



The HAIR-QoL measure Part 1: What are the quality of life issues for people with cancer with chemotherapy-induced alopecia?

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ABSTRACT

This paper describes the development of the provisional HAIR-QoL questionnaire on the impact of chemotherapy-induced alopecia on health-related quality of life. A total of 43 items have been developed.

Introduction: Chemotherapy Induced Alopecia (CIA) is the most visible side effect of chemotherapy treatment, carrying an important psychosocial burden, and negatively affecting health-related quality of life (HRQoL). No internationally validated instrument for the severity and impact of CIA exists for people with cancer for both sexes, which has hindered research in this area. Therefore, our aim was to develop a patient-reported measure for use in research and patient care.

Methods: We established a list of potential issues based on experiences of patients and healthcare professionals (HCPs) through a literature review, interviews, and focus groups with 52 patients in various cancer centres from three countries. Thereafter, a total of 51 eligible patients and 11 HCPs from four countries scored these issues on relevance and priority before translating into items for the provisional HAIR-QoL questionnaire.

Results: The literature search identified 293 issues, and focus groups and interviews another 618 issues. Removing duplicates and general HRQoL issues resulted in 95 pertinent issues across 6 health-related QoL domains: (1) meaning and importance of hair, (2) satisfaction with the received information regarding hair loss and preparedness, (3) impact of hair loss on self, (4) impact of hair loss on others, (5) management of changes/side effects, and (6) regrowth of hair. Differences in relevance scores could be detected between males and females, and were associated with 5 items on the wearing of a wig/head cover ($Z = 2.9-3.4$, p between 0.001 and 0.004). Also relevance scores for 'wearing a wig/head cover for my partner/children' were higher for female patients with breast cancer compared to other cancers ($Z = 3.2$, $p = 0.001$). The calculated scores on relevance and priority led to a total of 43 issues that have been translated into items.

Conclusion: This study shows that people with cancer with CIA experience important HRQoL issues, not adequately measured by existing HRQoL measures. CIA can affect male people with cancer as much as it can affect females. The provisional HAIR-QoL questionnaire provides an optimal approach for multidisciplinary teams who care for people with cancer in understanding their patients' concerns and priorities around CIA.

1. Introduction

Chemotherapy-induced alopecia (CIA) is one of the most common and distressing side effects related to cancer treatment (Dua et al.,

2017). The exact incidence of alopecia is rarely quantified; it is estimated that half of the people with cancer undergoing chemotherapy face severe alopecia. Although CIA is not life-threatening, it can cause a daily burden for many people with cancer and it may affect people with

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cancer's health-related quality of life (HRQoL) (Marks et al., 2019). The impact of CIA is described by people with cancer, relates to the domains of psychological, social and role functioning, besides physical manifestations (Versluis et al., 2022; Alphen van et al., 2020). Even though many studies and clinical practice have shown a high personal impact of CIA, little attention is afforded in the clinical setting and in scientific research (Hurk van den et al., 2015).

Most of the available instruments which measure people with cancer's HRQoL (e.g. QLQ-C30 (Aaronson et al., 1993), SF-36 (Brazier et al., 1992), EQ-5D (EuroQol, 1990)) do not include items related to alopecia. These instruments were initially developed for other purposes, for example, survivorship care and/or do not include specific symptoms. Several European Organization for Research and Treatment of Cancer (EORTC) cancer specific modules (e.g. BR23 (Sprangers et al., 1996)) and most symptom questionnaires (e.g. PRO-CTCAE (Basch et al., 2014) and the health care professionals version CTCAE (National Cancer Institute, 2009)) do contain an item about alopecia. These instruments are not sufficiently discerning to pick up the perspective of the person with cancer.

Measures to evaluate the impact of alopecia are mostly focused on gradually occurring alopecia related to underlying conditions, other than cancer and its treatment (Dolte et al., 2000; Fabbrocini et al., 2013; Fischer et al., 2001; Mendoza et al., 2013). For people with cancer, measures are not validated for gender and other cancers apart from breast cancer (Cho et al., 2014).

