions such as scalp-cooling, scalp compression, topical minoxidil, or phytotherapeutic agents [26, 37, 55]. In 21st century healthcare there continues to be a lack of focus on men affected by CIA and this review has underscored a lack of research in comparison to women. Further research should seek to understand the complex person-centered needs of men affected by CIA and to explore potential differences with demographic and clinical factors. Based on the limited existing studies which have been conducted, men have reported high levels of distress, altered body image and negative feelings towards hair loss, not dissimilar to women [20, 24, 31, 32, 37]. It has been well documented that people affected by alopecia experience higher levels of anxiety and depression and reduced quality of life due to the negative impact that CIA has on self-esteem and body image [13, 24, 31, 38, 48].

Alopecia is associated with loss of control, privacy, and has been found to have a negative effect on social activities, quality of life, and for some apprehension about being seen outside in their local communities. Hair loss is a visible indication that a person has a diagnosis of cancer. Consequently, people affected by CIA suffer from the stigma of alopecia in social interactions and have lost control over who they tell about their illness. Several of the included studies identified that people affected by CIA used avoidance coping strategies such as avoiding social events or being seen in public [12, 43, 45, 46]. Based on the coping theory of Lazarus and Folkman [56] coping is defined as behavioural and cognitive efforts to manage stressful encounters. In keeping with coping theory many of the participants employed avoidance coping strategies to manage distressing life situations because of their hair loss.

Chemotherapy associated hair loss may begin one to two weeks after chemotherapy reaching a maximum of two months [34]. Alopecia from chemotherapy can be reversible with new hair regeneration beginning one to two months after the discontinuation of chemotherapy. However, there is increasing evidence that persistent/permanent CIA can be experienced following treatment [57] while for other patients it will be a transient time. Alopecia has few physical harmful effects but may lead to significant psychological consequences in many areas of the person's life. Alopecia is a form of disfigurement that can affect a person's sense of self and identify. It is paramount for healthcare professionals to provide written and oral information as early as possible to enable patients to organise proactive self-management strategies to cope with the devastating impact that hair loss may have on them. Given the profound psychological impact that CIA has on patients we would recommend the use of holistic needs assessments in routine clinical practice to help identify those at clinical risk of anxiety and depression to enable timely appropriate referrals to clinical psychologists if needed [58].

It is important that oncology doctors and nurses adopt an individualised approach to educating patients about hair loss using a sensitive and practical manner. Services should provide a list of reputable wig suppliers in their local area. It was evident in this review that patients wanted practical information about the cost, fitting and choice of suitable wigs. Healthcare professionals must also be aware of need of on-going emotional and psychological support needed during hair re-growth and support for their family members. Parents also face the challenge of meeting the needs of their young children [39]. Staff working in hospitals are well placed to offer support and advise parents in communicating with their children about cancer and hair loss.

Limitations

There are several limitations worthy of comment. Firstly, one of the major challenges of this review was combining heterogeneous methodologies, and our findings are constrained due to the methodological limitations of the studies included. The review only included articles in the English language, and as such, it may limit our understanding of the area globally considering cultural and societal differences. Despite these limitations the review team followed a rigorous and transparent review methodology to promote reproducibility.

Conclusion

This systematic review contributes towards the understanding of the unmet supportive care needs of men and women affected by CIA. People affected by CIA may experience a range of unmet supportive care needs and oncology doctors and nurses are urged to use these findings in their everyday consultations to ensure effective, person-centred care and timely intervention to minimise the sequalae associated with CIA. Future research should focus on the supportive care needs of men affected by CIA and explore potential differences in demographic and clinical factors.

Compliance with Ethical Standards

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Table 1 Classification of the 11 domains of supportive care needs

From: Identifying the supportive care needs of men and women affected by chemotherapy-induced alopecia? A systematic review

Domain of need	Definition
Physical needs	Experience of hair loss
Psychological/emotional needs	Experience of psychological/emotional symptoms such as anxiety, depression, worry, despair and fear
Family-related needs	Experience of fears/concerns for the family, dysfunctional relationships, etc.
Social needs	Experience of reduced social support, social isolation, loneliness, etc.
Interpersonal/intimacy needs	Experience of difficulties with self-image and masculinities, compromised intimacy with partner, etc.
Practical needs	Experience of financial/economic support, etc.
Daily Living needs	Experience of restriction in daily living tasks such as exercise, housekeeping, etc.
Spiritual needs	Existential concerns such as fear of death and dying, and fears regarding after life
Health system/information	Experience of a lack of information of supportive care interventions, uncertainty of follow-up care, lack of information in relation to CIA, etc.
Patient-clinician communication needs	Quality of communication between patients and healthcare professionals, satisfaction with care, shared decision-making, etc.
Cognitive needs	Experience of cognitive impairments, memory loss, etc.

