

Title: Physical appearance and wellbeing in adults with incurable cancer: A thematic analysis

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ABSTRACT

Objectives: Existing research has established the importance of appearance concerns for individuals with cancer and identified appearance as an important factor in dying with dignity. No research, however, has explored in depth the role of appearance in the experiences of individuals who have incurable cancer. This research aims to explore patients' experiences and perspectives in relation to the role of appearance issues in adults with incurable cancer. *Methods:* Semi-structured interviews were conducted with 24 adults with incurable cancer (20 women, 4 men; mean age 54.5, SD 11.32). *Results:* Thematic analysis generated three themes: 'Identity: Embodying Cancer', 'Communication: Wearing your illness' and 'Support: Holistic Care'. Appearance was felt to be an important element of identity, which was often dominated by cancer, leading to feelings of separation from the participant's previous self. Appearance changes also influenced the way in which individuals communicated with their external world, forcing discussion of their diagnosis, and increasing focus on their cancer, with participants having to manage the emotional impact of this on loved ones, as well as the impact on their legacy. Finally, participants highlighted the positive impact of appearance-related support in their wellbeing and identified peer connections and re-focusing on the self as key elements of such support. *Conclusions:* Appearance changes play an important role in the experiences of individuals with incurable cancer with regards to both identity and communication and challenged participants' ability to maintain normalcy. Further psychosocial support relating to appearance concerns was considered necessary to promote dignity and provide truly holistic patient care.

INTRODUCTION

Whilst appearance concerns may have once appeared trivial in the context of cancer, the importance of appearance-related issues in relation to cancer diagnosis, treatment and quality of life is now widely recognized, with a significant and growing body of research exploring the impact of cancer and cancer treatment on body image [1]. A review of the psychosocial impact of cancer-related hair loss, for example, concluded that this can be a traumatic experience for many, associated with a feelings of identity loss and distress [2], and recent work has explored how research can be translated into

psychosocial interventions to support patients with appearance concerns [3,4]. Such research highlights how patients' quality of life (QoL) can be impacted by treatment side-effects and considers how clinicians might best support those who are negatively affected. Much of this research, however, has focused on patients whose cancer is considered curable and thus has aimed to support patients in 'survivorship'. It is unclear whether these same issues are as prevalent or distressing for individuals with incurable cancer, and there has been significantly less research to date exploring the role of appearance in the quality of life of these patients.

Existing knowledge relating to the importance of appearance concerns for patients with incurable cancer is predominantly derived from broader studies exploring QoL in metastatic breast cancer (MBC). In one qualitative study exploring quality of life, nearly half of women with MBC and significant distress were found to report appearance changes, including scarring, breast changes and weight gain, and many described these as a 'daily challenge' [5]. Another study suggested body image is highly influential in the quality of life of women with MBC and remains central to many patients nearing end of life [6]. Research exploring the meaning of QoL in patients treated for MBC found that they valued living as normally as possible, with appearance changes representing a distressing barrier to their usual social functioning and relationships [7], described elsewhere as an "instant trigger for others to label them as a cancer patient" [8]. However, there is limited research in this field. It is not clear to what extent individuals with different cancers share the experiences of those with metastatic breast cancer, and there has been no in-depth exploration of individuals' experiences with regards to appearance and incurable cancer,

More broadly, the potential role of appearance for individuals with incurable cancer can be seen within the 'dignity in dying' literature. Writers on this topic have highlighted appearance as an important element in "being human and being self" (pg.935), with changes in appearance representing a threat to a patient's dignity and self-image [9]. Negative changes in appearance have also been found to be associated with feelings of being less worthy of respect or esteem by others [10]. This has been further supported by research in the context of support and care, where body image is

considered an important element of dignity, psychological wellbeing and QoL, and an “essential part of feeling that one can relate to one’s family and friends from a position of self-respect” (pg. 101) [11].

In summary, whilst there exists a significant body of research establishing the importance of body image and appearance concerns to individuals with cancer, much of this research has focused on those whose cancer is considered curable, and thus the experience of appearance concerns for individuals with incurable cancer is unclear. Research exploring quality of life in individuals with MBC and the ‘dignity in dying’ literature has identified appearance as an important element for many patients. However, to date, no research has explored this specific facet of psychological wellbeing in depth and, specifically, there has been no qualitative exploration of patients’ experiences and beliefs related to appearance and incurable cancer. Thus, little is known about the role and relevance of appearance issues in incurable cancer, the support patients are currently offered in relation to appearance concerns, and how they would prefer to be supported in relation to these. The aim of this research is to begin to address this gap in the literature, through investigation of the role of appearance in the experiences and beliefs of adults with incurable cancer.

