Lost but found: A thematic analysis of cancer patients’ experience of coping with hair loss

By Hillary Smith

(MA, PGDip, MBACP Accred.)

Keywords: Hair loss, cancer, chemotherapy, counselling, support, coping

Abstract

Introduction: Research tells us 1 in 2 people will receive a diagnosis of cancer. Cancer is a global disease affecting adults and children, it pays no attention to gender, race or sexual orientation. This ever-expanding client group will endure side effects and psychological repercussions from a diagnosis and treatment. Despite not being a life-threatening side effect chemotherapy-induced hair loss should not be underestimated for its impact.

Aim: This qualitative study explored the lived experience of hair loss and what coping mechanisms and support were helpful to cancer patients, with a view to provide therapists with an understanding of the supportive needs of this client group and what they may bring to the therapy space.

Method: Semi-structured interviews were conducted with eleven participants, and thematic analysis was used to analyse the verbatim transcripts.

Findings: Five themes were identified: Impact of initial change; Hair loss as a metaphor; Hair loss as a distraction; Adjustment to new self; and Past reflections, future contemplations. These themes form a picture of progression through the hair loss experience from initial responses to adjustment with internal and external coping mechanisms to a reflective perspective.

Discussion: Participants stated that hair loss was an impactful side effect of their chemotherapy that represented their cancer and needed continual management. Adjusting to the hair loss was an individual process with commonalities involving camouflage, mental resilience and external support. Therapists can provide a vital support mechanism to assist cancer patients with their hair loss experience before, during and after cancer treatment.

Acknowledgements

The author would like to extend thanks and appreciation to all the participants who gave their time to discuss their experiences, without which this research would not have been possible. Paul’s Cancer Support Centre for their assistance in participant recruitment and providing interview space. Elizabeth Wilson at the University of East London for her support and guidance.

Introduction

For therapists, cancer patients represent a growing client group. According to Ahmad et al. (2015) there is a 50% lifetime risk of cancer for people born since 1960. This risk is cumulative and increases with longevity of life. This research led Cancer Research UK and Channel 4's collaboration 'Stand Up 2 Cancer' (2016) to use the slogan '1 in 2' to raise awareness of the risk. Is hair loss a side effect that should be of concern to a therapist? Current research into prevention of hair loss for cancer patients would indicate the answer is yes. 65% of patients receiving chemotherapy will experience hair loss according to Shah et al. (2018). With the number of people living and coping with cancer and treatment side effects, it is not just about survival but wellbeing. Macmillan (2013) produced a report estimating 'that at least 500,000 people living with and beyond cancer have one or more physical or psychosocial consequences of their cancer or its treatment that affects their lives on a long-term basis' (p.8). Talking therapies has and will continue to play a major role in the support network needed by this growing client group (Cancer Research UK, n.d.; National Counselling Society, 2019; Arch, Vanderkruik, Kirk & Carr, 2018).

Experience of hair loss from cancer treatment

Watanabe et al. (2019) study on long-term hair loss for breast cancer patients in Japan described hair loss as 'psychologically traumatic' (p. 2). The 1478 patients ranked hair loss as the most traumatic side effect with 82.6% describing hair loss as severe or moderate. The authors state that patients likely to experience hair loss should be informed of what is typical, which would allow time to prepare for the experience, and conclude that further studies with a focus on supporting patients with hair loss as well as prevention are needed.

Research into women's experiences of chemotherapy-induced hair loss are readily available (Clements, 2017; Trusson & Pilnick, 2017; Power & Condon, 2008; Freedman, 1994). Hansen's (2007) study concluded that hair loss for women represented a loss of femininity and was a symbolic sign of death. The use of wigs and make-up to camouflage the hair loss formed part of a process of identity formation.

Studies have focused on the consequences of chemotherapy-induced hair loss. Carpenter and Brockopp's (1994) mixed method study determined that female participants self-esteem was significantly lower whilst experiencing alopecia. Williams et al. (1999) study focused on how a person's identity is impacted, with an altered sense of self. The responses of others to a change in appearance is an additional consideration explored by Rasmussen, Hansen and Elverdam (2010). This study found that regardless of gender or cancer diagnosis, all visible body changes including hair, impacted social interactions and a need to hide body changes. These studies point to self-esteem, confidence, self-consciousness, identity and body image that could require addressing within a counselling or healthcare setting.

The temporary nature of the hair loss may cause the emotional impact to be underestimated (Borsellino & Young, 2011). According to Trüeb (2013) the trivialisation of hair loss by physicians and the view of hair loss as medically negligible could be seen to add to patient worry.

Alopecia

One area of research crossover is alopecia, a lifelong condition that requires coping strategies to manage its impact that is felt severely without a life-threatening diagnosis. Hunt and McHale's (2005) literature review of the psychological impact of alopecia summarised anxiety and depression as consequences, with sense of self and identity being affected. Cash (2001) explores the differences between men and women with androgenetic alopecia (AGA), men noting issues with social acceptance and self-consciousness. For women AGA is less known and more distressing, reducing a positive body image and quality of life. The study details coping strategies employed by men, of which wearing better clothing, camouflaging hair loss and seeking assurance from others would be relevant to cancer patients. Matzer, Egger and Kopera's (2011) study indicated for those with relapse or chronic alopecia active engagement and openness was the most helpful coping strategy. The study confirmed that 84% of participants experienced anxiety and depression, feeling unattractive and alienated from themselves and 80% reported social discomfort and withdrawal.

