Visible difference and social anxiety: An examination of relevant variables and the effectiveness of an acceptance-based intervention

Luke David Powell

Submitted in partial fulfilment for the award of Doctor of Clinical Psychology at the University of Sheffield.

May 2018

Declaration

I declare that this work has not been submitted for any other degree at the University of

Sheffield or any other institution. This thesis is my own original work and all other

sources have been referenced accordingly.

Structure and Word Counts

Section One: Literature Review

Excluding references	7,865
Including references	12,035
Including references and appendices	12,386

Section Two: Research Report

Excluding references	7,701
Including references	10,351
Including references and appendices	25,980

Total word count

Excluding references and appendices	15,794
Including references and appendices	38,594

Overall Abstract

The first part of this thesis is a systematic literature review examining the variables associated with social anxiety in adults living with skin conditions. The second part of this thesis is a randomised controlled trial examining the effectiveness of an acceptance-based self-help intervention which aimed to increase psychological flexibility in adults living with a visible difference in appearance.

Thirteen studies examining the relationship between social anxiety and other variables were included within the literature review. Moderate levels of social anxiety were present in the existing studies. Increased social anxiety was consistently associated with impairments in quality of life, increased distress, and reduced self-esteem. No clear link between social anxiety and skin condition visibility or severity was observed. The evidence examining the relationship between social anxiety and stigmatising experiences was limited but may suggest an association.

Participants within the research study (n = 284) were randomised to either an acceptance-based self-help condition or a waitlist condition for the four-week trial period. Participants self-reported moderate levels of fear of negative evaluation, distress and functional impairments associated with their visible difference in appearance. The intervention did not significantly improve psychological flexibility compared to the control condition. However, there was a significant reduction in functional impairments in the intervention condition. A significant reduction in fear of negative evaluation was also observed for the intervention condition within completer analyses, though this finding was non-significant in intention-to-treat analyses.

List of Contents

Part One: Literature Review

Variables associated with social anxiety in adults with a skin condition: A systematic

review

Literature Review Appendices

Part Two: Research Report

Acceptance-based self-help for individuals with a visible difference in appearance and

social anxiety: A randomised control trial

Research Report Appendices

[THIS PAGE HAS BEEN LEFT INTENTIONALLY BLANK]

Section One: Literature Review

Variables associated with social anxiety in adults with a skin condition: A systematic

review.

Abstract

Objectives. Many individuals with a skin condition experience social anxiety, which often centres around a fear of being negatively evaluated by others. This review aimed to examine factors associated with social anxiety in adults with a skin condition.

Methods. A systematic search of four databases: Psycinfo, Cinahl, Medline and Scopus was conducted. Studies which examined relationships between social anxiety and other variables in relation to a skin condition population were included. Thirteen studies were included and systematically appraised.

Results. Studies typically examined the relationship between social anxiety and the following variables: other forms of distress (mostly depression or general anxiety), skin condition visibility or severity, quality of life, and self-esteem. The existing studies indicate moderate levels of social anxiety are present within skin condition populations. Higher levels of social anxiety were associated with impairments in quality of life, increased distress and reduced self-esteem. The studies were equivocal with regards to the relationships between social anxiety and skin condition severity and visibility. The small number of studies which examined stigmatisation suggested it may have an association with social anxiety.

Conclusions. This review confirms social anxiety is a significant issue for people living with skin conditions and suggests social anxiety strongly associates with other psychological variables. As individuals living with skin conditions may benefit from psychological support, this review may indicate a need for screening tools for social anxiety within dermatology clinics.

Practitioner points:

- Social anxiety is common within adults living with a skin condition.

- Psychometric screening may be beneficial within dermatology clinics, as distress often goes untreated and does not associate with skin condition severity or visibility.

- Social anxiety most strongly relates to other psychological variables, such as self-esteem.

- Individuals living with a skin condition and experiencing social anxiety may benefit from support promoting an accepting or positive self-image.

- The findings of this review should be taken with caution due to the limited number of included studies.

- This review is limited by cross-sectional designs and cannot infer causal relationships between variables.

Introduction

Skin conditions affect millions of people worldwide with a lifetime prevalence above 30% and they are one of the foremost causes of global disease burden (Hay et al., 2014). Though the impact and extent of dermatological disease varies, they can result in significant life impairments. Whether present from birth or acquired, a visible difference in appearance, which may arise as part of a skin condition, can have a profound impact (Rumsey & Harcourt, 2004, 2005). Chronic skin conditions are associated with emotional distress at rates above those within the general population, and anxiety appears to be particularly prevalent (Parna, Aluoja, & Kingo, 2015). A multinational study demonstrated adults living with a skin condition had elevated rates of clinical depression and clinical anxiety compared to those without a skin condition; 10.1% compared to 4.3% and 17.2% compared to 11.1% for depression and anxiety respectively (Dalgard et al., 2015). Studies have suggested anxiety is typically elevated in skin condition populations above and beyond depression (Clarke et al., 2012; Cordeiro et al., 2010), though depression can also be common (Magin, Sibbritt, & Bailey, 2009). For example, in a recent meta-analysis, Osinubi et al. (2017) reported 1 in 4 people living with vitiligo experience depression. Furthermore, individuals with appearance differences often have comparable levels of social anxiety with individuals with agoraphobia (Newell & Marks, 2000). However, it is important to recognise there are many individuals who do not report distress or impairment due to their skin condition (Rumsey et al., 2002).

Many studies have examined whether living with a skin condition impacts upon quality of life; with impairments consistently demonstrated across skin conditions, including psoriasis (Kimball et al., 2010; Obradors et al., 2016), acne (Dunn, O'Neill, & Feldman, 2011), bullous pemphigold (Kouris et al., 2016), and vitiligo (Ghajarzadeh, Ghiasi, & Kheirhhah, 2012) to name a few. However, whilst it is important to

understand quality of life impairments; quality of life measurement acts as a measure of impact and does not enable identification of psychological factors which may contribute to impairment.

Qualitative studies have sought to examine the processes and experiences which underpin quality of life impairments and difficulties in adjusting to living with a skin condition (Johnston, Krakuska, Millings, & Thompson, 2018). Murray and Rhodes (2005) interviewed adults with severe acne to identify themes related to quality of life. A theme about self-identity emerged, which described how some individuals compared themselves to others to generate a view of their own self-worth. This is emphasised in another study using a population living with visible difference, which highlighted how difficulties with self-image, self-esteem and self-identity are the most prominent issues, over and above depression and anxiety, and lead to increased avoidance and social phobia (Magin et al., 2006). Within their findings, Murray and Rhodes (2005) described how the social burden of acne impacted on general social interactions, which included others not making physical contact with them and being stared at. These stigmatising experiences can be common for people living with visible differences, such as skin conditions (Thompson et al., 2002, 2010).

Experiences of stigma or prejudice may be one factor which could have a large impact upon quality of life through causing distress in social situations. The impact upon private, social and work life appears to be exaggerated by perceived and actual stigmatisation (Esch, Rubsan, Baum, & Busner, 2014). Individuals living with a skin condition often report having experienced discrimination, such as negative comments towards them (Thompson et al., 2010). A meta-ethnography conducted by Ablett and Thompson (2016) examined the experience of young people living with skin conditions, finding the primary issues for young people were appearance concern, feeling stigmatised and feeling different to others. The experience of stigma in adolescence is

5

associated with adverse psychological sequelae, with qualitative research suggesting experiencing stigma leads to increased social anxiety and shame, and decreased self-esteem (Magin et al., 2008; Thompson et al., 1999; Thompson & Kent, 2001). Experiences of stigma may mediate the impact of living with a skin condition on quality of life (Vardy et al., 2002).

These negative life events, peer experiences and culture can contribute to the development of social anxiety, driven by a desire to avoid these unwanted experiences. As well as there being an impact of actual stigmatisation experiences, individuals may also overestimate threat within social experiences, which consequently maintains the social anxiety (Thompson & Montgomery, 2018; Wong & Rapee, 2016). Social anxiety is defined as "A persistent fear of one or more social or performance situations in which the person is exposed to unfamiliar people or to possible scrutiny by others" (American Psychiatric Association, 2013).

Social anxiety is generally elevated in those with appearance concerns (Rumsey & Harcourt, 2004; Thompson & Kent, 2001) and avoidant coping strategies are often used (Magin et al., 2009). A sense of feeling judged by others, or experiencing self-directed emotions, such as shame, may result in an individual restricting their life or using concealment (Thompson & Kent, 2002; Tuckman, 2017).

Perhaps the best-known theories of social anxiety were created by Clark and Wells (1995) and Rapee and Heimberg (1997). Both models include a concept of an internal focus, with an attentional bias towards information which may be negatively appraised. There is evidence to support the role of attentional bias within social anxiety (Bar-Haim et al., 2007) and early evidence suggests attentional biases are present within adults living with visible differences, such as skin conditions (Rosser et al., 2010). Rapee and Heimberg's (1997) model has a slightly wider focus, as it includes the

6

concept of an audience and splits attention between internal and external information, whereas Clark and Wells (1995) focus upon internal experience. There is evidence to support the idea of a perceived audience (Schultz & Heimberg, 2008), which is important when considering the construct of fear of negative evaluation – and experiences of stigmatisation.

Fear of negative evaluation is a concern or expectation of being perceived negatively by others, and it is a central construct within social anxiety (Turner, Beidel, & Townsley, 1992). Unsurprisingly, individuals with concern about how their appearance is evaluated by others are likely to score highly in fear of negative evaluation; with individuals with skin conditions describing living with a fear of rejection (Borimnejad, Yekta, & Nasrabadi, 2006). However, appearance concern is just one aspect of fear of negative evaluation and is not always present in individuals with high levels of fear of negative evaluation. For example, fear of negative evaluation may exist within a population living with skin conditions, but this may be due to factors such as social isolation and stigmatisation experiences, rather than appearance concern – though there is likely to be overlap between these variables.

The existing literature strongly suggests the presence of a social burden of living with a skin condition which can result in feelings of social anxiety and fear of negative evaluation, amongst other psychological variables (Dalgard et al., 2015; Evers et al., 2005). However, experiences of distress may go untreated as clinicians are generally unable to detect distress in their patients (Richards et al., 2004) and screening is not routinely used. This may be due to clinicians primarily focusing upon the severity of the skin condition. Unfortunately, some individuals living with skin conditions have reported clinicians can be insensitive to emotional suffering and appear to trivialise patients' concerns (Magin et al., 2009).

The difficulty in recognising psychological needs of dermatological patients may be due to the presence of a subjective severity-adjustment relationship implicit within both clinical practice (Kleve et al., 2002) and social-cognitive theorising (Moss & Carr, 2004). This relationship assumes psychological distress may increase with greater severity of a skin condition. Though some findings are consistent with this relationship (Brown et al., 2010), the extent or severity of the skin condition does not always correlate with mental health status (Andrews et al., 2010; Finzi et al., 2007; Fortune et al., 2002; Fortune et al., 2004). Research has also demonstrated severity, or the type of skin condition are not consistent predictors of adjustment to a skin condition (Moss, 2005; Ong et al., 2007). There may also be variation in adjustment or social anxiety across skin conditions (Dalgard et al., 2015), however these differences are difficult to obtain as the majority of studies examine one type of skin condition only and variation within measurement further prevents comparison. Confounds, such as cultural differences may also impact upon comparisons across studies.

Much research has focused on adjustment and sought to examine factors which contribute to adjustment and there is agreement within the literature to suggest physical, cultural, psychosocial factors are important (Clarke, 1999; Falvey, 2012). Identifying factors contributing to the variation is important as it directs screening to ascertain risk of distress and may inform intervention targets. Other studies have highlighted family dynamics, attachment, the media and health beliefs as important factors (Adamson & Doud-Galli, 2009; Bogels, van Oosten, Muris, & Smulders, 2001; Kent & Thompson, 2002; Krakuska, Lavda, Thompson, & Millings, 2017). Indeed, frameworks have been created to explain adjustment factors (Appearance Research Council, 2014; Rumsey et al., 2012). The Appearance Research Council (2014) theorised a framework in which predisposing factors, such as age, gender, ethnicity, visibility, media and peer influences could lead to outcomes such as social anxiety, avoidance, depression, shame and

8

feelings of anxiety. They theorised this occurred through cognitive processes, including dispositional style, appearance-specific cognitions and socio-cognitive processing, such as whether the individual felt socially accepted.

It is clear physical, psychological and social aspects all play a role within living with skin conditions (Evers et al., 2005), and this review aims to examine the nature of relationships between social anxiety and other variables within adults with skin conditions. This will allow consideration of whether models of social anxiety are useful in understanding the individual variation in the social burden associated with skin conditions. This may also reveal factors which might be targeted in the holistic management of social anxiety associated with living with a skin condition. This review will examine quantitative studies using recognised measures of social anxiety and related concepts, such as fear of negative evaluation, in a systematic review.

Methods

This systematic review is registered on the international prospective register of systematic reviews (PROSPERO); with identifier CRD42018094197.

Identification of Relevant Papers

To identify studies which examined social anxiety with a population of individuals with a skin condition, searches were conducted on Psycinfo, Cinahl, Medline and Scopus databases in February 2018. The methodological approach was informed by guidance from the Centre for Reviews and Dissemination (2008).

As there is an array of skin conditions, where possible, terms were matched to broader subject headings in database searches (e.g. 'skin disorders'), and the most prevalent skin conditions were included as search criteria.

For retrieval, articles had to meet three criteria; firstly, the study had to be focussed on a recognised skin condition/disease, secondly the study design had to use appropriate survey methods, and finally the study had to use recognised measures of 'social anxiety', 'social phobia' or 'fear of negative evaluation'. The keyword searches were identical for all four databases:

1) *Population Search Criteria*: "psoriasis", "eczema", "atopic dermatitis", "alopecia", "rosacea", "vitiligo", "visible difference", "acne", "skin condition", "altered appearance", "unusual appearance" (all OR)

AND

2) *Design Search Criteria*: "factor*", "mediat*", "moderat*", "impact", "relationship", "model", "cross-sectional", "correlat*" (all OR)

AND

3) *Variable search criteria*: "social anxiety", "social phobia", "social worries", "fear of negative evaluation" (all OR).

Subject headings were used for Psycinfo and Medline. Subject headings for Psycinfo were: "skin disorders", "alopecia", "dermatitis" and "social anxiety". Subject headings for Medline were: "alopecia", "psoriasis", "eczema" and "skin". Further scoping through citation searches was also utilised.

Selection Criteria and Article Retrieval

Studies were included where participants were diagnosed with a skin condition, a measure of social anxiety was used, and analysis included examination of social anxiety in relation to other variables. Studies were excluded if they focused on other types of visible difference in appearance, such as craniofacial conditions, burns or surgical scarring. This was done in an attempt to increase the homogeneity of the

10

included participants, as their visible differences in appearance would have been caused by disease processes rather than physical trauma. Reviews, qualitative and intervention studies were excluded. Only journal articles available in English were retained.

Whole articles were read when the abstract indicated potential to meet inclusion criteria. References of relevant papers were also examined to identify further relevant studies. The PRISMA diagram (Moher, Liberati, Tetzlaff, Altman, & The PRISMA Group, 2009) shown in Figure 1 depicts the retrieval process. Conducting a meta-analysis was not possible due to the limited number of studies and lack of homogeneity across studies and their psychometric measurements.

Records identified through databases: Psycinfo ($k = 29$), Medline ($k = 63$), Scopus ($k = 99$), Cinahl ($k = 10$)	Articles identified through citation searches ($k = 7$)

Records screened ($k = 208$)	Records excluded on basis of title and abstract ($k = 118$) Duplicates removed ($k = 61$)

Full text articles assessed for eligibility ($k = 29$)	Excluded (k = 16) Did not measure social anxiety ($k = 7$) Did not examine relationship with social anxiety (k = 9)

Articles included in the review ($k = 13$)

Figure 1. PRISMA diagram showing flow of papers through the review.

Data Extraction and Quality Assessment

      The following information was extracted from each article: authors, design, participant information, psychometric measurements and recruitment strategy. Guidance provided by Cohen (1988) was used to review correlation effect sizes, where $r = .10$ to .29 were small, $r = .30$ to .49 were medium, and $r = .50$ and above were large.

      Quality of included studies was appraised using the appraisal tool for cross-sectional studies (AXIS: Downes, Brennan, Williams, & Dean, 2016). The AXIS tool was selected for appraisal as it is the one of only two appraisal tools specifically designed for cross-sectional methodology. The alternative appraisal for appraising cross-sectional designs; STrengthening the Reporting of OBservational studies in Epidemiology (STROBE: Berra et al., 2008) was not selected as it only assesses the quality of reporting and does not assess risk of bias. Other options were available, such as the Risk Of Bias In Non-randomised Studies - of Interventions (ROBINS-I: Sterne et al., 2016), however this is designed primarily for use with case-control and cohort studies and therefore falls short of allowing full appraisal of cross-sectional designs.

      Quality appraisal was used to review individual studies and gather an understanding of the quality of studies in this area generally, as well as allowing for recommendations for future research. Studies were not excluded on the basis of quality appraisal. To ensure accurate quality appraisal, four studies were rated by a peer researcher, discrepancies were resolved through discussion. The AXIS appraisal tool can be viewed in Appendix A. See Appendix B for the quality appraisal of selected studies.

Results

Thirteen studies were eligible for inclusion. Ten of the thirteen studies recruited from outpatient dermatology clinics with others using a dermatology register and sampling from dermatology-related groups/charities. With regards to skin conditions; four studies focused on psoriasis, three studies on acne and two studies on vitiligo (one study included both vitiligo and acne; Salman et al., 2016). Three studies included a range of dermatology outpatients, whilst individual studies examined individuals with eczema, and systemic sclerosis. Studies included between 49 and 318 participants and all used cross-sectional designs.

Across the retrieved studies there appeared to be several themes. Studies often examined: the severity of the skin condition, the impact on functioning and/or quality of life, stigmatisation, general distress, self-esteem, and demographic factors. The findings are consequently reported in relation to these factors, following by an appraisal of the research. Table 1 summarises the 13 studies in this review, their designs, sample characteristics, settings and psychometric measures.

Table 1. *Characteristics of included studies*

Author and year	Country	Design	Participants	Setting	Psychometric measures
Balkrishnan et al. (2006)	United States	Cross-sectional	73 women with a variety of skin conditions causing blemishes	Outpatient dermatology clinic	BASI, Skindex-16, FNE
Evren & Evren (2007)	Turkey	Cross-sectional	50 consecutive female outpatients with a dermatological condition	Outpatient dermatology clinic	LSAS, TAS-20, SCL-90-R, STAI, BDI
Kent & Keohane (2001)	United Kingdom	Cross-sectional	141 patients previously treated for psoriasis at a dermatology clinic	Postal responses from a dermatology patient register	BFNE, HADS, DLQI, RSE.