METHODS

Data collection

Semi-structured qualitative interviews were used to explore participants’ experiences and beliefs related to appearance and incurable cancer. Interviews were conducted by the first author, who is an experienced qualitative researcher in psychosocial oncology, with experience supporting family members with incurable cancer. Participants were recruited through local and national support organisations, including Dorothy House Hospice, Maggie’s Centres, Penny Brohn UK, Hospice UK, Marie Curie, Macmillan, Breast Cancer Now, and the National Cancer Research Institute (NCRI), using convenience and snowball sampling strategies. Adverts to take part in a research study exploring appearance and incurable cancer were placed on these organisations’ social media pages, newsletters, or other mailings, which directed interested individuals towards a participant information sheet and online consent form.

Participants were eligible to take part if they: had a diagnosis of incurable cancer, were 18+ years old, living in the UK and had sufficient proficiency to take part in an interview conducted in English. Participants were given the choice of taking part face-to-face (n=2), via telephone (n=21), or via video-call (n=1) in order to capture the experiences of a geographically dispersed group, reduce participant burden, and to encourage open communication regarding a sensitive topic. No differences in responses were noticed between these modes of communication. An interview schedule, devised by the authors, was used to guide interviews (see Table 1); questions in this schedule acted as a guide, however, questions were added or removed depending on appropriateness and the responses of the participant. This research received a favourable ethical opinion from the University of the West of England research ethics committee (ref: HAS.19.10.049).

Table 1. Interview schedule questions and prompts

Questions	Prompts
Could you tell me what made you want to talk to me today?	How did you find out about this research? What interested you about taking part?
I wonder if you could start by telling me a bit more about you and your experience of cancer?	When did you receive your diagnosis? What treatment have you had? Are you currently having any treatment? What kind of support have you/are you receiving?
Have you noticed any appearance changes related to your cancer or treatment?	(If yes), could you tell me more about these? How do you feel about this? Were you concerned about how your appearance might change?
Do you feel any pressure to look a certain way?	Is this different in different contexts? With different people? Or in different places?
Have you discussed the way you look with anyone else?	Do you discuss it with friends or family? Have any health professionals mentioned appearance in the context of your illness? (If yes), how? (If no), would you have liked them to? How do you feel about this?
Is there anything else you would like to add?	Do you have any questions for me?

Data analysis

Interview recordings were transcribed verbatim, with all participants given pseudonyms for the purposes of reporting. Thematic analysis was conducted by PT, in collaboration with JO, CM and DH, and analysis was conducted from a critical realist perspective; acknowledging the subjective nature of experience, whilst also assuming the existence of an 'external reality' in order to facilitate practical application of the research. Analysis followed five steps: 'data familiarisation', 'initial coding generation', 'searching for themes', 'reviewing and refining themes' and 'theme definition and labelling' [12]. Computer Aided Qualitative Data Analysis (CAQDAS) software was used throughout analysis. Standards for Reporting Qualitative Research (SRQR) guidelines have been used in reporting [13].

RESULTS

Twenty-four individuals with incurable cancer participated in this study (20 female; 4 male), with primary diagnoses including: cancers of the breast, kidney, vagina and bowel, melanoma, and myeloma. Appearance changes described included mastectomy, breast reconstruction, weight change, and scarring; and loss of hair or changes in hair pigmentation, including eyelashes and eyebrows.

Participants' mean age was 54.5 years (range 30-74; SD 11.32) and mean interview duration was 42 minutes. Further demographic information is presented in Table 2. Analysis generated 3 themes, which are each presented below with accompanying subthemes. These are: 'Identity: Embodying Cancer', 'Communication: Wearing your illness' and 'Support: Holistic Care' (see Table 3 for a summary of themes and exemplar quotes).