Counselling for cancer

There are many studies focussing on the efficacy of counselling interventions and approaches for cancer patients: Psychodynamic (Beutel et al., 2014); CBT (Ye et al., 2018); Motivational Interviewing (Spencer & Wheeler, 2016); Existential (Bauereiß et al., 2018); Narrative (Wise et al., 2018). As there is limited detail in these systematic reviews and randomised controlled trial studies on specific interventions with clients, the practical application is limited. The study by Omylinska-Thurston and Cooper (2014) highlights that cancer patients want to discuss overwhelming feelings and adjustment issues, where the relational skills of the counselling psychologist were key to what clients thought was most helpful.

Watson and Kissane (2011) provide a reference book on individual and group psychotherapy approaches for cancer care, providing comprehensive discussion of models and their efficacy, case examples and specific techniques which would be valuable to any therapist working with cancer patients. The absence of hair loss as a topic within this text is indicative of how hair loss can be trivialised against the enormity of a cancer diagnosis and demonstrates the need for specific research for therapists.

Lederberg and Holland (2011) note that flexibility is required by therapists and psycho-oncologists to meet the changing needs of each patient, with an understanding of the medical reality and prognosis to offer appropriate psychological support. Part of tailoring the support offered to this group would include an element of psycho-education regarding coping strategies.

This study set out to explore the lived experience of hair loss for cancer patients, and to provide therapists with an insight into the successful coping strategies used by the participants. From the interpreted findings, an aim was to provide an understanding of the topics of importance that may be presented in the therapy room when working with hair loss with this client group.

Methods

Design

A qualitative approach was undertaken to explore the lived experienced of hair loss for cancer patients and their coping strategies to manage this side effect. Thematic analysis was selected as it is not tied to any theoretical or epistemological stance and offers a flexible approach to analysing data over smaller or larger data sets (Nowell et al., 2017). Engagement with the research topic sat within an interpretivist paradigm where knowledge is mutually constructed and an exploration of how phenomena impact individuals is set alongside social interactions and meanings (O'Donoghue, 2007). The author's ontological position is subtle realism, which states that reality and research is subjective (Duncan & Nicol, 2004) and reality is known by our perspective in it (Angen, 2000).

Participants

All 11 participants (ten females, one male) had experienced chemotherapy-induced hair loss. As a retrospective study the age range of the participants at the time of experiencing hair loss varied (see Table 1). Ethical approval for the study was granted by the University of East London's Research Ethics Committee. There were four criteria for participant inclusion in the study. 1. Minimum of 18 years old. 2. Experienced hair loss from cancer treatment. 3. Treatment that induced the hair loss to be completed and regrowth of hair to have occurred. This enabled participants to reflect on the whole experience, alongside ethical considerations regarding causing distress to those still experiencing their treatment. 4. Not received counselling from the researcher, to ensure clear role boundaries are maintained during the interview process for the benefit of participant and researcher.

Participants were recruited with the assistance of the charity Paul's Cancer Support Centre, where the author is a volunteer counsellor. Interested participants were supplied with a comprehensive invitation letter and the schedule of questions to allow for an informed choice regarding participation. Participants were informed their confidentiality would be maintained with anonymised codes. Consent for audio recordings was obtained.

Data collection

Semi-structured interviews were conducted, allowing for a controlled focus on the research topic, with the flexibility for participants to express themselves and expand their answers on what they felt was significant (French, Reynolds & Swain, 2001). This sits comfortably within an interpretivist framework where the individual's lived experience and construction of their reality is to be explored (Ponterotto, 2005).

All participants were initially offered face-to-face interviews with location options being either at their home, at the author's private practice consulting room or at Paul's Cancer Support Centre. Eight interviews were conducted face-to-face. Two interviews were carried out via telephone, and one via video conference. All interviews were audio recorded and ranged from 40 to 130 minutes. The author conducted the interviews and produced verbatim transcripts. Participants were asked to describe: their treatment and the impact it had on their hair; their experience of hair loss; how they coped and behaved; the support they received; what was helpful or unhelpful; the influence of hair loss on any future treatment decisions.

Data analysis

The analytic method employed was thematic analysis, specifically the six-phase process described by Braun and Clarke (2006). An inductive analysis approach was used to code the transcripts systematically for semantic features. A broader analysis of the codes into themes collating relevant data extracts was undertaken. A two-level review of the themes considering the coded extracts and the entire data set allowed for theme refinement and ensured an accurate representation of the data set.