Krüger & Schallreuter (2015)	Germany	Cross-sectional with control	96 patients with vitiligo and 23 control participants	Outpatient clinic for "pigmentary disorders"	DLQI, BDI, ACS.
Lakuta & Przybyla-Basista (2017)	Poland	Cross-sectional	129 patients with psoriasis	Outpatient and inpatient dermatology clinics	BDI, SAQ, SS, BSQ, ASI-R
Leary, Rapp, Herbst, Exum, & Feldman (1998)	United States	Cross-sectional	318 individuals with psoriasis	Postal responses from a dermatology patient register plus individuals from a private dermatology clinic	BFNE, SAPASI, various Likert-style measures, including quality of life and stigmatisation
Loney, Standage, & Lewis (2008)	United Kingdom	Cross-sectional	50 individuals with acne	Volunteers from a national acne dermatology support group	SPAS (adapted), RSE, DLQI, simple measurements of severity and intention to exercise
Montgomery, Norman, Messenger, & Thompson (2016)	United Kingdom	Cross-sectional	120 individuals presenting at a dermatology clinic	Outpatient dermatology clinic	FFMQ, SSS, BFNE-S, HADS, DLQI
Richards, Herrick, Griffin, Gwilliam, & Fortune (2004)	United Kingdom	Cross-sectional	49 consecutive patients with systemic sclerosis	Outpatient clinics and inpatient wards at a city hospital	HADQI, FNE, BAQ, HADS
Salman, Kurt, Topcuoglu, & Demircay (2016)	Turkey	Cross-sectional with control	37 vitiligo and 27 acne patients with age and sex-matched control participants	Outpatient dermatology clinic	LSAS, HADS, DLQI
Schneider, Heuft, & Hockmann (2013)	Germany	Cross-sectional	49 consecutive patients with psoriasis	Private dermatology practice	ACS, SSQ, SOC, PASI

| Wittkowski, Richards, Griffiths, & Main (2004) | United Kingdom | Cross-sectional | 125 individuals with eczema | Convenience sampling through a self-help group within an eczema society. | DLQI, HADS, FNE, RSE, SPQ |
| Yarpuz, Saadet, Sanli, & Ozguven (2008) | Turkey | Cross-sectional with control | 83 patients with acne and 58 control participants | Outpatient dermatology clinic | HADS, RSE, LSAS, GAGS, ATQ |

ACS: Adjustment to Chronic Skin Disorders Questionnaire; ASI-R: Appearance Schemas Inventory – Revised; ATQ: Automatic Thoughts Questionnaire; BASI: Blemish Area and Severity Index; BAQ: Ben-Tovim Walker Body Attitudes Questionnaire; BDI: Beck Depression Inventory; BFNE: Brief Fear of Negative Evaluation Scale; BFNE-S: Brief Fear of Negative Evaluation Straight forward items; BSQ: Body Self Questionnaire; DLQI: Dermatology Life Quality Index; FFMQ: Five Facet Mindfulness Questionnaire; FNE: Fear of Negative Evaluation Scale; GAGS: Global Acne Grading Scale; HADS: Hospital Anxiety and Depression Scale; HAQDI: Health Assessment Questionnaire Disability Index; LSAS: Liebowitz Social Anxiety Questionnaire; PASI: Psoriasis Area and Severity Index; RSE: Rosenberg Self-Esteem Scale; SAPASI: Self-Administered Psoriasis Area Severity Index; SAQ: Social Anxiety Questionnaire; SCL-90-R: Symptom Checklist-Revised; SPAS: Social Physique Anxiety Scale; SOC: Sense of Coherence; SPQ: Stigmatisation and Psoriasis Questionnaire; SS: Stigmatisation Scale; SSQ: Social Support Questionnaire; SSS: Skin Shame Scale; STAI: State-Trait Anxiety Inventory; TAS-20: Toronto Alexithymia Scale.

Quality of retrieved studies

Studies were typically of adequate quality, sampling methods were appropriate, consent was gained and methods for testing significance were generally described by all studies. The designs were appropriate to answer the research questions and methods and results were well described in all but one study (Leary et al., 1998). Unfortunately, studies typically did not state whether there were any conflicts of interest or sources of funding, no sample sizes were justified and there may be issue with self-selection bias in some studies. Multiple studies opted to use Likert-style measurement, which is problematic as it does not allow for comparisons across samples and cannot be compared to normative data. Finally, four studies failed to adequately address

limitations, with three not discussing limitations in any detail, and such, their

conclusions are at an increased likelihood of overstating their findings.

Extent of social anxiety within populations

Social anxiety measurement varied across the included studies. Psychometric

measurement appeared to relate to the country in which the study took place, with all

three Turkish studies using the Liebowitz Social Anxiety Scale (LSAS: Liebowitz,

1987), both German studies used the social anxiety subscale within the Adjustment to

Chronic Skin Disorders Questionnaire (ACS: Stangier, Ehlers, & Gieler, 2003). All

British and American studies used a measure of fear of negative evaluation with the

exception of Loney et al. (2008), who used an adapted version of the Social Physique

Anxiety Scale (SPAS: Martin, Rejeski, Leary, McAuley, & Bane, 1997). Unfortunately,

comparing the extent of social anxiety across populations was not possible, as only two

studies reported mean LSAS scores, with the other two showing inconsistencies in their

tables. Kent and Keohane (2001) removed four items from the BFNE due to issues

reverse scoring items, which prevented comparison to other studies using this measure.

The variety of fear of negative evaluation measures makes comparison difficult. Scores

were generally indicative of a moderate to high level of social anxiety. Where studies

used the same psychometric measure, means were within one standard deviation of each

other, suggesting samples were at a similar level of social anxiety across studies.

Social anxiety and skin condition severity and visibility

The way in which the visibility or severity of a skin condition was measured

within the studies greatly varied, with no two studies using the same measure.

Generally, this appeared as a consequence of studies using skin condition specific

measures, such as the Global Acne Grading Scale (GAGS: Doshi et al., 1997). Three

studies used non-standardised Likert-style measures (Loney et al., 2008; Montgomery et

al., 2016; Richards et al., 2004) and only two studies included a clinical assessment of severity (Schneider et al., 2013; Yarpuz et al., 2008). Studies generally used objective ratings, such as shading affected areas, or noting the extent of the skin condition as a percentage. The terms severity and visibility are conflated within the literature.

The majority of studies (k = 5) found there was no significant correlation between social anxiety and severity or visibility of skin condition (Kent & Keohane, 2001; Leary et al., 1998; Salman et al., 2016; Wittkowksi et al., 2004; Yarpuz et al., 2008). Of these, it is of interest to note both the Leary et al. (1998), and Kent and Keohane (2001) studies suggest the relationship between social anxiety and visibility may only be evident in individuals with high levels of social anxiety.

Two of the three studies (Loney et al., 2008; Montgomery et al., 2016) which demonstrated a significant relationship between skin condition severity and social anxiety used subjective Likert ratings, which are less likely to correlate with dermatologist ratings (Fleischer et al., 1994) or have as good reliability or validity as objective measures (Feldman et al., 1996). However, Likert measures may present a more accurate rating of patient-rated concern with the skin condition. Richards et al. (2004) observed a significant relationship, using a broad severity measure which included other health problems, such as pulmonary disease and gastroenteritis as part of systemic sclerosis. One further study, Schneider et al. (2013) reported clinician rated psoriasis severity was one of three significant factors in predicting social anxiety (p = .046), along with feelings of helplessness social support. See Table 2 for correlation statistics of included studies.

Table 2. *Correlations between social anxiety and severity/ visibility of skin condition*

Study	Correlation co-efficient	Rating type	p value
Kent & Keohane (2001)	$r = .08$	Objective	$p > .05$
Leary et al. (1998)	$r = .02$	Objective	$p > .05$
Loney et al. (2008)	$r = .62$	Subjective	$p < .001$
Montgomery et al. (2016)	$r = .41$	Subjective	$p < .001$
Richards et al. (2004)	$r = .45$	Objective	$p < .01$
Salman et al. (2016)	$r = .21$	Subjective (vitiligo)	$p > .05$
	$r = .27$	Objective (vitiligo)	$p > .05$
	$r = -.05$	Subjective (acne)	$p > .05$
	$r = .14$	Objective (acne)	$p > .05$
Wittkowski et al. (2004)	$r = -.05$	Objective	$p > .05$
Yarpuz et al. (2008)	$r = .16$	Objective	$p > .05$
	$r = .00$	Subjective	$p > .05$

Social anxiety and quality of life and functional impairment

The studies demonstrate there is reduced quality of life and increased functional impairments associated with skin conditions. Seven studies utilised a quality of life measure and examined the relationship with social anxiety (Balkrishnan et al., 2006; Kent & Keohane, 2001; Loney et al., 2008; Richards et al., 2004; Salman et al., 2016; Schneider et al., 2013; Wittkowski et al., 2004). See Table 3 for correlation statistics of included studies.

Table 3. *Correlations between social anxiety and quality of life impairment*

Study	Correlation co-efficient	p value
Balkrishnan et al. (2006)	$r = .51$	p < .01
Kent & Keohane (2001)	$r = .27$	p < .01
Loney et al. (2008)	$r = -.65*$	p < .01
Richards et al. (2004)	$r = .06$	p > .05
Salman et al. (2016)	$r = .51$	p < .01
Schneider et al. (2013)	$r = .58$	p < .001
Wittkowski et al. (2004)	$r = .27$	p < .01

(*Negative statistic due to reporting differences, follows same direction as other findings)

The Dermatology Life Quality Index (DLQI: Finlay & Khan, 1994) was the predominantly used measure of quality of life, with mean scores ranging from 4.90 to 11.74 suggesting a moderate impact on quality of life within the included samples. Six studies, which all utilised the DLQI, found a significant correlation between quality of life and social anxiety, where increases in social anxiety led to increased impairment in quality of life (Balkrishnan et al., 2006; Kent & Keohane, 2001; Loney et al., 2008; Salman et al., 2016; Schneider et al., 2013; Wittkowski et al., 2004). One further study, which measured quality of life using a self-reported Likert scale for various life domains observed significant correlations between quality of life and social anxiety with regards to social life, family relationships, recreation and leisure and emotional wellbeing (Leary et al., 1998). However, significant correlations were not observed between quality of life and social anxiety in relation to sexual relationships, work, physical health or finance. Only one study reported no significant correlation between social anxiety and quality of life (Richards et al., 2004). This study used the Health Assessment Questionnaire Disability Index (HAQDI: Kirwan & Reeback, 1986) which

focuses on functional impairment (e.g. eating, dressing), which is unlikely to be sufficiently sensitive to the quality of life issues associated with skin conditions.

Three studies included social anxiety as a predictor variable in regression analyses where quality of life was the dependent variable (Balkrishnan et al., 2006; Kent & Keohane, 2001; Wittkowski et al., 2004). One further study examined whether social anxiety mediates the relationship between disease severity and quality of life (Loney et al., 2008). Balkrishnan et al. (2006) found lower quality of life was associated with increased fear of negative evaluation, and they also found three factors accounted for 48% of the variance in health-related quality of life; perception of quality of life without the skin condition, fear of negative evaluation and foundation use. Kent and Keohane (2001) analysed their data using a hierarchical regression, whereby DLQI scores were the dependent variable; anxiety, depression and self-esteem were entered in the first block, social anxiety and visibility were entered in the second block and negative experiences were entered at the third block. The first block explained 14.4% of the variance, and the addition of social anxiety and visibility increased this to 23.6%. History of negative experiences explained a further 2.2%. The contribution of social anxiety to the regression was significant ($p = .04$). Wittkowski et al. (2004) also aimed to predict DLQI scores using regression. Their findings indicated 46.7% variance in quality of life was explained by perceptions of stigmatisation, depression and disease severity in a sample of adults with eczema. Fear of negative evaluation did not significantly contribute to the model ($p = .26$). Finally, Loney et al. (2008) examined whether social anxiety mediated the relationship between acne severity and DLQI scores. When social anxiety was included in the regression equation, a significant beta co-efficient reduction was observed ($p < .001$), though the relationship between acne severity and DLQI remained significant. This suggested social anxiety partially mediated this relationship.

20

In summary, there appears to be moderate impairments in quality of life in individuals with a skin condition. There is evidence to suggest impairments in quality of life are associated with social anxiety (medium to large correlation effect sizes), and social anxiety may mediate the relationships between quality of life and other variables.

Social anxiety and distress

The Hospital Anxiety and Depression Scale (HADS: Zigmond & Snaith, 1983) was commonly used by the studies identified in this review to ascertain levels of distress. Scores on the anxiety subscale of the HADS were higher than the depression subscale for each of the six studies utilising this measure. Mean anxiety scores ranged between 7.50 to 10.19, with scores above 7 indicating caseness. Mean depression scores ranged between 4.80 to 6.80, slightly below the caseness score of 7. Other measures were utilised to measure state-trait anxiety, depression and psychiatric symptomology.

All studies which correlated social anxiety with general anxiety or depression, as measured by the HADS, showed significant positive correlations (see Table 4 for correlation statistics of included studies). Other measures revealed similar findings, with social anxiety significantly correlating with psychiatric comorbidity (Balkrishnan et al., 2006), state-trait anxiety and general symptomology (Evren & Evren, 2007). Additionally, Kruger and Schallreuter (2015) observed that their sample of adults with vitiligo showed significantly higher levels of social anxiety than a control group but were not significantly more depressed. Richards et al. (2004) examined whether fear of negative evaluation predicted variance within anxiety or depression. Their results demonstrated fear of negative evaluation significantly predicted anxiety, explaining 56% of the variance, but did not significantly predict depression. Evren and Evren (2007) used regression to examine factors which explain variance within social anxiety scores – using separate subscales for fear/anxiety and avoidance. Between 43 and 46%

of the variance within social anxiety was explained by two variables – trait anxiety and the 'difficulty in describing emotions' subscale of alexithymia.

Table 4. *Correlations between social anxiety and distress*

Study	Measurement	Correlation co-efficient	p value
Balkrishnan et al. (2006)	Psychiatric comorbidity	$r = .24*$	p < .05
Evren & Evren (2007)	Alexithymia	$r = .69$ to .71	p < .001
	Depression	$r = .45$ to .50	p < .001
	State anxiety	$r = .30$ to .33	p < .05
	Trait anxiety	$r = .59$ to .60	p < .001
Kent & Keohane (2001)	HADS anxiety	$r = .48$	p < .001
	HADS depression	$r = .20$	p < .05
Richards et al. (2004)	HADS anxiety	$r = .75$	p < .01
	HADS depression	$r = .42$	p < .01
Salman et al. (2016)	HADS (vitiligo)	$r = .70$	p < .01
	HADS (acne)	$r = .33$	p < .05
Wittkowski et al. (2004)	HADS anxiety	$r = .66$	p < .01
	HADS depression	$r = .41$	p < .01
Yarpuz et al. (2008)	HADS anxiety	$r = .63$	p < .01
	HADS depression	$r = .40$	p < .01

(*Spearman's rho non-parametric correlation used)

Correlations between social anxiety and HADS anxiety typically had large effects and ranged between $r = .48$ and $r = .75$. Correlations between social anxiety and HADS depression typically had medium effects and ranged between $r = .20$ and $r = .42$. These findings are not particularly surprising, given social anxiety is one aspect of general anxiety. Perhaps the most important suggestion is to remain aware to the fact

mental health difficulties may have increased prevalence in individuals with a skin condition (Rumsey & Harcourt, 2005).

Social anxiety and demographic variables

Mean ages across the studies varied widely from 21.8 (Yarpuz et al., 2008) to 53.0 (Richards et al., 2004). With the exception of Schneider et al. (2013), all samples had more female than male participants, with Balkrishnan et al. (2006) and, Evren and Evren (2007) having female only samples. Eight studies examined whether social anxiety was associated with age, with just two finding a significant correlation; both Montgomery et al. (2016) and Richards et al. (2004) reported social anxiety decreased with age.

Two studies analysed whether gender associated with social anxiety, finding no significant difference between genders (Loney et al., 2008; Montgomery et al., 2016). However, Lakuta and Przybyla-Basista (2017) found female gender increased the likelihood of higher levels of social anxiety in a pre-adult onset population with psoriasis.

Six studies examined whether the duration of the skin condition correlated with social anxiety, with all six finding non-significant relationships (Evren & Evren, 2004; Richards et al., 2004; Salman et al., 2016; Schneider et al., 2013; Wittkowski et al., 2004; Yarpuz et al., 2008). Similarly, five studies showed non-significant correlations between social anxiety and age of skin condition onset (Kruger & Schallreuter, 2015; Montgomery et al., 2016; Richards et al., 2004; Schneider et al., 2013; Wittkowski et al.,2004). However, Lakuta and Przybyla-Basista (2017) observed increased social anxiety in outpatients with pre-adult onset, compared to adult onset psoriasis ($t = 2.80$, p $< .01$).

Social anxiety and self-esteem

Four studies administered the Rosenberg Self-Esteem scale (RSE: Rosenberg, 1965). Direct comparison of these scores is limited, as this scale has been scored differently (using 0-3 or 1-4 on a four-point Likert scale) in previous research and it is unclear which scoring method has been used in the studies. The relationship between social anxiety and self-esteem was significant in British studies with adults with psoriasis (Kent & Keohane, 2001), acne (Loney et al., 2008) and eczema (Wittkowski et al., 2004), where increased social anxiety was associated with lower self-esteem. However, the direction is unclear from the reported statistics in the Wittkowski et al. (2004) study – the correlation co-efficient appears to suggest increased social anxiety correlated with greater self-esteem, though the method for scoring variables was not stated and it is not discussed further in the introduction. Yarpuz et al. (2008) observed no significant relationship between social anxiety and self-esteem in adults with acne. See Table 5 for correlation statistics of included studies. Loney et al. (2008) also examined whether social anxiety may mediate the relationship between disease severity and self-esteem, finding social anxiety was a significant partial mediator ($p < .001$). Overall, the studies included appear to suggest social anxiety is associated with self-esteem for individuals with skin conditions. However, this requires further exploration.

Table 5. *Correlations between social anxiety and self-esteem*

Study	Correlation co-efficient	P value
Kent & Keohane (2001)	$r = -.49$	$p < .01$
Loney et al. (2008)	$r = -.58$	$p < .01$
Wittkowski et al. (2004)	$r = .64$	$p < .01$
Yarpuz et al. (2008)	$r = .11$	$p > .05$

Social anxiety and other variables

      Social factors. Six studies examined social factors, including stigmatisation, history of negative experiences and social support (Kent & Keohane, 2001; Kruger & Schallreuter, 2015; Lakuta & Przybyla-Basista, 2017; Leary et al., 2008; Schneider et al., 2013; Wittkowski et al., 2004). No psychometric measures were repeated across studies, so direct comparisons cannot be made. Additionally, the methods in which social factors were examined with social anxiety varied. Leary et al. (2008) observed significant positive correlations between social avoidance and perceived stigmatisation, frequency and stressfulness of negative reactions from others (all $p < .05$) in a sample with psoriasis. Similarly, Wittkowski et al. (2004) observed a significant correlation where increased stigma was associated with increased social anxiety ($p < .01$). Kent and Keohane (2001) reported social anxiety was not significantly different between individuals who had experienced negative reactions and those who had not.