Table 2. Participant demographics

		Frequency (n=24)	Percentage (%)
Gender	Female	20	83%
	Male	4	17%

Ethnicity	White British	24	100%
Cancer type	Breast cancer	14	58%
	Kidney cancer	5	21%
	Myeloma	2	8%
	Bowel cancer	1	4%
	Vaginal cancer	1	4%
	Malignant melanoma	1	4%

Table 3. Thematic table, with exemplar quotes

Theme	Subtheme	Exemplar quote
Identity: Embodying cancer		“I think that was the biggest shock of the whole treatment was looking in the mirror one day and thinking 'I don't even recognise who this person is. Don't even look like me any more' “ (Lisa)
Communication: Wearing your illness	Forced disclosure	“I'm okay with people knowing I have cancer and, um, and I don't mind having that conversation, but I want to be in charge of when we have it.” (David)
	Focus on cancer	“I felt like everyone was looking at me, I felt it was really obvious, I felt it was really ... that I was standing out and you ... I just didn't want to” (Nicola)
Support: Holistic care	Acknowledging and validating	“the hospital always talk about symptoms and difficulties, having side effects and everything but nobody says 'How are you and' uh, you know and 'what's happening and how do you feel about this?’” (Julie)
	Peer connections	“sometimes you think ... you don't feel you can discuss it with other people that haven't got cancer because you just feel a bit vain and silly. But I think if you were in a group with other people you could raise

these things and other people would understand a bit more.” (Nicola)

Re-focusing on self “I don't want it to rule my life because it has done. For ... you know, various stages it has to, and I'm sure it will in the future, um ... and on some days it does because you're not feeling well and all the rest, but for most of it is not going to rule my life. And if I look alright then I am alright” (Jean)

Theme 1 - Identity: Embodying Cancer

Participants described cancer-related appearance changes as dominating their identity, representing them ‘becoming a cancer patient’ and embodying their diagnosis. One participant described “losing my hair and therefore losing my identity” as “the biggest challenge” (Susan) associated with treatment, and several participants described occasions when they felt they did not recognise their own reflection. This experience was distressing and further reinforced feelings of identity loss:

“I think that was the biggest shock of the whole treatment was looking in the mirror one day and thinking 'I don't even recognise who this person is. Don't even look like me any more’” (Lisa)

Importantly, participants stressed the difference between these appearance concerns and those they might have had prior to diagnosis, suggesting they should be viewed in terms of their profound impact on identity.

“I'm not a vain person. I'm not one of these sort of make-up people on every day and everything like that. I'm not that at all but [...] I feel that when you lose your hair you lose your identity. You become a cancer patient ... if you see what I mean?” (Julie)

Such changes were also discussed in terms of the poignancy of appearance change when cancer is considered incurable, as they were suggested to be representative of more profound changes to health and identity (“people normally get white hair when they're very old and getting close to end of life and it's just a reminder that I am close to

end of life even though I'm only 56" (Sheila)); and for some participants, who had experienced permanent appearance changes, these changes were felt to echo the nature of their illness, in that neither were anticipated to improve.

Whilst appearance concerns might often be thought of in terms of the extent to which a person's appearance conforms with societal norms, for these participants their appearance changes represented a more fundamental departure from their own sense of self. Moreover, the incurable nature of their cancer added an additional weight to these experiences and reinforced feelings of identity loss.

Theme 2 – Communication: Wearing your illness

Closely related to the complex relationships between appearance and identity explored above, cancer-related appearance change was associated with changed interactions with the external world and relationships with others. This theme is explored through two subthemes: 'Forced disclosure' and 'Focus on cancer'.

Forced disclosure

Cancer-related appearance changes were often associated with a lack of control over other's knowledge of the participant's illness and resulting interactions. For example, many participants felt their appearance was an immediate signal to others of their diagnosis, particularly in the case of hair loss.

"losing my hair was ... um ... absolutely crucifying because there I was then, I felt wearing the badge. So, the whole world knew that that lady there is going through chemotherapy because she's lost all her hair." (Susan)

Participants worried that this would lead to others speculating about their diagnosis or feeling forced to disclose their diagnosis to others, with appearance changes meaning the timing of these discussions was not under the individual's control ("I'm okay with people knowing I have cancer and, um, and I don't mind having that conversation, but I want to be in charge of when we have it." (David)). These conversations were described as particularly difficult, as they could often involve complex explanations and additional emotional labour to manage others' reactions.

Focus on cancer

Appearance changes were also described as a constant reminder to participants and their families of their illness, and attempts to maintain normality were difficult in the context of their changed appearance, which was “always a reminder” (Paul). This focus on cancer was felt to change interactions with others; for example, leading to unsolicited comments, and feelings of self-consciousness or vulnerability (“I felt like everyone was looking at me, I felt it was really obvious” (Lisa)). In addition, many participants were concerned about the emotional impact of appearance changes on their family, with an emphasis on children, grandchildren, and partners.