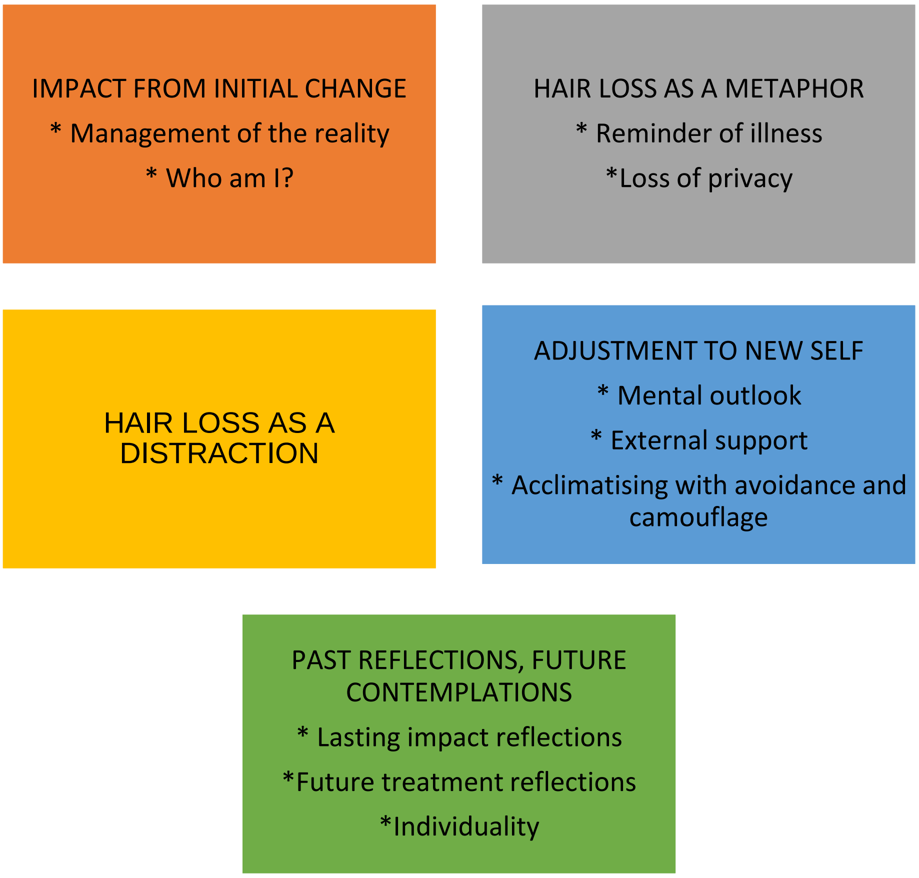
Reflexive statement

I have a strong interest in this research topic from my own experience working with cancer patients. Several clients have brought to my attention their difficulty with hair loss, which had influenced their decision to decline further chemotherapy against medical advice. As a therapist I advocate for client autonomy. However, if treatment options are declined due to lack of support to cope with distressing side effects, then exploring these experiences can only enlighten those providing support. I am aware I started the process of research with a perspective influenced by my experience, and to ensure my bias was as limited as possible I kept a journal of reflection throughout the research process.

Findings

The findings of this study have been organised into five themes: Impact of initial change; Hair loss as a metaphor; Hair loss as a distraction; Adjustment to new self; Past reflections, future contemplations. Four themes are divided into subthemes shown in Figure 1. There is a clear progression from initial responses to hair loss to a period of adjustment utilising both internal and external coping mechanisms and support to a perspective that is reflective of the hair loss experience.

Figure 1 Thematic map



Theme 1: Impact of initial change

Subtheme 1.1: Management of the reality

This subtheme captures the participants response to their hair loss and what action was taken to cope with the reality. Three female participants chose to cut their head hair shorter before significant loss occurred, as a way of softening the impact or an attempt to slow the loss. Seven female participants described getting to a point where shaving their heads was necessary either to avoid watching the rest of their hair fall out, or as a way of tiding up what remained. PT04 commented 'I think actually I would have gone through a bigger loss had it been slow…there are thoughts of just having clumps and bits of hair…that would have been much worse'. There does appear to be a correlation between the speed of hair falling and participants who discussed the need to shave their heads (see Table 2). The male participant PT01 who experienced a gradual loss of hair chose to shave his beard 'that was getting very ragged so I shaved what was left of it off but I didn't do anything with the rest of the hair I just let it sort of drop out'. The decision to shave was a way of taking control of what was being lost, offering a finality to the process, and acts a beginning to adjustment.

Subtheme 1.2: Who am I?

This subtheme centres on self-image and the negative language used by the female participants. Participants described not recognising their reflections, alongside the hair loss effecting their femininity and gender identity. PT09 stated 'I looked more boyish…it just looked ridiculous' from her first chemotherapy. PT11 said 'I just felt ugly'. PT04 described herself as a 'cross between a fat buddha and a very well-fed concentration survivor'.

The association of hair and identity was expressed as PT04 stated 'people would recognise me based on my hair…it was unique to me'. PT07 discussed her upbringing and its influence 'there was this big thing about a woman's hair being her glory'.

The combination of hair loss coupled with bloating from steroids had a negative impact on how participants viewed their changed appearance. PT05 stated 'your face changes completely…you become like a water melon…I just looked like an egg'. In addition, there was a connection made between the loss of eyebrows and eyelashes and appearing ill.

Theme 2: Hair loss as a metaphor

Subtheme 2.1: Reminder of illness

Participants found that the visual impact of the hair loss served as a direct reminder of their illness and discussed the prominence of it and its daily impact. PT10 commented 'it was an absolute constant reminder that you were ill because you couldn't get away from it'. PT11 described the hair loss as 'a tangible thing you can grasp is happening to you when it when it's happening…I didn't know what was going on in the cells in my body but I could see what was happening with my hair…I suppose it was making the whole cancer thing real'. As a way of making sense of an illness and treatment that operates at a cellular level, hair loss offers a visually discernible change to what might remain unseen.

