

ALTERED APPEARANCE AMONG ADOLESCENT CANCER PATIENTS

Title: The perspectives of health professionals on the psychosocial impact of an altered appearance among adolescents treated for cancer and how to improve appearance-related care.

Principle author: Dr Heidi Williamson BSc, MSc, DHealth, is a Senior Research Fellow at the Centre for Appearance Research at the University of the West of England, Bristol, UK.

Second author: Prof Nichola Rumsey BSc, MSc, PhD, is Co-director of the Centre for Appearance Research at the University of the West of England, Bristol, UK.

Corresponding author: Dr Heidi Williamson, the Centre for Appearance Research, Faculty of Health and Applied Sciences, Frenchay campus, University of the West of England, Coldharbour Lane, Bristol, BS16 1QY. Tel: 0117 3281572, Heidi3.williamson@uwe.ac.uk

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Abstract

An altered appearance can impact on the psychosocial well-being of adolescent cancer patients, yet patient reports imply a dearth of appearance-related support. Using a two-phase qualitatively driven mixed methods design, 62 health professionals from a range of UK oncology care settings, provided data relating to their views of the impact of appearance changes on adolescent patients (aged 12-18 years), of delivering appearance-related care, and their training needs. Integrated findings were divided into two main outcomes. The first comprises health professionals' perceptions of the psychosocial and behavioural impacts of appearance-related distress in their patients and their experiences of interventions that prevent or ameliorate appearance concern. The second illustrates personal barriers (among health professionals, adolescents and parents) and organisational barriers that inhibit the delivery of appearance-related support, together with suggestions about how these may be overcome. The needs of patients are extensive and varied, but due to the barriers identified can be poorly addressed. Nonetheless some practitioners are utilising a variety of interventions supported by theory and/or evidence of their success in other clinical areas. Recommendations are made for the content, design and co-ordination of interventions for adolescents and for the content of education programmes to meet the training needs identified by participants.

Introduction

Temporary or permanent changes in physical appearance as a result of cancer and its treatment, such as alopecia, scarring, limb loss, muscle wastage, skin and weight changes, excess body hair and interference with puberty and growth are consistently reported as a concern for adolescents (Williamson & Wallace, 2012). During adolescence an emerging capacity for abstract thinking, egocentrism and strong tendencies to engage in social comparison, increase awareness and preoccupation with weight, shape, physical features and sexual attractiveness (Holmbeck, 2002). The importance of appearance is further amplified by a youth culture that highly values appearance-related attributes (Smolak, 2004). Undesirable changes to appearance therefore place adolescents at additional risk of psychosocial distress, when already facing the extreme challenge of a cancer diagnosis.

Appearance-related concern among adolescent cancer patients has been correlated with decreased self-esteem, worry about sexual attractiveness, depression, social anxiety and avoidance, loneliness, suicidality and problems with treatment compliance (Fan & Eiser, 2009). Reduced self-esteem and social avoidance can persist into adulthood even when changes are no longer apparent (Sundberg, Lampic, Bjork, Arvidson & Wettergren, 2009).

The processes and factors that influence psychosocial adjustment to appearance change among adolescents have received limited attention. In accordance with findings from the wider appearance and body image literature (e.g., Moss, 2005), psycho-oncological research indicates that objective measures of visible difference may be less helpful in predicting adjustment than the individual's subjective assessment of the noticeability and severity of the difference (e.g., Wu & Chin, 2003). Among those who display resilience, social support and acceptance of their altered appearance from their family and close friends appear to be protective factors (Larouche & Chin-Peukert, 2006). Adolescents may also gain from using social skills, including confident responses to put others at ease, humour to deflect negative

attention and the provision of information to others in order to explain their difference (Williamson, Harcourt, Halliwell & Wallace; 2010).

In addition to support from friends and family, adolescents typically develop close and meaningful relationships with the multi-disciplinary oncology team (MDT) and, independently of their family, highly value their role in providing psychological care (Ramini Brown & Buckner 2008). However, reports suggests there may be a gap between current care provision and specific appearance-related support needs identified by adolescents and parents (Tindle, Denver & Lilley, 2009), with health professionals (HPs) overlooking or minimising concerns. Suggestions of inadequate support are substantiated by the observation that there are few, if any, evidence-based psychosocial interventions targeting appearance concerns available for use with this patient group (Jenkinson, Williamson, Byron-Daniels & Moss, 2015).