PRISMA 2009 Flow Diagram

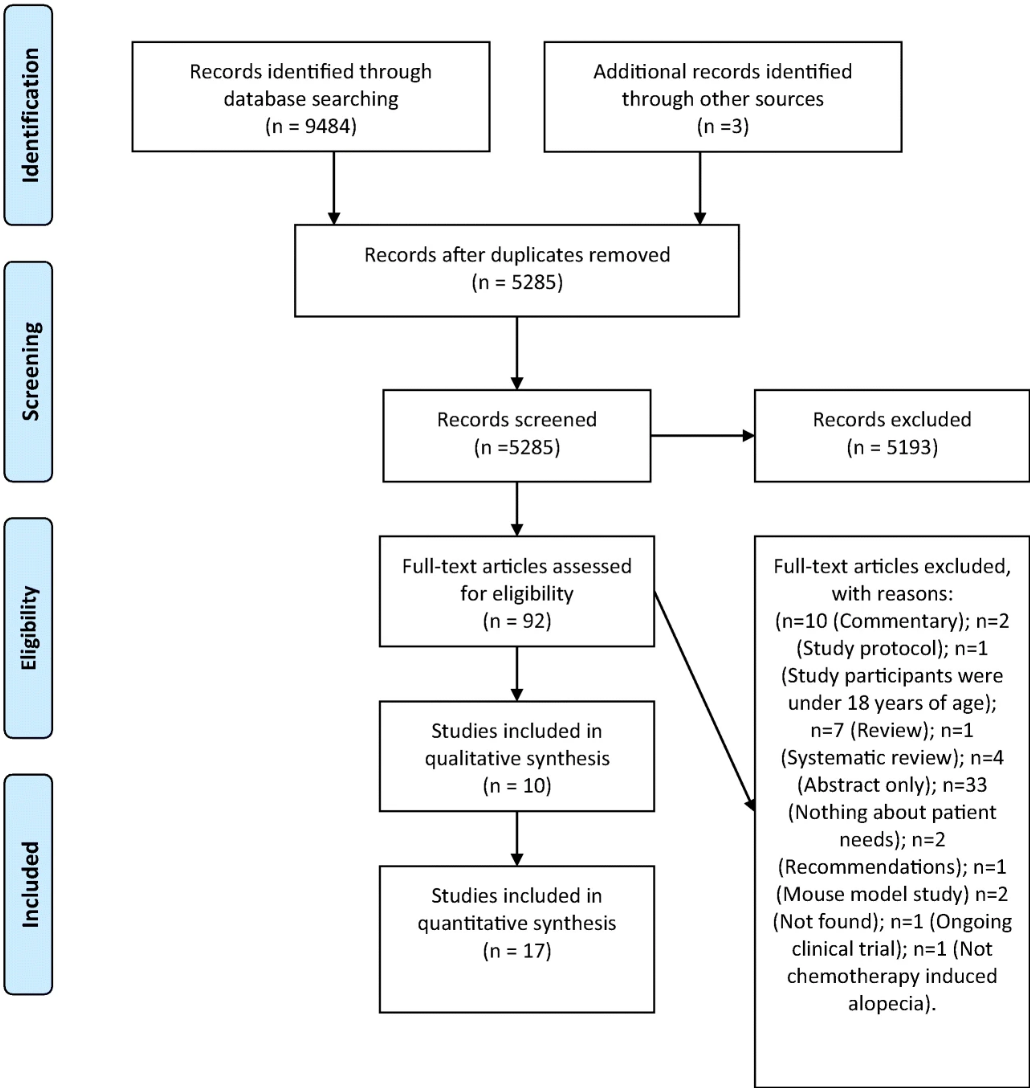
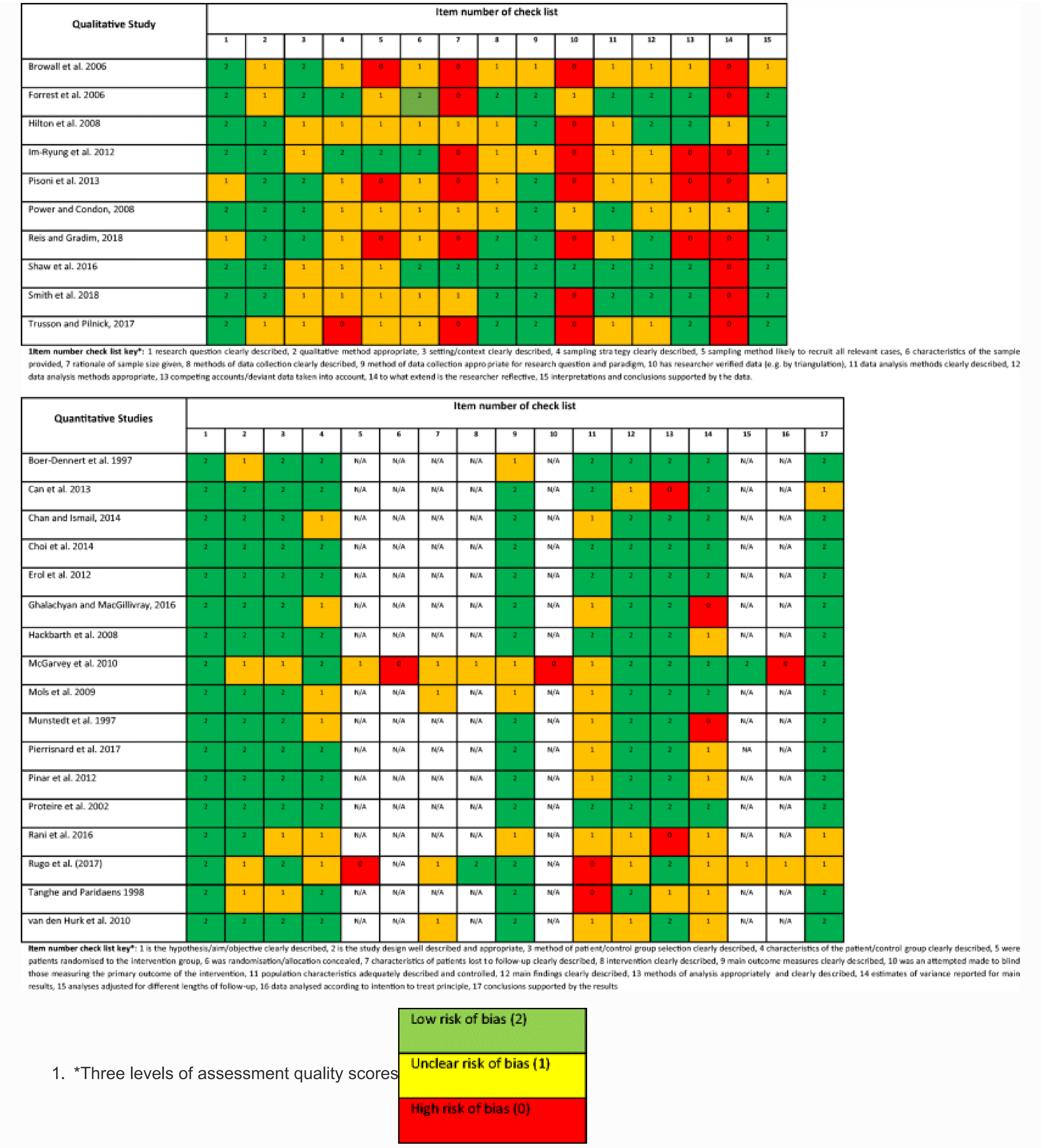


Table 2 Identifying the supportive care needs of men and women affected by chemotherapy-induced alopecia? A systematic review



Qualitative Study	Item number of check list														
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Browall et al. 2006	2	1	2	1	0	1	0	1	1	0	1	1	1	0	1
Forrest et al. 2006	2	1	2	2	1	2	0	2	2	1	2	2	2	0	2
Hilton et al. 2008	2	2	1	1	1	1	1	1	2	0	1	2	2	1	2
Im-Ryung et al. 2012	2	2	1	2	2	2	0	1	1	0	1	1	0	0	2
Pisoni et al. 2013	1	2	2	1	0	1	0	1	2	0	1	1	0	0	1
Power and Condon, 2008	2	2	2	1	1	1	1	1	2	1	2	1	1	1	2
Reis and Gradim, 2018	1	2	2	1	0	1	0	2	2	0	1	2	0	0	2
Shaw et al. 2016	2	2	1	1	1	2	2	2	2	2	2	2	2	0	2
Smith et al. 2018	2	2	1	1	1	1	1	2	2	0	2	2	2	0	2
Trusson and Pilnick, 2017	2	1	1	0	1	1	0	2	2	0	1	1	2	0	2

1Item number check list key*: 1 research question clearly described, 2 qualitative method appropriate, 3 setting/context clearly described, 4 sampling strategy clearly described, 5 sampling method likely to recruit all relevant cases, 6 characteristics of the sample provided, 7 rationale of sample size given, 8 methods of data collection clearly described, 9 method of data collection appropriate for research question and paradigm, 10 has researcher verified data (e.g. by triangulation), 11 data analysis methods clearly described, 12 data analysis methods appropriate, 13 competing accounts/deviant data taken into account, 14 to what extend is the researcher reflective, 15 interpretations and conclusions supported by the data.

