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**The need to address appearance-related distress across clinical conditions: How can
healthcare teams support patients?**

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Abstract

Evidence is accumulating about the nature and prevalence of appearance-related distress across a variety of clinical populations. Healthcare professionals (HCPs) working with specific patient groups are often aware of these difficulties and their detrimental effect on quality of life and wellbeing. However, many HCPs lack knowledge and skills on how to support patients, either within the team or via referral to relevant service-providers who have expertise in managing appearance-related distress. This is mainly due to a lack of information about screening, assessment measures and available interventions.

The aim of this article is to consider how HCPs can support patients who experience distress as a result of living with a long-term physical health condition that has altered their appearance. The article summarises the challenges for patients and HCPs surrounding body image, altered appearance and associated distress. Gaps in relation to screening measures, differing types of intervention, appearance-related skills training for healthcare teams, care pathways and access to services are identified. A summary of the limited range of interventions currently available has been mapped onto a stepped model of care, ranging from self-help to intensive therapies. Finally, readers are pointed to helpful resources for understanding, identifying, addressing and signposting patients with appearance-related distress.

Key words: Disfigurement, appearance-related distress, visible difference, psychosocial intervention, distress, body image

Key phrases

1. Poor body image and appearance-related distress can be a significant issue for patients with a range of clinical conditions.
2. To a great extent, the nature and impact of body image concerns are generic across different clinical populations.

3. HCPs are often aware of appearance-related distress in patients, but do not have the skills training to address the issue.
4. Some patients who experience appearance-related distress can be reticent to discuss their difficulties due to perceptions that it is not part of clinical care, or not important.
5. The limited range of interventions available can be mapped onto a stepped model of care that provides support from basic information provision through to psychiatric treatment.
6. Priority areas for further development include robust, easily administered screening measures and the development of generic care pathways, to ensure that all individuals receive appearance-related psychosocial intervention when required.

Introduction

There is growing recognition of the importance of appearance in long-term physical health conditions (Boyington et al, 2008). This has resulted in a steady accumulation of evidence about the nature and prevalence of appearance-related concerns across a variety of clinical populations (Rumsey & Harcourt, 2012). These include rheumatic and connective tissue disease (Jolly et al, 2011; Bode et al, 2010), dermatology (Fortune et al, 2004), diabetes (Baptiste-Roberts et al, 2005), and cancer (Sharpe et al, 2011). Although appearance-related concerns are not limited to clinical populations, the acquisition of a visible difference can exacerbate pre-existing body image distress and take people further away from their body image ideal (Rumsey & Harcourt, 2012). Despite this increase in appearance-related research, and the finding that 48% of the adult population with a visible difference experience at least borderline levels of clinical anxiety (Rumsey et al. 2004), there remains comparatively little work on how to support patients in routine clinical practice.

Much of the research into the conceptualisation and psychosocial impact of how people feel about their bodies uses the term 'body image'. Body image is the mental picture people have of their physical self, and equally importantly, the mental picture they believe others have of them (Grogan, 1999). It includes perceptions of, and attitudes to, their appearance, attractiveness, state of health, functionality, and sexuality. The concept also incorporates a person's sense of how their body image influences interactions (e.g. how they feel about themselves and other people's reactions to them), making it a major factor in social and interpersonal relationships (Luskin Biordi et al, 2006). The term visible difference refers to any condition that alters an individual's appearance (Rumsey & Harcourt, 2004). The term visible difference is often used by clinicians and academics to describe such conditions previously referred to as disfigurements, because visible difference is considered to be less stigmatising and pathologising (Rumsey & Harcourt, 2007). The term visible difference does not suggest that the appearance has been spoiled or is less attractive, but simply that it is different in some way from the perceived norm, whatever that may be.

The focus of this article is specifically on the issues experienced by some patients when their physical appearance alters as a consequence of their long-term physical health condition; this could include changes in skin texture, body shape or bodily movement (such as changes in gait or posture). It is the psychosocial difficulties in adjusting to an altered appearance associated with a long-term physical health condition which HCPs might encounter in their clinical practice. Many terms are used to describe the resultant psychosocial effects such as appearance concerns, body image concerns, and body image distress, but throughout this article the term 'appearance-related distress' will be used.