This study aims to identify patient-reported HRQoL issues as a first step in the development of an internationally validated CIA instrument for all people with cancer. It is important that this is a patient-reported measure as symptom experiences are highly personal and subjective (Bennion and Molassiotis, 2013).

2. Methods

This project was designed by adapting the EORTC Quality of Life Group module development guidelines (European Organization for Research and Treatment of Cancer, 2021; Holsti, 1969) comprising the following steps: (1) Generation of a HRQoL issue list through literature review, focus groups, and semi-structured interviews with patients, and quantitative research with health care providers (HCPs); (2) Testing and adapting the issue list and (3) transforming the identified issues into questionnaire items.

3. Compliance with ethical standards

All necessary permissions were granted by local ethics committees in each participating centre (Australia #13/254, Germany #2014-454-f-S, Netherlands #M16-0129, UK #14/WM/1234). Written informed consent was obtained from all individual participants included in the study.

3.1. Step 1: generation of a HRQoL-issue list

This phase consisted of: a) a review of the literature to identify relevant existing issues and questionnaires on the impact of alopecia; b) eliciting relevant domains through focus groups and semi structured interviews.

A literature search was performed in PUBMED to identify questionnaires measuring alopecia, including non-chemotherapy related, until January 1st 2014 (and updated in 2022). The following keywords were used: 'alopecia/ hair loss', 'quality of life/ health-related quality of life/ well-being/ symptoms/ distress' and 'questionnaire/ measure/ scale'. Retrieved issues were put in an issue list.

To identify and explore the most pertinent CIA-related HRQoL issues, focus groups or individual semi-structured interviews with patients were organised. The focus groups and interviews were performed using an interview guide developed by the research team. Eligible participants for these qualitative studies were recruited from different Cancer Care

centers: The Mater Hospital in North Sydney, Australia; University Hospitals Coventry and Warwickshire in the United Kingdom and the Catharina Hospital and Máxima Medical Center in the Netherlands. Eligibility criteria were as follows: 1. receiving or having received alopecia-inducing chemotherapy (>10% risk of severe CIA); 2. age 18 years or older and 3. providing informed consent. Exclusion criteria were: 1. participating in other HRQoL investigations that may interfere with this study; 2. being bald before initiation of chemotherapy and 3. having a psychiatric condition or major cognitive impairment that would hamper completion of self-reported HRQoL questionnaires.

Both focus groups and interviews comprised questions about the meaning of wellbeing, information about CIA, importance of hair, experiences with baldness, changes in everyday life, feelings about CIA, importance of covering or camouflage hair loss and expectations about regrowth of hair. The conversations included a final open question to report on any matter that had not been mentioned during the focus groups or interviews and to collect unanticipated issues. Focus groups and interviews were recorded, transcribed verbatim and analyzed for substantive patterns, via content analysis (Holsti, 1969), by researcher AA.

All potentially relevant issues collected were collated in one list and duplicates removed. In addition, issues that were not exact wording matches, but had essentially the same meaning, were merged into one issue. Issues across six health-related QoL themes (domains) were identified by three researchers (CH and colleagues). Four research team members (AY, CH, FB, JW) discussed the choices made and approved this issue list. The lists were translated into Dutch by two native speakers (CH and colleague) and into German by a translation officer.

3.2. Step 2: testing and adapting the list of pertinent issues

After informed consent, nurses presented the list of pertinent issues related to HRQoL to patients, in a private meeting room in their hospitals, with the exception of the German research group where HCPs tested and adapted the list. All participants were asked to rate the relevance of each issue for them personally on a four-point Likert scale: i) not at all, ii) a little, iii) quite a bit, iv) very much. Thereafter, participants were asked to indicate 10 issues they considered to be most troubling (yes/ no response categories). Furthermore, they were asked in an open question of other areas of concern that were not included in the issue list.