Quantitative Studies	Item number of check list																
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
Boer-Dennert et al. 1997	2	1	2	2	N/A	N/A	N/A	N/A	1	N/A	2	2	2	2	N/A	N/A	2
Can et al. 2013	2	2	2	2	N/A	N/A	N/A	N/A	2	N/A	2	1	0	2	N/A	N/A	1
Chan and Ismail, 2014	2	2	2	1	N/A	N/A	N/A	N/A	2	N/A	1	2	2	2	N/A	N/A	2
Choi et al. 2014	2	2	2	2	N/A	N/A	N/A	N/A	2	N/A	2	2	2	2	N/A	N/A	2
Erol et al. 2012	2	2	2	2	N/A	N/A	N/A	N/A	2	N/A	2	2	2	2	N/A	N/A	2
Ghalachyan and MacGillivray, 2016	2	2	2	1	N/A	N/A	N/A	N/A	2	N/A	1	2	2	0	N/A	N/A	2
Hackbarth et al. 2008	2	2	2	2	N/A	N/A	N/A	N/A	2	N/A	2	2	2	1	N/A	N/A	2
McGarvey et al. 2010	2	1	1	2	1	0	1	1	1	0	1	2	2	2	2	0	2
Mols et al. 2009	2	2	2	1	N/A	N/A	1	N/A	1	N/A	1	2	2	2	N/A	N/A	2
Munstedt et al. 1997	2	2	2	1	N/A	N/A	N/A	N/A	2	N/A	1	2	2	0	N/A	N/A	2
Pierrisnard et al. 2017	2	2	2	2	N/A	N/A	N/A	N/A	2	N/A	1	2	2	1	NA	N/A	2
Pinar et al. 2012	2	2	2	2	N/A	N/A	N/A	N/A	2	N/A	1	2	2	1	N/A	N/A	2
Proteire et al. 2002	2	2	2	2	N/A	N/A	N/A	N/A	2	N/A	2	2	2	2	N/A	N/A	2
Rani et al. 2016	2	2	1	1	N/A	N/A	N/A	N/A	1	N/A	1	1	0	1	N/A	N/A	1
Rugo et al. (2017)	2	1	2	1	0	N/A	1	2	2	N/A	0	1	2	1	1	1	1
Tanghe and Paridaens 1998	2	1	1	2	N/A	N/A	N/A	N/A	2	N/A	0	2	1	1	N/A	N/A	2
van den Hurk et al. 2010	2	2	2	2	N/A	N/A	1	N/A	2	N/A	1	1	2	1	N/A	N/A	2

Item number check list key*: 1 is the hypothesis/aim/objective clearly described, 2 is the study design well described and appropriate, 3 method of patient/control group selection clearly described, 4 characteristics of the patient/control group clearly described, 5 were patients randomised to the intervention group, 6 was randomisation/allocation concealed, 7 characteristics of patients lost to follow-up clearly described, 8 intervention clearly described, 9 main outcome measures clearly described, 10 was an attempted made to blind those measuring the primary outcome of the intervention, 11 population characteristics adequately described and controlled, 12 main findings clearly described, 13 methods of analysis appropriately and clearly described, 14 estimates of variance reported for main results, 15 analyses adjusted for different lengths of follow-up, 16 data analysed according to intention to treat principle, 17 conclusions supported by the results

1. *Three levels of assessment quality scores

🟩 Low risk of bias (2)
🟨 Unclear risk of bias (1)
🟥 High risk of bias (0)

Table 3 Overview of the included studies

From: Identifying the supportive care needs of men and women affected by chemotherapy-induced alopecia? A systematic review

Author and year	Purpose	Country	Sample size, mean age (SD, years), gender	Participants	Sampling	Response rate	Design	Time points	Data collection tools
Boer-Dennert et al., 1997	To explore patients' experiences of the side-effects of chemotherapy	The Netherlands	$N = 181$ 50 (range 18–78) years $N = 101$ male, $N = 80$ women	Breast cancer $N = 50$, soft-tissue sarcoma $N = 26$, testicular cancer $N = 20$, small-cell lung cancer $N = 13$, ovarian cancer $N = 9$, mesothelioma $N = 7$, unclassified $N = 32$	Convenience	91.8%	Cross-sectional survey	One time point	Questionnaire designed to explore symptom severity. Reliability and validity not reported
Browall et al., 2006	To explore the perceptions of women affected by breast cancer opting for chemotherapy	Sweden	N = 20 $N = 12$ (55–60 years), $N = 8$ (61–70 years) All women	Not reported	Convenience	Not reported	Qualitative	One time point	Semi-structured interviews, audio-recorded and transcribed verbatim. Interviews lasted approximately 60 min
Can et al., 2013	To determine the incidence of chemotherapy-induced alopecia and how it affects body image and quality of life in Turkish men and women with cancer	Turkey	$N = 405$ 51.7 (SD 14.25, 18–80) years $N = 201$ men, $N = 204$ women	Men: primary $N = 134$, metastatic $N = 67$ Women: primary $N = 146$, metastatic $N = 58$ No further details reported	Convenience	96.4%	Cross-sectional survey	One time point	Patient Information Form, Body Image Scale, Nightingale Symptom Assessment