The nature of appearance-related distress

While some research suggests that having a visible health condition, such as a skin disorder, can be particularly stigmatising (Belhadjali et al, 2007), there is also evidence that

subjective severity of appearance problems is more related to poor adjustment than objective severity (Moss, 2005). This challenges the idea that the extent and severity of bodily change is directly associated with the degree of psychosocial impact; and highlights the need to think of how to identify those patients who might be more susceptible to experiencing appearance-related distress. This has led to the recommendation that appearance-related distress is considered whether or not a condition is visible, and regardless of the degree of objective severity (Rumsey et al, 2002). Therefore, HCPs should be aware that any patient, irrespective of the degree of objective severity might experience severe levels of psychosocial distress.

Despite variability in severity and location of perceived visible differences, and the numerous social, personal and cultural characteristics that can contribute to adjustment, there are commonalities in how problems and difficulties manifest. These include, but are not limited to, embarrassment, shame, social anxiety, social avoidance, aggression and poor self-esteem (Rumsey & Harcourt, 2005). Such manifestations of appearance-related distress can be viewed as generic across clinical groups and not specific to any particular condition. Kent (2000) argued individuals live their lives on public display, where the existence of a visible difference is associated with unwanted exposure, potentially resulting in unwanted responses from others. This is supported by studies which have identified that some people with a visible difference experience difficulties with feedback from the public in the form of staring, name-calling and unsolicited questioning (Rumsey et al, 2004; Lansdown et al, 1997). These experiences can trigger appearance-related distress, with the development of feelings of not living up to cultural norms, and the activation of a negative internal representation of what is meant by attractiveness (Bessell et al, 2010). Individuals with these difficulties may be socially timid and appear withdrawn or shy, or display unhelpful safety or camouflaging behaviours. These behaviours can result in poorer social skills, either due to reduced social contact with others, or anxious and distracted behaviours where individuals attempt to hide their feature in some way (examples include wearing low-rimmed baseball

caps or training the hair across the face - both of which reduce eye contact - or wearing thick clothing to cover parts of their body, even in summer). Alternatively, individuals may appear defensive and be dismissive of their appearance. This can manifest as aggression, and is borne out of the negative response they have received from others (Bessell et al, 2010).

Addressing appearance-related distress in long-term physical health conditions

One reason for the historical lack of engagement with appearance-related concerns in healthcare settings is the dominance of the biomedical model, which assumes a separation of mind and body. Chronic term physical health conditions are conceptualised in terms of dysfunction of the biological body, with subsequent efforts focused on returning this biological body to normal functioning or preventing acute exacerbations of symptoms (Carrio et al, 2004). Despite increased understanding of the importance of psychosocial factors, the disease process is often viewed as more real and therefore more worthy of a clinician's attention (Carrio et al, 2004). Consequently the biomedical perspective continues to dominate explanations of the consequences of chronic term physical health conditions, the interventions that are available, and the way in which treatment is approached (Suls & Rothman, 2004). Biomedical frameworks may be further reinforced by the tendency of patients to put forward physical complaints that they attribute to a physical cause, thus colluding with the medical profession's selective attention towards physical symptoms, rather than psychosocial ones. Consequently, patients often struggle to feel that it is valid to discuss their concerns and difficulties with adjusting to their altered appearance with HCPs (Bessell et al, 2007). HCPs can be aware of appearance-related difficulties and their detrimental effect on quality of life, and may well advocate addressing appearance-related concerns (Semple et al, 2008; Monaghan et al, 2007), but in reality they often remain un-addressed. One of the key reasons for this is that HCPs often lack the confidence, resources and skills to provide appropriate support to patients with appearance-related distress (Clarke & Cooper, 2001).

