

Hair loss impact on quality of life of patients with oncological diseases - pilot study

Monika Szkultecka-Dębek¹, Katarzyna Oszajca², Patryk Wania², Mariola Drozd³

- ¹University of Social Sciences, SAN, Warsaw, Poland
- ²Student Research Club at the Department of Humanities and Social Medicine, Medical University of Lublin, Poland
- ³Department of Humanities and Social Medicine, Medical University of Lublin, Poland

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Corresponding author

Mariola Drozd, Department of Humanities and Social Medicine, Medical University of Lublin, Poland, ul. Chodźki 7, 20-093 Lublin, tel. 81 448 68 50.

e-mail: marioladrozd@umlub.pl

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Monika Szkultecka-Dębek - D 0000-0003-3025-8427 Katarzyna Oszajca - 🕞 0009-0009-0362-842X Mariola Drozd - 10 0000-0002-1214-2386 Patryk Wania - 10 0009-0005-9259-0478

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Hair loss impact on quality of life of patients with oncological diseases - pilot

In oncological treatment hair loss is one of the adverse events related to the use of cytostatic drugs. Hair loss is a problem that to affects people's wellbeing and quality of life.

The aim of the study was to check the impact of hair loss in those patients who alopecia induced by cytotoxic drug therapy.

The study performed from March to April 2018, and it was focused on the adult population of oncological patients who developed alopecia during oncological chemotherapy The study was conducted among 25 people. For that purpose a self designed two questionnaires were developed: one concerning the quality of life and the other the Hair Loss Impact Vignette (HLIV) and validated through the study.

Hair loss in men has little or no effect on shopping, housework and sports, while in women it only affects housework. Both in case of women and men, it has a very strong influence on social life, perception in the environment and contacts with partners, family and friends. The quality of life related to hair loss was the overall result was -0,74 and it is considered as a low. 78,9% of the interviewed women strongly agreed that losing their hair negatively affects their social life or leisure time activities. Both women and men in the vast majority of respondents declared feeling discomfort and depression in connection with the hair loss. Most of the surveyed women believe that the loss of eyebrows and eyelashes is as negative an experience as the loss of the hair on the head. For the majority of men surveyed, the scalp hair is more important than the eyebrows and eyelashes.

The study shows that hair loss in the course of cancer therapy with cytotoxic drugs has the greatest impact on the quality of life in relation to the social functioning and social activities, however does not significantly affect the individual activities.

The pilot study for HLIV vignette validation confirms that the tool is appropriate for use to assess the impact of the hair loss on patients' daily activities.

Keywords: quality of life, vignette, hair loss, oncology.

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Introduction

Due to the role that hair and hairstyle play in our culture and society, hair loss can be the cause of changes in the mental and emotional state of the patient, further affecting his social, professional and family life. In case of oncological treatment hair loss is one of the adverse events related to the use of cytostatic drugs for cancer therapy and according to a number of publications patients associate distress with losing their hair [1-3].

Cytotoxic drugs have a toxic effect on rapidly dividing cancer cells by disrupting their ability to divide, develop or inducing apoptosis. Those have a narrow therapeutic index, and their action often affects healthy, rapidly dividing cells in the body, such as the mucous membranes, bone marrow and hair follicles. The consequence of this is a number of side effects, such as vomiting, anaemia or hair loss [4]. Side effects of chemotherapy are an integral part of it, and if the dose is limited in order to reduce symptoms, the effective therapeutic effect may be lost, therefore, in order to ensure the patient's optimal quality of life during therapy, the side effects are treated symptomatically by administering antiemetic drugs, supplementing the diet with supplements or products of special nutritional purpose. Hair loss is, in most of the cases, impossible to prevent, and remedial measures are often not effective enough to replace the patient's hair loss.

The adverse drug reactions occurring during chemotherapy tr eatment due to cancer are common and often are related to the skin. Often these reactions are mild, however still some of them may require to implement modifications of the treatment regimens [5].

There might be cases of alopecia due to a different mechanism. That is the case of immunotherapy-induced hair loss which differs from the mechanism related to chemotherapy and it may be a manifestation of autoimmunity representing the immune-related adverse events [6]. According to published data alopecia is reported in 1% to 2% of patients receiving immune checkpoint inhibitors for cancer [7].

Since hair loss is a problem that, to a greater or lesser extent, affects people's well-being and quality of life the aim of the study was to check the impact of hair loss in those patients who suffer baldness or alopecia induced by cytotoxic drug therapy. For that purpose a self - designed Quality of Life questionnaire Related to Hair Loss (QoLRHL) and the Hair Loss Impact Vignette (HLIV) were developed and validated through the study.

