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Doctoral Thesis

Appearance-based Concerns and Psychosocial Functioning Following Complex Plastic Surgery for Female Melanoma Survivors

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Word Counts

	Main Text	Appendices (including tables, figures and references)	Total
Thesis Abstract	265	-	265
Literature Review	7997	9780	17777
Research Paper	7998	8745	16743
Critical Appraisal	3721	554	4275
Ethics Section	2898	9372	12273
Total	22,879	28,451	51,333

Thesis Abstract

This thesis aimed to qualitatively explore the experiences of living with an altered appearance related to the skin, and compromises a systematic literature review, an empirical research paper, and critical appraisal of the research undertaken.

The literature review synthesised qualitative research exploring the psychological experiences and appearance concerns of people with psoriasis. Utilising thematic synthesis, the results of 21 papers were synthesised to generate three themes: 'Constructing and navigating the psoriasis-identity', 'Appearance stigmatisation' and 'Acceptance and coping with an altered appearance'. Although there are individual differences in adjustment and coping, findings highlight the impact of psoriasis upon identity, psychological, and social functioning. Clinical implications and suggestions for future research are discussed.

The research paper explored the psychosocial functioning and appearance-based concerns of female melanoma survivors, who have undergone reconstructive plastic surgery as part of their treatment. Interpretative phenomenological analysis was utilised to analyse data from seven interviews. Three themes were identified: 'Constructing the melanoma-identity', 'Relating to others: experiencing dismissal and self-stigmatisation' and 'Grieving the life you had: psychosocial adjustment'. Findings highlighted the impact of appearance changes upon participants' sense of self and identity, in the context of beauty norms and societal narratives related to skin cancer. These findings are considered in relation to existing literature, and the implications for clinical practice are discussed.

The critical appraisal provides a summary of the research, along with reflections on methodological and ethical considerations. Limitations and clinical implications are also highlighted. The importance of reflexivity is considered, and personal reflections of the

research process, such as the impact of the lead researchers own lived experience, are discussed.

Declaration

This thesis presents research undertaken between September 2021 and July 2024 as a requirement of the Doctorate in Clinical Psychology at Lancaster University. The work presented here is my own, except where due reference is made. The work has not been submitted for any other academic award elsewhere.

Acknowledgements

Firstly, I would like to thank all the participants who gave their time to share their personal experiences of melanoma. Without their generosity and openness, this research would not have been possible. Thank you to Melanoma Focus for supporting me in developing study materials and advertising the study. I would also like to thank my research supervisor, Dr Craig Murray, field supervisor, Dr Katie Hatton, and clinical tutor, Dr Emma Munks, for their endless support, advice, and guidance throughout the thesis process.

To my late mum, Karen, who always dreamed that I would get a place on training, I hope I have made you proud. To my dad, Paul, thank you for always believing in me and supporting me throughout the highs and lows, I couldn't have done it without you. Jeff and Jan, thank you for your endless support over the past few months, and always being there when I've needed you.

Finally, thank you to my friends for encouraging me throughout the course. Amy, I'm so grateful to have gone through training with you, and for all of the friendship and laughter we've shared over the past three years.

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Section One: Literature Review

Body-image and appearance concerns for people with psoriasis: a systematic review and meta-synthesis

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Abstract

Background

Research highlights the significant impact of experiencing a chronic skin condition, such as psoriasis, upon psychosocial functioning. In particular, psoriasis patients may experience body-image concerns related to the visibility of psoriasis, which negatively impact upon relationships, engagement in valued activity, and wellbeing.

Aims

This review aimed to synthesise qualitative research exploring the appearance concerns of people with psoriasis, and the impact of altered appearance on psychosocial functioning.

Method

A systematic search of four databases was undertaken, resulting in 21 papers. A meta-synthesis was conducted utilising thematic synthesis to generate new interpretations regarding the experiences of psoriasis patients.

Results

Three themes were developed from the data: ‘Constructing and navigating the psoriasis-identity’, ‘Appearance stigmatisation’ and ‘Acceptance and coping with an altered appearance’.

Limitations

Three studies within the current review utilised the same participant sample, therefore consideration was given to not over-represent similar concepts across these papers. The current review was not pre-registered.

Conclusion

Although individual differences in adjustment and coping long-term were identified, findings highlight the impact of psoriasis upon identity and psychosocial functioning. Psychologists working within dermatology may drive systemic change by developing psycho-dermatological care frameworks, and offering consultation and training within multidisciplinary teams. Targeted therapies may support psoriasis patients to develop acceptance, and positive body-image.

Keywords: psoriasis, qualitative, appearance, body-image

Introduction

Skin Disease

As the largest organ of the human body, the skin is a communicative interface with the rest of the world (Brihan et al., 2020). It is constantly open to the observation and judgement of others, thus its appearance holds a key role in social interactions (Miniszewska et al., 2013; Owczarek & Jaworski, 2016). Skin disease (SD) is the fourth leading cause of non-fatal disease burden worldwide (Seth et al., 2017), yet its importance is often underestimated in healthcare due to its low mortality (Sanclemente et al., 2017), thus funding is frequently invested elsewhere (Zhang et al., 2019). Despite this, the psychosocial impact of living with SD is comparable to other chronic medical conditions (Hong et al., 2008).

Within the United Kingdom (UK), 60% of people experience a skin condition at some point of their life, and 70% of those experiencing scarring or SD are affected by negative changes in their self-confidence (British Skin Foundation, 2022). Other psychosocial difficulties reported by those with a SD include interpersonal difficulties, low self-esteem, social isolation and stigmatisation, and financial constraints associated with unemployment and sick leave (van Os Medendorp et al., 2015; Hua & Silverberg, 2018; Yew et al., 2020; Datta et al., 2015). People living with a SD are more likely to misuse alcohol (Yew et al., 2020), and experience embarrassment, shame, and suicidality (All Party Parliamentary Group on Skin, 2020). Psychosocial factors play a significant role in overall disease morbidity (Datta et al., 2015), with psychological stress significant in the development of SD (Alexopoulos & Chrousos, 2016; Dixon et al., 2018). The relationship between psychological stress and SD is complex in that various mechanisms facilitate the progression of SD. Psychological stress may activate the interaction between the nervous, endocrine, and immune systems, resulting in the onset of SD. Social stigma associated with SD may

exacerbate psychological distress, resulting in a vicious cycle (Zhang et al., 2023). Thus, understanding the psychosocial impact of SD is important in optimising patient care and improving treatment outcomes (Yew et al., 2020).

Psoriasis

Psoriasis is a chronic SD and autoimmune inflammatory condition, resulting in red, scaly plaques occurring on the skin (Parisi et al., 2020). Characterised by skin lesions and arthropathy (Khoury et al., 2014), psoriasis is a debilitating and painful condition proportionately affecting both sexes (Michalek et al., 2017). With a global prevalence rate of 2-3% (Sewerin et al., 2018), psoriasis is recognised as a significant public health concern due to the psychological, social, and economic burden it poses (World Health Organisation [WHO], 2016).

As psoriasis is a lifelong, relapsing condition, it has a significant and enduring impact upon quality of life (Blackstone et al., 2022). Alike other SD's (Zhang et al., 2023), psychological stress is a key predisposing and maintenance factor in psoriasis (Griffiths et al., 2021). Although the psychosocial impact of psoriasis is well-documented (Fuji et al., 2012; Stern et al., 2004), the needs of patients are frequently underestimated by healthcare professions (HCP's) (Kimball et al., 2005; Uhlenhake et al., 2010). Despite a growing body of evidence highlighting the clinical needs of psoriasis patients (Boehncke & Bremilla, 2018), there is an approximate 17-year lag in healthcare research findings being applied in clinical practice (Morris et al., 2011; Ashrafzadeh et al., 2020), perhaps explaining the increasing care burden. In recognising psoriasis as a non-communicable disease, WHO (2016) has highlighted a need to better understand the burden of psoriasis.

Psychosocial Functioning, Appearance, and Stigmatisation

Recently, studies exploring the burden of psoriasis have led to increased understanding of the psychosocial needs of patients. Such studies have highlighted the effects of psoriasis on body-image, self-esteem, and psychosocial functioning across relationships, sexual functioning, and wellbeing (Khoury et al., 2014). Research has also indicated that changes in appearance associated with psoriasis, such as visible skin lesions, may result in individuals facing stigmatisation (Pereira et al., 2012), which further exacerbates physical and psychological symptoms (Zhang et al., 2023). Recent National Institute for Health and Care Excellence [NICE] (2017) guidance has reflected these findings, highlighting the importance of assessing the impact of psoriasis on psychosocial wellbeing, although there is currently no guidance of how to best support people with appearance-based concerns.

Recently, research has highlighted the negative impact of psoriasis upon body-image (Nazik et al., 2017; Khoury et al., 2014; Woertman & van den Brink, 2012). In particular, people with psoriatic lesions in visible areas, such as the head, neck, and arms, are more likely to experience anxiety, depression, and hold a negative emotional attitude toward their body (Łakuta et al., 2018). One explanation for this may be that individuals experiencing higher levels of distress related to psoriasis may hold strong beliefs about the importance of physical appearance and its salience to their self-worth (Wojtyna et al., 2017). Body-image dissatisfaction may additionally result in reduced self-esteem, anger, and reduced disease acceptance (Sakson-Obada et al., 2017). This may result in people avoiding social situations, particularly when there is an expectation to expose their skin, such as during intimacy or sexual experiences (Gündüz et al., 2020).

Research has additionally explored how the visibility of psoriasis may lead to social and self-stigmatisation (Jankowiak et al., 2020). Visible lesions may elicit fear, disgust, or intolerance from others (Hrehorów et al., 2012), who may hold stigmatising views that the person living with psoriasis is contagious (Pearl et al., 2019). A study considering the impact

of anticipatory and perceived stigma on psoriasis patients found that approximately 66% of respondents anticipated others to perceive them as “unattractive”, and approximately 40% held the belief that others “stare at their skin disease” (Wan et al., 2020). Alarmingly, 20% of respondents also reported experiencing negative judgement from HCP’s. Although medical students are found to hold less stigmatising views than those more widely reported in society, approximately 35% stereotype psoriasis as unattractive, and 12.8% believe that psoriasis is not a serious disease (Pearl et al., 2019). A global survey of people living with moderate-to-severe psoriasis further highlights that 84% have experienced discrimination related to their condition (Armstrong et al., 2018). Stigmatising experiences may result in people with psoriasis withdrawing from social interaction, and experiencing depression and suicidality (Karia et al., 2015; Zieciak et al., 2017). As such, in one study almost half of psoriasis patients reported masking the appearance of skin lesions within their daily life, and one third of patients stated that they would prefer to have a different stigmatising condition, such as HIV (Wan et al., 2020). Thus developing an understanding of appearance-based concerns and the resulting stigma experienced by people with psoriasis, may aid greater social awareness and acceptance of the condition.

The Current Study

Systematic reviews have recently collated information around the psychosocial needs of psoriasis patients, although such reviews have had a broad focus across care needs (Snast et al., 2018; Zill et al., 2018), with only one review utilising qualitative methodology (Sumpton et al., 2020). To the author’s knowledge, currently, no reviews focus on appearance-based concerns and the wider implications of body-image on stigmatisation and psychosocial functioning for people with psoriasis. As individuals with a visible difference often experience interpersonal difficulties and reduced self-esteem (Harcourt et al., 2018), there is a need to further consider the appearance-based concerns of psoriasis patients. This is

particularly important as research has demonstrated that specialised psychological support around visible difference is effective (Clarke et al., 2013).

The aim of this meta-synthesis was to collate existing qualitative data regarding the experiences of psoriasis patients, with a focus on appearance-based concerns. The intention is that findings will support better understanding of the psychosocial needs of psoriasis patients, shaping psychologically informed person-centred treatment. This is important in addressing the relevance of clinical psychology interventions within physical health and dermatology services, particularly in considering how information, support, and intervention is offered. Understanding appearance-based concerns may assist in reducing the stigma faced by psoriasis patients. This may provide further considerations in how clinical guidelines are followed, including the development of a biopsychosocial approach within multidisciplinary settings.

Method

The PRISMA guidelines and 2020 checklist were utilised to ensure the transparent reporting of this review (Page et al., 2021). The review was not pre-registered.

Search Strategy

The search strategy was developed in consultation with the research supervisor and specialist subject librarian, and was informed by initial scoping searches of key terms related to the research question.

To identify qualitative empirical papers exploring the experiences and appearance-based concerns of people with psoriasis, a systematic literature search was conducted in January 2024 across four databases; PsychInfo (1887-present); Academic Search Ultimate (1984-present); CINAHL (1981-present), and MEDLINE (1946-present). The research question was broken down into three distinct concepts (psoriasis, qualitative methodology,

and psychological factors (relating to body-image, stigmatisation, and psychosocial functioning)), to construct an effective and comprehensive search strategy. Search terms were combined via the use of Boolean operators, and Medical Subject Headings (MeSH) terms were identified and utilised specific to each database. The Boolean operator 'OR' was used to search for terms within each concept, with 'AND' used between concepts. Near field searches were included (e.g. ((self or body) N5 (confiden* OR esteem OR disatisf* OR image OR worth OR accept* OR concerns OR perception))) to capture additional papers where fixed terminology was not used. For each concept, search fields were limited to title and abstract. Finally, backward and forward citation methods were used to identify additional papers not captured within the search. The search strategy and terms for each database are outlined in Table 1.

Inclusion and Exclusion Criteria

To be included in the review, studies had to meet the following criteria: 1) include participants over the age of 18 with a diagnosis of psoriasis, 2) include sufficient findings related to body-image (at least one paragraph discussing appearance-based concerns, or discussing behaviour change related to appearance), 3) utilised qualitative methods for data collection (mixed methods studies were considered where sufficient qualitative data was presented), 4) used an inductive method of qualitative analysis, 5) explored first person accounts, 6) were available in English, and 7) were published in a peer reviewed journal. Studies were excluded if they: 1) explored multiple dermatological conditions (e.g. eczema, acne) and did not present data on psoriasis in isolation, 2) focussed primarily on psoriatic arthritis where the needs of individuals may differ, 3) focussed on the development of a screening tool or intervention, 4) explored experiences relating to medical or pharmacological intervention, or 5) were a literature review.

Search Results

Prior to the inclusion and exclusion criteria being applied, 465 papers were identified. The results were collated using EndNote referencing software, and de-duplicated as per the steps outlined by Bramer et al., (2016). Following de-duplication, 289 studies were exported to Rayyan software where they were visually screened by title and abstract to assess eligibility. This process was repeated for full text screening where there was ambiguity of study content (e.g. if a paper abstract identified a theme of psychosocial functioning or stigmatisation). On reviewing the reference lists of included papers and utilising the 'cited by' feature on Google Scholar, one additional study was identified. In total, 21 papers were considered eligible and included in the review. Figure 1 illustrates the selection process.

Characteristics of Selected Studies

The selected papers were published between 1985 and 2023. Participants were recruited across 17 countries, and sample sizes ranged from two to 177. Eighteen papers used interviews to collect data, two used an ethnographic methodology compromising interview and observation, and one used narrative accounts and imagery. Further details of the selected papers, such as data collection and analysis are summarised in Table 2.

Quality Appraisal

The Critical Appraisal Skills Programme (CASP) Qualitative Checklist (2018) was utilised to assess the methodological quality of the included papers. The CASP was chosen due to being the most commonly used quality appraisal checklist for health-related qualitative syntheses (Dalton et al., 2017), with its use recommended by the Cochrane Qualitative and Implementation Methods Group (Noyes et al., 2018). Importantly, the checklist has been developed for use by novice qualitative researchers (Long et al., 2020), thus the lead researcher and second rater felt familiar with its use. The checklist consists of two screening

items and eight questions used to guide evaluation of various elements of study quality, such as research design and ethical considerations. A three-point scoring system was adopted, as defined by Duggleby et al. (2010). Aligned with this, a score of 1 indicates weak evidence, a score of 2 indicates moderate evidence, and 3 indicates strong evidence. Most studies were quality assessed independently by the lead researcher, with a selection of six studies evaluated by a second rater (a trainee clinical psychologist (CP) unrelated to the research) to ensure reliability of scores. Scores were generally consistent between raters although disagreements arose on items with a broader focus, such as those related to research findings and value of the research undertaken. Disagreements also presented where subjective language was used in descriptors for each item, for example, whether the findings presented 'adequate' evidence. Disagreements were discussed, resulting in some alterations. The scores for included studies ranged from 12 to 22, with a maximum possible score of 24 (Table 3).

The CASP scores were used as a framework to critically consider the studies, rather than excluding any; reflective of the ongoing debate as to what constitutes meaningful, high quality qualitative research (Mays & Pope, 2020). With a lack of standardisation across appraisal tools (Carroll & Booth, 2015), quality-appraisal of qualitative research is arguably subjective, influenced by the varying epistemologies within which the research is undertaken (Garside, 2014). Additionally, appraisal tools may not always capture meaningful information on the processes specific to qualitative research. For example, although some appraisal frameworks include criteria on the use of reflexivity, this is frequently under-reported in study methodology, thus impacting upon quality-appraisal scores (Franzel et al., 2013). As the inclusion or exclusion of studies may positively or negatively affect the final synthesis, there is further debate concerning how studies demonstrating 'weak' evidence should be utilised. Excluding studies appraised as being low quality may prioritise certain types of study, such as those theoretically situated in the current evidence base. Where study

findings are descriptive or novel, choosing to exclude them may result in meaningful information being missed (Majid & Vanstone, 2018). Thus, this review aimed to give a comprehensive overview of the current evidence base, utilising quality-appraisal to critically consider each study (Hannes & Macaitis, 2012).

Data Extraction and Synthesis

The meta-synthesis was based on the thematic synthesis approach developed by Thomas and Harden (2008). This approach was chosen due to its grounding in meta-ethnography and grounded theory, allowing for the synthesis of descriptively 'thin' and 'thicker' data (Flemming & Noyes, 2021). As per the proposed guidelines (Thomas & Harden, 2008), analysis consisted of three stages; coding 'line-by-line', the development of descriptive themes, and the development of analytic themes. Data was considered as any text situated under the 'results' or 'findings' subheading. A breakdown of the analysis process is outlined in appendix 1A. Table 4 identifies the contribution that each paper made to the themes.

Results

Three overarching themes were identified: 1) constructing and navigating the psoriasis-identity, 2) appearance stigmatisation, and 3) acceptance and coping with an altered appearance. A narrative summary of each theme is provided below, with quotes presented to illustrate findings.

Theme One: Constructing and Navigating the Psoriasis-Identity

This theme considers how people construct their psoriasis-identity, exploring concepts such as body-image, self-esteem, and self-perception. This theme consists of two subthemes: 1) challenges to body image and self-perception, and 2) psoriasis vs personal identity.

Challenges to body-image and self-perception. Body-image was central in how participants constructed their psoriasis-identity across studies. Many held negative self-beliefs around the appearance of psoriasis, using emotive language to describe psoriatic lesions as dirty, unattractive, and disgusting: *"It makes you feel dirty."* (Howard et al., 2012, p 50); "*You do feel ugly, yes, that's what it is – you don't like to show yourself."* (Narayanan et al., 2015, p.4). Such beliefs resulted in reduced self-confidence and self-esteem, which consequently impacted upon body-image. For some participants, psoriasis *became* their body-image in its entirety, where other positive elements of their appearance were overshadowed by its presence: "*I think [psoriasis] is just your self-image. You think "I can't be attractive because I look like this thing, like this leopard".* (Magin et al., 2009, p. 155). This put restrictions on their interactions with their external world, particularly in relation to sexual functioning and romantic relationships: *"I feel shy towards my boyfriend. I think he finds me unattractive, because of my patches… I don't feel sensual when my skin is rough and covered with knots."* (Khoury et al., 2014, p. 3).

Body-image concerns were perpetuated by comparison to 'healthy' individuals, and the likeness of psoriasis in appearance to other SD's, especially Leprosy. Comparison to 'healthy' individuals appeared to reinforce negative self-beliefs by emphasising a feeling of difference to other people. Drawing comparison between the appearance of psoriasis and Leprosy resulted in participants buying into the stigmatising views held by society that psoriasis is contagious, dirty, and shameful:

> *You compare yourself with healthy people. That makes you feel like you're ugly and everyone is staring at you. . . . You feel different from others. You are different. You have a disgusting body covered by marks and lesions. You feel like a leper. I feel unclean and sticky. Touching the rash disgusts me.* (Wahl et al., 2002, p. 254).

Difficulties navigating body-image concerns resulted in participants experiencing anger toward psoriasis, at times experiencing hatred toward their own body: *"I remember this one day, I took my shirt off and there was all these scales on the floor." Martin thought "this is disgusting, man" and he felt actually "repulsed by..." his "...own body."* (Watson et al., 2007, p. 355).

The visibility and severity of psoriatic lesions were considered important in body-image, wellbeing, and construction of psoriasis-identity. Increased visibility of psoriatic lesions negatively impacted engagement in activities of daily living:

> *I don't like having it and it bothers me. For me visibility has been the biggest frustration by far. […] I haven't been to a gym for like three months. Mainly because I can't cover the spots on my arms while wearing a T-shirt. I can cover my legs with sweatpants, but I'm not going to wear a sweater while working out.'* (Kouwenhoven et al, 2020, p. 16).

Lesions occurring on visible areas, such as the face, were considered particularly difficult to adjust to: *"Psoriasis has grown above my eyebrows. It is very painful and ugly, and it cannot cover the eyebrows. Why does it grow on my face? I feel very inferior."* (Lee et al., 2023, p. 4), whereas participants felt lucky if psoriatic lesions were confined to areas such as the torso: "*Yes, it [the psoriasis] was on body areas where you did not see it. And then, to be quite honest, it didn't bother me so much*." (Newi et al., 2022, p 3359). The negative, sustained, impact of visibility on body-image and wellbeing was evidenced by participants who had at times experienced total skin clearance. They shared feelings of hope and freedom when psoriasis was no longer visible: "*I suddenly found myself singing for joy. It was like getting out of prison. You were free. There was nothing holding you back anymore."* (Wahl et al., 2002, p 257), although positivity diminished when their condition relapsed: *"I had two years*

of being clear and then it starts creeping back and then the misery starts all over again. I really get quite low because of it sometimes." (Howard et al., 2012, p 50).

Psoriasis vs personal identity. Participants highlighted two key aspects of identity; psoriasis-identity and personal identity. For some, psoriasis-identity and personal identity became intertwined, describing that psoriasis shaped who they are. One participant described a sense of loss when they experienced total skin clearance: *"You are me and…(when in remission) I missed you terribly"* (Bundy et al., 2014, p. 827), demonstrating the enduring and significant presence of psoriasis across all areas of their life. For others, psoriasis was perceived as an invasive, frustrating condition, which was imposed upon them and remained separate to their personal identity*: "If only you knew what you put me through, you are not a friend you are the enemy within"* (Bundy et al., 2014, p. 828).

Due to the chronic, unpredictable, nature of psoriasis, participants reported a sense of being out of control in their body, which they attempted to manage with medication, routines, and diet: "*Any feelings of anger I cry…I'm irritated and it's because I'm feeling so out of control in my own body."* (Hughes & Hunter, 2022, p. 3). Where the unpredictability of psoriasis symptoms ruptured participants' previously held meanings about the self, such as believing that they were attractive, many experienced feelings of hopelessness: *"I just couldn't believe that something this ugly couldn't be cured."* (Watson et al., 2007, p. 355), leading some to resign themselves and their identity to psoriasis: *"I give in, as you will be with me uninvited for the rest of my life"* (Bundy et al., 2014, p. 828).

Across studies, participants described a lasting impact of psoriasis on their personality, becoming shy, insecure, and withdrawn due to their altered appearance: *"I think it kind of molded me into this really insecure person."* (Pariser et al., 2016, p 25); "*I'm an introvert … I'm a bit shy, I think because of it … I think it's changed me. When I was younger*

I was fairly confident and probably a bit more outgoing but over the years it's [psoriasis's] sort of worn me down." (Magin, 2009, p. 156). For some, this resulted in feelings of hatred toward themselves: *"Externally I smile and try to be jolly, inside I loathe myself and will be glad when it's over"* (Bundy et al., 2014, p. 827).

Several participants described a grieving process whereby they mourned their identity, but also their unfulfilled potential whilst living with psoriasis: "*That's how I used to look [points at picture on mantelpiece], it's like I miss myself. Running things, being in charge, being in the office, being up in management and now I'm just like this now."* (Narayanan et al., 2015, p. 3). Some drew comparisons with their peers, reflecting how they felt held back socially, and in their occupation due to the presence of psoriasis: "*I've seen all my friends do well…got nice cars…nice houses…and I'm in my fifties and live with my parents…I've missed out…that's been the biggest frustration…I've not fulfilled my potential."* (Hunter & Hughes, 2022, p. 3).

Theme Two: Appearance Stigmatisation

This theme encompasses how people living with psoriasis make sense of their altered appearance through interaction with others and their external world, navigating stigmatisation and societal beauty ideals.

When engaging in social interactions, participants experienced apprehension around how others would react to their appearance, particularly when meeting new people. Underpinning this, was fear of how visible symptoms may be interpreted as contagious, unhygienic, and unattractive, due to a lack of public awareness of psoriasis: *"It's the thought of your appearance to the world at large. It keeps coming back to how you think you appear to others. I think people think its lack of hygiene. They don't know".* (Jowett & Ryan, 1985,

p.426). Managing appearance was therefore considered central in preventing rejection: "*My life is based on preventing rejection."* (Wahl et al., 2002, p. 257).

For some participants, anticipatory stigma was perpetuated by already held negative self-beliefs, believing that others' perception of psoriatic lesions would mirror their own internal narrative: *"I think it's disgusting to look at, so other people must feel the same way. I tell myself that others think it is just as disgusting as I do."* (Wahl et al., 2002, p. 254); "*If you are self-conscious about something you … sort of project what you think they are thinking. They might have been looking at your shoes [and not at your psoriasis-affected legs], but that's how it is in your head."* (Magin et al., 2009, p. 155). However, for others, feelings of anticipatory stigma related to having previous experiences of overt stigmatisation in society, which increased vulnerability in future social interactions.

Location and severity of psoriatic lesions were also considered central in the degree of anticipatory stigma, with increased visibility found to heighten anticipatory stigma: *"When my disease is very serious, I am afraid that other people will look at me differently."* (Lee et al., 2023, p. 4). Where participants experienced heightened awareness of psoriatic lesions, they became fixated on how others would perceive their appearance, which resulted in feelings of anxiety. One participant referred to these feelings as paranoia, indicating an awareness that they may at times perceive neutral interactions through a negative lens: *"I spent an hour in the bathroom crying before I went to the pool because… you could see the psoriasis…I was like so paranoid."* (Hughes & Hunter, 2022, p. 5).

Alongside anticipatory stigma, participants experienced explicit stigmatisation, where they described navigating a societal narrative that psoriasis is contagious, unhygienic, and unattractive:

> *When people ask me about psoriasis and I tell them, they say "That's gross" or they ask "Is it is contagious?" Contagious, really? Is that the first thing on their minds? I have psoriasis through no fault of my own, but people still judge me for it, that is the worst part.* (Kouwenhoven et al., 2020, p. 16).