Explanations for this ‘gap’ are meagre but there are suggestions, from small qualitative studies with various clinical and typically adult groups, that implicit attitudes and assumptions held by both HPs and patients may be inhibiting the provision of appearance-specific psychosocial care. For example, viewing appearance changes from a biomedical perspective may result in HPs lacking cognisance of the psychosocial importance of an altered appearance and, as a result, inadvertently underestimating or dismissing its importance (Rumsey & Harcourt, 2004). In such cases patients can feel inhibited from seeking support for such a ‘trivial’ issue (Konradsen, Kirkevold & Zoffman, 2009) and opportunities to provide support are reduced (Rumsey, Clarke & White, 2003). In addition, lack of knowledge about how and when to deliver appearance-specific psychosocial support and suggestions of inadequate training in this area may also deter HP from initiating support (Shearsmith-Farthing & Alford, 2010).

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Despite HPs being in an excellent position to identify and ameliorate appearance-related concerns, the ways in which they might be actively involved in providing support has received scant attention. This study therefore aimed to gain insight into their views of the psychosocial impact of an altered appearance and factors influencing patient adjustment, and to examine the existing provision of appearance-related care with the intention of identifying ways in which this care might be improved.

Method

This study employed a sequential exploratory mixed methods model guided by pragmatic (Creswell & Plano-Clark, 2007) and critical realist (Bhaskar 1989) approaches. Consistent with the special emphasis within pragmatism on the problem-driven nature of inquiry and learning, the selection of methods were informed by the nature of the research problem. As very little, if any, research has been conducted in this area, an exploratory inductive approach using qualitative methods was given priority. By extending the study to include a quantitative investigation, a more useful, complete and balanced understanding of the problem allowed the findings to be generalised to a greater number of HPs from around the U.K.

In Phase One semi-structured interviews were employed with HPs with a variety of disciplinary backgrounds from a regional paediatric oncology unit, followed by a more structured approach in Phase Two using an online survey to triangulate emergent themes from Phase One with a larger sample. The survey was also designed to determine whether there were differing or additional perceptions among HPs working within other UK MDTs, and the extent to which responses were contextual and influenced by different work practices and support / referral pathways. Ethical approval was obtained from the authors' University.

Participants

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In Phase One purposeful and stratified sampling, with the imperative to collect rich data until saturation occurred, resulted in the recruitment of 14 participants (11 female) with different MDT roles (5 doctors, 5 nurses, 4 social workers/ psychologists) and several years of experience ($M = 13.6$, $SD = 1.8$). In Phase Two, the aim was to recruit participants working within as many MDTs as possible to attempt representation from those experiencing different work and support/referral practices. To achieve this, the Teenagers and Young Adults with Cancer group (TYAC: www.tyac.org.uk) was selected as a conduit to recruitment. The TYAC is a membership organisation that welcomes U.K. and international multi-disciplinary health professionals who care for young people with cancer.

Dissemination of the survey took place via e-mail to its U.K. membership of 250 oncology HPs. Forty-eight participants (92% female) completed the survey: 14.6% were Doctors, 27% Nurses, 10.4% Youth Workers, 10.42% Psychologists and the majority (43.8%) were Social Workers. Participants were asked for information pertaining to their care of adolescents aged 12-18 years, but to preserve anonymity were not asked to specify the hospital or unit in which they worked. However, Qualtrics location data indicated that they completed the survey in 28 locations spread around the UK. Within those areas there is variation in the setting within which adolescents receive care. Teenagers are treated at one of 13 teenage and young adult principal treatment centres. In addition there are about 90 paediatric oncology shared care units based in District General Hospitals that provide care as close as possible to the young person's home. The principal treatment centres decide which elements of specialist cancer care can be delivered in the shared care centres. In addition there are also various 'designated hospitals', commissioned to deliver cancer treatment and support to teenagers and young adults (National Institute for Health and Care Excellence (NICE), 2014).