Chan and Ismail., 2014	To assess the most common side-effects of chemotherapy, patients' perceptions of the side-effects and informational needs	Malaysia	$N = 90$ majority 45–64 (SD not reported) years $N = 7$ male, $N = 83$ women	Not reported	Convenience	90.90%	Cross-sectional study	One time point	Demographic details, checklist of sides effect, questions to evaluate perceptions of CIA, and informational needs. Reliability and validity not reported.
Choi et al., 2014	To assess CIA distress and its impact on body image, psychosocial well-being and depression in patients with breast cancer	Korea	$N = 168$ 48.4 (SD 8.4) years All women	I (33.9%), II (44.6%), III (16.7%), unknown (4.8%) No further details reported	Convenience	77.2%	Cross-sectional study	One time point	EORTC C30 and BR25, CIDS, CADS, CES-D
Erol et al., 2012	To identify the effects of CIA on body image and QOL in Turkish women with cancer who were or were not wearing headscarves	Turkey	$N = 204$ 49.62 (SD 13.74, range 19–80) years All women	Not specified	Convenience	Not reported	Cross-sectional study	One time point	Patient Information Form, BIS, N-SAS, face-to-face administration of questionnaires, NCI CTCAE
Forrest et al., 2006	To explore children's experiences of their parent's cancer, and informational needs	England	$N = 37$ mothers; $N = 31$ children Mothers aged 46.2 (SD 5.9) years Children 12.3 (SD 4.6) years All women, gender of children not reported	Stages I–III breast cancer	Convenience	50.60%	Qualitative study	One time point	Semi-structured interviews, audio-recorded and transcribed verbatim.
Ghalachyan and MacGillivray, 2016	To understand headwear-related needs of women experiencing CIA	USA	$N = 51$ 57 (19–77) years All women	Not specified	Purposive	Not reported	Mixed methods	One time point	Semi-structured interviews, blog, online survey
Hackbarth et al., 2008	To determine the prevalence of dermatological morbidity in patients receiving chemotherapy for women's	Germany	$N = 91$ 59 (33–79) years All women	54.9% initial cancer manifestation, 45.1% cancer recurrence. $N = 39$ breast cancer, $N = 32$ ovarian cancer, $N = 12$	Convenience	Not reported	Prospective survey	Two time points	Patient clinical and demographic form, evaluation of dermatological lesions, NCI CTCAE,

	cancers and evaluate the impact on QOL			fallopian cancer, $N = 1$ vaginal cancer					EORTC C30,
Hilton et al., 2008	A comparison of young men and women's experiences of CIA	The UK	$N = 19$ 18 to 38 years $N = 11$ men, $N = 8$ women	$N = 7$ testicular cancer, $N = 1$ ewings sarcoma, $N = 1$ burkitts lymphoma, $N = 1$ non-Hodgkins lymphoma, $N = 2$ leukaemia, $N = 2$ breast cancer, $N = 1$ colorectal cancer, $N = 2$ ovarian cancer, $N = 2$ NHL	Maximum variation	Not reported	Qualitative study	One time point	Semi-structured interviews lasted between 40 and 50 min, transcribed verbatim. Thematic analysis.
Im-Ryung et al., 2012	To explore perceptions, attitudes and experiences of CIA in women affected by breast cancer	Korea	$N = 21$ patients 45.5 (29 to 64) years All women	$N = 17$ primary, $N = 2$ cancer recurrence	Purposive	Not reported	Qualitative study	One time point	Semi-structured interviews, thematic analysis. Interviews lasted 60–90 min
McGarvey et al., 2010	To evaluate the impact of computer-imaging programme to prepare women for CIA	The USA	$N = 25$ intervention group, $N = 20$ control group, Intervention 51.72 (SD 10.55) years control 50.85 (SD 10.31) years All women	Intervention group $N = 15$ breast, $N = 8$ ovarian, $N = 1$ blood $N = 1$ melanoma, Control group: $N = 13$ breast, $N = 3$ ovarian, $N = 2$ lung, $N = 1$ blood, $N = 1$ melanoma	Purposive	Not reported	Mixed methods	T1 baseline; T2 following hair loss; T3 3 months follow-up	Qualitative data questions "did you enjoy using the system?" "Are you glad that you were able to try the system?" Weighted bias questions. Demographic questionnaire. BSI 18, GSI, IHQ, The Brief Cope.
Mols et al., 2009	To explore the severity and burden of hair loss caused by CIA	The Netherlands	$N = 98$ scalp cooling, $N = 168$ non-scalp cooling. Scalp cooling group 49.8 (SD not reported) years Non-scalp cooling 49.7 (SD not reported) years	All breast cancer	Purposive	65% Response rate	Prospective longitudinal survey	T1 before chemotherapy, T2 3 weeks after chemotherapy, T3 6 months after chemotherapy	WHO four-point scale hair loss, Questionnaires designed to assess severity of hair loss, burden of hair loss, burden of scalp cooling, wig usage, hair re-growth and body image

			All women						(reliability and validity not reported)
Munstedt et al., 1997	To investigate which parts of body concept are altered with CIA	Germany	$N = 29$ 57.5 (28–74) years All women	$N = 25$ ovarian, $N = 1$ fallopian tube, $N = 1$ carcinoma abdominis, $N = 2$ endometrial cancer stages I–IV	Purposive	60%	Cross-sectional survey	One time point	Frankfurt body-concept scale, Frankfurt self-concept scale
Pierrisnard et al., 2017	To assess perceptions regarding bodily changes as a result of breast cancer treatment and informational needs	France	$N = 192$ $N = 5 < 35$, $N = 80$ 35–50, $N = 107 > 50$ years All women	All breast cancer	Convenience	0.83%	Cross-sectional survey	One time point	14-item online questionnaire. Reliability and validity not reported.
Pinar et al., 2012	To explore strain and helplessness in family caregivers of patients affected by gynaecological cancer receiving chemotherapy	Turkey	$N = 338$ patients, $N = 338$ family caregivers Patients 56.1 (SD 11.4, range 24–80) years Family caregivers 42.3 (SD 10.3, range 22–72) years Gender not reported	$N = 94$ cervix, $N = 102$ endometria, $N = 112$ ovarian, $N = 30$ other (vulvar, vaginal)	Convenience	Not reported	Cross-sectional survey	One time point	Patient Information Form, Caregiver Information Form, BHS, CCS, C-SAS
Pisoni et al., 2013	To identify the difficulties experienced by women with BC undergoing chemotherapy	Brazil	$N = 10$ 30–53 (SD not reported) years All women	All breast cancer	Convenience	Not reported	Qualitative study	One time point	Semi-structured interviews, transcribed verbatim.
Proteire et al., 2002	To report applicability and efficacy of scalp-cooling system in breast cancer patients receiving chemotherapy	France	$N = 105$ ($N = 77$ scalp cooling/$N = 28$ refused scalp cooling). $N = 109$ reference patients Scalp cooling 50 (25–73) years, no scalp cooling 49 (29–72) years, reference patients 49 (29–73) years All women	All breast cancer	Purposive	Not reported	Case-control study	One time point	Patient Information Form, WHO four-point scale hair loss, 3-item hair loss questionnaire. Reliability and validity not reported.