Commonly reported experiences included others not wanting to touch their skin, staring, and making comments about their appearance. As a result, participants experienced rejection, exclusion, and discrimination, consequently affecting their body-image and self-esteem. In some cases discrimination was experienced broadly and overtly, affecting participants' engagement in activities of daily living, and occupation:

> *I lost three jobs and I suppose it happened because of my disease. Certainly people thought it was infectious, that they may get infected, so they went to the boss. (…) Surely they went to the boss and said he had to do something about it. He fired me because people are scared of such diseases.* (Janoska et al., 2016, p. 64)

Across studies, there was a shared sense that HCP's also held stigmatising narratives. Participants reported experiencing a lack of empathy for their altered body-image, and a disparity between how severe psoriasis is defined by HCP's and patients: *"I showed [GP] and he said ''well it's not that bad.'' That really upset me because it probably isn't bad compared to other people, but you don't want that from your doctor, you want some empathy"* (Nelson et al., 2013, p. 168). For some, the negative response from HCP's acted as confirmation of their own negative self-beliefs, and perpetuated feelings of embarrassment, shame, and hopelessness.

Distress related to stigmatisation appeared to be exacerbated by societal beauty ideals of perfect, flawless skin, which are presented within the media as being the norm: "*Media, models and fashion and they are showing people 'this is beautiful', 'this is what you need to*

look like'. (Magin et al., 2011, p. 181-185). Where the media fails to acknowledge the existence of less-than-perfect skin, those with psoriasis experienced a disparity between societal ideals and their own appearance, believing that psoriatic skin is incompatible with beauty: *"...media stuff and the advertisements for the soft skin on television makes me feel embarrassed ... it also makes me feel less attractive sexually to people, because I'm not the ideal, I'm not the perfect image."* (Magin et al, 2009, p. 153). Feeling unable to meet societal expectations left participants experiencing hopelessness and reduced self-esteem: "*I don't think I've got a hope of living up to [the ideal], all these magazines, they would make me depressed because I'd think 'why can't I have skin like that and a figure like that?' [...] something like reading a magazine could trigger that."* (Magin et al., 2011, p. 181-185).

Particularly, the media portrayal of perfect skin appeared to be more implicit in females' appearance concerns, related to femininity and sexual attractiveness: "*You've only got to look at the women in FHM and Playboy, they don't have skin diseases. [It] makes me feel less attractive sexually to people, because I'm not the ideal, I'm not the perfect image."* (Magin et al., 2010, p. 458).

Theme Three: Acceptance and coping with an altered appearance

This theme considers how those living with psoriasis develop acceptance of their diagnosis, and cope with appearance-based concerns. It compromises two sub-themes.

Avoidance and concealment. Across all studies, participants described an intention to hide the appearance of their skin, both publically, and intimately. Concealment of psoriatic lesions included the use of make-up, long clothing, and ointments, but psoriasis symptoms also restricted clothing choice: *"I've had shoes that I've not been able to wear. I always wear trousers and ankle socks. I can't wear nylon, it irritates my back. I wear cotton next to my*

skin" (Jowett & Ryan, 1985, 429). Concealment appeared to reduce feelings of anxiety, but paradoxically was also a source of distress, resulting in feelings of frustration and sadness:

> *I always wear jeans and long-sleeved blouses, even if it's 30 degrees outside. It looks stupid and people stare at me. I sweat and I'm irritated, but I prefer it that way… I pull my long-sleeved blouses down to my fingertips.* (Khoury et al., 2014, p. 3)

Within social situations, participants described engaging in checking behaviours, to ensure psoriatic lesions were not visible, although for some this became obsessive: "*I would get up early to apply creams, then get into work early so I could check myself in the toilets. I would check myself throughout the day, I became obsessive."* (Narayanan et al., 2015, p. 3). Others avoided social and intimate situations, particularly those where skin exposure was likely, such as swimming, or sexual relations. Some became withdrawn and isolated, preferring to be alone than have others see their appearance:

> *I have been hiding myself for a year, from anyone and from the outside world. I was living in my own bubble. […] I didn't invite people over either because I thought I would have to clean up all the flakes. So nobody visited me. My home didn't feel like home, it was just the place where I slept, like a den.* (Kouwenhoven et al., 2020, p. 16)

Some participants felt that the restrictions psoriasis imposed on their life resulted in a loss of spontaneity: "*Changes what you do, who you meet, opportunities you take, clothes you wear, you can never do anything spontaneously."* (Wheeler et al., 2022, p. 40). Others highlighted how avoidant strategies resulted in feelings of low mood and a mourning for the pre-psoriasis lifestyle:

> *You feel really MISERABLE. So, you really only go out in the dark (…) if you have the entire back of your head, everything damaged, open (...) and from your neck to*

your knees in one (...) practically red all the way through and, uh, everything is open, uh, it does look bad. You have no real life there. (Newi et al, 2022, p 3359).

For some participants, hiding psoriatic lesions served the purpose of preventing stigma, but also in restoring self-confidence: "*It's like if I've got to get something done [out in public] and I really don't have time to deal with the negativity, it's better to just cover it up and avoid the situation to begin with, that way it's not going to happen".* (Parkhouse, p. 252). Other participants described a desire to protect other people from feeling uncomfortable with their appearance: *"I avoid it. I don't push myself where… for example, I don't go to the swimming pool or the beach, because I would feel bad and I don't want anybody to feel uncomfortable… I avoid people."* (Janoska et al., 2016, p. 63).

Avoidance was particularly pertinent in intimate relationships, as nakedness was perceived as extremely exposing. Single participants avoided dating altogether: *"I've met several women I've got on well with, and I draw back from any kind of physical relationship. It's really blighted my life in the last 12 years"* (Nelson et al., 2013, p. 168), and those in established relationships often experienced shame and embarrassment, describing avoiding sexual activity when psoriasis symptoms were severe: "*Well I didn't really do anything [sexually intimate], if I had a breakout of psoriasis. I wouldn't really go there"* (Magin et al., 2010, p. 458), describing not wanting to be touched: "*I don't like to be touched as I feel they will be grossed out."* (Wheeler et al., 2022, p. 39). Some participants isolated themselves from their partner due to the negative self-beliefs they held: "*I have my own bed with sheets and blankets of my own. I isolate myself from my family. There's no other way."* (Zhong et al., 2021, p. 6).

Developing acceptance over time. Over time, participants adjusted to the changes psoriasis imposed upon their life, feeling that they developed acceptance of the condition. For

some, this arose from developing the perspective that other people experience skin conditions which are more visible and severe: "*I think I am one of those who are well off, since there are those who have more severe skin conditions."* (Uttjek et al., 2007, p. 368). Peer support also provided a sense of connection, supporting those with psoriasis to *"know that other people out there are going through similar things and are coping well"* (Hughes & Hunter, 2022, p. 6). Other participants felt that acceptance came from establishing a new routine post-diagnosis, which eventually became integrated within their identity:

> *You know you have your restrictions, and that you maybe have to think in different ways a bit, you have to prepare yourself in a slightly different way. You have to spend more time daubing and treating yourself. But this has turned into a routine, like washing yourself every day and getting ready in the morning. You just take that private moment. It has become a part of yourself; you learn to live with it.* (Uttjek et al., 2007, p. 368).

Age of onset and life-stage were considered important factors in acceptance of the condition. Childhood and adolescence were perceived as the worst time to receive a psoriasis diagnosis, due to the importance of appearance in experiencing bullying, the development of personal identity, and engagement in romantic relationships. Many spoke of challenging, stigmatising experiences when diagnosis was received during childhood:

> *"It's been many years. I got used to it, but when I saw that I didn't have it, I said: I can finally wear short sleeves. It's a torment, it really destroys the psyche. Because I can manage with it now, but as a child, when I went to school, it was hard…"* (Janoska et al., 2016, p. 63).

Adolescence and early adulthood were also considered key developmental stages, during which time altered appearance significantly impacted upon body-image and

functioning across relationships. For some participants this had a lasting impact into adulthood:

> *I'm in my fifties…never been married, haven't got a girlfriend so it's affected me…when you're in your late teens and early twenties and your mates are getting girlfriends…that passed me by… because I was self-conscious of it…my skin being bad, and thinking 'who would want me?'…'I'm a mess'.* (Hughes & Hunter, 2022, p. 4).

Participants who received diagnosis in adulthood felt lucky they did not have to navigate body-image concerns at a vulnerable age, particularly for those already in established romantic relationships: *I got it when I wasn't as vulnerable….the thought of being a teenager with psoriasis is pretty chilling.* (Hughes & Hunter, 2022, p. 6). For most, age promoted acceptance, however for some the physical changes of aging further impacted self-confidence and body image, particularly for those not in a romantic relationship:

> *It is worse now when I am older, with the physical changes of aging as well. The worst thing with psoriasis is that it is visible and I cannot make it disappear. I feel restricted to loneliness, neither starting a new relation with a man, nor looking for a new job.* (Uttjek et al., 2007., p. 367).

Discussion

This review synthesised qualitative findings from 21 papers exploring the psychological experiences of people living with psoriasis, with a focus on appearance-based concerns. This process generated three themes: 'constructing and navigating the psoriasis-identity', 'appearance stigmatisation', and 'acceptance and coping with an altered appearance'. Although a thematic synthesis by Sumpton et al. (2020) has previously collated information on the experience of living with psoriasis, this has a broad focus across

psychosocial functioning. The current review is the first meta-synthesis of its kind to bring together qualitative data specific to appearance-based concerns and the implications of this related to stigmatisation and functioning, thus providing detailed insights. In addition to the insights of Sumpton et al. (2020), this review explores appearance concerns in detail, considering how altered appearance may result in identity changes and self-stigmatisation.

The synthesis revealed that participants reported challenging beliefs about the self, their relation to others, and their existence in the world, derived from their experience of living with psoriasis. These beliefs are shaped and perpetuated by stigmatising experiences, psychological distress, and avoidant coping. Through synthesis of studies across multiple countries, this review considers the shared, universal impact of psoriasis across Western, and non-Western cultures.

The onset of psoriasis appeared to represent the loss of the 'normal', healthy, self, where study participants described adapting to an altered appearance and chronic illness that imposed restrictions across their life. Many described low mood, anger, avoidance and anxiety, and some felt that they eventually developed acceptance of their psoriasis-identity. These experiences hold similarities to those described in Kübler-Ross and Kessler's (2005) grief cycle theory, suggesting that the loss of a 'normal' appearance may be experienced in a way similar to bereavement. Perhaps a permanent shift in the constructs and beliefs previously held about the self, for some resulted in the loss of valued or affirmative personal identities. Despite a shared consensus that psoriasis results in a changed identity, there were differences in how people constructed their psoriasis-identity. For some, psoriasis embodied the whole self, whereas others experienced psoriasis as an external threat to their identity, describing hatred toward what they perceived as an unwanted companion. These processes can be understood through Charmaz's (1995) conceptualisation of illness identity, which may be considered as the degree to which chronic illness becomes enmeshed within personal

identity. Four states of illness identity have recently been theorised; engulfment, rejection, acceptance, and enrichment (Oris et al., 2018). Acceptance and enrichment relate to adaptive psychological functioning, whereas rejection and engulfment are considered maladaptive. It is possible that participants experienced engulfment, in which psoriasis dominated all aspects of their personal identity and daily functioning; or rejection, where psoriasis was perceived as a threat, thus rejected as part of the personal identity.

Although commonalities were described by participants across studies, differences were also highlighted. Whilst the psychosocial entailments experienced by males were comparable to that of females, two studies highlighted the impact of societal beauty ideals targeted towards females (Magin et al, 2011; Bundy et al., 2014). Within traditional, and social media, beauty, physical appearance, and sexual appeal are considered central concepts in a female's value (Åberg et al., 2020; Ward et al., 2020). Thus, the appearance of psoriatic lesions challenges such beauty ideals, resulting in females feeling unfeminine, and not sexually attractive. However, such beauty ideals reflect Westernised beauty standards, and it is important to consider that the studies presented by Magin et al. (2011) and Bundy et al (2014) were conducted in the UK and Australia. Although Western media has influenced cultures and societies globally (Chen, 2021), non-Western cultures may place less value on appearance and may experience less pressure to attain beauty ideals (Kakar et al., 2023).

Across studies, the time of onset was considered an important factor in psychological distress and acceptance, with divergence noted in long-term coping, dependent on life-stage at diagnosis. There was a consensus that experiencing psoriasis at key developmental stages such as childhood and adolescence has a significant impact upon identity, peer relationships, and romantic relationships. According to Erikson, identity is constructed during adolescence, through the relationship between the individual and society (Kasinath, 2013). Thus, appearance plays a central role in the development and maintenance of a positive body-

image, and experiencing an altered appearance at this life-stage may result in negative psychosocial outcomes (Fox et al., 2007; Gonzalez et al., 2017). In the current review, participants who experienced psoriasis during childhood or adolescence reported a lasting impact into adulthood, describing difficulty in romantic relationships, with some remaining single, and feeling that they had been unable to fulfil opportunities in their life, such as those related to their career.

Clinical Implications

The current review has several important clinical implications pertinent to the role of a CP (British Psychological Society [BPS], 2017).

For psoriasis, NICE guidance recommends the assessment of physical, social, and psychological wellbeing (NICE, 2017). Specialised care is indicated for those experiencing significant psychosocial distress, although its provision remains limited, despite increasing demand globally (Aguliar-Duran et al., 2014; Marshall et al., 2016). The current review highlights the psychosocial nature of difficulties experienced by those adjusting to a diagnosis of psoriasis, indicating a high level of need for psychological support. Therefore, services may benefit from adopting a stepped model of psycho-dermatological care (Bewley et al., 2012; Shah, 2018), with CP's embedded within the multidisciplinary team (MDT). Previous research has indicated that a holistic, integrative approach to dermatological care fosters an understanding of psychosocial needs in medical professionals (Orion et al., 2012; Mohandas et al., 2013), which may support psoriasis patients in feeling heard and understood.

In the context of current findings, where visibility of psoriasis is considered the most difficult aspect of the condition to adjust to, the use of outcome measures to explore body-image concerns is indicated. Whilst the model proposed by the British Dermatology

Association (Bewley et al., 2012) is considered gold-standard, it only advises the use of the Dermatology Life Questionnaire (Finlay & Khan, 1994) and the Hospital Anxiety and Depression Scale (Snaith & Zigmond, 1986) to assess psychological distress, overlooking appearance-concerns. Shah (2018) has recently suggested adaptations to the model, including the incorporation of additional outcome measures, although there is currently a lack of consensus of most appropriate measures, theories, and intervention, in dermatological care, resulting in inconsistencies across treatment. Consolidating varying constructs of appearance-concerns to produce an overarching framework of psoriasis care may inform policy development and improve standards of care (Atkinson et al., 2020), aligned with the role of CP's in service development.

Working clinically with body-image, CP's may also utilise therapeutic models aimed at developing acceptance of, and promoting compassion for, an altered appearance, such as Acceptance and Commitment Therapy (ACT) and Compassion Focused Therapy (Clarke et al., 2022). ACT may support people to diffuse from negative self-beliefs related to their appearance and prevent engagement in experiential avoidance (Alikhah et al., 2023).The incorporation of positive body-image in clinical practice may support those with psoriasis to broaden their conceptualisation of the body beyond appearance, considering concepts such as functionality in how they construct the self (Atkinson et al., 2020). Where psychological support focuses on the alleviation of negative body-image rather than the enhancement of positive body-image, individuals may be prevented from experiencing appreciation and respect for their body, which may negatively impact long-term outcomes (Tylka & Wood-Barcalow, 2015).

Currently, appearance interventions exist on an individual level, overlooking the impact of overarching systems and society on generating and perpetuating psychological difficulty (Shah, 2018). CP's may be placed to enhance the understanding of psychosocial

factors within MDT's through the offer of consultation, training, and supervision, supporting staff to develop a compassionate understanding of difficulties faced (Patel & Jafferany, 2020). Additionally, CP's may engage in advocacy by challenging negative social discourses when engaging with other professionals, and in society more broadly (Shah, 2018). This may also involve disseminating research findings to a larger audience, engaging with government ministers, lawyers and policy makers.

Much of the literature included in this review focused on psychosocial difficulties related to reduced self-esteem and body-image. However, within included studies, some participants described developing acceptance of their altered appearance, aligning with concepts of positive body-image. Previous literature has highlighted the importance of cognitive reframing, active coping; such as the use of humour, spirituality, and supportive relationships (Egan et al., 2011), and self-compassion (Clarke et al., 2022), in promoting adjustment to altered appearance more broadly (Egan et al., 2011), although there is limited evidence focussing on psoriasis-specific coping. Research exploring concepts such as positive body-image and positive illness identity may increase understanding of how protective constructs interact with appearance outcomes in psoriasis care (Atkinson et al., 2020), allowing for the development of standardised, valid, measures and intervention.

Limitations and Future Research

A key limitation of the study reflects the methodological approach of systematic reviews, considering susceptibility to bias. Within qualitative synthesis, there is a reliance on the researcher to select, appraise, and synthesise studies, meaning that selection of studies is subjective, and may give rise to selection bias (Maeda et al., 2022). To mitigate bias, within the present study coding and generation of descriptive themes were completed by the lead

researcher, with final analytic themes discussed with, and finalised in collaboration with the academic and field supervisors.

Additionally, 21 papers were included within the review, but these were not representative of 21 studies. Three papers presented in the review (Magin et al., 2009; Magin et al., 2010; Magin et al., 2011) utilised the same participant sample, therefore careful consideration was given to ensure that each paper presented unique or novel findings, evidenced by data extracts that were not replicated across papers. Consideration was also given to not over-represent similar concepts across these papers within the results section, utilising a range of studies to evidence the content of themes and subthemes.

This meta-synthesis was the first to synthesise qualitative findings on the experiences of appearance-based concerns of people living with psoriasis. Although it offers a comprehensive review of the evidence base, its synthesis reflects current understandings, thus highlighting areas for future research. Exploring cultural differences in how people living with psoriasis construct their identity may support person-centred care across healthcare systems, with improved outcomes. Within this review, the role of the media and societal beauty ideals were highlighted as being influential to appearance satisfaction, although this was considered through a Western lens. Future research may explore the relationship between non-Western beauty ideals and adjustment to psoriasis.

Conclusion

Findings from the current review suggest that people living with psoriasis may experience appearance-concerns related to negative self-beliefs, stigmatising experiences, and avoidant coping. Appearance-concerns may result in reduced self-esteem, self-confidence, and negative body-image, leading to a changed identity. The review highlights the role of CP's in promoting psychological wellbeing through individual, and systemic practice and the need

for further research exploring cultural differences in the lived experience and appearance concerns of psoriasis patients.

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Table 1: Search terms applied to each database

Academic Search Ultimate	
Search Terms Combined With AND	
	((DE "BODY image" OR DE "PERSON schemas" OR DE "SELF-perception" OR DE "SELF-esteem" OR DE "SELF-confidence" OR DE "BODY image disturbance" OR DE "BODY dysmorphic disorder" OR DE "SOCIAL stigma")) OR TI (((Self or Body) N5 (confiden* OR esteem OR disatisf* OR image OR worth OR accept* OR concerns OR perception)) OR appearance OR visibil* OR identity OR self-conscious* OR “body dysmorph*” OR bdd OR attractive OR beauty OR disfigure* OR stigma OR “social exclusion” OR ((Psychological or Psychosocial or Social) N2 (burden OR stress OR functioning OR impact)) OR “skin clearance”) OR AB (((Self or Body) N5 (confiden* OR esteem OR disatisf* OR image OR worth OR accept* OR concerns OR perception)) OR appearance OR visibil* OR identity OR self-conscious* OR “body dysmorph*” OR bdd OR attractive OR beauty OR disfigure* OR stigma OR “social exclusion” OR ((Psychological or Psychosocial or Social) N2 (burden OR stress OR functioning OR impact)) OR “skin clearance”)
	((DE "QUALITATIVE research" OR DE "QUALITATIVE research methodology" OR DE "MIXED methods research")) OR TI (Qualitat* OR "Grounded Theory” OR Interview* OR Observation* OR Narrat* OR Ethno* OR "Focus Group" or hermeneutic OR open-ended or thematic or “phenomeno*” OR “content analysis” OR “mixed method*”) OR AB (Qualitat* OR "Grounded Theory” OR Interview* OR Observation* OR Narrat* OR Ethno* OR "Focus Group" or hermeneutic OR open-ended or thematic or “phenomeno*” OR “content analysis” OR “mixed method*”)
	DE "PSORIASIS" OR TI (Psoriasi* OR psoriatic) OR AB (Psoriasi* OR psoriatic)

CINAHL	
Search terms combined with AND	
	((MH "Body Image Disturbance (Saba CCC)") OR (MH "Personal Identity Disturbance (Saba CCC)") OR (MH "Body Image") OR (MH "Body Dissatisfaction") OR (MH "Personal Appearance") OR (MH "Disfigurement") OR (MH "Self-Esteem (Iowa NOC)") OR (MH "Self Esteem Disturbance (NANDA)") OR (MH "Self Concept") OR (MH "Confidence") OR (MH "Beauty") OR (MH "Stigma")) OR TI (((Self or Body) N5 (confiden* OR esteem OR disatisf* OR image OR worth OR accept* OR concerns OR perception)) OR appearance OR visibil* OR identity OR self-conscious* OR “body dysmorph*” OR bdd OR attractive OR beauty OR disfigure* OR stigma OR “social exclusion” OR ((Psychological or Psychosocial or Social) N2 (burden OR stress OR functioning OR impact)) OR “skin clearance”) OR AB (((Self or Body) N5 (confiden* OR esteem OR disatisf* OR image OR worth OR accept* OR concerns OR perception)) OR appearance OR visibil* OR identity OR self-conscious* OR “body dysmorph*” OR bdd OR attractive OR beauty OR disfigure* OR stigma OR “social exclusion” OR ((Psychological or Psychosocial or Social) N2 (burden OR stress OR functioning OR impact)) OR “skin clearance”)
	((MH "Qualitative Studies") OR (MH "Phenomenology") OR (MH "Multimethod Studies") OR (MH "Interviews")) OR TI (Qualitat* OR "Grounded Theory” OR Interview* OR Observation* OR Narrat* OR Ethno* OR "Focus Group" or hermeneutic OR open-ended or thematic or “phenomeno*” OR “content analysis” OR “mixed method*”) OR AB (Qualitat* OR "Grounded Theory” OR Interview* OR Observation* OR Narrat* OR Ethno* OR "Focus Group" or hermeneutic OR open-ended or thematic or “phenomeno*” OR “content analysis” OR “mixed method*”)

	(MH "Psoriasis") OR TI (Psoriasi* OR psoriatic) OR AB (Psoriasi* OR psoriatic)
MEDLINE	
Search terms combined with AND	
	((MH "Body Image") OR (MH "Body Dissatisfaction") OR (MH "Body Dysmorphic Disorders") OR (MH "Physical Appearance, Body") OR (MH "Self Concept") OR (MH "Beauty") OR (MH "Social Stigma")) OR TI (((Self or Body) N5 (confiden* OR esteem OR disatisf* OR image OR worth OR accept* OR concerns OR perception)) OR appearance OR visibil* OR identity OR self-conscious* OR “body dysmorph*” OR bdd OR attractive OR beauty OR disfigure* OR stigma OR “social exclusion” OR ((Psychological or Psychosocial or Social) N2 (burden OR stress OR functioning OR impact)) OR “skin clearance”) OR AB (((Self or Body) N5 (confiden* OR esteem OR disatisf* OR image OR worth OR accept* OR concerns OR perception)) OR appearance OR visibil* OR identity OR self-conscious* OR “body dysmorph*” OR bdd OR attractive OR beauty OR disfigure* OR stigma OR “social exclusion” OR ((Psychological or Psychosocial or Social) N2 (burden OR stress OR functioning OR impact)) OR “skin clearance”)
	((MH "Qualitative Research") OR (MH "Hermeneutics") OR (MH "Interview, Psychological") OR (MH "Focus Groups")) OR TI (Qualitat* OR "Grounded Theory” OR Interview* OR Observation* OR Narrat* OR Ethno* OR "Focus Group" or hermeneutic OR open-ended or thematic or “phenomeno*” OR “content analysis” OR “mixed method*”) OR AB (Qualitat* OR "Grounded Theory” OR Interview* OR Observation* OR Narrat* OR Ethno* OR "Focus Group" or hermeneutic OR open-ended or thematic or “phenomeno*” OR “content analysis” OR “mixed method*”)

	(MH "Psoriasis") OR TI (Psoriasi* OR psoriatic) OR AB (Psoriasi* OR psoriatic)
PsychINFO	
Search terms combined with AND	
	((DE "Self-Perception" OR DE "Body Esteem" OR DE "Body Dissatisfaction" OR DE "Body Dysmorphic Disorder" OR DE "Body Image" OR DE "Body Image Disturbances" OR DE "Self-Esteem" OR DE "Self-Acceptance" OR DE "Self-Concept" OR DE "Self-Confidence" OR DE "Self-Regard" OR DE "Self-Worth" OR DE "Physical Appearance" OR DE "Physical Attractiveness" OR DE "Physical Disfigurement" OR DE "Stigma" OR DE "Self-Stigma")) OR TI (((Self or Body) N5 (confiden* OR esteem OR disatisf* OR image OR worth OR accept* OR concerns OR perception)) OR appearance OR visibil* OR identity OR self-conscious* OR “body dysmorph*” OR bdd OR attractive OR beauty OR disfigure* OR stigma OR “social exclusion” OR ((Psychological or Psychosocial or Social) N2 (burden OR stress OR functioning OR impact)) OR “skin clearance”) OR AB (((Self or Body) N5 (confiden* OR esteem OR disatisf* OR image OR worth OR accept* OR concerns OR perception)) OR appearance OR visibil* OR identity OR self-conscious* OR “body dysmorph*” OR bdd OR attractive OR beauty OR disfigure* OR stigma OR “social exclusion” OR ((Psychological or Psychosocial or Social) N2 (burden OR stress OR functioning OR impact)) OR “skin clearance”)
	((DE "Qualitative Measures" OR DE "Qualitative Methods" OR DE "Mixed Methods Research" OR DE "Hermeneutics" OR DE "Phenomenology" OR DE "Interviews")) OR TI (Qualitat* OR "Grounded Theory” OR Interview* OR Observation* OR Narrat* OR Ethno* OR "Focus Group" or hermeneutic OR open-ended or thematic or “phenomeno*” OR “content analysis” OR “mixed method*”) OR AB (Qualitat* OR "Grounded Theory”

OR Interview* OR Observation* OR Narrat* OR Ethno* OR "Focus Group" or hermeneutic OR open-ended or thematic or “phenomeno*” OR “content analysis” OR “mixed method*”)

TI (Psoriasi* OR psoriatic) OR AB (Psoriasi* OR psoriatic)