      Two studies examined whether social factors could explain variance within social anxiety scores. Schneider et al. (2013) reported social support was one of three significant factors in predicting social anxiety ($p = .046$), along with feelings of helplessness and psoriasis severity. Lakuta and Przybyla-Basista (2017) split their sample of individuals with psoriasis into those with pre-adult onset and adult onset. 52% of the variance in social anxiety in individuals with pre-adult onset psoriasis was explained by three factors; stigmatisation ($p < .001$), self-evaluative salience of experience and female gender. A reduced amount of variance in social anxiety was explained within the adult-onset group; with 38% variance significantly predicted by stigmatisation and self-evaluative salience of experience. Low-key stigmatisation including questions about their appearance by strangers was reported by 90% of the sample in Kruger and Schallreuter's (2015) study, whereas 76% of the sample reported having never experienced high-key stigmatisation – such as negative comments due to

their skin condition. Neither high or low-key stigmatisation was significantly related to socially avoidant behaviour in their population with vitiligo.

Overall, this paints a mixed picture as to whether perceived stigmatisation and experiences of stigmatisation may increase social anxiety within adults with skin conditions. The data does appear to show an association between social anxiety and stigmatisation, but it is unclear whether there are differences between perceived stigmatisation and actual negative experiences, or whether factors, such as type of skin condition, or area affected by skin condition change this relationship.

Body and appearance concerns. Three studies examined the relationship between social anxiety and body image or concerns about appearance. As previously stated, self-evaluative salience of appearance was a significant predictor of social anxiety in both pre-adult ($p < .05$) and adult onset ($p < .001$) psoriasis in Lakuta and Przybyla-Basista's study (2017); with a stronger emphasis placed on appearance in outpatients who developed psoriasis as an adult. In Richards et al.'s (2004) study of adults with systemic sclerosis, the body attitudes questionnaire (BAQ: Ben-Tovim & Walker, 1991) was utilised to assess individual's attitudes towards their own bodies. Social anxiety was significantly correlated with the disparagement subscale of the BAQ ($r = .40$, $p < .01$), with increases in social anxiety associated with increased disparagement of their bodies. Social anxiety did not correlate to the strength or attractiveness scales of the BAQ.

Balkrishnan et al. (2006) also examined the associated between appearance and social anxiety. In their study of women with severe facial blemishes, a significant non-parametric correlation was observed between foundation use and social anxiety ($p < .01$), with those with higher social anxiety more likely to use foundations; however, this should be interpreted with caution as a high proportion of the sample reported

26

foundation use. Taken together these findings emphasise the importance of self-conscious emotions with regards to social anxiety.

Additional study correlates. There were three extra variables which were studied by individual studies in relation to social anxiety. Loney et al. (2008) examined intention to exercise, Montgomery et al. (2016) examined mindfulness, and Yarpuz et al. (2008) examined automatic thoughts. Loney et al. (2008) reported a significant correlation between social anxiety and intention to exercise ($r = -.49$, p < .01), where increased social anxiety reduced an individuals' intention to exercise. Furthermore, they found social anxiety was a significant partial mediator in the relationship between acne severity and intention to exercise.

Montgomery et al. (2016) observed significant correlations between social anxiety and four aspects of mindfulness: "describe" (p < .05), "observe", "act-aware" and "non-judgemental" (all p < .01, unless stated). There was no significant relationship between social anxiety and non-reactivity to inner experience. In subsequent regression analyses, Montgomery et al. (2016) reported, mindfulness explained 41% variance in social anxiety after controlling for subjective severity. This suggests internal processes are important in the development of social anxiety in skin conditions. Furthermore, Yarpuz et al. (2008) showed a significant correlation between social anxiety and frequency of negative automatic thoughts ($r = .56$, p < .01), emphasising the importance of cognitions.

Limitations of included studies

There are a range of issues within the selected studies. The nature of the samples in the extant studies is a significant issue; samples were self-selected, and justification was not given for any of the thirteen sample sizes, which ranged between 49 and 318. In an attempt to overcome the potential for selection bias, a small number of studies

attempted to recruit consecutive patients from outpatient clinics, with the intent of making their findings more generalisable (Evren & Evren, 2007; Richards et al., 2004; Schneider et al., 2013). However, self-selection was particularly problematic for studies using postal surveys for recruitment, with Kent and Keohane (2001) achieving only a 32% response rate. This is an issue as there may be differences between responders and non-responders in postal surveys, which introduces bias into the study. Measures were almost exclusively self-rated, and thus, there is a risk of self-report bias and self-report is not a substitute for clinical assessment (Sampogna, Sera, & Abedi, 2004). Positively, there was some consistency in the use of measures, with the LSAS, RSE and HADS regularly utilised. Many studies also measured fear of negative evaluation, but through the various measures available.

Discussion

This review sought to examine the factors associated with social anxiety in adults living with skin conditions. There appeared to be good evidence to support relationships between quality of life and social anxiety, and distress and social anxiety. The existing studies support the suggestion that there is an association between social anxiety and self-esteem and may indicate a link between social anxiety and other self-conscious emotions. The existing studies are equivocal with regards to whether social factors, such as stigmatisation, and biomedical factors such as severity or visibility of the skin condition have a relationship with social anxiety. Demographic factors, such as age of onset and duration of the skin condition did not appear to have a relationship with social anxiety in the majority of studies. These findings suggest demographic and biomedical factors are less likely to associate with social anxiety than psychological factors.

The finding that social anxiety most strongly related to other psychological factors rather than demographic or biomedical factors mirrors Thompson and Kent's (2001) review of factors associated with adjustment in individuals with a visible difference in appearance. In their review, Thompson and Kent (2001) referred to an individual's "view from the inside" reflective of self-schema and self-worth, which may be heavily invested within appearance. This is important given research has typically found self-perceptions of appearance do not strongly relate to social reality (Ben-Tovim & Walker, 1995).

Thompson and Kent (2001) added the way individuals interpret their visible difference in appearance is influenced by both cognitive self-schemas and the social context – emphasising predisposing factors, such as peer influence. More recently, the Appearance Research Council (2014) described how predisposing factors may lead to negative adjustment outcomes, such as social anxiety, depression and feelings of inadequacy, due to biases within cognitive processes. The extant studies have not typically explored the relationship between cognitive processes and social anxiety, so further comment upon the Appearance Research Council's framework cannot be provided. The limited number of studies within this review which included a cognitive component support the notion that thinking styles relate to the experience of social anxiety. It is also of interest to note very few studies examine variables which may be protective against social anxiety; with Montgomery et al. (2016) a notable exception having examined the impact of mindfulness. Cognitive processes have been indicated as a central interplay between predisposing factors and negative outcomes, such as social anxiety, and further investigation is required.

Conceptually, it may not appear surprising social anxiety has stronger relationships with psychological variables, given social anxiety is a psychological variable. A meta-analytic review of factors associated with internalised stigma

concluded psychosocial variables are "conceptually intercepting and experientially intertwined"; with their findings demonstrating only self-esteem has emerged as a consistent cross-sectional and longitudinal variable with a significant relationship to internalised stigma (Livingston & Boyd, 2010). Indeed, the prominent models of social anxiety strongly emphasise internal factors, specifically self-schema, attentional bias and expectation of social rejection.

The processes underlying social anxiety in adults with skin conditions appear to be similar to adults in the general population; and whilst there is mixed support for social variables influencing social anxiety, these appear to have a lesser role than self-conscious thoughts and feelings. However, there is a paucity in quantitative research examining the onset of social anxiety within individuals living with a skin condition and qualitative studies suggest internalised experiences of stigma are common. This suggests stigmatisation experiences may be highly important in the onset of social anxiety within individuals living with a skin condition (Ablett & Thompson, 2016) and this is likely to differ from the general population. Social avoidance as a consequence of experiencing stigma may be a strategy to avoid potential discomfort of conscious exposure to negative self-schema, which in turn may reduce self-efficacy and opportunity to feel accepted and build self-esteem (Newell, 1999).

Within this review, evidence appeared to suggest self-esteem decreases as social anxiety increases. Leary et al. (1995) theorised self-esteem could be viewed as a gauge of acceptance or rejection – a "sociometer". Thus, as an individual felt more accepted, their self-esteem would be likely to increase, and if an individual were to avoid social situations, they would have less opportunity to experience feeling accepted, and their self-esteem may decrease. Given the findings of this review, developing a positive self-image, or self-acceptance, may be important, as this may protect against reduced self-esteem in spite of potential stigmatising experiences. Consequently, having negative

30

self-schema; or a view of oneself which perceives the self as not meeting ideal standards, may contribute to attentional biases, overestimation of rejection and social avoidance (Rapee & Heimberg, 1997). This finding has been observed in adults with disordered eating, where body shame and appearance anxiety result in increased body surveillance (Brown & Dittmar, 2005; Slater & Tiggerman, 2010).

Limitations

There are various limitations to this systematic review. This review aimed to examine social anxiety within adults living with skin conditions and consequently viewed samples with skin conditions as a homogenous group. However, the impact of skin conditions is likely to vary across conditions (Leidovici et al., 2010). Variance across samples was evident as mean ages of participants were diverse. There may have also been cultural differences, which have not been examined within this review.

Another clear limitation is that all included studies utilised cross-sectional designs, which does not allow for inferences of causality. Focusing upon linear correlations has also narrowed the focus within this area, and it is possible relationships between variables may not be linear (Moss, 2005). Evidence supporting a non-linear relationship was suggested by both Kent and Keohane (2001) and Leary et al.'s (1998) studies with regards to the relationship between skin condition severity and social anxiety. Furthermore, using cross-sectional data implies stability in individuals' presentations, though presentations may change over time due to factors including experiences of rejection or life events. This review, and the included studies, did not examine variables including life events and caution should be taken in attributing distress solely to the skin condition.

Though this review includes critical appraisal, the focus of the appraisal was to highlight common issues within this research area and to identify ways to improve

future research. The AXIS tool does not provide a score for quality of studies and so weighting of studies was not used, which may be viewed as a limitation. However, numerical scales can be problematic as the items may be difficult to assign weight to and can limit the utility of the appraisal (Higgins et al., 2011; Juni et al., 1999). This review also did not examine for publication bias, and so may be exaggerating findings, given non-significant findings are less likely to be published. This review only included articles which were available in English language and studied adults, in doing so, the findings of this review may have been restricted. Furthermore, studies were not excluded on the basis of quality appraisal and weighting was not used to distinguish between the rigour of each study's findings.

There may have also been overlap in psychometric measurement across included variables, as psychosocial variables are likely to involve similar processes. This review included fear of negative evaluation as a measure of social anxiety, and whilst it is a central construct, it may have introduced bias within examination of relationships between social anxiety and other factors. This review also chose to distinguish between social anxiety and appearance concern, and thus studies using the Derriford Appearance Scale (DAS: Carr, Moss, & Harris, 2005) as a measure of social anxiety were not included, which may have limited the findings. The lack of detailed and consistent measurement of social anxiety across studies limits this review.

Recommendations for future research

Research is required in this area to continue examination of self-related variables within individuals with a skin condition who experience social anxiety. Specifically, research utilising longitudinal designs or mixed methods, with sufficiently large samples are required. Longitudinal or prospective studies may wish to examine the onset of social anxiety within individuals living with skin conditions, examining factors

32

such as perceived and actual episodes of stigmatisation. This is particularly important as relationships between variables, such as social anxiety and stigmatisation may not be linear.

Future research is required to examine psychological variables, this review indicates a need to focus upon examining the role of thoughts about self, others, and cognitive processes more generally, such as dispositional style. There are a range of potential psychological variables, which may be amenable to change that have not yet been examined, such as self-acceptance or psychological flexibility. Future studies may benefit from using measures of quality of life and self-esteem, and may wish to examine factors, such as skin condition severity from a number of viewpoints, including subjective, objective and clinician-rated.

Implications

The findings of this review demonstrate moderate levels of social anxiety are common in adults living with a skin condition. There is likely to be a benefit of psychological screening in settings such as dermatology outpatient clinics, to enable individuals to access the appropriate support. Screening should ideally include measurements of self-image or self-esteem, and social anxiety. Psychological interventions may wish to work upon these variables. This may enable individuals to move from avoidance to confrontation, as conceptualised within Newell's (1999) psychosocial fear-avoidance model. Illness acceptance leads to better outcomes (Adamska & Miniszewska, 2016) and may help reduce anxiety sensitivity, which can be increased in individuals with a skin condition (Dixon, Witcraft, McCowan, & Brodell, 2018). Increased anxiety sensitivity can lead to a feedback loop of increased stress, which may be exacerbated by negative experiences, such as episodes of stigmatisation (Montgomery & Thompson, 2018).

Within this review, variables associated with social anxiety are similar to those expected within the general population, in accordance with models of social anxiety (Clark & Wells, 1995; Rapee & Heimberg, 1997). However, the onset of social anxiety may associate with experiences of stigma, which is likely to be different to the general population.

Conclusions

A systematic literature search retrieved 13 papers which had studied social anxiety in relation to other variables, using a sample of adults living with a skin condition. The findings demonstrate social anxiety strongly associates to other psychological variables, such as general anxiety, depression and lowered self-esteem, as well as quality of life. Whilst there was limited evidence to support a relationship between social anxiety and experiences of stigma, no clear relationships were found between social anxiety and demographic or biomedical factors. Further studies are required to assess the impact of cognitive processes upon social anxiety within this population.

References

Ablett, K., & Thompson, A. R. (2016). Parental, child, and adolescent experience of

chronic skin conditions: A meta-ethnography and review of the qualitative

literature. *Body Image*, *19*, 175-185. doi:10.1016/j.bodyim.2016.10.001

Adamska, M., & Miniszewska, J. (2016). Determinants of acceptance of an illness in

the case of patients suffering from psoriasis treated in the hospital and outpatient

clinic settings. *Health Psychology Report*, *4*, 54-64. doi:10.5114/hpr.2015.53958

Adamson, P., & Doud Galli, S. (2009). Modern concepts of beauty. *Plastic Surgical

Nursing*, *29*, 5-9. doi:10.1097/01.psn.0000347717.98155.8d

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental

disorders* (5th Ed.). Arlington, VA: American Psychiatric Publishing.

Andrews, R. M., Browne, A. L., Drummond, P. D., & Wood, F. M. (2010). The impact

of personality and coping on the development of depressive symptoms in adult

burns survivors. *Burns*, *36*, 29-37. doi:10.1016/j.burns.2009.06.202

Appearance Research Council (2014). Deriving a cognitive behavioural treatment

model: identifying factors and processes contributing to successful adjustment to

disfiguring conditions. In A. Clarke, A. R. Thompson, E. Jenkinson, N. Rumsey,

& R. Newell (Eds.), *CBT for appearance anxiety* (pp. 34-47). Chichester: Wiley.

Balkrishnan, R., McMichael, A. J., Hu, J. Y., Camacho, F. T., Shew, K. R., Bouloc, A.,

. . . Feldman, S. R. (2006). Correlates of health-related quality of life in women

with severe facial blemishes. *International Journal of Dermatology*, *45*, 111-

115. doi:10.1111/j.1365-4632.2004.02371.x

Bar-Haim, Y., Lamy, D., Pergamin, L., Bakermans-Kranenburg, M. J., & van

    Ijzendoorn, M. H. (2007). Threat-related attentional bias in anxious and non-

    anxious individuals: A meta-analytic study. *Psychological Bulletin*, *133*, 1-24.

    doi:10.1037/0033-2909.133.1.1

Ben-Tovim, D. I., & Walker, M. K. (1991). The development of the ben-tovim walker

    body attitudes questionnaire (BAQ), a new measure of women's attitudes

    towards their own bodies. *Psychological Medicine*, *21*, 775-784.

    doi:10.1017/S0033291700022406

Ben-Tovim, D., & Walker, M. K. (1995). Body image, disfigurement and disability.

    Journal of Psychosomatic Research, *39*, 283-291.

    doi:10.1016/0022-3999(94)00143-S

Berra, S., Elorza-Ricart, J. M., Estrada, M.D., & Sanchez, E. (2008). A tool (corrected)

    for the critical appraisal of epidemiological cross-sectional studies. *Gaceta*

    Sanitaria, *22*, 492-497.

Bogels, S. M., van Oosten, A., Muris, P., & Smulders, D. (2001). Familial correlates of

    social anxiety in children and adolescents. *Behaviour Research and Therapy*, *39*,

    273-287. doi:10.1016/S0005-7967(00)00005-X

Borimnejad, L., Yekta, Z. P., & Nasrabadi, A. N. (2006). Lived Experience of Women

    Suffering from Vitiligo: A Phenomenological Study. *The Qualitative Report*, *11*,

    335-349. doi:10.1111/j.1471-6712.2007.00547.x

Brown, A. & Dittmar, H. (2005). Think "thin" and feel bad: the role of appearance

    schema activation, attention level, and thin-ideal internalisation for young

    women's responses to ultra-thin media ideals. *Journal of Social and Clinical*

    Psychology, *24*, 1088-1113. doi:10.1521/jscp.2005.24.8.1088

Brown, B. C., Moss, T. P., McGrouther, D. A., & Bayat, A. (2010). Skin scar

    preconceptions must be challenged: Importance of self-perception in skin

    scarring. *Journal of Plastic and Reconstructive and Anaesthetic Surgery*, *63*,

    1022-1029. doi:10.1016/j.bjps.2009.03.019

Carr, T., Moss, T., & Harris, D. (2005). The DAS24: a short form of the Derriford

    Appearance Scale DAS59 to measure individual responses to living with

    problems of appearance. *British Journal of Health Psychology*, *10*, 285-298.

    doi:10.1348/135910705X27613

Centre for Reviews and Dissemination. (2008). *Systematic reviews: CRD's guidance for*

    undertaking reviews in health care. York, United Kingdom: Centre for Reviews

    and Dissemination. doi:10.1016/S1473-3099.10.70065-7

Clarke, A. (1999). Psychosocial aspects of facial disfigurement: problems, management

    and the role of a lay-led organisation. *Psychology, Health & Medicine*, *2*, 128-

    141. doi:10.1080/135485099106270

Clarke, A., Hansen, E., White, P., & Butler, P. E. M. (2012). Low priority? A

    consecutive study of appearance and anxiety in 500 patients received for

    cosmetic surgery in UK practice. *Psychology, Health & Medicine*, *17*, 440-446.

    doi:10.1080/13548506.2011.626433

Clark, D. & Wells, A. (1995). A cognitive model of social phobia. In R. G. Heimberg, M. R. Liebowitz, D. A. Hope & F. R. Schneier (Eds.) *Social phobia: Diagnosis, assessment and treatment* (pp. 69-93). New York, Guilford.

Cohen, J. (1988). *Statistical power analysis for the behavioural sciences* (2nd Ed.). Hillsdale, New Jersey: Lawrence Earlbaum.