3.2.1. Decision on provisional questionnaire items

We used the following criteria for the inclusion of issues: for the patient, a mean score of > 1.75 and priority percentage of > 15%, and for the HCP a mean score of > 2.00 and priority percentage of > 25%. For patients, two points were assigned for every criterion that was met. For HCPs, one point was assigned for every criterion met (European Organization for Research and Treatment of Cancer, 2021). Thereby more weight was given to the patients where a discrepancy on mean scores was observed between patients and HCPs. Total scores were calculated by summing responses for all items, issues that had ≥ 4 points were selected for inclusion in the provisional Hair-QoL questionnaire.

Differences in results between language, gender, age (<50, 50-63, ≥ 63), cancer type (breast versus other) were analysed using the Mann Whitney U Test and Kruskal Wallis One Way ANOVA.

3.3. Step 3: transforming the identified issues into questionnaire items

Issues which met the criteria in Step 2 were included in Step 3 to develop a new set of items for the questionnaire. The EORTC Item Bank was used to search existing EORTC items for questions matching the provisional list (after granted access from the EORTC). Where issues had previously been used in other questionnaires, the original wording was selected. If issues were not found in the item bank, the appropriate wording for new items were phrased by two researchers (CH and JW)

independently, each blinded to the work of the other. Both researchers exchanged their suggestions for the item list, compared and discussed them until consensus was reached. The provisional version of the HAIR-QoL was circulated among the research team for their independent review. Consensus was reached by an iterative process by email after two rounds. The HAIR-QoL group (all authors) approved the last draft of the provisional item list.

4. Results

4.1. Step 1: generation of a HRQoL-issue list

The literature search resulted in 8 relevant questionnaires published until 2013 (Dolte et al., 2000; Fabbrocini et al., 2013; Fischer et al., 2001; Mendoza et al., 2013; Finlay and Khan, 1994; Chren et al., 1996; Endo et al., 2012; Higaki et al., 2009). This identified 293 relevant issues.

An updated PUBMED search for alopecia measures (November 2022) showed that there were from 2014 and onwards only the CADS (Cho et al., 2014) for CIA and 3 new measures for other underlying conditions (Li et al., 2018; Winnette et al., 2021; Wyrwich et al., 2020). As an exception, one of these was not focused on scalp hair but on eyebrows and eyelashes (and nails) (Wyrwich et al., 2020). Furthermore, there were translation and validation studies of the measures used before 2014 (Guerra-Tapia et al., 2019; Essa et al., 2018; Wyrwich et al., 2022; Grugnetti et al., 2018; Shimizu et al., 2018; Cong et al., 2020; Mendoza et al., 2018; Nasimi et al., 2020).

The six focus groups (two in each country) involved 45 patients and a further 7 patients participated in a semi-structured interview, yielding 618 issues.

After selecting the relevant issues for CIA, it resulted in a list of 222 potentially relevant issues (supplementary Table A.1). This list was reduced to 95 issues after removing duplicates and general HRQoL items. These issues were subdivided into 6 themes: (1) meaning and importance of hair, (2) satisfaction with the received information regarding hair loss and preparedness, (3) impact of hair loss on self, (4) impact of hair loss on others, (5) management of changes/side effects, (6) regrowth of hair.

4.2. Step 2: testing and adapting the list of pertinent issues

The relevance of each issue was assessed by 57 patients (Table 1) with a broad variety of cancer types and treatments (i.e., 42 different chemotherapy regimens). Most participants were white Caucasian/European ($n = 49$, 86%); and 35 (61%) were patients with breast cancer. For most patients (72%), the time since their last chemotherapy was less than one year, 20 (35%) patients were in early-stage disease and had received adjuvant treatment, 15 (26%) had metastatic and 3 (5%) advanced stage disease, and the mean age was 55.0 (SD= 11.2) years.

One patient answered 2 relevance scores and the lowest score was selected. In addition, if no relevance score was given for an issue, but it was selected for the top 10, the issue was included in for the top 10 analyses ($n = 3$ patients).

