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**Evaluating the effectiveness of psychosocial interventions for individuals with visible differences: a systematic review of the empirical literature.**

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Abstract: The objective of this review was to systematically identify and evaluate all known studies testing empirically the efficacy of psychosocial intervention programmes for adults with visible differences. Twelve papers met the inclusion criteria. None of the papers demonstrated adequately the clinical effectiveness of the interventions. The review concluded that further research was needed to demonstrate adequately the effectiveness of existing interventions, and a greater number of Randomised Controlled Trials (RCTs) and experimental studies were required to increase the methodological validity of intervention studies.

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Dear Professor Cash,

The following document entitled "Psychosocial interventions for visible differences: A systematic review" has now been revised. We thank you for your comments and those of Dr Grogan which we have incorporated into the manuscript. The following changes have been made to meet with your recommendations. Each comment has been addressed specifically.

Yours sincerely

Alyson Bessell

We have completed the editorial review process for your revised manuscript submitted for publication in *Body Image: An International Journal of Research*. You were admirably responsive to the initial set of reviews and feedback.

The appended Associate Editor's comments indicate that there remain a few minor items for your modification before we can accept your informative paper for publication in the journal.

To her requested changes, I wish to add a few minor matters:

1. Please replace all underlining (of headers etc.) with italics.

All underlining has been replaced with italics

2. Please delete notations about where to insert tables.

These have been deleted

3. In the references, APA style does not include a parenthetical issue number after the volume unless each issue begins pagination with page 1 (which is rare).

The parenthetical issue numbers have been removed where necessary.

4. Also in the references: Beck's book title is ". . . disorders (not disorder). I do not believe that psoriasis and vitiligo are capitalized. Do not capitalize shame in the *Body shame* book.

These changes have been made – thank you

5. We don't need the large blank Yes/No column in the Appendix. The listing of the criteria/questions in a nontabular format should suffice.

This column has been removed

When you revise the paper, please include a covering letter stating how your revision addresses the points made by the Dr. Grogan and myself.

There are a few minor revisions that will be required before publication. I have these noted below. Please make these changes and resubmit.

1. Please change the title at the top of the Introduction to the revised title 'Evaluating the Effectiveness...'. The previous title has been retained here. Please also make the Running Header on the manuscript consistent with the Running Head on the title page.

The title on the introduction page has been changed and the running head now matches that given on the title page – thank you

2. Please add 'The term' before 'Visible differences' on the first page of the Introduction.

This has been added

3. Delete the word 'often' in line 4 of page 3 so that this reads 'Some individuals with visible differences have been found to...'

This has been removed

4. On p.3, please give a reference after 'unsolicited questioning about appearance' (line 11).

The reference of Kleve and Robinson 1999 has been added here and placed in the references

5. On p.4, give a reference after 'overreactions to others to altered appearance' (line 6 from bottom).

The reference of Robinson 1997 has been added here and placed in the references

6. p.8, line 8, replace 'was' with 'were'. Please check that data are always referred to as plural in the rest of the paper.

This has been changed and all other references to data have been checked and are plural – thank you

7. On p. 19, please rephrase the second sentence of the Discussion so that it is grammatically correct.

The opening sentences of the introduction have been changed so that they now read: "The strength of the evidence to support the effectiveness of the existing interventions from this narrative synthesis is poor. The

methodological quality of the included studies was limited and small intervention effect sizes were observed.”

8. On p.20, line 10, please replace 'the review is unable to draw any firm conclusions' with 'it was not possible to draw any firm conclusions'.

This has been changed

9. On p.22, line 6, replace 'hard-to-react' with 'hard-to-reach'.

This has been changed – thank you

10. On p.22, line 17, replace 'individuals' with 'individual'.

This has been changed - thank you

RUNNING HEAD: Interventions review for visible differences

Evaluating the Effectiveness of Psychosocial Interventions for individuals with Visible

Differences: A Systematic Review of the Empirical Literature

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KEY WORDS: Visible differences, psychosocial, narrative synthesis

AUTHOR NOTE

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Clarke and Dr Andrew Thompson for reviewing the references in this paper to ensure a complete list of included evaluation studies.

### Abstract

The objective of this review was to systematically identify and evaluate all known studies testing empirically the efficacy of psychosocial intervention programmes for adults with visible differences. Twelve papers met the inclusion criteria. None of the papers demonstrated adequately the clinical effectiveness of the interventions. The review concluded that further research was needed to demonstrate adequately the effectiveness of existing interventions, and a greater number of Randomised Controlled Trials (RCTs) and experimental studies were required to increase the methodological validity of intervention studies.



## Evaluating the Effectiveness of Psychosocial Interventions for Individuals with Visible Differences: A Systematic Review of the Empirical Literature

The term visible differences refers to any kind of disfiguring condition, whether congenital or acquired that leave an individual with an altered appearance, for example skin conditions, burns, scarring or craniofacial abnormalities. Some individuals with visible differences have been found to experience psychosocial adjustment problems that can lead to social anxiety and isolation (Rumsey, Clarke, White, Wyn-Williams, & Garlick, 2004; Rumsey & Harcourt, 2004). As such, their presence presents a clear challenge to a positive body image for those affected and have led to the development of numerous psychosocial intervention programmes designed to address the psychological, as well as the physical needs and difficulties experienced by those with visible differences. The psychosocial difficulties experienced by some of those with visible differences include name calling, staring and unsolicited questioning about their appearance (Kleve & Robinson, 1999). These can further increase the sense of isolation experienced. Furthermore, individuals with visible differences can experience body image difficulties as they can find it hard to accept their appearance, which in turn can affect self-concept (Kent & Thompson, 2002). Physical difficulties surrounding loss of function or painful scarring or skin can further exacerbate the feelings of anxiety and depression and need addressing by psychosocial interventions. Psychosocial interventions are vital for patients, as research has demonstrated that large numbers of individuals with visible difference experience psychosocial disturbances and have reported a need for such interventions to help them cope more effectively (Rumsey et al., 2004; Carr, Harris & James, 2000)

The UK charity Changing Faces has been a driving force in establishing counselling services and social skills-based workshops to aid psychosocial rehabilitation (Clarke, 1996).

