Interventions to Support Patients Affected by an Altered Appearance

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Abstract

Changes to appearance as a result of disease and treatment can be a source of considerable distress for many patients. In this chapter we apply a stepped model of care as a framework to consider the use of psychosocial approaches to support people whose appearance and/or body image has changed as a result of cancer. In doing so, we explore the use of a range of interventions, from societal level approaches aiming to shift attitudes towards appearance amongst the general population through to high level interventions for patients with high levels of distress, delivered by psychosocial specialists with expertise in this field. We also reflect on the challenges facing health professionals and researchers who are looking to provide evidence-based care, and offer suggestions for the future direction of research.

Keywords

body image, altered appearance, cancer, interventions, support

Introduction

Changes to appearance as consequence of cancer and its treatment can be a constant reminder to the patient of their diagnosis, and an indicator of their condition to other people. These changes may be temporary (such as pallor associated with severe anemia and hair loss during chemotherapy) or persist after treatment (for example, scarring). Medical and surgical advances in recent years have increased the range of treatment options and, in some instances, procedures that aim to 'improve' appearance and restore form and function are now available (for example, numerous surgical options to recreate a breast shape after mastectomy). However, these developments in treatment are not a panacea for the appearance-related distress that many patients experience. There is, therefore, a need for psychosocial support and body image interventions alongside medical and surgical treatment.

As we have seen previously in this text (***Editors – please add cross-reference to our chapter on altered appearance here***), many individuals who have been diagnosed with cancer find themselves preoccupied by the changes to their appearance and/or functional aspects of their body image because of the challenge to their own identity and the scrutiny and unsolicited interest provoked in other people when appearance changes are visible to them. Often their concerns are dismissed by other people as inconsequential ("*you'll get used to it*") or the legitimacy of their concerns is challenged ("*just be thankful that the cancer has been successfully treated*") or they are unaware that effective interventions to support people affected by appearance-related concerns are available. ("*there's nothing we can do about that: it's all up to you now*"). However, over recent years, considerable progress has been made in better understanding how appearance-related concerns and body image issues arise,

under what circumstances they can be problematic, and the ways in which psychological intervention can be helpful.

Systematic reviews of interventions to support adults and young people affected by an altered appearance or visible difference of any kind, including those resulting from cancer, have highlighted the dominance of Cognitive Behavioural Therapy (CBT) and Social Interaction Skills Training (SIST) in this field to date. [1-4] In addition, a systematic review of 24 body image interventions specific to women treated for breast cancer identified 7 that had significantly improved body image either in the short term or at follow-up, [5] several of which centred around physical-activity. [6-8] However, these systematic reviews have all highlighted methodological limitations, including small sample sizes, questionable suitability of control/comparison groups and outcome measures, and limited use of randomized controlled trials, which have made it difficult to draw definitive conclusions about the effectiveness of the interventions under consideration.

In this chapter we consider the use of psychosocial approaches to support people whose appearance and/or body image has changed as a result of cancer, and reflect on the challenges facing health professionals and researchers who are looking to provide evidence-based care. We also refer to interventions that are looking to support patients making decisions about reconstructive surgery that aims to restore their appearance, since these procedures have been referred to as 'body image surgery'. We have not included physical activity approaches since they are not typically delivered by mental health specialists. Further, some previous evaluative studies have identified possible adverse consequences from physical activity, in relation to injury and worsening of fatigue, both during and following active treatment for cancer. [9,10]

When contemplating how to organise this chapter, we considered a number of viable approaches. Using a biomedical approach would involve considering different types of cancer, individually, and possible interventions to address the specific psychosocial difficulties associated with each one. This would have the advantage of allowing varying functional difficulties to be considered; it is important to acknowledge that for some diagnoses, such as those affecting the head and neck, changes in appearance are closely allied to changes in function such as speech and eating. However, whilst this biomedical approach would be valid, it would be unduly lengthy and repetitive since many of the appearance-related issues facing cancer patients (for example, managing other people's reactions to an altered appearance) are common, irrespective of their specific diagnosis. In contrast, a generic approach such as that proposed by the British Psychological Society's Division of Clinical Psychology Faculty for Oncology and Palliative Care (SIGOPAC) recommends that all cancer patients, irrespective of specific diagnosis, could benefit from support and treatment for common issues including anxiety, depression, coping with functional change, uncertainly of prognosis, and treatment decisions[11]. Again, this could be a useful structure, but both of these approaches have been well described elsewhere and would limit the opportunity to focus specifically on altered appearance, in depth. Importantly, previous research suggests that targeting risk factors specific to body image is more effective than targeting general stress-vulnerability factors[12] and the largest study to date of factors and processes predicting adjustment to visible difference[13] also concluded that interventions aimed at appearance-specific constructs will be more effective and beneficial than general psychosocial interventions.

We have therefore chosen to focus this chapter on appearance-specific interventions and to structure it in terms of the stepped care framework developed by members of the Centre for Appearance Research at the University of the West of England, Bristol in the UK. [14] Figure 1.1 (below) illustrates the CAR Framework, edited to demonstrate both generic and cancer-specific interventions. Stepped care models such as this, where interventions become more intense as one moves up the framework, are common in other areas including support for depression or eating disorders (Bower & Gilbody, 2005). The UK's National Institute of Clinical Excellence (NICE) offers stepped care models for mental health, such as general anxiety disorder or panic disorders, with all suspected presentations of the condition at step one (with recommended interventions at this level including information and assessment), through levels of ascending severity to the most severe presentations at level 4 (highly specialized interventions). NICE guidelines propose that an individual starts at the lowest step possible (with the least intrusive interventions) and progresses through each step sequentially, if needed. In contrast, the CAR framework suggests that people may begin at any level on the pyramid and move fluidly through the other levels as required.

Whilst an established framework such as the NICE stepped care model could have been used in the current context, we recognize the benefits of a more targeted, appearance-specific approach and therefore use the CAR framework to illustrate a range of appearance-specific interventions deemed suitable for a variety of cancer diagnosis, highlighting whether these are cancer-specific or for people with visible differences more broadly. We believe this framework will be a useful starting point for clinicians working with cancer patients, since it considers the differing needs of individuals with appearance concerns.

<Figure 1.1 here>

The CAR Framework of Appearance-Related Interventions

The CAR framework is a stepped model of care summarising interventions for populations of people experiencing distress due to an altered appearance or visible difference of any kind. In other words, it is not cancer-specific. It is worth stressing that our use of this framework does not imply that everyone who experiences an altered appearance as a result of cancer will require all the interventions at every level of the framework; some people are not unduly worried by the changes to how they look and may see these as a manageable 'price to be paid' for treatment of their cancer. In other words, people with low appearance investment, and those considered to demonstrate positive growth from the experience may not be particularly troubled or distressed by changes to their appearance.