No difference in relevance scores could be detected between language groups or age groups. For males versus females, variations in relevance scores were associated with 5 items on the wearing of a wig/head cover (more relevant for female patients) ($Z = 2.9$ – 3.4 , p between 0.001 and 0.004). Relevance scores for 'wearing a wig/head cover for my partner/children' were higher for female patients with breast cancer (compared to other cancers) ($Z = 3.2$, $p = 0.001$).

Thirty-one (54%) patients indicated the 10 most important issues, representing the majority of the sample. A further 11 patients indicated more than 10 issues as 'most important' (19%) and 15 patients indicated less than 10 issues or data were missing. For the purposes of analysis of the relevance scores, data from all patients who indicated at least 10 issues were included in the analysis. Evaluation was suitable for 51

Table 1

Demographic and clinical details of patient focus groups and interviews.

		n = 57	%
Country (language)	Netherlands (Dutch)	16	28
	Australia (English)	6	11
	Germany (German)	17	30
	UK (English)	18	32
Age (years)	Mean (SD)	55.0 (11.2)	
	Range	29–72	
Sex	Male	12	21
	Female	39	68
Ethnicity	White/Caucasian/North, East or West European	49	86
	Black/Afro Caribbean/North African	4	7
	South Asian/Indian	3	5
	East Asian/Chinese	1	2
	Missing	0	0
Type of cancer	Breast	35	61
	Prostate	5	9
	Lung	1	2
	Gynaecological	2	4
	Pancreatic	2	4
	Lymphoma	1	2
	Sarcoma	1	2
	Cholangiocellular carcinoma	1	2
	Extragenital germ cell tumour	1	2
	Breast AND Gynaecological	1	2
	Oropharyngeal squamous cell carcinoma	1	2
	Gynaecological AND bowel	1	2
	Missing	5	9
Time since last chemo (years)	Mean (SD)	1.09 (0.29)	
	< 1 year	41	72
	1–2 years	4	7
	Missing	12	21
Stage	(early) Adjuvant	20	35
	Metastatic	15	26
	Local advanced	3	5
	Missing	19	33
	Not applicable, no/modest hair loss	18	32
Use wig/head cover	Yes	17	30
	No (bald head inside and outside house)	5	9
	Missing	11	19
Growth of hair	Yes, growth started	12	21
	Yes, I had an acceptable hairstyle again	5	9
	No, not yet	11	19
	Missing	23	40

patients (39 female, 12 male).

Additional remarks made by the patients did not raise any extra issues and no issue had been marked as being upsetting.

Eleven HCPs tested and adapted the list (4 oncologists, 5 nurses, 1 psychotherapist and 1 whose profession was unknown). The calculated scores led to selection of 43 issues (Table 2). The decision of considering the relevance scores of only the patients who indicated 10 or more issues did not change the results of the relevance analysis, nor the priority percentages.

As the themes on impact of hair loss on others, the management of changes and side effects and regrowth of hair are only relevant in case of severe hair loss, they had lower priority scores. Therefore a 'not applicable' response was added to the questionnaire items which covered these themes.

4.3. Step 3: transforming the identified issues into questionnaire items

The Step 3 translation from a list of issues into questionnaire items is displayed in Table 3. The process of developing the appropriate wording was initially started by CH and JW and then, reviewed by the whole research team. The provisional version of the HAIR-QoL measure contained 43 items which has moved forward to the next stage of

Table 2
Relevance and priority scores of patients and HCPs for issues selected for the item list (≥ 4 points).