Working with appearance concerns

Kent (2000) recommended an integrated model that addresses body image dissatisfaction and the negative assumptions associated with appearance concerns. He also suggested that it is important to target social anxiety with exposure therapy (introducing people to feared social situations). However, as there is a very real tendency for individuals to experience negative responses from others, it is important to boost social skills too, in order to provide individuals with the techniques that they will need to deal with these responses. The authors have adapted Kent's (2000) model (Fig 1) to highlight how intervention delivery can be mapped on to these specific difficulties to provide a comprehensive package of support for individuals with visible differences, taking a combined social skills (promoting ability to respond positively in social situations and handle difficult responses to appearance) and cognitive-behavioural approach (addressing negative assumptions about one's appearance based on cultural norms of appearance, and addressing negative thoughts about one's body image).

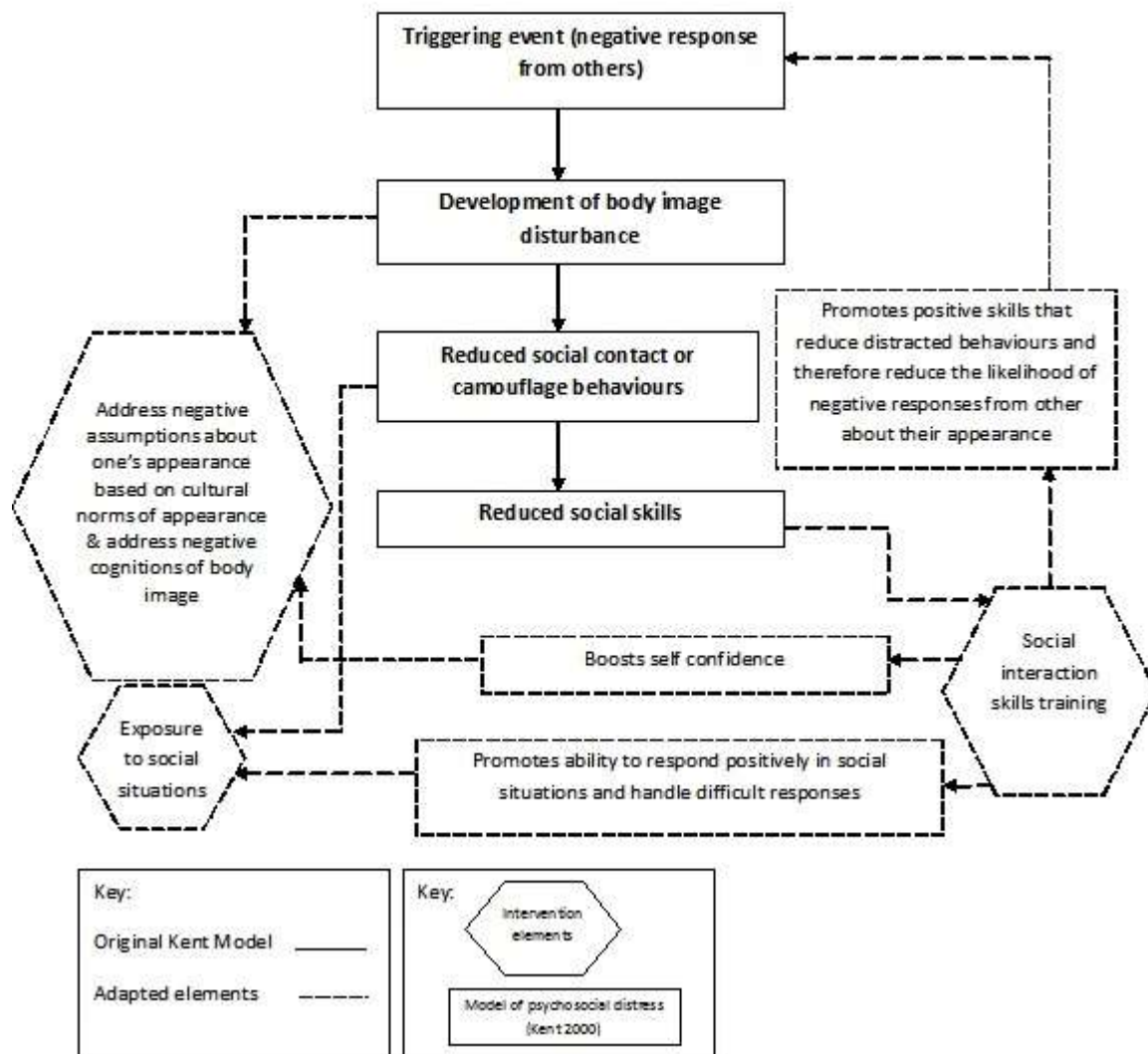


Figure 1: Kent's (2000) Model of Psychosocial Distress with Mapped Intervention

Approaches for Individuals with Visible Differences

A range of psychosocial interventions exists that provide information, support and guidance, as well as clinical services to those with visible differences. These forms of support range from: leaflets and online sources; self-help groups, support groups and help lines (either administered through health services or through the voluntary sector); general psychological support in the form of information from HCPs; through to more specialised services such as

health, counselling and clinical psychology, and liaison psychiatry. These services are invaluable to patients but they need to be provided in an integrated manner, with HCPs being able to refer easily to the most appropriate pathway for individuals. For this to be possible, HCPs need information about the services that exist and the level of care each pathway provides (Table 3), and collaboration between health services and voluntary organisations is paramount. It is also important that the offer of psychological care for appearance-related distress is seen as a routine aspect of care, which will inherently encourage uptake and reduce the feeling of stigma that offering such support might elicit. This process of normalising may help to prevent appearance-related distress as well as treat patients who have already gone on to experience psychosocial difficulties.

Methods for screening clients

Routine assessment within a tiered approach intervention model is a way of identifying those individuals whose needs can be met by self-support information, support groups or resources within the clinical team. Within some healthcare settings, waiting times to psychologists and psychiatrists are often long. However, if appropriate assessments were conducted and a clear referral protocol established, with only those with a moderate to high degree of distress being referred for specialist