The triangular shape of the framework is a useful descriptor since the numbers of people represented is smaller at the apex whilst the expertise and training of those delivering the interventions here is greater (i.e. far fewer people are likely to require specialist one-to-one interventions delivered by a highly trained psychosocial specialist (level 5) compared with the numbers who could benefit from targeted information available in clinics (at level 1)). Level 0 interventions in the framework are intended to inform the general population. Level 1 interventions are targeted to a specific patient group; such interventions can be useful for patients with lower levels of appearance distress, and may offer benefits more broadly to a given population. Interventions at levels 2 and above are designed for those who experience body image distress, or worry or ruminate about their altered looks and body image, and whose day-to-day lives are negatively impacted as a result (the psychosocial impact of an altered appearance is considered at length in chapter X [***note to Editors, please cross-***

reference to our chapter on altered appearance] of this volume). This framework can be used to summarise ways of supporting people to overcome challenges associated with appearance and body image issues, and to promote positive adjustment, acceptance by others and diversity of appearance. Social interaction skills and CBT are evident at all levels, and whilst there is good evidence for the effectiveness of these generally and specifically with people experiencing body image distress, [1,15-17] large scale trials comparing different approaches in an oncology setting are still needed.

We now consider interventions at each level of the CAR framework, starting with the most general, lowest level (level 0) and moving up the triangle to the most intense, which warrant specialist support for patients with complex needs.

Level 0 – General Population and Societal Campaigns

Societal interventions (level 0 on the framework) aim to promote understanding and acceptance of diversity in appearance, with the expectation that people whose appearance has altered might be less troubled by how they look, and receive less attention about it from others, if society was more accepting and placed less importance on appearance and idealised images of beauty. Both traditional (TV, press, radio) and social media have a significant role to play at this level. The depiction in the media and elsewhere of people who have been diagnosed with and treated for cancer often involves images that rely on visible changes to appearance (typically hair loss) in order to indicate the presence of the disease, but this can raise some dilemmas. For example, charities that seek to support people affected by cancer and/or fund research in this field often use images of women and young people with chemotherapy-induced alopecia when seeking to raise funds for their cause. Whilst this may

prove financially fruitful, some may argue that such images can also reinforce the view that an altered appearance due to cancer treatment is a fundamentally negative experience and an indicator of a person's diagnosis. This might be the case for many patients, yet many others manage the challenge of hair loss and other appearance changes very well and resent being identified and labelled by virtue of their appearance.

The UK charity Changing Faces campaigns to promote acceptance of diversity of appearance and to challenge negative attitudes towards people who look in any way different from 'the norm'. The charity's activities aimed at the general public are examples of level 0 interventions. For example, campaigns that have involved posters displayed on the London underground included a woman who had acquired a facial disfigurement as a result of cancer treatment, alongside text that encouraged the viewer to treat them in same way as they would any other person (for example, a message that read "*I know you're dying to ask what happened to me, but don't make it your first question…. You'll also realise, like all my friends do, that once you've got to know me, you won't see my disfigurement anymore*"; see Figure 1.2) with the aim of changing attitudes and promoting positive acceptance rather than stigmatizing behaviours such as avoidance. These posters were particularly powerful since they were displayed where there would usually be adverts for beauty products and clothing, with digitally enhanced images that could be heralded as examples of the unattainable beauty ideals typically promoted by the media. These idealized images will never be achievable for most people, including those whose appearance has shifted even further from these ideals because of the impact of cancer treatment. More recently, the charity's 'Face Equality' campaign has aimed to work with the media to try to inform the public about, and change negative attitudes towards, people with a visible difference of any sort. [18]

<Figure 1.2 here>

Breast Cancer Care, the largest UK-based charity specifically set up to support people affected by the disease, ran a body image campaign which included a video of women talking about their experiences of body image after breast cancer. [19] This resource, available through the charity's website (www.breastcancercare.org.uk/body), is a level 0 intervention since it can influence the general public's views and understanding of the impact of appearance changes for those affected.

Social activism campaigns, defined as intentional actions aiming to bring about social change, are further examples of level 0 interventions. These often employ social media as a powerful tool to deliver and promote messages and change. For example, in 2014, images of an Australian woman, Beth Whaanga, made international headlines for revealing the impact that hysterectomy, mastectomy and breast reconstruction scars, and weight changes and hair loss had had on her body since she was diagnosed as having breast cancer. The reactions and comments about these images were both positive and negative, with some people expressing their discomfort with seeing changes to appearance that were being graphically revealed but are usually hidden from public view. The subsequent campaign (https://www.facebook.com/underthereddress) aims to achieve respect for people with cancer, awareness of what they are going through and positive body image amongst those affected, under the slogan "*scars aren't ugly, they mean you're alive*".

Whilst interventions at level 0 can aim to change societal attitudes, evaluating their impact and effectiveness can be challenging and many have not been the focus of rigorous research. This is needed, to ensure that there are no unexpected consequences of these

interventions. For example, a small focus group study of reactions to some of the Changing Faces posters found that some people felt they were being somewhat accused of negative attitudes and behaviours that they did not consider themselves to have. [20]

There is clearly a place for interventions at the general population/societal level, but even if they were to change some people's attitudes, they would be unlikely to remedy all the concerns that cancer patients have. Interventions offering support at an individual or patient group level are still needed.

Level 1 – Information Provision through Targeted Campaigns

Interventions at this level are targeted towards specific populations (such as patient groups) rather than particular individuals on the basis of their specific assessed need. These should be easy for patients to access and for health professionals to provide or direct patients towards, and may be sufficient for patients who have a low level of need. Examples of interventions at this level include condition-specific leaflets and websites providing information, advice and techniques. However, like any intervention involving information-provision, it is important that they are reviewed regularly and kept up-to-date.

At this level, it is relevant to incorporate support for body image and appearance changes as part of routine care for all cancer patients and encouraging an ethos of care in which these are given the recognition they deserve. This includes ways of identifying those in need of support (considered later in this chapter), providing pre-surgical information about how appearance or functioning might be altered by treatment and ensuring that all patients are prepared for significant events such as seeing the results of surgery that has changed how they look, rather than letting this occur in an ad-hoc, unsupported manner. However, despite

the number and variety of resources at this level, there is a lack of evidence to support their effectiveness in reducing patients' appearance-related distress.