No.	Issue	Relevance mean		Percentage priority		Criteria	Points
		Patient n = 57	HCP n = 11	Patient n = 43	HCP n = 9	Fulfilled	
1	Feeling self-conscious about my hair	2.66	3.40	24%	56%	4	6
2	Wanting to still look normal	3.41	3.50	64%	56%	4	6
3	Maintaining my self esteem	3.21	3.70	23%	56%	4	6
4	Hair contributes to my personal attractiveness	3.09	3.30	21%	33%	4	6
5	Feeling good about my appearance	3.16	3.50	30%	33%	4	6
6	Feeling good when my hair looks good	3.19	3.10	18%	11%	3	5
7	Feeling confident	3.04	3.50	12%	44%	3	4
8	My hair loss is the least of my problems	2.68	2.00	36%	22%	2	4
9	Effect on my perception of self (self-awareness)	2.67	3.00	8%	33%	3	5
10	Shock felt when I realised I might lose my hair from chemotherapy	2.46	3.20	16%	50%	4	6
11	Coping with amount of information given about chemotherapy	2.93	3.44	21%	13%	3	5
12	Accepting the fact that everyone tends to lose their hair during chemotherapy.	2.83	2.67	20%	13%	3	5
13	Satisfaction with information given about my hair loss	3.21	3.33	17%	13%	3	5
14	Fear of losing my hair	2.77	3.40	19%	38%	4	6
15	Wanting to keep my hair	3.18	3.10	16%	13%	3	5
16	Accepting that it was likely my hair loss would be significant	3.07	3.00	43%	13%	3	5
17	Feeling hair loss was a sign that the drugs were working	2.64	2.27	24%	0%	3	5
18	Realising the seriousness of disease	2.93	2.91	35%	33%	4	6
19	Feeling that hair loss was the worst effect of treatment	1.93	2.73	14%	11%	3	5
20	Being reminded of my illness (when I look in the mirror)	2.71	3.55	26%	78%	4	6
21	Hair loss is a barrier for active way of life	1.96	2.75	10%	29%	3	4
22	Feeling different from others	2.16	3.30	10%	44%	3	4
23	Change in my attitude towards my hair	1.96	2.56	2%	13%	3	5
24	Looking forward to my hair regrowth	3.49	3.30	38%	22%	3	5
25	Still feeling the same person for others	3.79	2.20	25%	11%	3	5
26	Feeling that other people judge me differently when seeing my hair loss	2.06	3.10	17%	56%	4	6
27	Hair loss showing other people that I am ill	2.87	3.80	24%	78%	4	6
28	Acceptance of my hair loss by family members/children	2.98	2.80	15%	56%	3	4
29	Managing people's reactions to my hair loss / baldness	2.47	3.20	11%	33%	3	4
30	Not wanting sympathy	2.60	3.00	20%	22%	3	5
31	Feeling that maintaining my appearance is important for my partner	2.52	3.22	20%	22%	3	4
32	Acceptance of hair loss by my partner	3.18	2.80	23%	11%	3	5
33	Tenderness of my scalp	2.09	2.64	24%	0%	3	5
34	Use of wig to camouflage my hair loss	2.22	2.91	8%	33%	3	4
35	Feeling better with a wig/head cover	2.75	3.27	29%	22%	3	5
36	Importance of feeling comfortable with my wig/head cover	3.07	2.64	21%	22%	3	4
37	Concern about losing my eyebrows and eyelashes	2.91	3.27	41%	33%	4	6
38	Changed facial features	2.55	3.18	23%	22%	3	5
39	Concern about regrowth of the eyebrows and eyelashes	2.54	2.91	28%	33%	4	6
40	Fear of it not growing back	2.36	2.55	25%	22%	3	5
41	Speed of regrowth different than expected	1.90	2.64	8%	33%	3	4
42	Happiness when regrowth started	3.40	3.27	39%	11%	3	5
43	Place of regrowth (other areas)	2.63	2.55	19%	22%	3	5

development. This involves testing on a new sample of patients and conducting psychometric testing, i.e. described in the HAIR-QoL measure Part 2 (Winstanley et al., 2023).

5. Discussion

This study has developed a set of items suitable for including in an instrument to measure the impact of CIA on people with cancer's HRQoL. The 43 items show that CIA may influence many aspects in daily life, as also reported in other recent studies (Versluis et al., 2022; Alphen van et al., 2020).