support, this would be an effective use of resources, and facilitate more timely management of those with the greatest need. As highlighted by Hutchinson et al (2006), appropriate referral can only take place if there is an accurate assessment process. This involves ascertaining both the level and type of intervention that would be most appropriate for each individual. However, many clinicians report that they are too pressed for time during routine inpatient and outpatient care to conduct formalised assessments using standardised questionnaires, especially if they have targets for clinical outcomes that must be achieved.

The different approaches to screening/assessment of need that could be adopted include the following (please note: more information about the approaches listed below can be

sought by contacting the first author for a resource pack or by contacting the relevant paper authors):

1. Clinical Interview using questions such as those highlighted by Rumsey et al (2002)
2. Scaling questions (such as those designed to highlight difficulties associated with aggression or self-esteem, or simply to identify the presence of appearance-related distress) (Table 1)
3. Utilising appropriate standardised questionnaires, for example, the Derriford Appearance Scale (DAS-24; Carr et al, 2004), which has been designed for use with clinical populations.

Table 1: Example scaling questions for use during screening

How serious do you feel your reason is for being here?											
Very serious	10	9	8	7	6	5	4	3	2	1	Not at all serious
How confident are you in dealing with your reason for being here?											
Very confident	10	9	8	7	6	5	4	3	2	1	Not at all confident
How motivated are you to deal with your reason for being here?											
Very motivated	10	9	8	7	6	5	4	3	2	1	Not at all motivated

Assessment can also be undertaken as part of usual consultation using BATHE (Stuart & Lieberman, 2008), an acronym for a way of structuring clinical interviews such that patient concerns are not only identified but contextualised, and appropriate support for the presenting problem can be discussed. BATHE comprises four questions and a statement of empathy (or validation) (Table 2). According to Stuart & Lieberman (2008, p 65-66) “when practitioners apply the BATHE technique as part of the history of present illness in the consultation (see the bulleted list in Table 2, below), an effective and efficient therapeutic intervention is structured into every patient encounter. The context of the visit has been incorporated into the session, patients’ emotional reactions are addressed, and there is closure. A very basic screening for anxiety & depression has also been accomplished”. The authors recommend BATHE as an additional approach to screening patients, to identify if

they are experiencing appearance-related distress, and how that may be manifesting itself. It can be particularly useful for HCPs with limited experience of managing appearance-related distress. The technique can also help HCPs to identify appropriate sources of help based upon the patients' distress, and more importantly, the patient's own needs and wishes.