Procedure

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Phase One participants consented to a single face-to-face audio-recorded semi-structured interview (40-90 minutes long). Questions were informed by the research aims and literature relating to adolescent experiences of appearance changes during treatment, in particular a previous study with adolescents and their parents (Williamson et al, 2010). This study insinuated that while the MDT plays an extensive and important supportive role in young peoples' lives, HPs may vary in their willingness, confidence and / or ability to deliver appearance-related support and that parental views and concerns may influence the attention given to appearance-related issues.

Questions were reviewed by a consultant Oncologist and two senior members of the Centre for Appearance Research (www.uwe.ac.uk/CAR) and explored the health professional's role, their perspective on the appearance changes that concern patients and the psychosocial impact of these changes. Participants were asked to share their experiences and views on providing appearance-related support and opinions regarding how, if at all, appearance-related care might be improved.

Phase Two participants completed an online survey that took 20-30 minutes to complete. Survey questions were based on the Phase One interview schedule and emerging themes identified in the Phase One analysis of interviews. In summary, these indicated that while appearance-related distress can significantly impact on psychosocial well-being, this distress can fluctuate and be exacerbated or ameliorated by various individual factors, in addition numerous barriers and facilitators can influence the provision of appearance-specific support by health professionals. A combination of closed and open-ended questions enabled the collection of qualitative data with the aim of enriching or challenging these themes. The survey was divided in to four sections. The first collected details on participants' roles and experience in the field. The second explored views/experience regarding the impact of appearance change on patients (e.g., What, if any, are the greatest worries or problems

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adolescents experience because of their changing or changed appearance?). The third explored their confidence and experiences of providing appearance-related support and of referring elsewhere for expert support (e.g., Is it your role to provide support? If yes, how confident do you feel? If no, whose role should it be? What help, support or practical interventions do you provide?). This section also included pre-coded questions generating quantitative data with 12 Likert items developed from statements indicative of barriers to care provision identified in Phase One and a six-point scale to determine the extent of agreement (from strongly agree to strongly disagree). For example, “I don’t have time to discuss appearance”; “appearance is not a patient priority”; “patients don’t talk... to protect parents”. Participants were also given an opportunity to express their own views on these statements or add other factors that from their perspective inhibit the delivery of care. Section four asked for respondents’ views on ways to improve care (e.g.: Would you like to know more about how to support adolescents, what type of training would be helpful, do you feel adolescents’ needs are met, and what additional care, if any, might be helpful to the adolescent patient with appearance concerns?).

Prior to its distribution, three HPs cognisant of the Phase One findings assessed the survey for errors, ambiguity and bias. In addition, five non-TYAC members (two doctors and three nurses) tested the functionality of the survey. No modifications were necessary.

Analysis

Phase One data were analysed using inductive thematic analysis (ITA). This approach was selected as no pre-existing theoretical framework was used and because ITA is compatible with critical realist theory and able to summarise key features of a large body of data whilst still able to highlight similarities and differences across participants (Hayes, 2000). The implementation of ITA followed Braun and Clarke’s (2006) five stage process. The findings were reviewed by the second author, with a 95% inter-rater reliability.

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Open ended questions in Phase Two generated extensive qualitative data often in note format, that were analysed using a four stage deductive content analytic approach (Hsieh & Shannon, 2005); useful for survey data and compatible with our aims to validate or extend the theoretical framework emerging from Phase One. The same coder (lead author) re-coded and re-categorised a subset of the data sample to establish construct validity and verify coding decisions. Quantitative data, percentages generated from closed questions (yes or no) and from the Likert items (reduced to the nominal levels of 'accept' or 'reject' in relation to the statements indicative of barriers to care provision) were analysed using SPSS package for Windows version 21. Findings from Phase One and Two were then integrated and interpreted as a whole.

The process of interpreting the entire analysis from a mixed methods design is renowned for being challenging. Mixed methods researchers typically experience uncertainty about the best way to approach the integration of evidence from differing perspectives, including uncertainties about the relative weight that should be given to findings from different methods (e.g., interviews versus survey) and the influence of this decision when findings contradict each other (Bryman, 2007). However, rather than focusing on these issues, Dellinger and Leech (2007) advise researchers to regard tensions and negotiations associated with evidence from differing perspectives as a natural and acceptable part of creating and understanding meaning; their emphasis is on the interpretative nature of finding meanings in data, whether represented by words or numbers. Bryman (2007) also reminds researchers that the linking of analysis should not lose sight of the rationale for conducting mixed methods research in the first place.