Subtheme 2.2: Loss of privacy

The participants expressed a loss of privacy around their diagnosis due to the visuality of the hair loss to others. PT08 disclosed 'I kept control over who knew I had a blood cancer for many years…but all of a sudden I was outed'. This extended into ways of camouflaging the hair loss on the scalp, as PT04 commented 'I just felt I had a neon sign that said cancer cancer cancer' when wearing a beanie cap.

Theme 3: Hair loss as a distraction

When a side effect as observable as hair loss presents itself, some participants found it could offer respite to the devastation felt from a diagnosis of cancer and the uncertainty that surrounds it. PT08 commented that hair loss 'was a diversion from the very serious nature of my illness… it became a bit of a sort of a transitional object really that I could you know focus on'. PT04 reflected 'actually if you talked to me during my treatment I blamed everything on the treatment…I wasn't sick as far as I was concerned it was the treatment that was making me sick'. With shifting side effects hair loss was discussed as a key feature, which had stability throughout treatment. When comparing hair loss with mortality, the latter is considerably more difficult to accept and comprehend, which was summarised by PT04 'it's easier to be devastated about that than it is about the cancer'.

Theme 4: Adjustment to new self

Subtheme 4.1: Mental outlook

This subtheme collates the participants reassuring self-talk that helped with adjustment to their new image. Thinking centred on the temporary nature of the hair loss as PT03 stated 'what really kept me focused is the knowing that it's temporary'. Self-talk that minimised the hair loss was present, with comparisons to more serious side effects and pain. PT01 commented 'in the whole scheme of things it's a relatively minor part of it…you've got to concentrate on the more important things of receiving treatment and keeping your spirits up'. Participants viewed their hair loss as an inevitable part of the treatment process, and an indicator that the chemotherapy was working, alongside efforts to make the most of the situation. PT10 commented 'it was one of those necessary evils really'. PT02 reflected 'there's nothing you can do about it so just have to make the most of it really…just have to embrace it'.

Subtheme.4.2: External support

External support featured clearly in the participants stories with three distinctions: family and friends; other patients; medical and non-medical professionals. These external groups offered a layering effect of support that was crucial to the participants ability to cope with the hair loss, their diagnosis and treatment.

Maintaining a social network of people who knew about their diagnosis was important as it offered both emotional and practical support. Family members played a significant role in caring for participants and aiding with managing the hair loss and changed appearance. Many of the participants recalled having assistance with shaving their heads or help with camouflaging ideas. PT08 commented 'I tried to make it as fun as possible…and had a head scarf tying party…and people bought me scarves'.

Participants found that other cancer patients were a crucial resource for support and information. PT06 stated 'I had the opportunity of going and meeting another patient…she was a big big inspiration for me'. PT07 commented 'I think the best advice is to talk to somebody who's lost their hair who basically you know has been through it already and come out the other side'.

Practical workshops on camouflaging skills were key to some female participants in building coping mechanisms. Assistance with wigs, how to tie head scarves, and make-up lessons all featured as helpful activities for participants who were able to attend what was on offer locally. Communication and care from medical professionals were valuable, as PT05 commented on her nurse 'she was really really supportive and had seen so many bald women…she was looking at us like we were just normal so that was really nice'. However, PT10 stated 'I got a lot more support from the other people going through chemo…than we did from a lot of the medical staff at our hospital'. PT07 described 'there was no understanding that even though the chemotherapy unit was saying they can't actually formally recommend a company to go to or a hairdresser to go to the suggestions that they gave were all for white women really'.

Subtheme 4.3: Acclimatising with avoidance and camouflage

Three participants made specific reference to avoiding mirrors as a way of coping initially with the impact of hair loss. All female participants engaged in forms of camouflage to cover or hide the hair loss from their scalp and face. Participants felt self-conscious with an awareness of people staring and wanting to look normal. PT02 commented 'I did wear a wig when I went out I would never have not worn a wig…far too self-conscious'. PT07 said 'I bought two scarves and head wraps…that helped as people were used to seeing me in scarves and head wraps'. Make-up played an important role as PT11 stated 'I wore quite a lot of make-up then…just anything to make myself look better'.

Climate influenced the ease of transition with hair loss alongside blending in with a crowd as PT03 commented 'going out there with my hat on…that's definitely the best way I was able to cope because I felt almost normal wearing the hat when I was outside'. Temperature, correct fitting and comfort with wigs and head coverings lead to experimenting with alternatives.

Many participants discussed the change to camouflage techniques that they utilised as part of a process of experimenting and acceptance. Some participants were able to abandon their camouflage items once they started to feel better or knew the treatment was working. PT05 commented 'I was just charged by the positive outcome…so I just decided not to wear the wig anymore and erm embrace it'. When asked why she felt able to stop using the wig PT05 replied 'the fact I was a survivor so nothing else mattered'.

Theme 5: Past reflections, future contemplations

Subtheme 5.1: Lasting impact reflections

This subtheme captures the participants reflections on their hair loss experience. When asked if the hair loss had a lasting impact PT01 stated 'no none at all'. PT03 responded 'while it lasted yes…it is in the past because I have my hair back but it's definitely something that will be with me forever'.

An element of perspective had been gained through the experience which allowed some participants to reflect on the hair loss as being smaller in comparison to more existential concerns. PT08 reflected 'when you're going through chemo you get a bit of perspective…and it's about survival not about worrying about your hair'. PT06 stated 'it made me a stronger person…you can survive without hair'. The difference between how hair loss was experienced in the moment and reflected on was summarised by PT11 'this becomes something that you can just put behind you…that in the grand scheme of things it's such a little part of your life…it really isn't as important as it feels but does feel huge'.

