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# Giving A Face to Chemotherapy-Induced Alopecia: A Feasibility Study on Drawings by Patients

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## ABSTRACT

**Objective:** Individuals with cancer experience the impact of chemotherapy on hair loss in different ways. The aim of this pilot study was to explore patients' experiences of alopecia through patients' drawings. **Methods:** Fifteen female patients diagnosed with cancer and treated with chemotherapy were recruited at the oncological day-care unit of a teaching hospital in the Netherlands. Participants completed a semi-structured interview about alopecia. They drew their head and hair before and during chemotherapy and completed the Brief Illness Perception Questionnaire (B-IPQ). **Results:** The drawings revealed predominantly physical effects, rather than emotions. Emotions were evident in the text that patients wrote under the drawings and in the B-IPQ open question about the perceived

consequences of alopecia. The overall impact of alopecia that emerged from the drawings and the B-IPQ corresponded to the information retrieved from the interviews, namely disappointment, insecurity, sadness, and confrontation. **Conclusions:** Drawings expose cognitive and emotional responses to alopecia that may be relatively unexplored when using traditional assessment methods such as questionnaires or interviews. In future research, the drawing instructions need to be more specifically focused on feelings in order to better capture emotional reactions to hair loss.

**Key words:** Alopecia, cancer, chemotherapy, drawings, emotions, illness perceptions

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## Introduction

One frequently occurring side effect of chemotherapy is alopecia. In the Netherlands, over 15,000 cancer patients face alopecia every year. Patients often lose hair on the head, eyelashes, eyebrows, and other parts of their body.<sup>[1]</sup> Once chemotherapy stops, hair will start to regrow in most patients.<sup>[2]</sup> Nevertheless, many patients are distressed by temporary alopecia.

Hair plays a particularly important role when it comes to our individuality, attractiveness, and appearance.<sup>[3]</sup> For many women, hair is seen as part of personality, sexuality, and femininity.<sup>[4]</sup> In addition, eyebrows and eyelashes play a major role in facial expressions.<sup>[1,5]</sup> Emotional consequences of hair loss described in the literature include low self-esteem, anxiety, depression, negative body image, and reduced well-being.<sup>[6,7]</sup> A bald head is characteristic of a person with cancer and signifies illness. Many women choose a wig to camouflage these aspects and to feel better.<sup>[8]</sup> In interviews, patients mention the importance of appearance in social situations and the experience of social distress due to alopecia.<sup>[9]</sup>

Alopecia is one of the side effects of chemotherapeutic treatment that has the largest emotional impact.<sup>[3]</sup> Patients are often ashamed when their hair starts to fall out. Cancer becomes visible, and this violates privacy.<sup>[10]</sup> Sometimes, hair loss is more traumatic for female breast cancer patients than the loss of a breast because it can be camouflaged less easily.<sup>[11]</sup> Hair loss can also contribute to reduced quality of life because patients are continuously reminded of their alopecia – and therefore cancer – in daily life.<sup>[12]</sup>

The impact of alopecia depends on the patient's expectations of alopecia, the amount of information given in advance, and a person's coping skills to deal with the situation.<sup>[11]</sup> Alopecia does not have the same impact on all patients. It can be regarded as very severe by some patients, whereas others see it as only a side effect.<sup>[13]</sup> In general, the impact of alopecia is underestimated by oncological health-care professionals.<sup>[14]</sup>

To date, the impact of alopecia has been assessed by interviews and questionnaires.<sup>[10,12]</sup> Asking patients to draw their hair loss may reveal the impact of alopecia in a different way.<sup>[15]</sup> New insights might be created because patients are given the opportunity to choose how to draw their condition, instead of answering in limited categories in a questionnaire. A patient does not have to use words, like in an interview, which might make it easier for some people to express their feelings.<sup>[16]</sup> In this feasibility study, patients with cancer were asked to draw their head before and during chemotherapy. The drawings combined with responses to a questionnaire assessing illness perceptions, could provide a more complete overview of the impact of alopecia.

