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 trial 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 (17) 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 sequelae associated with CIA.

Keywords 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 the twenty-first 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 psychosocial 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 experiences 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 the same supportive care interventions, to cope with the distress of CIA, as they provide to 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 11 primary domains of need [2]. 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 is informed by the Supportive Care Needs Framework [27] (see Table 1 for supportive care needs classification).

Literature search

The CINAHL, MEDLINE, PsychINFO, Scopus and Cochrane (CCTR and CDSR) controlled trial 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 [28].

### 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 has been used in a similar systematic review [2]. The quantitative appraisal tool assessed a range of designs including the following: randomised controlled trials (RCT), non-RCT, cohort, case-control and 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 [29].
Results

Of the 5285 publications retrieved from the search, 5193 were excluded following the application of the inclusion/exclusion criteria (see Fig. 1). The remaining 92 publications were 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, 30–36], qualitative study [12, 20, 23, 37–44], mixed methods [45, 46], prospective longitudinal survey [47–49], case-control study [50] and cohort study [51]. 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 ($n = 2$), the UK ($n = 3$), the USA ($n = 3$), 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, 30, 31, 36] 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, 23, 30–33, 35, 36, 40–48]. Across the majority of the studies, the participants ranked hair loss as one of the most distressing side-effects of chemotherapy [30, 35, 40, 41, 47] which resulted in decreased physical well-being [13, 24, 32, 33]. 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

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**Fig. 1** Results of PRISMA