Cordeiro, C. N., Clarke, A., White, P., Sivakumar, B., Ong, J., & Butler, P. E. (2010). A quantitative comparison of psychological and emotional health measures in 360 plastic surgery candidates: Is there a difference between aesthetic and reconstructive patients? *Annals of Plastic Surgery*, *65*, 349-353. doi:10.1097/SAP.0b013e3181c1fe5e

Dalgard, F. J., Gieler, U., Tomas-Aragones, L., Lien, L., Poot, F., Jemec, G. B. E., Misery, L., … Kupfer, J. (2015) The psychological burden of skin diseases: A cross-sectional multicentre study among dermatological out-patients in 13 European countries. *Journal of Investigative Dermatology*, *135*, 984-991. doi:10.1038/jid.2014.53

Dixon, L. J., Witcraft, S. M., McCowan, N. K., & Brodell, R. T. (2018). Stress and skin disease quality of life: the moderating role of anxiety sensitivity social concerns. *British Journal of Dermatology*, *178*, 951-957. doi:10.1111/bjd.16082

Doshi, A., Zaheer, A., & Stiller, M. J. (1997). A comparison of current acne grading systems and proposal of a novel system. *International Journal of Dermatology*, *36*, 416-418. doi:10.1046/j.1365-4362.1997.00099.x

Downes, M. J., Brennan, M. L., Williams, H. C., & Dean, R. S. (2016). Development of a critical appraisal tool to assess the quality of cross-sectional studies (AXIS). *BMJ Open*, *6*, 1-7. doi:10.1136/bmjopen-2016-011458

Dunn, L K., O'Neill, J. L., & Feldman, S. R. (2011). Acne in adolescents: Quality of life, self-esteem, mood and psychological disorders. *Dermatology Online Journal*, *17*, 1.

Esch, M., Rubsam, M., Baum, E., & Bosner, S. (2015). Experiences and perceptions of people with chronic skin disease: A qualitative study. *British Journal of Medicine & Medical Research*, *6*, 106-113. doi:10.9734/BJMMR/2015/13783

Evers, A. W. M., Lu, Y., Duller, P., Van der valk, P. G. M., Kraaimaat, F. W., & Van de Kerkhof, P. C. M. (2005). Common burden of chronic skin diseases? Contributors to psychological distress in adults with psoriasis and atopic dermatitis. *British Journal of Dermatology*, *152*, 1275-1281. doi:10.1111/j.1365-2133.2005.06565.x

Evren, B., & Evren, C. (2007). Relationship between alexithymia and social anxiety in female outpatients with dermatological disorder presenting for psychiatric consultation. *Journal of Clinical Psychology in Medical Settings*, *14*, 258-265. doi:10.1007/s10880-007-9072-9

Falvey, H. (2012). Cross-cultural differences. In Rumsey, N., & Harcourt, D. (Eds.) *The Oxford handbook of the psychology of appearance* (pp. 36-46). London: Oxford University Press.

Feldman, S. R., Fleischer, A. B., Reboussin, D. M., Rapp, S. R., Exum, M. L., Clark, A.
R., & Nurre, L. (1996). The self-administered psoriasis area and severity index
is valid and reliable. *Journal of Investigative Dermatology*, *106*, 183-186.
doi: 10.1111/1523-1747.ep12329912

Finlay, A. Y., & Khan, G. K. (1994). Dermatology life quality index (DLQI) – A simple
measure for routine clinical use. *Clinical and Experimental Dermatology*, *19*,
210-216. doi:10.1111/j.1365-2230.1994.tb01167.x

Finzi, A., Colombo, D., Caputo, A., Andreassi, L., Chimenti, S., Vena, G., ... Gianetti,
A. (2007). Psychological distress and coping strategies in patients with psoriasis:
The PSYCHAE study. *Journal of the European Academy of Dermatology and
Venereology*, *21*, 1161-9. doi:10.1111/j.1468- 3083.2007.02079.x

Fleischer, A. B., Rapp, S. R., Reboussin, D. M., Vanarthos, J. C., & Feldman, S. R.
(1994). Patient measurement of psoriasis severity with a structured instrument.
Journal of Investigative Dermatology, *102*, 967-969.
doi:10.1111/1523-1747.ep12384205

Fortune, D. G., Richards, H. L., Griffiths, C. E. M., & Main, C. J. (2002). Psychological
stress, distress and disability in patients with psoriasis: Consensus and variation
in the contribution of illness perceptions, coping and alexithymia. *British
Journal of Clinical Psychology*, *41*, 157-174. doi:10.1348/014466502163949

Fortune, D. G., Richards, H. L., Main, C. J., Kirby, B., Bowcock, S., & Griffiths, C. E.
(2004). Successful treatment of psoriasis improves psoriasis-specific but not
more general aspects of patients' well-being. *British Journal of Dermatology*,
151, 1219-1226. doi:10.1111/j.1365-2133.2004.06222.x

40

Ghajarzadeh, M., Ghiasi, M., & Kheirkhah, S. (2012). Associations between skin disease and quality of life: A comparison of psoriasis, vitiligo, and alopecia areata. *Acta Medica Iranica*, *50*, 511–515.

Hay, R. J., Johns, N. E., Williams, H. C., Bolliger, I. W., Dellavalle, R. P., Margolis, D. J., ... & Michaud, C. (2014). The global burden of skin disease in 2010: An analysis of the prevalence and impact of skin conditions. *Journal of Investigative Dermatology*, *134*, 1527–1534. doi:10.1038/jid.2013.446

Higgins, J. P., Altman, D. G., Gøtzsche, P. C., Jüni, P., Moher, D., Oxman, A. D., ... & Sterne, J. A (2011) The Cochrane Collaboration's tool for assessing risk of bias in randomised trials. *BMJ*, *343*, 1-9. doi:10.1136/bmj.d5928

Johnston, S. A., Krasuska, M., Millings, A., Lavda, A. C., & Thompson, A. R. (2018). Experiences of rosacea and its treatment: An interpretative phenomenological analysis. *British Journal of Dermatology*, *178*, 154-160. doi:10.1111/bjd.15780

Juni, P., Witschi, A., Bloch, R., & Egger, M. (1999). The hazards of scoring the quality of clinical trials for meta-analysis. *JAMA*, *282*, 1054–1060. doi:10.1001/jama.282.11.1054

Kent, G., & Keohane, S. (2001). Social anxiety and disfigurement: The moderating effects of fear of negative evaluation and past experience. *British Journal of Clinical Psychology*, *40*, 23-34. doi:10.1348/014466501163454

Kent, G., & Thompson, A. R. (2002) Models of disfigurement: Implications for treatment. In P. Gilbert & J. Miles (Eds.) *Understanding body shame* (pp. 106-116). Hove: Brunner-Routledge.

Kimball, A. B., Gieler, U., Linder, D., Sampogna, F., Warren, R. B., & Augustin, M.

 (2010). Psoriasis: Is the impairment to the patient's life cumulative? *Journal of*

 the European Academy of Dermatology and Venereology, *24*, 989-1004.

 doi:10.1111/j.1468-3083.2010.03705.x

Kirwan, J. R., & Reeback, J. S. (1986). Stanford health assessment questionnaire

 modified to assess disability in British patients with rheumatoid arthritis. *British*

 Journal of Rheumatology, *25*, 206-209. doi:10.1093/rheumatology/25.2.206

Kleve, L., Rumsey, N., Wyn-Williams, M., & White, P. (2002). The effectiveness of

 cognitive-behavioural interventions provided at outlook: A disfigurement

 support unit. *Journal of Evaluation in Clinical Practice*, *8*, 387-395.

 doi:10.1046/j.1365-2753.2002.00348.x

Kouris, A., Platsidaki, E., Christodoulou, C., Kalliopi, A., Korkoliakou, P., Stefanaki,

 C., ... Kontochristopoulos, G. (2016). Quality of life, depression, anxiety and

 loneliness in patients with bullous pemphigold. A case control study. *Anais*

 Brasileiros de Dermatologia, *91*, 601-603.

 doi:10.1590/abd1806-4841.20164935

Krakuska, M., Lavda, A. C., Thompson, A. R., & Millings, A. (2017). The role of adult

 attachment orientation and coping in psychological adjustment to living with

 skin conditions. *British Journal of Dermatology*, advance online publication.

 doi:10.1111/bjd.16268

Kruger, C., & Schallreuter, K. U. (2015). Stigmatisation, avoidance behaviour and

 difficulties in coping are common among adult patients with vitiligo. *Acta*

 Dermato-Venereologica, *95*, 553-558. doi:10.2340/00015555-1981.

Lakuta, P., & Przybyla-Basista, H. (2017). Toward a better understanding of social

    anxiety and depression in psoriasis patients: The role of determinants, mediators,

    and moderators. *Journal of Psychosomatic Research*, *94*, 32-38.

    doi:10.1016/j.jpsychores.2017.01.007

Leary, M. R. (1999). Making sense of self-esteem. *Current Directions in Psychological*

    Science, *8*, 32–35. doi:10.1111/1467-8721.00008

Leary, M. R., Rapp, S. R., Herbst, K. C., Lyn Exum, M., & Feldman, R. (1998).

    Interpersonal concerns and psychological difficulties of psoriasis patients:

    Effects of disease severity and fear of negative evaluation. *Health Psychology*, *6*,

    530-536. doi:10.1037/0278-6133.17.6.530

Leary, M. R., Schreindorfer, L., & Haupt, A. (1995). The role of self-esteem in

    emotional and behavioural problems: Why is low self-esteem dysfunctional?

    Journal of Social and Clinical Psychology, *12*, 297-314.

    doi:10.1521/jscp.1995.14.3.297

Leibovici, V., Canetti, L., Yahalomi, S., Cooper- Kazaz, R., Bonne, O., Ingber, A., &

    Bachar, E. (2010). Well being, psychopathology and coping strategies in

    psoriasis compared with atopic dermatitis: A controlled study. *Journal of the*

    European Academy of Dermatology and Venereology, *24*, 897-903.

    doi:10.1111/j.1468-3083.2009.03542.x

Liebowitz, M. R. (1987). "Social phobia". Anxiety. *Modern Trends in*

    Pharmacopsychiatry, *22*, 141–173. doi:10.1159/000414022.

Livingston, J, D., & Boyd, J. E. (2010). Correlates and consequences of internalized stigma for people living with mental illness: A systematic review and meta-analysis. *Social Science and Medicine*, *71*, 2150-2161. doi:10.1016/j.socscimed.2010.09.030

Loney, T., Standage, M., & Lewis, S. (2008). Not just 'skin deep': Psychosocial effects of dermatological-related social anxiety in a sample of acne patients. *Journal of Health Psychology*, *13*, 47-54. doi:10.1177/1359105307084311

Magin, P., Adams, J., Heading, G., Pond, D., & Smith, W. (2006). Psychological sequelae of acne vulgaris: Results of a qualitative study. *Canadian Family Physician*, *52*, 978-979.

Magin, P., Adams, J., Heading, G., Pond, D., & Smith, W. (2008). Experiences of appearance- related teasing and bullying in skin diseases and their psychological sequelae: Results of a qualitative study. *Scandinavian Journal of Caring Sciences*, *22*, 430-436. doi:10.1111/j.1471-6712.2007.00547.x

Magin, P., Adams, J., Heading, G., Pond, D., & Smith, W. (2009). The psychological sequelae of psoriasis: Results of a qualitative study. *Psychology, Health & Medicine*, *14*, 150-161. doi:10.1080/13548500802512294.

Magin, P., Adams, J., Heading, G., & Pond, D. (2009). Patients with skin disease and their relationships with their doctors: A qualitative study of patients with acne, psoriasis and eczema. *Medical Journal of Australia*, *190*, 62-64.

Magin, P., Sibbritt, D., & Bailey, K. (2009). The relationship between psychiatric illnesses and skin disease. *Archives of Dermatology*, *145*, 896-902. doi:10.1001/archdermatol.2009.155.

Martin, K. A., Rejeski, W. J., Leary, M. R., McAuley, E., & Bane, S. (1997). Is the

    Social Physique Anxiety Scale really multidimensional? Conceptual and

    statistical arguments for a unidimensional model. *Journal of Sport and Exercise*

    Psychology, *19*, 359-367. doi:10.1123/jsep.19.4.359

Moher, D., Liberti, A., Tetzlaff, J., Altman, D. G., & The PRISMA Group. (2009).

    Preferred reporting items for systematic reviews and meta-analyses: The

    PRISMA statement. *PLOS Medicine*, *6*, e1000097.

    doi:10.1371/journal.pmed.1000097

Montgomery, K., Norman, P., Messenger, A., Thompson, A. R. (2016) The importance

    of mindfulness in psychosocial distress and quality of life in dermatology

    patients. *British Journal of Dermatology*, *175*, 930-936. doi:10.1111/bjd.14719

Moss, T. P., & Carr, T. (2004) Understanding adjustment to disfigurement: The role of

    self-concept. *Psychology & Health*, *19*, 737-748.

    doi:10.1080/08870440410001722967

Murray, C. D., & Rhodes, K. (2005). Nobody likes damaged goods: The experience of

    adult visible acne. *British Journal of Health Psychology*, *10*, 183-202.

    doi:10.1348/135910705X26128

Newell, R. (1999). Altered body image: A fear-avoidance model of psychosocial

    difficulties following disfigurement. *Journal of Advanced Nursing*, *30*, 1230-

    1238. doi:10.1046/j.1365-2648.1999.01185.x

Newell, R., & Marks, I. (2000). Phobic nature of social difficulty in facially disfigured

    people. *The British Journal of Psychiatry*, *176*, 177-181.

Obradors, M., Blanch, C., Comellas, M., Figueras, M., & Lizan, L. (2016). Health-related quality of life in patients with psoriasis: A systematic review of the European literature. *Quality of Life Research*, *25*, 2739-2754. doi:10.1007/s11136-016-1321-7

Ong, J. L., Clarke, A., Johnson, M., White, P., Withey, S., & Butler, P. E. (2007). Does severity predict distress? The relationship between subjective and objective measures of severity in patients treated for facial lipoatrophy. *Body Image*, *4*, 239-248. doi:10.1016/j.bodyim.2007.05.003

Osinubi, O., Grainge, M. J., Hong, L., Ahmed, A., Batchelor, J. M., Grindlay, D., ... & Ratib, S. (2017). The prevalence of psychological co- morbidity in people with vitiligo: A systematic review and meta- analysis. *British Journal of Dermatology*, *178*, 863-878. doi:10.1111/bjd.16049

Parna, E., Aluoja, A., & Kingo, K. (2015). Quality of life and emotional state in chronic skin disease. *Acta Dermato-Venereologica*, *95*, 312–316. doi:10.2340/00015555-1920.

Rapee, R.M., & Heimberg, R.G., (1997). A cognitive behavioral model of anxiety in social phobia. *Behaviour Research and Therapy*, *35*, 741–756. doi:10.1016/S0005-7967(97)00022-3

Richards, H. L., Fortune, D. G., Weidmann, A., Sweeney, S. K., & Griffiths, C. E. (2004). Detection of psychological distress in patients with psoriasis: Low consensus between dermatologist and patient. *British Journal of Dermatology*, *151*, 1227-1233. doi:10.1111/j.1365-2133.2004.06221.x

Richards, H. L., Herrick, A. L., Griffin, K., Gwilliam, P. D. H., & Fortune, D. G. (2004). Psychological adjustment to systemic sclerosis- exploring the association of disease factors, functional ability, body related attitudes and fear of negative evaluation. *Psychology, Health & Medicine*, *9*, 29-39. doi:10.1080/13548500310001637733

Rosenberg, M. (1965). *Society and the adolescent self-image*. Princeton, New Jersey: Princeton University Press.

Rosser, B. A., Moss, T. P., & Rumsey, N. (2010). Attentional and interpretative biases in appearance concern: An investigation of biases in appearance-related information processing. *Body Image*, *7*, 251-254. doi:10.1016/j.bodyim.2010.02.007

Rumsey, N., Clarke, A., & Musa, M. (2002). Altered body image: The psychosocial needs of patients. *British Journal of Community Nursing*, *7*, 563-566. doi:10.12968/bjcn.2002.7.11.10886

Rumsey, N., & Harcourt, D. (2004). Body image and disfigurement: Issues and interventions. *Body Image*, *1*, 83-97. doi:10.1016/S1740-1445(03)00005-6

Rumsey, N., & Harcourt, D. (2005). *The psychology of appearance*. Maidenhead: Open university press.

Rumsey, N., Charlton., R., Clarke, A., Harcourt, D., James, H., Jenkinson. (2014). Factors associated with distress and positive adjustment in people with disfigurement: evidence from a large multi-centred study. In Clarke, A., Thompson, A. R., Jenkinson, E., Rumsey, N., & Newell, R. (Eds.), *CBT for appearance anxiety* (pp. 201-239). Wiley: Chichester.

Salman, A., Kurt, E., Topcuoglu, V., & Demircay, Z. (2016). Social anxiety and quality

of life in vitiligo and acne patients with facial involvement: A cross-sectional

controlled study. *American Journal of Clinical Dermatology*, *17*, 305-311.

doi:10.1007/s40257-016-0172-x

Sampogna, F., Sera, F., & Abeni, D. (2004). Measures of clinical severity, quality of

life, and psychological distress in patients with psoriasis: A cluster analysis.

Journal of Investigative Dermatology, *122*, 602-607. doi:10.1046/j.0022-

202X.2003.09101.x

Schneider, G., Heuft, G., & Hockmann, J. (2013). Determinants of social anxiety and

social avoidance in psoriasis outpatients. *Journal of the European Academy of

Dermatology and Venereology*, *27*, 383-386.

doi:10.1111/j.1468-3083.2011.04307.x.

Schultz, L. T., & Heimberg, R. G. (2008). Attentional focus in social anxiety disorder:

Potential for interactive processes. *Clinical Psychology Review*, *28*, 1206-1221.

doi:10.1016/j.cpr.2008.04.003

Slater, A., & Tiggerman, M. (2010). Body image and disordered eating in adolescent

girls and boys: A test of objectification theory. *Sex Roles*, *62*, 42-9.

doi:10.1007/s11199-010-9794-2

Staniger, U., Ehlers, A., & Gieler, U. (2003). Measuring adjustment to chronic skin

disorders: Validation of a self-report measure. *Psychological Assessment*, *15*,

532-549. doi:10.1037/1040-3590.15.4.532

Sterne, J. A. C., Hernan, M. A., Reeves, B. C., Savovic, J., Berkman, N. D.,

    Viswanathan, M., … Higgins, J. P. T. (2016). ROBINS-I: A tool for assessing

    risk of bias in non-randomised studies of interventions. *BMJ*, *355*, 1-7.

    doi:10.1136/bmj.i4919

Thompson, A. R., Clarke, S. A., Newell. R, Gawkrodger, G., & The Appearance

    Research Collaboration (2010). Vitiligo linked to stigmatisation in British South

    Asian women: A qualitative study of the experiences of living with vitiligo.