Power and Condon, 2008	To explore the lived experience of women affected by CIA	Ireland	$N = 5$ 37–56 years All women	All breast cancer	Purposive	Not reported	Qualitative study	One time point	Unstructured interviews lasted 60 min. Colizzi's analysis framework
Rani et al., 2016	To assess the effect of alopecia on perceived body image among breast cancer patients	India	$N = 60$ 38.4% aged 41–50 years (no further date reported) All women	Not specified	Convenience	Not reported	Qualitative study	One time point	Patient Information Form, Modified Body Image Scale, WHO four-point scale hair loss
Reis and Gradim, 2018	To explore the meaning of alopecia for women undergoing chemotherapy	Brazil	$N = 13$ 49 years (SD not reported) All women	All breast cancer	Convenience	Not reported	Qualitative study	One time point	Semi-structured interviews recorded and transcribed verbatim. Thematic analysis
Rugo et al., (2017)	To explore experiences of scalp cooling and CIA in women affected by breast cancer	USA	$N = 122$ ($N = 106$ scalp cooling, $N = 16$ control group) 53 (28–77) years All women	All breast cancer	Purposive	92.4%	Cohort study	T 1 last chemotherapy cycle, T 2 after completion of chemotherapy	EORTC C30 and BR23, Common Terminology Criteria for Adverse Events, hair photographs
Shaw et al., 2016	To explore patients' perceptions and experience of scalp cooling	Australia	$N = 17$ 55.2 (43–74) years All women	All breast cancer	Convenience	Not reported	Qualitative study	One time point	Four focus groups and three interviews. Transcribed verbatim, thematic analysis
Smith et al., 2018	To explore perceptions of women affected by breast cancer opting for chemotherapy	Australia	$N = 25$ 50 (35–64) years All women	All breast cancer	Purposive	Not reported	Qualitative study	One time point	Five focus groups, duration 57 min. Thematic analysis, constant comparative methodology
Tanghe and Paridaens, 1998	To explore symptom occurrence and Distress associated with CIA	Belgium	$N = 189$ patients, $N = 51$ nurses 53 (SD 14.61) years $N = 148$ women and $N = 41$ men	$N = 103$ breast cancer, $N = 30$ lymphoma, $N = 25$ ovarian, $N = 31$ other	Convenience	58.5%	Cross-sectional survey	One time point	The Adapted Symptoms Distress Scale
Trusson and Pilnick, 2017	Describe women's experiences with CIA	UK	$N = 24$ 54 (42–80) years All women	All breast cancer	Purposive	Not reported	Qualitative study	One time point	Semi-structured interviews, transcribed verbatim, thematic analysis
	To explore experiences of scalp cooling		$N = 98$ scalp-cooled patients, $N = 168$ non-				Prospective	Time 1: before chemotherapy; time 2 3 weeks	WHO Four-point scale hair loss, Psychophysical

Table 3 Identifying the supportive care needs of men and women affected by chemotherapy-induced alopecia? A systematic review

van den Hurk et al., 2010	and CIA in women affected by breast cancer.	Denmark	scalp-cooled 49 years (SD not reported) years All women	All breast cancer	Purposive	Not reported	longitudinal survey	after chemotherapy; time 3 6 months after chemotherapy	Scaling Method, EORTC C30 and BR23, BIS, MBA, HADS

1. *BIS*, Body Image Scale; *BSI*, Brief Symptom Inventory; *BHS*, Beck Hopelessness Scale; *CIA*, chemotherapy-induced alopecia; *CADS*, Chemotherapy-Induced Alopecia Distress Scale; *CSS*, Caregiver Strain Scale; *CED-S*, Centre for Epidemiological Studies Depression Scale; *HADS*, Hospital Anxiety and Depression Scale; *QOL*, quality of life; *EORTC C30*, European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 and Breast Module BR23; *GSI*, Global Severity Index; *IHQ*, Importance of Hair Questionnaire; *N-SAS*, Nightingale Symptom Assessment Scale; *N-ASDS*, The Adapted Symptom Distress Scale; *NCI CTCAE*, National Cancer Institute Criteria; *MBA*, Measure of Body Appreciation; *WHO*, World Health Organisation for Hair Loss

Table 4 Frequency of unmet needs by domain

From: Identifying the supportive care needs of men and women affected by chemotherapy-induced alopecia? A systematic review

Study	Physical needs	Psychological/emotional needs	Cognitive needs	Patient-clinician communications needs	Health system needs	Spiritual needs	Daily living needs	Interpersonal/intimacy needs	Practical needs	Family-related needs	Social needs	Number of domains explored within each study
Boer-Dennert et al., 1997			-	-	-	-	-	-	-		-	3
Browall et al., 2006	-		-	-	-	-	-		-		-	3
Can et al., 2013			-	-	-	-	-		-		-	4
Chan and Ismail., 2014	-		-			-	-	-	-	-	-	3
Choi et al., 2014				-	-	-	-	-	-	-		4
Erol et al., 2012			-	-	-	-			-	-		5
Forrest et al., 2006	-		-			-	-	-	-		-	4
Ghalachyan and MacGillivray, 2016			-	-		-		-		-		6
Hackbarth et al., 2008		-	-	-	-	-		-	-	-	-	2
Hilton et al., 2008			-	-		-				-		7
Im-Ryung et al., 2012												11
McGarvey et al., 2010			-	-	-	-	-	-			-	4
Mols et al., 2009			-	-	-	-	-				-	5
Munstedt et al., 1997			-	-	-	-	-		-	-	-	3
Pierrisnard et al., 2017	-		-		-	-	-	-	-	-	-	2
Pinar et al.,												

2012			-	-	-	-	-	-			-	4
Pisoni et al., 2013	-		-	-	-		-	-	-		-	3
Proteire et al., 2002	-		-	-	-	-	-	-	-	-	-	1
Power and Condon, 2008				-		-						8
Rani et al., 2016			-	-	-	-	-		-	-	-	3
Reis and Gradim, 2018		-	-	-		-	-	-	-			4
Rugo et al., (2017)	-		-	-	-	-	-		-	-	-	2
Shaw et al., 2016						-		-		-	-	7
Smith et al., 2018						-	-					9
Tanghe and Paridaens, 1998			-	-	-	-	-	-	-	-	-	2
Trusson and Pilnick, 2017				-	-	-	-	-	-	-		4
van den Hurk et al., 2010	-		-	-	-	-	-	-		-	-	2
Total number of domains across studies	19	25	5	6	9	2	7	11	10	12	9	115