Guided by Bryman (2007) the integration of findings was therefore conceptualised as a two-stage process: the examination of convergence, complementarity and discrepancy

between the findings preceded the construction of a theoretical framework of the research problem based on our cumulative and developing understanding.

Findings

Integrated findings are divided into two main outcomes or theoretical frameworks that cut across the findings from the interviews and survey (a strategy for representing integrated findings suggested by Farmer, Robinson, Elliott & Eyles, 2006). The first incorporates health professionals' perceptions of the psychosocial impact of appearance change and details interventions that a minority group of HPs use and believe prevent or ameliorate appearance concerns: this is represented in Figure 1. The second presents a picture of the barriers that inhibit the delivery of appearance-related care and health professionals' views on how some of these barriers can be overcome: this is represented in Figure 2.

Health Professionals' perspectives on the psychosocial impact of appearance change and interventions to prevent or ameliorate concerns.

Eighty seven percent of participants believed that appearance-related distress is common amongst patients when anticipating treatment, during treatment, as well as following treatment and that this is a major challenge: "how they look and how their peers treat them is one of the biggest angsts for most" (Doctor). Participants believed that both girls and boys can experience concerns but boys may be more reluctant to discuss them and therefore appear to struggle less. However, the degree of distress experienced by patients was perceived to vary and fluctuate and, as illustrated in Figure 1, is typically influenced by pre-existing individual differences, expectations of changes, the perceived permanency of appearance changes, physical condition, social circumstances and experiences of personal growth: "it depends on the individual, how confident they are, their past experiences and how they feel about their own body image before treatment" (Nurse). Participants were

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particularly surprised that patients with a terminal diagnosis can also be preoccupied with appearance change: "he's really worrying about these stretch marks and I thought...you know you're dying!" (Social Worker / Psychologist).

Participants felt that at the heart of appearance distress is the experience of looking and being treated differently to their peers, feeling unattractive compared to society's beauty norms and fear of negative evaluation by others, including being teased. For those with extreme or poorly addressed issues, participants observed a psychosocial and behavioural pattern indicative of reduced self-esteem and confidence, together with a failure to access social support leading to isolation, depression and decreased therapeutic compliance: "He wouldn't receive chemotherapy and steroids because of weight gain and worries about being bullied" (Doctor). Contradictions to this widely shared assessment of adolescent experiences were unusual, but nonetheless some participants felt appearance changes were a low priority for patients: "Appearance rarely comes up, few are bothered. I get the impression that they are quite self-contained. There is little impact of what they look like, things like losing hair" (Doctor). Interventions typically focused on providing information to describe the physical impact of treatment. Group activities involving make-up, clothes and wig specialists were appreciated for their ability to provide girls (there was no evidence of an equivalent activity for boys) with skills to enhance and conceal changes and to receive appearance-specific peer support. A small number of participants drawn from a variety of professional backgrounds within the MDT also used a combination of psychosocial interventions tailored to meet individual needs at specific points throughout the patient journey. Techniques included the development of close and trusting relationships with patients and using a person-centred approach to promote discussions about the degree and specific focus of appearance concerns: "Most of what I do involves just listening.... It's also important not to belittle how they feel, that's the biggest thing, allowing them to have their chance to talk about it and express how

they feel about it" (Nurse). For patients, particularly boys, who struggled with verbal expression, some advocated the use of written or video diaries: "I just said 'write down how you feel and about how you look'. He wrote 'I'm pissed off... because I look disgusting'" (Social Worker / Psychologist). Other simple psychological interventions included validating rather than dismissing concerns, identifying positive role models with similar appearance changes (including celebrities) and providing positive reassurance about the adolescent's appearance.

In a few instances more complex interventions were employed, including identifying significant others within the adolescent's social circle who would benefit from education and support to assist the adolescent to manage the social consequences of appearance change when returning to normal social activities: "We worked with her best friend who was with her all the time, and if that best friend couldn't be there another one would be there with her. If people challenged her, they stood up for her" (Social Worker / Psychologist). Some promoted working in partnership and employing goal-setting techniques to meet appearance-related challenges: "We work together, they know what will work, we just gently suggest, and facilitate what they need" (Social Worker / Psychologist). Others taught social skills to help manage difficult social situations and cognitive behavioural techniques to identify and challenge negative appearance-specific cognitions: "She was worried that everyone was going to stare and speak behind her back. I said why do you think that will happen? We talked about what usually happens ...and came up with examples of people responding positively: it's about challenging their thoughts and worries and giving strategies" (Nurse). Forty five percent of participants expressed disappointment at the lack of appearance-specific expertise available via hospital-based psychologists or, in the absence of this service, from family doctors.