The HRQoL items generated in this study matched only 5 items of the Chemotherapy-induced Alopecia Distress Scale (CADS) questionnaire (Cho et al., 2014). These were four items of the Hair-QoL domain (3) about impact of hair loss on self, and one in domain (4) about impact of hair loss on others. The CADS was developed for Korean women with breast cancer and has been translated and validated for the Italian (Grugnetti et al., 2018) and Chinese (Cong et al., 2020) language. It evaluates distress using 4 domains: (1) physical, (2) emotional, (3) activity and (4) relationship. The authors concluded that the CADS was more strongly associated with body image than with overall HRQoL (Cho et al., 2014). Our Hair-QoL questionnaire allows to explore

additional domains related to HRQoL and hair loss as we also incorporate: (1) meaning and importance of hair, (2) satisfaction with the received information regarding hair loss and preparedness, (5) management of changes/side effects, and (6) regrowth of hair. The items for our Hair-QoL questionnaire have been developed based on female and male patients from European countries and Australia, potentially suitable for all types of cancer.

CIA can greatly affect many male people with cancer as much as it can affect females (Hilton et al., 2008). For some people with cancer, hair loss is a logical consequence of the treatment (Rosman, 2004). It does, however, not change the fact that there may well be differences in the use of wigs or head covers.

5.1. Study limitations

Limitations of this study were that a small number of participants did not follow the correct methodology, e.g., not choosing 10 priority scores. However, sensitivity analyses showed no influence on the issue list. In addition, only small numbers of HCPs completed the issue list, unlike people with cancer. Since this provisional HAIR-QoL is a patient-reported outcome measure (PROM), it is of utmost importance to involve large numbers of people with cancer in the further refinement of

Table 3
Operationalisation of the 43 issues into items.

#	Issues	Final question = Items
THEME 1: MEANING AND IMPORTANCE OF HAIR		
1	Feeling self-conscious about my hair	Has your hair loss made you feel more self-conscious?
2	Wanting to still look normal	Have you worried about being able to keep looking normal?
3	Maintaining my self esteem	Have you been concerned about maintaining your self esteem
4	Hair contributes to my personal attractiveness	Have you felt that hair contributes to your personal attractiveness?
5	Feeling good about my appearance	Have you felt good about your appearance despite your hair loss?
6	Feeling good when my hair looks good	When your hair looks good, does it make you feel good about yourself?
7	Feeling confident	Have you felt confident despite your hair loss?
8	My hair loss is the least of my problems	Have you felt your hair loss to be the least of your problems?
9	Effect on my perception of self (self-awareness)	Have you felt that your hair loss has affected your perception of self (self-awareness)?
THEME 2: PREPAREDNESS/INFORMATION GIVEN, SATISFACTION		
10	Shock felt when I realised I might lose my hair from chemotherapy	When you were told you needed chemotherapy, were you shocked to realise you would lose your hair?'
11	Coping with amount of information given about chemotherapy	Have you been able to cope with the amount of information given about chemotherapy?
12	Accepting the fact that everyone tends to lose their hair during chemotherapy	Have you had difficulty accepting the fact that everyone tends to lose their hair during chemotherapy?
13	Satisfaction with information given about my hair loss	Have you been satisfied with the information given about your hair loss?
14	Fear of losing my hair	Have you been concerned about losing your hair?
15	Wanting to keep my hair	Did you wish you could have kept your hair? Have you wanted to keep your hair?
16	Accepting that it was likely my hair loss would be significant	Have you been concerned that your hair loss would be significant?
THEME 3: IMPACT OF HAIR LOSS ON SELF		
17	Feeling hair loss was a sign that the drugs were working	Have you felt hair loss to be a sign that the drugs were working?
18	Realising the seriousness of disease	Has the loss of your hair made you realise the seriousness of your disease?
19	Being reminded of my illness (when I look in the mirror)	Did looking in the mirror (at your face) remind you of your illness?
20	Hair loss is a barrier for active way of life	Have you felt able to carry on with an active life as normal?
21	Feeling different from others	Have you felt different from others because of your hair loss?
22	Change in my attitude towards my hair	Have you changed your attitude towards your hair?
23	Looking forward to my hair regrowth	Have you been concerned about how long it would take for your hair to regrow?
24	Still feeling the same person for others	Did you still feel the same person inside, despite your hair loss?
THEME 4: IMPACT OF HAIR LOSS ON OTHERS (if applicable)		
25	Feeling that other people judge me differently when seeing my hair loss	Have you felt that other people judge you differently when seeing your hair loss?
26	Hair loss showing other people that I am ill	Have you been concerned that your hair loss showed other people that you were ill?
27	Acceptance of my hair loss by family members/children	Have you felt concerned about how your family/friends would accept your hair loss
28	Managing people's reactions to my hair loss / baldness	Have you been concerned about coping with people's reactions to your hair loss/ baldness?
29	Not wanting sympathy	Have you found it difficult to accept sympathy from strangers, because of your hair loss?