They have also played a key role in providing health education resources for individuals. Furthermore, many British National Health Service (NHS) clinics have adopted cognitive-behavioural based treatment plans. Cognitive behaviour therapy (CBT) has long been used as an effective intervention for those experiencing affective disorders, including depression, generalised anxiety and social anxiety (Beck, 1976). Many similarities exist between problems reported by those with visible differences, and those suffering from social anxiety. Research has suggested that individuals with visible differences experience the same fear-avoidance issues associated with social situations as those who experience social anxiety (Newell & Marks, 2000). This suggests that this type of therapy may be effective in addressing psychosocial adjustment difficulties in individuals with visible differences. Additionally, a meta-analysis of CBT interventions has found it to be very effective at addressing body image concerns in non-visibly different populations (Jarry & Ip, 2005).

Interventions often aim to help individuals to become more accepting of their own appearance whilst teaching them how to become more confident. Research has suggested that individuals with visible differences are often so anxious about their own appearance that they project their negative thoughts onto others (Kleck & Strenta, 1980). This often leads to them assuming, often wrongly, that people are responding negatively to them because of their appearance. This is not to say that all the problems experienced by those with visible differences are due to faulty perception. Many of the responses individuals experience are negative and are due to the overreactions of others to altered appearance (Robinson, 1997). Therefore, techniques have concentrated on addressing these negative thoughts, increasing positive thinking and enhancing communication skills in social situations in an attempt to distract attention away from the difference. Both social skills training (SST) and CBT are common intervention types for adults with visible differences. Other treatment programmes have included the use of self-help materials, such as leaflets (Newell & Clarke, 2000) and

social support groups (Bremer-Schulte, Cormane, Van Dijk, & Wuite, 1985; Cooper & Burnside, 1996; Kang Seng & Siew Nee, 1997; Price, Mottahedin, & Mayo, 1991).

Although these techniques for the visibly different are based on data documenting the nature of the difficulties of those with visible difference, and are commonly used in clinical settings, only a small number of studies have examined the effectiveness of such psychosocial interventions.

The aim of the present study was to conduct a systematic review of all the research papers assessing the effectiveness of psychosocial intervention programmes for adults with visible differences. This study assessed the relative strengths and weaknesses of each study, and each technique described within the papers, in order to draw conclusions regarding the quality of the existing evidence supporting the use of such intervention techniques. The overall intention of this study was to identify methodological issues in need of further attention in this area of research. Furthermore, we hoped that this review would aid in the development of new intervention programmes within the field of visible differences.

## Method

### *Search Strategy*

To locate papers relating to psychosocial interventions for individuals with visible differences a series of population and intervention search criteria were adopted. The search process was conducted from January to February 2006 and repeated again in July 2006.

‘Population’ search terms included: visibly different, facially disfigured, visibly disfigured, facial disfigurement, visible difference, visible disfigurement, disfigure and searches were conducted using specific conditions which are known to impact on appearance.

‘Intervention’ search terms included psychosocial intervention, intervention, psychosocial treatment, treatment, cognitive behavioural therapy, social skills training,

counselling. Psychosocial interventions were defined as any program that incorporates techniques that aim to reduce psychosocial distress, by reducing anxiety and depression and increasing social activities. Methods of delivery include group sessions, telephone counselling, individual counselling and self-help materials.

The databases searched included: EMBASE, Medline, Psychinfo, Social Care Online, Social Sciences Citation Index, Allied and Alternative Medicine Database, Applied Social Sciences Index and Abstracts, British Nursing Index, Campbell Collaboration, Cumulative Index to Nursing and Allied Health Literature, Cochrane Library, Evidence-based medicine review, Health Management Information Consortium, International Bibliography of the Social Sciences, ISI Web of Science conference Proceedings, Latin American & Caribbean Health Sciences Literature (LILACS), National Research Register (UK), OTseeker, and the British Library Grey Literature Database. Reference lists of noted papers were searched in order to pick up any missing publications.

The review aimed to evaluate clinical effectiveness in terms of improvement in psychological symptoms and both interpersonal and social functioning. Furthermore, the review assessed effectiveness in terms of preference, satisfaction and acceptability of treatment and assessed each technique for effectiveness across a range of different individuals varying in ethnicity, socioeconomic status, age, sex and type of visible difference. All papers relating to adults (17 years and over) with noticeable visible differences were included in the review process. This included a wide range of different conditions from congenital skin conditions and abnormalities to cancer patients, or those with scars resulting from injury. The intervention types included CBT, SST, support groups and counselling all delivered either alone or as part of a package of care. The outcome measures included improvements in psychological symptoms, interpersonal and social functioning, satisfaction, and preference, site of delivery and acceptability of treatment. All published and unpublished papers were

assessed according to the accepted hierarchy of evidence, whereby systematic reviews of randomised controlled trials are taken to be the most authoritative forms of evidence, with uncontrolled observational studies the least authoritative (Centre for Reviews & Dissemination, 2001).