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Methods

The study performed from March to April 2018, was approved by the Ethical Committee in Lublin and it was focused on the adult population of oncological patients who developed alopecia during oncological therapy. The research material consisted of data collected on the basis of self--designed demographic questionnaire, QoLRHL and the HLIV vignette in order to collect additional information specific to hair loss related issues. The vignette was designed and validated based on the experience from similar previous studies [8, 9]. The research was carried out by an interviewer who collected the respondents' answers in a direct contact. The questionnaire aimed to define respondents' general characteristics. The HLIV vignette, was the technique for measuring the impact of hair loss on patients' quality of life. The vignette consists of two parts. The first part of the vignette is descriptive and dedicated to collect qualitative information from the patient. The second part is based on Likert scale with 5 steps to assess quantitatively hair loss impact on the daily activities. In order to validate and verify whether the HLIV vignette can be used to assess the impact of hair loss on patients daily activities the tool was used among the patients from the Oncology Clinic of the Lublin Region Oncology Center who underwent therapy during which they lost their hair.

The validation was to develop a special scale used for the numerical presentation of the obtained results and allowing for their interpretation. The vignette includes one open-ended question, to which the patients provide answers without limitations, in an open way. The answers were not valued.

The answers to the closed questions were assigned the following values: significant impact (score -2), medium impact (score -1), small impact (score 1), indifferent (score 2) and no impact (score 0). Then, scores from all questions should be summed up and divided by the total number of questions included in the vignette. The calculations are made according to the following formula:

$$HLIV = \frac{\sum_{i=1}^{7} p}{7}$$

HLIV - vignette value;

p – value of the question.

The obtained vignette value should be on a scale of 2 to -2. The interpretation of the obtained result should be carried out in accordance with the kev:

- 1.1-2.0 very low impact on daily activity;
- > 0-1.0 low impact on daily activity;

- 0 no impact on daily activity;
- < 0 −1.0 high impact on daily activity;
- -1.1- -2.0 very high impact on daily activity.

The self-designed QoLRHL was an additional tool used for assessing the quality of life dependent on hair loss, containing opinions of other people that had to be confirmed or denied in relation to each patients personal experience. The questions addressed different aspects of patients life having impact on quality of life, like physical functioning, work, leisure activities, social life. The questionnaire was focused on to what extent did the hair loss in the last quarter impacted patients daily activities. The QoLRHL impact was calculated in the same way as described above.

Samples with some of the questions included in the vignettes and the QoLRHL questionnaire are presented at figure 1.

Statistical significance analysis set at 0.05 was performed and the P values based on 2-sided t tests. All analysis were conducted with MS Excel 2019.

Results

The vignette was validated based on a population of 25 respondents who participated in the study (5 men and 20 women). All respondents were adults: 4 persons up to 30 years of age, 6 persons were aged 31-40, 6 persons aged 41-50, 4 persons aged 51-60 and 5 persons were over 60 years old.

a) OCENA JAKOŚCI ŻYCIA ZALEŻNEJ OD UTRATY WŁOSÓW

Chcielibyśmy zapytać Pana/Pania o własna opinie na temat utraty włosów. Nie ma dobrych i złych odpowiedzi. Jesteśmy zainteresowani Pana/i osobistym zdaniem

Celem tego kwestionariusza jest zbadanie w jakim stopniu utrata włosów wpływała na Pana/Pani życie w ostatnim kwartale.

W jakim stopniu w ostatnim kwartale odczuwał/a Pan/Pani utratę włosów?

- Bardzo mocno
- Bardzo
- Wcale

Poniżej przytoczone są wypowiedzi innych ludzi, ich ogólna opinia o własnych włosach. Prosze wskazać jak bardzo Pan/i zgadza się lub nie zgadza z nimi, zaznaczając właściwą odpowiedź. (Można zaznaczyć tylko 1 raz w linii).

pytanie	Zdecydowanie zgadzam się	Zgadzam się	Trudno powiedzieć	Nie zgadzam się	Zdecydowanie nie zgadzam się
Stan moich włosów wprawia mnie					
w zakłopotanie lub zażenowanie.					
Utrata włosów przeszkadza mi					
w codziennej działalności,					
tj. robieniu zakupów, wykonywaniu					
prac domowych.					
Utrata włosów wpływa negatywnie					
na moje życie towarzyskie lub spędzanie					
wolnego czasu.					
Utrata włosów wpływa negatywnie					
na mój ubiór.					
Utrata włosów przeszkadza mi					
w uprawianiu sportu.					
Utrata włosów utrudnia mi pracę					
zawodową lub naukę.					
Utrata włosów uniemożliwia mi pracę					
zawodową lub naukę.					
Utrata włosów stanowi problem					
w kontakcie z partnerem lub partnerką,					
przyjaciółmi lub rodziną.					
Utrata włosów wpływa negatywnie					
na mój wygląd.					
Utrata włosów wpływa na postrzeganie					
mnie w środowisku,					
w którym mieszkam/pracuję.					