    British Journal of Dermatology, *163*, 481-486.

    doi:10.1111/j.1365-2133.2010.09828.x

Thompson, A. R., & Kent, G. (2001). Adjusting to disfigurement: Processes involved in

    dealing with being visibly different. *Clinical Psychology Review*, *21*, 663-682.

    doi:10.1016/S0272-7358(00)00056-8

Thompson, A. R., Kent, G., & Smith, J. A. (2002). Living with vitiligo: Dealing with

    difference. *British Journal of Health Psychology*, *7*, 213-225.

    doi:10.1348/135910702169457

Thompson, A. R., & Montgomery, K. (2018). Stress and more stress: The importance in

    skin disease of worrying about what others think. *British Journal of*

    Dermatology, *178*, 821-822. doi:10.1111/bjd.16469

Thompson. K. J., Heinberg, L. J., Altabe, M., & Tantleff-Dunn, S. (1999). Appearance-

    related feedback. In K. J. Thompson., L. J. Heinberg, M. Altabe., & S. Tantleff-

    Dunn. *Extracting beauty: theory, assessment, and treatment of body image* (pp.

    151-74). Washington DC: American Psychological Association.

Tuckman, A. (2017). The potential psychological impact of skin conditions. *Dermatology and Therapy*, *7*, 53-57. doi:10.1007/s13555-016-0169-7

Turner, S. M., Beidel, D. C., & Townsley, R. M. (1992). Social phobia: A comparison of specific and generalized subtypes and avoidant personality disorder. *Journal of Abnormal Psychology*, *101*, 326-331. doi:10.1037/0021-843X.101.2.326

Vardy, D., Besser, A., Amir, M., Gesthalter, B., Biton, A., & Buskila, D. (2002). Experiences of stigmatization play a role in mediating the impact of disease severity on quality of life in psoriasis patients. *British Journal of Dermatology*, *147*, 736-742. doi:10.1046/j.1365-2133.2002.04899.x

Wittkowski, A., Richards, H. L., Griffiths, C. E. M., Main, C. J. (2004). The impact of psychological and clinical factors on quality of life in individuals with atopic dermatitis. *Journal of Psychosomatic Research*, *57*, 195-200. doi:10.1016/S0022-3999(03)00572-5

Wong, Q. J. J., & Rapee, R. M. (2016). The aetiology and maintenance of social anxiety disorder: a synthesis of complementary theoretical model and formulation of a new integrated model. *Journal of Affective Disorders*, *203*, 84-100. doi:10.1016/j.jad.2016.05.069

Yarpuz, A. Y., Saadet, E. D., Sanli, H. E., Ozguven, H. D. (2008). Social anxiety level in acne vulgaris patients and its relationship to clinical variables. *Turkish Journal of Psychiatry*, *19*, 1-8.

Zigmond, A. S., & Snaith, R.P. (1983). The hospital anxiety and depression scale, *Acta Psychiatrica Scandinavica*, *67*, 361-370. doi:10.1111/j.1600-0447.1983.tb09716.x

50

Appendix A – AXIS critical appraisal tool (Downes, Brennan, Williams & Dean, 2016).

Introduction

1 Were the aims/objectives of the study clear?

Methods

2 Was the study design appropriate for the stated aim(s)?

3 Was the sample size justified?

4 Was the target/reference population clearly defined? (Is it clear who the research was about?)

5 Was the sample frame taken from an appropriate population base so that it closely represented the target/reference population under investigation?

6 Was the selection process likely to select subjects/participants that were representative of the target/reference population under investigation?

7 Were measures undertaken to address and categorise non-responders?

8 Were the risk factor and outcome variables measured appropriate to the aims of the study?

9 Were the risk factor and outcome variables measured correctly using instruments/ measurements that had been trialled, piloted or published previously?

10 Is it clear what was used to determined statistical significance and/or precision estimates? (e.g. p values, CIs)

11 Were the methods (including statistical methods) sufficiently described to enable them to be repeated?

Results

12 Were the basic data adequately described?

13 Does the response rate raise concerns about non-response bias?

14 If appropriate, was information about non-responders described?

15 Were the results internally consistent?

16 Were the results for the analyses described in the methods, presented?

Discussion

17 Were the authors' discussions and conclusions justified by the results?

18 Were the limitations of the study discussed?

Other

19 Were there any funding sources or conflicts of interest that may affect the authors' interpretation of the results?

20 Was ethical approval or consent of participants attained?

Appendix B – Quality appraisal of the included studies

Study (lead author)	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
Balkrishnan	amber	green	red	green	green	green	N/A	green	green	green	green	green	amber	N/A	green	amber	green	green	amber	green
Evren	green	amber	red	amber	green	green	N/A	green	green	green	green	green	green	N/A	green	green	green	green	amber	green
Kent	green	green	red	green	green	amber	N/A	green	green	green	green	green	red	N/A	green	green	green	green	amber	green
Kruger	green	green	red	green	green	green	N/A	green	green	green	green	green	green	N/A	green	green	amber	red	amber	green
Lakuta	green	green	red	green	green	green	N/A	green	green	green	green	green	green	N/A	green	green	green	green	amber	green
Leary	red	amber	red	green	green	amber	N/A	amber	green	green	red	red	amber	N/A	green	amber	green	red	amber	amber
Loney	green	green	red	green	green	amber	N/A	green	amber	green	green	green	red	N/A	green	green	green	green	green	green
Montgomery	green	green	red	green	green	green	N/A	green	green	green	green	green	amber	N/A	green	green	green	green	green	green
Richards	green	green	red	amber	green	green	N/A	green	green	green	green	green	green	N/A	green	green	green	green	amber	green
Salman	green	green	red	green	green	green	N/A	green	green	green	green	green	amber	N/A	green	green	green	green	green	green
Schneider	green	green	red	green	green	green	N/A	green	amber	green	green	green	green	N/A	green	amber	amber	amber	green	green
Wittkowski	green	green	red	green	green	amber	N/A	green	green	green	green	green	amber	N/A	green	green	green	green	green	green
Yarpuz	green	green	red	green	green	green	N/A	green	green	green	green	green	amber	N/A	red	green	green	red	amber	green

- Where green represents good quality, amber indicates uncertain quality and red represents issues with the quality.

Section Two: Research Report

Acceptance-based self-help for individuals with a visible difference in appearance
and social anxiety: A randomised control trial

Abstract

Objectives. Adults living with a visible difference in appearance commonly report high levels of psychosocial distress and impairments in quality of life. Specialist psychological support is not readily available, so self-help may be of value. Theoretically, acceptance-based approaches might be particularly beneficial for this population. This study examined the effectiveness of an acceptance-based self-help intervention.

Methods. Individuals living with a visible difference (n = 284) and experiencing social anxiety were recruited. Participants were randomised to a four-week intervention or a waitlist control condition. Outcome measures included psychological flexibility, fear of negative evaluation and impairments in functioning.

Results. Clinically significant levels of distress were present within the population. ANCOVAs, controlling for baseline scores, indicated no significant differences in psychological flexibility or fear of negative evaluation between conditions. Significant improvements in functioning were demonstrated by the intervention group at follow-up. Completer analyses suggested the intervention significantly reduced fear of negative evaluation; however, attrition was high. Qualitative feedback was positive.

Conclusions. Acceptance-based self-help interventions may have potential to provide effective treatments for adults living with a visible difference.

Practitioner points

- Support is required to aid the high levels of distress in adults living with visible difference; screening may help identify those in need of psychological support.

- Self-help interventions may fit within stepped care models of treatment.

- This is the first study to examine the effectiveness of an acceptance-based intervention with a sample of adults living with a visible difference in appearance.

- Acceptance-based interventions may have potential to provide effective treatment for distress associated with living with a visible difference.

- The present study is limited by significant levels of attrition, particularly within the intervention condition.

- The present study relies on self-report measurement.

Introduction

Psychosocial burden of visible difference

Appearance is unique to each individual, and yet some appearances are considered atypical where they are increasingly dissimilar from culturally defined norms. Visible differences in appearance may present due to a range of factors, such as skin conditions, craniofacial differences, burns, and scarring. Visible differences are common; dermatological conditions such as psoriasis, eczema and alopecia are amongst the most common new complaints presented in general medical services (Schofield, Grindlay, & Williams, 2009). Additionally, a leading charity for people with 'visible difference' estimates 1,345,000 individuals in the United Kingdom have a visible difference affecting their face or body (Changing Faces, 2007). Accounts of experiences of stigmatisation are not uncommon in the literature (Thompson et al., 2002, 2010), and there is an acknowledgement of a psychosocial burden of increased distress associated with living with conditions which affect appearance (Rumsey & Harcourt, 2004; Thompson & Kent, 2001).

Rates of anxiety and depression are elevated in comparison to the general population (Dalgard et al., 2015; Parna, Aluoja, & Kingo, 2015), with up to 30% of individuals with a dermatological condition seeking support for their distress (Fried, 2013; Thompson, 2012). Living with a visible difference in appearance also has a negative impact on quality of life (Ghajarzadeh, Ghiasi, & Kheirhhah, 2012; Obradors et al., 2016), with impairments associated with disability, loss of earnings, self-esteem and social interactions (All Party Parliamentary Report on Skin, 2013). However, there are individuals who do not experience distress or difficulty adjusting and don't feel their visible difference has a large impact on their life (Egan, Harcourt, Rumsey, & Appearance Research Collaboration, 2011; Rumsey, 2002). The variation in individual

adjustment is affected by interaction of physical, cultural and psychosocial factors and specific psychological variables (Falvey, 2012). Understanding these may help identify targets for intervention (Clarke, Thompson, Jenkinson, Rumsey, & Newell, 2014). Such psychological variables may include the value placed upon appearance (MacLeod, Shepherd, & Thompson, 2016), optimism (Coneo, Thompson, & Lavda, 2016) and self-esteem (Clarke et al., 2014).

There is general consensus about the predominant difficulties experienced by individuals with a visible difference. These difficulties include negative self-evaluation, anxiety, depression, and difficult interactions with others, which often includes being stared at and receiving unsolicited appearance-related comments or questions. Within those who experience difficulty, research suggests avoidant coping styles caused by both perceived stigmatisation and actual stigmatisation, are most likely to account for the variation in distress (Moss & Rosser, 2012; Thompson & Kent, 2001). Both actual and perceived stigmatisation can lead to a fear of being negatively evaluated by others and consequently, behavioural avoidance. This pattern typically leads to social anxiety (Lovegrove & Rumsey, 2005) - "A persistent fear of one or more social or performance situations in which the person is exposed to unfamiliar people or to possible scrutiny by others" (American Psychiatric Association, 2013). Social anxiety is then maintained by attentional bias towards perceived appearance judgements, and negative interpretations of events (Rapee & Heimberg, 1997). These attentional biases may increase anxiety sensitivity, where neutral events or reactions may be interpreted as threatening or negative (Dixon et al., 2018). Furthermore, individuals may internalise perceived stigmatisation, with a detrimental effect on their self-image and self-esteem (Ablett & Thompson, 2016).

58

In trying to alleviate anxiety, individuals often remove themselves from potentially threatening situations, which reinforces withdrawal and limits social interactions (Newell, 1999).

Psychological interventions for living with visible difference

Norman and Moss (2015) updated a systematic review by Bessell and Moss (2007) which examined intervention studies for adults living with a visible difference. Norman and Moss's (2015) review included 16 studies, which typically administered Cognitive Behavioural Therapy (CBT) and concluded the evidence to suggest interventions have been efficacious is poor, due to limited study quality. Whilst there were some positive findings, the review stated randomised controlled trials were required. Similar findings have been observed with interventions for children living with visible difference (Jenkinson, Williamson, Byron-Daniel, & Moss, 2015). Muftin and Thompson (2013) conducted a systematic review of self-help intervention studies for adults with a visible difference. Their review included eleven studies and provided tentative support for the use of self-help to manage anxiety associated with living with a visible difference. This review also highlighted the focus upon CBT interventions and suggested future studies should be clear about the rationale behind their treatment model and should assess usability and acceptability. In summary, there is potential for effective interventions for adults living with a visible difference who experience anxiety.

Self-help

Whilst there may be benefit of psychological support for adults living with a visible difference, clinicians often focus upon the biomedical aspect of the visible difference and are poor at predicting distress in dermatological outpatients (Richards et al., 2004). This problem is amplified by the limited access dermatologists have to a

psychologist, or psychotherapist (Lowry, Shah, Fleming, Taylor, & Bewley, 2014).

Furthermore, professionals working in mainstream mental health services are unlikely

to have specialist dermatological knowledge and may not be viewed as acceptable by

patients (Thompson, 2014).

As access to specialist psychological support is very limited, self-help

interventions, designed for use with people living with a visible difference, may be

beneficial. Self-help interventions may also provide a way forward in the current

climate of stretched mental health services and may fit well into a stepped care model.

Reviews have demonstrated guided self-help can have comparable effects to face-to-

face interventions for depression and anxiety (Cuijpers, Donker, van Straten, Li, &

Andersson, 2010), and can be effective in reducing social anxiety (Lewis, Pearce, &

Bisson, 2012). However, the review by Lewis, Pearce, and Bisson (2012) suggested

therapist-administered treatments were more effective, and self-help increased in

effectiveness with the addition of guidance and multimedia. It is unclear how much

therapist contact is necessary for treatment of anxiety, and it may depend upon anxiety

complexity and the motivation of the individual (Newman, Erickson, Przeworski, &

Dzus, 2003). These reviews highlight an issue in defining self-help, as some included

therapist contact and longer treatments than others. Additionally, the adherence to self-

help is rarely reported, making it difficult to assess the effectiveness of self-help, as

attrition is typically higher in the absence of therapist guidance. Despite this, early

findings suggest self-help may be beneficial for adults living with a visible difference

who experience anxiety (Muftin & Thompson, 2013).

Psychological intervention models

The vast majority of interventions for people living with a visible difference have been CBT-based. Whilst these interventions have shown promise and are likely to encourage individuals to move away from avoidance cycles, CBT also focuses on cognitive biases. Behavioural experiments and thought challenging are designed to overcome attentional biases and negative perceptions. Whilst these might be powerful mechanisms which can encourage psychological improvement, they can become harmful where there is evidence to confirm threatening thoughts and beliefs. This is problematic when considering individuals living with a visible difference are likely to encounter stigmatising experiences. CBT self-help may try and help an individual overcome an anxiety provoking thought such as "other people will stare or point at me" by asking the individual to test whether this happens. Whilst, it may be effective if there is no evidence to support this thought, supporting evidence may increase distress.

Another strategy which may be effective, regardless of whether stigmatisation experiences are present, is acceptance. Acceptance within a therapeutic approach may be useful as it redirects attention away from distress towards personal values, encouraging value-directed behaviours; which may also overcome avoidance cycles (Walser & Hayes, 2006). Acceptance and Commitment Therapy (ACT) is a treatment which emphasises acceptance, in the context of increasing 'psychological flexibility' – the ability to consciously engage meaningfully with values whilst being in contact with painful experiences. ACT was first described by Hayes, Strosahl, and Wilson (1999). Within the ACT model, there are six processes which aim to develop psychological flexibility: contact with the present moment, values, committed action, self-as-context, defusion and acceptance.

ACT has shown promising effectiveness in several populations, including body image dissatisfaction (Griffiths, Williamson, Zucchelli, Paraskeva, & Moss, 2018),

anxiety and depression (A-Tjak et al., 2015), though it is still developing as a therapy

and requires more randomised controlled trials to demonstrate efficacy (Ost et al.,

2014). Studies also suggest ACT self-help interventions are effective with difficulties

including: depression (Lappalainen et al., 2015), anxiety (Ritzert et al., 2016), health

anxiety (Hoffman, Rask, Ljotsson, & Frostholm, 2018) and long-term health conditions,

including chronic pain and tinnitus (Trompetter et al., 2015). A systematic review by

Cavanagh, Strauss, Forder, and Jones (2014) suggested mindfulness and acceptance-

based self-help is effective in improving depression, anxiety and acceptance outcomes

compared to control conditions, with small to medium effect sizes. More recently,

French, Golijani-Moghaddam, and Schroder (2017) conducted a meta-analysis

specifically examining randomised ACT self-help interventions. Thirteen studies were

included in their meta-analysis which suggested small effect sizes for improvements in

depression ($g = 0.34$), anxiety ($g = .35$) and psychological flexibility ($g = 0.42$),

compared to control conditions. These findings suggest ACT-based self-help may

benefit individuals living with a visible difference and experiencing social anxiety.

The present study

This study will examine whether a newly developed acceptance-based self-help

intervention is effective at increasing psychological flexibility and decreasing fear of

negative evaluation and impairments in functioning, compared to a waitlist control

condition in adults living with a visible difference.

Hypotheses

1) Participants in the self-help intervention condition will demonstrate a significant

increase their psychological flexibility as measured by the Comprehensive

assessment of Acceptance and Commitment Therapy processes (CompACT:

Francis, Dawson, & Golijani-Moghaddam, 2016).

2) Participants receiving self-help intervention will demonstrate a significant decrease in social anxiety as measured by the Brief Fear of Negative Evaluation scale-II (BFNE-II: Carleton, Collimore, & Asmundson, 2007) in comparison to the control group.

3) Participants in the self-help intervention condition will demonstrate a significant reduction in functioning impairment in relation to visible difference, as measured by the work and social adjustment scale (WSAS: Marks, 1986), compared to the control group.

Methods

Ethical approval

Ethical approval was granted by the ethics committee of the University of Sheffield's Psychology Department on 12th February 2017. (See Appendix A for approval letter).

Design

A randomised controlled trial was conducted in accordance with CONSORT guidelines (Schulz, Altman, & Moher, 2010) to examine the effectiveness of acceptance-based self-help materials. Self-help materials were created by the lead author and had not been examined previously.

The independent variables in the study were time and condition. There were two levels for time: baseline and four-week follow-up. There were also two levels for condition: waitlist or acceptance-based self-help. After confirming eligibility, participants were randomised by the online survey provider, Qualtrics, at a ratio of 1:1. Participants were not informed of the condition they had been assigned to until the end of the survey.

Primary and secondary outcome measures

To examine the effectiveness of the self-help intervention, three established self-report measures were utilised. One additional self-report measure was used at baseline to ensure there was no significant difference in distress across groups. The primary outcome measure concerned psychological flexibility, as measured by the Comprehensive assessment of Acceptance and Commitment Therapy processes (CompACT: Francis, et al., 2016). The secondary outcome measures were social anxiety, measured by the Brief Fear of Negative Evaluation scale II (BFNE-II: Carleton et al., 2007), and functioning impairments, measured by the Work and Social Adjustment Scale (WSAS: Marks, 1986). The CORE-10 (Barkham et al., 2013) was used to ensure randomisation was successful in terms of distress, at baseline. These measures can be viewed in Appendices B-E.

Comprehensive assessment of Acceptance and Commitment Therapy processes. The CompACT (Francis et al., 2016) is a 23-item measure of psychological flexibility, in which items are rated on a seven-point Likert scale. The CompACT has a three-factor structure which broadly defines the "triflex" in ACT: "behavioural awareness" (contacting the present moment & self-as-context), "openness to experience" (defusion & acceptance), and "valued action" (values & committed action) (Harris, 2013). These three factors combine to give an overall psychological flexibility score. The majority of research examining psychological flexibility has used the Acceptance and Action Questionnaire II (AAQ-II: Bond et al., 2011). The CompACT has been selected as opposed to the AAQ-II, as the AAQ-II appears to conflate ACT processes with distress outcome variables (Wolgast, 2014), which are theoretically distinct.