Recent research has shown that drawings identify patients' illness representations. The drawings can be included as an additional outcome measure, for example, to predict time to return to work or the course of side effects. A systematic review study on drawing research by Broadbent *et al.* lists 101 studies about patients' drawings of their illness.<sup>[15]</sup>

## Methods

### Patients

Participants ( $n = 15$ ) were recruited from the oncological day-care unit of Máxima Medical Centre, a regional teaching hospital in the Netherlands, between October and November 2017. Patients were included if they had the prospect of severe alopecia, if they had had at least two chemotherapy treatments with or without scalp cooling, and if the last treatment was not longer than 1 month ago. If patients had no hair loss because of scalp cooling, they could still participate in this study. Patients needed to be proficient in Dutch and needed to be 18 years of age or older. Alopecia was defined as severe when patients were eligible for scalp cooling or were given a prescription for compensation for a wig by their health-care insurance. Patients were excluded from the study if they were bald before the start of the chemotherapy or when they had a mental condition which prohibited completing questionnaires, interviews, and drawings. At the days the researcher (KvA) was present at the day-care unit, the oncology nurses approached each eligible patient. The nurse informed the patients about the study and if they were willing to participate, written informed consent was obtained. Then, the researcher guided the patient through the assessments. The study was approved by the institutional medical ethics committee (ethics committee number N17.148).

### Measures

This study was a cross-sectional pilot study that took place during chemotherapy in the hospital. Which chemotherapy session it was, differed per patient. Each patient followed the same sequence of assessments in a mixed-methods design that will be explained in detail below. In summary, they started with a qualitative oral interview, then they completed a drawing exercise which was quantitatively scored by the researchers. The patients also completed a qualitative description of the drawing, followed by a quantitative paper questionnaire including the Brief Illness Perception Questionnaire (B-IPQ) and sociodemographic and clinical characteristics.

### Interview

The researcher (KvA) first interviewed the patient, addressing the following questions: (1) What did you

(a) expect and (b) experience with regard to the impact of alopecia on your daily life? (2) Which aspect plays the most essential role when thinking about the impact of your alopecia: emotional, social, physical, body image, mood? The researcher especially focused on the emotional aspects mentioned to compare if these were also shown in the drawings. The interviews were audiotaped and transcribed verbatim and analyzed by one researcher (KvA). The transcripts were evaluated using content analysis. The researcher first assigned preliminary codes to the data, describing the content. Thereafter, patterns and themes were searched in the codes across the 15 interviews. These themes were finally defined and named.

### Drawings

After the interview, the patient was asked to create at least two drawings (I and II) on an A4-piece of paper with three 10 cm × 10 cm boxes. The instructions (in Dutch) based on previous drawing research<sup>[17]</sup> were as follows:

*Draw what your head and hair looked like before the start of chemotherapy (drawing I), during chemotherapy without head covering (drawing II) and (if applicable) another drawing with head covering (drawing III). We are not interested in your drawing ability, a simple sketch is fine. We are interested in your ideas about any changes in your appearance, only of your head and hair. You can choose to use colors in your drawings. Can you briefly describe what you have drawn on the dashed line beneath the drawings?*

The drawings were scored on main characteristics by four independent observers: two applied psychology students (KvA, AV), a medical psychologist (AAK), and an epidemiologist (CvdH). The scoring forms with only Likert scales included facial expression (eyes, mouth, and total). The expressions were scored as “negative,” “neutral,” or “positive” and resulted in a final score after reaching consensus. The significance of the written text beneath the drawings was important for this pilot study to check on correspondence with the drawings and on additional information besides the drawings. The texts were for drawings I, II, and III separately categorized into domains by one researcher (KvA).

### Brief Illness Perception Questionnaire

Finally, the patients filled out a newly developed score on the severity of hair loss, i.e. a pictorial combined with a Visual Analog Scale (0 = no hair loss and 100 = total hair loss) as well as the validated Dutch version of the B-IPQ.<sup>[18]</sup> Because this study was not targeting the perception of cancer itself but the perception of alopecia, the B-IPQ was adapted: the word “illness” was replaced by “alopecia.” The item about treatment control was omitted because patients mentioned that they did not understand the question and for most patients, their answers were not

in line with their answers on other B-IPQ questions. This resulted in seven questions on a scale from 0 to 10, and an open question.<sup>[19]</sup> The open question was defined as: *What are the three most important consequences of alopecia?* The seven dimensions of the B-IPQ were consequences (how much alopecia influenced the patients’ life), timeline (the perceived duration of the alopecia), personal control (how much patients felt in control of their alopecia), identity (physical complaints caused by alopecia), concern (to what extent, patients were concerned about alopecia), understanding (to what extent, patients understood their alopecia), and emotional response (how much alopecia had affected the patients emotionally).