Online resources offering easy access to other patients' experiences fit this category of intervention. In some instances, patients' experiences are the primary focus of the resource. For example, the website Healthtalk Online provides information about a range of health issues through videos and audio recordings of people's real life experiences, including those associated with changes to appearance due to different types of cancer and treatment (http://www.healthtalk.org/peoples-experiences/cancer). Elsewhere they are included as a single component within broader resources, such as those aiming to support patients through treatment decision making. For example, the online breast reconstruction decision aid BRECONDA,[21] includes video clips of women talking about how they made their choice about surgery. Research has examined both the benefits and possible negative impact on patients of hearing about other people's first-hand experiences, and of contributing experiences themselves. [22] For example, patients may find valuable information which can serve to alleviate fears, and inform treatment decisions and coping strategies. However, if the experiences are biased, inaccurate, or atypical, the information may be distorted, and potentially lead to patients making worse decisions. Similarly, whilst hearing about others' experiences and contributing their own can help patients feeling connected to and supported by others who are facing similar difficulties, this may also evoke feelings of anxiety or despair, or perhaps even guilt an inadequacy if others appear to be coping better.

Web-based resources provided by cancer charities also offer self-help psycho-educational material concerning treatment-related appearance changes. UK-based Macmillan Cancer Support provides information and practical advice regarding cancer treatment and camouflage, in addition to psychological strategies to help manage appearance-related

anxiety, unhelpful thinking, and the reactions of others. Similarly, Breast Cancer Care (www.breastcancercare.org.uk) provides a downloadable 'Moving Forward' pack containing information on a wide range of issues which may arise following treatment. It includes three pages specifically addressing body image concerns, and signposting women to other parts of the pack which discuss the use of a prosthesis and clothing. While these online self-help sources of psycho-educational body image guidance may be helpful, to our knowledge, neither have undergone rigorous evaluation. Regarding similar interventions for other cancer groups, a pilot test was conducted of a psychoeducational booklet for patients undergoing treatment for oral cancer. [23] A multi-disciplinary group of health professionals developed the booklet, which was reviewed by patients themselves before pilot testing. It contained information about the cancer and treatment, in addition to effective coping strategies, including ways to help manage appearance concerns, particularly when in social situations. The booklet was found to be acceptable, and significant improvements in body image were identified among the intervention group 3 months later compared with a control group.

Activities and resources aimed at targeting an entire school system, rather than at patient groups, are further examples of interventions at this level. For example, young people who are treated for cancer are likely to be away from school for a considerable period of time. Returning to school can be a worrying time, particularly for those whose appearance has altered considerably as a result of the treatment they have undergone. This can be particularly difficult for those in adolescence, a time in life where appearance is typically very (if not *the most*) important issue for young people. [24] Advising all staff at the school (including, for example, catering staff, school nurses, caretakers, and not only the child's teacher) on how to support the child appropriately, how to respond to other children's questions, deal with bullying and teasing, and how to facilitate their successful reintegration

without drawing further attention to their altered appearance or reinforce negative stereotypes are examples of whole school, level 1 interventions (see, for example, the resources for use in primary and secondary schools available through the charity, Changing Faces https://www.changingfaces.org.uk/resources/education). Alongside these whole school interventions, re-entry programmes that support the young person themselves in developing skills to help them deal with the questions and attention they may attract when they return to school,[25] could be useful in this instance. This example of a level 1 and higher level intervention being used in combination to support a young person both individually and by educating and supporting those around them, is an interesting illustration of the need to consider the impact of cancer on body image from a range of perspectives and in terms of a mixed economy of intervention. However, the limited research demonstrating effectiveness of interventions at this level has been highlighted previously. [12,26]

Level 2 – Self-Administered Interventions without Specialist Input

Level two on the CAR framework includes stand-alone, self-administered interventions that do not involve "specialist" (i.e. a fully trained, highly skilled practitioner working across the whole area of body image) input in their delivery. Interventions at this level target individuals for whom brief psycho-educational material will not suffice, but are not in need of individualized intervention to address their body image concerns. Such individuals may require support in form of support groups led by other patients that are educational or supportive in nature, or self-help manuals, such as "The Body Image Workbook[27]", which are written by specialists, but are self-administered. Whilst potentially helpful, interventions of this nature do not tend to be evaluated for their effects.

Other interventions at this level which have undergone evaluation include behavioural camouflage-based interventions. Many patients who have lost, or fear losing, their hair during chemotherapy choose to wear a wig in an attempt to restore their 'normal' appearance and sense of self, [28] avoid the reactions of other people and save themselves and others any awkwardness or discomfort about their appearance. Interventions aiming to support patients affected by hair loss, for example through workshops delivering advice and techniques on using make up, wigs, hats and headscarves, are widely available and, therefore, often easily accessible for many patients. For example, the Look Good Feel Better intervention (www.lookgoodfeelbetter.org) aims to improve self-esteem and quality of life of people undergoing cancer treatment. Workshops are delivered by beauty professionals who volunteer to teach small groups of people how to use makeup, wigs, and skin and nail products in an attempt to disguise any changes to appearance (including the loss of eyelashes and eyebrows) to improve how they feel about their appearance and reduce feelings of stigmatization. A significant improvement in self-image, social interaction and anxiety was reported after attending a single workshop[29] but was no longer evident two weeks later. Further, an intervention which taught a sample of patients with oral cancer (over 90% of which were men) to apply camouflage makeup was found improve satisfaction with two items on the Body Areas Satisfaction Scale (the face and body weight) 3 months later. [30] Similarly, HeadStrong is a volunteer-led service provided by Breast Cancer Care in the UK offering advice on scalp care, and the use of hats and headscarves to disguise hair loss as an alternative to wigs. A small qualitative study found that women valued the opportunity to learn a range of techniques to cover their alopecia and described the sessions as being helpful, but not necessarily meeting all their needs. [31] In particular, they still felt a need for emotional support to help them manage their feelings about hair loss.

Methods such as these that rely on camouflage-based techniques can be useful additions to a varied toolbox of interventions for any patient, so that they are confident in using an array of strategies depending on the particular circumstances and issues they are facing. However, camouflage-based approaches can become problematic if a person is over-reliant on them to the extent that they unable to continue with normal day-to-day activities without them. Furthermore, relying on covering up or disguising changes to appearance means that an individual is faced with the challenge of how and when to 'reveal' their altered appearance which may become a particularly stressful issue, for example in the context of establishing new intimate relationships.

Recently, researchers explored the use of an expressive writing exercise (a widely used therapeutic approach with a long track record of effectiveness with other patient and non-patient groups), incorporating principles of mindfulness (which has been shown in previous studies to benefit people with body image concerns) and compassion-focussed therapy (including self-kindness, mindful awareness, and a sense of common humanity), as an intervention for women treated for breast cancer. [32] They reported improved body image attitudes amongst women who were given self-compassionate-focused prompts to write about their thoughts and feelings about their bodies, compared with those who wrote about their bodies without any structured guidance. This study shows the potential for an easily accessible, self-administered paper-based intervention of this sort, which could be adapted for testing with other cancer patient groups.