**PRISMA 2009 Flow Diagram**

- Records identified through database searching ($n = 9484$)
- Additional records identified through other sources ($n = 3$)
  - Records after duplicates removed ($n = 5285$)
  - Records screened ($n = 5285$)
  - Records excluded ($n = 5193$)
  - Full-text articles assessed for eligibility ($n = 92$)
    - Studies included in qualitative synthesis ($n = 10$)
    - Studies included in quantitative synthesis ($n = 17$)
  - Full-text articles excluded, with reasons:
    - $n = 10$ (Commentary); $n = 2$ (Study protocol); $n = 1$ (Study participants were under 18 years of age); $n = 7$ (Review); $n = 1$ (Systematic review); $n = 4$ (Abstract only); $n = 33$ (Nothing about patient needs); $n = 2$ (Recommendations); $n = 1$ (Mouse model study); $n = 2$ (Not found); $n = 1$ (Ongoing clinical trial); $n = 1$ (Not chemotherapy induced alopecia).
caused by CIA included soreness and pain on the scalp, skin and eye irritation and dryness inside of the nose [12, 43, 48]. Patients also described the experience of wearing a wig as a physical burden [12, 46] which was difficult and exhausting due to trying on multiple wigs [46]. Some women wore protective glasses while outside to prevent debris entering their eyes due to the loss of their eye lashes [43]. The experience of re-growth of eyelashes was associated with pruritis [43].
| 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 (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 (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 (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 side effects, 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 (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 (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 | Stages I-III breast cancer                                                    | Convenience 50.60% | Qualitative study | One time point | Semi-structured interviews, audio-recorded and transcribed verbatim. |
| Author and year     | Purpose                                                                 | Country         | Sample size, mean age (SD, years), gender | Participants                                                                 | Sampling       | Response rate | Design         | Time points | Data collection tools                                                                 |
|--------------------|--------------------------------------------------------------------------|-----------------|------------------------------------------|-------------------------------------------------------------------------------|----------------|---------------|----------------|-------------|--------------------------------------------------------------------------------------------|
| Ghalachyan and     | 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                                          |
| MacGillivray, 2016 |                                                                          |                 |                                           |                                                                               |                |               |                |             |                                                                             |
| Hackbarth et al.,  | To determine the prevalence of dermatological morbidity in patients      | Germany         | N=91 59 (33–79) years All women           | 54.9% initial cancer manifestation, 45.1% cancer recurrence, N= 39 breast cancer, | Convenience    | Not reported  | Prospective survey | Two time points | Patient clinical and demographic form, evaluation of dermatological lesions, NCI CTCAE, EORTC C30, |
| 2008               | receiving chemotherapy for women’s cancers and evaluate the impact on QOL |                 |                                           | N = 32 ovarian cancer, N = 12 fallopian cancer, N = 1 vaginal cancer             |                |               |                |             |                                                                             |
| Hilton et al., 20  | 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 | Maximum variation | Not reported  | Qualitative study | One time point | Semi-structured interviews lasted between 40 and 50 min, transcribed verbatim, thematic analysis. |
| 8                  |                                                                          |                 |                                           | non-Hodgkins lymphoma, N = 2 leukaemia, N = 2 breast cancer, N = 1 colorectal cancer, N = 2 ovarian cancer, N = 2 NHL |                |               |                |             |                                                                             |
| Im-Ryung et al.,   | To explore perceptions, attitudes and experiences of CIA in women         | 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. |
| 2012               | affected by breast cancer                                                |                 |                                           |                                                                               |                |               |                |             |                                                                             |
| McGarvey et al.,   | To evaluate the impact of computer-imaging programme to prepare women    | 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. |
| 2010               | for CIA                                                                  |                 |                                           |                                                                               |                |               |                |             |                                                                             |
| 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. | All breast cancer                                                              | Purposive      | 65% Response rate | Prospective longitudinal survey | T1 before chemotherapy, T2 3 weeks after | WHO four-point scale hair loss, Questionnaires |
|                   |                                                                          |                 |                                           |                                                                               |                |               |                |             |                                                                             |
| Author and year | Purpose | Country | Sample size, mean age (SD, years), gender | Participants | Sampling | Response rate | Design | Time points | Data collection tools |
|----------------|---------|---------|------------------------------------------|-------------|----------|--------------|--------|-------------|---------------------|
| 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 | 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 | | India | N=60 Not specified | All women | Convenience | Not reported | | One time point | |
| Author and year       | Purpose                                                                 | Country          | Sample size, mean age (SD, years), gender | Participants | Sampling   | Response rate | Design                  | Time points                                      | Data collection tools                                                                 |
|-----------------------|--------------------------------------------------------------------------|------------------|------------------------------------------|--------------|------------|---------------|-------------------------|------------------------------------------------|-----------------------------------------------------------------------------------------|
| To assess the effect of alopecia on perceived body image among breast cancer patients |                                                                           |                  | 38.4% aged 41–50 years (no further date reported) | All women   | Qualitative study |               |                         | Patient Information Form, Modified Body Image Scale, WHO four-point scale hair loss |
| Reis and Gradim, 2018 | To explore the meaning of Brazil alopecia for women undergoing chemotherapy | Brazil           | N = 13, 49 years (SD not reported)        | All women   | 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) | 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 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 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          | Convenience | Cross-sectional survey | 58.5% | One time point | The Adapted Symptom Distress Scale                   |
| Trusson and Pilnick, 2017 | Describe women’s experiences with CIA                                      | UK               | N = 24, 54 (42–80) years                | All breast cancer | Purposive | Not reported | Qualitative study | One time point                                      | Semi-structured interviews, transcribed verbatim, thematic analysis |
| van den Hurk et al., 2010 | To explore experiences of scalp cooling and CIA in women affected by breast cancer. | Denmark          | N = 98 scalp-cooled patients, N = 168 non-scalp-cooled 49 years (SD not reported) | All breast cancer | Purposive | Not reported | Prospective longitudinal survey | Time 1: before chemotherapy; time 2 3 weeks after chemotherapy; time 3 6 months after chemotherapy | WHO Four-point scale hair loss, Psychophysical Scaling Method, EORTC C30 and BR23, BIS, MBA, HADS |

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.
Psychological needs

Emotional needs were consistently reported across 25 of the included studies. Women ranked hair loss as the second most distressing symptom, whereas men ranked hair loss as the third most distressing symptom [30]. 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 [37, 44]. Psychological well-being scores were consistently lower in both men and women for those affected by partial or complete hair loss [24, 32]. 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 [38]. Children expressed distress at observing the side-effects of chemotherapy, and seeing their mothers losing their hair was particularly upsetting for them [38].