The mean scores of the B-IPQ items/dimensions were calculated, and the answers to the open question about the most important consequences of alopecia were categorized by one researcher (KvA). The results were compared with the most applicable reference group, namely Dutch patients with breast cancer.<sup>[20]</sup> In that study, illness perceptions were assessed 2 months after the first chemotherapy course.

Per patient, both the interview and B-IPQ were compared with the drawings to check whether the latter provided an overall picture of the emotional impact of alopecia. The descriptive statistics were performed using IBM SPSS Statistics for Windows, version 24 (IBM Corp., Armonk, N.Y., USA).

### Results

Patients’ sociodemographic and clinical characteristics are summarized in Table 1. All patients were Caucasian, most had breast cancer, had not experienced alopecia before, and used a head cover. Half of them had scalp cooling, and the mean patient-rated score of hair loss was 59 (standard deviation 37 on a 0–100 scale).

### Interview

The domains retrieved from the interviews are shown in Table 2. All the ten patients who were confronted with alopecia mentioned its emotional impact: disappointment and insecurity, sadness, shame, and confrontation. The physical aspects, such as the offset of alopecia, were experienced in different ways and described as pain, coldness, or change of hair structure. Most of the patients cut their hair when the alopecia started. They did not want to be confronted with the continuous loss of their hair anymore as it made them sad.

The main reason given for wearing a wig ( $n = 7$ ) was that patients could be anonymous again. *“I can just go to the supermarket without anyone staring at me”* (patient 6). Because of the wig, patients felt less reminded about their illness *“Sometimes I just don’t want to look like a patient, for example when you go out for dinner or something like that”* (patient 12).



Table 1: Patient characteristics (n=15)

Characteristics	n (%)
<b>Demographic characteristics</b>	
Age (years), mean (SD)	52 (13.8)
<b>Education</b>	
High school	3 (20)
Secondary education	6 (40)
Postsecondary education	4 (26)
University education	1 (7)
Other	1 (7)
<b>Family composition</b>	
Single	4 (27)
With partner	5 (33)
With partner and children living at home	5 (33)
With partner and children living away from home	1 (7)
<b>Work situation</b>	
Full time (>30 h per week)	1 (7)
Part time (<30 h per week)	4 (26)
Retired	3 (20)
Temporary home related to disease	2 (13)
Long-term home related to disease	3 (20)
Unemployed/no paid work	2 (7)
<b>Medical characteristics</b>	
<b>Type of cancer</b>	
Breast cancer	12 (80)
Cervical cancer	2 (13)
Lymphoma	1 (7)
<b>Previous alopecia due to cancer</b>	
Yes	3 (20)
No	12 (80)
<b>Scalp cooling during chemotherapy</b>	
Yes	8 (53)
No	7 (47)
<b>Head covering</b>	
Wig	2 (13)
Another head cover	3 (20)
Both	4 (27)
No head cover	6 (40)

SD: Standard deviation

Two patients indicated that they wore a wig because of their children “I chose a wig for my children because it looks less confronting” (patient 9). Disadvantages of a wig were also mentioned. Four patients said that they found their wig uncomfortable: warm and hard to style and it did not look like their own hair. Four patients mentioned the loss of eyebrows and/or lashes. They said it was hard to make particular facial expressions because of this loss. Some people shared more moderate opinions that they were less concerned about their hair loss. Two patients saw their hair loss as an associated side effect of cancer and were less worried about it.

**Drawings**

All the 15 patients were able to finish the drawings, see examples in Figure 1. Four patients who were having scalp