Level 3 – Self-Administered Interventions Facilitated by a Trained Professional

Interventions categorised as being at level 3 involve the input of a trained professional (i.e. a health professional from differing backgrounds who has mental-health training), alongside self-administered support, and can be delivered one-to-one or in a group format. Interventions at level 3 target patients who experience a degree of body image concerns which cannot be addressed by behavioral camouflage approaches nor self-help materials alone, but do not require the support of a fully trained practitioner with expertise in body image issues.

As one example of a level 3 intervention, a 2-day social interaction skills workshop for people with a variety of visible differences was shown to improve self-reports of social avoidance and distress, and confidence in meeting strangers and new people. Participants exchanged and practiced ideas for managing common experiences such as staring and negative comments, planned a series of graded exposure tasks and shared progress at a follow up session (for more detail see Robinson et al. 1996)[17] These improvements were sustained at 6 week and 6 month follow up. This study included participants with visible differences that were a result of cancer treatment, although the small sample size precluded an analysis of the benefits of the intervention for different patient groups and the lack of a control group is a further limitation. However, the significance of this study should not be overlooked since it informed the development and evaluation of future interventions in this field. Similarly, a specialist nurse-delivered social rehabilitation programme for head and neck cancer patients was found to decrease social embarrassment and consequently improve social functioning. [33] However, this study was limited by its small sample and absence of a control group.

Further examples of level 3 interventions aimed at women with breast cancer include a nurse-led informational and emotional consultation, evaluated in a controlled study. [34] The intervention comprised of a two-hour face-to-face session pre-operatively, followed by

another session over the telephone 3 days after surgery. The consultation provided information and support relating to the disease, the treatment and prognosis, and appearance changes following surgery. No significant improvements in body image were reported immediately, but delayed positive effects were seen at 2 month follow-up, whereby women felt less self-conscious, more feminine and sexually attractive, and less dissatisfied with their body, appearance, and scarring . Furthermore, an RCT evaluated an 8-week group intervention covering topics including body image, relationships and sexuality, delivered by a variety of expert health professionals. [35] Positive effects on body image were seen at both post-intervention and 6 month follow-up. In the UK, the charity Breast Cancer Care currently offers a four week half-day course as part of its 'Moving Forward' programme (see also above). Delivered by a range of experts, it provides information, support, and guidance on topics including healthy eating, exercise, cancer fatigue, menopausal symptoms, lymphedema, and intimacy and relationships in order to help women adjust to life following completion of active treatment. Body image is explored briefly during the last topic. A non-controlled 2 year evaluation demonstrated improvements across several domains, including confidence and reassurance. [36] Despite these promising findings, a greater focus on body image than what is currently provided in the 'Moving Forward' course may be needed.

Patients undergoing cancer treatment often face difficult treatment decisions that can affect their body image. The PEGASUS intervention provides an example of a level 3 intervention to facilitate decision making about breast reconstruction after mastectomy., This intervention uses a one-to-one goal-focused approach to help trained professionals (coaches) support women in clarifying their expectations and priorities about surgery ahead of a consultation in which the decision about treatment is made as a shared endeavor between the patient and surgical team. [37] This approach has been well received by clinicians and women contemplating breast reconstruction, [37] and the effectiveness of the intervention in terms of

patient satisfaction with decision making and the outcome of surgery, and body image, will be determined when ongoing trials are complete.

Amongst the challenges in delivering any face-to-face intervention that involves an element of professional input are the cost and time involved for both the therapist and patient. An additional challenge when providing support for people with cancer who are reporting social anxiety as a result of appearance-related concerns is that travelling to appointments and/or taking part in a group intervention could raise anxieties around being the focus of other people's attention and meeting strangers. Furthermore, some cancer patients find it difficult to seek support and take part in interventions that are provided in settings they associate with their diagnosis and treatment. Researchers have therefore explored the possibility of providing intervention at this level in ways that are more convenient for patients and do not involve face-to-face contact. This work has tended to revolve around the development of online interventions, offering the ability to access interventions at a time and place that suits each individual. However, it is imperative that any new type or mode of delivering an intervention is rigorously tested to ensure it is both acceptable and feasible to deliver support this way.

To date, online interventions have usually been based on a cognitive behavioural (CBT) model, and are proving to be both acceptable to users and effective in generating and maintaining change. For example, the online Face IT programme specifically supports adults with an altered or unusual appearance of any kind. [38] It is based on a CBT model used for face-to-face interventions and comprises of 8 modules, including sessions on body image anxiety, graded exposure, social skills training and self-monitoring of outcome. Initially, a health professional was on hand when Face IT was being used in a clinic setting, to help with

any technical problems if they should arise and clarify any issues raised in the programme that were not clear. However, users (including those who were unfamiliar with using computers prior to the study) reported high levels of acceptability. Data of effectiveness was determined by a randomised trial comparing Face IT users with a group having therapy as normal. [38] The sample included adults with a range of disfigurements, including some with cancer. Both the intervention and control groups showed considerable reduction in anxiety and increased confidence in their own ability to manage their condition. Most importantly, changes in the intervention condition at six months were not only maintained but increased, suggesting that people continued to use and benefit from the skills and approaches they had learned. Notably, Face IT compared favourably with the face-to-face approach delivered by highly trained health professionals, demonstrating that some interventions might be delivered in a more cost-effective yet still appropriate manner. This programme has since been further modified for remote use (http://www.faceitonline.org.uk).

The success of Face IT for adults led to interest in its possible use with young people. Health professionals and young people aged 12-17 years with a range of visible differences welcomed the prospect of an online intervention specifically to support those whose lives were being negatively affected by anxiety associated with their appearance. [39] However, it needed to be adapted to meet the specific needs of a younger population and to make it appealing and engaging for them. The subsequent intervention (YP Face IT – www.ypfaceit.co.uk) consists of 7 weekly interactive sessions aiming to reduce appearance-related difficulties through advice and by teaching coping skills based on CBT and social skills training. Initial feasibility work has reported very positive feedback from young people, their parents and health professionals alike, [40] but, at the time of writing, a full randomized trial to evaluate it against treatment as usual is still needed.

Example of a level 3 intervention:

Tim lost an eye as part of his treatment for cancer as a child. He was settled into a small community where most people knew him, and he experienced few difficulties until he went to university in a large city. At this stage he felt shy and unused to people staring at him. His fear of negative evaluation increased to the point that he found it easier not to socialise and became isolated. Completing the online Face IT programme (discussed above) allowed him to consider other explanations for people's responses to him and to challenge his belief that they thought him 'odd'. Approach strategies based on good social skills were tested gradually and his confidence increased. At the end of the programme he reported reduced anxiety and had formed a group of friends that he regularly went out with. Six-month follow up showed that he had continued to make gains.