Figure 1: PRISMA 2020 flow diagram

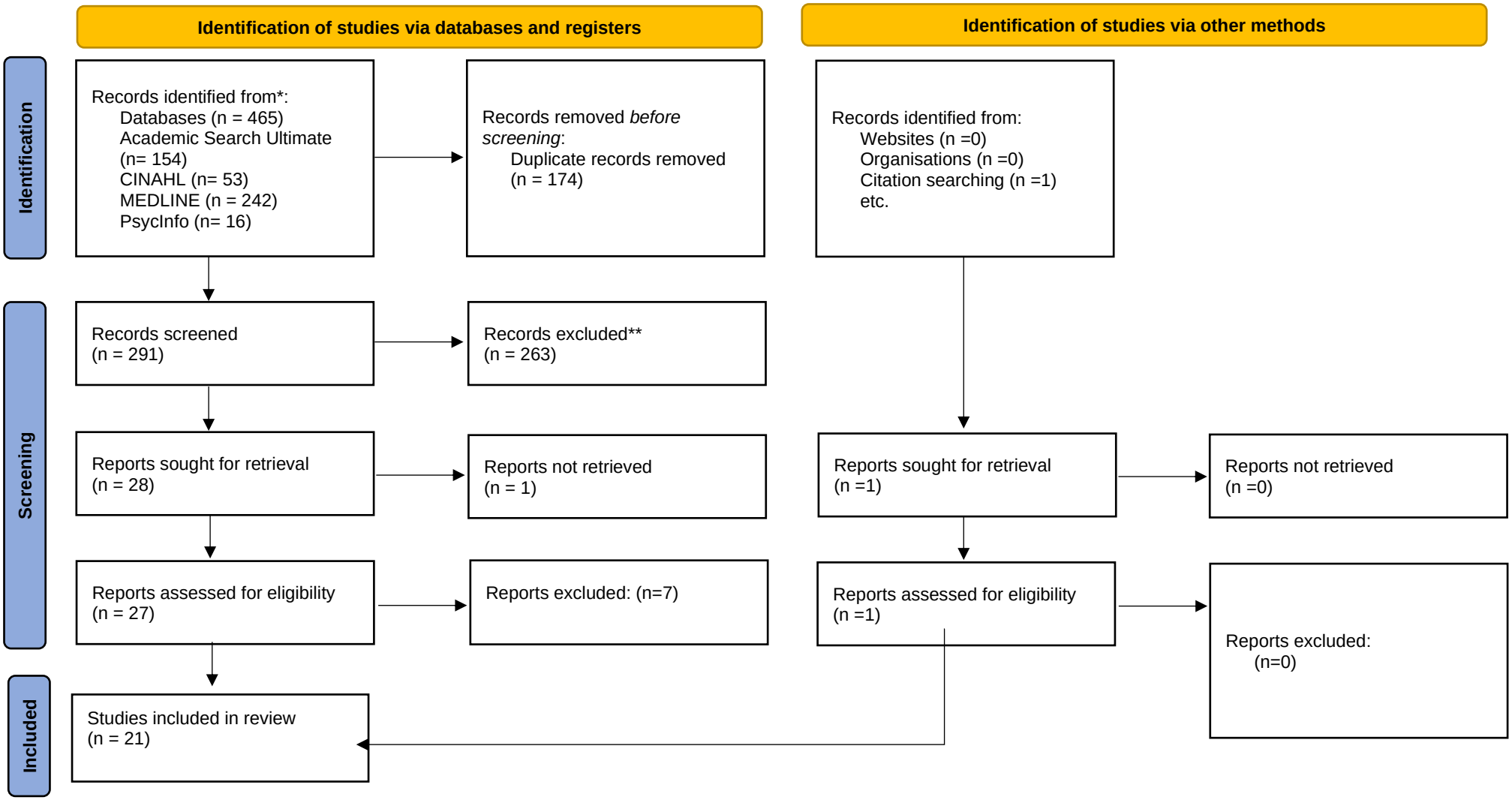

Table 2: Summary information of the selected papers

Author(s)	Year	Location	Research Aim	Participants	Design and Data Collection	Data Analysis
Bundy, Borthwick, McAteer, Cordingley, Howells, Bristow, & McBride	2014	UK	To develop understanding of the lived experience of psoriasis	104 postcards were returned, although some participants returned more than one. Personal data was not collected, thus the final sample size is not known.	Participants were asked to write a postcard titled 'dear psoriasis' describing how it makes them feel/think and how it has impacted their life	Modified grounded theory approach with an element of constant comparison and thematic analysis
Howard, Ahmed, & Cream	2012	UK	To explore the lived experiences of people living with psoriasis, considering the impact on physical health, psychological wellbeing, and social functioning.	Nine participants	Semi-structured interview	Colaizzi's (1978) descriptive phenomenological method

Hughes & Hunter	2022	UK	To explore the lived experiences of people with psoriasis with attention to the potential role of anger in the onset and progression of the condition	12 participants (*n* = 5 females, *n* = 7 males)	Semi-structured interview	Thematic analysis
Janoska, Pawlak & Kubiak	2016	Poland	To explore the psychological entailments of psoriasis	Two participants (a 48 year old female, and a 23 year old male)	Structured interview and direct observation	Psychobiological method and direct observation
Jowett & Ryan	1985	UK	To explore the social impact of psoriasis	100 participants who had a diagnosis of psoriasis, eczema, or acne. 38 participants had a diagnosis of psoriasis.	Structured interview	Data analysis methodology not stated

				Age ranged between 16-79 years.		
Khoury, Danielsen & Skiveren	2014	Denmark	To explore the influence of psoriasis on patients' body image	Eight participants (*n* = 4 females, *n* = 4 males, age ranged between 21-59)	Semi-structured interview	Template analysis
Kouwenhoven, van Der Ploeg & van de Kerkhof	2020	Netherlands	To explore treatment goals for people living with psoriasis	15 participants (*n* = 7 females, *n* = 8 males, age ranged between 18-71)	Semi-structured interview	Template analysis
Lee, Huo & Chen	2023	Taiwan	To explore the experiences and coping of people living with psoriasis.	20 participants	Semi-structured interview	Content analysis
Magin, Adams,	2011	Australia	To explore the psychological	62 participants with psoriasis, eczema, or	Semi-structured interview	Thematic analysis

Heading & Pond			entailments of skin disease.	acne. 29 participants had a diagnosis of psoriasis.		
Magin, Adams, Heading & Pond	2010	Australia	To explore the impact of acne, psoriasis and atopic eczema upon sexual functioning and sexual relationships.	62 participants with psoriasis, eczema, or acne. 29 participants had a diagnosis of psoriasis.	Semi-structured interview	Thematic analysis
Magin, Adams, Heading, Pond, & Smith	2009	Australia	To investigate the psychological comorbidities in psoriasis.	29 (*n* = 18 females, *n* = 11 males, age ranged between 25-73)	Semi-structured interview	Thematic analysis
Narayanan, Guyatt, Franceschetti, & Hautamaki	2014	US, France, Germany, Italy, Spain, the UK, Brazil, and Canada.	To assess the impact of psoriasis on health-related quality of life.	50 participants	Patients underwent their daily activities, while researchers filmed the patients and took detailed field notes. Researchers had an unstructured	Frameworks from anthropology and behavioural economics

					discussion guide, but the interactions were driven by the patient.	
Nelson, Chew-Graham, Griffiths, & Cordingley	2013	UK	To explore in depth the perspectives of people living with psoriasis including coping responses, self-care strategies and how consultations with healthcare professionals in both primary and secondary care are experienced.	29 participants (*n* = 14 females, *n* = 15 males)	Semi-structured interview	Framework analysis
Newi, Tsianakas, von Martial, Sommer, & Blome	2022	Germany	To explore the importance of subjective well-being as an outcome of psoriasis treatment	11 participants (*n* = 3 females, *n* = 8 males, age ranged between 24-63)	Semi-structured interview	Content analysis

			from patient's perspective.			
Pariser, Schenkel, Carter, Farahi, Brown, Ellis, & Psoriasis Patient Interview Study Group	2016	USA	To explore lived experiences of psoriasis, including symptoms, treatments, impact on daily lives and patient-reported functioning.	Ninety participants	Semi-structured interview	Two coders iteratively developed a qualitative codebook from the qualitative data captured in patient interviews. Dominant trends were identified in each interview and compared across results of the other interviews to generate themes or patterns in the ways that patients described their symptoms, bother rankings and disease impact on their lives.

Parkhouse	2019	USA	To explore the lived experiences of stigma-stress among people living with psoriasis	23 participants (*n* = 18 females, *n* = 5 males, age ranged between 19-78)	Semi-structured interview	Grounded theory
Uttjek, Nygren, Stenberg, & Dufåker	2007	Sweden	To explore the lived experiences of people with psoriasis	18 participants (*n* = 9 females, *n* = 9 males, age ranged between 37-74)	Semi-structured interview	Elements of content analysis and grounded theory
Wahl, Gjengedal, & Hanestad	2002	Norway	To explore the experiences of living with psoriasis, and the impact of psoriasis on social and psychological processes.	22 participants (*n* = 12 females, *n* = 10 males, age ranged between 20-80)	Open-ended interview	Grounded theory
Watson & De Bruin	2007	South Africa	To describe the lived experiences of people with psoriasis and the	7 participants	Open-ended interview	Existential phenomenology methodology

			impact of psoriasis on their concept of self.			
Wheeler, Guterres, Bewley, & Thompson	2022	UK	To explore the experiences of those living with a skin condition, and their views on seeking psychological support.	544 participants who had a diagnosis of a skin condition. 177 participants had a diagnosis of psoriasis.	Survey with qualitative responses	Thematic analysis
Zhong, Yang, Mao, Chai, & Li	2021	China	To explore the impact of moderate-to-severe psoriasis on quality of life.	22 participants (*n* = 8 females, *n* = 14 males, age ranged between 18-70)	Semi-structured interview	Thematic analysis

Table 3. Quality Appraisal of the selected papers using Critical Appraisal Skills Programme (CASP)

CASP (2019) Questions	Newi et al., (2022)	Pariser et al., (2016)	Howard et al., (2012)	Jowett & Ryan (1985)	Magin et al., (2009)	Magin et al., (2011)	Magin et al., (2010)	Narayanan et al., (2015)	Nelson et al., (2013)	Parkhouse et al., (2019)	Kouwenhoven et al., (2020)	Janoska et al., (2016)	Uitjek et al., (2007)	Wahl et al., (2002)	Watson et al., (2007)	Wheeler et al., (2022)	Zhong et al., (2021)	Lee et al., (2023)	Khoury et al., (2014)	Hughes & Hunter (2022)	Bundy et al., (2014)
Was the research design appropriate to address the aims of the research?	2	2	2	1	3	2	2	3	3	3	2	2	2	2	3	3	2	2	2	2	2
Was the recruitment strategy appropriate to the aims of the research?	2	3	2	2	3	3	3	2	3	3	2	2	3	2	3	3	3	2	2	2	2
Was the data collected in a way that addressed the research issue?	2	2	2	2	3	3	3	2	3	3	3	2	3	3	1	2	3	3	2	2	2
Has the relationship between researcher and participants been adequately considered?	1	1	2	1	2	1	3	1	1	2	1	1	1	1	1	1	1	2	1	1	1

Have ethical issues been taken into consideration?	1	1	2	1	3	1	1	1	2	2	1	1	2	2	1	2	3	2	2	2	1
Was the data analysis sufficiently rigorous?	1	2	2	1	2	2	2	1	3	3	2	1	2	3	2	2	2	2	2	2	3
Is there a clear statement of findings?	3	2	3	2	2	2	2	3	3	3	2	2	3	2	2	2	2	2	2	2	2
How valuable is the research?	3	1	3	2	2	3	3	2	2	3	1	1	1	1	3	2	2	1	1	3	2
Total	15	14	18	12	20	17	19	15	20	22	14	12	17	16	16	17	18	16	14	16	15

1 = little to no justification or explanation

2 = moderate justification or explanation but not fully elaborated on

3 = extensive justification or explanation

Table 4. Contribution of each paper to final themes

	Newi et al., (2022)	Pariser et al., (2016)	Howard et al., (2012)	Jowett & Ryan (1985)	Magin et al., (2009)	Magin et al., (2011)	Magin et al., (2010)	Narayanan et al., (2015)	Nelson et al., (2013)	Parkhouse et al., (2019)	Kouwenhoven et al., (2020)	Janoska et al., (2016)	Uitjek et al., (2007)	Wahl et al., (2002)	Watson et al., (2007)	Wheeler et al., (2022)	Zhong et al., (2021)	Lee et al., (2023)	Khoury et al., (2014)	Hughes & Hunter (2022)	Bundy et al., (2014)
Theme One: Constructing and Navigating the Psoriasis-Identity	X	X	X		X		X	X	X		X			X	X	X	X	X	X	X	X
Challenges to body image and self-perception	X	X	X		X		X	X	X		X			X	X	X	X	X	X		X
Psoriasis vs personal identity		X			X			X							X				X	X	X
Theme Two: Appearance Stigmatisation	X	X	X	X	X	X	X		X	X	X	X	X	X			X	X		X	
Theme Three: Acceptance and coping with an altered appearance	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Avoidance and concealment	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Developing acceptance over time												X	X		X			X		X	X

Appendix 1-A Journal Instructions for Authors

Instructions to Authors

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The ***European Journal of Health Psychology*** strives to promote theory and practice in the analysis of psychological approaches to health and disease. The journal publishes high-quality empirical or experimental research, as well as sound practice-oriented articles, current methodological developments, and comprehensive critical reviews of the scientific literature.

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[1] Stroup, D.F., Berlin, J.A., Morton, S.C., Olkin, I., Williamson, G.D., Rennie, D., Moher, D. Becker, B.J., Sipe, T.A., & Thacker,

S.B. (2000). Meta-analysis of observational studies in epidemiology. A proposal for reporting. Meta-analysis of Observational Studies in Epidemiology (MOOSE) Group. *Journal of the American Medical Association, 283*(15), 2008-2012. https://doi.org/10.1001/jama.283.15.2008

Journal of Health Psychology are required to include a PRISMA statement (https://www.prisma-statement.org/) as a supplemental file for review (the final document will be included as ESM). In addition, authors of meta-analyses should include the information recommended by the APA's Meta-Analysis Reporting Methods (MARS), which can be found at http://www.apastyle.org/manual/related/JARS-MARS.pdf.

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Hilverda, F., & Vollmann, M. (2021). *Risk perception of COVID-19 and vaccine uptake among university students in The Netherlands* [Raw data]. Erasmus University Rotterdam Data Repository. https://doi.org/10.25397/eur.17182292

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Appendix 1-B Detailed Breakdown of Analysis Process – As Outlined by Thomas and Harden (2008)

1. Each study was read several times, to increase familiarity with the dataset, whilst line-by-line coding was completed.
2. Codes were grouped into clusters of similar concepts, to generate descriptive themes.
3. Descriptive themes were compared and interpreted to develop analytic themes.
4. The analytic themes were discussed with the research and field supervisors, and amendments were made where necessary.

Appendix 1-C Example of transformation of line-by-line coding to descriptive and analytical themes

Theme Three: Acceptance and coping with an altered appearance

Line-by-line codes	Descriptive Themes	Analytic Theme
• Being young, single, and experiencing an 'ugly' disease is devastating • Age promotes acceptance – wearing clothing that shows psoriasis at an older age • Having psoriasis as a child/teenager would be difficult • During adolescence covering the body, rarely wearing a skirt • Feeling able to manage it as an adult, but struggling to cope as a child at school • Becoming more aware of the importance of physical appearance as a teenager	Importance of life-stage in adjustment	**Theme Three: Acceptance and coping with an altered appearance** a) Developing acceptance over time b) Avoidance and concealment

• Feeling restricted to loneliness regarding career and romantic relationships • Avoiding meeting romantic partners when you are single • Avoiding intimacy as the other person will be ‘grossed out’ • Wearing long sleeve tops to conceal psoriasis when single and out dancing • Having to wear a lot of clothing to maintain personal appearance • Dressing in clothes that feel unnatural (e.g. in summer)	Wishing to conceal psoriatic lesions

Section Two: Research Paper

Appearance-based Concerns and Psychosocial Functioning Following Complex Plastic Surgery for Female Melanoma Survivors

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Prepared for submission to *Journal of Psychosocial Oncology*

Abstract

Background

Melanoma is an aggressive form of skin cancer, for which primary treatment options involve surgical removal. Surgery results in permanent changes in appearance, particularly for those undergoing complex reconstructive surgery. Melanoma survivors may therefore experience ongoing body-image concerns and psychosocial distress, with females more likely to report a lasting impact on their wellbeing. However, qualitative research exploring the experiences of melanoma survivors remains limited.

Aims

This study aimed to explore the experiences of female melanoma survivors who have undergone reconstructive plastic surgery, with a focus on appearance-based concerns and psychosocial functioning.

Methods

Semi-structured interviews took place with seven people who had undergone reconstructive plastic surgery as a part of their treatment for melanoma. Interviews were recorded, transcribed, and analysed using interpretative phenomenological analysis.

Results

Three themes were developed: ‘Constructing the melanoma-identity’, ‘Relating to others: experiencing dismissal and self-stigmatisation’ and ‘Grieving the life you had: psychosocial adjustment’. Findings highlight the impact of appearance changes upon participants’ sense-of-self and identity.

Conclusions

Psychologists could offer person-centred therapies aligned with concepts of post-traumatic growth and positive body-image. They may offer consultation and training to develop compassion for body-image concerns in multidisciplinary teams.

Introduction

Cancer is the second-leading cause of death worldwide, with an estimated 19.3 million new cases and 10.0 million deaths reported in 2020 (Cao et al., 2021; Ferlay et al., 2021). The psychological entailments of receiving a cancer diagnosis are widely documented, with half of people reporting anxiety or depression at the time of diagnosis (National Institute for Health and Care Excellence [NICE], 2004). Reaction to receiving a cancer diagnosis is context-dependent, although may include denial, forced acceptance, and pessimism for the future (Shahmari et al., 2023). Variance in acceptance of diagnosis may relate to differences across life-stage, culture, treatment options and prognosis (Secinti et al., 2019; Novirianthy et al., 2023). Reflecting the complexity and intertwinement of these factors, psychosocial difficulties often endure beyond the course of the illness (Ağaç & Özçetin, 2021), including emotional difficulties such as fear of recurrence, altered body-image, and changes in social, sexual, or physical functioning (Costa et al., 2016). Suicidality is higher amongst cancer patients than the general population, due to concepts such as perceived burdensomeness and thwarted belongingness (Misono et al., 2008; Amiri & Behnezhad, 2020; Schomberg et al., 2021). Thus, understanding the experiences of cancer survivors may support healthcare professionals (HCP's) in promoting quality of life (QOL) (Jacobsen & Wagner, 2012).

Body-image and Appearance Concerns

Body-image is a significant psychosocial issue experienced by people living with cancer (Fingeret et al., 2014). Considered a multifaceted construct, body-image refers to thoughts, feelings, and behaviours related to the body in its entirety, including its functioning and appearance (Fingeret, 2010). For cancer patients, visible changes in the body resulting from surgical procedure or pharmacological therapy, such as hair loss, weight gain, and scarring, may impact body-image negatively (Snöbohm et al., 2010). Experiencing altered

body-image may increase apprehension of judgment from others, which may further impact upon psychosocial functioning, such as engagement in relationships and sexual functioning (Rhee et al., 2005).

Variation in the psychological entailments and body-image concerns experienced by cancer patients is impacted by factors such as cancer subtype, location, and treatment (Linden et al., 2012; Niedzwiedz et al., 2019). For patients with visible tumours such as skin cancer (SC), primary treatment options involve surgical removal (van Egmond et al., 2021), resulting in permanent changes in appearance. This may result in long-term changes in self-esteem and body-image, which may subsequently lead to negative changes in how an individual constructs their identity (Melissant et al., 2018).

The Psychosocial Impact of Skin Cancer

SC is an umbrella term accounting for non-melanoma skin cancer (NMSC), and melanoma (Nikolouzakis et al., 2020). Melanoma represents the most aggressive form of SC, holding a significant risk of cancer-related death (Cancer Research UK, 2020; Giblin & Thomas, 2007). Resulting from malignancy of the skins pigment cells (melanocytes), ultraviolet radiation (UV) exposure is a significant risk factor in melanoma development, alongside predisposing factors such as genetics (Görig et al., 2020). As melanoma is primarily cutaneous, initial treatment involves surgery, with adjuvant therapies offered where there is evidence of metastasis (NICE, 2022). Surgery may involve excision biopsy, followed by wide local excision (WLE), and sentinel lymph node biopsy (SLNB) (Ferrandiz et al., 2012). In complex cases, WLE may be performed under plastic surgery due to requiring a reconstructive procedure. Approximately 325,000 melanoma cases were reported worldwide in 2020, with this predicted to reach 510,000 by 2040 (Sood et al., 2021; Curti et al., 2021; Arnold et al., 2022). Whilst various preventative health campaigns have aimed to increase

awareness of the risks of UV exposure (Buller et al., 2011; Centers for Disease Control and Prevention, 2012; Makin et al., 2013), the number of melanoma cases has continued to rise (Sood et al., 2021; Curti et al., 2021; Arnold et al., 2022).

Despite a large evidence base exploring the psychosocial needs of people with cancer broadly, research exploring the needs of people with SC remains limited (Bath-Hextall et al., 2017). Qualitative research has typically explored the experiences of NMSC patients, focusing on head and neck procedures (Lee et al., 2016; van Egmond et al., 2021). Although such studies have investigated the needs of people with complex SC diagnoses, this has largely focused on care needs (van Egmond et al., 2021). However, research has highlighted that body-image dissatisfaction has a profound psychological impact for SC survivors (Vaidya et al., 2019), with reduced engagement in meaningful activity due to feelings of shame and self-consciousness related to scarring (Lee et al., 2016). Whilst this decreases over time (Lee et al., 2016), patients receiving reconstructive surgery report ongoing disappointment with recovery, even if they are shown photographs of the expected result pre-surgery (van Egmond et al., 2021).

Although such studies highlight the negative impact of SC surgery on body-image and functioning, the prognosis and treatment of NMSC and melanoma differs. SC patients experiencing lesions across the body may require complex reconstructive surgery, particularly for melanoma (Pasquali et al., 2016). One study exploring the care needs of female melanoma survivors found that those with a distal extremity tumour experienced significantly greater body-image distress than those with a proximal extremity tumour (Atkinson et al., 2013), indicating that tumour location is important in post-operative wellbeing. Melanoma survivors are more likely to report ongoing psychosocial distress related to fear of recurrence and poor prognosis (Molassiotis et al., 2014), whilst the needs of NMSC survivors revolve more around physical functioning (Sampogna et al., 2019).

Where research considers the experiences of melanoma survivors, quantitative methodology is typically utilised, with studies drawing comparisons between melanoma and other cancer subtypes (Ranieri et al., 2022; Engel et al., 2014). Broadly, quantitative research highlights the impact of receiving a melanoma diagnosis upon long-term QOL, with difficulties experienced described as mostly psychological in nature (Kasparian et al., 2009). Specifically, melanoma survivors may experience difficulties across social functioning, self-image, relationships, and wellbeing (Stamataki et al., 2014). Within quantitative research, appearance-related distress for melanoma survivors is reportedly low (Atkinson et al., 2013; Bassino et al., 2017). However, the validity of such studies can be criticised for measuring body-image constructs using measures that are not specific to scarring, or melanoma. Quantitative studies have, however, highlighted gender differences in body-image satisfaction for melanoma survivors. Females are more likely to report appearance distress post-operatively (Vaidya et al., 2019; Lichtenthal et al., 2005; Newton-Bishop et al., 2004), and are significantly more likely than males to note a decrease in pre-operative activity levels up to 12-months post-operatively (Robinson, 2019).

In contrast, qualitative studies highlight the negative impact of melanoma surgical procedures and post-surgical complications upon identity. Across qualitative literature, survivors report shock at appearance changes, experiencing feelings of disfigurement post-surgery (Stamataki et al., 2014; Vogel et al., 2017). For melanoma survivors, altered body-image reflects a disparity between pre-surgery expectations of scarring, and actual scar appearance (Stamataki et al., 2014; Vogel et al., 2017). As identified in quantitative research (Bassino et al., 2017), these feelings are exacerbated by a mismatch in survivors own perception of their scar, and that of HCP's. However, one study reported that some survivors downplay their altered body-image (Stamataki et al.,2014), which may reflect the stigma

associated with having a SC diagnosis, where severity of melanoma is underestimated (Vogel et al., 2017).

The Current Study

To summarise, the psychosocial difficulties and body-image concerns of melanoma survivors have been overlooked. Where reported, this is often in comparison to other cancer subtypes, utilising quantitative methodology, which is limited in understanding lived experience and meaning-making. As initial treatment for melanoma relies on surgery, comparison cannot be drawn with other cancers when considering body-image, as adjuvant therapies result in differing appearance changes. As studies draw conclusion from quantitative, often observational, methodology, further qualitative research is needed to understand the differences in experience for people living with melanoma, in isolation. Central to this is understanding the sense-making of people diagnosed with melanoma across survivorship.

The present research study aims to explore appearance-based concerns of melanoma survivors who have undergone complex surgical procedures, such as plastic surgery reconstruction. As females experience more body-image concerns post-operatively (Vaidya et al., 2019), this study will explore how appearance affects survivorship and psychological functioning, for females. Insights into appearance-based concerns may support HCP's in understanding how body-image contributes to post-operative wellbeing, and consider delivery of care. This may highlight when psychological interventions are best placed, such as pre-operatively to prepare patients for surgery.

The research aims are (i) to develop an understanding of the experiences and appearance concerns of female melanoma survivors who have undergone complex plastic

surgery, and (ii) to develop an understanding of how these experiences are understood, and coped with by survivors.

Method

Design

The study was concerned with understanding the lived experience of melanoma, therefore a qualitative approach was utilised. Interpretative Phenomenological Analysis (IPA) (Smith et al., 2022) was the methodological approach undertaken, due to its grounding in phenomenology, hermeneutics, and idiography, aiming to understand the lived experience of participants, through their own, and the researcher's, sense-making. IPA focuses on the detailed analysis of each particular case, and is concerned with producing an idiographic analysis for a small, well-defined (homogenous) participant group (Smith & Shinebourne, 2012). Importantly, IPA recognises the active role of the researcher in the interpretation of participants' experiences, which itself may be influenced by the researchers own experiences, assumptions, and beliefs. Semi-structured interviews were utilised in line with IPA guidance (Smith et al., 2022) to elicit detailed information about pertinent experiences, whilst enabling flexibility for the discovery of novel themes (Pietkiewicz & Smith, 2014).

Participants and Recruitment

To facilitate detailed case-by-case analysis in line with IPA's idiographic approach, small, homogenous samples are recommended (Smith et al., 2022). Although exact numbers are not stipulated, published studies typically have a sample size of 4-10, with 6-10 interviews considered sufficient for a professional doctorate (Smith et al., 2022). Within the current study, these recommendations were used to generate an approximate sample size. However, the final participant sample was continuously reviewed in line with concepts such as data saturation and information power, where dynamic factors such as quality of dialogue

and sample specificity were considered alongside the theoretical underpinnings of IPA (Malterud et al., 2016). Purposive sampling was utilised to recruit approximately 6-10 participants whose experiences were relevant to the research aims. Inclusion and exclusion criteria are displayed in Figure 2.

The decision to only include female participants was informed by literature indicating that the experiences of male and female SC survivors differ. As females reportedly experience more body-image concerns post-operatively (Vaidya et al., 2019), the aim of excluding males was to create a more homogenous sample.

Participants were required to be at least three months post-surgery to allow adjustment to receiving a cancer diagnosis. Individuals with ongoing health difficulties were excluded as concerns related to prognosis or treatment may elicit distress.

Recruitment followed a stepped approach. Initially, UK based melanoma charities were contacted and asked to share the participant information sheet (PIS) across their mailing lists, and via social media. They were also invited to share an advertisement within charity publications or at conferences. Of five charities contacted, one agreed to advertise the study. However, this did not yield the participant sample required, therefore the social media platforms Facebook and Twitter were utilised to share the study across a wider platform. Due to having lived experience of melanoma, the lead researcher was a member of several UK Facebook support groups. After contacting administration, one group agreed to advertise the study anonymously, to ensure that participants could not contact the lead researcher personally.