Subtheme 5.2: Further treatment reflections

When asked about future treatments all participants confirmed they would not decline chemotherapy based on the possibility of hair loss. PT04 stated ‘we have our comfort blankets and hair in particular can be a kind of a comfort blanket but to think that I would risk dying because of my hair seems a very frivolous thing’.

Participants felt they would better manage the hair loss a second time. PT05 reflected ‘if I had to go through it again it wouldn’t be as devastating as last time’. Three participants said they would shave their heads as a pre-emptive action to cope with the hair loss a second time.

Two participants had experienced hair loss from separate treatments. For PT09 maturity played a role in managing her hair loss. The first experience PT09 describes ‘I found it difficult to accept…I tried to hide it’. Whereas ‘second time round I didn’t have so many issues with it it was just more my health…you’re older a bit more confident…I found it really liberating’. PT02 commented ‘the hair loss didn’t worry me at all the second time…the first time you do yeah you just feel that bit more self-conscious’.

Subtheme 5.3: Individuality

This subtheme centres on the participants reflections and appreciation of what an individual experience hair loss is. PT01 commented ‘each person has an experience which is individual to him or her and I don’t think you can generalise’. PT02 stated ‘I think my attitude was probably different to a lot of people…for me losing my hair wasn’t the worse thing’. PT05 said ‘every experience is different it’s like a pregnancy’. PT10 commented ‘it’s time to adjust and find you know the best way you can do that…it’s just individual’. Much of the individuality of the experience relates to the variation in the areas of hair loss and the timeframe in which the hair was lost (see Table 2).

Discussion

There are clear stages of preparation, initial response, adjustment, acceptance and reflection within the hair loss experience which informs how an individual will cope.

The diversity regarding speed of hair loss within the study group (see Table 2) appears to have a direct correlation with how the participants prepared and responded initially, therefore is of importance to therapists. Therapists should be cognisant of their reaction to a client’s loss of hair and changed appearance, as well as being mindful of mirrors or window reflections in a treatment room which may serve as a distraction for a client avoiding their reflection.

Mental and behavioural preparation as part of anticipatory coping strategies may be helpful (Frith, Harcourt and Fussell, 2017; Borsellino and Young, 2011). Engagement with any preparation may be influenced by acceptance of the hair loss or time available to comprehend and plan. Despite participants being informed of hair loss occurring, what is consistent across most female participants was action to shave their scalps occurred once significant hair had fallen. This action coincided with the reality of the hair loss occurring and reflects a need to take control. Those patients trying the cold cap as a preventative measure may be less likely to prepare for the hair loss.

There is an association with hair, gender and identity (Rasmussen and Marriott, 2019; Arikan Dönmez, 2018; Johnson and Bankhead, 2014; Weitz, 2004; Synnott, 1987). There are far fewer studies comparing the gender response to hair loss (Hilton et al., 2008). What the current study has reiterated is that the female participants struggled at least initially to connect with their reflections, and what the change meant for their gender identity. As part of facilitating the adjustment to the self-image, clients may need help exploring the shocking impact of the hair loss and understanding what role their hair played as part of their identity. There is a conflict within some participants of being devastated by the hair loss initially and preoccupied with their appearance to a reflective and critical position of questioning their own vanity, without seeing the distraction as a coping strategy. The unrelenting visual nature of hair loss and its management can require effort, mental resilience and experimentation. Therapists may find that the loss of privacy from their clients' changed appearance and their embodiment of the cancer patient stereotype could feature as a starting topic to deeper work on exploring the meaning of their diagnosis.

Theme 3 *Hair loss as a distraction* offers a conflict to theme 2 *Hair loss as a metaphor*. It may be tempting to encourage any client to let go of the distress of hair loss, but what is left in its absence? For some participants hair loss was something to focus on, a way of trying to comprehend what was happening without contemplating their own mortality. After all it is the treatment that causes hair loss not the cancer itself. Therapists should consider what their clients gain from focussing on hair loss and what they may be avoiding that is too difficult to confront. The loss of hair may offer a way of exploring one's own mortality albeit indirectly. Cancer patients will experience a plethora of treatment side effects which could be the focus of therapy until treatment success is confirmed and a reduction in the physical demands allows for reflection.

The ability for participants to draw on positive thoughts regarding their hair loss appeared to alter over time. Within the hair loss experience some participants were able to find comfort from the temporary nature, treatment success and comparison to other side effects earlier, whereas other participants took longer. Similarities occurred with Rosman's (2004) study regarding how female participants utilised a positive mental outlook on hair loss after experiencing a devastating initial impact. The current study participants found that being told positive comments repeatedly did not help, they had to get there of their own accord. The impact of others attempting to boost positivity could be taken as a rejection of negative feelings, a sense of being dismissed or misunderstood. Part of any therapeutic work could centre on the well-intentioned action of others that clients find themselves facing.

Strong family and friend's involvement aided how participants coped with their diagnosis, treatment and hair loss. What might be crucial for therapists to explore with clients is their practical and emotional support networks.