Supplementary Table 2 Unmet supportive care needs

Author and Year	Physical Needs	Psychological/Emotional Needs	Cognitive Needs	Patient-Clinician Communication Needs	Health System/Information Needs	Spiritual Needs	Daily Living Needs	Interpersonal/intimacy Needs	Practical Needs	Family Related Needs	Social Needs
Boer-Dennert et al., 1997	Patients ranked nausea, vomiting and hair loss as the most distressing side-effects	Compared to men women ranked hair loss significantly higher than vomiting (p<0.001) and they ranked depression and anxiety higher than men (p<0.001). Males ranked hair loss top 3rd ranked distressing symptoms and females ranked hair loss top 2nd most distressing symptoms.	Not reported	Not reported	Not reported	Not reported	Not reported	Not reported	Not reported	Patients receiving doxorubicin regimes reported hair loss as the most distressing experience compared to other regimes. Patients expressed much more concern on the impact of CIA on their families and partners.	Not reported
Browall et al., 2006	Not reported	Women were afraid of what the treatment would do to their looks (hair loss) and this made them feel even sicker psychologically. One woman expressed more fear about the treatment than the illness itself. Patients articulated that it was psychologically extremely painful losing their hair and described CIA as being worse than losing a breast.	Not reported	Not reported	Not reported	Not reported	Not reported	Women were afraid that the disease and its consequences would change their normalcy and identity to become a cancer case.	Not reported	It was more difficult for the spouses to cope with the impact of cancer and treatment than for the women themselves.	Not reported
Can et al., 2013	Physical well-being was lower in men and women with partial or complete CIA.	Psychological well-being was lower in men and women with partial or complete CIA compared to men and women without CIA. Men affected by partial CIA their body image scores were lower than those with complete CIA. Body image scores were lower for younger patients that older patients (p=0.001). Body image was also lower for those with a lower income compared to those with a higher income (p=0.001).	Not reported	Not reported	Not reported	Not reported	Not reported	No difference in body image scores between men and women in respect of degree of CIA. The higher degree of CIA was associated with lower body image in both men and women.	Not reported	Not reported	Social well-being was lower in men and women with CIA compared to men and women without CIA.

Author and Year	Physical Needs	Psychological/Emotional Needs	Cognitive Needs	Patient-Clinician Communication Needs	Health System/Information Needs	Spiritual Needs	Daily Living Needs	Interpersonal/intimacy Needs	Practical Needs	Family Related Needs	Social Needs
Chan and Ismail, 2014	Not reported	10% of patients were worried about hair loss.	Not reported	54% of all patients reported that information about chemotherapy-related side effects was important to them.	Patients wanted more information about side-effects and how to manage these.	Not reported	Not reported	Not reported	Not reported	Not reported	Not reported
Choi et al. 2014	Women with severe CIA distress reported lower physical well-being (P<0.001).	Women with high CIA distress was statistically associated with higher depression scores (P<0.001). After adjusting for clinical and demographic variables, body image, overall health, psychosocial well-being and depression was associated with severe CIA distress (P<0.001).	Women with severe CIA distress reported reduced cognitive functioning (P<0.001).	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Women with severe CIA distress reported lower social functioning (P<0.001).
Erol et al., 2012	Subgroup analysis for women who had alopecia had lower physical and total well-being than the women who had no Alopecia.	Psychological and total well-being scores were lower for women wearing head scarves compared to women who did not wear a head scarf.	Not reported	Not reported	Not reported	Not reported	More than half (53.9%) of the patients wore headscarves during their daily life.	Body image scores were statistically associated with the degree of CIA.	Not reported	Not reported	Women with alopecia had lower social well-being than women without alopecia, independently of wearing/not wearing a headscarf.
Forrest et al. 2006	Not reported.	Children often said that chemotherapy, with its debilitating side effects and hair loss were the worst aspect of their mother's treatment. Hair loss was a key issue for children psychologically.	Not reported	Children felt excluded from the nurse or doctor caring for their mother. Older children reported that they wanted more information about the cancer and the therapy regimes.	Women articulated that they received enough information but were confused in how much information to give to their children due to fear of upset. Children also would have benefited from more information and preparation because the early hospital experience and CIA was distressing and frightening.	Not reported	Not reported	Not reported	Not reported	Children found it difficult and distressing seeing their mothers with wigs because they no longer looked like their mothers. Children were also concerned when their mothers became tearful in front of the mirror.	Not reported

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Ghalachyan and MacGillivray, 2016	Hair loss was a difficult physical consequence of treatment for the women.	Women emphasised the importance for headwear not to look like a “cancer hat”.	Not reported	Not reported	Fit, comfort, style, visual appeal, thermal properties, shape and colour were rated as important features of headwear.	Not reported	77.5% of the respondents wore wigs, 72.5% wore hats, 52.5% wore scarves, 20% wore nothing and 5% wore other types of headwear.	Not reported	The findings showed that women were not adequately satisfied with their chemotherapy headwear and the current marketplace for it.	Not reported	Women valued headwear which helped them blending in with society to preventing stares and assumptions. Concealing illness was important.
Hackbarth et al., 2008	Some reported CIA as the most unpleasant consequence of treatment.	Not reported	Not reported	Not reported	Not reported	Not reported	A considerable number of patients reported that alopecia severely limited their daily activities.	Not reported	Not reported	Not reported	Not reported
Hilton et al., 2008	Young men and women described experiences of significant hair loss in detail, such as finding hair on the pillow or losing handful of hair when they washed their hair.	Young men appeared to have as much difficulties adjusting to CIA and to other people’s reactions as women. The experience of CIA was also associated with the public acknowledgement of being ill "reality". CIA caused feelings of vulnerability. CIA transformed their identity to that "being a cancer patient" and for some negative perceptions from others related to pity, disgust and thinking that they "looked unclean".	Not reported	Not reported	Women articulated that they did not feel that they had enough information and felt ill prepared for the other people's reactions to their altered and more androgynous appearance.	Not reported	Both men and women articulated that they experienced CIA and none felt prepared to deal with the reality.	Some men were concerned about looking less macho, or more childlike and vulnerable with no hair. The most striking comparison in men and women’s experiences of CIA was that only men spoke about hair loss from other parts of the body (arm hair public hair, arm and legs and toes hair) and this was linked to difficulties when starting a new relationship. Women did not comment on hair loss below their eyes. Men articulated that their hair was part of their identity.	Men and women spoke about their efforts to cover up hair loss describing wearing hats, wigs and scarves but only women spoke about receiving encouragement by others in strategies to cover/disguise their hair loss. People reactions ranged from the practicalities of having to clear up their hair loss to the emotional turmoil of clumps of hair falling out.	Not reported	Both men and women voiced worries about being perceived as aggressive, threatening or a "skin head". Dominant theme was that CIA forced them to confront their cancer experience publicly and signified a lack of control for both men and women.