“I really want to stay looking as normal as possible and less as a cancer patient as long as I can for the kids. I think that's my main concern really.” (Nicola)

This was also a concern to participants in terms of their legacy, with several participants discussing anxiety around how family and friends would remember them, and not wishing their changed appearance to dominate this memory:

“the thing that's always been in my head 'I don't want to die bald!' I don't want that to be the image for my kids. I don't want that lasting image for my husband of me being bald and then dead. And that's massively important.” (Emma)

In both subthemes, ‘Forced disclosure’ and ‘Focus on cancer’, appearance changes were felt to provide an external indicator of their illness and remove an element of control from participants interactions. This challenged their attempts to maintain normality in the context of their illness, with the ultimate challenge to this control demonstrated in the impact on others memories of them.

Theme 3 - Support: Holistic care

This final theme explores the importance of receiving support in relation to appearance concerns and the impact on wellbeing. Participants either highlighted this in the context of positive experiences of support or as an element that was missing from their care, and, through these discussions, several key issues became clear. These are

represented by three subthemes: 'Acknowledging and validating', 'Peer connections' and 'Re-focusing on self'.

Acknowledging and validating

A distressing experience for many was feeling as if appearance concerns were frivolous or not valid in the context of their illness, with some experiencing dismissive attitudes from clinicians when they raised concerns relating to their appearance.

“they just sit there and look at you as if to say 'Are you mad?' [...] So, I don't think they grasp ... have a grasp of it at all.” (Susan)

Participants suggested appearance change was often discussed pragmatically by clinicians, for example, discussing potential hair loss but without an opportunity to discuss the psychological impact.

“the hospital always talk about symptoms and difficulties, having side effects and everything but nobody says 'How are you and' uh, you know and 'what's happening and how do you feel about this?’” (Julie)

This approach reinforced participant's thoughts that their concerns would be seen as frivolous in this context; and whilst participants expressed varying opinions regarding the most appropriate place to receive additional support (e.g. via the hospital, day centre or hospice), many called for their care to include some acknowledgement of their appearance concerns in order to treat the “whole you” (Julie).

Peer connections

Peer connections were also felt to be an important element of support, acting as a forum where concerns were validated by others and practical advice could be shared. Participants felt less self-conscious sharing their concerns with similar others and were less worried about being met with negative reactions:

“you don't feel you can discuss it with other people that haven't got cancer because you just feel a bit vain and silly. But I think if you were in a group with other people you could raise these things and other people would understand a bit more.” (Nicola)

Gender, age and diagnosis were felt to be important commonalities when accessing peer support, with such similarities determining whether participant's felt comfortable in a group setting. Diagnosis was felt to be particularly important, with some participants feeling their concerns differed from individuals with a primary cancer diagnosis, as well as not wanting to highlight to these individuals the potential for the cancer to return: "they say 'Oh I'm fine, it's all gone.' You don't want to turn round and say 'Well, yes, um, it could come back.'" (Janet).

Re-focusing on self

Finally, many participants spoke of the importance of re-focusing their attention on their self, with descriptions of using clothes, hair, make-up or skincare to regain a sense of normality or control in the context of the cancer ("It is not going to rule my life and if I look alright then I am alright" (Jean)).

Using appearance in this way was described as a form of "*therapy*" (Paul), with a positive impact on mental health, and many were encouraged to do this after attending specific appearance-related support sessions such as those offering practical advice on make up, wigs and other head coverings alongside opportunities to share concerns and experiences with similar others. Several participants also described how refocusing on self and using appearance as a tool encouraged them to focus on the future.

"when you're told that you've got an illness that's not curable, that ... that your first reaction is 'Well, I can't buy any more clothes because it's not worth it because I won't be around to wear them [laughs].' And, actually, almost being given permission to say 'Well, stuff that. Let's go and buy some anyway' um, that gives you a bit of a sort of uplift as well." (Karen)

This element of support was described as particularly poignant in the context of an incurable cancer diagnosis when focusing on the future could otherwise feel difficult. Similarly, the two other elements of support represented in this theme, 'acknowledging and validating' and 'peer connections' were also felt to be particularly important within incurable cancer, with both demonstrating the importance of others understanding the

complexities of their experience and addressing participant's worry that appearance concerns could be seen as unimportant in the context of their illness.