The CompACT has demonstrated a good internal consistency ($\alpha = .91$) and strongly correlates with the AAQ-II ($r = 0.79$). The CompACT provides an overall

psychological flexibility score, ranging between 0-138, with higher scores indicating greater psychological flexibility. Theoretically, higher psychological flexibility scores associate with decreased distress (Francis et al., 2016).

Brief Fear of Negative Evaluation scale II. The BFNE-II (Carleton et al., 2007) is a 12-item revised version of the Brief Fear of Negative Evaluation scale (BFNE; Leary, 1983) and is used to measure fear of negative evaluation (e.g. "I am afraid that others will not approve of me"). Fear of negative evaluation refers to a person's tolerance for the possibility they may be judged disparagingly or hostilely by others (Leary, 1983). Fear of negative evaluation is a central construct within social anxiety which promotes the development and expression of general fears and anxiety (Reiss & McNally, 1985). A five-point Likert scale is used to self-report fear of negative evaluation, ranging from 0 (not at all characteristic of me) to 4 (extremely characteristic of me). The BFNE-II demonstrates excellent internal consistency (α = .95), correlates highly with the BFNE, and factor analyses have supported a unitary solution (Carleton et al., 2007). A cut-off score of 25 may be indicative of clinically significant social anxiety (Carleton, Collimore, McCabe, & Anthony, 2011). Possible scores range between 0-48, with higher scores indicating greater fear of negative evaluation.

Work and Social Adjustment Scale. The WSAS (Marks, 1986) is a five-item measure of impaired functioning, examining impairments in work, social leisure, private leisure, home management and close relationships. It is a simple and reliable measure, with good internal consistency (α = 0.70 to 0.94) and test–retest (α = 0.84) reliability (Mundt, Marks, Shear & Greist, 2004). The WSAS is highly acceptable to clinical patients (Crawford et al., 2011), is sensitive to change, and measures a factor distinct from anxiety and depression (Zahra et al., 2014). Whilst the WSAS is a measurement of impairment in functioning, to a lesser extent it is viewed as a measurement of quality of

life. The WSAS relates daily functioning to a specific difficulty (in this study, visible difference), which allows focused outcome measurement. Possible scores on the WSAS measure range between 0-40, with higher numbers indicating greater impairments in functioning and quality of life.

CORE-10. The CORE-10 (Barkham et al., 2013) was designed as an easy-to-use measure of general distress. The measure consists of 10 items which are rated on a five-point Likert scale, ranging from "not at all" to "most or all of the time". Each item is scored between 0-4, giving a maximum possible score of 40, where higher numbers are indicative of greater distress. The CORE-10 has demonstrated high internal reliability ($\alpha = 0.90$), with high sensitivity and specificity. The CORE-10 correlates highly with the 34-item CORE-OM ($r = 0.94$) and is viewed as a feasible and acceptable outcome measure (Barkham et al., 2013).

Intervention

The acceptance-based self-help intervention (see Appendix F) was developed by the lead author of this study with advice from a supervisor and experts by experience. The self-help intervention is entitled: "*Surviving to Thriving: ACT self-help for living well with a visible difference in appearance*" and is based upon ACT. The self-help intervention can be broadly split into three main sections; 1) increasing awareness of internal processes and mindfulness 2) changing the relationship with thoughts and bringing in compassion, and 3) value-based action and practical strategies for managing stigmatisation. Though value-based action is mostly present in the later stages of the booklet, it is explained and encouraged from the start, in line with recent research recommendation (Gloster et al., 2017). The self-help intervention aimed to increase psychological flexibility through addressing all six ACT processes. However, due to the abstract nature of "self-as-context", the self-help intervention does not explicitly focus on this area. Common ACT techniques are included throughout the self-help

66

intervention, including: thought defusion, value identification and the use of metaphors – such as "the passengers on the bus" metaphor (Hayes, 2005). The self-help intervention included a pdf booklet, audio files and a lived experience video, in which an individual with visible difference, caused by a burns injury, talks about their experience, with some links to ACT (see *http://bit.ly/surviving_to_thriving*). Audio exercises were also transcribed within the booklet, all audio exercises were created and transcribed by the lead author, based on exercises commonly used in ACT. A suggested timetable for completing the self-help intervention within the four-week trial period was included. Feedback on the self-help intervention was given by two individuals with lived experience of a visible difference and changes were made in accordance with their feedback. Prior to recruitment, feedback was sought from a local ACT expert, Dr Christopher Graham, who reviewed the self-help intervention and confirmed it was consistent with ACT.

Participants

Online recruitment of participants occurred between August and December 2017. For inclusion in the study, participants had to self-identify with having a visible difference in appearance, self-report experiencing social anxiety, be aged 18 years or above and be fluent in the English language. Participants were excluded if they were currently in receipt of psychotherapy. Prior to completing the outcome measures and entering the study, participants were required to respond to questions assessing their eligibility. If they did not meet the criteria for inclusion in the study, they were advised to contact a medical practitioner if they felt in need of psychological support.

G*Power version 3.1.9.2 (Faul, Erdfelder, Lang, & Buchner, 2007) was used to conduct a power analysis. To obtain 80% power, with an alpha of 0.05, a medium effect size ($f = 0.25$), with two timepoints, two conditions and one covariate; a sample size of

128 was required. As this study was completed online and the self-help intervention did not include therapist contact, attrition was estimated to be in the region of 50% based upon previous attrition rates from similar trials (37%: Bundy et al., 2013; 51%: Hudson, 2015; 52%: Lane, 2017). Therefore, 256 participants would be required (128 per group). In aiming to minimise attrition, participants were given the option to be entered into a prize draw for one of two £25 vouchers, if they completed questions at follow-up.

All participants were recruited online. International and United Kingdom based charities and organisations associated with visible differences were contacted and asked to advertise the study through their websites and social media pages. As part of this contact, charities and organisations were given a template advertisement (see Appendix G). Additionally, advertisement in relevant social media groups with administrative permission was used to aid recruitment. A recruitment advert was also disseminated to the University of Sheffield's volunteer mailing list. The full list of charities and social media groups who agreed to advertise the study can be found in Appendix H.

Procedure

Recruitment advertisements included a link to the study, which was hosted online through Qualtrics survey software. Prior to entering the study, participants viewed information about the study (see Appendix I), answered questions about their eligibility and provided consent (see Appendix J). The survey software randomly allocated participants to condition at the point immediately following their informed consent. Following this, participants provided demographic information, including their visible difference, country of residence, age and skin colour. Participants then completed the BFNE-II, WSAS, CORE-10 and CompACT.

Participants were aware from the information provided they would be randomly allocated to receive the self-help materials immediately, or after a delay of four weeks.

Participants who were randomised to the intervention condition were able to access the self-help intervention at the end of the survey by clicking on a link. They were also e-mailed the self-help materials. Figure 1 provides a visual representation of the survey at baseline.
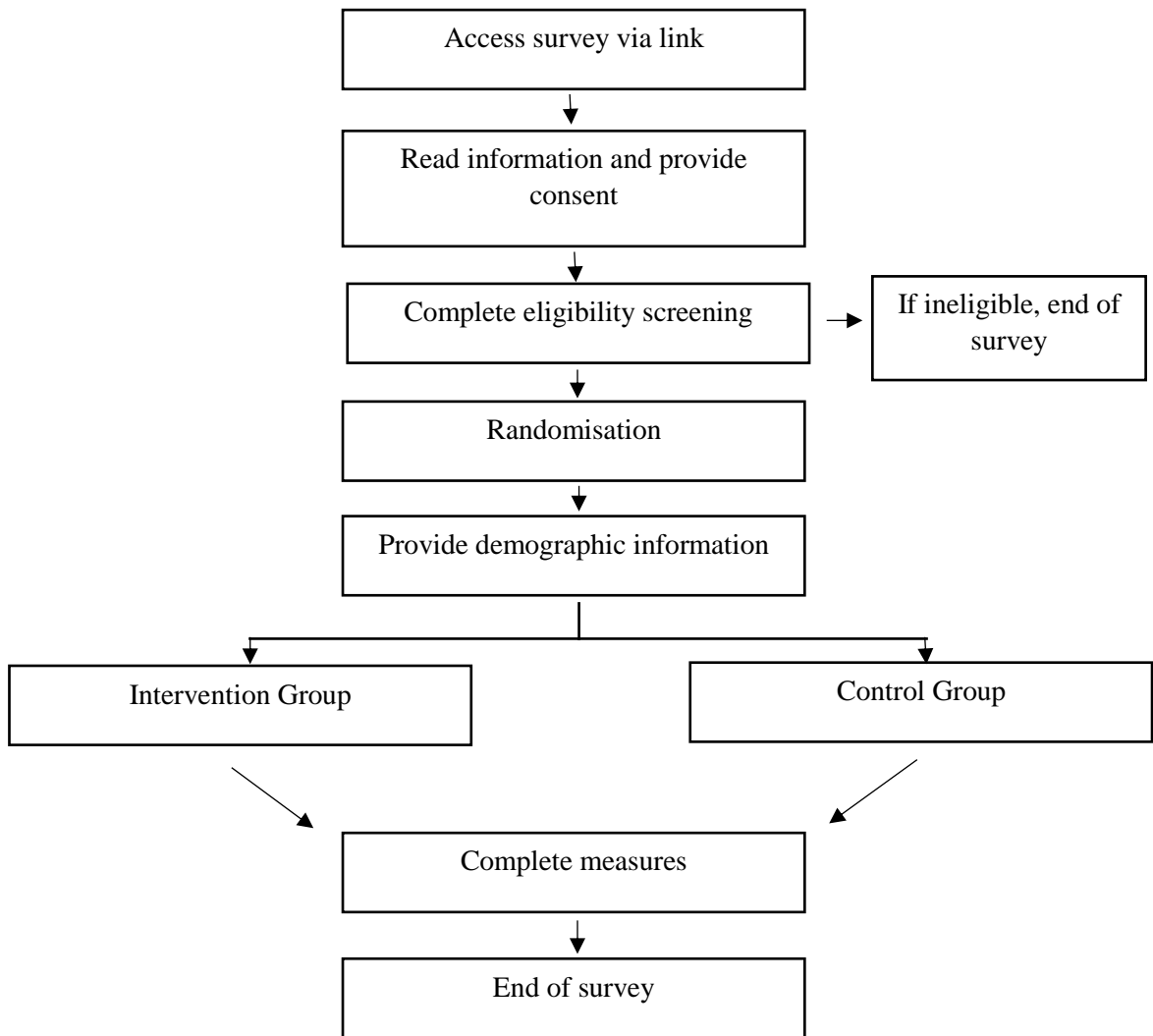
```
┌─────────────────────────────────┐
│      Access survey via link      │
└─────────────────────────────────┘
                 ↓
┌─────────────────────────────────┐
│   Read information and provide   │
│             consent              │
└─────────────────────────────────┘
                 ↓
┌─────────────────────────────────┐        ┌─────────────────────┐
│   Complete eligibility screening │  →     │ If ineligible, end of│
│                                  │        │        survey        │
└─────────────────────────────────┘        └─────────────────────┘
                 ↓
┌─────────────────────────────────┐
│          Randomisation           │
└─────────────────────────────────┘
                 ↓
┌─────────────────────────────────┐
│  Provide demographic information │
└─────────────────────────────────┘
        ↓                    ↓
┌──────────────────┐   ┌──────────────────┐
│ Intervention Group│   │   Control Group  │
└──────────────────┘   └──────────────────┘
        ↘                    ↙
        ┌─────────────────────────┐
        │    Complete measures     │
        └─────────────────────────┘
                 ↓
        ┌─────────────────────────┐
        │      End of survey       │
        └─────────────────────────┘
```

Figure 1. *Flow of participants through the survey at baseline*.

After the four-week period had passed, an e-mail was sent to participants asking them to complete follow-up measures. Participants from the intervention condition were also asked to indicate whether they had found the self-help intervention understandable and helpful on five-point Likert scales. Intervention participants were also given the opportunity to provide open-text feedback on the self-help materials and were asked to

indicate how much they had used the self-help intervention in the four-week period. Individuals randomised to the waitlist were emailed the self-help materials after the four-week period. Figure 2 provides a visual representation of the survey at follow-up.
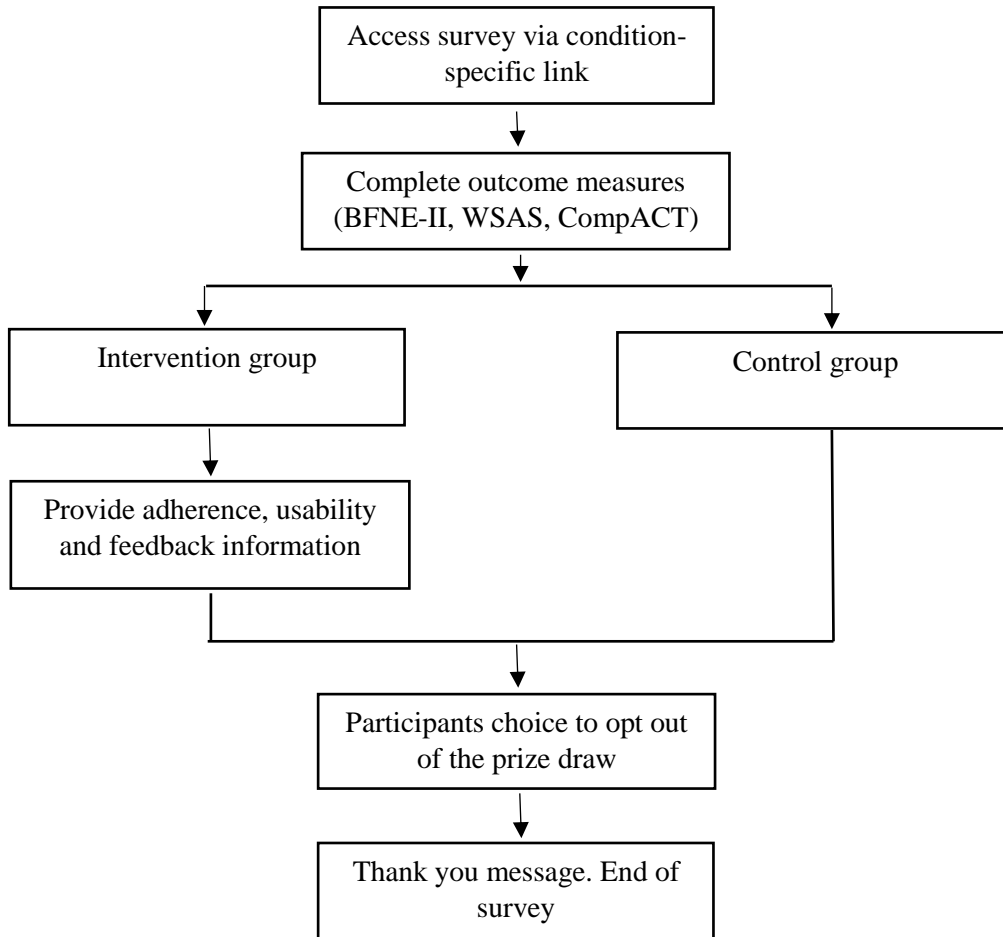

Figure 2. *Participant flow through the survey at follow-up.*

Data security and management

Data provided by participants was kept confidential and stored in encrypted files on password protected computers. As part of the survey, participants had to create a user identification, which was used to match data between timepoints. User identifications were stored separately from participant responses.

Data analyses

Whilst complete data was available for the BFNE-II and WSAS at follow-up, five responses were not fully completed on the online software and thus there were three less responses to the CompACT from the waitlist and two from the intervention conditions. Scoring of the outcome measures was completed within the online survey software. Data were exported into SPSS version 23.0 for analysis. Data were analysed for normality and equality of variance, to ascertain whether assumptions of parametric testing were met. Levene's test for homogeneity was non-significant for all outcome measures, however the Shapiro-Wilk test for normality was significant for the CompACT, BFNE-II and WSAS. This could be problematic as violations to the normality assumption may increase Type I error rates when using parametric tests. Histograms showed the pattern of data was similar across conditions and timepoints. However, there is little benefit of using non-parametric analyses as minimal difference exists between using ANCOVA and non-parametric equivalents in terms of a type I error rate and statistical power (Olejnik & Algina, 1985), and similar findings are gained from using rank ANCOVAs (Olejnik & Algina, 1984; Vickers, 2005).

Data were tested using a series of ANCOVAs, in which scores at follow-up were the dependent variable, condition was the independent variable and scores at baseline were used as covariates. General distress, as measured by the CORE-10, was not included as a covariate as it was not significantly different across conditions. These were completed for all three outcome measures as intention to treat (ITT) analyses and repeated for complete case analyses. ANCOVA was selected as it yields optimal statistical power for evaluating randomised controlled trials (Blance, Tu, Baelum & Gilthorpe, 2007). Further analyses were completed to examine randomisation, attrition and adherence patterns. All analyses are reported using a significance criterion alpha set at .05, and all are two-tailed.

Registering as trial

The study was registered on 'Clinical Trials.gov' website with the identifier

NCT03205839 (see *https://clinicaltrials.gov/ct2/show/NCT03205839*).

<div align="center">

Results

</div>

Demographic characteristics

A total of 381 individuals were randomised to condition having provided

informed consent and passed eligibility assessment. The full survey was completed by

284 individuals, who were then entered in to the study. Of these, 145 were randomly

allocated to the intervention condition and 139 to the control condition. At follow-up,

responses were received from 46 (32%) individuals from the intervention condition and

82 (59%) individuals in the control condition. This represents an attrition rate of 55%,

though attrition was far greater in the intervention condition. The flow of participants

through the study can be found in Figure 3. Participant demographic characteristics are

shown in Table 1.