Table 3 (continued)

#	Issues	Final question = Items
30	Feeling that maintaining my appearance is important for my partner	How important do you think maintaining your appearance is for others (e.g. partner, family, friends)?
31	Importance of continuing to work	How important is it to you to continue your normal work, despite your hair loss?
32	Acceptance of hair loss by my partner	Have you been concerned about how your partner would accept your hair loss?
THEME 5: MANAGEMENT OF CHANGES/SIDE EFFECTS (if applicable)		
33	Tenderness of my scalp	Did your scalp feel tender because of your hair loss?
34	Use of wig to camouflage my hair loss	Have you used a wig or head cover to camouflage your hair loss?
35	Feeling better with a wig/head cover	Have you felt better when wearing a wig or head cover?
36	Importance of feeling comfortable with my wig/head cover	How important was it to feel comfortable with your wig/head cover?
37	Concern about losing my eyebrows and eyelashes	Have you been concerned about losing your eyebrows and eyelashes, in addition to your scalp hair?
38	Changed facial features	Have you been concerned that your facial features have changed?
39	Concern about regrowth of the eyebrows and eyelashes	Have you been concerned about your eyebrows and eyelashes not growing back?
THEME 6 – REGROWTH (if applicable)		
40	Fear of it not growing back	Have you been concerned about your hair not growing back?
41	Speed of regrowth different than expected	Have you felt the speed of regrowth to be different than expected?
42	Happiness when regrowth started	How happy were you when regrowth started?
43	Place of regrowth (other areas)	Have you experienced hair regrowth on other areas of the body?

this measure. The strengths of the study are the international, multi-disciplinary methodology with an inclusion of HCPs and patients, including minorities and males.

5.2. Clinical implications

As the provisional HAIR-QoL questionnaire identifies aspects of daily life influenced by CIA, it provides an optimal approach for multidisciplinary teams who care for people with cancer in understanding their patients' concerns and priorities around CIA. As the impact of CIA on the patient's HRQoL may influence the shared decision-making for the treatment type (Hesketh et al., 2004), it is important for clinicians and pharmaceutical industries to incorporate CIA as a patient-reported outcome (PRO) in daily care and in clinical trials of new agents, as well as in research to investigate methods to preserve hair e.g. scalp cooling.

6. Conclusion

In conclusion, this newly developed questionnaire on the impact of CIA on HRQoL adds breadth to the knowledge from existing PRO measures in cancer care and to supportive care research. This item list is ready for future international testing in larger groups of people with cancer and HCPs to finalise the HAIR-QoL measure.

The provisional HAIR-QoL questionnaire has been tested in hospitals in 5 continents and is published elsewhere (Winstanley et al., 2023).

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CRedit authorship contribution statement

Authors CH, JW, AY and FB have contributed to conception and design of the study. Authors CH, JW, AA, DS, AY and FB have contributed to acquisition of data and CH and JW have performed the analyses. All authors have been involved in interpretation of data and in drafting the manuscript.

Consent to participate

Written informed consent was obtained from all individual participants included in the study.

Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Frances Boyle and Julie Winstanley reports financial support was provided by The Friends of The Mater Foundation. C van den Hurk reports financial support was provided by Paxman Ltd.

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Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.ymecc.2023.100002](https://doi.org/10.1016/j.ymecc.2023.100002).

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