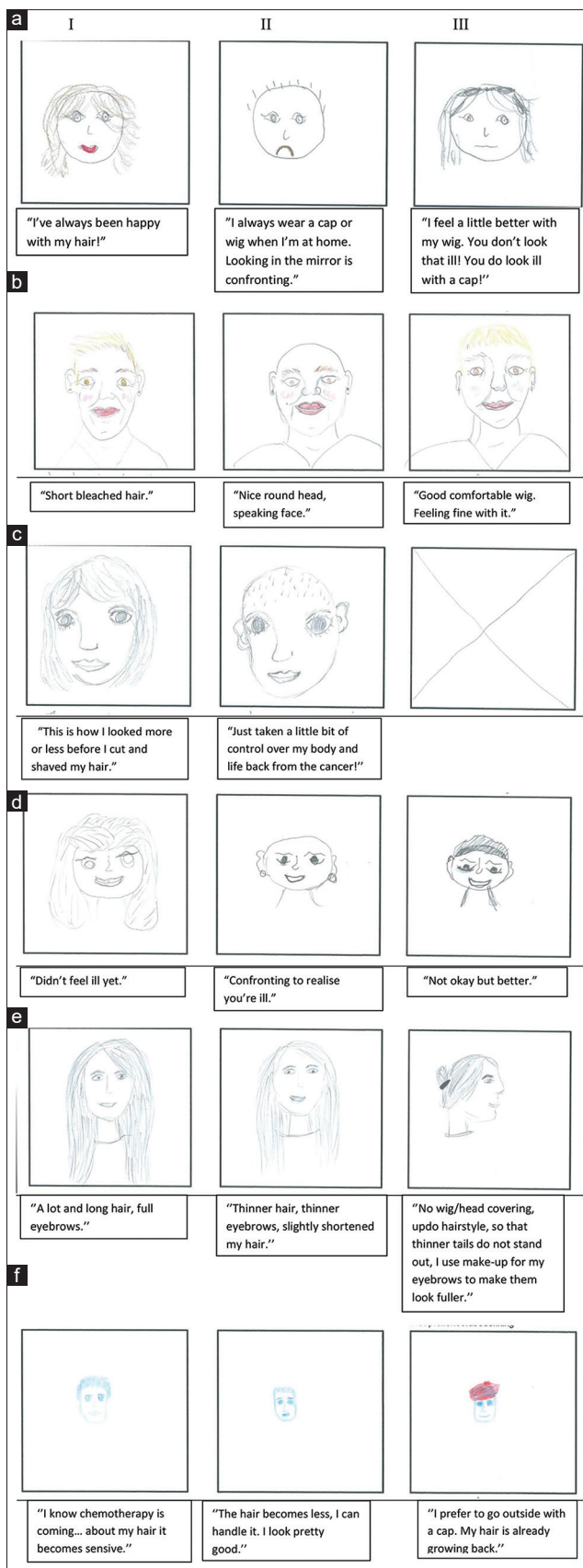


Figure 1: Examples of drawings before (I) and during chemotherapy, with (II) and without head cover (III). (a) Patient 10. (b) Patient 9. (c) Patient 14. (d) Patient 3. (e) Patient 5. (f) Patient 1

Table 2: Domains from the interviews

Domains	Answers of the patients
Confrontation with alopecia	<p>"When I see myself in the mirror, it's just really confronting; those are the bad moments." (Patient 3)</p> <p>"I just did not want to take a shower anymore because I knew I was going to pull my hair out and literally have my hair in my hands." (Patient 6)</p> <p>"In my house, on my pillow, my coats, there was just hair everywhere. You have actually lost control because you don't know how much hair will fall out. I was just a premature bird with only a few tufts." (Patient 10)</p>
Emotional reactions to alopecia	
Disappointment, insecurity	<p>"Seeing myself in the mirror and actually seeing someone else than I used to be, caused a kind of disappointment and some insecurity." (patient 5)</p> <p>"I don't want to look like a fool you know, you want to look good." (Patient 1)</p> <p>"When I'm alone in my own house I don't really care, but when I go outside I don't want other people to see my bald head." (Patient 7)</p>
Sadness	<p>"I did cry for a while when I was at the hairdressers and he started cutting my hair." (Patient 3)</p> <p>"My hair fell out in just one weekend. I was really sad at that time." (Patient 6)</p>
Moderate opinions	<p>"My hair will grow in 1 year, I prefer that this cancer stops. You can wear a cap or a scarf but you can't do anything with that cancer." (Patient 7)</p> <p>"It's just hair. Save your energy and focus on the things you can influence and let this just happen." (Patient 12)</p> <p>"If others don't want to see my bald head, they just have to look the other way." (Patient 2)</p>
Shame	<p>"When people see a woman with a bald head, that's just cancer." (Patient 3)</p> <p>"You want to look nice, not with such a bald head." (Patient 2)</p> <p>"Only my daughter has seen my bald head." (Patient 13)</p>
Loss of eyebrows/eyelashes	<p>"I found it really hard to lose my eyebrows, your whole mimic is just gone and you really got a pale face." (Patient 6)</p> <p>"My eyebrows and eyelashes are all less and that is confronting because that is your face." (Patient 12)</p>