Level 4: Support Delivered via a Specialist

Support at this level could be provided face-to-face or at a distance via telephone or e-mail support, and either one-to-one or in a group setting. Key differences between level 3 and level 4 interventions, is that the latter are for patients with a greater level of need and are delivered by specialists with expertise around psychosocial support specifically for people affected by body image-related distress. Level 4 interventions may be warranted, for instance, in patients with high levels of preoccupation about appearance or functional changes, who are highly avoidant of viewing themselves in the mirror, frequently engage in social isolation due to body image concerns, or have high levels of relationship distress. Specialists delivering interventions at this level could include a clinical psychologist,

psychiatrist, counsellor or social worker with specific training and experience in body image-related issues, as opposed to a professional with only generalized training in the delivery of mental health interventions.

The benefit of CBT-based support for women who have undergone treatment for breast cancer has already been demonstrated by interventions at lower levels of the CAR framework. Many interventions at level 4 also use CBT but, importantly, they are delivered by a psychosocial specialist. For example, a controlled evaluation of a 14 week group-based CBT intervention delivered by two psychologists reported significant improvements in body image among women who had undergone surgical treatment. [41] These positive effects were maintained at 6 months follow-up. Body image was addressed in five of the sessions that explored concerns relating to altered appearance, presenting oneself to others, changes in sexuality, and facilitating self-acceptance.

Variations of CBT have also been used as a basis for other interventions at this level. For example, a group intervention using Rational Emotive Behaviour Therapy (REBT, a form of CBT) specifically targeted body image among women who had previously undergone a mastectomy. The psychiatrist-led intervention was shown to have large positive effects on body image. [42] Sessions focused on adaptive skills, problem solving, and muscle relaxation, and participants were required to complete between-session tasks at home. Nonetheless, the absence of a follow-up evaluation impedes understanding of the long-term effects of the intervention and, although the study was controlled, other aspects of the methodology were less rigorous (e.g., randomisation was not conducted and there was no blinding of the participants, facilitator, or outcome assessor), so these findings should be interpreted with caution. In contrast, a more methodologically rigorous study evaluated a

group-based mindfulness and yoga programme among women with breast cancer. [7] Two-hour sessions based on a mindfulness-based stress reduction programme were delivered by two clinical psychologists for 8 weeks. Whilst body image was a secondary outcome of the intervention, large post-intervention effects were reported on the body image of women in the intervention group, but this improvement was not maintained two months later.

Couple-based interventions at this level have also demonstrated potential for improving body image [***note to Editors, please cross-reference to the chapter on couples]***. For example, a randomized controlled study evaluated 'CanCOPE', a psychologist-delivered intervention for couples within which the woman had been diagnosed with breast or gynecological cancer. [43] Information and counselling aimed to help couples conjointly cope and support one another, by teaching communication and partner support, in addition to sexual counselling. It was delivered across five two-hour sessions in the couples' homes and two additional 30-minute telephone calls. However, while the intervention was found to increase women's perceptions of their partners' acceptance of their body, it did not significantly improve their own self-acceptance of it.

An additional example of level 4 intervention is the programme of support offered by the UK charity Changing Faces (see www.changingfaces.org). Managing people remotely via e-mail or telephone calls, highly trained specialists offer informed pragmatic support for people reporting appearance-related anxiety, including those diagnosed and treated for cancer of any kind. Beyond the UK, organisations such as The Sunshine Social Welfare Foundation in Taiwan provide specialist support for people with a range of disfigurements. In 2011, 65% of the charity's clients were oral cancer survivors (source: https://www.sunshine.org.tw).

Example of a level 4 intervention:

Martha telephoned a charitable support organization specializing in psychosocial support for people affected by an altered appearance following surgery to remove a basal cell carcinoma on her nose. Unfortunately her treatment resulted in the removal of a significant lesion so that she now described herself as having a large facial disfigurement. She was reluctant to leave the house, feared the comments and questions of others and could see no way in which she could assume her former lifestyle including job and family responsibilities. Working with Martha, the specialist therapist provided written information outlining common responses to her condition and typical approach strategies that other people with a similar disfigurement had found helpful. Together they agreed on a graded programme which she could use to tackle her fears, one step at a time. Details of Martha's progress were recorded and sent back to the therapist by post. Gradually she recovered sufficiently to attend a two-day workshop run by the charity, where a group of patients shared experiences and worked on developing new skills for managing their condition, with a particular focus on dealing with unwanted intrusions or comments from other people. Armed with a set of strategies that she had developed and practiced over time, Martha successfully returned to her previous employment.

Level 5: Systematic Specialist Led Therapy

Levels 4 and 5 of the framework both refer to interventions delivered by psychosocial specialists trained to support people with body image distress. However, level 5 interventions

are delivered face-to-face by fully trained practitioners with additional years of experience who are capable of supporting patients with the highest level of complex needs or comorbidities. Patients in need of interventions at level 5 could include those with suicidal ideation, debilitating levels of anxiety or depression related to body image changes, inability to make treatment decisions that affect body image, or those with traumatic responses to body image-related treatment changes. These patients are likely to require support from a multidisciplinary team, and may also require psychotropic medications.

A psychologist, psychiatrist, or counsellor with specialized body image training providing interventions at this level would use an established model of therapy with a good evidence of effectiveness in managing body image and appearance related concerns. The CBT-based manual developed by Clarke and colleagues, [44] was underpinned by the framework developed from a study of 1265 adults with a range of visible differences, [45] together with examples from clinical practice and relevant components from Clark and Wells' classic model of social phobia (particularly with regard to the management of rumination). [46] The manual describes session-by-session outlines as examples of working with body image problems, which could be adapted to meet the needs of individuals with any type of cancer. First, an assessment of the individual's body image anxiety is made in order to understand the extent to which they are affected by appearance-related concerns as a result of cancer and its treatment. This assessment contains three key factors:

- The discrepancy between the individual's current appearance and what they consider to be 'ideal' or acceptable. Note that it is the discrepancy between *subjective* ratings and ideals of appearance that is important. The *objective* appearance as ranked by observers often bears no relationship to the assessment of appearance made by

patients themselves. This fact can be bewildering to health professionals and relatives who tend to offer reassurance that '*it doesn't look too bad'* or *'you look good'*. Clinical experience also suggests that psychological adjustment to a change in appearance lags consistently behind the physical process of scar maturation and healing, so that people may still feel very preoccupied with appearance change whilst health professionals and relatives are reassuring them that their wound has healed and they look okay.

- The value they place on appearance. Where appearance is generally not regarded as important, the impact of appearance change tends to be less. This is unrelated to age or gender.
- The impact of appearance-related concerns on cognitions, feelings and behaviour on day-to-day life.