Table 2: Description of Stuart & Lieberman's (2008) BATHE technique for use within consultations

BATHE	Incorporating BATHE into a consultation
<p>B = Background (what is going on in your life?)</p> <p>A = Affect (how do you feel about that?)</p> <p>T = Trouble (what about the situation troubles you the most?)</p> <p>H = Handling (how are you handling that?)</p> <p>E = Empathy (that must be difficult for you.)</p>	<ul style="list-style-type: none"> ● History of present illness ● BATHE ● Further medical history (if appropriate) ● Appropriate physical examination ● Ordering of tests (if necessary) ● Diagnosis (if possible/appropriate) ● Prescription (if appropriate) ● Arranging further appointment (if appropriate) ● Signposting other sources of help (if appropriate)

Interventions

The tiered intervention model of Hutchinson et al (2006) is very useful in clearly describing ways of meeting different needs. Based on community cancer care, it describes five levels at which psychosocial support can be provided by different professionals. This stepped care approach has not only been successfully utilised for psychological distress within oncology, but has been successfully utilised in behavioural family interventions. The tiered model of psychological care is based on the concept that following assessment/screening for psychological distress the individual is matched to an appropriate level of intervention based

on level of distress and expressed need. These tiered intervention models suggest a framework that grades interventions according to level of care/input required on a tiered continuum of strength, with those higher up the continuum denoting more severe psychological distress managed by specialist HCPs.

The authors have adapted the Hutchinson et al (2006) model to make it specific to visible difference to give an idea of the resources that are available at the possible levels of intervention (Table 3). Unfortunately, many of the interventions outlined have not been sufficiently evaluated in randomised controlled trials to support their effectiveness (Bessell & Moss, 2007). However, there is a considerable body of evidence suggesting the different elements of intervention can lead to positive outcomes on a range of variables, including psychological distress (Papadopoulos et al, 2004; Kleve et al; 2002), self-esteem (Lawrence et al, 2006; Rumsey & Harcourt, 2005), quality of life (Flexen et al, 2011; Parsad et al, 2003) and social functioning (Bessell et al, 2012; Kleve et al, 2002).

Table 3: Hierarchy of interventions (Hutchinson et al, 2006)

Intervention level	Method	Resources
Level 1: minimal to mild distress (universal care)	General information about disfigurement/appearance-related distress and practical concerns	Information provided in leaflets, online or audiovisual (e.g. Changing Faces, condition-specific such as Macmillan Cancer Support) Telephone help-lines e.g. Changing Faces Provision of general emotional support by all staff responsible for patient care
Level 2: mild to moderate distress (supportive care)	Supportive care: <ul style="list-style-type: none"> • psychoeducation • emotional support • peer support • problem-solving 	Telephone help-lines e.g. Changing faces Self-help manuals/on-line CBT intervention programme (e.g. Face IT (www.faceitonline.org.uk)) *Peer support groups
Level 3: moderate distress (extended care)	Time-limited, semi-structured or manualised treatment focused on how to deal with appearance-related distress Focused counselling	Social skills workshops e.g. Changing Faces On-line CBT intervention programme (e.g. Face IT (www.faceitonline.org.uk)) Professional led support group (e.g. offered by integrated services) Individual therapy by trained health

		professional e.g. social worker, counsellor
Level 4: moderate to severe distress (specialist care)	Specialist psychological intervention such as anxiety management by a trained, accredited and supervised professional	Psychosocial therapy offered by integrated services (individualised, couple or group)
Level 5: severe distress (acute care)	Specialist psychological and psychiatric intervention for multiple, complex or severe problems that may include suicide ideation and personality issues	Mental health team offered by integrated services e.g. psychologist, psychiatrist, multidisciplinary mental health services