Recruitment took place between March and September 2023. In total, seven participants took part in the study, aged between 44 and 77, with a mean age of 60. Time

since diagnosis ranged between 2-7 years, with a mean duration of 5 years. The key demographics of participants' diagnoses are illustrated in Table 1.

Data Collection

Individuals viewing the social media advertisement could access an electronic copy of the PIS, which asked them to contact the lead researcher to register interest. Participants were asked to indicate a preference on the interview medium, either Microsoft Teams, telephone, or face-to-face. As the study was open across the UK, face-to-face interviews were only offered within a specific geographical area. Five participants opted to be interviewed over Microsoft Teams, and two via telephone.

Interviews were conducted between April and November 2023. An interview schedule was developed through a literature search, and in discussion with a melanoma charity and the field supervisor (a clinical psychologist (CP) in oncology). Questions explored participants' care experiences and the impact of melanoma on psychological functioning, appearance, and social functioning; for example *"When you first saw your scar(s) following surgery, how did you feel emotionally?"*

Interviews began by reviewing participants' understanding of the research, answering questions, and clarifying the limitations of confidentiality. Participants had the option of returning an electronic consent form, or providing audio consent at the beginning of the interview. As the PIS highlighted the lead researchers' own diagnosis, this was briefly discussed. Participants were made aware that the lead researcher would not share their own experiences during interview, but would allow questions at the end. It was hoped that implementing this boundary would assist the researcher in bracketing their experiences, to privilege the participants' own meaning-making. Interviews lasted between 58 and 89 minutes, guided by each participants' narrative. Following the interview, participants were

thanked and given the opportunity to ask questions, before being provided with a debrief form containing contact details for further support.

The research proposal was reviewed by the research team at Lancaster University.

Analysis

Interviews were transcribed verbatim by the lead researcher with pseudonyms selected by participants. Data analysis incorporated the stages set out by Smith et al (2022) and, for auditing purposes, followed the steps outlined by Murray and Wilde (2020).Appendix 2D offers a detailed breakdown of the analysis process.

Throughout the analysis process, the academic supervisor reviewed themes generated. At times, this supported the grouping of themes and development of theme titles. As the lead researcher had lived experience of melanoma, this was important in ensuring validity of findings, and as a form of quality assurance.

Reflexivity

A key component of IPA is recognising the active role of the researcher within the research process (Smith et al., 2022). Engaging in a ‘double hermeneutic’, the researcher assumes a central role in making sense of participants’ sense-making, allowing them to uncover the dual meanings of a phenomena (Shaw, 2010; Tuffour, 2017). As the researcher is bound by their own understandings, it is important to adopt a reflexive position, considering how these conceptualisations may impact upon data analysis (Smythe et al., 2019). As interaction with data is fluid and continuous, reflexivity is considered a way of *being* rather than a stage of analysis (Engward & Goldspink, 2020). Thus, throughout data collection and analysis I kept a journal to reflect on experiences and assumptions related to the research, and engaged in supervisory sessions with the academic and field supervisors.

Having lived experience of melanoma, considering my own preconceptions throughout data collection and analysis was important. As participants were aware of my diagnosis, I considered how this may lead to them noting comparisons or divergences between us. Likewise, I considered my own experience of similarities or differences, and the emotional response this could elicit. Following one interview I reflected with the academic supervisor about differences I noted around melanoma location and life-stage at diagnosis. Having the opportunity to consider the participant's sense-making within the supervisory relationship enabled me to develop new insights (Engward & Goldspink, 2020), which resulted in the interview schedule being amended to capture additional information. Utilising supervision in this way is key within IPA research, as engaging in prolonged periods of analysis may result in the researcher overlooking a key facet of participants' understanding (Smith, 2011).

Ethics

Ethical approval was granted by Lancaster University FHM Research Ethics Committee. Professional guidelines were considered (Oates et al., 2021; Health and Care Professions Council, 2016), and reflection was sustained throughout the study in line with qualitative research aims (Smith et al., 2022). As digital platforms are increasingly utilised for data collection (Lobe et al., 2020), particular consideration was given to consent and safeguarding processes. Participants could access an electronic PIS, and received an electronic consent form 24-hours prior to interview to ensure informed consent. Participants were invited to return this via email, or provide audio consent at the beginning of interview. Consent was revisited during interview where forms were returned in advance.

As interviews occurred remotely, ethical challenges related to duty of care were considered. Within qualitative research participants may be affected in ways that cannot

always be anticipated (Butterfield et al., 2009). As participants described personal cancer experiences, particular consideration was given to their wellbeing throughout. Considering safeguarding issues and risk, a safety plan was agreed with the thesis supervisors. Following interview, participants were provided with a debrief sheet detailing various support organisations. Participants were offered a full copy and/or summary of the research paper.

Results

Theme One: Constructing the melanoma-identity

This theme considers how participants made sense of appearance changes in constructing their melanoma-identity. It consists of three subthemes.

"I felt like Frankenstein" – body-image altered by scarring. On viewing WLE scarring for the first time, all participants expressed shock as scarring was worse than their expectations. Even where HCP's discussed scarring prior to surgery, participants felt uninformed, believing that the procedure would be similar to the excision biopsy, so were surprised by the depth and size of scarring:

> *…she took a lot of time with me at my first appointment where she explained that I might have to have a graft but if possible she would do a flap, and she actually drew it all out for me. But even so, I had no idea of the scale of it. When that first dressing came off I was absolutely gobsmacked as to how extensive the surgery had been.* (Maggie)

Distress appeared exacerbated by the delay between surgery and seeing scarring for the first time, when dressings were removed. During this time, participants had begun to make sense of their diagnosis and melanoma-identity, but were unaware of the extent of appearance changes. Therefore, the unveiling of scarring elicited a strong emotional response, and represented a loss of identity:

> *I remember the first time they took the dressing off, I cried. And I saw how bad it was. Yeah, I've still got the pictures on my phone now… and nothing prepared me for that. I found that really, really distressing.* (Tilly)

A shift in participants' sense-of-self was reflected in the emotive language used to describe seeing scarring for the first time, labelling their altered appearance as ugly and monstrous: "*I felt like Frankenstein. Yeah, I absolutely felt like a monster*" (Alex).

The passing of time was considered important in adjusting to scarring, however, this appeared a complex process associated with a myriad of emotions. For some participants, negative self-beliefs were enduring and resulted in feelings of hopelessness: "*It's two years on, it's just horrible. What is there that can help for scars, no one's ever said anything. I wasn't offered a solution to that. It's like you've just gotta put up with it."* (Paula). Some adjusted to their appearance as scarring reduced and they became desensitised to seeing it. Others still held negative self-beliefs, but were able to reconcile appearance concerns by reminding themselves that the melanoma did not metastasise and redirecting their focus to survivorship:

> *It's like that dual-sided thing of the reminder of the butchery, but then also the reminder that I'm not dead. So yay! So that usually wins, but I have to go through that like 'urgh, disfigured' and then 'alive'. So it's not a straight path at all.* (Alex)

Extent of distress appeared related to the number of SC's experienced. Participants with one melanoma diagnosis (Maggie, Paula, Alex, Joylyn, Tilly, Pisces) often focussed on appearance changes in describing their experience. Conversely, Chezwh had experienced multiple SC surgeries, and began to find comfort in scarring. She reflected that having multiple diagnoses kept the threat of metastasis at the forefront of her mind, whereas having lesions removed gave a sense of control:

> *I'd rather look at a scar than look at a mole, because that mole's got the potential to do whatever it wants to do, which is beyond my control. If it's not there, even if it's a scar, then it's gone. So yeah, I'm quite happy with as many surgeries as they want and as many little scars.*

Navigating identity changes in a world of beauty ideals. Participants described the impact of appearance changes on how they constructed their personal identity. Age and life-stage at the time of diagnosis were central in how participants understood their melanoma-identity. Being young, female, and single, were characteristics perceived as being difficult in adjusting to appearance and identity changes: "*It's not like I was a young girl or a young lady and I, you know, I had to sort of, to show my legs off"*. (Joylyn)

Whilst young adulthood was considered a challenging time to undergo melanoma surgery, most participants reported a negative impact of appearance change regardless of life-stage. Alex underwent surgery whilst adjusting to her peri-menopausal identity, highlighting that there are already *"so many different pinch-points"* for females. She offered an alternative view, that experiencing appearance changes at a young age perhaps allows you to construct a positive melanoma-identity, whereas for those at a later life-stage feelings of hopelessness persist as appearance changes feel final:

> *When you wake up and then you don't recognise yourself, and you realise that's you for the rest of your life. You know and I can understand that when you're young… but I think when you're young you can grow around that. If you know what I mean? Whereas that's not really happening so much for me.*

Some participants reflected upon the misalignment between their own body-image, and Western beauty ideals in how they understood their identity. Adjustment to post-surgical body-image was two-fold; involving acceptance of scarring, and no longer being able to tan.

Despite being aware of the risks associated with UV exposure in melanoma development, participants reflected on how post-diagnosis they still perceived a tan as aesthetically pleasing: *"You look so healthy…oh god that's so… of course you're not healthy with a suntan. But you look nice, you feel good"* (Paula). For those who held such views, not being able to tan exacerbated appearance concerns, and created a sense of being different to others in society. The media were considered central in perpetuating unattainable beauty standards, where being tanned is desirable and presented in such a way to outweigh the risks of UV exposure:

> *You look in the magazines… this golden tan, sun kissed… you think about the language there, you know? He's a bronzed whatever… if you're talking macho he's got to be bronzed. You can't have pale and insipid. You've got to be bronzed. And the power of advertising is stronger than the fear of developing melanoma.* (Pisces)

Experiencing an altered appearance also challenged participants' beliefs about their value and role in society as a female. Alex considered how growing up under the male gaze and being subject to Western beauty ideals contributes to appearance distress following melanoma surgery:

> *The function of a woman when I was growing up was to be pleasing to a man's eye, and I still have that ingrained in me in a lot of ways. And so it's very hard to unpick that when I feel objectively disfigured.*

Participants described positive adjustment to their melanoma-identity over time. Chezwh considered that pre-melanoma, being tanned increased her confidence, but receiving a melanoma diagnosis allowed her to re-evaluate the importance she places on appearance. She reflected that worrying about appearance earlier in life had resulted in the development of melanoma, and that realising this had changed her perspective on the importance of living:

I'm just not bothered about my appearance like I used to be. I would say that would be it. My appearance… it, two things in my life that I've always had, I've always done and have left me with issues are being thin, and being brown. And so now, it doesn't matter. That was so important.

Participants also considered how appearance changes became entwined or were separate to their personal identity. For Pisces, a turning point was realising that her appearance did not define who she was internally, and she had not lost the person she was pre-diagnosis: *"They said, "Well, it doesn't make any difference. You're still you". And I thought, "Yes, I'm still me". A scar doesn't change who I am, I'm still me. And that was really important".* Alternatively, Alex described how meeting new people enabled her to incorporate appearance changes into her melanoma-identity, and increase her confidence, as they would not draw comparisons to her pre-surgery appearance: "*We're not going to know anybody else. So I do feel like it'll be, like, almost like a coming out party of me with my scar as just 'This is just part of who I am. And it's not a big deal'".*

Managing an altered appearance. Participants utilised several methods to mask their appearance publicly. This included wearing long clothing and using make-up, creams, and massage to reduce the appearance of scarring, and using fake tan. Reasons for concealing scarring varied across participants, and related to avoiding negative responses from others, protecting scarring from further UV damage, or increasing self-confidence.

Some participants concealed scarring due to anticipatory stigma, or previous stigmatising experiences:

I thought that children would kind of point and go 'Eurgh! What's that?'. And I had friends that were really kind of like 'oh god you've got that on your leg', so the first

> *year I covered it completely. I just wore long maxi dresses and I wouldn't have it out at all.* (Maggie)

Other participants hoped to increase their own psychological coping and confidence:

> *I've always been quite a confident person. I just think… I don't want anyone looking at it, like my son's wedding there's no way I'd put a dress on with it low at the back so people can see it. I'd just feel so… obviously, everyone knows I've had it done, but I don't show it.* (Paula)

The decision of whether to conceal scarring appeared complex. Participants reported conflict between wanting to improve appearance by concealing scarring but feeling alienated at times they wore sun protective clothing. Pisces described how dressing differently to others reinforced the loss of identity she had experienced:

> *I felt a bit of a freak, you know, I felt like an alien, I think. I'll go to the market, I would walk along, and everybody there, they were in their skimpy little tops, and their little shorts, and their flip flops, and their ponytails, and I thought "Why can't I be like that? This is how I used to be. Why can't I be like that? Look, here I am in a silly hat. I hate it. Hat, smothered in factor 50, and it's all making me come out in spots. I've got long sleeves. I'm hot. I'm walking along. People are looking at me". And I felt alienated at first.*

The visibility of scarring was considered significant in appearance-related distress. Lesions on the face appeared difficult to adjust to as concealment options were limited: "*I think that must be really hard… to have it on your face as well. Obviously your back, your arm, your leg, your stomach, you can cover over can't you? But your face… it's hard"* (Paula). Participants with scarring in less visible areas initially chose to conceal their appearance with long clothing, although, over time described a shift in their perspective. This

appeared related to an increase in vigilance to other people's imperfections, allowing them to accept and publicly show their own: *"Would you see me on at a beach and think 'eurgh, look at that lady's back' you probably wouldn't even… who's looking at anyone else? Everyone's got their own hang ups and god knows what haven't they?"* (Paula).

Theme Two: Relating to others: experiencing dismissal and self-stigmatisation

Participants reported navigating a societal narrative that melanoma is not a serious cancer. This related to others believing that melanoma cannot metastasise and is cured with surgery, as it is often categorised alongside SCs with better prognosis. Across interviews, there was a shared sense that only melanoma survivors understood the severity of the condition, which was experienced as isolating in society, but empowering in peer relations. Maggie utilised zoomorphism to emphasise how lived experience of melanoma differs significantly from societal narratives:

> *Melanoma is such a beast, and people don't realise it's a beast, they're think 'oh you just cut it out and you're done with it.' I hate the fact that melanoma is lumped in as SC. I don't think that melanoma should even be discussed as SC, it should be a standalone, on its own.*

As primary treatment options for melanoma involve surgery, appearance changes typically associated with cancer, such as hair loss, do not align with the experiences of melanoma survivors. Participants highlighted how melanoma-related appearance concerns are often overlooked in society. However, unlike other cancers, Pisces considered appearance changes to be the worst aspect of living with melanoma:

> *Melanoma is disfiguring, that is the main thing about the after effects, never mind the dangers to your life and the dangers of metastasizing, it is a disfiguring cancer, and I think that put a lot of people… Okay, you know, if you have a breast removed, that's*

> *disfiguring, but you could… you can cover it and you know, you might have a few noughts and crosses if you've had bowel cancer, or you have a stoma.*

Participants experienced misalignment between their own perception of scarring, and that of others, resulting in feelings of invalidation. HCP's often described their scarring as a "*great job*" (Alex), neat, or "*fabulous"* (Joylyn), without acknowledging participants' own perception:

> *Every time I say to him 'I don't like the scar'. I tell him that it feels tight, it pulls my back, it's horrible, I don't like looking at it. And he just says 'I think they've done a good job, you don't have a lot of flesh on your back, there's nothing else they could do, so they had to do a skin flap'. What can I say? What else can I do? But it's not his back is it? I said to him 'It's not your back, it's my back'.* (Paula)

Some participants experienced this as dismissive, describing that it elicited feelings of guilt, frustration, and isolation. However, for others, being told that scarring looked neat offered reassurance that their skin was healing well, as HCP's were considered knowledgeable:

> *It was reassuring because I felt had I had to dress it myself and look at it, I wouldn't have thought that. But because she was very experienced at what she was doing, and she knew, she could tell me that was fine.* (Joylyn)

For some participants, experiencing constant dismissal resulted in self-stigmatisation, which appeared to make adjustment more challenging. Tilly described how working in a specialist cancer hospital left her feeling dismissed by colleagues, and led her to frequently dismiss her own experiences as she felt other cancer patients had worse experiences: "*I'm almost looking at that again thinking well my battle is nothing compared to that, you know, he's had half a lung removed. I've had a bit of skin removed off my leg. It's not that big a*

deal". For Alex, experiencing dismissal and societal narratives around melanoma resulted in survivor's guilt, where she felt unable to identify as a cancer survivor:

> *There's the sort of survivors guilt if you only have like stage 1A, whereas people who have 'real' melanoma, right… can I say I have cancer? I only had a 1A… it was removed. Do you know what I mean? It's that sort of, are you a fraud to the cancer people, like to the people who really have it?* (Alex)

Theme Three: Grieving the life you had: psychosocial adjustment

Psychosocial adjustment was considered one of the most challenging aspects of living with melanoma. Participants had to adapt to lifelong risk, where fear of metastasis, or dying, is always present. Some participants found that with time, the threat of melanoma felt comparable to other day-to-day risks. Others felt they had developed sufficient coping strategies to minimise risk, such as finding a sun cream they felt worked well. However, several participants highlighted that the visibility of scarring kept melanoma at the forefront of their mind:

> *"I think about it every time I have a shower and I look at this, my credit card as I call it. It's as big as a credit card, this thing, this great white square on my thigh. I would think indirectly… I probably think about it most days actually."* (Pisces)

Participants experienced a grieving process of their pre-diagnosis life, and future plans. Several participants identified as a "*sun-worshiper*" pre-diagnosis and described a sense of loss and newfound fear of the sun post-diagnosis: "*It's like we've lost someone. It's like we've lost the sun. It sounds strange doesn't it, but it's like you've lost that one thing that you love, laying there, the warmth"* (Paula).

In contrast to other cancers, participants felt that melanoma had an enduring impact upon lifestyle that did not resolve even after remission. The sun was considered inescapable, and a constant reminder of how life had changed:

> *"Other cancers don't seem to affect your lifestyle quite as much as a melanoma. People don't understand what it's like when you have to hide yourself from the very thing that everybody else is seeking, i.e. the sun. And it's lovely lying on the grass with the sun on your arms, the sun on your face, not sunbathing, but just feeling the warmth of the sun, and suddenly that very life giver is the thing that you're most afraid of. The beautiful sun."* (Pisces)

Participants felt afraid to spend time outdoors post-diagnosis, discussing how melanoma impacted their hobbies and social interactions, leaving them isolated. Some lost friends, and single participants considered how their lifestyle may negatively affect dating. Chezwh considered how her identity was also impacted by having to come off donation registers: "*Having to come off the bone marrow, the blood and the organ donation. That has been massive for me."*

There was a shared sense that coping improved over time, with many participants feeling able to return to previous hobbies. Underpinning this, appeared to a changed perspective on the fragility of life. For some participants, coping felt like a choice:

> *"I think, you know, whatever life chucks at you, I think you've just gotta deal with it. But it's bloody hard when something is chucked at you. But you can't live like that… life is surely for living isn't it?" (*Paula)

Discussion

This study addresses a gap in psycho-oncology literature by exploring how female melanoma survivors make sense of their altered appearance after reconstructive plastic

surgery, and the impact of this on psychosocial functioning. Three themes were developed: 'Constructing the melanoma-identity', 'Relating to others: experiencing dismissal and self-stigmatisation', and 'Grieving the life you had: psychosocial adjustment'. As the current study had a narrow aim, included a highly specific participant sample, and interviews elicited rich, detailed information, a small sample size was indicated (Malterud et al., 2016). Seven melanoma survivors were therefore invited to share their experiences, which was considered appropriate in achieving sufficient information power.

The first theme details novel findings on how participants adjusted to melanoma-related appearance changes. On viewing WLE scarring for the first time, all participants reported shock, describing feeling uninformed by HCP's about the extent of scarring. Participants used negative emotive language to discuss their appearance, describing a loss of feminine identity that resulted from experiencing a sudden, and permanent change in appearance. This had an enduring impact upon body-image and how participants communicated with their external world, as they feared judgment. Participants related this to experiencing a misalignment between societal beauty ideals of clear, tanned skin, and their own scarred, pale appearance. These experiences may be understood through The Sociocultural Model of body-image (Tiggemann, 2011). This proposes that societal beauty ideals become deeply internalised, and body-image satisfaction relates to individual perceived alignment with such ideals. Within Western cultures, the media portrays beauty as central in a female's value (Åberg et al., 2020; Ward et al., 2020), meaning changes in physical appearance may present a threat. The Tripartite Influence Model highlights two mechanisms that may contribute to body dissatisfaction in this way; an individual's perception of alignment with beauty ideals, and drawing appearance comparisons (Thompson et al., 1999).

Where a lack of preparedness increases distress for breast cancer survivors on viewing scarring for the first time, some survivors experience a positive reaction to their altered appearance (Herring et al., 2019). Some found scarring to be better than anticipated, whereas others took a pragmatic view, valuing survivorship over their appearance. However, within the current study all participants described a negative initial response to scarring, which may indicate differences in the way melanoma survivors make sense of appearance changes. Participants drew comparison with other cancer subtypes, describing melanoma as more disfiguring, with an enduring impact upon lifestyle, even during remission. One way of understanding the salience of appearance concerns for melanoma survivors, could be through considering their dual identity as both a dermatology and oncology patient, which both present discrete body-image concerns. Oncological body-image concerns broadly capture any cancer-related appearance change such as scarring, hair loss, weight gain, and complications such as lymphedema. Importantly, many of these changes are reversible, thus body-image may improve over time (White & Hood, 2011). Thus, severity and complexity of oncological body-image concerns may be understood in relation to the speed and permanence of appearance change (for example, gradual, temporary hair loss, compared to sudden, permanent scarring). On the other hand, dermatological body-image distress relates to the visibility of the skin, as it acts as an interface with the external world and represents various societal roles (Thompson, 2011). Melanoma appearance concerns could therefore be understood not only through the permanence of surgical scarring, but also the visibility and unpredictability of melanoma occurring across the body.

The second theme considers how societal narratives perpetuate dismissal, shame, and self-stigmatisation for melanoma survivors. All participants described experiencing the narrative that melanoma is not as severe as other cancer subtypes. This appeared to reflect melanoma following a different treatment pathway, where treatment side effects did not align

with those typically associated with cancer. Navigating this narrative left participants feeling invalidated, with unmet psychological needs. Importantly, some felt that HCP's also held these narratives, which has previously been found to exacerbate feelings of isolation for melanoma survivors (Bird et al., 2015). Participants often held a negative perception of scarring, but were told by HCP's that it was neat. Whilst this was typically experienced as dismissive, HCP's may consider disease impact in relation to cancer stage, rather than functioning or severity of scarring (Stamataki et al., 2014). Whilst HCP's are aware of the potential impact of melanoma on wellbeing, this varies between individuals, with some patients feeling reassured by surgical excision, and others experiencing ongoing distress (Kamminga et al., 2023). Although this highlights the importance of individualised survivorship care (Husson et al., 2010), melanoma guidance continues to be medically orientated and does not consider psychosocial aspects (Kamminga et al., 2023). This may reflect the current lack of research exploring the experiences of melanoma survivors, where HCP's face the challenge of meeting individualised needs with limited evidence-based guidance (Bird et al., 2015). The current study may therefore offer novel insights into the experiences of those receiving survivorship care, with implications for the development of clinical guidelines. For some participants, navigating dismissal across society and care relationships also resulted in self-stigmatising beliefs, which challenged their identity as a cancer survivor. This may be understood via the progressive model of self-stigmatisation (Corrigan et al., 2011), whereby societal stereotypes become internalised through awareness, personal agreement, and self-concurrence, and may negatively affect self-esteem and self-efficacy. For some participants, stigmatising narratives may have become deeply ingrained with their sense-of-self, resulting in isolation. This evidences a need for increased public awareness on the experiences of melanoma survivors.

The final theme considers the psychosocial impact of melanoma. All participants described a fear of metastasis or death, a common experience reported by cancer survivors (Krok-Schoen et al., 2018), including those with melanoma (Molassiotis et al., 2014). During survivorship, experiencing reminders of cancer may perpetuate the fear of reoccurrence (Almeida et al., 2019). For participants in this study, the visibility of scarring was salient in serving as a constant reminder of their experience. Whilst coping improved over time, the risk of UV exposure reminded participants how their lives had changed due to melanoma. They felt that melanoma differed from other cancers, in that it altered their relationship with the sun, meaning that many no longer engaged in outdoor leisure activities, and felt reluctant to travel abroad. This is consistent with previous findings (Vogel et al., 2017), that suggest melanoma survivors may enhance sun protective behaviours following diagnosis (Oliveria et al., 2013). The psychosocial difficulties reported by participants may be understood through Folkman's (1997) model of appraisal and coping. Appraisal relates to an individual's evaluation of a stressful event, and the personal significance it upholds in their life, which influences emotion and subsequent coping. In the context of this study, participants may perceive receiving a melanoma diagnosis as a threat, or loss of identity, resulting in a lack of control. As the sun acts as a constant risk factor, participants possibly continue to feel out of control, which is associated with emotion-focused coping, such as avoidance.

A sense of loss was multifaceted and intrinsically linked across themes. Participants described the initial loss that came with receiving a melanoma diagnosis, and multiple secondary losses, such as those associated with identity, relationships, and hypervigilance about managing appearance. Participants described feelings of anxiety, anger, and loss, which are consistent with Ross and Kessler's (2005) grief cycle theory. Oncology literature highlights the multiple physical and symbolic losses that contribute to the development of anticipatory grief (Tacon, 2011), including the loss of personal identity, independence,

physical functioning, and family or societal role (Hottensen, 2010). Thus, adaptation to a changed self is considered a crucial aspect of cancer recovery (Foster & Fenlon, 2011).

Clinical Implications

As patients' initial expectations of scarring impact upon post-operative quality of life (Auer et al., 2016), the current study evidences a need for better provision of information about likely surgical outcomes. Additionally, participants described ongoing dismissal from HCP's, which may reflect HCP's underestimating the psychological needs of melanoma survivors. Considering this, CP's working in oncology and dermatology multidisciplinary teams (MDT's) could provide training on body-image concepts. The offer of consultation may support MDT's to adopt a compassionate stance in working with melanoma survivors, which may promote positive adjustment.

For those experiencing pre-existing body-image concerns, offering CP intervention pre-surgery may increase preparedness and reduce the impact of surgery on long-term adjustment. On a case-by-case basis, individuals may benefit from receiving psychological support on viewing WLE scarring for the first time. Importantly, HCP's should routinely screen for body-image concerns following diagnosis, and be supported to refer to CP utilising a psycho-oncological framework. Given that the body-image concerns of melanoma survivors may be considered through both a dermatological and oncological lens, CP's may be involved in developing a framework to capture the succinct needs of SC.

With time, some participants described adjustment to scarring, aligned with post-traumatic growth and positive body-image. Therapeutic modalities such as Acceptance and Commitment Therapy and Compassion Focused Therapy draw upon concepts such as cognitive reframing and self-compassion to promote adjustment to altered appearance (Zucchelli et al., 2021; Fan et al., 2023), and may therefore be effective in supporting

adjustment to melanoma-related appearance changes. The use of Positive Psychology interventions in breast cancer care has been found to enhance the mind-body connection and support patients in their sense-making, whilst generating hope for the future (Casellas-Grau et al., 2014). As research exploring psychological interventions in melanoma care is limited, CP's may be involved in the development of standardised measures and intervention.