Papers that were not included for review included any treatment that was not specific to visible differences, such as standard CBT or standard counselling. Any treatment aimed at young people under the age of 17 years was also excluded. Additionally, any persons or treatment designed to treat body dysmorphic disorder or eating disorders such as bulimia nervosa or anorexia nervosa were also removed. It was also decided to exclude any visible differences that were not considered to be commonly on display such as breast reconstruction or abdominal injury. This was due to the vast amount of literature present on these kinds of conditions. These types of conditions do fall within the remit of visible differences, but it was considered that the needs of individuals with “hidden” differences maybe different to those with normally visible differences, meaning that different intervention techniques may be appropriate.

The original search yielded a total of 20,317 references. The titles of each article were read to identify titles that were at all relevant to the topic area. The first reviewer looked for the inclusion of terms such as “evaluation”, “efficacy”, “psychosocial intervention” and “visible difference” in the title specifically. A short list of 168 articles with relevant titles was produced. Each abstract was read once and those that did not relate to psychosocial interventions specifically for visible differences were removed (these included medical intervention papers and standard psychosocial interventions within the general population). This produced a second short list of 19 references. These 19 papers were analysed independently by two reviewers against the inclusion and exclusion criteria. All papers that did not look at the target population or were not psychosocial in nature were excluded. All

studies that did not assess clinical effectiveness were also excluded. This resulted in agreement to include 12 of the 19 papers. A team of experts verified these final studies selected for inclusion. The team of experts consisted of academics and clinical psychologists with extensive knowledge of the visible difference literature. The experts viewed the suggested list and confirmed that to the best of their knowledge, the list encompassed all papers in this field.

### *Methods of Analysis and Synthesis*

Data from included studies was extracted by one reviewer and confirmed by a second. Any disagreements were resolved by discussion and referral to the papers. Information pertaining to population characteristics, effect sizes, drop out rates, satisfaction with intervention, changes in psychological symptoms, changes in social and interpersonal functioning, location of intervention and content of intervention were collected. A third reviewer then made a final check.

The twelve papers included within the review consisted of varying methodological styles from case-series through to Randomised Controlled Trials (RCTs). This amount of heterogeneity does not lend itself to a quantitative synthesis; therefore, the papers were analysed using a narrative synthesis. All studies were assessed against research criteria (Appendix A). Each point on the checklist was counted as one mark. Papers were scored on the basis of how many of the criteria they met. The findings of this systematic review were assessed according to types of intervention. Each type of studies, e.g. case-series, before and after studies and experimental studies were assessed using different criteria. The scoring can be seen in Table 1.

## Results

There were 6 different types of intervention styles contained within the twelve reviewed articles. These were: self-help materials, individual CBT, group-based CBT, group-based person-centred therapy, group-based social skills training and support group-based interventions. The most notable methodological issues from each paper are presented. The studies included in this review are shown in Table 2.

### *Self-help Interventions*

Newell and Clarke (2000) conducted the only RCT into the effectiveness of psychosocial interventions for individuals with visible differences. The study assessed the effectiveness of a small CBT-based self-help booklet for individuals with visible differences suffering from phobic avoidance. The study employed 106 participants recruited through UK dermatology and plastic surgery outpatients departments and the media. All participants consisted of individuals with facial disfigurements resulting from dermatological conditions or conditions requiring plastic surgery. Participants (18 male, 88 female) were over 17 years of age. The intervention consisted of a self-help booklet consisting of 18 A5 pages containing an explanation of anxiety, its relationship to everyday life and to changes in facial appearance. The relationship between avoidance and anxiety was also stated. Cognitive-behaviour therapy (CBT) strategies for coping with anxiety were presented. The comparison group consisted of non-treatment controls that were promised treatment once the study had ended. The self-help booklet was mailed to participants for them to use in their own homes.

The procedure employed in this study was not completely random and did not use blinding of participants, assessors or analysts. The control and treatment groups were comparable at baseline, but the sample was not representative of the target population. The

authors only included participants with minor psychosocial difficulties, meaning that the findings cannot be generalised to individuals with more severe problems. The inclusion criteria used in this study was set so low that only those participants with mild social avoidance were included in the analysis. The study employed appropriate statistical analyses and the outcome measures were objective, appropriate and reported in sufficient detail. No large differences were identified between the before and after data, and no follow-up period was employed. Taking into account the above methodological considerations, the study was found to have limited validity. Therefore, there is only limited evidence to support the use of self-help interventions with individuals with visible differences.

#### *Individual CBT-based interventions*

Two studies assessed the effectiveness of individual CBT-based interventions (Kleve, Rumsey, Wyn-Williams & White, 2002; Papadopoulos, Bor & Legg, 1999). Papadopoulos et al. (1999) assessed the effectiveness of individual CBT-based counselling for individuals with vitiligo using an experimental design. The study employed 16 vitiligo patients recruited through UK dermatology outpatients departments. Participants (8 male, 8 female) were over 18 years of age, with a mean age of 39 years. The intervention consisted of eight, one-hour weekly sessions of CBT-based individual counselling. The comparison group consisted of a conventional treatment control group, which was no medical treatment.