Table 1. *Baseline demographic characteristics of participants*

Variable	Total (n = 284)	Intervention (n = 145)	Control (n = 139)
Age, *M* (SD)	40.14 (12.71)	40.92 (12.69)	39.32 (12.71)
Gender, *n* (%)			
Female	257 (90.5)	134 (92.4)	123 (88.5)
Male	25 (8.8)	11 (7.6)	14 (10.1)
Other	2 (0.7)	-	2 (1.4)
Skin Colour, *n* (%)			
White	255 (89.8)	124 (85.5)	131 (94.2)
Non-white	29 (10.2)	21 (14.5)	8 (5.8)
Country of Residence, *n* (%)			
United Kingdom	199 (70.1)	99 (68.3)	100 (71.9)
North America	52 (18.3)	26 (17.9)	26 (18.7)
Australasia	11 (3.9)	7 (4.8)	4 (2.9)
Other	22 (7.7)	13 (9.0)	9 (6.5)
Visible Difference, *n* (%)			
Alopecia	89 (31.3)	45 (31.0)	44 (31.7)
Acquired scarring	31 (10.9)	16 (11.0)	15 (10.8)
Birthmark	23 (8.1)	12 (8.3)	11 (7.9)
Psoriasis	20 (7.0)	12 (8.3)	8 (5.8)
Rosacea	16 (5.6)	6 (4.1)	10 (7.2)
Eczema	13 (4.6)	7 (4.8)	6 (4.3)
Craniofacial	12 (4.2)	7 (4.8)	5 (3.6)
Vitiligo	11 (3.9)	6 (4.1)	5 (3.6)
Burns	10 (3.5)	4 (2.8)	6 (4.3)
Acne	10 (3.5)	6 (4.1)	4 (2.9)
Multiple	17 (6.0)	9 (6.2)	8 (5.8)
Other	32 (11.3)	15 (10.4)	17 (12.2)

Enrolment	473 visits to the survey webpage	
	381 eligible participants randomised to condition	
	Allocated to intervention (*n* = 190)	Allocated to waitlist (*n* = 191)
Allocation	Completed measures (*n* = 145)	Completed measures (*n* = 139)
Follow-up	Completed measures (*n* = 46)	Completed measures (*n* = 82)
Analyses	Included in ITT analyses (*n* = 145)	Included in ITT analyses (*n* = 139)
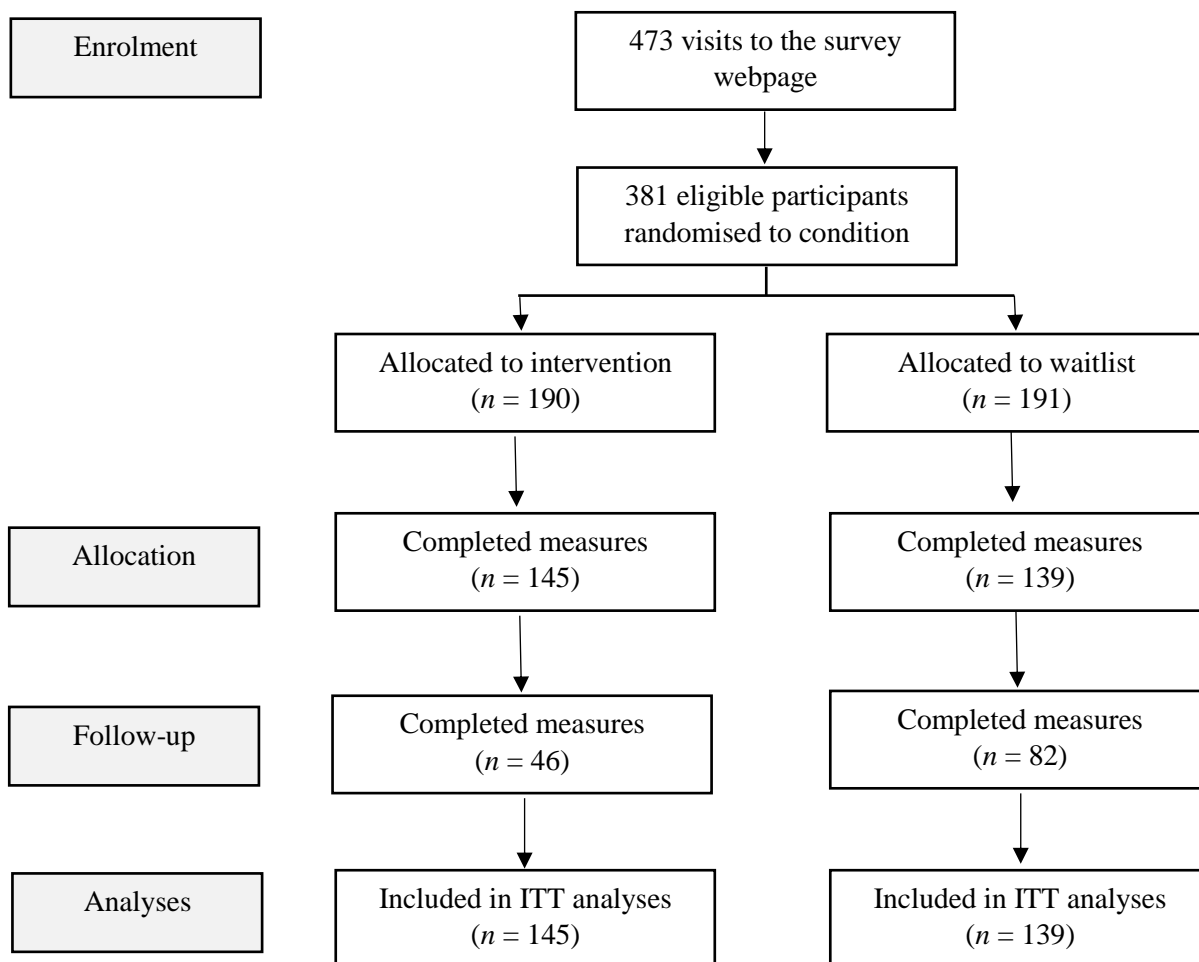
Figure 3. *Participant flow*

Randomisation Checks

To assess whether randomisation was successful, a series of independent sample t-tests and chi-squared tests were performed on baseline data. T-tests were used to examine for differences in age, or scores on the four outcome measures. No significant differences were found between groups for any continuous variables; age (t (1,283) = 1.057, p = .292), CompACT (t (1,283) = 1.667, p = .097), BFNE-II (t (1,283) = -1.116, p = .265), WSAS (t (1,283) = -1.330, p = .185) or CORE-10 (t (1,283) = -.792, p = .429). Chi-squared tests were utilised to examine differences between groups on categorical variables. As chi-squared tests are most useful when there are five data points within each label (e.g. visible difference type), some labels were merged (e.g.

74

Canada and USA became "North America"). Chi-squared tests revealed no significant differences between groups with regards to visible difference type ($\chi2$ = 3.490, p = .991) or country of residence ($\chi2$ = 1.424, p = .700). However, there was a significant difference with regards to skin colour ($\chi2$ = 5.896, p = .015) with individuals with white skin colour more likely to be assigned to the control group. However, further analyses showed no significant difference in terms of skin colour on any of the outcome measures: BFNE-II (t (1,283) = .421, p = .517), CompACT (t (1,283) = .155, p = .694) and WSAS (t (1,283) = 1.551, p = .214), so this was not controlled for in subsequent analyses. Overall, the randomisation process was successful.

Baseline outcome measure scores

For a summary of baseline scores, see Table 2. Examination of scores at baseline provides an indication of the extent of difficulties experienced within this population. As the CompACT is a recently developed measure, there are no norms available to compare the sample to. The mean score on the BFNE-II, 33.75, demonstrates high levels of fear of negative evaluation; Carleton et al. (2011) have suggested a score or 25 or above may indicate clinically significant social anxiety. The mean score on the WSAS, 13.35, is also above the clinical threshold for impairment (10) (Mundt, Marks, Shear, & Greist, 2004). Additionally, the mean score of distress, as measured by the CORE-10 is indicative of a moderately distressed clinical population (15-20).

Table 2. *Mean outcome measure scores at baseline*

Outcome Measure	Mean (SD) (n = 284)
CompACT	64.64 (18.08)
BFNE-II	33.75 (10.19)
WSAS	13.35 (9.43)
CORE-10	19.88 (8.04)

Effectiveness of the self-help intervention

Intention to treat analyses (ITT). One-way between condition ANCOVAs were conducted to compare differences between conditions at follow-up; where the co-variate was participant score at baseline. ITT analyses used a last observation carried forward (LOCF) method, which assumes no change from the baseline score. Though often perceived as a conservative method, it is often viewed as the only alternative to excluding participants from analysis (Altman, 2009).

ITT analyses indicated there was no significant effect of condition upon the primary measure, psychological flexibility, (F (1,283) = 2.394, p = .123). Similarly, there was no significant effect of condition upon fear of negative evaluation, (F (1,283) = 2.449, p = .119). However, a significant difference was observed on impairments in functioning/ quality of life between groups, (F (1,283) = 16.382, p < .001), with individuals in the intervention condition reporting less impairment. Table 3 shows the mean scores by condition at baseline and follow-up in the ITT analyses.

Table 3. *Mean outcome measure scores by time and condition from ITT analyses*

Outcome Measure	Condition	Baseline M (SD)	Follow-up M (SD)
CompACT	Intervention	66.39 (17.53)	67.28 (17.46)
	Waitlist	62.82 (18.51)	62.55 (19.09)
BFNE-II	Intervention	33.09 (10.60)	31.68 (11.38)
	Waitlist	34.44 (9.74)	33.83 (9.63)
WSAS	Intervention	12.62 (8.81)	11.29 (8.28)
	Waitlist	14.11 (10.02)	14.85 (10.14)

Attrition Analyses. Of the 284 participants who completed outcome measurement at baseline, 128 completed outcome measurement at follow-up, of which 82 were from the waitlist condition and 46 were from the intervention condition. The overall attrition rate is 54.9%, with 68.3% attrition from the intervention condition and 41% attrition from the control condition. Fewer participants completed the CompACT at follow-up (79 from the control condition and 44 from the intervention condition). The high attrition rate was expected given that the study was online and time-limited. A series of chi-squared tests and independent t-tests were conducted to examine for differences between completers and non-completers.

Independent t-tests demonstrated no significant differences between completers and non-completers in age (t (283) = -.276, p = .783), or baseline scores of psychological flexibility (t (283) = -.362, p = .718), fear of negative evaluation (t (283) = -1.077, p = .282), functioning impairments (t (283) = -.308, p = .758) or general distress (t (283) = .143, p = .886). Chi-squared tests demonstrated no significant difference between completers and non-completers with regards to skin colour ($\chi2$ = .665, p = .415), type of visible difference ($\chi2$ = 17.229, p = .141), or gender ($\chi2$ = .032, p = .984). However, significant differences between completers and non-completers were found with regards to country of residence ($\chi2$ = 9.708, p = .021) and condition ($\chi2$ = 21.315, p = < .001); where individuals were more likely to complete the study at the follow-up if they were from the United Kingdom and randomly allocated to the waitlist. See Table 4 for a comparison of baseline outcome scores by completers and non-completers.

Table 4. *Baseline outcome scores by completers and non-completers*

Outcome Measure	Completers M (SD)	Non-completers M (SD)
CompACT	65.07 (18.00)	64.29 (18.19)
BFNE-II	34.47 (9.58)	33.16 (10.66)
WSAS	13.54 (9.11)	13.19 (9.71)
CORE-10	19.80 (7.85)	19.94 (8.22)

Complete case analyses. In addition to the ITT analyses, a series of ANCOVAs were conducted to compare the outcomes between the intervention and waitlist conditions, only using data from participants who had completed measures at both time points. Baseline scores were used as covariates, and follow-up scores were the dependent variables. Due to the significantly higher attrition rate in the intervention condition, these results should be interpreted with caution, as the equality of variance assumption was not met. See Table 5 for outcome means by completers.

Complete case analyses indicated there was no significant effect of condition upon the primary measure, psychological flexibility, (F (1,122) = 2.922, p = .090). However, a significant effect of condition upon fear of negative evaluation was observed, (F (1,127) = 7.297, p = .008) where those in the intervention condition reported a reduction in fear of negative evaluation compared to the waitlist condition. The mean score at follow-up for those in the intervention condition (30.11) remains indicative of a clinical population, as defined by a score above 25. A significant difference was also observed on impaired functioning/ quality of life between groups, (F (1,127) = 16.061, p < .001), with individuals in the intervention condition reporting less impairment.

Table 5. *Outcome scores at baseline and follow-up for completers only*

Outcome Measure	Condition (N)	Baseline M (SD)	Follow-up M (SD)
CompACT	Intervention (N = 46)	66.30 (18.56)	69.25 (18.19)
	Waitlist (N = 82)	64.81 (18.56)	64.37 (19.59)
BFNE-II	Intervention (N = 46)	34.54 (9.96)	30.11 (12.38)
	Waitlist (N = 82)	34.43 (9.42)	33.39 (9.21)
WSAS	Intervention (N = 44)	14.70 (9.62)	10.50 (8.32)
	Waitlist (N = 79)	12.89 (8.81)	14.15 (9.17)

As the assumption of equal variance across conditions was not met for complete case analysis, subsequent analyses were conducted. Complete case scores at baseline and follow-up were converted into rank order scores, and an ANCOVA was completed using ranked data. This becomes a non-parametric test, which may overcome problems associated with heterogeneity of variance (Conover, 1999).

Rank ANCOVAs, using baseline data as covariates revealed an identical pattern of significance to the parametric ANCOVAs. No significant difference was observed between conditions in psychological flexibility ($F_{(1,122)}$ = 3.029, p = .084), however significant differences were observed between conditions in fear of negative evaluation ($F_{(1,127)}$ = 6.060, p = .015) and impaired functioning/ quality of life ($F_{(1,127)}$ = 18.850, p < .001). These analyses indicated the self-help intervention to be effective at reducing fear of negative evaluation and functioning impairment compared to the waitlist.

Psychological flexibility factors. The CompACT (Francis et al., 2016), has a three-factor structure; "openness to experience", "behavioural awareness" and "valued action". ANCOVA analyses, using scores at baseline as covariates were conducted to

analyse for changes on these factors across conditions. No significant differences were found between conditions on openness to experience (F (1,122) = 3.033, p = .084), behavioural awareness (F (1,122) = 2.343, p = .128) or valued action (F (1,122) = .440, p = .508). Factor means across groups are shown in Table 6.

Table 6. *CompACT factor scores at baseline and follow-up for completers only*

CompACT Factor	Condition	Baseline M (SD)	Follow-up M (SD)
Openness to Experience	Intervention	20.80 (9.15)	23.45 (8.92)
	Waitlist	22.04 (9.11)	22.42 (9.28)
Behavioural Awareness	Intervention	13.02 (6.40)	13.64 (6.46)
	Waitlist	13.47 (5.97)	12.73 (6.34)
Valued Action	Intervention	32.48 (7.39)	32.16 (7.66)
	Waitlist	29.30 (7.86)	29.22 (7.92)

Adherence tests. On completion of the follow-up measures, those allocated to the intervention condition were asked to indicate how much their adherence. Responses were then categorised into low, moderate and high adherence. Of the 44 completers, 5 were categorised to low adherence, 18 to moderate adherence and 21 to high adherence groups. To examine adherence, change scores were calculated from baseline to follow-up for all three outcome measures. Three-way ANOVAs, with adherence as the independent variable and change score as the dependent variable revealed no impact of adherence on psychological flexibility (F (2,44) = .992, p = .379), fear of negative evaluation (F (2,44) = 1.033, p = .365) or impaired functioning/ quality of life (F (2,44) = 1.264, p = .293).

Discussion

The present study found moderate levels of distress and fear of negative evaluation within a varied population of adults living with a visible difference. The acceptance-based self-help intervention developed in this study did not significantly demonstrate improvements in psychological flexibility compared to the waitlist control group. However, the intervention was significantly more effective at reducing functional impairment compared to the waitlist control group. Completer analyses suggested the intervention was also significantly more effective at reducing fear of negative evaluation compared to the control group; however, this was not demonstrated in ITT analyses. The high attrition rate, especially from individuals randomly allocated to the intervention condition limits the findings of this study.

Qualitative feedback suggests those who completed follow-up measures typically perceived the self-help intervention as helpful and understandable. However, several comments were received about the length of the intervention, given the four-week timescale between data collection points. The self-help intervention was 46 A4 pages in length (36 excluding audio exercise transcriptions) and was expected to be worked through within the four-week period. Similar studies, which have assessed unguided self-help interventions over four-week periods have been substantially shorter, with slightly reduced attrition rates, though attrition remained high. Hudson (2015) examined a 7-page compassion focused self-help intervention, with 51% attrition, whereas Lane (2017) examined a 16-page CBT self-help intervention, with 52% attrition. This study had a 55% attrition rate, though it was much higher in the intervention condition (68%). This suggests the self-help intervention requires modification prior to any subsequent use, and longer timescales to follow-up may be indicated.

The self-help intervention did not significantly improve our primary outcome of interest, psychological flexibility, compared to a waitlist control group. This finding is unexpected given significant positive change occurred in reducing fear of negative evaluation (in completer analyses only) and reducing impairment in functioning. Assuming these findings are valid, this raises two main possibilities: 1) improvement in psychological flexibility was not the catalyst for positive change, 2) psychological flexibility requires practice and takes time to develop and emerge.

In considering whether psychological flexibility was not the cause of positive change, one possibility is the self-help intervention did not adequately target psychological flexibility. A central part of the theory behind ACT is improvements in psychological flexibility should be mirrored by improvements in mental wellbeing (Wicksell, Olsson, & Hayes, 2010). This does not necessarily mean improvements in wellbeing should be mirrored by improvements in psychological flexibility if other treatments are used, but this should theoretically be evident if an ACT treatment model is employed. This brings into question whether the intervention was sufficiently acceptance-based. The self-help intervention was developed by a trainee clinical psychologist familiar with ACT and reviewed for ACT consistency by a local expert. However, it may be that some learning processes within ACT, such as mindfulness, are less effective in the absence of a responsive teacher and guided learning process (Segal, Williams, & Teasdale, 2018). Understandably it may be difficult for an individual to experience unwanted internal experiences (such as thoughts, emotions and negative memories) as mental events rather than truths, and guidance is likely to facilitate this process (Cavanagh et al., 2015). The meta-analysis conducted by French et al. (2017) found self-help ACT significantly improved psychological flexibility; however, this became non-significant when examining self-administered self-help (without clinician contact), which is a finding consistent with this study.

82

A second potential explanation for the findings of this study is improvements in psychological flexibility require time to develop. Though non-significant, change in overall psychological flexibility scores were in the expected direction. The short, four-week, duration between timepoints in this study and the absence of further follow-ups prevent further examination of this explanation. Whilst there was no significant change on individual factor scales within the CompACT, it is of interest to note change was predominantly observed in the "openness to experience" factor, and not at all in the "valued action" factor of psychological flexibility. A recent study has suggested engaging in valued behaviours precipitates changes in struggling with internal experiences and suffering (Gloster et al., 2017), but this study does not reflect that finding. The valued action factor is associated with 'values' and 'committed action' processes within ACT and it may be the timescale was too short for people to engage in value-directed behaviours, or participants may have lacked motivation or belief without the guidance of a therapist. The openness to experience factor is associated with 'acceptance' and 'defusion' within ACT and this self-help intervention appeared to have the greatest impact on this factor, though not significantly. Of the three factors within the CompACT, openness to experiences has the strongest correlation with the AAQ-II measure of psychological flexibility, distress, and social functioning. This may aid our understanding of the findings in this study, as functioning was significantly improved whilst fear of negative evaluation also improved in completers. This suggests the intervention may have started to change participant's relationship with their thoughts, such as whether they perceive their visible difference in appearance as limiting their functioning, whilst having a minimal or no effect on actual behaviour change. However, this should be taken with caution as no behavioural measures were utilised. This explanation may fit alongside the first – that changes in psychological flexibility are not

the catalyst to change or may be concurrent. Alternatively, psychological flexibility measures which are more sensitive in detecting early change may be required.