Briefly, at the lowest level there is universal care for all people affected by visible difference who experience minimal to mild distress. Their needs may be met by general appearance-related information on a range of common problems, and delivered by a range of service providers in printed, electronic or audio-visual form. Care at this level is relatively inexpensive and easily accessible. At level two there is supportive care for mild to moderate distress. Here, needs may be met by psychoeducation and emotional support via community-based peer support programmes, telephone help lines, manual or on-line therapy programmes. At level three there is extended care for moderate distress, with time-limited, semi-structured treatment delivered through individual or group therapy led by a trained health professional. This could include problem solving skills and overcoming social isolation. Level four is specialist care for moderate to severe distress. Support at this level has a narrow focus with a trained therapist, for example cognitive behavioural therapy (CBT) for anxiety disorders or inter-personal therapy for sexual and relationship problems. Finally, there is acute care for severe distress (level five), which entails a broad focus on multiple problems, including suicide ideation and family system problems. This tier requires the input of specialist, possibly multi-disciplinary, mental health professionals.

Stepped care is based on two core principles. First, treatment should always have the best chance of delivering positive outcomes while burdening the patient as little as possible. Second, a system of scheduled review must be in place to enable stepping up to more

intensive treatments, stepping down to less intensive treatment, or stepping out when no treatment is required (Department of Health, 2008). Stepped care may be implemented in one of two ways: (i) in a pure stepped approach, where almost all patients are offered a low-intensity treatment as the initial step in a treatment programme or (ii) where higher-intensity treatments are reserved for those patients who do not benefit from the initial low-intensity step. In contrast, a stratified approach assesses patients and allocates them to either low-intensity or high-intensity steps as an initial treatment option. A stratified approach is most clinically useful with patients assigned to the appropriate level of care following assessment. This approach leads to more rapid response for those with acute issues and ensures that all levels of care are utilised appropriately (Department of Health, 2008).

As stated earlier, many HCPs are aware that their patients have appearance-related problems but many are unsure of how to meet their needs. One of the challenges is that HCPs have a lack of skills, training and confidence in managing appearance-related distress. HCPs often use blocking techniques when patients start to communicate about sensitive issues, as there is the fear of not knowing what to say or making the situation worse; this in turn inhibits the expression of emotional concern and/or distress (Turner et al, 2007; Wilkinson, 1991). Nevertheless, as demonstrated by Clarke (2000), such skills and abilities can be developed through appropriate training courses that focus on identifying potential appearance-related distress, asking appropriate questions, or use of appropriate screening measures, and signposting accordingly. Training courses are available from organisations such as Changing Faces or through continuing professional development courses (CPD) such as those run by the first author. (A free resource pack for HCPs is available on request from the first author.) Furthermore, research is ongoing at the Centre for Appearance Research (CAR) (<http://hls.uwe.ac.uk/research/car.aspx>), a specialist centre dedicated to understanding the nature and extent of support needs for people experiencing appearance-related distress, and designing interventions to meet these needs.

CONCLUSION

Appearance-related distress affects a significant number of patients with a range of clinical conditions; but essentially the effects, such as social anxiety, aggression, social avoidance and poor self-esteem, can be considered generic. HCPs are often aware that altered appearance causes distress but do not have the confidence or training to assess and/or address the concerns. The authors of this article are researchers and clinicians working in the field of visible difference, who have an applied focus and are aware of the gap between meeting needs in theory and in practice. Therefore, this article has mapped existing interventions onto a stepped model of care using an adaptation of the Hutchinson et al (2006) model to provide a framework for interventions available for individuals with appearance-related distress. The paper also provided information about different methods of screening to support HCPs to allocate support appropriately based on levels of distress.

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