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Discrepancies in relation to who should deliver interventions and the timing of their delivery were found. While some believed doctors and nurses should be responsible for delivering medical information and psychosocial specialists responsible for psychosocial interventions, others believed in a multi-disciplinary approach, characterized as: "team awareness/experience and support, so that the young person can choose who they feel most comfortable seeking this support from" (Doctor). Similarly, differences in the style of support delivery were apparent between those who adopted a proactive approach to raising the issue of appearance and those who responded reactively, leaving it up to the adolescent to request support. For example a Specialist Nurse preferred to: "bring it up early on, we need to invest in that discussion to put support networks there, or at least discuss feelings, before changes happen, otherwise problems arise like reluctance for treatment and not taking medicines." Whereas a Doctor felt, "we shouldn't offer support for all to prevent it happening, because it may not happen, and you may end up providing an awful lot of support for something that really isn't an issue. You just have to respond to it." These inconsistencies appear partly responsible for the observation that care is often uncoordinated: "We manage it in a very ad hoc fashion. We assume it's being addressed, but unless someone is allocated to this, it gets missed" (Nurse).

Barriers inhibiting appearance-related care and perspectives on how to improve appearance-related support

The majority of participants (70%) indicated that care falls short of levels they perceive necessary to meet adolescents' appearance-related needs. Participants felt that appearance can be a difficult issue to discuss, particularly in the context of the practical and emotional pressures associated with managing vulnerable young people with a life-threatening disease and their parents. Participants identified a variety of personal and organisational barriers

impeding the identification of appearance-related distress and the delivery of interventions.

A summary of these barriers is presented in Figure 2.

Barriers associated with organizational constraints and reluctance to discuss appearance concerns were identified more frequently than barriers associated with personal competence. However, even when individual participants felt personally competent, they stressed that many of their colleagues were not, and 91% of those surveyed requested education to address deficits in knowledge and to provide strategies to improve care. Participants' suggestions for improvements have been organized into five main areas. 1. *Validating and normalising adolescents' appearance concerns* by raising or encouraging appearance-related discussions via a screening tool or peer support interventions. 2. *Educating parents and significant others* about the psychosocial impact of appearance change and how to provide support. 3. *A co-ordinated plan of appearance-related care* incorporating a tool to assess for appearance-related support needs and providing guidance on how to escalate care and access psychological expertise as required. 4. *Training and education* including information regarding communication and support strategies to address psychosocial concerns and opportunities to share experiences of 'best practice' with experienced colleagues. 5. *A directory of appearance-specific services* and organisations within and external to the hospital.

Discussion

Participants from multi-disciplinary oncology teams across the UK provided evidence of the widespread and sometimes overwhelming psychosocial consequences of appearance distress among patients, indicating their belief that adjustment to appearance changes is multi-factorial and dynamic. Coping ability can fluctuate throughout the cancer journey in response to contextual changes such as increased social exposure or physical symptoms and can be influenced by individual differences and risk factors (Figure 1).

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The data suggest that the tendency in all adolescents to value appearance attributes and to compare and evaluate their own appearance against that of peers and cultural norms is not suspended during the cancer experience. This tendency, in conjunction with fear or actual experiences of negative appearance-related attention from others, was considered by participants to pre-dispose patients to appearance distress. The findings reinforce the value of viewing the psychosocial impact of appearance change from a developmental perspective (Holmbeck, 2002) and the contribution socio-cultural theory can make in identifying the external pressures patients experience as a result of operating within a youth culture that values appearance and stigmatizes difference (Smolak, 2004).