Winieta – utrata włosów u pacjentów poddanych terapiom przeciwnowotworowym²

Dotychczas był aktywny zawodowo, spędzał czas wolny z rodziną i przyjaciółmi, podróżował, uprawiał sport

Jednym ze skutków terapii jest utrata włosów, która ma wpływ na jego życie codzienne takie jak: robienie zakupów, wykonywanie prac domowych, życie towarzyskie, spędzanie wolnego czasu, uprawianie sportu,

wykonywanie pracy zawodowej, kontakty z partnerką, rodziną, przyjaciółmi, postrzeganie w środowisku

Proszę opisać, na które z Pana aktywności dnia codziennego ma największy wpływ zwiększona utrata

wpływ

w związku ze

wpływu

wpływ

U mężczyzny w wieku średnim wykryto nowotwór, który wymagał leczenia chemioterapią

Proszę wskazać stopień utrudnienia w wykonywaniu codziennych czynności

zwiększoną/całkowitą utratą włosów (przy każdym proszę wybrać jedną odpowiedź). wpływ

Od czasu rozpoczęcia leczenia przeciwnowotworowego obserwuje różne objawy uboczne terapii.

Jednak choroba spowodowała, że jego tryb życia uległ zmianie.

Winieta – utrata włosów u pacjentów poddanych terapiom przeciwnowotworowym¹

U kobiety w wieku średnim wykryto nowotwór, który wymagał leczenia chemioterapią Dotychczas była aktywna zawodowo, spędzała czas wolny z rodziną i przyjaciółmi, podróżowała, uprawiała sport. Jednak choroba spowodowała, że jej tryb życia uległ zmianie.

Od czasu rozpoczęcia leczenia przeciwnowotworowego obserwuje różne objawy uboczne terapii Jednym ze skutków terapii jest utrata włosów, która ma wpływ na jej życie codzienne takie jak: robienie zakupów, wykonywanie prac domowych, życie towarzyskie, spędzanie wolnego czasu, uprawianie sportu, wykonywanie pracy zawodowej, kontakty z partnerem, rodziną, przyjaciółmi, postrzeganie w środowisku gdzie mieszka i pracuje.

Proszę opisać, na które z Pani aktywności dnia codziennego ma największy wpływ zwiększona utrata włosów?

Proszę wskazać stopień utrudnienia w wykonywaniu codziennych czynności w związku ze

czynność	duży wpływ	średni wpływ	obojętne	mały wpływ	brak wpływu
Robienie zakupów					
Wykonywanie prac domowych					
Spędzanie czasu wolnego					
Życie towarzyskie					
Kontakty z partnerem, rodziną, przyjaciółmi					
Uprawianie sportu					
Postrzeganie w środowisku					

Robienie zakupów

przyjaciółmi Uprawianie sportu Postrzeganie w środowisku

włosów?

Część 2.

b)

Opis Mężczyzna

gdzie mieszka i pracuje

Wykonywanie prac domowych Spedzanie czasu wolnego Życie towarzyskie

Kontakty z partnerką, rodziną,

Figure 1. QoL questionnaire (a) and HLIV vignette (b) sample, Polish version. Rycina 1. Próba kwestionariusza QoL (a) i winiety HLIV (b), wersja polska.



Opracowały dr n. farm. Mariola Drozd, dr n. med. Monika Szkultecka-Debel

¹ Opracowały dr n. med. Monika Szkultecka-Debek, dr n farm. Mariola Drozd

² Opracowały dr n. med. Monika Szkultecka-Debek, dr hab. n. farm. Mariola Drozd



Table 1. Vignette results.