Table 3: Written text categorized in domains and drawings (I, II or III)

Emotional aspects	Physical aspects	Cancer-related aspects
Excited/tensed (I)	Own, long, half-length, short,	I felt healthy (I)
Can handle it (II)	thin, colorless hair (I, II)	Didn't feel ill (I, III)
Confronting (II)	Cutting/shaving (II)	To realise you're ill (II)
Not fun (II, III)	Bald (II)	Took control over the cancer (II)
Weird (II)	Cap (II, III)	To look less ill (III)
Earnest/serious/severe (II)	Wig (II, III)	
Terrible (II)	Eyebrows/eyelashes (I, II, III)	
Happy (I, III)	Hair starts growing (II, III)	
More pleasant (III)	Make-up (III)	

cooling and one without scalp cooling did not wear any head covering, so they only created the first two drawings. Every patient drew their face and the physical condition of their hair. The facial expressions were positive in eight drawings (53%) and neutral in seven drawings before the start of the chemotherapy. In the second drawings, i.e., during chemotherapy, facial expressions were positive in five drawings (36%), neutral in nine drawings, and negative in one drawing. In the drawings with head covering, there were seven positive (70%) and three neutral drawings (30%). There was only one patient who drew three different emotions [Figure 1a]. Three other patients drew a difference in emotion; two were positive before (I) and neutral during chemotherapy (II). One patient drew a difference in emotion during chemotherapy: the second drawing was neutral and the third was positive [Figure 1f].

The text beneath the drawings gave extra information for 12 patients [Table 3]. Words including *happy*, *terrible*, *confronting*, and *excited* described how patients felt at that moment. However, in eight of these patients, no emotions

were evident in their drawings [e.g. Figure 1b-d]. The written text of four patients added extra physical details [Figure 1e].

The domains of the written text are summarized in Table 3. Positive emotions were mostly mentioned beneath drawings I and III. Six patients used colors in their drawings. Only one patient expressed how she experienced alopecia by using colors [Figure 1a]. Other patients only used colors to emphasize physical aspects such as hair color or make-up. The loss of eyebrows/eyelashes was seen in the drawings of four patients.

### Brief Illness Perception Questionnaire

The mean scores on the B-IPQ are listed in Table 4. Most scores were between 0 and 4. Overall, the B-IPQ showed that the cognitive and emotional impact of alopecia was low to moderate, and patients felt that they understood their alopecia well. Patients in this study answered lower on each item compared to a previous study where the B-IPQ was utilized to measure the illness perceptions of cancer among women with breast cancer.<sup>[21]</sup> The answers to the open question regarding the most important consequences of alopecia were categorized into emotional ( $n = 11$ ), social ( $n = 4$ ), and physical ( $n = 6$ ) domains [Table 5].

### Association between drawings, Brief Illness Perception Questionnaire, and interviews

In ten patients, findings from the drawings with the additional text matched findings from the interviews and B-IPQ and showed the impact of alopecia on several domains. The themes that emerged from the interview were the confrontation and emotional reaction to alopecia, shame, and the loss of eyebrows and eyelashes. The B-IPQ

Table 4: B-IPQ scores regarding perception of alopecia compared with a reference group of perception of breast cancer

B-IPQ	Perception of alopecia (n=15) Mean (SD)	Perception of breast cancer (n=22) <sup>[21]</sup> Mean (SD)
Consequences ("0" no effects at all - severely effects my life "10")	3.47 (3.36)	7.36 (1.87)
Timeline ("0" a very short time - forever "10")	2.20 (1.86)	5.45 (2.79)
Personal control ("0" absolutely no control - extreme amount of control "10")	2.27 (3.59)	4.90 (2.95)
Identity ("0" no physical complaints at all - many severe physical complaints "10")	0.53 (1.13)	4.27 (2.57)
Concern ("0" not at all concerned - extremely concerned "10")	1.93 (2.91)	6.50 (2.70)
Understanding ("0" don't understand at all - understand very clearly "10")	6.40 (4.05)	6.80 (2.73)
Emotional response ("0" not at all affected emotionally - extremely affected emotionally "10")	3.73 (3.49)	5.77 (2.99)