For many patients, it was important that the headwear did not look like a “cancer hat” [20, 45] to reduce the associated stigma [48]. 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, 33–35, 39, 40, 43, 46, 48, 50]. Even following hair re-growth, people affected by CIA continued to experience difficulties with confidence, self-esteem and anxiety [40]. Noteworthy, interventions including scalp cooling to prevent hair loss were associated with improved quality of life domain scores for some women [51].

Cognitive needs

Women affected by severe CIA-induced distress reported reduced cognitive functioning \((p < 0.001)\) [13]. Women expressed cognitive needs around madarosis [43] and being hyper vigilant around hair care behaviours [23]. 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 [44]. 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 [23]. 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 [43]. Women also expressed the need for information to be available to them to provide to their hairdressers about hair care [23]. 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 [38].

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, 31, 40, 42, 43] and how to source correct fitting headwear [45]. 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 [38]. Importantly, some patients expressed disappointment that scalp cooling was not offered to them as part of their decision-making process [23].

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 representing hope and renewed life [12]. Others expressed that CIA invoked feelings of hopelessness, but they used spirituality as a coping mechanism [39].

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, 40, 45] in the
community and workplaces [12]. Daily living was restricted by being unable to go out in public, for example to get shopping, exercise and work and going to childcare facilities [12, 38]. 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 headwear [12, 24, 32, 44, 45]. However, there was a negative economic burden in the cost of purchasing headwear and the upkeep of them through washing and drying [12]. Others would have valued more detailed information and education when undergoing scalp cooling on their daily lives [23].

**Interpersonal/intimacy needs**

Alopecia had a profound consequence on body image for both men and women [32]. 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 [37]. Women felt a lack of connection with their appearance and were unable to associate with it or recognise their reflection in the mirror [43]. 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 linked to their masculinity [20]. For both men and women, hair was part of their identity and sexuality [40]. 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 [33].

**Practical needs**

Practical needs were related to the need to conceal/disguise their hair loss by wearing hats, scarves and wigs [12, 20, 45]. Women found it helpful having a family member with them when trying on wigs to provide encouragement and feedback [46, 48]. Many women found practical strategies of using eyebrow pencils, eyeliners and eye shadow was helpful to cover up patchy hair loss or replicate eyebrows [43], but they were dissatisfied with the cosmetic result. For the most part, women expressed the importance of taking their time when choosing their wig [40].

**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 [30], 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 [37]. Children also found it distressing seeing their mothers with wigs because they no longer looked like their mother [38]. 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, 39, 42, 48]. 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 [40].

**Social needs**

Social well-being was negatively affected for both men and women [31]. Reduced social function was associated with CIA distress [13, 32]. Women valued headwear which helped them blend into society to help minimise stares and conceal their illness [45]. 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 [43]. Many used avoidance coping strategies to stay home to prevent them experiencing sympathy from people in public [12, 43, 44]. Alopecia prevented people from enjoying a social life. Despite the negative feelings towards wearing a wig, they endured it to be accepted into society [40, 42, 43].

**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-Clarkian informational needs (6/27), cognitive needs (5/27) and spiritual needs (2/27) (see Table 4; 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 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 [52]. 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 [23].

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, 36, 53]. In the twenty-first 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 with women. Further research should seek to understand the complex person-centred 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, 30, 31, 36]. 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, 30, 37, 46].

Alopecia is associated with loss of control and 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, 42–44]. Based on the coping theory of Lazarus and Folkman [54], coping is defined as behavioural and cognitive efforts to manage stressful encounters. In keeping with the 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 2 weeks after chemotherapy reaching a maximum of 2 months [33]. Alopecia from chemotherapy can be reversible with new hair regeneration beginning one to 2 months after the discontinuation of chemotherapy. However, there is increasing evidence that persistent/permanent CIA can be experienced following treatment [55], 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 identity. 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 [56].

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 the 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 [38]. 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
| 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    | -              | ✓                              | -               | -                                      | -                   | ✓               | -                 | -                         | -              | -                   | -           | 3                                               |
| 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)         | -              | ✓                              | -               | -                                      | -                   | -               | ✓                 | -                         | -              | -                   | -           | 4                                               |
| 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** | **Total number of domains across studies** |
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.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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