Therapists may find that clients disclose anxiety over a lack of information. Shock of the initial diagnosis and pain influenced how much information participants were able to retain. Participants stated that information on why the hair loss occurs and the hair growth cycle, alongside practical guidance on how to treat their scalp and prepare for hair regrowth would have been helpful. Much of this information was provided by other cancer patients. The impact of *chemo brain* on cognitive function was significant for participants as it impeded their memory, recalling words and concentration, all of which may impede therapeutic work as well as attendance. Therapists should be mindful that repetition of thoughts or topics could be due to a combination of the client's working process and *chemo brain*.

Despite not wanting to experience hair loss again, all participants stated that hair loss would not cause them to decline or choose a reduced treatment protocol for further treatment, therefore this study did not concur with other studies (Tierney & Taylor, 1991; Hesketh et al., 2004). It is important to be mindful that the participants in this study were not currently experiencing major hair loss at the time of being interviewed nor were they undergoing palliative treatment plans.

Some participants found their hair loss experience liberating and were able to reflect on it positively. As this study has shown there is a change in the participant's perspective to the hair loss, as time proceeds and hair grows, so does an ability to reflect positively on the experience. Therapists need to be aware of this evolution, and where their client is at present. With a broadening of perspective and a comparison of hair loss versus survival, some clients may react disparagingly towards themselves for focusing on their hair more than their life.

Participants reflected that hair loss is an individual experience, and a learning process evolved. For the female participants there was a period of experimentation with camouflage techniques. This concurs with Hansen's (2007) study where camouflaging the hair loss was part of identity formation. A client may need encouragement and reassurance to explore and experiment with how to adjust to their hair loss. Possible referral suggestions to support services need to consider a client's energy levels, physical mobility and what services are available locally. With a growing online network of support groups on different platforms considering what skills and technological devices a client has access to could alter any suggestions offered.

The issue of service provision according to race was raised. There is a need to ensure that support is offered and tailored equally to individuals. Understanding the different needs of cancer patients on a racial and cultural level is fundamental for therapists and all other health care professionals.

Limitations of study

A limitation with this study is the gender imbalance of the participants. Additional male participant contributions could have offered alternative viewpoints. Representation from Black, Asian and Minority Ethnic participants was lower than White participants which could impact the findings. Regional differences in support and NHS provision need to be considered, as most participants were based in London access to wider support networks and charitable services would have been more prevalent.

Further research

As stated by Hilton et al. (2008) further research into the male experience of hair loss from cancer treatment requires a focused attention. There is a lack of research on the experiences of hair loss for Black, Asian and Minority Ethnic cancer patients in the UK. With Britain being a multiracial and multicultural society further research into the experience of cancer and hair loss for different racial and cultural groups is needed.

Conclusion

The findings of this study offer an insight into the lived experience of hair loss for cancer patients with reference to coping strategies and supportive needs. Hair loss should not be underestimated regarding its physical and emotional impact, it represents complex associations with illness, dying, and self-image that require support on emotional and practical levels. The hair loss experience is an individual journey that begins with loss followed by finding an evolving coping style before reaching the other side and a reflective perspective.

References

Ahmad, A., Ormiston-Smith, N., & Sasieni, P. (2015) Trend in the lifetimes risk of developing cancer in Great Britain: comparison of risk for those born from 1930 to 1960. *British Journal of Cancer, 112*(5), 943-947. DOI:10.1038/bjc.2014.606

Angen, M. (2000) Evaluating interpretive inquiry: reviewing the validity debate and opening the dialogue. *Qualitative Health Research, 10*(3) 378-395. DOI: 10.1177/104973230001000308

Arch, J., Vanderkruik, R., Kirk, A., & Carr, A. (2018) A closer lens: cancer survivors' supportive intervention preferences and interventions received. *Psycho-oncology, 27*(5) 1434-1441. DOI:10.1002/pon.4526

Arikan Dönmez, A. (2018) The most apparent aspect of chemotherapy: Alopecia: Is it possible to prevent it? Sdü Sağlik Bilimleri Enstitüsü Dergisi, 9(2) 150-155. DOI:10.22312/sdusbed.324863

Bauereiß, N., Obermaier, S., Özünal, S., & Baumeister, H. (2018) Effects of existential interventions on spiritual, psychological, and physical well-being in adult patients with cancer: systematic review and meta-analysis of randomized controlled trials. *Psycho-Oncology,* 27(11) 2531-2545. DOI:10.1002pon.4829

Beutel, M., Weißflog, G., Leuteritz, K., Wiltink, J., Haselbacher, A., Ruckes, C.,… Brähler, E. (2014) Efficacy of short-term psychodynamic psychotherapy (SPSS) with depressed breast cancer patients: results of a randomized controlled multicentre trial. *Annals of Oncology,* 25(2) 378-384. DOI:10.1093/annonc/mdt526

Borsellino, M. & Young, M. (2011) Anticipatory coping: Taking control of hair loss. Clinical Journal of Oncology Nursing 15(3) 311-315.

Braun, V., & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2) 77-101. DOI:10.1191/1478088706qp063oa

Cancer Research UK. (Accessed 2019, April 17) Coping with cancer how counselling can help. Retrieved from https://www.cancerresearchuk.org/about-cancer/coping/emotionally/talking-about-cancer/counselling/how-counselling-can-help

Carpenter, J., & Brockopp, D. (1994) Evaluation of self-esteem of women with cancer receiving chemotherapy. *Oncology Nursing Forum*, 21(4) 751-757.