B-IPQ: Brief Illness Perception Questionnaire

Table 5: Open question B-IPQ categorized in domains (the numbers represent the number of patients that mentioned this)

Emotional aspects	Physical aspects	Social related aspects
Dreaming about my hair (2)	Hopefully more beautiful hair	Confrontation with illness (4)
Lower self-esteem (2)	after treatment (2)	Confrontation with the outside world (4)
It's hard (4)	Different structure of the hair (2)	It costs more money (1)
Loss of femininity (2)	My head is cold and the wig is sweaty (1)	It is cheaper to use less cosmetics (1)
It made me insecure (1)		
Nothing, no worries (1)		

provides insight into the emotional impact perception. The main similarities with the drawings without additional text were the physical aspects: amount/degree of hair loss and the choice for any head covering. The emotional aspects were only sometimes similar to the facial expressions in the drawings. Association on emotions was mainly found because of the text below the drawings.

It appeared that some details about hair loss, such as reasons to choose for scalp cooling and/or head covering, as well as the experienced confrontation with alopecia only, emerged from the interviews. In five patients, the interview had added value for determining the impact of alopecia, mainly about personal issues, such as the failure of scalp cooling or the impact of alopecia on the patient's job.

## Discussion

To our knowledge, this is the first study to explore the impact of chemotherapy-induced alopecia with drawings. Patients expressed the impact of hair loss differently in drawings compared to questionnaires or interviews only for the physical aspects. The amount of hair loss was depicted in drawings more clearly than patients mentioned in interviews. However, there was minimal change of emotions visible in the drawings, and it was not clear whether patients deliberately drew emotions associated with the hair loss. The

drawing instructions mainly asked about the physical aspects of alopecia and did not ask about the emotional aspects, which is crucial to learn about the overall impact.<sup>[22,23]</sup> Hence, using the current method, only combined with a text below the drawings, the overall view is comparable to an interview and the B-IPQ. Drawings combined with the B-IPQ provided a complete overview of the impact of alopecia, and the interviews mainly added extra details.

The mean perceptions of the B-IPQ scores for alopecia were relatively low in comparison with that of the reference group [Table 4]. It seems that the perception of alopecia is less severe than the perception of breast cancer itself. However, the text below the drawings as well as the open I-BPQ question, and the interview, showed that alopecia was confronting to almost all patients and did affect their life on several domains. This is in line with the literature.<sup>[3,10,24-26]</sup>

This study had some limitations. First of all, the patients did not draw emotional aspects, therefore it is advised that the instructions are adapted. The suggested instructions are *We want to ask you to draw your feelings about your appearance of what your head and hair looked like before the start of the chemotherapy (drawing I), during chemotherapy without head covering (drawing II), and (if applicable) another drawing with head covering (drawing III). We are not interested in your drawing talent, a simple sketch is fine. We are interested in your ideas about any changes in your appearance and your feelings about it, only of your head and hair. Explain your feelings beneath the drawings on the dashed line.*

Besides, patients did not add at least some words under each drawing. They should be motivated to do so in future studies as the text is important to get a complete view of alopecia, especially when there is no additional interview or questionnaire about hair loss.

Another limitation is that the written texts and interviews were transcribed and analyzed by only one researcher, which might have caused interviewer bias. Besides, the

scoring sheet for the drawings did not include ratings of differences in emotions between drawings within patients. In order to limit subjectivity, this latter aspect will be adjusted in the sheet for a future drawing study.

## Conclusion

The drawing method is feasible to retrieve knowledge about the emotional impact of alopecia. As the impact of alopecia seems to be underestimated by health-care professionals,<sup>[14]</sup> drawings could lead to new insights and ultimately to improved patient information to cope with alopecia and support patients. Drawings made with the new instructions are expected to reveal different domains of how patients experience alopecia and specifically the course of their perceptions about alopecia over time.<sup>[15]</sup>

## Informed consent

Informed consent was required for this study and was obtained from all individual participants included in the study.

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## Conflicts of interest

There are no conflicts of interest.

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