The researchers conducted an a priori sample size calculation prior to the commencement of the study and both the statistical analyses and outcome measures were suitable and objective. The authors reported that the treatment and control groups were comparable on demographic measures at baseline, but there was no data relating to comparability on the baseline tests across the two conditions. The follow-up study contained an adequate number of people and the period of time was sufficient to measure sustained



treatment effects. The study did not employ a randomisation technique and there were no large differences between the before and after data. The study was found to have limited validity.

Kleve et al. (2002) evaluated the effectiveness of 3 to 6 sessions of CBT-based therapy to address the psychosocial issues experienced by individuals with visible differences using a before and after design. The study employed 36 participants recruited through referral to a specialist outpatient psychological clinic at Frenchay hospital, Bristol, UK by General Practitioners (33%), plastic surgeons (30%), dermatologists, an orthodontist, a neurosurgeon, an ophthalmic surgeon & a psychologist. Patients' conditions consisted of facial disfigurements (75%), upper body disfigurements (17%), lower body disfigurement (3%) and hand injury (3%). Participants (27 female, 9 male) were between 17 and 72 years, with a mean age of 34 years. The intervention consisted of between 3 and 6 sessions of CBT-based sessions.

This study employed different individuals for conducting and evaluating the intervention, but the study did not employ a control group. The statistical analyses and outcome measures were appropriate, objective and reported in sufficient detail. The period of follow-up employed was sufficient, as was the number of participants taking part in the follow-up session. The study identified large differences between before and after data. The researchers included an acceptability rating for the intervention that demonstrated that the participants generally found the intervention to be acceptable. The study was found to provide limited evidence. Overall only limited evidence was identified in support of individual CBT-based interventions for individuals with visible differences.

*Person-Centred Group Interventions (Group sessions of humanistic counselling)*

Papadopoulos, Walker and Anthis (2004) compared the effectiveness of 2 different group-based interventions against a treatment as usual (no medical treatment) control group using an experimental design. The study employed 47 vitiligo patients recruited through UK dermatology outpatients departments and the UK Vitiligo Society. Participants (13 male, 31 female) were over 18 years of age, with a mean age of 36 years. The first intervention consisted of eight, one-and-a-half-hour weekly sessions of CBT-based group counselling. The second intervention consisted of 8, 1.5-hour weekly sessions of person-centred group counselling. The comparison group consisted of a conventional treatment control group of no medical treatment.

This particular study did not employ a truly random selection process and did not use blinding of participants, assessors or analysts. An a priori sample size was conducted before the study commenced, and based on this figure the sample size used was just below that considered to be sufficient. The sample chosen, however, were not representative of the vitiligo population as a whole, with only mild symptoms being presented. The study employed objective and appropriate outcome measures, but the absence of vital statistics (the means for the outcome measures at baseline) meant that the results were not reported in sufficient detail. The groups were, however, comparable at baseline on demographic factors. Furthermore, the statistical analyses employed by the researchers were not suitable to the study, with no consideration being made for type 1 errors. The follow-ups were well conducted with appropriate period of follow-up being employed and sufficient numbers of participants taking part in both follow-up sessions. There were no large differences identified between the before and after data. The study was found to have poor validity. Therefore, only poor evidence can be found in support of person-centred group counselling interventions.

*Support Group Interventions*

Four studies employed a support group structure (Kang Seng & Siew Nee, 1997; Cooper & Burnside, 1996; Price et al., 1991; Bremer-Schulte et al., 1985). All four interventions were designed to enable individuals to cope more effectively with their respective conditions, both medically, and psychosocially.

Kang Seng and Siew Nee (1997) used a support group-based structure to address issues associated with psoriasis. The study employed 10 China-based psoriasis patients recruited through the Chinese Psoriasis Association and a social worker's caseload. Participants (6 male, 4 female) were aged between 25 and 53 years, with a mean age of 38 years. The intervention consisted of seven weekly group sessions discussing the psychosocial and medical aspects of psoriasis.

The study employed a case-series design. No follow-up was employed in this study and the outcome measures were neither objective nor appropriate, with no measures of functioning being included in the design. The statistical analyses were appropriate to the study, but the outcome measures were not reported in sufficient detail, with only percentages being provided in the results section. The study did not employ a control group. The researchers did include an acceptability analysis in the form of a semi-structured interview. The group support structure was found to be acceptable to the participants. This paper was found to have poor validity.

Cooper and Burnside (1996) used the group support structure to address issues associated with burn care evaluated using a case-series design. The study employed 34 participants recruited through a UK occupational therapy department. All participants consisted of individuals who had experienced burn injuries. Participants (24 male, 10 female) were between 19 and 78 years of age, with a mean age of 43 years. The intervention consisted

of open monthly group sessions (26 groups over three years) discussing psychosocial and medical issues of burn care.

The statistical analyses in this study were not appropriate with only percentages being presented in the results section. Outcome measures were not objective or appropriate, with no measures of functioning. Neither were they reported in sufficient detail. No follow-up period was employed in this study and no control group was used for comparison. As with the previous study, the researchers did include a qualitative acceptability analysis that demonstrated that participants did find the intervention type acceptable. Overall the study provided no evidence to support the intervention.

Price et al. (1991) also looked at the effects of support groups for individuals with psoriasis but employed an experimental design. This particular study looked at the impact of psychological therapy on the reduction of psychosocial difficulties in adult patients with psoriasis. The study employed 31 UK psoriasis patients recruited through attendance at a dermatology clinic. The data from the present study is based on 23 patients, as data were not collected from the remaining eight. The participants (12 male, 11 female) were aged 18 to 65 years. The intervention consisted of a series of two separate small group therapies comprising eight weekly sessions lasting 90 minutes. The technique included relaxation techniques, self-hypnosis and support group discussions of difficulties provided by a clinical psychologist.