In addition, the Appearance Research Collaboration's (ARC) framework for understanding adjustment to visible difference among adults (Thompson, 2012) may also be pertinent. This framework identifies similar socio-cognitive risk factors for appearance distress among adults to those observed by participants in this study. These included high levels of appearance salience (the centrality and importance ascribed to appearance in the self-concept), a predilection for upward, less adaptive, social comparisons, high levels of self/ideal appearance discrepancy and negative self-evaluations of appearance. High levels of personal investment in appearance (valence) might also account for the 'disproportionate' levels of distress in response to relatively small appearance changes witnessed in some patients. Indications that socio-cognitive factors may account for individual differences in adjustment among adolescents, suggests that screening is appropriate to identify those at risk, rather than relying on the personal assumptions of staff in assessing patient need. Equally, interventions targeting appearance-specific cognitions, for example via cognitive therapy, may also benefit this age-group as they have adults (Clarke, Thompson, Jenkinson, Rumsey & Newell, 2014).

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Fluctuations in appearance distress were frequently observed by participants who also noted that concerns can be minimised when the adolescent prioritises physical effects (feeling unwell and pain), and heightened when social activity resumes and patients inevitably compare their appearance to healthy peers (Russell, Harcourt, Henderson & Marks, 2010). Identifying this as a risky period for distress can inform tailored intervention delivery.

Reports of patients managing their appearance anxiety with avoidance behaviours (e.g., declining hospital visits from friends and refusing school) are of particular relevance to care providers. Avoidance is likely to limit opportunities to develop alternative coping strategies to manage stigmatising reactions to their visible difference (Coughlan & Clarke, 2002) and curtail access to vital family, peer and school support that can help patients manage the appearance challenges incurred during the cancer journey (Woodgate, 2006). Support from key friends has been identified as an important resource to enable social activity (Larouche & Chin-Peukert, 2006) and maintain self-esteem (Dumont & Provost, 1999). Most participants were mindful of the importance of social support but not all were aware of the role appearance distress has in deterring patients from accessing this help.

Participants also provided evidence that appearance-related distress can decrease therapeutic compliance. Kondryn, Edmondson, Hill and O'Brien (2011) have urged clinicians to consider the complex world in which the adolescent patient lives when seeking explanations for why up to 63% adolescents do not fully adhere to therapy. Accounts that appearance concerns can instigate non-adherence and potentially impact survival make it imperative for HPs to tackle barriers that may prevent or inhibit appearance-related discussions and limit access to basic or specialist psychosocial support.

This includes educating those who lack knowledge regarding the potential impacts of appearance changes on patients, expanding their focus beyond the biomedical indices of treatment success, and dispelling the misperception that initiating 'appearance talk' may

exacerbate patient or parental anxiety and that support should be delayed until survival is considered likely (see also Konradsen et al, 2009; Rumsey Clarke, White, Wyn-Williams & Garlick, 2004). Those participants who had expressed a reluctance to initiate a dialogue may have felt ill-equipped to manage psychosocial concerns, perhaps assuming that these require complex psychosocial interventions. In the experience of others, however, often simple interventions are effective, including preparation for appearance change, the validation and normalisation of concerns; the education of peers, family and school, the promotion of effective social support and the provision of strategies to prepare the patient for any negative social responses.

Participants advocating early discussions believed appearance changes were likely to be of concern to patients, while recognizing that adolescents were unlikely to initiate discussions and share worries themselves. For these participants, early intervention was believed to have a preventive effect, providing adolescents with the opportunity to develop strategies to prepare for, control and manage any psychosocial consequences of change. Long-term planning was also considered helpful for patients ruminating about future social difficulties and providing strategies to increase patient control over potentially challenging social interactions (e.g. teasing) was also described as valuable. High levels of social self-efficacy have been reported to moderate appearance distress among adults (Hagedoorn & Molleman, 2006) and social interaction skills training has shown promising results among younger children (Varni, Katz, Colegrove, & Dolgin, 1993).

Even participants who were relatively confident about their ability to support patients with appearance concerns requested additional guidance however, particularly in relation to initiating appearance talk and in identify their patients' specific needs. The Body Image Instrument (Kopel, Eiser, Cool, Grimer & Carter, 1998) may be a helpful tool to stimulate discussions and establish the level and specifics of appearance concern. A few participants

recommended the value of person-centred communication techniques to facilitate discussion and disclosure, and of techniques for patients to explore their feelings in written or visual formats: a practice endorsed by Rickwood, Deane & Wilson (2007).