After establishing a shared understanding of the rationale for intervention, the therapist then works with their patient to modify the factors identified in the assessment and reduce the impact of the appearance change. Targeting and challenging beliefs about appearance is achieved largely through a focus on recognizing/ changing maladaptive behaviour, building social skills, using graded exposure in social settings and using the results of these behavioural experiments to modify prevailing beliefs and underlying assumptions. This approach, laid out in the manual, has been widely used by clinical psychologists, but has yet to be evaluated.

Example of a level 5 intervention:

Elizabeth was referred to an experienced clinical psychologist with expertise in appearance-related issues following her diagnosis of breast cancer and treatment that included a mastectomy. In a careful, in-depth assessment, the psychologist established that Elizabeth's anxiety centred on the appearance of her breast whilst she awaited reconstructive surgery and the excessive weight that she had put on as a result of chemotherapy. She felt that no one recognised her and that her appearance meant that she was no longer the person she had been before her illness. Thus her body image anxiety led to a challenge of her core beliefs about who she was and whether she could function in the way that she had done previously. Because of this loss of confidence, she no longer felt able to have an intimate relationship with her partner or to return to work, and was fearful that she would lose her job. The psychologist then worked with her to set out a formulation of her difficulties and to explain how the different emotions, beliefs and behaviours that she experienced made sense given her history. Over a period of several weeks they challenged her fears that she could no longer function by agreeing on specific tasks that she would complete at home, strategies to support the gradual resumption of intimacy and tackling her weight management issues through graded exercise and use of food diaries. This was then fed back into the formulation to challenge her beliefs and revise her expectations about herself. At the end of therapy she was less preoccupied with her weight, was able to be more accepting of the appearance of her breast, resumed an intimate relationship with her partner and had returned to work on a gradual re-entry programme, describing herself as much more confident about making a full recovery.

Using the CAR framework has helped demonstrate a range of interventions that could help to meet the needs of cancer patients with varying levels of appearance-related distress. However, evidence-based interventions are not necessarily available or easily accessible to those who may benefit from them. Amongst the possible reasons for this are a number of issues which we believe health professionals and researchers could address. We consider these in the following sections.

Considerations for Health Professionals

It has been suggested that health professionals may not appreciate the importance of addressing appearance concerns with cancer patients, or perhaps are unsure of how to broach the topic with them. [47-49] In addition, the time restrictions on individual consultations during busy clinics can make it extremely difficult for health professionals to assess individuals' needs. [50] This highlights the role for education and training in how to discuss appearance issues appropriately with patients. Yet, whilst raising health professionals' awareness and understanding of the potential impact of appearance and body image issues is key, it is important not to overgeneralise the negative experiences reported by many cancer patients and to assume that all patients with cancer have concerns about their appearance. Knowing when and how to intervene is imperative, since many cancer patients can manage the challenges they face without the need for specialist intervention. This is one of the reasons why a stepped model of care, such as the CAR framework outlined above, can be so useful in guiding health professionals towards low intensity interventions such as clear communication and information provision for *all* their patients, with a gradient of increasingly more intense interventions to meet the individual needs of each patient.

Using a test of implicit (unconscious) attitudes towards appearance, a study of 1,000 nationally-representative members of the general public concluded that participants showed a strong bias against people with a visible difference. [51] Relating this finding to the topic at hand, it is important for both health professionals and researchers working within oncology to be conscious and aware of their own attitudes towards appearance, including the importance they place on it and assumptions they make about it, as a first step towards being able to provide appropriate supportive care for their patients with or without appearance-related concerns. Chapter [***note to Editors, please cross-reference to our chapter on altered appearance]*** in this volume considers some common 'myths' about appearance, particularly those associated with an altered or unusual appearance such as that resulting from cancer treatment.

Health professionals should also carefully consider the language they use in relation to appearance, especially during their interactions with patients. For example, it is common within the medical and surgical professions to use terminology such as 'defect', 'deformity', 'deficit' or 'flaw'. Whilst issues around the language used in this area has been a topic of considerable discussion and debate for many years, a shift towards language with less negative connotations, for example 'changed appearance' or 'difference' would be useful. Likewise, phrases such as 'looking better' or 'improving' when referring to the results of surgery (particularly reconstructive procedures) might inadvertently promote prevailing societal 'beauty myths' about the importance of 'looking good' and not having visible scars, and thereby fuel individual insecurities and influencing, albeit unconsciously, a person's evaluation of how they look after surgery and, potentially, decisions about further surgery.

A key issue facing professionals who are looking to support cancer patients affected by appearance-related and body image concerns is the question of how best to identify those who are likely to benefit from the variety of interventions including those outlined earlier in this chapter. Many professionals (as well as patients' parents/carers) are very aware of physical symptoms, such as pain and nausea, experienced by those for whom they are responsible, and discussing such issues is part and parcel of routine care. In contrast, they may be unaware that appearance concerns are causing their patients distress, or fail to realise the extent of such distress and the impact it is having on a person's life. One approach to assessment by psychosocial specialists has been outlined above, but it is also important for health professionals who are not experts in this field to be able to gauge the impact of appearance changes on their patients' lives. A useful way of doing this is to proactively explore a patient's body image, even if the patient does not voluntarily bring up any related issues themselves. Fingeret has developed a framework for health professionals to discuss body image difficulties with patients, referred to as 'The Three C's'. [52] It proposes that at the beginning of the appointment, the patient should be reminded that body image concerns following the diagnosis and treatment of cancer are '*common'*. Normalizing body image difficulties in this manner is believed to reduce feelings of embarrassment and stigma. Subsequently, through the use of open-ended questions, health professionals are encouraged to ask the patient about the specific nature of the body image '*concerns*' they are experiencing. These may be associated with appearance- or function- related changes, and may also comprise of fears about the effects of impending treatment. Lastly, patients are asked about the '*consequences*' of their body image concerns. Health professionals should look out for adverse effects upon emotional, social, and occupational functioning.

Screening tools can also be used to identify patients that may benefit from support around appearance-related issues and could indicate the type and level of intervention that they may find helpful. These tools need not be unduly onerous, either for the person with cancer (or their parent/carer), or for health professionals and those potentially providing support. They also need to be rigorously validated so they are underpinned by strong research to support and encourage their take up and use by professionals looking to provide evidence-based practice. One approach that has been shown to help patients identify issues (including body image) that they would like to discuss with health professionals, [53,54] is the Patient Concerns Inventory (PCI). [55] This was originally developed for use with head and neck cancer patients and has since been used with those with breast cancer or brain tumours. It is a 56 item measure listing an array of possible issues that may be of concern to patients (including one item specifically about appearance) which is completed by patients prior to their consultation, allowing them to indicate their particular concerns which can then be used to promote discussions during the subsequent consultation.