	Activity impact (n = 25)					HLIV (n = 25)		
Activity	Significant impact	Medium impact	Small impact	Indifferent	No impact	Men	Women	Medium impact
Shopping	7	7	2	4	5	0.80	-0.65	-0.36
Home activities	1	4	1	6	13	1.00	0.80	0.84
Spending free time	13	5	0	4	3	-0.40	-1.15	-1.00
Social life	19	3	3	0	0	-2.00	-1.40	-1.52
Contacts with partner, family, friends	14	3	2	2	4	-0.80	-0.85	-0.84
Sport activities	7	1	1	6	10	1.60	-0.10	0.24
Perception in your environment	18	2	2	1	2	-1.00	-1.35	-1.28
Total						-0.11	-0.67	-0.56
P-value					***************************************	0	.08	_

Table 2. Quality of life related to hair loss – assessment results (n = 19).

	Strongly agree	Agree	Undecided	Disagree	Strongly disagree	QoLRHL
My hair condition makes me uncomfortable10 or embarrassed	13	2	0	1	3	-1.11
Losing my hair disturbs my daily activities, such as shopping, doing housework	11	3	0	1	3	-0.95
Losing my hair negatively affects my social life or my leisure time activities	15	0	1	0	3	-1.26
Hair loss negatively affects my outfit	7	2	5	2	3	-0.42
Losing my hair disturbs me in my sport activities	5	2	5	0	7	0.11
Losing my hair makes my job or study difficult	9	2	4	1	5	-0.47
Losing my hair prevents me from working or studying	6	3	4	2	3	-0.37
Hair loss is a problem when in contact with your partner, friends or family	11	2	1	1	4	-0.79
Losing my hair has a negative impact on my appearance	12	3	1	0	3	-1.11
Losing my hair affects the perception of me in my environment	13	0	3	0	3	-1.05
Total QoLRHL	-		-		-	-0.74

17 respondents were city residents and 8 declared living in a village.

The results were analyzed by the declared impact on different activities and by gender (table 1). Most of the respondents declared significant impact of experiencing hair loss on their social life and the perception in their environment. The less significant impact was on home activities, where most of the respondents (52%) declared no

Table 3. Drug-induced hair loss impact on selected psychological aspects.

Feelings	Gender	Yes	No	p-value
Decreased sense of attractiveness		15	5	
Feeling depressed	women	16	4	0.906
Feeling of discomfort		16	4	
Decreased sense of attractiveness		3	2	
Feeling depressed	men	4	1	0.711
Feeling of discomfort		4	1	

impact, and only 1 respondent assessed the impact as significant. Another type of affected activities were related to contact with the partner and spending free time (56% and 52% respectively). According to the finding of the pilot study hair loss in men has little or no effect on shopping, housework and sports, while in women it only affects housework. Both in case of women and men, it has a very strong influence on social life, perception in the environment and contacts with partners, family and friends.

The QoLRHL (table 2) was assessed on a group of 19 women and the overall result was -0,74 and it is considered as a low. 7 of the respondents declared that they experienced very strongly hair loss in the last quarter (36,8%), and 78,9% of the interviewed women strongly agreed that losing their hair negatively affects their social life or leisure time activities. Also a high number of respondents declared a strong agreement in relation to the effect of hair loss on their perception in their

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Table 4. Feelings related to the loss of eyebrows and eyelashes.

Feelings	Women (n = 20)	Men (n = 5)	p-value
The loss of eyebrows and eyelashes is as negative as the loss of scalp hair	13	1	
Scalp hair is more important than eyebrows and eyelashes	5	4	0.07
Eyebrows and eyelashes are more important than scalp hair	2	0	

environment and feeling embarrassed or uncomfortable due to their hair condition (in both cases 68,4% of respondents).

The effect of hair loss after chemotherapy on the psychological aspect such as discomfort, depression and attractiveness was also assessed. The results are presented in table 3.

Both women and men in the vast majority of respondents declared feeling discomfort and depression in connection with the hair loss. In the case of decreased feelings of attractiveness, 2 men and 5 women answered negatively to this question. The sensation of scalp hair loss was also compared to the loss of the eyebrows and eyelashes. The results are presented in table 4.

Most of the surveyed women believe that the loss of eyebrows and eyelashes is as negative an experience as the loss of the hair on the head. However, for the majority of male respondents, the scalp hair is more important than the eyebrows and eyelashes, and as a consequence the former is a more negative experience. For only 2 women, the loss of eyebrow and eyelash hair was more important than the loss of the hair on the head.