The outcome measures used were objective and appropriate, and had been reported in sufficient detail. The results identified large differences in the before and after data for the anxiety measures and this finding was maintained at 6-month follow-up. This study employed an acceptability analysis of the intervention and found patients to be very enthusiastic about the intervention. Overall the study provided only poor evidence to support the intervention.

Bremer-Schulte et al. (1985) employed a series of Dutch psoriasis patients to take part in a support group to help address both medical and psychosocial aspects of psoriasis. This study employed 56 Dutch adult psoriasis patients younger than 70 years of age recruited from dermatology departments in 4 hospitals surrounding Amsterdam and from the psoriasis patient organisation. Twenty-eight of the patients took part in the intervention group, which consisted of 10 weekly two-hour group sessions of a support group where patients discussed both the somatic and emotional aspects of psoriasis. A fellow psoriasis patient and a physician ran this intervention. This intervention was compared against a waiting list control consisting of 28 patients.

This study also employed an experimental design. No attrition characteristics were provided in the paper regarding the waiting list controls. The study failed to report the outcome measures in sufficient detail to allow for the data to be effectively analysed, with the absence of means and standard deviations for the test measures across conditions. The authors devised the outcome measure used for the quantitative part of the study and it was unclear whether this was an objective measure. It would have been more appropriate to use a standardised measure. The data was not provided in sufficient detail to assess whether large differences existed between the before and after data. The follow-up period of the study involved a sufficient number of participants and occurred after a sufficient period of time.

The study also included some qualitative data. The goal of the qualitative assessment was to look at the effects of the intervention on anxiety and depression. However, it was unclear why the authors chose to assess these factors using qualitative, rather than quantitative data when many standardised measures exist to measure both anxiety and depression. There was also no clear discussion of the evidence for and against the reduction in anxiety and depression, making it impossible to defend the authors' conclusions regarding a reduction in both measures. Overall, taking into account both the quantitative and qualitative data supplied

by the authors, there is no evidence to support the effectiveness of this intervention at reducing psychosocial difficulties. Overall the four studies demonstrated that the evidence for the effectiveness of support groups for helping individuals with visible differences is poor to none.

#### *Group Social Skills Training Interventions*

Feigenbaum (1981) assessed the effectiveness of a 10-week group-based social skills training program for addressing the psychological needs of head and neck cancer patients with highly visible disfigurements. The study employed 17 participants recruited from patient lists at the Department of Otolaryngology Clinic, University of Cologne. The mean age of participants was 56 years. The intervention consisted of 10 weekly two-hour group social skills sessions. The groups discussed 36 social skills training areas falling within four categories: ability to make contact, ability to demand and express wishes, ability to reject, and ability to stand being criticised. Seven individuals took part in the intervention group. The comparison group consisted of 10 waiting list controls. Two behaviour therapists, one male and one female, undertaking Masters Theses delivered the intervention.

This study employed an experimental design. The main problem with this particular investigation was the lack of reported statistics throughout the entire paper. No means or standard deviations were provided for any of the outcome measures, no data was provided relating to the self-assessment of changes during therapy, no statistics were provided for the data collected at the 2-year follow-up, and no data was available to compare the groups at baseline. The authors stated that baseline comparability was achieved, but this claim cannot be supported in the absence of sufficient data. Furthermore, no information was provided regarding the reliability or validity for the outcome test scales used. Therefore, the outcome measures cannot be said to have been appropriate. Additionally, many of the tests used in the study were self-designed and did not appear to have been validated prior to use in this study.

Where statistics were stated, these were found to be inappropriate, with the researchers failing to use multiple analyses of variance.

There was, however, no attrition during the main part of the study, and the dropout rate at the 2-year follow was provided. The researcher also included information regarding the causes of attrition, although failed to provide attrition characteristics for the follow-up session. Both the rate of participants taking part in the follow-up and the period of follow-up were sufficient. Large differences were presented between the before and after data. Overall this study was found to have poor validity.

Robinson, Rumsey and Partridge (1996) assessed the effectiveness of a 2-day social skills workshop for individuals with visible differences using a before and after design. The study employed 106 UK participants recruited through both self-referrals and clinical referrals. All participants consisted of individuals with disfiguring conditions. Most participants had facial disfigurements consisting of burns, clefts, birthmarks, facial palsies, cancer-related disfigurements, vitiligo and acne. Participants (23 male, 41 female) were aged 17 – 75 years, with a mean age of 38 years.

This study employed a person independent of the researchers to conduct the intervention. Although the outcome measures were both objective and appropriate, and reported in sufficient detail, the statistical analyses were not suitable to the study, with the researchers failing to carry out multiple comparisons. The study failed to employ a control group. Large difference were found between the before and after data, and the follow-up period employed was adequate. Unfortunately, the rate of attrition at follow-up was so high that an insufficient number of participants were included in the data set. The researchers did include a qualitative form of an acceptability analyses and found that participants considered the format to be acceptable. Overall the study was found to provide limited evidence for the

clinical effectiveness of group social skills training interventions. Overall, poor to limited support has been identified for the use of group SST with individuals with visible differences.