Author and Year	Physical Needs	Psychological/Emotional Needs	Cognitive Needs	Patient-Clinician Communication Needs	Health System/Information Needs	Spiritual Needs	Daily Living Needs	Interpersonal/intimacy Needs	Practical Needs	Family Related Needs	Social Needs
Im-Ryung et al. 2012	Physical distress caused by CIA included: irritation, soreness and pain on scalp, dryness inside the nose, difficulty to open eyes and difficulties urinating. Participants classified wearing a wig as a physical burden. Nose pain caused by the mucus due to lost nostril hair and eye dryness due to loss of eyelashes.	Psychological distress caused by CIA included: being sad, depressed, frightened, low self-esteem, guilt feeling about past behaviours, impact of perceptions and attitudes of other people. Participants said the CIA was the most traumatizing and painful experience that was beyond their imagination. Most participants described CIA as disturbing and they never wanted to experience it again. 11/15 (73.3%) broke into tears while expressing the psychological impact that CIA had on them. Women articulated it was frightening and depressing seeing their hair fall out each morning and experienced a loss of self-esteem. For many of them it was the moment that they add to admit to themselves that they had cancer. Patients were distressed that they thought that their hair would not grow back.	Active coping strategies included concealing using hats, wigs, scarves, passive strategies to minimise social interactions with people.	Lack of preparedness and coping strategies for CIA, with limited information about CIA and how to manage it. They reported a lack of appropriate support and attention from medical staff. Patients were given information about the side-effect of CIA, but none received any practical support to help with their self-management of CIA.	Women reported limited information about CIA, most patients received information from mass media outlets like the internet. No health system information was provided to them. Most patients looked for information and purchased wigs or hats once their hair started to fall out instead of planning ahead. Some patients bought wigs based upon shop owners advise and that they did not know enough information about the condition of their scalp.	Baldness represented being sick and new hair represented hope and renewed life.	Limits daily activities (shopping, exercise and childcare). Need to conceal alopecia at workplaces and in community. Economic burden. Wigs required a lot of care with washing and drying. Loss of privacy and limitations in daily activities.	Some patients never bothered about their looks or appearance, until after their experience CIA.	Patients reported that discomfort with the wigs or hats for more intense when raining, windy or hot. Patient experienced more discomfort and distress in summer than in winter.	Patients who had children wore wigs even at home in case their children's friends visited because of fear of teasing from other children. Patients with emotional support from their family members helped, especially from spouses, although women could be easily hurt by what family members said about alopecia.	Patients wore their wigs for work and formal occasions. Specifically, people reactions such as avoidance or sympathy made patients feel down and prevented them from enjoying a good social life. Patient would rather stay home that facing people in public settings due to CIA distress.
McGarvey et al., 2010	Physically trying on wigs and changing hair styles was as difficult and exhausting.	CIA caused psychological distress. Avoidance coping was positively correlated with hair loss distress (r=0.3, p=0.03)	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Not reported.	Estimated costs for the HAAIR intervention was $5000. Women would have found having the opportunity to try on more wigs helpful and the opportunity	Having a family member during the process of trying on wigs to provide feedback and support was important to women.	Not reported

									to add eyebrows.		
Author and Year	**Physical Needs**	**Psychological/Emotional Needs**	**Cognitive Needs**	**Patient-Clinician Communication Needs**	**Health System/Information Needs**	**Spiritual Needs**	**Daily Living Needs**	**Interpersonal/intimacy Needs**	**Practical Needs**	**Family Related Needs**	**Social Needs**
Mols et al., 2009	The loss of hair, eyelashes and eyebrows was a physical burden to patients.	Hair loss caused significant psychological distress. All participants coped with CIA by camouflaging and hiding, and patients concealed hair loss in public to hide the visual stigma. CIA constantly reminded them that they had cancer. CIA also caused stress.	Not reported	Not reported	Not reported	Not reported	Not reported	71% of the participants stated hair loss made them feel unattractive and 58% of the patients stated that hair loss was a problem for them. Even though hair loss was temporary it was still a burden to them.	Most of the participants either used a wig, scarf, cap or a hat to cover up their hair loss. Some reported that a wig caused skin irritation. Other practical problems included the costs associated with a wig.	All most all of the participants relied on family support.	
Munstedt et al., 1997	Patients had significantly lower state of health, physical fitness after CIA.	46% of patients perceived CIA as the most troublesome and traumatic side effect of chemotherapy. Patients had significantly lower self-esteem than before the treatment. Self-esteem and self-concept were also lower 6-8 months after the completion of the treatment, compared to pre-treatment scores.	Not reported	Not reported	Not reported	Not reported	Not reported	13.3% of the women were afraid they will be rejected by their partners before treatment, only 1 person (3.3%) reported feeling rejected during the treatment.	Not reported	Not reported	Not reported
Pierrisnard et al. 2017	Not reported	Participants experienced fear of the opinions of others (52%) and anxiety (31%).	Not reported	26% of the participants felt that they needed additional information about alopecia.	Not reported	Not reported	Not reported	Not reported	Not reported	Not reported	Not reported
Pinar et al. 2012	Across all the patients 92.8% experienced hair loss and 20.7% reported bother from CIA.	Family caregiver's experienced mild levels of hopelessness. Patients experienced feelings of vulnerability, loss of control and uncertainly as a result of CIA.	Not reported	Not reported	Not reported	Not reported	Not reported	Not reported	Family caregivers identified financial and hidden costs of cancer that may affect caregiver burden. Family caregivers with lowers levels of personal and social support experienced higher levels of distress.	The mean duration of caregiving was 54.1 months with average caregiving hours reported as 6.8, range 4 to 24 hours per day. Caregivers tasks included: dressing/bathing, transportation, managing finances or bills, preparing meals, feeding, administering	Not reported