Strengths and Limitations

To the author's knowledge, this is the first study exploring the impact of appearance on psychosocial functioning for female melanoma survivors who have undergone plastic surgery.

Participants were recruited via a Facebook support group, thus were self-selecting and may have held specific characteristics, such as experiencing a greater need for social support, or salient appearance concerns. To mitigate selection bias, the study was advertised in multiple locations. One explanation why recruitment solely occurred through Facebook may reflect the safety existing within the group, and a sense of coherence created through the lead researchers own personal membership. However, this possibly excluded those with differing experiences, which is an important consideration for future research.

Additionally, whilst the sample was considered homogenous, there were several differences between participants' experiences, such as the total number of SC surgeries and time since surgical procedure. This may have impacted participants sense-making, and recollection of their experiences.

The sample was UK-based, with remote interviews allowing the inclusion of participants from a broader geographical area. Telephone interviews possibly offered a protective aspect where participants could talk openly about their altered appearance, as their scarring was not visible to the interviewer.

However, these findings may not be representative of melanoma survivors globally with differing healthcare provisions. Existing research evidences variance in the beauty ideals experienced between ethnicities and cultures (Jackson et al., 2020), therefore findings from this study cannot be transferred cross-culturally, as they solely reflect white, Western perspectives.

Future Research

The current study provides novel insights into the appearance concerns of female melanoma survivors who have undergone plastic surgery. Future research may offer further insights, for example, exploring in detail the salience of appearance distress in viewing WLE scarring for the first time.

As participants emphasised the importance of life-stage at the time of melanoma surgery in distress, further research may consider the appearance concerns and psychosocial functioning of those experiencing melanoma at a younger age.

As this study did not include males, and all participants described their ethnic origin as white, future research should explore experiences from various populations, to identify similarities and differences. Particularly, research exploring melanoma-related appearance concerns in relation to non-Western beauty ideals may support the provision of individualised healthcare and have implications for the development of psychological intervention.

Conclusions

This study explored the lived experiences of female melanoma survivors who have undergone plastic surgery, using IPA. Findings demonstrate the various appearance concerns and psychosocial difficulties experienced, particularly in adjusting to an altered identity. CP's may support survivors to develop acceptance, and positive body-image. They may offer training and consultation to HCP's, and contribute to policy and service development. Future

research may seek to understand experiences across the lifespan, of males, and those from non-Western cultures.

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Table 1. Participant Demographics

Participant pseudonym	Total number of melanoma diagnoses	Location of melanoma	Stage of melanoma
Maggie	1	Leg	2a
Paula	1	Back	1b
Chezwh	2	1) Abdomen 2) Ear	1) 1a 2) Insitu
Alex	1	Lower eyelid	1a
Tilly	1	Leg	2a
Joylyn	1	Leg	2b
Pisces	1	Leg	1b

Table 2. Inclusion and Exclusion Criteria

Inclusion Criteria
To have received a diagnosis of malignant melanoma, situated anywhere on the body.
To have undergone reconstructive plastic surgery (for example skin graft, or skin flap procedure) as part of their treatment.
To be at least three months post-surgery.
Female.
Aged 18 or over at the time of surgical procedure.
Able to converse in English.
To live in the UK.
Exclusion Criteria
If there is evidence of current metastatic disease, in which the cancer has spread from the original tumour.
If individuals are undergoing further treatment, such as immunotherapy.
If individuals are currently experiencing significant mental health difficulties, such as post-traumatic stress disorder.

Table 3. Final Themes and Individual Participant Themes

Final Theme	Participant Theme
Theme 1: Constructing the melanoma identity	Alex: An identity changed by surgery Alex: Feeling like a monster, like Frankenstein Alex: Masking scarring to align with beauty ideals Chezwh: My scars are "a battle I've won" Joylyn: My sign of survival: adjustment to scarring Maggie: Feeling gobsmacked by the scar – adapting to altered appearance Paula: Feeling hopeless about my altered appearance Pisces: Masking the visibility of scarring Pisces: Adjusting to an altered appearance/identity in society Tilly: Feeling gobsmacked, unprepared and uninformed: adjusting to altered appearance
Theme 2: Relating to others: experiencing dismissal and self-stigmatisation	Alex: Am I allowed to say I have cancer? Chezwh: Melanoma needs to be classed as a proper cancer Joylyn: Increasing awareness of melanoma Joylyn: "melanoma isn't a severe cancer" Maggie: Losing relationships to melanoma Maggie: The importance of connectedness with people who understand Maggie: Being dismissed in society Paula: Feeling understood: Relational difficulties and needs when living with melanoma Pisces: Thick skinned and angry toward societal narratives Pisces: Needing the right support at the right time Tilly: Being supported helps you to support others Tilly: "If you're going to get cancer it's a good one to get"
Theme 3: Grieving the life you had: psychosocial adjustment	Alex: Grieving the sun Chezwh: The emotional impact of living with melanoma Chezwh: Melanoma is "all my fault" Chezwh: Life is very, very important now

	Joylyn: Taking one day at a time – adjusting to the lifelong threat of melanoma Maggie: Making sense of a melanoma diagnosis Paula: Grieving and living with the past Paula: Making sense of the future and your role in shaping it Paula: Receiving and living with a melanoma diagnosis Pisces: I only think about melanoma when the sun shines – adjusting to life with melanoma Pisces: Having to hide from the one thing everyone is seeking Tilly: Adjusting to life with melanoma

Appendix 2-A Journal Instructions for Authors

About the Journal

Journal of Psychosocial Oncology is an international, peer-reviewed journal publishing high-quality, original research. Please see the journal's Aims & Scope for information about its focus and peer-review policy.

Please note that this journal only publishes manuscripts in English.

Journal of Psychosocial Oncology accepts the following types of article:

- Original Research
- Systematic Reviews/Meta-analyses
- Brief Reports
- Book Reviews
- Art of Psychosocial Oncology
- Clinical Case Studies
- Innovative Programs and Clinical Approaches

The Journal of Psychosocial Oncology (JPO) publishes manuscripts that focus on research in the field of psychosocial oncology including, but not limited to, hypothesis testing, program evaluation, intervention research, systematic reviews, and theory development. We are interested in research and innovative programmatic approaches to care that advances our understanding of psychosocial aspects of cancer and informs health professions who provide psychosocial services to cancer patients, their families, and caregivers. Each manuscript is accepted for consideration with the understanding that it has not been published elsewhere and that it has not been submitted simultaneously for publication elsewhere. Papers will be recommended for publication based on the quality of the work and suitability for the audience. Questions should be sent to: Penny Damaskos, PhD, MSW; pdamaskos01@gmail.com.

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Preparing Your Paper

Article Types

Original Research

- Should be written with the following elements in the following order: Purpose/Objectives, Design/Research Approach, Sample/Participants, Methods/Methodological Approach, Findings, Conclusions/Interpretation, Implications for Psychosocial Providers or Policy
- Should be no more than 4000 words, inclusive of:
  - Abstract
- Should contain a structured abstract of 150 words.

Original Research reports on studies that can be quantitative, qualitative, or mixed methods. We suggest that authors use Consolidated Standards of Reporting Trials (CONSORT) guidelines for submissions on randomized clinical trials and Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines for qualitative research.

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- Should be written with the following elements in the following order: Problem Identification, Literature Search, Data Evaluation/Synthesis, Conclusions
- Should be no more than 5000 words, inclusive of:
  - Abstract
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- Should be written with the following elements in the following order:
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- Should be written with the following elements in the following order:

These submissions review recently published books that make a potential contribution to the knowledge and practice of psychosocial oncology. The review should be a critical evaluation of the book and written in a professional manner.

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- Should be written with the following elements in the following order:
- Should be no more than 1000 words

This Section invites articles submitted by oncology social workers and related disciplines as authors focusing on the care of people living with cancer. The Art of Psychosocial Oncology invites practicing clinicians to reflect the voices of clients and clinicians, including contemporary issues, challenges and creative strategies. This Section is looking for articles that address the daily emotional impact of cancer, psychosocial interventions, and your personal reflections on your practice, including its impact on you. Creative submissions are encouraged including poetry and narrative pieces. Submissions may be short articles, narratives and poems, should not exceed 1000 words, and do not require an abstract. If appropriate for your format, please include 2-3 relevant reference citations.

Formatting Instructions:
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- Should contain between 4 and 6 **keywords**. Read making your article more discoverable, including information on choosing a title and search engine optimization.

Clinical Case Studies

- Should be written with the following elements in the following order: title page; abstract; keywords; main text introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list)
- Should be no more than 4000 words, inclusive of:
  - Abstract
- Should contain a structured abstract of 300 words.

This Section invites submissions that focus on the care of people with cancer that illustrate theoretical approaches to clinical care.

1. Case Introduction
2. Presenting issue/ History & Assessment
3. Theoretical and/or Research Basis for clinical approach
4. Case Conceptualization (include clinician's theoretical approach and assessment of interventions)
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6. Treatment Implications of the case
7. Recommendations & Follow up

Please select the "case report" article type at the point of submission.

Innovative Programs and Clinical Approaches

- Should be written with the following elements in the following order: title page; abstract; keywords; main text introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list)
- Should be no more than 4000 words, inclusive of:
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- Should contain a structured abstract of 300 words.

This section invites submissions that describe innovative programmatic and clinical approaches to psychosocial care in oncology. Manuscripts that illustrate interprofessional collaboration are encouraged. Submissions should be written with the following elements and demonstrate innovative approaches to psychosocial care in oncology:

1. Reason for Program/Background
2. Program Design description including Theoretical Approach (s)
3. Methods/Execution
4. Results/Barriers Encountered & Interpretation
5. Conclusion & Recommendations
6. Implications for Oncology Psychosocial Providers or Policy

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Authors may submit their paper in any scholarly format or layout. Manuscripts may be supplied as single or multiple files. These can be Word, rich text format (rtf), open document format (odt), PDF, or LaTeX files. Figures and tables can be placed within the text or submitted as separate documents. Figures should be of sufficient resolution to enable refereeing.

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Updated 6th June 2024

Appendix 2-B Initial Coding Excerpt - Alex

Notations	Transcript
	I: Thinking about when you first saw your scar, how did that impact you emotionally, that first moment, they took the dressing off and you saw it for the first time?
Seeing the scar for the first time was terrifying Worrying about scaring the kids with the scar Feeling like the scar was so disfiguring	A: It was terrifying. It was terrifying. And I've got kids and so like, we were worried about scaring them. You know, it was so terrifying, like, because it was involved all here [gestures] and it was like the bruising was… I even got, like, bruising on this side from it. It was… it was so disfiguring. And the body's amazing, you know, the way it can heal, and when you see how bad you look and you don't… you can't imagine that you would ever look any different than that, you know. So I was… I was just shocked. I felt like Frankenstein. Yeah, I absolutely felt like a monster and I knew it would get better, but you *don't.* It's hard to keep sight of everything when it's happening. You know what I mean? It's just so terrifying. Absolutely terrifying. And it's so painful. But… and again, now I'm going to contradict myself. You know, it's healed really well [laughs]. It *has* healed well. You know what I mean? It *has*, aside from that bit where they it got messed up. The scar itself here, it's beautiful. It's not 3 dimensional. Do you know what I mean? The way the skin's sagging, it's just because it's not a tight area. You know? It's like they did do a really good job. And I do feel like I said, I feel grateful that it could have, it could have been a lot worse. But it doesn't negate the horror of knowing that something has changed for the worse, appearance wise, and that is absolutely nothing you can do about it.
The body is amazing at healing – you can't imagine you'd ever recover from surgery Feeling shocked on seeing the scar for the first time I felt like a monster, like Frankenstein You know your appearance will improve, but you *don't* It's hard to keep sight of everything when you're caught up on it – terrifying Feeling that the scar has healed really well – it's beautiful Feeling that the scar looks good, but it doesn't take away the pain of knowing your appearance has changed for the worse Everything happened quickly, which was good, but I had no idea what was going to happen	I: Yeah. Do you feel, sort of before the surgery when you had those initial expectations of what it would look like, do you feel like they were accurate following surgery? Do you feel that the healthcare

	professionals gave you enough of an idea of what the scarring would be like?
Having a different surgeon, when we'd already made a treatment plan Having to advocate for myself when the surgeon wanted to change my treatment plan Everything felt shitty leading up to the surgery, which made me very anxious Having a positive experience of advocating for myself – agreeing a sedative etc	A: I don't know. It was very swift so… and again, luckily swift, good… in a good way swift, but I don't… when I was going for that biopsy the first time, yeah, I had absolutely no idea that if it was bad, what… what was going to happen as a result. Like I had no idea that that's the train I was on and that there was no getting off. I had absolutely no idea. There were also two options for the surgery, whether it was a graft or a flap. And my… the surgeon I spoke to, we agree that we would do a flap. And then when I went, I had a problem. When we went to the… go do it, she wasn't there, it was somebody else. And he was like, "right. So we're going to do a skin graft". I'm like, "no, we're not". And it was literally the pre… It was, I was in my… what's it called? The dressing gown like right before surgery. And he's showing me what he's going to do. And I was like, "no, this is not what we agreed". We agreed the flap and da da da, and the flap is *so* much more complex. It's so much more complex. If it goes well, it's good. If it goes poorly, then it's bad. So he… I then had to advocate for myself and tell him, you know, like, what I had agreed with the other lady, with the lady, and so then he had to work his head around it and come to terms with it and then agree to do it. And then I didn't feel confident that he was on board, do you know what I mean? Like he hadn't thought about it last night when he was going to sleep, how he was going to do it. He's thinking about it right now. You know what I mean? And then we had a problem with the anaesthesiologist as well. Just a disconnect with what was agreed. So everything was shitty, right, leading up to the surgery. So I went in very, very anxious 'cause I didn't want to be put under general. And they were like, "well, we're gonna" and I'm like, well, no, you're not. Because that's not what we agreed. And they're like, "well, we'll just do local then". I'm like, "no you're not because I'm gonna faint". So we agreed

The surgery was wonderful and the staff were amazing If I didn’t advocate for myself I would have ended up with something I didn’t want If I hadn’t advocated for myself my scar would have looked different, it would have had a secondary site	a sedative, and anyway, so they made me wait hours and they had to find a special guy who came and did it, and it was really good. And the actual surgery was wonderful and the guys were amazing. But it was that’s the NHS it's like, “oh, well, staffing issues we’ll just stick someone else in and… do you know what I mean? And if I hadn’t advocated for myself, I would have ended up with something I didn't want. You know? Yeah. And with the scarring, it would have been different scarring. If you have a graft, it's like an island, isn't it? It would be like a patch and then you have a secondary site, and I didn’t want a secondary site and I didn't want not-face-skin on my face. And then if it rejects it, it's like a big deal.

Appendix 2-C Audit Trail Example for One Participant – Paula

Theme	Description of Theme	Notations	Quotes
Grieving and living with the past	This theme reflects Paula's experience of changes in her lifestyle and the grieving process associated with this. Paula described that throughout her life she had always identified as a sun worshiper. She described that she loved feeling the warmth of the sun and being tanned. Paula feels that since being diagnosed with melanoma she has experienced a grieving process, describing that the one thing she loves is now gone, and that for her the loss compares to the loss of a person. Paula makes sense of this through her identity as a sun worshiper and feels that her grief is worse than for people who don't enjoy being in the sun. Paula spoke about not being able to escape the sun as it is always there, and how this serves as a constant reminder of the changes in her life. Initially, Paula found it extremely difficult to be outside in the sun after diagnosis, but over the past two years has gradually found it easier to cope. In making sense of this, Paula identified that having strategies in place	Being a sunworshipper makes things feel worse – it feels like something is gone from life I've gotta live with melanoma forever Avoiding the sun to keep myself safe Adjusting to being in the sun (lying under a brolley, rash vest) The one thing I really loved is gone I've proved to myself I can still enjoy a holiday You can't escape the sun It feels like we've lost someone Enjoying the warmth, the suntan	"I've had three holidays since, the first holiday was so hard, it was unbelievable. The two since have been alright, I think I'm alright now. I can be in the sun, I can sit in the shade, I can read a book, I can still do it, but you know, there's people walking around brown and you just look at them and think… I don't know, it was just the one thing – sitting in the sun, I really loved. So that's gone. So the thing that I really… so if you'd said to me, 'right you can never – I don't really drink a lot at all, you can never I don't know, eat a bit of chocolate again, or a cake' I would deal with that, I would deal with that. But the sun, you can't escape it. Alright, I know we can put the sun lotion on, it's just not the same. I literally lived for our holidays, we've been all over the world, we've been some beautiful places. It's just not the same anymore. It's not the same." "She said it's like we've lost someone. It's like we've lost the sun. It sounds strange doesn't it, but it's like you've lost that one thing that you love, laying there, the warmth. I had a counsellor she went 'what is it that you like about it?', I said the warmth, the sun tan, all this – it's gone." "I think it's the one thing I *literally loved*. Being in the sun. I loved to sit out there, when it was warm here I'd sit in my office, I'd sit out in the garden, just really loved being out there." "The thought that I can never do that again, it's quite hard to take. It's getting… the last two years have got easier. If you spoke to me two years

such as using a UV umbrella and rash vest has made her feel safer. Additionally, as Paula has begun to process grief and developed some acceptance of her diagnosis, she recognises that she is avoiding the sun to keep herself safe. Paula has adjusted to these strategies becoming a new way of being, as she shared that melanoma if forever and that 'not wearing sun protection would be absolute suicide', even though she experiences some feelings that people may be judging her for not sitting in the sun. More recently, Paula has begun to enjoy holidays abroad again and feels that she has proved to herself that she can enjoy other elements of the holiday without having a suntan or being fearful of the sun. Adjusting to using different sun safe behaviours on holiday has made Paula feel more empathetic towards others and she described developing an understanding of why other people avoid the sun, where she previously may have made judgements.

I used to love being in the sun
Feeling alright about going on holiday now
Being outside in the sun gets easier over time
Over time being able to enjoy holidays again
It gets easier to cope over time
It's knowing I can be in the sun
Not wearing sun protection would be absolute suicide for me

ago you probably would've committed me because I couldn't even go out into the sun. But I can now. So it is *definitely* getting easier."

"As times gone on everybody does say it gets easier. And meeting new people and they're going 'oh I don't wanna go out, I'm frightened, I don't want to go on holiday' and people are saying 'it *does* get easier'. So it's knowing now that I can be in the sun, I don't have to sit out for eight hours a day with carrot oil on and burn up, like you know, a chicken in the oven. I can… I went on holiday in February, it was my birthday and me and my husband went to Egypt for a week. I laid… I didn't lay in the sun, I laid under the brolley thing. I kept my swimsuit on, had like a little you know, throw thing over it, like a beach dress."

"But I still enjoyed it. I'm not laying there, my friend off the group bought me some Skinny Tan, so I put a bit of that on every night so I had a night little glow about me that wasn't the sun. And I really enjoyed the holiday. I really, really enjoyed it."

"And if I lay in the sun, god knows what… you know I could get more couldn't I, so I've gotta do it for myself."

"I can't lay in the sun, but I can still have a holiday, and I've proved to myself this year that I can do it. I can do it, I really enjoyed it."

"Especially the ones that's been the sun worshipers, the ones we've lived for our holidays, you know we've sat round the pool all day. Yeah, and them ones, you know, we definitely feel… you know, like literally like somethings gone, like somethings gone out of our life. It's gone. We can't… the thing we loved, we can't do anymore."

"I seen so many burnt people in Egypt, literally made me feel quite… but you can't say to someone like can you? 'You're just bright red and you're

still laying there'. That to me is just madness, that'd be like suicide for us wouldn't it? That would be *absolute suicide*. Suicide to do that."

"Because if someone said to me two years ago 'you'll be able to go on holiday and you'll enjoy it' I'd have gone 'You're joking. Not in a million years. I'm never going to enjoy a holiday again'. But I have, and I will enjoy more. And I'm right up for… I really wanna go again."

Appendix 2-D Description of Analysis Process – As Outlined By Murray & Wilde (2020)

1. Familiarisation with the data: transcripts were analysed in isolation to ensure an idiographic approach. Transcripts were read repeatedly, with the audio recording also played.
2. Initial coding: information relevant to the research question was highlighted, with notations or initial codes generated and added to a side column. These notations included descriptive and interpretative summaries of the participant's experience.
3. Grouping codes: once notations had been generated for the whole interview, they were printed on separate pieces of paper and iteratively grouped until they formed discrete groups relating to various aspects of a participant's experience.
4. Producing iterative summaries: after grouping codes, a narrative account was written to summarise each group of notations, capturing the most salient experiences and interpretations of the participant. Theme titles were also generated. This process was completed for each interview separately, with each analysis bracketed, to not influence interpretation of subsequent transcripts.
5. Merging analysis across transcripts: similarities and divergences were considered across participants' data. All individual participant theme titles were printed on separate pieces of paper and grouped until they formed discrete themes. Synthesised narrative summaries were then generated from initial participant narratives.

Section Three: Critical Appraisal

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This critical appraisal begins with a summary of the findings of the systematic literature review and empirical paper and the synergies between them. Next, strengths and limitations of the empirical paper are explored, alongside discussion of methodological issues, reflexivity, and my own personal reflections of undertaking this research.

Overview of findings

The systematic literature review synthesised qualitative research exploring body-image and appearance concerns for people with psoriasis. Using thematic synthesis (Thomas & Harden, 2008) across 21 papers, three main themes were identified: 1) constructing and navigating the psoriasis identity, 2) appearance stigmatisation, and 3) acceptance and coping with an altered appearance. Across themes, participants reported experiencing challenging beliefs about the self, their relation to others, and their existence in the world, which derived from their experience of living with psoriasis.

The second part of this thesis presented an empirical study exploring the appearance concerns and psychosocial functioning of female melanoma survivors who have undergone plastic surgery. Seven participants took part in semi-structured interview exploring their experiences of receiving care, appearance concerns, and psychosocial functioning, adjustment and coping, whilst navigating a melanoma diagnosis. Data was analysed using interpretative phenomenological analysis (IPA), which generated three main themes: 1) Constructing the melanoma-identity, 2) Relating to others: negative vs positive social interaction, and 3) Grieving the life you had: psychosocial adjustment.

Considering both studies together, changes in appearance were found to result in psychological distress and for some, an altered identity. A common emphasis in the findings of both studies was the role of societal beauty norms in how identity is constructed, and therefore how appearance changes are understood. Reduced self-esteem, confidence, and

negative body-image therefore appeared linked to anticipatory, and experienced stigma, for people living with either psoriasis, or melanoma. However, divergence was noted in the ways that stigma was experienced in each study. In the systematic literature review, participants across studies reported experiencing stigma explicitly, for example, being called a Leper, being stared at, and being asked to leave public areas. These experiences reflected the condition being negatively exaggerated, and exacerbated anticipatory stigma and isolation for participants. However, in the empirical study, participants experienced stigma amidst the societal narrative that skin cancer *"is not a real cancer"*, meaning that their appearance concerns and psychosocial needs were often misunderstood and dismissed. For some participants in the empirical study, this created a sense of inner conflict, as they perceived their appearance to misalign with Western societal beauty ideals, but their scarring appearance was often minimised by others.

Additionally, across both papers, the onset of psoriasis or diagnosis of melanoma appeared to represent a loss of the 'normal', functioning, self, which echoed the stages outlined in Kübler-Ross and Kessler's (2005) grief cycle theory. This synergy highlights how changes in appearance which are permanent or part of a chronic condition, may be experienced in a way similar to bereavement, thus emphasising the need for appearance concerns to be considered in healthcare settings. Particularly pertinent, was how people with psoriasis, or melanoma, constructed their post-diagnosis identity. For some, appearance changes became entwined with personal identity, whereas for others melanoma or psoriasis was perceived as a constant, external threat to identity.

Methodological Considerations

Recruitment/Participants

It was intended that recruitment would follow a stepped process, where the empirical study would be initially advertised by melanoma charities, before being shared across Twitter, or X, and Facebook, if charity advertisement did not yield a sufficient number of participants. Although multiple melanoma charities were contacted, only one replied, agreeing to review study materials and advertise the study across platforms. During the recruitment process, there was no interest expressed in response to charity advertisement, therefore a Twitter account was set up for the sole purpose of advertising the study. Whilst it was hoped that the use of Twitter would reach a larger audience, such as those with lived experience in addition to healthcare professionals and researchers this was also unsuccessful in generating interest. I was already a member of melanoma Facebook support groups due to my own lived experience, therefore at this stage I discussed with my supervisor the appropriateness of advertising through a group supporting those with a diagnosis of stage 1, or stage 2 melanoma, where surgery was the primary treatment option. Posting anonymously, but with an acknowledgement of my own melanoma diagnosis, generated a lot of interest, and I was able to successfully recruit all participants through the group. Whilst advertising through a support group allowed me to directly reach out to people with melanoma, given that previous recruitment methods had generated no interest, I have since reflected on the meaning of my own lived experience in aiding recruitment. After hearing participants' shared narrative of being dismissed by healthcare professionals, I wonder if my dual identity of being a healthcare professional/researcher, but also a melanoma survivor, meant that participants were able to experience this study as safe, and free of judgement.

Seven participants took part in semi-structured interview, which was considered appropriate for IPA, particularly doctoral research (Smith et al., 2022). Having a relatively large sample size resulted in rich data, although resulted in a large volume of data for analysis. Given my inexperience of using qualitative methodology, I initially underestimated

the time required for transcription and analysis of each interview, thus found this a challenging aspect of the thesis. However, including several participants in the study who had varying experiences allowed for novel insights to arise. For example, interviewing different people allowed me to consider the importance of life-stage at the time of diagnosis in how appearance changes were made sense of by participants.

Within the empirical study, all participants were white, and UK based at the time of interview, which may have played a role in how they constructed their melanoma-identity and navigated appearance changes. For example, as participants were UK based, their altered appearance existed within Western beauty ideals, and their experiences of healthcare provision largely related to the NHS, which is a system currently under immense strain (Cooksley et al., 2023). Additionally, all participants were aged between 44 and 77, reflecting mid, and late adulthood (Levinson, 1986). Early adulthood is a period in which individuals face a number of milestones which may be impacted by physical attractiveness, such as entering into a significant romantic relationship (Chatterjee et al., 2021). I therefore considered whether the participant sample reflected melanoma incidence statistics (Cancer Research UK, 2021), or if difference in life-stage made it more, or less difficult for people to share their experience of appearance changes. As participants were self-selecting, perhaps those of a younger age, who were navigating milestones related to their appearance, experienced heightened appearance distress and did not feel able to talk openly about their experience. It is possible that participants in the current study had begun to positively adjust to appearance changes and felt more able to reflect on their experiences.

Whilst IPA explores convergence and divergence of experience within a homogenous group (Smith et al., 2022), it is important to consider the differences between participants. Some participants had experienced one melanoma, or skin cancer diagnosis, whereas others had experienced multiple. The number of cancer diagnoses appeared to impact upon

participants' sense-making, with one participant who had several skin cancers describing that they perceived scarring positively as it became a sign of survival, and control. Perhaps for those with one melanoma, distance from diagnosis allowed them to refocus from the threat of metastasis and their own mortality, therefore long-term changes in appearance became more distressing. Additionally, it is important to consider biases in collecting data retrospectively. Some participants had experienced melanoma diagnosis and surgery several years before interview, which may have impacted their recollection.