A minority of participants (predominantly nurses) were successfully utilising cognitive behavioural techniques to identify and challenge negative appearance-related cognitions. These were employed instinctively rather than in a systematic way, but the premise for their use is justified (Thompson 2012; Norman & Moss, 2015). More comprehensive CBT approaches are used by psychologists; however, for units in which this service is unavailable, some of the techniques in Clarke et al's (2014) manual of CBT for appearance-anxiety could perhaps be adapted for use by MDT members.

Some participants believed that parents, motivated by their need to protect themselves and their child from further distress, or by their concern that they lack the knowledge or skills to help, can unintentionally block their child's attempts to share their appearance worries. Williamson et al (2010) suggest that parents can benefit their child if they engage with their concerns and work in partnership to support them as they face social challenges. The same study also identified that some parents need support from HPs to do this and HPs could usefully assess the family's ability to support the adolescent and intervene if required. In this study a small number of Social Workers/Psychologists and Specialist Nurses took time to educate the patient's friends, family and peers about treatment side-effects and strategies for providing effective support to mitigate negative social experiences and bolster the patient's self-esteem. A sensible strategy, as perceived criticism by family and friends exacerbates appearance dissatisfaction (Jones, Vigfusdottir & Lee 2004).

The inability to provide the resources necessary for individualised support was also described as obstructing appearance-related care; lack of time, poor continuity in care and insufficient private areas were frequently discussed barriers. In response, participants argued

that a co-ordinated plan of appearance-focused care led by an allocated member of the team would improve the quality of care.

Limitations that compromise the reliability of the findings of this study include the risk of bias from relying on self-report data and using a small self-selected survey sample. HPs can be unwilling to report accurately on their practice and may be prone to over-estimating their performance. Selecting the TYAC as a sampling frame and the poor response rate increased the likelihood of those responding being systematically different to those not motivated to join the TYAC and not self-selecting to join the study. In addition, although one can assume, from the number of regions represented, that participants worked within a range of oncology services across the UK and within MDTs with potentially different compositions, we did not systematically investigate whether HPs experiences and work practices were influenced by the circumstances within which they operated. Variation still exists in the oncology services adolescents receive in the UK (NICE, 2014) and their access to health professionals with knowledge specific to their psychosocial needs can vary depending on whether they are cared for within Teenage oncology, paediatric or adult units. Further research addressing this limitation is required. Furthermore, although qualitative data suggested that the provision of appearance-related care is dependent on the individual and the perspectives they hold rather than their professional role, this was not investigated systematically.

Nonetheless, participants in this study - those on the frontline of care delivery – have confirmed that addressing appearance issues and concerns is a highly relevant task, and their perspectives regarding inadequacies in the provision of appearance-related care are sufficiently concerning to warrant further research to increase the reliability and generalisability of findings from this exploratory study. Equally, HPs current use of interventions (many of which are supported by theory and evidence to suggest their likely

success but are not employed in a coordinated manner) and suggestions for overcoming the barriers they identify to care provision (see Figure 2) - via interventions, training initiatives targeting appearance distress and improving the co-ordination of care delivery - require further investigation and ultimately evaluation of their acceptability to patient, parent and HP groups.

Patients in particular need to be involved in confirming, refuting or adding to the interventions HPs have suggested and to the framework representing the potential negative psychosocial impact of an altered appearance (Figure 1). Of particular interest would be the views of boys. Our findings suggest that boys have different appearance-related needs to girls that are currently not being met. Conducting research with male survivors to elucidate this finding and to ascertain preferences relating to the type of support and preferred method of delivery is therefore a priority for future research. In addition, HPs requested a brief screening tool to help them predict those with a pre-disposition towards appearance-related distress, in order that they may provide more intense support to those at greatest risk. The dynamic nature of appearance distress would suggest such a tool would not be infallible, but nonetheless it may be of use to direct susceptible adolescents towards higher level interventions early on in the treatment path before appearance changes occur.

In conclusion, our findings suggest further research is required to increase the reliability of the insights and perspectives of health professionals summarized in Figures 1 & 2. However, valuable groundwork in informing the content of educational programmes for HPs and also the design of appearance-related interventions for adolescents treated for cancer has been completed. Health professionals can reflect on these findings in relation to their own practice and experience of caring for adolescents who are anticipating or experiencing an altered appearance.

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