Discussion

The negative influence of baldness on well--being, self-esteem and the quality of life that follows it seems to be justified by the role it plays the hair of the head in the cultural context. The oldest object that testify the special role of hair in the image come from around 30,000 years BCE - the sculpture of Venus from Willendorf, in addition to the exposed sexual characteristics, such as the hips and breasts, has braids carved on a faceless head [10]. Among ancient civilizations, modelling hairstyles, the use of combs, and cosmetics for aesthetic purposes were common practice [11]. In many cultures, hair played a role in rituals, especially in rituals of passage, such as haircuts practiced in the Slavic region accompanying young boys entering adulthood or haircuts associated with the transition of the bride to a married state [12, 13]. In different periods, in different cultures, and among different civilizations, hairstyles were a symbol of status, social position, tribal affiliation or religion practiced [14]. Nowadays,

the hairstyle primarily plays a role in self-identification, building one's own image and identity. It can be an element that distinguishes individual subcultures.

Even if patients who are undergoing chemotherapy treatment are prepared in advance to what can be expected as an adverse event of the therapy, the time when it becomes reality it can cause distress [15, 16]. Hair - loss as well as weight loss, vomiting, infection or nausea are perceived as those events which are most feared in relation to cancer treatment [17]. Alopecia is expected to be observed in 65% of oncological patients after chemotherapy [18]. However even when patients know that in most of the cases the effect is temporary they are affected emotionally and experience the impact of the hair loss on their daily activities and quality of life.

The results of the performed study show that hair loss has the strongest impact on social contacts, i.e. the part of life in which the external appearance is most exposed and subject to evaluation. There is a noticeable tendency regarding social activities, according to which the lack of hair causes discomfort more often in relation to the activities outside the immediate environment, and less often among family, colleagues and those people who are up to date with the patient's life situation. The least frequently reported negative impact was on activities, which were predominantly individual, carried out alone or with negligible participation of others, such as physical activity or studying. The cultural context of hair and its impact on the psyche is also evidenced by the differences in coping strategies between men and women. Men more often take loss with humour, referring to baldness, as a sign of masculinity and they try to mask hair loss to a lesser extent, while women rarely refer to hair directly and mask hair loss more frequently and more efficiently [19].

Similar results were found by other researchers who studied the impact of alopecia after chemotherapy on quality of life. A Turkish study with the use of Chemotherapy-induced Alopecia Quality of Life Scale obtained low scores and confirmed that patients' quality of life was negatively affected by hair loss [20]. Within a multicenter study including patients with persistent chemotherapy-induced or endocrine therapy-induced alopecia after chemotherapy treatment the quality of life was assess with the Hairdex questionnaire. A negative emotional effect was reported by both groups and lower quality of life was observed in the persistent chemotherapy-induced alopecia [21].

Kang D et al. indicate that clinicians should be aware of alopecia as a worrying adverse event and there should be developed supportive care strategies in order to prepare patients for hair loss and to minimize the impact on patients well-being. According to the authors the development of more satisfactory alopecia management strategies should be one of the main research challenges in clinical oncology [22].

With regard to targeted therapies, it is known that these therapies are also associated with an increased risk of alopecia. According to data published by Belum VR et all when studying incidence and risk of developing alopecia during oncological treatment alopecia of all grades was reported in 677/3238 patients treated with targeted therapies, showing an overall hazard ratio of 7.9 (95% CI 6.2–10.09) in comparison to placebo (67/2373 patients). According to authors it is crucial for the maintenance therapy, adherence to therapy and in order to be able to maintain patients' quality of life [23].

Alopecia is also a common however still underreported adverse event of the hormone-based cancer therapies. The long-term use of such treatment in oncology increases its importance in relation to the impact on the quality of life of patients with cancer [24].

Limitations

The limitations of the study include a relatively small number of respondents and the fact that it was conducted only among patients of one hospital. However, according to our knowledge, this is the first study covering the impact of drug-induced alopecia on the quality of life in Poland. Participants in the study participated in the study voluntarily, and there was no control group included in the study. Participants in the study may have had a previous problem with hair loss, observed before the use of oncological drugs. Despite these limitations, the study showed a high incidence of alopecia, which according to respondents affected their quality of life.

We hope that this study findings will enable to use HLIV vignette as a tool to better adjust the therapeutic approach in the case of patients treated for cancer in assessing the impact of the side effect of alopecia on their quality of life.

Conclusions

The study shows that hair loss in the course of cancer therapy with cytotoxic drugs has the greatest impact on the quality of life in relation to the social functioning and social activities, however does not significantly affect the individual activities

The pilot study for HLIV vignette validation confirms that the tool is appropriate for use to assess the impact of the hair loss on patients' daily activities.

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