Data collection

Participants were given the option of engaging in interview face-to-face, via Microsoft Teams, or via the telephone. Five participants requested for the interview to take place via Microsoft Teams, and two over the telephone, allowing for participation across a broad geographical area. The use of remote interviews has become an increasingly popular, and viable, method of data collection following the covid-19 pandemic, due to posing a number of benefits (Loughran et al., 2022). Video interviewing allows for increased accessibility, whilst replicating the reciprocation experienced within face-to-face interviewing. However, video interviewing may exclude those without internet access (Waugh, 2023), such as older participants, or those from a lower socioeconomic background. Within a UK study, 10% of the adult population were identified as 'non-users' of the internet, of which 12.1% were located in the North East (Watts, 2020). To mitigate such disadvantages, participants were also able to interview via the telephone. The limitations of telephone interviews are well documented; for example, presenting a barrier in communication which may result in misunderstandings, or may prevent the generation of meaningful conversation (Rubin & Rubin, 2011). However, these limitations are considered to be overstated within the evidence base (Cachia & Millward, 2011), and overall, remote

interviews do not differ significantly from face-to-face interaction in terms of subjective interviewer ratings, and substantive coding (Johnson et al., 2021).

Considering the benefits and limitations of offering remote interviews, I found it more difficult to engage in telephone interviews, possibly due to experiencing barriers in communication. In particular, I found it challenging not being able to see participants to assess nonverbal cues, such as body language or facial expressions. Given that the interview topic was likely to elicit an emotive response from participants, I found it difficult at times to gauge how the interview was going, or whether it was appropriate to ask a sensitive question, when relying solely on verbal communication. This possibly impacted upon rapport (Farooq, 2015), making it more challenging for participants to be vulnerable. However, given the context of the current study, reflecting upon experiencing an altered appearance may have resulted in participants feeling self-conscious, particularly if scarring was visible during the interview. Therefore, telephone interviews may alternatively have offered a protective mechanism for participants, where they were more able to talk openly about their experiences.

When coding interview transcripts, I also found it more difficult to contextualise participants' experiences when the interview had taken place over the telephone, perhaps highlighting how I rely heavily on nonverbal communication in my own sense-making. Although this was initially challenging, as I immersed myself within the data through the process of IPA, I felt that it did not impact upon my ability to analyse and draw meaning from participants' experiences.

The use of IPA

IPA was chosen for data analysis due to its grounding in phenomenology, hermeneutics, and idiography, aiming to understand the unique lived experience of each

participant, through their own, and the researcher's sense-making (Smith et al., 2022). I felt that IPA corresponded well with the study aims, which were concerned with understanding the appearance concerns and experiences of females who had undergone plastic surgery as part of their melanoma treatment. Given my own lived experience of melanoma, the principle of hermeneutics felt particularly salient, as remaining aware of my own experiences supported me to 'bracket' preconceptions throughout data collection and analysis (Smith et al., 2022). As there is no prescriptive guidance for conducting IPA, I decided to follow the approach of Murray and Wilde (2020), as my research supervisor is a co-author, and I was therefore able to seek their guidance throughout. Whilst other qualitative methodologies may have offered insight into the research area, I felt that they lacked an idiographic, hermeneutic, focus. For example, grounded theory is concerned with informing theory based around a process, therefore does not focus on personal meaning making (Birks & Mills, 2015). Within thematic analysis, transcripts are often analysed as one dataset from the outset, meaning that there is less focus on idiography when understanding participant experiences (Braun & Clarke, 2006).

Ethical Considerations

People living with a cancer diagnosis, and specifically a melanoma diagnosis, are vulnerable to experiencing psychological distress (National Institute for Health and Care Excellence [NICE], 2004). I was mindful that for participants, discussing their experience of melanoma may result in heightened distress, particularly as for some this had been the first time that they had spoken openly about their experiences. Considering this, I took steps to minimise potential distress. At the beginning of interview I spoke with participants about what to expect, and reminded them that they could take a break, or withdraw at any point. Following interview, I offered a period of time for a verbal debrief, and sent out support resources via email. During debrief, I also allowed participants to ask about my experience of

melanoma. All participants were curious, and shared that hearing my experience made them feel connected on a human level, which helped to validate their experiences.

During interviews, no adverse events occurred. However, at times, participants become visibly upset whilst sharing their experiences. At these times, I drew upon my therapeutic skills to demonstrate active listening and empathy.

Reflexivity

Reflexivity is considered as the researchers' attentiveness to their own biases and relationship to the research topic, in understanding how they may influence the research process (Engward & Goldspink, 2020). Within IPA, reflexivity is considered an integral aspect of the analytic process, where the researcher is required to consider how their interpretations of participants' accounts may be influenced by pre-existing assumptions, or experiences (Smith et al., 2022). Thus, the job of the IPA researcher is to uncover dual meanings attributed to the research topic, considering the sense-making of the participant, and their own interpretation (Shaw, 2010). With this in mind, I kept a reflective diary throughout the research process in order to document my thoughts and emotional responses, and regularly discussed these in supervision.

Throughout the process of conducting interviews, I was aware of my own identity as a person who had lived experience of the research phenomena. From the point of advertisement, participants were aware of my own lived experience, and I wondered how this may impact upon the interview process. Interestingly, although the study was advertised through multiple channels (via a melanoma charity and across social media), participants were solely recruited through a Facebook support group, which I was already a member of through my own experiences. Perhaps participants' awareness of my own melanoma diagnosis created a sense of cohesion, and enabled them to feel comfortable in sharing their

own experience. Given that participants reported experiencing dismissal from HCP's, my dual identity as a trainee clinical psychologist, and melanoma survivor, may have created psychological safety, and a non-judgemental space. However, it was also important to consider how my lived experience may negatively impact upon the interview process. Firstly, as participants were aged between 44 and 77, their life experiences likely differed significantly from my own, as I was aged 23 at the time of diagnosis. I wondered if this may elicit feelings of difference, and make it more challenging for participants to share their own account. I also was aware of how my own experience of melanoma had resulted in preconceived ideas and beliefs about the research. In order to mitigate my own biases, it was important to identify and bracket my own beliefs, to allow the exploration of new or novel information. The extract below demonstrates how I utilised reflexivity to identify, and bracket my own biases:

> I felt surprised that experiencing more skin cancer diagnoses resulted in less appearance concerns, with more focus on survival and post-traumatic growth. Having had only one melanoma diagnosis myself, meant that I subconsciously believed that having multiple surgeries would make appearance-concerns worse. But in actual fact, the participant found scars reassuring as it gave them control over the melanoma. (Diary extract 05/05/2023).

Within this research, I took on the role of an insider through my lived experience of melanoma (Merton, 1972). Insiders benefit from having increased knowledge of the research phenomena and are able to collect data more efficiently due to being accepted by participants (Dwyer & Buckle, 2009), resulting in the co-construction of knowledge (Chaudry, 2019). However, insiders are subject to their own biases and loyalty to the topic being investigated (Brannick & Coghlan, 2007). However, in the context of the current study, the dichotomy of insider/outsider is more complex than solely receiving a melanoma diagnosis, and is

impacted by other factors such as age, number of skin cancers, and socioeconomic status (Wilkinson & Kitzinger, 2013). Similarity and difference are not unitary, therefore it is likely I took on a "hybrid insider/outsider position" (Paechter, 2013) within the study. For example, I have lived experience of melanoma, but navigated this at a completely different life-stage to all participants, thus experienced differences in psychosocial adjustment. Being able to identify and bracket my own experiences may have increased my awareness of difference (for example, in life-stage, length of time since diagnosis), allowing me to ask naïve questions to elicit rich information (Chhabra, 2020).

Personal Reflections and Challenges

I found the process of completing the thesis to be challenging yet rewarding, from both a personal and professional perspective. From a personal perspective, I thoroughly enjoyed undertaking this research, as melanoma, and oncology more broadly, are areas that I am passionate about. I found it fascinating to hear the experiences of the participants, and appreciated their willingness to share their narrative with me. Given my own lived experience of melanoma, there were however times that I found the interview process emotive. Alike many of the participants, this was the first time that I had the opportunity to speak at length with other people who were diagnosed with melanoma. During debrief, participants shared that being interviewed by someone who had lived experience felt validating, containing, and empowering, which mirrored my own experience of being able to listen to their narratives. To monitor and manage my own emotional response to the research, I utilised supervision with my research and field supervisors.

Prior to training, I had limited research experience which led me to doubt my ability to undertake the thesis project. Throughout the research process, I feel that I have developed research skills central to the role of a clinical psychologist (British Psychological Society

[BPS], 2017) and increased my confidence and motivation in continuing with research post-qualification. During the research process, I initially found it challenging conducting interviews. As research interviews were a new experience for me, I noticed that I often found myself feeling nervous, particularly as interviews all took place online or via the telephone. Because of my lack of experience and confidence in conducting interviews, I found that for the first couple I stuck rigidly to the interview guide. After recognising that I missed opportunities to explore participants' sense-making in detail, I reflected with my research supervisor, and in following interviews developed confidence in sitting with uncertainty, allowing space for novel information to arise. I also noted that within the first couple of interviews, I felt a pull toward clinical skills, such as validating or empathising with participants' experiences, and found it difficult to sit with my role as a researcher. An extract following the first interview I conducted highlights my reflections on this:

> Found it more challenging than I expected to switch between therapy and interviewing – I found myself wanting to empathise and validate. I wonder if some of this relates to my own experiences, and feeling that I could empathise with a lot of information shared. I haven't previously had much contact with other melanoma survivors, so wonder if this impacted upon my experience of the interview. (Diary extract 14/04/2023).

In particular, I noticed that sitting within the research role at first felt cold, as though moving on to ask another question, rather than offering empathy, would dismiss a participant's experience. Over time, I felt more confident within the researcher role, recognising that the process of being interviewed felt validating in itself for participants, and that I could still offer empathy without being drawn into the role of a clinician. Pilot interviews may have been helpful during this process, allowing me to increase my confidence and experience of delivering interviews.

Future research

Considering the synergies in participants' experiences across the systematic literature review and empirical study, future research may aim to explore the salience of societal narratives, and beauty ideals in how people with permanent, or chronic, changes in appearance adjust, and construct their post-diagnosis identity. This may offer further insight into the body-image difficulties experienced by these groups, allowing for the development of psychological intervention targeted at promoting acceptance and positive body-image. However, studies considering societal beauty ideals within the systematic literature review were based in Western cultures, and within the empirical study all participants were white and UK based. Therefore, exploring the importance of beauty ideals cross-culturally is important in understanding the commonalities and divergences in how appearance changes are understood for non-Western populations. Understanding the salience of appearance across cultures may also indicate broader societal changes, for example how 'beauty' is portrayed within the media.

Within the systematic literature review, differences were noted between the experiences of males and females in adjusting to appearance changes. The empirical study focused on the experiences of females, as preliminary research has suggested that females experience heightened appearance distress following melanoma surgery, and are more likely to disengage from activity than males (Vaidya et al., 2019; Robinson, 2019). However, males are less likely to express psychological distress and seek support (Liddon et al., 2018), therefore this may reflect a difference in coping with appearance changes, rather than an absence of appearance distress for males. Future research may therefore seek to explore how males make sense of appearance changes and adjust to their post-diagnosis identity.

Conclusion and dissemination plan

The thesis explored the experiences of female melanoma survivors who have undergone plastic surgery as part of their treatment, with a focus on appearance-based concerns and psychosocial functioning. The critical appraisal offers reflection of the research process, such as ethical and methodological consideration, and limitations of both the systematic review and empirical study.

A summary of the empirical paper was presented to trainee clinical psychologists and research staff as part of the Lancaster Doctorate in Clinical Psychology, at the thesis presentation day in April 2024. The systematic literature review will be submitted for publication in the European Journal of Health Psychology, and the empirical paper will be submitted for publication in the Journal of Psychosocial Oncology. Finally, a full copy, or summary, of the empirical paper will be sent to all participants who requested this, and to the charity involved in advertising the research.

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Section Four: Ethics

Sarah Yates

Doctorate in Clinical Psychology

Division of Health Research

Lancaster University

All correspondence should be sent to:

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Faculty of Health and Medicine

Health Innovation One

Sir John Fisher Drive

Lancaster University

Lancaster LA1 4AT

Email: *s.yates3@lancaster.ac.uk*

Research Ethics Application Form v1.9.0 **RECR**

Appearance-based Concerns and Psychosocial Functioning Following Complex PlasticSurgery for Female Melanoma Survivors - Approved

Information Regarding this Research Project

Are you conducting a research project?(for more information on research projects please see our ethics pages)

(•) **Yes** ( ) **No**

Does your research only involve animals?

( ) **Yes** (•) **No**

Are you undertaking this research as/are you filling this form out as:

( ) **Academic/Research**

( ) **StaffNon Academic**

( ) **Staff**

(•)

( ) Staff Undertaking a Programme of

StudyPhD or DClinPsy student

Undergraduate, Masters, Master by Research, MPhil or other taught postgraduate programme

Which Faculty are you in?

Faculty of Health and Medicine

Which department are you in?

Health Research

Will your project require NHS REC approval? (If you are not sure please read the guidance in the information button)

○ Yes ◉ No

Do you need Health Research Authority (HRA) approval? (Please read the guidance in the information button)

○ Yes ◉ No

Have you already obtained, or will you be applying for ethical approval, from another institution outside of Lancaster University? (Forexample, an external institution such as: another University's Research Ethics Committee, the NHS or an institution abroad (eg an IRB in the USA)? Please select one of the following:

◉

○ No, I do not need ethical approval from an external institution.

○ Yes, I have already received ethical approval from an external institution.

Is this an amendment to a project previously approved by Lancaster University?

○ Yes ◉ No

Will your research involve any of the following? (Multiple selections are possible, please see i icon for details)

☑

☐ Human Participants

☐

☐ Data relating to humans (Secondary/Pre-existing data only)

☐ Data collection from online sources such as social media platforms, discussion forums, online chat-roomsHuman

Project Information

Please confirm/amend the title of this project.

Appearance-based Concerns and Psychosocial Functioning Following Complex Plastic Surgery for Female Melanoma Survivors

Estimated Project Start Date 28/08/2022

Estimated End Date 28/04/2024

Is this a funded Project?

○ ◉

Funding Information

Funding information

Please note

Your ACP reference number can be found on your grant application, it will start with an A and be followed by 6 numbers, e.g.A123456 Your Agresso ID is your grant code for expenditure allocated by post-award, e.g. EAA7001.

Research Site(s) Information

Will you be recruiting participants from research sites outside of Lancaster University? *(E.g. Schools, workplaces, etc; please readthe guidance in the information button for more information)*

Yes No

Please provide the number, type and location of external research sites that you are using (please see help text for details).

The study has the option of face-to-face or remote participation. Because of this, the lead researcher may need to visit between approximately 1 and 10 private homes in England. Where face-to-face interviews are conducted, the lead researcher will follow Lancaster University's Lone Researching Policy and Lone Worker Guidance, which they have read and familiarised themselves with. In line with this, the lead researcher will have a 'safety partner' for interviews taking place at a participant's home. This will involve providing the safety partner with a sealed envelope, containing the participants address. If the lead researcher has not made contactwith their safety partner by an agreed time after interview, the safety partner will open the envelope and seek further support if necessary. This aims to maintain confidentiality of participants, whilst ensuring researcher safety.

Applicant Details

Are you the named Principal Investigator at Lancaster University?

○ Yes ◉ No

Please check your contact details are correct. You can update these fields via the personal details section located in the top right of the screen. Click on your name and email address in the top right to access "Personal details". For more details on how to do this, pleaseread the guidance

First Name

Sarah

Surname

Yates

Department

Faculty

Email

Principal Investigator

Search for principal investigator name: *If you cannot find the PI in the system please contact rso-systems@lancaster.ac.uk to havethem added.*

First Name

Craig

Surname

Murray

Department

Health Research

Faculty

Email

Supervisor Details

Search for your supervisor's name. *If you cannot find your supervisor in the system please contact rso-systems@lancaster.ac.uk tohave them added.*

First Name

Craig

Surname

Murray

Department

Health Research

Faculty

Faculty of Health and Medicine

Email

c.murray@lancaster.ac.uk

Do you need to add a second supervisor to sign off on this project?

Yes No

Additional Team Members

Other then those already added, please select which type of team members will be working on this project:

- [ ]
- [ ] I am not working with any other team members.Staff
- [ ]
- [x] Student

Please list all external contacts here:

First Name

Surname

Organisation

Details about the participants

As you are conducting research with Human Participants/Tissue you will need to answer the following questions before yourapplication can be reviewed.

If you have any queries about this please contact your Ethics Officer before proceeding.

What's the minimum number of participants needed for this project?

6

What's the maximum number of expected participants?

10

Do you intend to recruit participants from online sources such as social media platforms, discussion forums, or online chat rooms?

- (•) Yes
- ( ) No

Will you get written consent and give a participant information sheet with a written description of your research to all potentialparticipants?

○ Yes ◉ No ○ I don't know

Will any participants be asked to take part in the study without their consent or knowledge at the time or will deception of any sort beinvolved?

○ Yes ◉ No ○ I don't know

Is your research with any vulnerable groups?

(Vulnerable group as defined by Lancaster University Guidelines)

◉ **Yes** ○ **No** ○ **I don't know**

Is your research with any adults (aged 18 or older)?

◉ **Yes** ○ **No**

Is your research data collected with completely anonymous adult (aged 18 or older) participants, with no contact details or other uniquely identifying information (e.g. date of birth) being recorded?

○ **Yes** ◉ **No**

Is your research with adult participants (aged 18 years, or older) in private interactions (for example, one to one interviews, online questionnaires)?

◉ **Yes** ○ **No**

Is your research with any young people (under 18 years old)?

○ **Yes** ◉ **No** ○ **I don't know**

Does your research involve discussion of personally sensitive subjects which the participant might not be willing to otherwise talk about in public (e.g. medical conditions)?

◉ Yes ○ No ○ I don't know

Could the study induce psychological stress or anxiety, or produce humiliation or cause harm or negative consequences beyond the risks encountered in a participant's usual everyday life?

(•) Yes ( ) No ( ) I don't know

Is there a risk that the nature of the research topic might lead to disclosures from the participant concerning either:

- Their own or others involvement in illegal activities
-

(•) Yes ( ) No ( ) I don't know

Does the study involve any of the following:

- Physically intrusive procedures including touching or attaching equipment to participants
- Administration of substances
-
- Ultrasound or sources of non-ionising radiation (e.g. lasers)Sources of
- ionising radiation, (e.g. X-rays)

( ) Yes (•) No ( ) I don't know

etails about Participant relationships

Do you have a current or prior relationship with potential participants? For example, teaching or assessing students or managing orinfluencing staff (this list is not exhaustive).

Yes No I don't know

If you need written permission from a senior manager in an organisation where research will take place (e.g. school, business) will you gain this in advance of undertaking your research?

Yes No I don't know N/A

Will you be using a gatekeeper to access participants?

Yes No I don't know if I will be using a gatekeeper

Will participants be subjected to any undue incentives to participate?

( ) Yes (•) No ( ) I don't know

Will you ensure that there is no perceived pressure to participate?

- [x] Yes
- [ ] No
- [ ] I don't know

Participant data

Will you be using video recording or photography as part of your research or publication of results?

- [ ] Yes
- [x] No

Will you be using audio recording as part of your research?

- [x] Yes
- [ ] No

Will you be using audio recordings in outputs (e.g. giving a presentation in a conference, using it for teaching)?

- [ ] Yes
- [x] No

Will you be using portable devices to record participants (e.g. audio, video recorders, mobile phone, etc)?

- [x] No
- [ ] Yes, and all portable devices will be encrypted as per the Lancaster University ISS standards, in particular where they are used for recording identifiable data
- [ ] Yes, but these cannot be encrypted because they do not have encryption functionality. Therefore I confirm that any identifiable data (including audio and video recordings of participants) will be deleted from the recording device(s) as quickly as possible (e.g. when it has been transferred to a secure medium, such as a password protected and encrypted laptop or stored in OneDrive) and that the device will be stored securely in the meantime

Will you be using other portable storage devices in particular for identifiable data (e.g. laptop, USB drive, etc)? (Please read the help text)

- [ ] No
- [x] Yes, and they will be encrypted as per the Lancaster University ISS standards in particular where they are used for recording identifiable data

Will anybody external to the research team be transcribing the research data?

- [ ] Yes
- [x] No

Online Sources

Does your research comply with the site(s) terms and conditions? Before completing the section below please read the 'Social Media Guidance for Researchers'

- (•) Yes
- ( ) No
- ( ) It's unclear in the terms and

Is there a reasonable expectation of privacy?

- (•) Yes
- ( ) No

Because there is a reasonable expectation of privacy, you must obtain consent from site users. Therefore you will need to upload a copy of the Participant Information Sheet & Consent form that you intend to use to obtain their informed

General Queries

Does the funder or any organisations involved in the research have a vested interest in specific research outcomes that would affectthe independence of the research?

Yes No I don't know

Does any member of the research team, or their families and friends, have any links to the funder or organisations involved in theresearch?

Yes No I don't know

Can the research results be freely disseminated?

Yes No I don't know

Will you use data from potentially illicit, illegal, or unethical sources (e.g. pornography, related to terrorism, dark web, leaked information)?

Yes No I don't know

Will you be gathering/working with any special category personal data?

- (•) Yes
- ( ) No
- ( ) I don't know

Are there any other ethical considerations which haven't been covered?

(•) Yes ( ) No ( ) I don't know

REC Review Details

Based on the answers you have given so far you will need to answer some additional questions to allow reviewers to assess your application.

It is recommended that you do not proceed until you have completed **all of the previous questions**.Please confirm

that you have finished answering the previous questions and are happy to proceed.

☑ I confirm that I have answered all of the previous questions, and am happy to proceed with the application.

Questions for REC Review

Summarise your research protocol in lay terms (indicative maximum length 150 words).

Note: The summary of the protocol should concisely but clearly tell the Ethics Committee (in simple terms and in a way which would be understandable to a general audience) what you are broadly planning to do in your study. Your study will be reviewed by colleagues from different disciplines who will not be familiar with your specific field of research and it may also be reviewed by the lay members of the Research Ethics Committee; therefore avoid jargon and use simple terms. A helpful format may include a sentence or two about the background/ "problem" the research is addressing, why it is important, followed by a description of the basic design and target population. Think of it as a snapshot of your study.

This study will explore the experiences of a group of adult females who have had complex surgery and reconstruction for melanoma skin cancer. This includes procedures such as skin graft where healthy skin is used to cover lost or damaged skin. The study will focus on changes in how people look following surgery, for example visible scarring. It will consider how people adapt to changes in how they look. Because of this, we will talk to people about their experience of surgery and ask them about how they feel about this. We will aim to talk to 6-10 people and will find them using social media sites, support groups and charities. We will identify what thingspeople have in common and any differences in their experiences. We will use this information to consider what help people get when they are told they have melanoma and when they have surgery.

Participant Information

State the Aims and Objectives of the project in Lay persons' language.

- To understand the experiences of females with melanoma skin cancer, who have had complex surgery
- To think about how females with melanoma understand their experiences
- To understand how females with melanoma skin cancer cope
- To think about how clinical psychologists might help people when they are told they have melanoma and when they have surgery

Please explain the number of participants you intend to include in your study and explain your rationale in detail (eg who will berecruited, how, where from; and expected availability of participants). If your study contains multiple parts eg interviews, focus groups, online questionnaires) please clearly explain the numbers and recruitment details for each of these cohorts (see help text).

Interpretative Phenomenological Analysis (IPA) will be used to analyse data. IPA requires small homogenous samples. Although exact numbers are not stipulated in IPA guidance, for a professional doctorate recruitment of approximately 5 participants is suggested within literature to be sufficient. In line with this, the current study will attempt to recruit approximately 6-10 participants in order to examine within and between participants' accounts in an interpretative and detailed manner, whilst ensuring the amount of qualitative data gathered is not overwhelming due to the time intensive nature of conducting IPA.

Participants will all be adult females, living in the UK and have undergone complex surgical procedure and reconstruction as treatment of melanoma. There will be an expectation that participants are able to converse in English and are at least three months post- surgery. Participants will be excluded if there is evidence that they currently have metastatic disease, or if they are undergoing further treatment, such as immunotherapy. Finally, participants with a significant mental health diagnosis, such as post-traumatic stress disorder will be excluded, as sharing such experiences may exacerbate distress.

Participants will be recruited via relevant melanoma charities and online support groups, through dissemination of the participant information sheet across a number of platforms. Advertisement will take place in a staged manner. Initially, relevant UK based melanoma charities will be contacted and asked if they are able to advertise the study, by sharing the participant information sheet with their mailing lists, and via their

You have selected that you are not getting written consent using a Participant Information Sheet with a written description of yourresearch. Please indicate why you are not using a Participant Information Sheet, and how you are obtaining consent.

All participants will be provided with a participant information sheet prior. All participants will receive a consent form via post or email atleast 24hours prior to the interview taking place. Participants who are being interviewed via Microsoft Teams or telephone will be asked to return their completed consent form using a pre-stamped envelope, or to print and scan the form before returning it via email. Participants engaging in face-to-face interviews will be asked to sign the consent form immediately before the interview takes place. However, participants may instead give verbal consent in order to improve accessibility. In this case, each item will be read out by the lead researcher and verbally agreed to before the interview commences. The verbal consent will be recorded.

As you have indicated that you are working with a vulnerable group please describe the intended participants, and why they areneeded for this research.

Participants will be female adults who have a diagnosis of melanoma and have undergone reconstructive plastic surgery as part of their treatment. The proposed study explores the lived experiences of these individuals, aiming to understand how participants makesense of their experiences, therefore inclusion of these participants is essential. This will hopefully allow consideration for how healthcare provision can be improved to meet the needs of melanoma patients. This might include consideration of how melanoma patients can be supported to scaffold a positive post-illness identity and develop effective coping to improve long term quality of life and wellbeing.

You have selected that the research may involve personal sensitive topics that participants may not be willing to otherwise talk about. Please indicate what discomfort, inconvenience or harm could be caused to the participant and what steps you will take to mitigate or manage these situations.

As participants will be discussing personal experiences related to cancer diagnosis and treatment, there is a possibility that they may experience distress during, or after interview. Additionally, as qualitative research outcomes are unpredictable, participants may be affected in ways that cannot always be anticipated, which may further result in psychological harm if not carefully managed. To address this, the interviewer will monitor participants' emotional response throughout interview, and in the event a participant becomes distressed, the interview will be stopped. The participant will be given the time they need to recover and make an informed decision on whether they would like to continue with the interview. Additionally, in the event that a participant becomes distressed, clinical skills such as active listening, will be utilised by the interviewerto contain the participant's distress and validate their feelings. If the interview is being conducted over Microsoft Teams or telephone, the participant may also be signposted to support resources, such as the Melanoma Helpline (https://melanomafocus.org/melanoma- helpline/) for support specifically related to melanoma, or Samaritans (https://www.samaritans.org/) for general support. The participant information sheet and debrief form also highlight further mental health support resources and melanoma charities, in the event that a participant experiences distress prior to, or following interview.

You have indicated that you will collect identifying information from the participants. Please describe all the personal information that you gather for your study which might be used to identify your participants.