### *Group CBT-based Interventions*

Papadopoulos et al. (2004) assessed the effectiveness of 2 different group-based interventions for addressing the psychosocial needs of individuals with vitiligo against a treatment as usual (no medical treatment) control group using an experimental design. This paper is discussed within the person-centred group therapy section of this review. Overall the study was found to have poor validity. The authors' claim that the CBT approach employed in this study may be appropriate for treating anxiety and depression alone. However, these claims cannot be substantiated due to a lack of data. The authors failed to include the relevant subscales on the General Health Questionnaire (GHQ) necessary to support their claims.

Fortune, Richards, Kirby, Bowcock, Main and Griffiths (2002) and Fortune, Richards, Griffiths and Main (2004) assessed the effectiveness of a cognitive-behaviour group intervention for addressing illness perceptions and coping strategies in individuals with psoriasis against standard pharmacological treatment. The study employed 93 psoriasis patients recruited through the Psoriasis speciality clinic at Hope Hospital, Manchester, UK. Any participants experiencing other medical conditions were excluded from the study. Participants were aged between 18 and 69 years. Assignment to the two treatment groups was based on patient preference random allocation. The intervention group consisted of six, two-and-a-half-hour sessions of CBT group therapy also addressing illness education and stress-management. A clinical psychologist and a team of nursing staff administered the intervention. These individuals were not the authors of the paper. The control group was given standard treatment, which in this case was pharmacological treatment without psychological intervention.



The two papers reported on different aspects of the same study. The study employed an experimental approach but failed to employ a truly random selection process or to use appropriate blinding of participants, assessors or analysts. The randomisation technique consisted of a patient preference allocation. An Intention-To-Treat (ITT) analysis was used to assess clinical change. The control and treatment groups were comparable on demographic characteristics, clinical severity, coping strategies and illness perception at baseline. The outcome measures employed were objective and appropriate, and were reported in sufficient detail. The statistical analyses were appropriate to the study design.

The attrition rate at post-treatment was comparable across the two treatment groups, but at follow-up a greater number of control participants dropped out compared with those in the intervention group. No information was given about attrition characteristics or cause. Large differences were detected between before and after data on most measures. The study failed to conduct an acceptability analysis to assess how happy participants were with the structure of the intervention, although the selection process was based on preference, indicating that at least initially a large number of participants were interested in taking up the intervention. Overall the study was found to have limited validity. Overall poor-to-limited support exists for the use of group CBT interventions with individuals with visible differences.

Overall, the results from this review indicate that no fully satisfactory studies have been found in the literature to support the efficacy of existing psychosocial interventions for visible differences.

## Discussion

The strength of the evidence to support the effectiveness of the existing interventions from this narrative synthesis is poor. The methodological quality of the included studies was

limited and small intervention effect sizes were observed. The studies looked at differing interventions making judgments about consistency across studies impossible because each study used different intervention settings, e.g. group, self-help or face-to-face and paradigms, e.g. CBT, SST or person-centred.

The length of intervention required was unclear with studies ranging from 3 to 10 sessions, or no actual therapy sessions at all in the case of the self-help materials. No firm conclusions can be made regarding the optimum therapy time required to reduce psychosocial difficulties, or the most appropriate setting for these interventions. Neither can conclusions be drawn about the level of therapist contact or expertise required to produce optimum results. Due to the wide-ranging use of therapeutic paradigms of each intervention, it was not possible to draw any firm conclusions regarding the acceptable content of psychosocial interventions for the visibly different population, or the adequate implementation of these interventions. The participant populations were also varied in terms of conditions and symptom severity. Further studies need to be conducted to establish which interventions are most effective for specific sub-populations.

Most of the interventions reviewed in this study were based at centres in large cities. Even the interventions that did offer more widespread services provided centres that were based only in large towns. Only the self-help materials allowed distribution across a wide area. Therefore, the current interventions have failed to provide a service that is widely available, and by their location often excludes those who come from rural areas. This is always a problem when providing such an intervention, but further research is needed to ensure that those in remote areas can access these interventions. Similarly, a large percentage of clients with visible differences experience social avoidance problems. Expecting these individuals to travel long distances to large towns or cities to take up support services is unrealistic. Service provision needs to allow for these individuals, with interventions being

made available much closer to home. Future studies may be able to address these difficulties with the introduction of internet-based interventions such as the program currently being designed by the authors (Bessell, Harcourt & Moss, 2007).

It must be emphasised that despite the methodological problems associated with assessing these interventions, the techniques themselves are still important. Although their effectiveness has not been adequately demonstrated, these interventions are necessary for increasing service provision for individuals with visible differences. These include interventions run by the specialist psychological outpatient clinic at Frenchay Hospital in Bristol, UK, the UK charity Changing Faces and other techniques in the US, such as the social skills interventions run by Kathy Kapp-Simon for adolescents with cleft lip and palate through the charity AboutFace USA in Illinois, and those run by Pat Blakeney for those with burns injuries at Galveston Burns Hospital in Texas. They are also needed to address the issue of an overall package of care for visibly different clients from medical treatment right through to adjustment and psychosocial functioning. For these reasons, further testing of these interventions is a fundamental step.

The current interventions have provided some support for the CBT and SST models. These techniques offer individuals practical solutions to some of their social difficulties without pathologising them. Although it is clear that there is a need for individuals to have access to resources such as grief or trauma counselling, particularly after an acquired difference in order to cope with changes in body image, many individuals simply require brief solution-focussed interventions. This can be provided by CBT and SST techniques. Furthermore, evidence from the acceptability measures used in some of the studies that involved these approaches has suggested that individuals with visible differences do find these types of interventions acceptable. This is further supported by a felt needs assessment recently conducted with potential service users within the field of visible difference, which

identified that most service users found the idea of CBT or SST to be acceptable and positive (Bessell et al, 2007). This is an interesting point to note as it demonstrates that individuals with visible differences do not find the idea of interventions associated with their appearance stigmatising, as has often been a concern by experts in the past.