Cash, T. (2001) The psychology of hair loss and its implications for patient care. *Clinics in Dermatology*, *19*(2) 161-166. DOI:10.1016/S0738-081X(00)00127-9

Channel 4. (2016, October 13) Stand up 2 cancer: One in two will get cancer. Retrieved from https://www.channel4.com/programmes/stand-up-to-cancer/articles/all/one-in-two-will-get-cancer/4862 (Accessed 2019, March 30).

Clements, M. (2017) Chemotherapy-induced alopecia and quality-of-life: Ovarian and uterine cancer patients and the aesthetics of disease. *Graduate Theses and Dissertations*. Retrieved from http://scholarcommons.usf.edu/etd/6815

Duncan, E., & Nicol, M. (2004) Subtle realism and occupational therapy: an alternative approach to knowledge generation and evaluation. *British Journal of Occupational Therapy, 67*(10) 453-456.

Freedman, T. (1994) Social and cultural dimensions of hair loss in women treated for breast cancer. *Cancer Nursing, 17*(4) 334-341. DOI:10.1097/00002820-199408000-00006

French, S., Reynolds, F., & Swain, J. (2001) *Practical research a guide for therapists* (2nd Ed.) Oxford, England: Butterworth Heinemann.

Frith, H., Harcourt, D., & Fussell, A. (2007) Anticipating an altered appearance: Women undergoing chemotherapy treatment for breast cancer. *European Journal of Oncology Nursing*, *11*(5), 385-391. DOI:10.1016/j.ejon.2007.03.002

Hansen, H. (2007) Hair loss induced by chemotherapy: An anthropological study of women, cancer and rehabilitation. *Anthropology & Medicine*, *14*(1), 15-16. DOI:10.1080/13648470601106335

Hesketh, P., Batchelor, D., Golant, M., Lyman, G., Rhodes, N., & Yardley, D. (2004) Chemotherapy-induced alopecia: psychosocial impact and therapeutic approaches. *Supportive Care in Cancer*, *12*(8) 543-549. DOI:10.1007/s00520-003-0562-5

Hilton, S., Hunt, K., Emslie, C., Salinas, M., & Ziebland, S. (2008) Have men been overlooked? A comparison of young men and women's experiences of chemotherapy-induced alopecia. *Psycho-Oncology, 17*(6) 577-583. DOI:10.1002/pon.1272

Hunt, N., & McHale, S. (2005) The psychological impact of alopecia. *BMJ, 331*(7522) 951-953. DOI:10.1136/bmj.331.7522.951

Johnson, T. & Bankhead, T. (2014) Hair It Is: Examining the Experiences of Black Women with Natural Hair. *Open Journal of Social Sciences*, 2, 86-100. DOI:10.4236/jss.2014.21010.

Lederberg, M., & Holland, J. (2011) Supportive psychotherapy in cancer care: an essential ingredient of all therapy. In Watson, M. & Holland, J., (Eds) *Handbook of psychotherapy in cancer care* (pp. 3-14) Chichester, England: John Wiley & Sons.

Macmillan. (2013, July) Throwing light on the consequences of cancer and its treatment. Retrieved from https://www.macmillan.org.uk/documents/aboutus/research/researchandevaluationreports/throwinglightontheconsequencesofcanceranditstreatment.pdf (Accessed 2019, March 30).

Matzer, F., Egger, J., & Kopera, D. (2011) Psychosocial stress and coping in alopecia areata: a questionnaire survey and qualitative study among 45 patients. *Acta Dermato-Venereologica*, *91*(3) 318-327. DOI:10.2340/00015555-1031

National Counselling Society (2019, January 8) Counselling for cancer. Retrieved from https://www.nationalcounsellingsociety.org/blog/counselling-for-cancer/ (Accessed 2019, April 17)

Nowell, L., Norris, J., White, D., & Moules, N. (2017) Thematic analysis: striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods 16*(1) 1-13. DOI:10.1177/1609-406917733847

O'Donoghue, T.A. (2007) *Planning your qualitative research project an introduction to interpretivist research in education*. London, England: Routledge.

Omylinska-Thurston, J., & Cooper, M. (2014) Helpful process in psychological therapy for patients with primary cancer: a qualitative interview study. *Counselling and Psychotherapy Research*, *14*(2) 84-92. DOI:10.1080/14733145.2013.813952

Ponterotto, J. (2005) Qualitative research in counselling psychology: a primer on research paradigms and philosophy of science. *Journal of Counseling Psychology, 52*(2) 126-136. DOI:10.1037/00220167.52.2.126

Power, S., & Condon, C. (2008) Chemotherapy-induced alopecia: a phenomenological study. *Cancer Nursing Practice, 7*(7) 44-47. DOI:10.7748/cnp2008.09.7.7.44.c6682

Rasmussen, D., Hanson, H., & Elverdam, B. (2010) How cancer survivors experience their changed body encountering others. *European Journal of Oncology Nursing*, *14*(2) 154-159. DOI:10.1016/j.ejon.2009.10.001

Rasmussen, T. & Marriott, P. (2019, May 3.) Vibrant colors, buzzcuts, & freedom: This is non-binary hair in all its glory. Retrieved from https://www.refinery29.com/en-us/non-binary-hairstyles-hair-color

Rosman, S. (2004) Cancer and stigma: experience of patients with chemotherapy-induced alopecia. *Patient Education and Counseling, 52*(3)333-339. DOI:10.2016/S0738-3991(03)00040-5