Participants will be asked to complete an 'Expression of Interest' form prior to taking part in the study. This requests personal information including their: gender, date of birth, age and ethnicity. UK participants will also be asked to provide an email address or telephone number for contact purposes, based on their preference. International participants will be asked to provide their email address and will not be given the option to provide a telephone number, due to a lack of funds.
During the write-up of the study, personal information will not be used. During interview, participants will be asked to give apseudonym that they would like to be used for any direct quotes used.

Please describe how the data will be collected and stored.

The study will use a qualitative research design in which data is collected via one-to-one semi-structured interviews with participants. Interviews will be offered face-to-face, over Microsoft Teams, or over telephone. Participants engaging in interview over Microsoft Teams will be given the option whether they have their camera turned on, or off. All interviews will be recorded and transcribed by the lead researcher. All data will remain confidential, and steps will be taken to ensure anonymity, such as the use of pseudonyms during transcription of data. Interviews will be audio recorded using Lancaster University voice recording equipment. All recordings will be stored securely on Lancaster University Virtual Private Network (VPN) immediately after the interview has taken place. Data will be stored in a password protected file space on the University server and made available to the research supervisor using OneDrive.
Once recordings have been transferred to the VPN and transcribed, they will be deleted from the recording device. The audio files will also be deleted from the VPN once the thesis has been formally assessed. Anonymised electronic transcripts will be stored on the VPN indefinitely and may be transferred to a publicly available database.

Please describe how long the data will be stored and who is responsible for the deletion of the data.

All audio recordings, anonymised transcripts, and documents containing personal data, will be stored securely on Lancaster University Virtual Private Network (VPN) on the day that the interview takes place. Data will be stored in a password protected file space on the University server and made available to the thesis supervisor using OneDrive. Once

the thesis project has been assessed, the lead researcher (Sarah Yates) will delete the audio files. Once the study is complete, the lead researcher will transfer the transcripts and consent forms to the DClinPsy Research Coordinator via a secure method that has been approved by the University. Documents containing personal data (consent forms, expression of interest forms) will be destroyed after 12 months by the DClinPsy Research Coordinator. Anonymised electronic transcripts will be stored on the VPN indefinitely and may be transferred to a publicly available database.

You stated that the study could induce psychological stress or anxiety, or produce humiliation or cause harm or negative consequences beyond the risks encountered in a participant's usual, everyday life. Please describe the question(s) and situation(s) that could lead to these outcomes and explain how you will mitigate this.

During the interview, participants will be asked questions about their experiences of living with melanoma, covering areas such as their experience of care, psychological impact, adjustment and coping, appearance and functioning, and social impact. Participants may find that discussing their experiences distressing, particularly if they have not had much opportunity to discuss these previously.
Additionally, participants may not always be able to anticipate in advance the impact that discussing their experiences may have upon them. To minimise distress, participants will be informed of the purpose of the study prior to taking part, and the Participant Information Sheet will contain brief information on the areas that will be covered during interview. This will support potential participants in making an informed decision on whether they would like to take part. Participants will also be required to have had surgery at least three months prior to the interview taking place. This is to allow for some adjustment, as distress may be particularly heightened around the time of diagnosis and surgery.

During the interview, the interviewer will monitor participants' emotional response, and in the event a participant becomes distressed, the interview will be stopped. The participant will be given the time they need to recover and make an informed decision on whether they would like to continue with the interview. Participants will be provided with contact details for support resources, such as the Melanoma Helpline (https://melanomafocus.org/melanoma-helpline/) for support specifically related to melanoma, or Samaritans (https://www.samaritans.org/) for general support. These resources, and details of further melanoma charities will be provided on the Participant Information Sheet, and the Debrief Form.

You have selected that there is a risk that the nature of the research might lead to disclosures from the participant. What kind ofinformation might participants disclose? How will you manage that situation?

Due to participants discussing a physical health condition, there is some risk that participants may disclose the use of substances as pain relief, or to support coping. In the event that risk, or safeguarding issues present, the interviewer will follow professional guidelines, including policies set out by Lancaster University (such as the Ethics Code of Practice) and Lancashire and South Cumbria Foundation Trust (LSCFT) (Safeguarding and Protecting Children and Adults Policy). At the time of a disclosure, clarification will be gained about what has been shared, and risk will be explored in more detail. The interviewer will draw upon clinical skills to assess the presenting risk; exploring risk of harm to self and others, plans and intent. If there is any concern related to the wellbeing and safety of the participant, a safety plan will be developed. This will include the participant accessing support, such as speaking to their GP, a friend or family member, or presenting at a local Accident and Emergency department. It will be agreed that the lead researcher will contact the participant the following day to ensure that they have been able to access appropriate support. In the event of significant risk of harm, the lead researcher will use details acquired before the interview to contact relevant agencies, such as the emergency services.

In the event of safeguarding concerns, the lead researcher will seek guidance and support from the research and field supervisors, whilst continuing to follow Lancaster University and LSCFT policies. This may include seeking advice from supervisors if the lead researcher is unsure whether a concern needs to be raised with other agencies. If an urgent risk or safeguarding concern presents, the interviewer will share all personal information that they have (e.g. email address) with relevant agencies, such as the emergency services, to access immediate support.

Information about the Research

What are your dissemination plans? E.g publishing in PhD thesis, publishing in academic journal, presenting in a conference (talk or poster).

It is planned that the study will be submitted for publication in an academic journal and PhD thesis. A summary of findings, or a full copy of the publication will be offered to participants and stakeholders. Additionally, the findings of the study will also be shared with fellow trainee clinical psychologists at Lancaster University during a thesis presentation. If interest is shown from UK based melanomacharities, the lead researcher would also consider sharing the findings at a conference.

Online Sources

You have indicated site users have a reasonable expectation of privacy and therefore you will need to obtain consent to use their data for this project. Please explain how you propose to obtain consent.

Informed consent will be gained from participants before conducting interviews. The lead researcher will ensure that participants have read the participant information sheet and had the opportunity to ask any questions or gain further information prior to engaging in the interview. Participants will be asked to sign a consent form or may verbally consent to take part in the study. The consent process will inform participants of the purpose of the study, outline the methodology, and discuss confidentiality and right to withdraw. All participants will receive the participant information sheet and consent form via email or post, at least 24 hours prior to the interview taking place. For interviews taking place remotely, participants will have the option to print, scan, and return their consent form via email, or return the form using a pre-stamped envelope. During face-to-face interviews, the consent form will be signed immediately before the interview takes place. Participants may instead give verbal consent in order to improve accessibility. In this instance, the researcher would read out each item from the consent form, and the participant would offer verbal agreement. The verbal consent willbe recorded.

General Queries

You have indicated that you will be gathering/working with special category data. Please confirm here how you will comply with data protection law (GDPR) for use of special category personal data.

The use of special category data will involve collecting information on ethnicity, and participant's diagnosis of melanoma (for example, staging). All special category data will be stored on Lancaster University Virtual Private Network, and will only be accessible to the leadresearcher, Sarah Yates, and research supervisor, Dr Craig Murray. This data will be retained for the duration of the study. DClinPsy Research Coordinator via a secure method that has been approved by the University. Documents containing personal data (consent forms, expression of interest) will be destroyed after 12 months by the DClinPsy Research Coordinator.

You have stated that there are other ethical considerations that have not been covered. Please explain what these other ethicalconsiderations are, and how you would mitigate concerns regarding this research project.

The lead researcher has lived experience of melanoma, the condition being researched. As such, information may be shared within the interview that has an impact on the lead researcher. To manage this, reflective supervision spaces will be offered by the field supervisor throughout the period of data collection. It is hoped that this reflective space will also support an awareness and reduction of any biases the lead researcher may hold in interpreting the data. As such, these spaces will focus on the impact of the interviews on the lead researcher, and no participant information will be shared with the field supervisor. Additionally, the lead researcher will keep a reflective log throughout the thesis project. This will serve a dual purpose; of identifying any expectations or biases which mayimpact data analysis, but also as a method of debrief and containment outside of formal supervision sessions.

Further, as participants are offered the opportunity to take part in face-to-face interviews, the physical safety of the lead

Data Storage

How long will you retain the research data?

Audio recordings generated during interview will be retained for the duration of the proposed study and stored on Lancaster University Virtual Private Network. Once the thesis project has been formally assessed, the lead researcher, Sarah Yates, will deleteany audio files.

How long and where will you store any personal and/or sensitive data?

Any personally identifiable information will be stored on Lancaster University Virtual Private Network, and only the lead researcher, Sarah Yates, and research supervisor, Dr Craig Murray, will have access to this. Once the study is complete, the lead researcher will transfer the expression of interest forms and consent forms to the DClinPsy Research Coordinator via a secure method that has been approved by the University. Documents containing personal data (consent forms and expression of interest forms) will be destroyed after 12 months.

Please explain when and how you will anonymise data and delete any identifiable record?

The lead researcher, Sarah Yates, will be responsible for transcribing all audio files generated during interview. During transcription, the lead researcher will use the pseudonym selected by the participant at the beginning of their interview. Additionally, any direct quotations used in the write-up of the study will be presented so as to minimise the possibility of any personally identifiable information (such as the real names of people, and places, institutions or dates).

Project Documentation*

Important Notice about uploaded documents:

When your application has been reviewed if you are asked to make any changes to your uploaded documents please highlight thechanges on the updated document(s) using the highlighter so that they are easy to see.

Please confirm that you have read and applied, where appropriate, the guidance on completing the Participant Information Sheet,Consent Form, and other related documents and that you followed the guidance in the help button for a quality check of these documents. For information and guidance, please use the relevant link below:

FST Ethics Webpage

FHM Ethics Webpage

FASS-LUMS Ethics Webpage

REAMS Webpage

☑ I confirm that I have followed the guidance.

In addition to completing this form you must submit all supporting materials.

Please indicate which of the following documents are appropriate for your project:

- [x] Research Proposal (DClinPsy)
- [ ] Advertising materials (posters, emails)
- [x] Letters/emails of invitation to participate
- [x] Consent forms
- [ ] Participant information sheet(s)
- [x] Interview question guides Focus
- [ ] group scripts
- [x] Questionnaires, surveys, demographic sheetsWorkshop
- [ ] guide(s)
- [ ] Debrief sheet(s)
- [ ] Transcription (confidentiality) agreement
- [ ] Other

Please upload the documents in the correct sections below:

Please ensure these are the latest version of the documents to prevent the application being returned for corrections you havealready made.

As you are in a DClinPsy course please upload your Research Proposal for this project.

Documents

Type	Document Name	File Name	Version Date	Version	Size
Research Proposal	thesis protocol	thesis protocol.docx	20/12/2022	2	43.1 KB

Please upload all consent forms to be used in this project.

Documents

Type	Document Name	File Name	Version Date	Version	Size
Consent Form	Consent form final	Consent form final.docx	19/12/2022	2	30.4 KB

Please upload all Participant Information Sheets:

Documents

Type	Document Name	File Name	Version Date	Version	Size
Participant Information	Sheet	Participant Information Sheet	Participant Information Sheet - FINAL UK	participants	

Participant Information Sheet - FINAL UKparticipants.docx	Participant Information Sheet - FINAL UKparticipants.docx	19/12/2022	2 - UK participants	36.6 KB
Participant Information Sheet - FINAL International participants	Participant Information Sheet - FINAL International participants.docx	19/12/2022	2 - Int participants	36.7 KB

Please upload all advertising materials (posters, emails)

Documents

Type Name	Document Name	File	Date	Version	Size
Advertising materials	charity advertisement - FINAL UK participants	charity advertisement - FINAL UK participants.docx	24/10/2022	1 - UK participants	13.1 KB
Advertising materials	charity advertisement - FINAL International participants	charity advertisement - FINAL International participants.docx	24/10/2022	1 - Int participants	13.1 KB
Advertising materials	Social Media Advertisement - FINAL UK participants	Social Media Advertisement - FINAL UK participants.docx	24/10/2022	1 - UK participants	14.0 KB
Advertising materials	Social Media Advertisement - FINAL International participants	Social Media Advertisement - FINAL International participants.docx	24/10/2022	1 - Int participants	12.0 KB
Advertising materials					

Please upload all different Interview Question Guides.

Documents

Type	Document Name	File Name	Version Date	Version	Size
Interview question guide	Interview schedule	Interview schedule.docx	24/10/2022	1	15.9 KB

Please upload all Questionnaires, surveys, demographic sheets

Documents

Type Name	Document Name	File	Date	Version	Size

Questionnaires, surveys, demographic sheets	Expression of Interest Form - UK participants	Expression of Interest Form - UK participants.docx	19/12/2022	2 - UK participants	24.1 KB
Questionnaires, surveys, demographic sheets	Expression of Interest Form -International participants	Expression of Interest Form - International participants.docx	19/12/2022	2 - Int participants	19.1 KB

Please upload a copy of your Debrief sheet.

Documents

Type	Document Name	File Name	Version Date	Version	Size
Debrief sheet	Debrief form - UK participants	Debrief form - UK participants.docx	24/10/2022	1 - UK participants	16.7 KB
Debrief sheet	Debrief form - international participants	Debrief form - international participants.docx	24/10/2022	1 - Int participants	14.2 KB

Declaration

Please Note

Research Services monitors projects entered into the online system, and may select projects for quality control.

☑ **All research at Lancaster university must comply with the LU data storage and governance guidance as well as the General Data Protection Regulation (GDPR) and the UK Data Protection Act 2018. (Data Protection Guidance webpage)**

☑ I confirm that I have read and will comply with the LU Data Storage and Governance guidance and that my data use and storage plans comply with the General data Protection Regulation (GDPR) and the UK Data Protection Act 2018.

Have you that you have undertaken a health and safety risk assessment for your project through your departmental process? (Healthand Safety Guidance)

I have undertaken a health and safety assesment for your project through my departmental process, and where required willfollow the appropriate guidance for the control and management of any foreseeable risks.

When you are satisfied that this application has been completed please click "Request" below to send this application to yoursupervisor for approval.

Signed: This form was signed by Dr Craig Murray (c.murray@lancaster.ac.uk) on 20/12/2022 09:27

As you have stated that you are not the PI you will need to have the PI sign off on this application.

As the applicant please click "Request". *Please note that you cannot request a signature from yourself.*

Signed: This form was signed by Dr Craig Murray (c.murray@lancaster.ac.uk) on 20/12/2022 09:27

Please read the terms and conditions below:

You have read and will abide by Lancaster University's Code of Practice and will ensure that all staff and students involved in the project will also abide by it.
If appropriate a confidentiality agreement will be used.

You will complete a data management plan with the Library if appropriate. Guidance from Library.

You will provide your contact details, as well as those of either your supervisor (for students) or an appropriate person forcomplaints (such as HoD) to any participants with whom you interact, so they know whom to contact in case of questions or complaints?

That University policy will be followed for secure storage of identifiable data on all portable devices and if necessary you willseek guidance from ISS.

That you have completed the ISS Information Security training and passed the assessment.That you will abide by Lancaster University's lone working policy for field work if appropriate.

On behalf of the institution you accept responsibility for the project in relation to promoting good research practice and the prevention of misconduct (including plagiarism and fabrication or misrepresentation of results).

To the best of your knowledge the information you have provided is correct at the time of submission.If anything changes in your research project you will submit an amendment.

Applicant Only: To complete and submit this application please click "Sign" below:

Signed: This form was signed by Sarah Yates (s.yates3@lancaster.ac.uk) on 20/12/2022 09:04

Appendix 4-A Research Protocol

Study Title: Appearance-based Concerns and Psychosocial Functioning Following Complex Plastic Surgery for Female Melanoma Survivors

Investigator details:

Lead researcher: Sarah Yates

Research/programme supervisor: Dr Craig Murray

Field supervisor: Dr Katie Hatton

Introduction

Cancer is a leading cause of death worldwide, with an estimated 19.3 million new cases and approximately 10.0 million deaths reported in 2020 (Cao et al., 2021; Ferlay et al., 2021). On receiving a diagnosis, approximately half of cancer patients report feeling anxious or depressed when adjusting to traumatic life events (National Institute for Health and Care Excellence [NICE], 2004), and may experience further psychological difficulties throughout the course of their illness, such as fear of reoccurrence (Ağaç & Özçetin, 2021). Rates of suicidality are higher amongst cancer patients compared to the general population, due to concepts such as perceived burdensomeness and thwarted belongingness (Misono et al., 2008; Amiri & Behnezhad, 2020; Schomberg et al., 2021). Thus, understanding the psychological entailments of cancer experience is important in promoting quality of life (QOL) and wellbeing throughout treatment (Jacobsen & Wagner, 2012).

Additionally, the psychological challenges faced by cancer patients may be impacted by factors such as cancer type, location and treatment options (Linden et al., 2012; Niedzwiedz et al., 2019). Patients with visible tumours often experience psychological distress, as treatment options such as surgery can lead to permanent changes in appearance, which may impact self-esteem and identity (Melissant et al., 2018). Research indicates this can further impact upon physical and psychosocial functioning, such as engagement in relationships and sexual functioning (Rhee et al., 2005).

Skin cancer is an invasive condition for which initial treatment options involve surgical removal (van Egmond et al., 2021). Currently, between 2 and 3 million non-melanoma skin cancers (NMSC) and approximately 132,000 melanomas are diagnosed globally each year (World Health Organization [WHO], 2002). As primary treatment for skin cancer involves surgery the psychological entailments of this patient group may differ to that of other cancers (van Egmond et al., 2021). Additionally, variation is found between surgical procedures used to treat skin cancer, with less invasive procedures such as mohs surgery (a procedure in which the surgeon removes thin layers of skin one layer at a time, examining each layer to determine if cancer remains) often used to treat NMSC, and more complex skin cancers such as melanoma requiring surgical excision, reconstruction and sentinel lymph node biopsy (SLNB) (Ferrandiz et al., 2012). Surgical procedures may contribute to heightened distress, by further impacting physical functioning and body-image (Lee et al., 2016; van Hensbergen, 2021).

Although initial treatment options for skin cancer typically vary from treatment options for other cancers, research exploring the psychological needs of skin cancer patients remains limited (Bath-Hextall et al., 2017). Some qualitative research has acknowledged that a lack of emotional support from healthcare professionals (HCP's) may further contribute to psychological distress experienced by those with a skin cancer diagnosis (Stamataki et al., 2014), highlighting how better understanding of the experiences of skin cancer patients may shape psychologically informed person-centred treatment.

Additionally, qualitative studies exploring the experiences of skin cancer patients are found to often focus on surgical procedures to the head and neck (Lee et al., 2016; van Egmond et al., 2021). However, it is important to consider that skin cancer patients experiencing lesions across the body may require more complex reconstructive surgery, particularly for melanoma (Pasquali et al., 2016). Research further highlights differences in peri-operative wellbeing between skin cancer subgroups, with melanoma patients more likely than NMSC patients to experience distress and report an impact of surgery on psychosocial functioning, whilst the needs of NMSC patients revolve more around physical functioning (Sampogna et al., 2019).

Whilst some research has investigated the needs of patients with a complex skin cancer diagnosis, this has had a broader scope across care needs, such as continuity of care and need for improved information (van Egmond et al., 2021). Research indicates that body-image dissatisfaction is found to have a profound effect for skin cancer patients (Vaidya et al., 2019), with a noted reduction in engagement in meaningful activity due to feelings of shame and self-consciousness related to scarring (Lee et al., 2016). Whilst this is found to reduce over time (Lee et al., 2016), van Egmond et al. (2021) suggests that patients receiving plastic surgery reconstruction report ongoing disappointment with recovery, even if individuals are shown photographs of the expected result prior to surgery, suggesting that the complexity of procedures may be an important factor in long-term appearance satisfaction. Additionally, females are found to experience heightened psychosocial distress related to appearance (Vaidya et al., 2019), and are significantly more likely than males to note a decrease in pre-operative activity levels up to 12 months post-operatively (Robinson, 2019).

As such, the present research study will explore appearance-based concerns of melanoma patients who have undergone complex surgical procedures, such as skin graft or plastic surgery reconstruction. As females experience more body-image concerns post-

operatively (Vaidya et al., 2019), this study will explore how appearance affects survivorship and other aspects of psychological functioning such as identity, for female patients. Insights into appearance-based concerns may support HCP's in understanding body-image as a mediating factor for wellbeing post-operatively, and consider delivery of care, such as in the provision of information pre-operatively. This may offer insight into when psychological interventions are best placed, such as pre-operatively to prepare patients for surgery.

The research questions are (i) 'what are female melanoma survivors' experiences of complex surgical and reconstructive procedures and their impact on appearance satisfaction?', and (ii) 'what are the meanings and psychological outcomes of these procedures and experiences?'. The research aims are (i) to develop an understanding of the experiences of female melanoma survivors who have undergone complex plastic surgery, (ii) to develop an understanding of how these experiences are understood, and coped with by survivors, (iii) to consider the role of psychological theory in understanding these experiences, and (iv) to consider how clinical psychologists working within oncology and dermatology settings can use their skills to support patients receiving treatment for melanoma, and inform service development.

Method

Design

The study will use a qualitative research design in which data is collected via one-to-one semi-structured interviews with participants. As the current study is interested in exploring how participants make sense of their personal experiences, data will be analysed using Interpretative Phenomenological Analysis (IPA). IPA is an approach developed in psychology with a focus on phenomenology (lived experience) and hermeneutics (the interpretative activity, or meaning-making, of both participants and researcher). It also focusses on the detailed analysis of phenomena or cases, and is therefore concerned with producing an idiographic analysis for a small, well-defined (homogenous) participant group (Smith & Shinebourne, 2012).

Individual semi-structured interviews will be conducted in order to capture information relevant to key themes identified in previous research literature, whilst allowing flexibility for discussion around original and unexpected themes that may arise (Pietkiewicz

& Smith, 2014). The researcher will follow the lead of the participant in terms of the direction of the interview, asking prompting questions at times that are appropriate. The interview questions are guided by the research aims and previous literature. Interviews are expected to last for one hour, but will remain flexible if the participant wishes to share further material. Additionally, interviews will also be paused, or terminated at the request of the participant.

To ensure flexibility and accessibility around data collection, participants will be offered the opportunity to engage in interviews across a range of platforms. Participants will be offered face-to-face, telephone, or video interviews, conducted over Microsoft Teams (MS Teams). Participants engaging in interview over Microsoft Teams will be given the option whether they have their camera turned on, or off. As participants may live anywhere within the United Kingdom (UK), face-to-face meetings will only be considered for participants living within a specific geographical area due to travel costs and time constraints.

Sampling and Participants

The IPA methodology utilised requires small homogenous samples. Although exact numbers are not stipulated in IPA guidance, Smith et al. (2009) suggests that for a professional doctorate recruitment of approximately five participants is sufficient. In line with this, the current study will attempt to recruit approximately 6-10 participants in order to examine within and between participants' accounts in an interpretative and detailed manner, whilst ensuring the amount of qualitative data gathered is not overwhelming due to the time intensive nature of conducting IPA.

Participants will have undergone complex surgical procedure and reconstruction as treatment of melanoma. The specific inclusion and exclusion criterion are as follows:

Inclusion

- To have received a diagnosis of malignant melanoma, situated anywhere on the body.
- To have undergone reconstructive plastic surgery (for example skin graft, or skin flap procedure) as part of their treatment.
- To be at least three month post-surgery.
- Female.
- Aged 18 or over at the time of surgical procedure.
- Able to converse in English.

- To live in the UK.

The rationale of including only female participants in the current study, is as the experiences of male and female skin cancer survivors are found to differ. Females are found to experience more body-image concerns post-operatively (Vaidya et al., 2019), and as such the current study aims to explore how appearance affects survivorship and other aspects of psychological functioning, such as identity.

Additionally, participants are required to be a minimum of three months post-surgery. This is as individuals who have recently been diagnosed with melanoma and had initial surgery, may be adjusting to diagnosis and experience heightened distress related to this.

Whilst participants are required to live in the UK, in the event that there is difficulty in recruiting a sufficient participant sample, the search will be expanded to include international participants.

Exclusion

- If there is evidence of current metastatic disease, in which the cancer has spread from the original tumour.
- If individuals are undergoing further treatment, such as immunotherapy.
- If individuals have a significant mental health diagnosis, such as post-traumatic stress disorder.

The rationale for this is as the levels of distress faced by individuals with ongoing health difficulties may be further heightened by concerns related to prognosis and the impact of treatments. As such, the challenges and experiences faced by this population may differ significantly. Further, if individuals experience mental health difficulties, particularly related to melanoma, revisiting their experiences may exacerbate distress.

Recruitment

Participants will be recruited via melanoma charities and online support groups, through dissemination of the participant information sheet across a number of platforms. Advertisement will take place in a staged manner. Initially, relevant UK based melanoma charities will be contacted and asked if they are able to advertise the study. If this does not yield the participant sample required, the lead researcher will also reach out to melanoma

support groups via Facebook. Finally, the lead researcher will create a Twitter account, to share the details of the study to a wider platform.

Dissemination by relevant charities.

Appropriate charities will be contacted by the lead researcher via phone and/or email. If they are happy to do so, charities will be asked to share the participant information sheet with their mailing lists, and via their home webpage and social media accounts. Charities will also be asked to advertise the study in any publications they have, and any conferences or events they have taking place. They will be sent an advertisement if they are happy to do so. The lead researcher intends to contact the following UK based charities; MelanomaUK, Melanoma-Me, Melanoma Focus, Skcin and Melanoma Fund. In the event that these charities are not able to advertise the present study, or there are difficulties in recruiting, the lead researcher may contact further UK based charities, before considering broadening participation to international participants.

Facebook.

The lead researcher will provide relevant UK based charities, and Facebook support groups, with a copy of the participant information sheet and social media advertisement. Where charities or support groups are not UK based, the participant materials shared will clearly indicate that UK based participants are sought. Charities with a pre-existing Facebook account will be asked to share these resources across their site, from which participants will be able to access study details and contact the lead researcher if they wish to take part. Because of this, a specific account is not required to be set up. Where the lead researcher contacts support groups who only have a Facebook presence, the researcher will ensure that their account is set at the highest privacy setting, and will only contact the group administration via private message.

Twitter.

A specific Twitter account will be set up by the lead researcher for the sole purpose of advertising the study. The account will only be active during the time that the study takes place, and will be deleted following completion of the thesis. The account will have a link to the participant information sheet on a research advertising space for DClinPsy students. The participant materials shared on this platform will again clearly indicate that the study aims to recruit UK based participants. Relevant UK based charities with a Twitter presence will also

be asked to consider ‘re-tweeting’ the post to reach a wider audience. Again, this will allow participants to access study details and contact the lead researcher if they wish to take part, or would like further information.

Recruitment will follow a stepped process. Initially, participation will be open to UK residents. In the event that there is difficulty in recruiting a sufficient participant sample due to the specificity of the group being researched, the search will be expanded to include international participants. In this case, the lead researcher will again follow the above recruitment plan, also contacting international charities. If there are further difficulties in recruiting with these measures in place, the search may be widened by recruitment through the NHS, although this will additionally require the approval of NHS Ethics.