Credit must be given to the existing studies for trying to evaluate interventions for such a hard-to-reach population. Designing interventions specifically for certain conditions classified as affecting appearance can be very difficult due to the rarity of some conditions. Even when designing interventions for a wide range of conditions, the population can still be difficult to reach leading to low sample sizes and the population can vary widely, making generalisability a problem. Future research needs to consider the use of multi-site studies in order to recruit larger numbers of participants and thus increase the reliability of the findings of such evaluations.

Despite the lack of evidence to support the existing interventions in this review, other reviews have produced more favourable findings in other aspects of appearance research. A meta-analysis of body image cognitive-behavioural programs found strong support for the interventions' abilities to reduce body image difficulties (Jarry & Ip, 2005). The review incorporated self-help, therapist-led, group and individual CBT techniques used in conjunction with other techniques such as psychoeducation, and perception training. The review identified significant effects of the different therapy types, with response prevention and exposure techniques proving most effective. It concluded that therapist-led interventions were most effective, although any CBT intervention has positive treatment effects. In relation to self-help materials, the report emphasised the importance of therapist-led interventions and a previous study indicated that even minimal therapist contact is more effective than none at all (Jarry & Berardi, 2004). The most important aspects of CBT for modifying body image were found to be psychoeducation, self-monitoring, cognitive restructuring, exposure,

response prevention and desensitisation. The report looked at the effects of such interventions on both clinical and non-clinical populations and found improvements in both groups, with the greatest improvement being demonstrated in the clinical population.

Although the study predominantly looked at the effects of such interventions on body image, it also looked at their effects on other psychological measures such as depression, anxiety and self-esteem. Significant improvements were identified on all of these measures and all were maintained at follow-up. This identifies that CBT is an effective intervention for reducing psychosocial difficulties. This study is encouraging for the field of visible differences. Body image research focuses on participants who have appearance-related concerns, but do not experience actual objective visible differences, and as such deals with a different population. Although the authors were keen to point out that the findings did not stretch to visible differences, there are many parallels when considering the psychosocial difficulties that both populations experience. Many individuals with visible differences experience body image concerns as a result of a discrepancy between their actual and ideal selves (Higgins 1987). Therefore, it is likely that CBT could provide similar results for individuals with visible differences.

The lack of sufficient evidence for the effectiveness of the existing interventions allows much scope for future research. The field of interventions for visible differences has long been ignored and the inclusion of only twelve papers in this review is testament to this. Many more studies need to be conducted into the effectiveness of existing interventions, with particular attention being paid to providing more RCTs and experimental studies. Current practice involves very limited testing of the effectiveness of interventions, and this needs to be addressed. Within the UK, the lack of service provision within the NHS has led to an increased need amongst this population (Bessell et al, 2007). The authors suggest that the reason for the lack of scientifically tested interventions is that many self-funded charities have

had to pick up the shortfall in service provision and these organisations have been more concerned with spending money on providing services than on evaluating them. Furthermore, with limited money available for research into visible difference, research centres are hard pushed to carry out cheap and quick evaluations whilst ensuring scientific rigour does not suffer. The resources involved in performing fully blind RCTs for psychosocial interventions are expensive and require large clinical and research team, which most budgets do not allow for.

Not only are more studies needed, but also these studies need to be of a higher methodological quality to allow firm conclusions to be drawn. Studies need to include ITT analyses as standard, provide more detailed information about attrition characteristics, rates and causes, measure interventions against control groups as standard, include more comprehensive inclusion and exclusion criterion and systematically use standardised outcome measures to analyse effects. Greater sample sizes are required in order to obtain more robust data. Furthermore, attention needs to be paid to measuring patient acceptability, and interventions need to be compared in order to assess patient preference.

Overall this review concludes that to date there is insufficient information available regarding the optimal setting for interventions of this nature, the optimal service provider or the optimal intervention type. All these factors must be addressed in order to demonstrate effectiveness in the future.

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## Appendix A: Methodological Assessment Criteria

Quality Criterion
<b>1.Exclusion/Inclusion Criteria</b> Was the exclusion & inclusion criterion for participants made explicit?
<b>2. Randomisation Method</b> Was the method of generating the allocation sequence truly random?
<b>3. Concealment of Randomisation</b> Was the allocation sequence concealed?
<b>4. Blinding: Outcome Assessors</b> Were outcome assessors blinded to the treatment allocation?
<b>5. Blinding: Participants</b> Were participants blinded to their treatment allocation?
<b>6. Blinding: Data analysts</b> Were data analysts blinded to the treatment allocation?
<b>7. Blinding Check</b> Was the success of blinding checked?
<b>8. Baseline Comparability</b> Were groups similar at baseline regarding prognostic factors?
<b>9. Is Sample Representative?</b> Are those included representative of the target group in general?
<b>10. Sample Size Calculation</b> Was an a priori sample size calculation conducted?
<b>11. Attrition Rate</b> Was the loss of participants similar across groups?
<b>12. Attrition Characteristics</b> Were the characteristics of the attrition group compared with those in the study?
<b>13. Attrition Cause</b> Were the reasons for attrition provided in the study?
<b>14. Treatment Comparability</b> Were groups treated identically other than the named intervention?
<b>15. Treatment Factors</b> Other than the interventions provided, were there any other care factors that could have affected outcome?
<b>16. Intention-to-Treat Analysis</b> Did the analysis include an intention-to-treat analysis?
<b>17. Statistical Analysis</b> Were the statistical analyses suitable to the study?
<b>18. Outcome Measures</b> Were objective & appropriate outcome used measurements used?
<b>19. Outcomes and Estimation</b> Are relevant outcomes reported in sufficient details?
<b>20. Are there large differences in Before and After Data?</b> Are there statistically significant large differences in functioning between before and after data?