										medications injections and shopping.	
Author and Year	**Physical Needs**	**Psychological/Emotional Needs**	**Cognitive Needs**	**Patient-Clinician Communication Needs**	**Health System/Information Needs**	**Spiritual Needs**	**Daily Living Needs**	**Interpersonal/intimacy Needs**	**Practical Needs**	**Family Related Needs**	**Social Needs**
Pisoni et al. 2013	Not reported.	CIA caused the women significant distress.	Not reported.	Not reported.	Not reported.	Women experienced a sense of hopelessness and used spirituality as a coping mechanism.	Not reported.	Not reported.	Not reported.	Family support was critical during the experience of CIA.	Not reported.
Power and Condon, 2008	Importance of physical hair was major theme.	All participants experienced trauma associated with CIA. Three women did not appreciate the significance of their hair until they lost it. Women needed support even through time of hair re-growth. Even after hair re-growth women continued to experience anxiety and problems with confidence and self-esteem issues. Feelings of shame/lack of confidence/feeling different were common.	Not reported	Not reported	Much of the distress was due to the lack of information provided to patients by healthcare professionals about CIA.	Not reported	The daily living with a wig impacted life.	Women mourned the loss of their hair and wondered if they would be the same ever again. One woman spoke of concerns about the loss of her pubic hair which posed a serious threat to her sexuality and femininity.	All participants stressed the importance of taking the time to choose a suitable wig.	All the women considered protecting their children from the impact of CIA. Women also found support groups helpful as they were able to disclose feelings that they could not have shared with their family. All participants considered formal and informal support as important to help cope with CIA.	All participants spoke of their relationship with the wig, it was uncomfortable and associated with feelings of awkwardness. Despite the negative feelings towards the wig they endured it to be accepted into society.
Proteire et al., 2002	Not reported	High severity of distress was caused by alopecia	Not reported	Not reported	Not reported	Not reported	Not reported	Not reported	Not reported	Not reported	Not reported
Rani et al. 2016	Perceived physical appearance was reportedly the most affected by CIA.	Participants used different coping strategies to manage the experience of CIA.	Not reported	Not reported	Not reported	Not reported	Not reported	CIA affected intimacy with their partner and perceived body image.	Not reported.	Not reported.	Not reported.
Reis and Gradim, 2018	Hiding alopecia by wearing a wig was important.	Not reported	Not reported	Not reported	Referring to support groups was important, and women felt that this information should come from the healthcare team. Lack of information about alopecia	Not reported	Not reported	Not reported	Not reported	Patients needed help and care from family and friends.	Participants expressed the societal stigma around alopecia was difficult.
Rugo et al., (2017)	Not reported	Scalp-cooling intervention improved quality of life domains 1 month after treatment. Women were upset about their hair loss.	Not reported	Not reported	Not reported	Not reported	Not reported	105 women responded "quite a bit or very much" to feeling less feminine as a result of disease or treatment and found it difficult to look at themselves naked; women were	Not reported	Not reported	Not reported

								upset about their hair loss.			
Author and Year	**Physical Needs**	**Psychological/Emotional Needs**	**Cognitive Needs**	**Patient-Clinician Communication Needs**	**Health System/Information Needs**	**Spiritual Needs**	**Daily Living Needs**	**Interpersonal/intimacy Needs**	**Practical Needs**	**Family Related Needs**	**Social Needs**
Shaw et al. 2016	Scalp-cooled participants reported a range of hair loss experiences. Scalp-cooled participants also highlighted the level of pain and discomfort associated with scalp cooling was greater than they had expected. Although none of the participants reported significant side effects such as headaches, several reported pain, anxiety and length of treatment as issues. from thinning of hair to considerable or complete hair loss.	Optimism and wishful thinking were the primary motivators driving participant expectations. Not surprisingly, many scalp-cooled participants described the distress they experienced when their hair started to fall out and gave graphic accounts of when they realised that they were losing their hair. Participants reported less shock and were more likely to actively control hair loss by shaving their head once hair loss commenced.	For a small number of participants, a consequence of their high expectations was anxiety and hyper vigilance around hair care and hair loss	Hair care was also a source of stress for some scalp-cooled participants as many perceived that they had insufficient information about the types of products to use or how often they should wash their hair to minimise hair loss. They also expressed a need for information to give their hairdressers, as they were also unaware of how to care for hair during scalp cooling.	They also received little information from either the oncologist or the nursing staff about how to care for their hair during treatment or information that could be given to hairdressers. A number of the non-scalp-cooled participants reported the option was not presented as part of their treatment decision-making. These participants generally became aware of scalp cooling through other patients, and three were offered the option but declined.	Not reported	Women were able to disguise. Participants highlighted the need for greater patient education and more detailed written information outlining what to expect when undergoing scalp cooling.	Not reported	Experiences of scalp cooling confirmed the technology to be an acceptable supportive care intervention for hair loss	Not reported	Not reported
Smith et al. 2018	Eyebrows created definition and structure to their face and eyelashes were important part of femininity. Eyebrows and eyelashes were important facets in expression. Increased tearing, associated dryness, irritated eyes were common complaints. Women found it difficult to be outside because of the risk of debris or foreign particles entering their eyes. This discomfort resulted in women wearing protective glasses while outside. Growth of eyelashes was associated with pruritis (prickling or tingling of the eyelid).	The loss of eyebrows and eyelashes caused significant distress. Other found the discussion of ongoing toxicities of chemotherapy distressing. Loss of eyebrows and eyelashes was a visible reminder of cancer. Women experienced a lack of self-confidence.	Women's understanding of madarosis was limited.	Multiple women falsely believed that scalp cooling would prevent madarosis as well as alopecia which resulted in significant distress when their eyebrows and eyelashes fell out. Patients would have valued more information.	No participants were aware of the possible delay between alopecia and madarosis, all reported incorrect assumption that hair loss would occur simultaneously. They received little if any information upfront regarding madarosis and felt unprepared when it did occur.	Not reported	Not reported	Women felt a lack of connection with their appearance, and unable to associate with or recognise their reflection.	Eyebrow pencils, eyeliner and eye shadow were used to enhance areas of patchy hair loss or to replicate eyebrows in case of complete madarosis. Most women reported dissatisfaction of cosmetic results. Artificial eyelashes were not successful due to the requirement to adhere to existing eye lashes.	Women felt that madarosis was no concern to their family in contrast to the experience of CIA, which impacted negatively on their relationships, particularly their younger children.	Women reported a change in appearance resulted in decreased ability to communicate with others. Women described avoidance of going outside the home, making purposeful decisions to avoid public areas and unnecessary social interactions. This impacted the way that women socialised in the broader community.

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Tanghe and Paridaens 1998	Patients (86%) and nurses (80%) reported alopecia as the most frequent observable physical symptom.	Patients reported alopecia and mouth problems as the continuously observable symptoms causing the most distress.	Not reported	Not reported	Not reported	Not reported	Not reported	Not reported	Not reported	Not reported	Not reported
Trusson and Pilnick, 2017	When women were seen without hair, they believed it affected how they were perceived by other people.	Most women who lost their hair found it more distressing and upsetting than the mastectomy.	Some women found benefit CIA because they perceived that their chemotherapy was working to get rid of their cancer.	Not reported	Not reported	Not reported	Not reported	Not reported	Not reported	Not reported	Women found it difficult going out in their local communities.
van den Hurk et al. 2010	Not reported	Patients expressed that CIA was one of the most distressing problems during and after treatment.	Not reported	Not reported	Not reported	Not reported	Not reported	Not reported	Scalp cooling was considered effective in terms of no need of head covering in 32 of 62 evaluable patients (52%).	Not reported	Not reported