Procedure

Participants will be recruited through relevant melanoma charities and support groups. Several UK based melanoma charities have been identified, and the lead researcher will contact them to discuss advertisement of the study once it has gained ethical approval. The charities will be asked if they are able to advertise the study through social media, mailing lists, and within any charity publications. If possible, the lead researcher may also offer to attend any online/virtual meetings associated with the charities to advertise the study. The charities will be asked to share the participant information sheet, which will contain an email address for participants to contact should they wish to take part. If potential participants contact this address, the lead researcher will ask them to complete an expression of interest form. This will collect some demographic details (such as gender and ethnicity), and also include questions about their melanoma diagnosis; for example what stage their cancer was at diagnosis, and what stage it is currently. UK participants will also be asked to provide an email address or telephone number for contact purposes, based on their preference. International participants will be asked to provide their email address and will not be given the option to provide a telephone number, due to a lack of funds. The expression of interest will also ask UK participants to state their preference on the interview medium. To support with their decision, participants will also be sent a link to an accessible online guide of how to use MS Teams (https://support.microsoft.com/en-us/office/sign-in-and-get-started-with-teams-6723dc43-dbc0-46e6-af49-8a2d1c5cb937). Following completion of the expression of interest form, the lead researcher will arrange an interview in line with the participants’ expressed preferences. However, it is noted that face-to-face interviews will only be

conducted within a specific geographical area. All participants will receive a consent form via post or email at least 24hours prior to the interview taking place. Participants who are being interviewed via MS Teams or telephone will be asked to return their completed consent form using a pre-stamped envelope, or to print and scan the form before returning it via email. Participants engaging in face-to-face interviews will be asked to sign the consent form immediately before the interview takes place. Alternatively, participants may instead give verbal consent in order to improve accessibility. In this case, each item will be read out by the lead researcher and verbally agreed to before the interview commences. The verbal consent will be recorded. The interview will last for approximately 60 minutes, after which time the participant will receive a debrief form containing further support resources. The lead researcher will also follow safeguarding procedures if risk or concern arise during the interview. To support this process, the lead researcher will check the location of each participant during interview. This information will only be used in the event that significant risk of harm presents within the interview, and will be used to seek support for the participant.

Where face-to-face interviews are conducted, the lead researcher will follow Lancaster University's ***Lone Researching Policy*** and ***Lone Worker Guidance***. In line with this, the lead researcher will have a 'safety partner' for interviews taking place at a participant's home. This will involve providing the safety partner with a sealed envelope, containing the participant's address. If the lead researcher has not made contact with their safety partner by an agreed time after interview, the safety partner will open the envelope and seek further support if necessary, for example by contacting one of the programme directors. This aims to maintain confidentiality of participants, whilst ensuring researcher safety.

All interviews will be recorded and transcribed by the lead researcher. All data will remain confidential, and steps will be taken to ensure anonymity; such as the use of pseudonyms during transcription of data. Interviews will be audio recorded using Lancaster University voice recording equipment, and all recordings will be stored securely on Lancaster University Virtual Private Network (VPN) immediately after the interview has taken place. Data will be stored in a password protected file space on the University server and made available to the research supervisor using OneDrive. Once recordings have been transferred to the VPN and transcribed, they will be deleted from the recording device. These audio files will also be deleted from the VPN once the thesis has been formally assessed. Anonymised

electronic transcripts will be stored on the VPN indefinitely, and may be transferred to a publicly available database.

Materials

Participant materials include a participant information sheet, consent form, debrief form, and expression of interest form. The debrief form contains relevant UK contact numbers for participants who require additional support. These will be shared via relevant melanoma and skin cancer charities, and will be advertised via the lead researcher's Twitter account. This account will be created once ethical approval has been gained, for the sole purpose of advertising the study. A brief advertisement has further been developed for use within charity publications.

A semi-structured interview schedule will be used, to guide the interviewer and participant to explore various topics related to the participants' experience. The interviewer will take a flexible approach, considering the most appropriate times to ask questions based on the responses of the participant.

The schedule and questions have been developed based upon previous research exploring the needs and experiences of skin cancer survivors. Stakeholders have also been consulted. A melanoma charity, Melanoma Focus (https://melanomafocus.org/), has been contacted by the lead researcher, and their feedback has been incorporated into the design of the proposed study materials and interview schedule.

Further materials may include the use of a Dictaphone, a research phone, and a laptop to conduct interviews via a video platform, which are available to the lead researcher via Lancaster University.

Costs

Where possible, face-to-face interviews may take place. However, as participants may live anywhere in the UK, this may not always be possible. Where relevant, participants will be offered travel expenses up to £20 in accordance with research policy on, and payed funds available from, the DClinPsy programme.

Proposed Analysis

Data will be analysed using IPA, due to its idiographic focus, which aims to give detailed examinations of personal lived experience, and how people make sense of their

experiences (Smith & Shinebourne, 2012). Developed as a methodology for psychological research, IPA allows for data to be explored through a psychological lens, during which the researcher aims to make interpretation via the application of psychological theory, whilst giving evidence of the participants' sense making (Pietkiewicz & Smith, 2014).

There will be several steps to data analysis as outlined by Murray and Wilde (2020). Each transcript will be closely analysed and coded in isolation, to ensure that the lead researchers analysis and sense-making of subsequent transcripts is not influenced by the contents of previous transcripts. From this, the lead researcher will generate emergent themes, before seeking to explore relationships between themes and cluster themes for each individual participant. Finally, overarching themes will be developed to capture the experiences of multiple participants.

Throughout data analysis, the lead researcher will remain aware of their own perspective, particularly due to having lived experience of this condition. As such, the research supervisor will also have input in data analysis to ensure validity of findings, and as a form of quality assurance. The lead researcher will also utilise supervision with both the thesis supervisor and field supervisor throughout analysis, to discuss themes and reflect upon interpretations.

Ethical Considerations

Consent

Informed consent will be gained from participants before conducting interviews. The lead researcher will ensure that participants have read the participant information sheet and had the opportunity to ask any questions or gain further information prior to engaging in the interview. Participants will be asked to sign a consent form, or may verbally consent to take part in the study. The consent process will inform participants of the purpose of the study, outline the methodology, and discuss confidentiality and right to withdraw. All participants will receive the participant information sheet and consent form via email or post, at least 24 hours prior to the interview taking place. For interviews taking place remotely, participants will have the option to print, scan, and return their consent form via email, or return the form using a pre-stamped envelope. During face-to-face interviews, the consent form will be signed immediately before the interview takes place. Participants may instead give verbal

consent in order to improve accessibility. In this instance, the researcher would read out each item from the consent form, and the participant would offer verbal agreement. The verbal consent will be recorded.

Confidentiality

All information shared by participants within the study will remain confidential. However, there are some limits to this. If a participant discloses information that suggests there is a risk of harm to themselves, or somebody else, the lead researcher has a duty of care to share this with relevant agencies. In this case, where possible, the lead researcher will make the participant aware of the need to share this information.

Data collected as a part of the study will also be anonymised. Interviews will be audio recorded using voice recording equipment from Lancaster University. All recordings will be stored securely on Lancaster University VPN on the day that the interview takes place, and will be retained for the duration of the research. Data will be stored in a password protected file space on the University server and made available to the research supervisor using OneDrive. Once the thesis project has been assessed, the lead researcher will delete the audio files. At the point of interview, participants will be asked to select a pseudonym, and data will be transcribed by the lead researcher using these pseudonyms. This will allow participants to identify their contribution within the final publication, but will allow anonymity. During data analysis, only the lead researcher, Sarah Yates, and research supervisor, Dr Craig Murray, will have access to the recordings stored on the VPN. Anonymised transcripts may also be shared with the research supervisor, and on occasion with the field supervisor, Dr Katie Hatton, as part of the analysis process. Themes generated will be representative of the entire participant sample, as opposed to individual participants to further support anonymity. Additionally, any direct quotations used in the write-up of the study will be presented so as to minimise the possibility of any personally identifiable information (such as the real names of people, and places, institutions or dates).

Once the study is complete, the lead researcher will transfer the transcripts and consent forms to the DClinPsy Research Coordinator via a secure method that has been approved by the University. Documents containing personal data (consent forms and expression of interest forms) will be destroyed after 12 months. Anonymised electronic transcripts will be stored on the VPN indefinitely, and may be transferred to a publicly available database.

Distress and Safeguarding

As participants will be discussing personal experiences related to cancer diagnosis and treatment, there is a possibility that they may experience distress during, or after interview. Additionally, as qualitative research outcomes are unpredictable, participants may be affected in ways that cannot always be anticipated (Butterfield et al., 2009) which may further result in psychological harm if not carefully managed. To address this, the interviewer will monitor participants' emotional response throughout interview, and in the event a participant becomes distressed, the interview will be stopped. The participant will be given the time they need to recover and make an informed decision on whether they would like to continue with the interview.

Additionally, in the event that a participant becomes distressed, clinical skills such as active listening, will be utilised by the interviewer to contain the participant's distress and validate their feelings. If the interview is being conducted over MS Teams or telephone, the participant may also be signposted to support resources, such as the Melanoma Helpline (https://melanomafocus.org/melanoma-helpline/) for support specifically related to melanoma, or Samaritans (https://www.samaritans.org/) for general support. The participant information sheet and debrief form also highlight further mental health support resources and melanoma charities, in the event that a participant experiences distress prior to, or following interview.

In the event that risk or safeguarding issues present, the interviewer will follow professional guidelines, including policies set out by Lancaster University (such as the ***Ethics Code of Practice***) and Lancashire and South Cumbria Foundation Trust (LSCFT) (***Safeguarding and Protecting Children and Adults Policy***). At the time of a disclosure, clarification will be gained about what has been shared, and risk will be explored in more detail. The interviewer will draw upon clinical skills to assess the presenting risk; exploring risk of harm to self and others, plans and intent. If there is any concern related to the wellbeing and safety of the participant, a safety plan will be developed. This will include the participant accessing support, such as speaking to their GP, a friend or family member, or presenting at a local Accident and Emergency department. It will be agreed that the lead researcher will contact the participant the following day to ensure that they have been able to access appropriate support. In the event of significant risk of harm, the lead researcher will use details acquired before the interview (such as name and email address) to contact the

emergency services. In the event that the inclusion criteria of the study is broadened to include international participants, contact details for relevant charities providing international support will also be provided to participants. Once the interview has come to an end, the lead researcher will contact the research and field supervisors to ensure that the participant has been supported appropriately.

In the event of safeguarding concerns, the lead researcher will seek guidance and support from the research and field supervisors, whilst continuing to follow Lancaster University and LSCFT policies. This may include seeking advice from supervisors if the lead researcher is unsure whether a concern needs to be raised with other agencies. If an urgent risk or safeguarding concern presents, the interviewer will share the participants address with relevant agencies, such as the emergency services, to access immediate support.

Withdrawal

Participants are able to withdraw from the study at any point prior to the interview taking place, without providing a reason. Within qualitative research, consent is best considered an ongoing process, as the outcomes of interviews are often unforeseeable and unpredictable (Sabar, 2008; Josselson, 2007). In order to ensure that participants have sufficient time to reflect on the information they have shared, and make an informed decision about their data being analysed, there will be a two week period following interview where participants are able to request withdrawal of their data. Within this time, participants may also request a copy of the transcript of their interview, and negotiate exclusion of certain responses if they would still like their data to be included more broadly. After two weeks, the data will be analysed and incorporated into themes. At this stage, it may not be possible for data to be withdrawn, although every attempt will be made to extract participants' data from the study, if requested prior to publication. This will be made clear to participants at the initial point of consent, and during interview.

Researcher Safety

As the lead researcher has personal experiences related to the project topic, material may be discussed within interviews that the interviewer finds distressing. To address this, and manage the impact of this upon the lead researcher, reflective supervision spaces will be offered by the field supervisor throughout the period of data collection. It is hoped that this reflective space will also support an awareness and reduction of any biases the lead researcher may hold in interpreting the data. As such, these spaces will focus on the impact of

the interviews on the lead researcher, and no participant information will be shared with the field supervisor. Additionally, the lead researcher will keep a reflective log throughout the thesis project. This will serve a dual purpose; of identifying any expectations or biases which may impact data analysis, but also as a method of debrief and containment outside of formal supervision sessions. This is important as debrief and reflection are found to be important aspects of researcher wellbeing when conducting qualitative research on sensitive topics (Bahn & Weatherill, 2012; Sabar & Sabar, 2017).

Where the lead researcher conducts face-to-face interviews the ***Lancaster University's Lone Worker Guidance*** will be followed, as previously discussed, in order to minimise physical risk. Interviews conducted over MS Teams and telephone will also mitigate risk of physical harm to the lead researcher.

Study Oversubscription

The lead researcher will approach oversubscription with sensitivity, discussing this openly with potential participants. They would be offered a summary of the findings of the research, or a copy of the full paper, once the study is complete.

Timescale and Dissemination

The proposed study forms part of the thesis completed within the DClinPsy programme, and is required to be submitted to Lancaster University by May 2024. It is anticipated that participants will be interviewed between April and June 2023, once ethical approval has been gained. If submitted for publication, it is anticipated that this will occur by September 2024, and stakeholders and participants will also receive a summary of findings via post or email within this timeframe.

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Appendix 4-B Participant Information Sheet

Research Information Sheet – UK Participants

UK females' views on appearance and difficulties experienced after plastic surgery for melanoma

Hello, my name is Sarah Yates and I am training to be a clinical psychologist at Lancaster University, Lancaster, United Kingdom. As part of my training, I am conducting a study with females who have had reconstructive plastic surgery as part of their treatment for melanoma. My interest in this topic comes from my own experience of living with melanoma.

Thank you for taking the time to read this information sheet. *If you would like to take part, or would like some further information, please contact me at* *s.yates3@lancaster.ac.uk*

What is the study about?

The purpose of this study is to explore the experiences of female adults who have undergone complex surgery and reconstruction as part of their treatment for melanoma. The study will consider the impact of this surgery on their psychological wellbeing.

Why have I been approached?

You have been approached as the study involves collecting information from females who have lived experience of melanoma. To take part, you are required to have undergone complex surgery and reconstruction, such as skin graft or skin flap, as a part of your treatment. You must also be over the age of 18, be based in the UK, and not currently be undergoing any further treatment for your melanoma, such as immunotherapy.

There is limited research exploring the needs and experiences of melanoma patients, particularly in how people adjust to their appearance and functioning after surgery. This research is looking to address that gap and give melanoma survivors a platform to share their experiences. This will hopefully inform how healthcare professionals support people around their diagnosis and surgery.

What will I be asked to do if I take part?

If you choose to take part, you will be asked to take part in an interview. The interview will take place via telephone, Microsoft Teams, or face-to-face, with the lead researcher, Sarah Yates, and will last approximately 45 – 60 minutes. The interview will be audio recorded. During the interview you will be asked different questions about your experience of melanoma and the impact this has had on different areas of your life. The interview will be about your own personal experiences, but more general questions may explore your experience of diagnosis and treatment, your experience of surgery and any concerns related to appearance and functioning, and how you have coped.

Do I have to take part?

No. It is completely up to you to decide whether or not to take part.

Will my information be identifiable?

No. All information shared in the interview will be confidential, and all data will be anonymised. During the interview I will record our conversation on an audio recorder. After the interview I will type what we have discussed and change any personal information (for example people's names you mention, or places). At the beginning of the interview I will also ask you to choose a false name which I will use as a reference for any direct quotes used in the write-up of this study. All of your personal data, such as your name and age, will be confidential and will be kept separately from your interview responses.

All data collected within this study will be stored securely in University approved cloud storage. Only the researchers conducting this study will be able to access this data. All files will be encrypted and stored on a password protected computer. Once the thesis project has been examined, all recordings will be deleted. Any hard copies of questionnaires will be kept securely in a locked cabinet for ten years after which they will be destroyed. A transcript of your interview responses using a false name may be kept indefinitely, and may be transferred to a public database. This would not include any of your personal information.

There are however some limits to confidentiality. If you share something during the interview that makes me think that there is a significant risk of harm to you, or someone else, I will have to break confidentiality and speak to a member of staff about this. If you share something that makes me think you are at immediate risk of harm, I may have to contact the emergency services. Because of this, before your interview I may ask you where you are. If possible, I will tell you if I have to contact the emergency services.

What will happen to the results?

The results will be summarised and reported in a thesis which will be assessed as a part of the lead researchers Doctorate in Clinical Psychology qualification. The thesis may also be submitted for publication in an academic or professional journal. An accessible summary of the findings will also be available and offered to all participants and stakeholders involved in the study.

Are there any risks?

There are no risks anticipated with participating in this study. However, discussing a very personal experience may feel upsetting. If you experience distress at any point, including during interview or after participation, you are encouraged to inform the lead researcher, and contact the support numbers provided at the end of this sheet.

Are there any benefits to taking part?

There are no direct benefits to participating in this study, although you may find it interesting. It is also hoped that shared experiences will support healthcare professionals in better understanding how to support people with melanoma around their diagnosis and treatment. This may have an indirect benefit, by improving healthcare provision in the future.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the lead researcher:

Sarah Yates

Doctorate in Clinical Psychology

Furness College

Lancaster University

Lancaster

LA1 4YG

Email: s.yates3@lancaster.ac.uk

You could also gain further information from the research supervisor:

Dr Craig Murray

Doctorate in Clinical Psychology

Furness College

Lancaster University

Lancaster

LA1 4YG

Email: c.murray@lancaster.ac.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Dr Ian Smith
Research Director, DClinPsy Programme
Tel: 01524 592282
Email: i.smith@lancaster.ac.uk
Doctorate in Clinical Psychology
Furness College
Lancaster University
Lancaster
LA1 4YG

If you wish to speak to someone outside of the Doctorate in Clinical Psychology Programme, you may also contact:

Dr Laura Machin

Chair of FHM REC

Tel: +44 (0)1524 594973

Email: l.machin@lancaster.ac.uk

Faculty of Health and Medicine

(Lancaster Medical School)

Lancaster University

Lancaster

LA1 4YG

Thank you for taking the time to read this information sheet.

Resources in the event of distress

If you experience distress at any point during, or after taking part, the below resources may be of assistance:

For support directly related to melanoma:

- **Melanoma Helpline (manned by experienced skin cancer nurse specialists)**
  Tel: 0808 801 0777 (currently open 1-2pm and 7-9pm Monday-Friday and 7-9pm on Sunday)

For general mental health support:

- **Samaritans - 24/7 helpline**
  Tel: 116 123 (free)

- **Shout - 24/7 text service**
  Text SHOUT to 85258

If you wish for additional information related to melanoma, there are a number of UK charities that can be contacted. I have listed the details below of charities that I am aware of:

- https://www.melanomauk.org.uk/
- https://melanoma-me.org.uk/
- https://melanomafocus.org/
- https://www.skcin.org/
- https://www.melanoma-fund.co.uk

Appendix 4-C Advert to be placed in relevant charity publications

Expression of Interest to be Advertised in Relevant Charity Publications

Are you an adult female living in the UK, who has undergone reconstructive surgery as part of your treatment for melanoma? Opportunity to be involved in research and share your experience…

Hello, my name is Sarah Yates and I am training to be a clinical psychologist at Lancaster University, Lancaster, United Kingdom. As part of my training, I am researching the experiences of females who have had reconstructive plastic surgery as part of their treatment for melanoma. My interest in this topic comes from my own experience of living with melanoma. The study will involve an interview with myself, in which we will talk about your experiences of living with melanoma, including the impact of surgery on your psychological wellbeing. The interview will be completed either face-to-face, via Microsoft Teams, or over the telephone, depending on your location. Data will be anonymised, and a pseudonym (false name) will be used for any direct quotations used in the write-up of the study.

If you require further information, or would like to take part, then please do not hesitate to contact me at s.yates3@lancaster.ac.uk or tweet at (twitter address).

I look forward to hearing from you,

Sarah Yates

Trainee Clinical Psychologist

Lancaster University

Appendix 4-D Social Media Advertisement

Twitter (max. 280 characters) and Facebook

Option 1

Are you an adult female living in the UK, who has undergone reconstructive surgery as part of your treatment for melanoma? Opportunity to be involved in research and share your experience…

(Electronic link to participant information sheet)

Option 2

Are you a female living with melanoma in the UK, and have experienced reconstructive surgery? Opportunity to be involved in research and share your experience …

(Electronic link to participant information sheet)

Option 3

Have you experienced reconstructive surgery for melanoma? Research opportunity for adult females living in the UK

(Electronic link to participant information sheet)

Appendix 4-E Expression of Interest Form

Research Study: ***UK females' views on appearance and difficulties experienced after plastic surgery for melanoma***

DOB: _____

Age: _____

Ethnicity: _____

When did you first receive a diagnosis of melanoma? _____

When was your first surgery for melanoma? _____

What was the stage of your melanoma at diagnosis? _____

What is the stage of your melanoma now? _____

How many skin cancers have you had in total? _____

I am interested in taking part in this study. Please contact me on:

Telephone number: _____

Email: _____

I would prefer to be contacted by

Telephone ☐ Email ☐

I would prefer to be interviewed via (please indicate first and second preference)

Microsoft Teams ☐ Telephone ☐ Face-to-face ☐

Would you like a copy of the research paper, or a summary, when it is finalised?

Full copy: Yes ☐ No ☐

Summary: Yes ☐ No ☐

Appendix 4-F Consent Form

CONSENT FORM

Project Title: Appearance-based Concerns and Psychosocial Functioning Following Complex Plastic Surgery for Female Melanoma Survivors

Name of Researchers: Sarah Yates, Dr Craig Murray, Dr Katie Hatton
Email: s.yates3@lancaster.ac.uk

Please tick each box

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time during my participation in this study and within 2 weeks after I took part in the study, without giving any reason. If I withdraw within 2 weeks of taking part in the study my data will be removed.	☐
3. I understand that any information given by me may be used in future reports, academic articles, publications or presentations by the researcher/s, but my personal information will not be included and all reasonable steps will be taken to protect the anonymity of the participants involved in this project.	☐
4. I understand that my name will not appear in any reports, articles or presentation without my consent.	☐
5. I understand that any interviews will be audio-recorded. I understand that this will be transcribed and that data will be protected on encrypted devices and kept secure.	☐
6. I understand that once my data has been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of publication.	☐
7. I understand that my anonymised interview transcript will be shared with the researcher's supervisor, Dr Craig Murray and may be shared with the researcher's field supervisor, Dr Katie Hatton.	☐
8. I understand that any information I give will remain strictly confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the lead researcher has a duty of care to share this information.	☐
9. I understand that data will be kept according to University guidelines for a minimum of 10 years after the end of the study.	☐
10. I understand that a transcript from my interview will be stored indefinitely and may be transferred to a public database. I understand that this will not contain any of my personal information and will use a pseudonym (false name).	☐

11. I agree to take part in the above study.	☐

_____ _____ _____

Name of Participant Date Signature

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

Signature of Researcher /person taking the consent_____ Date _____ Day/month/year

One copy of this form will be given to the participant and the original kept in the files of the researcher at Lancaster University

Appendix 4-G Semi-Structured Interview Schedule

Experience of Care

Did you face any challenges around receiving a diagnosis? (For example, a delay in diagnosis, misdiagnosis)

(If UK participant) Did you receive treatment through the NHS or private sector?

After being diagnosed with melanoma, how prepared did you feel for surgery? (E.g. were you given the details of a skin cancer clinical nurse specialist to support you?)

How would you describe your relationship with the healthcare services supporting you? Did you feel satisfied with the information they gave you about your diagnosis and treatment options?

Did you feel that your needs were understood and adequately met?

How involved did you feel in making decisions related to your treatment options and care?

What were your initial expectations of surgery and recovery? In hindsight, do you feel your expectations were met?

Is there anything that would have improved your experience of receiving care?

If you could give advice, or make any changes to the healthcare services that supported you, what would you say?

Psychological Impact, Adjustment and Coping

What are the main challenges of living with a melanoma diagnosis?

How have your emotions changed between diagnosis, and now?

What helps you cope?

If any, what support have you received from professionals or organisations related to the emotional impact of having melanoma? How have you experienced this support?

How often do you think about melanoma?

How do you feel about the future whilst living with melanoma?

What do you feel is the most important focus of your life now? Has this changed since being diagnosed with melanoma?

Appearance and Functioning

In what ways has your appearance changed following surgery?

Have you experienced any complications of surgery or recovery?

(If so) What impact have these complications had on your emotional wellbeing?

(If so) How have you coped with the impact of these complications?

What were your initial expectations of scarring, and did you feel these were accurate following surgery?

How satisfied did you feel with scarring initially?

When you first saw your scar(s) following surgery, how did you feel emotionally?

How do you feel about your scar(s) now?

Do you do anything to alter the visibility of your scar(s)?

Does having a scar impact upon other areas of your life (for example, your social interactions)? If so, what impact does this have?

How have you adjusted to changes in your appearance?

Have you noticed any changes in your confidence since having surgery?

Social Impact

Has there been any impact upon your relationships? If so, what changes have you experienced?

How do you feel that others understand your condition?

What impact has melanoma had upon your social life? Have any changes in your social life impacted upon your emotional wellbeing?

Appendix 4-H Debrief Form

Sarah Yates

Email: s.yates3@lancaster.ac.uk

DClinPsy Lancaster University

Clinical Psychology

Division of Health Research

Lancaster

LA1 4YG

Research Supervisor: Dr Craig Murray

Email: c.murray@lancaster.ac.uk

Thank you for taking part in this study. The study was aimed at exploring the experiences of adult females who have undergone complex surgery and reconstruction for Melanoma.

If you have any questions or concerns related to the study, please contact the lead researcher, Sarah Yates, at s.yates3@lancaster.ac.uk in the first instance. You may also wish to contact the research supervisor, Dr Craig Murray at c.murray@lancaster.ac.uk.

Following the interview you may experience a range of emotions. This may include sadness or feelings of loss as you remember your experiences how these have affected you. Please be reassured that this is completely normal, but there are lots of support agencies out there that you may find beneficial.

If you wish for additional support and information related to melanoma, there are a number of UK charities that can be contacted. I have listed the details below of charities that I am aware of:

- https://www.melanomauk.org.uk/
- https://melanoma-me.org.uk/
- https://melanomafocus.org/
- https://www.skcin.org/
- https://www.melanoma-fund.co.uk/

For emotional support related to melanoma, you can contact the Melanoma Helpline. This service is manned by experienced skin cancer nurse specialists, and operates between 1-2pm and 7-9pm Monday-Friday, and 7-9pm on Sundays. You can also contact Samaritans by calling 116 123 or contact SHOUT by texting SHOUT to 85258 for further emotional support. Both of these services are free of charge and offer 24/7 support. There is also an international charity called Befrienders Worldwide, which may offer further support: https://www.befrienders.org

Finally, I would like to thank you for participating in this research and I wish you all the best for the future.

Kind regards,

Sarah Yates

Trainee Clinical Psychologist

Lancaster University

Appendix 4-I FHMREC Ethical Approval Letter

Name: Sarah Yates

Supervisor: Craig Murray

Department: Doctorate in Clinical Psychology

FHM **REC Reference:** FHM-2022-0938-RECR-2

Title: Appearance-based Concerns and Psychosocial Functioning Following Complex Plastic Surgery for Female Melanoma Survivors

Dear Sarah Yates,

Thank you for submitting your ethics application in REAMS, Lancaster University's online ethics review system for research. The application was recommended for approval by the FHM Research Ethics Committee, and on behalf of the Committee, I can confirm that approval has been granted for this application.

As Principal Investigator/Co-Investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licences and approvals have been obtained.

- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress).

- submitting any changes to your application, including in your participant facing materials (see attached amendment guidance).

Please keep a copy of this email for your records. Please contact me if you have any queries or require further information.

Yours sincerely,

Dr Laura Machin
Chair of the Faculty of Health and Medicine Research Ethics Committee
fhmresearchsupport@lancaster.ac.uk

Lancaster University