Increasing awareness amongst health professionals of the nature and incidence of appearance issues experienced by their patients is a first step towards improving care, but only if they are confident and able to then put this knowledge into practice. Including this within medical and surgical training, and continuing professional development (CPD) courses could help health professionals to raise these issues with patients. Recently, a range of training materials for health professionals have been developed to raise their awareness and understanding of the issues facing their patients (see www.whenlooks.eu). Doing so could be one step towards ensuring patients' appearance-related needs are recognized. Yet, even if these needs are identified, professionals may not address them if they feel unprepared or lack confidence in dealing with them. The phrase "the silencing of disfigurement" was coined to

describe health professionals choosing not to discuss appearance issues when working with head and neck cancer patients, [56] in part because they did not feel able to help if patients did report having concerns. This "silencing of appearance" by health professionals, and others, could be a far more widespread issue affecting all cancer patients, and not only those with head and neck cancer. Researchers have also reported general practitioners' difficulty in raising the issue of appearance with young people with visible differences, including those resulting from cancer treatment. [57] The potential consequence is that the issue goes unaddressed as patients might not raise their concerns about their appearance for fear of being considered vain or ungrateful for the treatment they have received. [58]

Regarding when support about body image issues should be provided, it has been recommended that health professionals consider the stage at which a patient is at in their treatment journey. It has been suggested that the needs of women undergoing breast reconstruction would be better met if they were supported according to whether they are awaiting the initial reconstructive surgery, have undergone some surgery or have completed the whole reconstructive process. [59] This sound advice might also be relevant to patients undergoing other treatments, and those with other cancer diagnoses.

There are suggestions that health professionals may overlook, trivialise or minimise cancer patients' concerns and distress associated with their appearance. A qualitative study with 14 health professionals working in a single paediatric oncology centre and a survey of 48 health professionals from across the UK explored their views on the appearance concerns experienced by young people with cancer and the provision of support and interventions to meet these needs. [58] Most of the interviewees (87%) thought that appearance was a particular concern for their patients throughout every stage of their cancer diagnosis and treatment. Yet

it might be assumed that patients with advanced diagnosis, and those with metastatic disease, will not consider appearance-related issues to be important and therefore not candidates for body image interventions. Indeed, some participants in the study admitted to being surprised that appearance concerns were an issue for patients who were terminally ill and some thought appearance was a low priority for them. [58] However, limited research with this group indicates that it is, for some, a major concern. [60] It is therefore important that interventions are offered to patients even with incurable cancers, and that further research is conducted to ensure that interventions are meeting any specific needs this patient group have in terms of their content and delivery.

Considerations for Researchers

A recent systematic review concluded that there is still considerable potential for further development and rigorous evaluation of body image interventions for women treated for breast cancer. [5] We advocate for future intervention research to have an exclusive and explicit focus on body image, rather than including body image as a small component of broader interventions attempting to address the extensive range of psychosocial concerns that can accompany diagnosis, treatment and recovery. This specific focus has greater potential to validate the concerns of individuals, and increase the probability that the interventions will be successful in the long-term. Amongst the other recommendations made from this systematic review are that interventions based on physical activity may be attractive, but consideration should be given to whether a psychological approach may be more appropriate for individuals who are physically restricted as a consequence of current treatment. Finally, researchers are encouraged to report the content and delivery format of interventions, so as to enable both replication and assessment of the monetary costs and resources necessary for

their implementation. These recommendations can also be directed towards interventions for other cancer groups.

Rigorous methodology is needed to reduce the risk of bias and consequently increase confidence in the validity of positive findings. Accordingly, the use of pre-test post-test designs and control groups is encouraged, in order to achieve an acceptable level of internal validity. Further, while the randomisation of participants decreases selection bias, ethical issues can arise when individuals with cancer are randomly allocated to conditions (Bottomley provides an overview of considerations regarding the suitablity of randomisation in psycho-oncology research). [61] The use of randomized controlled trials to evaluate body image interventions can raise particular concerns. Individuals may be in desperate need of support, implying it could be unethical to use a waitlist- or passive- control group which would delay participants' access to support. These individuals may consequently decide to use other forms of psychosocial or cosmetic support in the meantime, instead of waiting to undergo the evaluated intervention.

Several frameworks are available to direct researchers through the development and evaluation of new health interventions (e.g., the Intervention Mapping protocol; [62] the PRECEDE-PROCEED model; [63]). We recommend the adoption of the Medical Research Council's (MRC) framework for the development and evaluation of complex interventions, [64] which consists of four stages (Development, Feasibility/Piloting, Evaluation, Implementation) that do not need to be pursued in a linear or even cyclical sequence. Following guidelines such as these in the future development of body image interventions for cancer patients will maximize the likelihood that they will be effective and taken up by stakeholders, including funders and policy makers. The MRC framework recognizes the

potential usefulness of alternative experimental designs, such as cluster-randomised trials, stepped wedge designs, preference trials and randomised consent designs, and N-of-1 designs, rather than relying on RCTs. [64]

As highlighted in examples throughout this chapter, most studies of the effectiveness of interventions in this field have relied on small sample sizes. A further methodological limitation is the lack of control groups in many studies, making it impossible to know whether any changes in outcomes were due to the intervention alone or could, perhaps, have been due to other factors. To complicate matters further, researchers have, to date, used a wide range of condition-specific and general measures to evaluate the effects of interventions to support cancer patients affected by appearance-related distress and concerns. This variability in the measures used has precluded meta-analysis of results within systematic reviews, and thereby prevented definitive conclusions about which are the most effective interventions. Establishing a consensus approach to measurement would alleviate the challenges associated with the comparison of evaluative studies. In the meantime, it is important to continue to employ validated and reliable scales to measure body image. While a single core measure may be preferred, employing a combination of measures may allow the assessment of multiple dimensions of body image, including perceptions, thoughts, feelings and behaviour relating to the body and appearance. Researchers are also encouraged to consider using cancer-specific measures (for example, the Body Image subscale of the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC-QLQ30) Breast Cancer Module [65]), as well as measures developed in the wider body image field (e.g., the Multidimensional Body-Self Relations Questionnaire; [66,67]).

Finally, most evaluations of interventions in this field have collected limited follow-up data, thereby restricting our understanding of their longer-term impact including whether interventions that have been shown to be effective in the short-term (post-test) continue to demonstrate sustained improvements on body image, or whether those which were non-effective at post-test offer delayed benefits. The Society of Prevention Research recommends follow-up of at least six months in order to establish efficacy, [68] although ideally follow-up will be longer than this since changes to appearance and bodily function, and therefore associated body image, may differ in relation to an individual's stage and regime of treatment. This may consequently influence the timing of the effects of the intervention. Further, researchers are encouraged to include several consistent follow-up points, so as to facilitate comparisons of maintained improvements between studies.