DISCUSSION

Little is known about the role and relevance of appearance in incurable cancer; therefore, this study aimed to investigate patients' experiences and perspectives of this topic. Three themes were identified: 'Identity: Embodying Cancer', 'Communication: Wearing your illness' and 'Support: Holistic Care'. Appearance was felt to be an important element of participant's identity and communication with their external world, both of which were felt to be dominated by cancer-related appearance changes and led to an increased focus on cancer. Many participants found this distressing and were concerned about the emotional impact of this change on their friends and family, as well as the impact on their relationships with others and other's memory of them. These findings demonstrate important similarities between this group and individuals with curable disease, as well as highlighting the nuance associated with appearance concerns in incurable cancer due to associations with legacy, identity and the permanence of appearance changes. Appearance was felt to be an important element of psychological wellbeing for many participants, as well as an area where they would like further support, with a focus on peer connections and strategies that encourage a re-focusing on the self.

A thread that can be seen running through each of these themes is 'maintaining normality', with cancer-related appearance changes felt to challenge participants' feelings of control and their attempts to maintain an element of familiarity in the context of their diagnosis. This can be seen in the way that appearance changes brought the focus onto cancer in various areas of life, including personal identity and relationships, as well as positive experiences of support that had re-focused attention on the self and away from the cancer. These findings are supported by previous research, which has found women living with MBC want to maintain normalcy and focus their attention away from their cancer [7,14], as well as research that has suggested appearance change can act as an immediate indicator to others of their diagnosis [7,8]. Such research has also previously highlighted concerns around relationships with others changing once

their diagnosis was revealed [7], with the current research demonstrating the applicability of these issues to individuals with incurable cancer more broadly and the role of appearance changes in these issues. Similarly, whilst there is existing literature surrounding the importance of patient-centred communication in end of life care [15], these findings also highlight the importance of exploring appearance concerns as part of this communication, in part to validate these concerns for patients when they may not feel comfortable raising them.

These results build on the existing literature establishing the role of appearance in primary cancer diagnoses, suggesting that appearance also plays an important role in the experiences of individuals with incurable cancer. The findings suggest that appearance changes may not be being widely acknowledged as a concern for patients with incurable cancer and there is a need for awareness raising and training for healthcare professionals on how to broach appearance as a topic for discussion, as well as encouraging a culture where it is felt as appropriate to discuss appearance-related issues as it is to discuss issues such as pain and fatigue.

Limitations

The results of this exploratory study represent shared experiences across a range of cancer diagnoses, ages, and genders. However, there may be differences between these groups that were not explored in this study. In addition, participants volunteered to take part with knowledge that the study concerned the role and relevance of appearance change in incurable cancer, and thus our participants represent those who feel is a particularly important element of their cancer experience. It is important that these results are interpreted within the aim to establish the role and relevance of appearance for individuals with incurable cancer, rather than to establish the prevalence of appearance concerns within this group.

Clinical implications

These results of this study and the sentiments expressed by participants provide an important insight for clinicians who support individuals with incurable cancer, and reinforce the importance of exploring whether patients have appearance concerns,

acknowledging and validating these concerns, and referring for further psychological or practical support when appropriate. Importantly, as well as raising awareness of the potential role of appearance in the experiences of this patient group, this study also suggests the need to provide accessible specific appearance-related support for individuals with incurable cancer.

Further research

Future research could build upon this research by investigating experiences within specific groups according to cancer type, treatment, age, gender, or appearance changes, or using quantitative methods to explore the prevalence of appearance concerns. Although this study focused on the experiences of adults, this topic may also have relevance to children and adolescents with incurable cancer, and their families. Research is also required to explore appearance-related issues in the context of non-malignant incurable illnesses (e.g. cachexia in heart failure) to establish whether the experiences reported in this study are specific to cancer or also relevant in other patient groups. This could have implications for the development of psychological interventions.

Conclusion

This study aimed to explore the role and relevance of appearance in the wellbeing of adults with incurable cancer – a topic that has received little attention from researchers in the past. These findings suggest that appearance concerns can play an important role in the experiences of people with incurable cancer and are not unique to those with treatable conditions, as well as highlighting the potential nuance associated with appearance concerns in incurable cancer due to associations with legacy, identity and the permanence of appearance changes. Appearance was felt to dominate identity, impacting on the way in which participants are perceived and communicate with their external world. Furthermore, this study identifies a worry amongst participants that their concerns could be perceived as frivolous in the context of their illness, and a need for further holistic support in this group.

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Competing interest

None declared

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Contributors

PT, JO, CM, and DH designed the study and the interview schedule. PT recruited participants and conducted data collection. PT analysed the data in collaboration with JO, CM and DH. PT drafted the paper, and PT, JO, CM and DH revised the paper. PT is guarantor.

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