<b>21. Acceptability of Intervention</b> Was an analysis of acceptability of intervention provided?
<b>22. Adequacy of Follow-up</b> Did a sufficient number of participants provide post-intervention data?
<b>23. Adequacy of Follow-up Period</b> Did a sufficient period of time elapse prior to follow-up?
<b>24. Generalisability of Intervention to Visible Differences</b> Are the results generalisable to all clients with visible differences?

Table 1  
Scoring of methodological Validity

Study Type	Scoring				
	No Evidence	Poor Evidence	Limited Evidence	Good Evidence	Excellent Evidence
<b>RCT &amp; Quasi-experimental</b>	0-4	5-9	10-14	15-19	20+
<b>Before and after</b>	0-2	3-5	6-8	9-11	12+
<b>Case series</b>	0-2	3-5	6-8	9-11	12+

Table 2  
Data Extraction Summary of Included Studies

Study	Participants	Intervention	Context	Control	Outcome
<b>Newell &amp; Clarke (2000)</b>	108 UK-based dermatology/ plastic surgery outpatients	CBT-based self-help booklet	Clients' homes	No treatment control	Fear Questionnaire Social Adjustment Questionnaire General Health Questionnaire Hospital Anxiety & Depression Scale Administered at pre-intervention and 3-mth post-leaflet distribution
<b>Papadopoulos et al. (1999)</b>	16 UK-based vitiligo patients	8, 1-hour weekly sessions, CBT-based individual counselling	Counselling rooms at City University, London, UK	Conventional treatment – No medical treatment	Dermatology Life Quality Index Rosenberg Self-esteem Scale Situational Inventory of Body Image Dysphoria Body Image Automatic Thoughts Questionnaire Administered at pre and post-intervention and 5-mth follow-up
<b>Kleve et al. (2002)</b>	36 UK-based visibly different patients	CBT-based program. 3-6 weekly sessions	British National Health Service Clinic	No Control	Hospital Anxiety and Depression Scales Positive And Negative Affect Scale Satisfaction With Life Scale Derriford Appearance Scale Social Situations Questionnaire Administered at pre and post-intervention and 6-mth follow-up
<b>Papadopoulos et al. (2004)</b>	47 UK-based vitiligo patients	8, 90 min, weekly group CBT sessions or	Counselling rooms at London	No medical treatment	Rosenberg Self-Esteem Scale Body Image Automatic Thoughts Questionnaire

		8, 90 min, weekly group person-centred sessions	Metropolitan University, UK			Situational Inventory of Body Image Dysphoria General Health Questionnaire Perceived Stress Scale Dermatology Quality of Life Index Administered at pre and post-intervention and 6 and 12-mth follow-up
<b>Kang Seng &amp; Siew Nee (1997)</b>	10 China-based psoriasis patients	7 weekly support group sessions	Not reported	No Control		Non-standardised Questionnaire to assess effectiveness Administered post-intervention
<b>Cooper &amp; Burnside (1996)</b>	34 UK-based Burns patients	26 Monthly support group sessions	Regional occupational therapy units, UK	No control		Self-designed survey of 15 key areas of service provision Administered post-intervention
<b>Price et al. (1991)</b>	23 UK-based Psoriasis patients	8, 90-min support group sessions	Not reported	Not reported		Hospital Anxiety and Depression Scale, self-esteem, social adjustment, EPQ-R Administered at pre and post-intervention and 6-mth follow up
<b>Bremer-Schulte et al. (1985)</b>	42 Dutch Psoriasis patients	10 weekly 2-hour support group sessions	Not reported	Waiting list control		Equilibrium Assessment and qualitative assessment of anxiety, depression and mastering of skills Administered at pre and post-intervention and 3-mth follow up

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<b>Fiegenbaum (1981)</b>	17 Germany-based head and neck cancer patients	Group therapy 10, 2-hour weekly sessions	Not reported	Control waiting list patients	Self-Insecurity Questionnaire Self-designed questionnaires measuring anxiety in social situations, self-discontent & subjective measure of therapy effects Administered at pre and post-intervention and 2-year follow-up
<b>Robinson et al. (1996)</b>	106 UK-based visibly different clients	2-day group social skills workshop	Not reported	No control	Hospital Anxiety and Depression Scales Social Avoidance and Distress Scale Open-ended questionnaire Administered at pre and post-intervention and 6-mth follow up
<b>Fortune et al. (2002; 2004)</b>	93 UK-based psoriasis patients	6, 2.5-hour CBT group sessions	British National Health Service Clinic	Standard medical treatment	Illness Perception Questionnaire, COPE, TAS-20 (measures alexithymia) Psoriasis Disability Index, Hospital Anxiety and Depression Scales, Psoriasis Life Stress Inventory, Psoriasis Area and Severity Index

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