Looking Ahead

Body image and the nature and incidence of appearance-related concerns are dynamic, evolving issues. For example, younger age groups are now reporting anxiety about body image and growing numbers of men are expressing concern about appearance. Researchers and clinicians need to respond to this shifting landscape, to ensure that the care they provide for their patients is informed by an evidence-base and the latest thinking in the fields of both body image and psycho-oncology.

There is still considerable potential for new interventions in this area. It could be fruitful to explore further the use of intervention approaches that have been used in other areas of psycho-oncology but have received less research attention specifically in relation to body image and appearance issues. For example, third wave CBT approaches such as

Acceptance and Commitment Therapy (ACT), Dialectical Behaviour Therapy (DBT) and Mindfulness have started to be explored, [32] but warrant further studies of their acceptability and feasibility, and consideration of which aspects of complex interventions are most effective, for who and when.

Online interventions outlined above (for example, YP Face IT), are increasing access to interventions and offering the potential for support to be available at any time of day. However, it is important to remember that not all patients will want or be able to use online support, and that online provision and further developments should not be at the expense of developments with face-to-face support. Future developments in this area might also include the use of apps and other new and emerging technology.

An exciting development would be to examine whether interventions developed within the broader body image field might be acceptable and effective for use with individuals experiencing body image concerns as a consequence of appearance and bodily changes resulting from cancer and its treatment. For example, a rigorously evaluated and effective group-based CBT programme aimed at women in midlife, [69] may be appropriate for use with women treated for breast cancer, given that many women with the disease are diagnosed in midlife and are therefore likely to still be vulnerable to similar influences and body image concerns as those without cancer. However, such interventions may require adaption in order to best address any unique body image concerns of specific cancer groups. This is important given the likelihood of condition-specific issues which warrant attention. For example, patients with a stoma often have concerns relating to intimacy, whilst many of those with head and neck cancer may experience anxiety around eating in public.

Finally, since most research in this area has involved women with breast cancer, there is still a need for further studies involving other patient groups, and to include greater consideration of interventions to support young people with an altered appearance due to cancer treatment, and other groups currently under-represented in the published research. Further research should also explore the needs and experiences of people close to the person with an altered appearance (for example partners, children, siblings, grandparents, teachers, employers) in order to identify if there is a need for intervention or support to help them as well as the patient. Again, a tiered approach might be useful, differing in the type and intensity of support needed.

Conclusion

This chapter has introduced a range of interventions, all with the common aim of improving outcomes for cancer patients with appearance-related and body image concerns. By using the framework of a stepped model of care specific to altered appearance, we have shown how patients might be offered access to appropriate interventions to meet their individual, specific needs. The level at which any particular intervention sits on this framework might sometimes be open to debate, but for us the important issue is the translation and implementation of research, so that health professionals and researchers alike all continue to build the evidence-base and increase access to resources that patients might benefit from. Clearly, there is still a lot of work to be done, but we remain excited by the possibilities that lie ahead.

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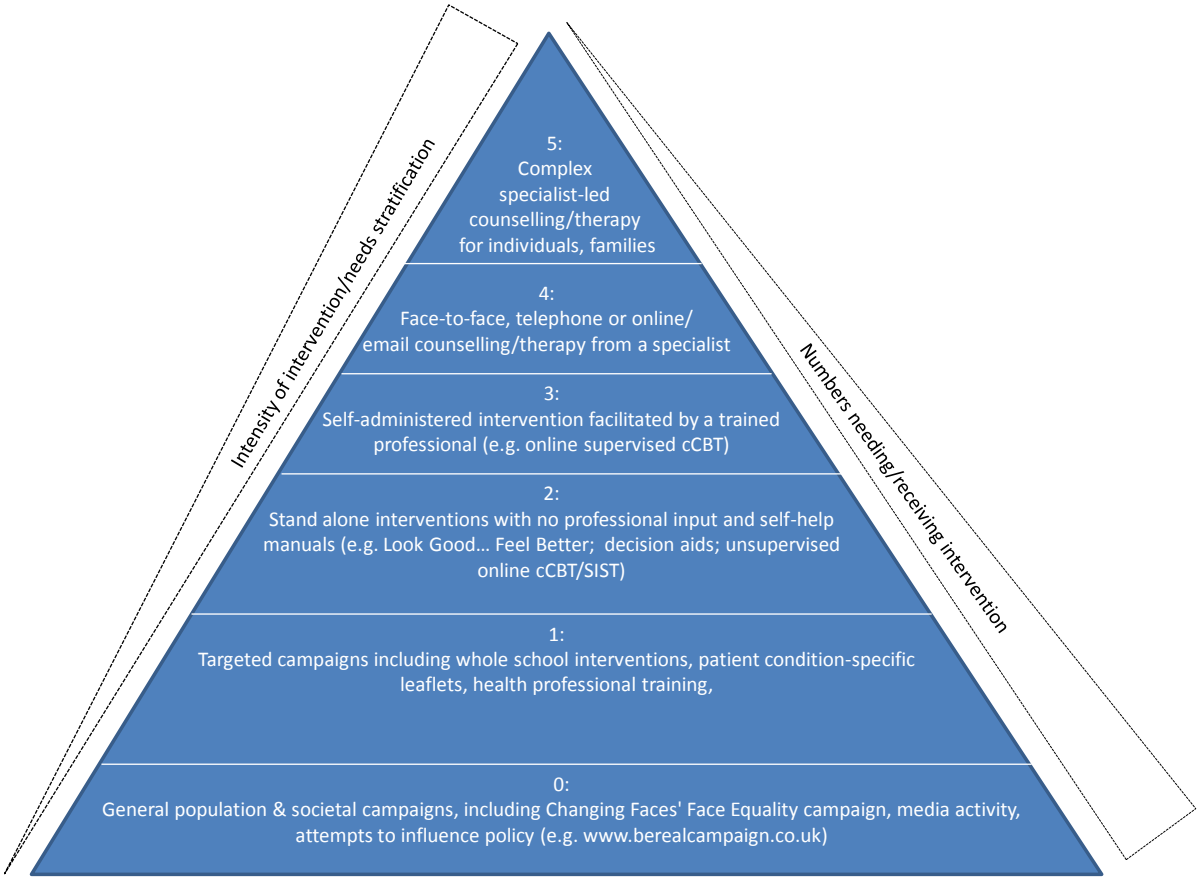

Figure 1.1 The CAR framework of appearance-related interventions (from Rumsey N, Harcourt D. Where do we go from here? In: Rumsey N, Harcourt D, eds. *The Oxford Handbook of the Psychology of Appearance.* Oxford, England: Oxford University Press, 2012: 679