Shah, V., Wikramanayake, T., Delcanto, G., Van Den Hurk, C., Wu, S., Lacouture, M., & Jimenez, J. (2018) Scalp hypothermia as a preventative measure for chemotherapy-induced alopecia: a review of controlled clinical trials. *Journal of the European Academy of Dermatology & Venereology, 32*(5) 720-734. DOI:10.1111/jdv.14612

Spencer, J., & Wheeler, S. (2016) A systematic review of motivational interviewing interventions in cancer patients and survivors. *Patient Education and Counseling*, *99*(7) 1099-1105. DOI:10.1016/j.pec.2016.02.003

Synnott, A. (1987). Shame and Glory: A Sociology of Hair. *The British Journal of Sociology, 38*(3), 381-413. DOI:10.2307/590695

Tierney, A., & Taylor, J. (1991) Chemotherapy-induced hair loss. *Nursing Standard*, *5*(38) 29-31.

Trüeb, R. (2013) The difficult hair loss patient: a particular challenge. *International Journal of Trichology*, *5*(3) 110-114. DOI10.4103/0974-7753.125597

Trusson, D., & Pilnick, A. (2017) The role of hair loss in cancer identity: Perceptions of chemotherapy-induced alopecia among women treated for early-stage breast cancer or ductal carcinoma in situ. *Cancer Nursing, 40*(2) 9-16. DOI: 10.1097/NCC.0000000000000373

Watanabe, T., Yagata, H., Saito, M., Okada, H., Yajima, T., Tamai, N.,... Ohashi, Y. (2019) A multicenter survey of temporal changes in chemotherapy-induced hair loss in breast cancer patients. *PLoS ONE 14*(1): e0208118. DOI:10.1371/ journal.pone.0208118

Watson, M., & Kissane, D. (2011) *Handbook of psychotherapy in cancer care*. Chichester, England: John Wiley & Sons.

Weitz, R. (2004) *Rapunzel's daughters what women's hair tells us about women's lives.* New York, USA: Farrar, Straus and Giroux.

Williams, J., Wood, C., & Cunningham-Warburton, P. (1999) A narrative study of chemotherapy-induced alopecia. *Oncology Nursing Forum*, *26*(9) 1463-1468

Wise, M., Marchand, L., Roberts, L., & Chih, Ming-Yuan (2018) Suffering in advanced cancer: a randomized Control trial of a narrative intervention. *Journal of Palliative Medicine, 21*(2) 200-207. DOI:10.1089/jpm.2017.0007

Ye, M., Du, K., Zhou, J., Zhou, Q., Shou, M., Hu, B.,... Liu, Z. (2018) A meta-analysis of the efficacy of cognitive behaviour therapy on quality of life and psychological health of breast cancer survivors and patients. *Psycho-Oncology, 27*(7) 1695-1703. DOI:10.1002/pon.4687

Table 1 Participant demographic

Code	Age	Gender	Ethnicity	Cancer	Age*	Treatment description
PT01	77	Male	White	Lymphoma	76	Chemotherapy, radiotherapy
PT02	49	Female	White	Breast	31	Surgery, chemotherapy, radiotherapy
PT02	49	Female	White	Breast	36	Surgery, chemotherapy
PT03	46	Female	White	Breast	45	Chemotherapy, surgery, radiotherapy, immunotherapy
PT04	59	Female	White	Lymphoma	54	Chemotherapy, radiotherapy
PT05	45	Female	White	Breast	45	Surgery, radiotherapy, chemotherapy
PT06	44	Female	Asian Sri Lankan	Ovarian	43	Surgery, chemotherapy, surgery
PT07	62	Female	Black African Caribbean	Breast	59	Chemotherapy, surgery, radiotherapy, immunotherapy
PT08	55	Female	White	Lymphoma	54	Watch and wait 3 years, chemotherapy, immunotherapy
PT09	44	Female	Asian Chinese	Lymphoma	20	Chemotherapy
PT09	44	Female	Asian Chinese	Lymphoma	34, 35	Chemotherapy, radiotherapy, chemotherapy
PT10	48	Female	White	Lymphoma	45	Chemotherapy
PT11	53	Female	White	Lymphoma	22	Chemotherapy

* Age at the time of treatment

Table 2 Areas and speed of hair loss

Code	Areas of hair loss	Timeframe of hair loss into treatment	Timeframe for hair to fall
PT01	Total loss on scalp and face, partial loss of body hair	2 weeks	Gradual for 2-3 months
PT02	Total loss	3-4 weeks	1 week, then shaved scalp
PT02	Total loss	3-4 weeks	1 week, then shaved scalp
PT03	Total loss	4-6 weeks	2-3 weeks
PT04	Total loss	2-3 weeks	Shaved scalp prior to it falling
PT05	Total loss	2-3 weeks	2 days
PT06	Total loss	3-4 weeks	Gradual for 3 months
PT07	Total loss	2-3 weeks	1 day
PT08	Total loss	2-3 weeks	1-2 days
PT09	Total loss	4 weeks	Gradual for 3 months
PT09	1st: thinning of all hair 2nd: total loss	1st: 4 weeks 2nd:1 week	1st: continuous thinning 2nd: 3 weeks
PT10	Total loss apart from forearms	6 weeks	1 week, then shaved scalp
PT11	Total loss on body and scalp with thinning of eyelashes and eyebrows	2 weeks	1-2 weeks