Strengths and limitations

Whilst studies have previously examined acceptance-based interventions for body image concerns and weight stigma (Griffiths et al., 2018), this is the first study to empirically examine the effectiveness of an acceptance-based intervention for adults living with a visible difference. Positively this study addressed advice from a previous review (Norman & Moss, 2015) by using a randomised design with a control condition. Furthermore, this study recognised limitations in previous studies and addressed these by ascertaining participants' viewpoint through collecting qualitative data and examining adherence to self-help. Though this study did not provide any therapeutic contact, multimedia was used within the self-help intervention, through audio exercises and a lived experience video, which may have had benefits for the effectiveness of the study (Lewis et al., 2012).

However, this study has several limitations. The major issue with this study is the high attrition rate, especially within the intervention condition, which suggests an element of the self-help intervention was not acceptable. Qualitative feedback suggested this may have been the length of the self-help intervention and burden of working through it over the four-week period. Whilst input was received on the self-help intervention from two adults with lived experience of visible difference, the intervention is likely to have benefitted from greater co-production, which may have helped to reduce attrition.

High attrition rates are common in internet-based health behaviour change interventions (Kohl, Crutzen, & de Vries, 2013). High attrition rates are also problematic due to the use of LOCF ITT analyses. As the attrition rate was 68% in the

84

intervention condition, this greatly reduced the potential for effectiveness to be demonstrated, increasing the likelihood of a type II error. Conversely, examining completers only introduces bias into the findings, increasing the likelihood of a type I error, as completers may have been more amenable to change or may have had greater motivation (Bell, Kenward, Fairclough & Horton, 2013). A further issue within the study design was presenting the CompACT as the final measure in the questionnaires, this led to fewer responses at follow-up on this measure, as people exited the survey software having completed just the WSAS and BFNE-II. This limited the data available for use examining psychological flexibility and we may assume attrition at this particular stage in the survey was due to the increased length (23 items) of this measure. Shorter measures may help reduce the burden of outcome measures in future studies or presenting the longest outcome measure at the beginning of the questionnaires. The order in which questionnaires were presented was identical for each participant.

Issues also exist within the sample, whilst visible differences are diverse, and a diverse range of participants was hoped for, 90.5% of participants were female and over 30% of the sample experienced alopecia. This may limit the generalisability of the findings. Additionally, the recruitment strategy may have introduced bias as the study was advertised via the internet and mostly through charities and organisations. This may have resulted in those with limited access to computers, or those less technologically able being less likely to take part. It is also possible individuals who access information from charities and organisations may be different from those who don't, for example, their visible difference may be more noticeable, or they may be more accepting of their visible difference and feel able to communicate with others about their appearance. Individuals were also asked to self-assess their eligibility for the study and data was not collected about the noticeability of the visible difference. This study is also subject to

self-report bias, since objective measures of psychological or biomedical health characteristics were not obtained.

The use of the CompACT, whilst theoretically based, may limit this study, as no norms exist for this new measure, so the extent to which psychological flexibility existed in the sample at baseline is unknown. Furthermore, the test-retest reliability is unknown, and the three-factor structure has not been empirically tested, thus the primary use as a global measure of psychological flexibility in this study.

This study would have also benefitted from using an extended follow-up, or an increased frequency of timepoints for data collection, as it would have allowed for changes in outcome measurement over time. This would have enabled assessment of whether gains were maintained and whether psychological flexibility does indeed develop over time and with new experiences.

The intervention was based on ACT and used many recognised strategies and techniques from ACT, as was deemed consistent with ACT by an expert in the field. Whilst the self-help intervention tried to include all aspects of ACT, the nature of the 'self-as-context' concept meant it was more difficult to include within the intervention. This may have reduced the potential for change within psychological flexibility and renders the self-help intervention 'acceptance-based' rather than ACT; as ACT requires all six core processes (Hayes, Strosahl, & Wilson, 2011).

Recommendations for future research

Future research may wish to examine the utility of acceptance-based interventions which include an element of therapist contact, as they often demonstrate improved effectiveness (Hirai & Clum, 2006). Studies may wish to recruit through health settings, such as dermatological clinics to recruit a sample with greater generalisability and ascertain whether self-help interventions could fit within a stepped

care model. Future studies should continue to assess the acceptability of interventions and may wish to include detailed qualitative aspects to their studies to improve interventions. Further studies are needed to assess whether increasing psychological flexibility is a mechanism for improvement in mental health within populations living with a visible difference. One such method, which may provide beneficial inside into this area, would be a case series.

Clinical implications

Significant levels of distress, fear of negative evaluation and functional impairments are present with adults living with a visible difference. Routine screening in relevant clinics may be beneficial, so psychological support can be accessed.

Acceptance-based interventions have potential to provide effective support to adults living with a visible difference. However, these interventions may be less effective in the absence of a clinician.

Conclusions

This research examined the effectiveness of an acceptance-based self-help intervention in a randomised controlled trial. The self-help intervention significantly improved functioning impairments relating to visible difference, but significant improvements were not observed in psychological flexibility or fear of negative evaluation compared to the control condition in ITT analyses. Fear of negative evaluation did significantly improve compared to the control condition in completer analyses. Acceptance-based approaches have potential to improve the lives of people living with visible difference and further studies are required to investigate this area.

References

A-Tjak, J. G., Davis, M. L., Morina, N., Powers, M. B., Smits, J. A., & Emmelkamp P. M. (2015) A meta-analysis of the efficacy of acceptance and commitment therapy for clinically relevant mental and physical health problems. *Psychotherapy and Psychosomatics, 84*, 30-36. doi:10.1159/000365764

Ablett, K., & Thompson, A. R. (2016). Parental, child, and adolescent experience of chronic skin conditions: A meta-ethnography and review of the qualitative literature. *Body Image*, *19*, 175-185. doi:10.1016/j.bodyim.2016.10.001

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th Ed.). Arlington, VA: American Psychiatric Publishing.

All Party Parliamentary Report on Skin. (2013). *The psychological and social impact of skin disease on people's lives*. London, UK: All Party Parliamentary Group on Skin.

Altman, D. G. (2009). Missing outcomes in randomized trials: Addressing the dilemma. *Open Medicine*, *3*, 51-53.

Barkham, M., Bewick, B., Mullin, T., Gilbody, S., Connell, J., Cahill, J., Mellor-Clark, J., ... & Evans, C. (2013). The CORE-10: A short measure of psychological distress for routine use in the psychological therapies. *Counselling and Psychotherapy Research*, *13*, 3-13. doi:10.1080/14733145.2012.729069

Bell, M. L., Kenward, M. G., Fairclough, D. L., & Horton, N. J. (2013). Differential dropout and bias in randomised controlled trials: when it matters and when it may not. *BMJ, 346*, e8668. doi:10.1136/bmj.e8668

Bessell, A., & Moss, T. P. (2007). Evaluating the effectiveness of psychosocial interventions for individuals with visible differences: A systematic review of the empirical literature. *Body Image*, *4*, 227-238. doi:10.1016/j.bodyim.2007.04.005

Blance, A., Tu, Y., Baelum, V., & Gilthorpe, M. S. (2007). Statistical issues on the analysis of change in follow-up studies in dental research. *Community Dentistry and Oral Epidemiology*, *35*, 412-420. doi:10.1111/j.1600-0528.2007.00407.x

Bond, F. W., Hayes, S. C., Baer, R. A., Carpenter, K. M., Guenole, N., Orcutt, H. K., … & Zettle, R. D. (2011). Preliminary psychometric properties of the Acceptance and Action Questionnaire - II: A revised measure of psychological flexibility and experiential avoidance. *Behavior Therapy, 42*, 676-688. doi:10.1016/j.beth.2011.03.007

Bundy, C., Pinder, B., Bucci, S., Reeves, D., Griffiths, C. E. M., & Tarrier, N. (2013). A novel, web- based, psychological intervention for people with psoriasis: The electronic Targeted Intervention for Psoriasis (eTIPs) study. *British Journal of Dermatology*, *169*, 329-336. doi:10.1111/bjd.12350.

Carleton, R. N., Collimore, K. C., & Asmundson, G. J. (2007). Social anxiety and fear of negative evaluation: Construct validity of the BFNE-II. *Journal of Anxiety Disorders*, *21*, 131-141. doi:10.1016/j.janxdis.2006.03.010

Carleton, R. N., Collimore, K. C., McCabe, R. E., & Antony, M. M. (2011). Addressing revisions to the brief fear of negative evaluation scale: Measuring fear of negative evaluation across anxiety and mood disorders. *Journal of Anxiety Disorders*, *25*, 822-828. doi:10.1016/j.janxdis.2011.04.002

Cavanagh, K., Strauss, C., Forder, L., & Jones, F. (2014). Can mindfulness and
acceptance be learnt by self-help?: A systematic review and meta-analysis of
mindfulness and acceptance-based self-help interventions. *Clinical Psychology
Review, 34,* 118-129. doi:10.1016/j.cpr.2014.01.001

Changing Faces. (2007). *The incidence and prevalence of disfigurement*. Retrieved from
https://www.changingfaces.org.uk/wp-content/uploads/2016/03/FE-Campaign-
Epidemiology-2-pages.pdf.

Clarke, A., Thompson A. R., Jenkinson, E., Rumsey, N., & Newell, R. (2014). *CBT for
appearance anxiety: Psychosocial interventions for anxiety due to visible
difference*. West Sussex, UK: Wiley Blackwell.

Conover, W. J. (1999). *Practical nonparametric statics*. New York: John Wiley &
Sons.

Crawford, M. J., Robotham, D., Thana, L., Patterson, S., Weaver, T., Barber, R., ... &
Rose, D. (2011). Selecting outcome measures in mental health: The views of
service users. *Journal of Mental Health*, *20*, 336-346.
doi:10.3109/09638237.2011.577114

Cuijpers, P., Donker, T., van Straten, A., Li, J., & Andersson, G. (2010). Is guided self-
help as effective as face-to-face psychotherapy for depression and anxiety
disorders? A systematic review and meta-analysis of comparative outcome
studies. *Psychological Medicine*, *40*, 1943-1957. doi:
10.1017/S0033291710000772

Dalgard, F. J., Gieler, U., Tomas-Aragones, L., Lien, L., Poot, F., Jemec, G. B. E., …
Kupfer, J. (2015). The psychological burden of skin diseases: A cross sectional
multicentre study among dermatological out-patients in 13 European countries.
Journal of Investigative Dermatology, *135*, 984-991. doi:10.1038/jid.2014.530

Dixon, L. J., Witcraft, S. M., McCowan, N. K., & Brodell, R. T. (2018). Stress and skin
disease quality of life: The moderating role of anxiety sensitivity social
concerns. *British Journal of Dermatology*, *178*, 951-957. doi:10.1111/bjd.16082

Egan, K., Harcourt, D., Rumsey, N., & Appearance Research Collaboration. (2011). A
qualitative study of the experiences of people who identify themselves as having
adjusted positively to a visible difference. *Journal of Health Psychology*, *16*,
739-749. doi:10.1177/1359105310390246

Falvey, H. (2012). Cross-cultural differences. In Rumsey, N., & Harcourt, D. (Eds.) *The
Oxford handbook of the psychology of appearance* (pp. 36-46). London: Oxford
University Press.

Faul, F., Erdfelder, E., Lang, A. G., & Buchner, A. (2007). G* Power 3: A flexible
statistical power analysis program for the social, behavioral, and biomedical
sciences. *Behavior Research Methods*, *39*, 175-191. doi:10.3758/BF03193146

Francis, A., Dawson, D., & Golijani-Moghaddam, N. (2016). The development and
validation of the Comprehensive assessment of Acceptance and Commitment
Therapy processes (CompACT). *Journal of Contextual Behavioral Science*, *5*,
134-145. doi:10.1016/j.jcbs.2016.05.003

Fried, R. G. (2013). Nonpharmacologic management of psychodermatologic conditions. *Seminars in Cutaneous Medicine and Surgery*, *32*, 119-125. doi:10.1111/j.1529-8019.2008.00171.x

French, K., Golijani-Moghaddam, N., & Schroder, T. (2017). What is the evidence for the efficacy of self-help acceptance and commitment therapy? A systematic review and meta-analysis. *Journal of Contextual Behavioral Science*, *6*, 360-374. doi:10.1016/j.jcbs.2017.08.002

Ghajarzadeh, M., Ghiasi, M., & Kheirkhah, S. (2012). Associations between skin disease and quality of life: A comparison of psoriasis, vitiligo, and alopecia areata. *Acta Medica Iranica*, *50*, 511–515.

Gloster, A. T., Klotsche, J., Ciarrochi, J., Eifert, G., Sonntag, R., Wittchen, H. U., & Hoyer, J. (2017). Increasing valued behaviors precedes reduction in suffering: Findings from a randomized controlled trial using ACT. *Behaviour Research and Therapy*, *91*, 64-71. doi:10.1016/j.brat.2017.01.013.

Griffiths, C., Williamson, H., Zucchelli, F., Paraskeva, N., & Moss, T. (2018). A systematic review of the effectiveness of Acceptance and Commitment Therapy (ACT) for body image dissatisfaction and weight self-stigma in adults. *Journal of Contemporary Psychotherapy*, *48*, 1-16. doi:10.1007/s10879-018-9384-0

Harris, R. (2013). *Getting unstuck in ACT. A clinician's guide to overcoming obstacles in acceptance and commitment therapy*. New Harbinger: Oakland.

Hayes, S. C. (2005). *Get out of your mind and into your life: The new acceptance and commitment therapy*. New Harbinger: Oakland.

92

Hayes, S. C., Strosahl, K., & Wilson, K. G. (1999). *Acceptance and Commitment Therapy: An experiential approach to behavior change* (Eds.). New York: Guilford Press.

Hayes, S. C., Strosahl, K., & Wilson, K. G. (2011). *Acceptance and Commitment Therapy: An experiential approach to behavior change* (2nd Ed.). New York: Guilford Press.

Hirai, M., & Clum, G. A. (2006). A meta-analytic study of self-help interventions for anxiety problems. *Behavior Therapy*, *37*, 99-111. doi:10.1016/j.beth.2005.05.002

Hoffmann, D., Rask, C. U., Hedman-Lagerlöf, E., Ljótsson, B., & Frostholm, L. (2018). Development and feasibility testing of internet-delivered acceptance and commitment therapy for severe health anxiety: Pilot Study. *JMIR Mental Health*, *5*, e28. doi:10.2196/mental.9198

Hudson, M. P. (2015). *The role of self-compassion in adjustment to long-term physical health conditions*. DClinPsy thesis, University of Sheffield, UK.

Jenkinson, E., Williamson, H., Byron-Daniel, J., & Moss, T. P. (2015). Systematic review: Psychosocial interventions for children and young people with visible differences resulting from appearance altering conditions, injury, or treatment effects. *Journal of Pediatric Psychology*, *40*, 1017-1033. doi:10.1093/jpepsy/jsv048

Kohl, L. F., Crutzen, R., & de Vries, N. K. (2013). Online prevention aimed at lifestyle behaviors: A systematic review of reviews. *Journal of Medical Internet Research*, *15,* e46. doi:10.2196/jmir.2665

Lane, J. C. (2017). *Using if-then planning in independently delivered and self-help interventions to promote physical and mental health*. DClinPsy thesis, University of Sheffield, UK.

Lappalainen, P., Langrial, S., Oinas-Kukkonen, H., Tolvanen, A., & Lappalainen, R. (2015). Web-based acceptance and commitment therapy for depressive symptoms with minimal support: A randomized controlled trial. *Behavior Modification, 39*, 805-834. doi:10.1177/0145445515598142

Leary, M. R. (1983). A brief version of the fear of negative evaluation scale. *Personality and Social Psychology Bulletin*, *9*, 371-375. doi:10.1177/0146167283093007

Lewis, C., Pearce, J., & Bisson, J. I. (2012). Efficacy, cost-effectiveness and acceptability of self-help interventions for anxiety disorders: Systematic review. *British Journal of Psychiatry*, *200*, 15–21. doi:10.1192/bjp.bp.110.084756

Lovegrove, E. & Rumsey, N. (2005). Ignoring it doesn't make it stop: Adolescents, appearance, and bullying. *The Cleft Palate-Craniofacial Journal*, *42*, 33-44. doi:10.1597/03-097.5.1

Lowry, C. L., Shah, R., Fleming, R., Taylor, R., & Bewley, A. (2014). A study of service provision in psychocutaneous medicine. *Clinical and Experimental Dermatology*, *39*, 13-18. doi:10.1111/ced.12235

MacLeod, R., Shepherd, L., & Thompson, A. R. (2016). Posttraumatic stress symptomatology and appearance distress following burn injury: An interpretative phenomenological analysis. *Health Psychology*, *35*, 1197-1204. doi:10.1037/hea0000391.

Marks, I. (1986). *Behavioural Psychotherapy*. Bristol: John Wright.

Moss, T. P., & Rosser, B. A. (2012). The moderated relationship of appearance valence on appearance self-consciousness: Development and testing of new measures of appearance schema components. *PLoS ONE*, *7*, e50605. doi:10.1371/journal.pone.0050605.

Muftin, Z., & Thompson, A. R. (2013). A systematic review of self-help for disfigurement: Effectiveness, usability and acceptability. *Body Image*, *10*, 442-450. doi:10.1016/j.bodyim. 2013.07.005

Mundt, J. C., Marks, I. M., Shear, K., & Greist, J. H. (2002). The work and social adjustment scale: A simple measure of impairment in function. *British Journal of Psychiatry*, *180*, 461–464. doi:10.1192/bjp.180.5.461

Newell, R. (1999). Altered body image: A fear-avoidance model of psychosocial difficulties following disfigurement. *Journal of Advanced Nursing*, *30*, 1230-1238. doi:10.1046/j.1365-2648.1999.01185.x

Newman, M. G., Erickson, T., Przeworski, A., & Dzus, E. (2003). Self- help and minimal- contact therapies for anxiety disorders: Is human contact necessary for therapeutic efficacy?. *Journal of Clinical Psychology*, *59*, 251-274. doi:10.1002/jclp.10128

Norman, A., & Moss, T. P. (2015). Psychosocial interventions for adults with visible differences: A systematic review. *PeerJ*, *3*, e870. doi:10.7717/peerj.870

Obradors, M., Blanch, C., Comellas, M., Figueras, M., & Lizan, L. (2016). Health-related quality of life in patients with psoriasis: A systematic review of the European literature. *Quality of Life Research*, *25*, 2739-2754. doi:10.1007/s11136-016-1321-7

Olejnik, S. F., & Algina, J. (1984). Parametric ANCOVA and the rank transform ANCOVA when the data are conditionally non-normal and heteroscedastic. *Journal of Educational Statistics*, *9*, 129-149.

Olejnik, S. F., & Algina, J. (1985). A review of nonparametric alternatives to analysis of covariance. *Evaluation Review*, *9*, 51-83. doi:10.1177/0193841X8500900104

Ost, L. G. (2014). The efficacy of acceptance and commitment therapy: An updated systematic review and meta-analysis. *Behaviour Research and Therapy, 61*, 105-121. doi:10.1016/j.brat.2014.07.018

Parna, E., Aluoja, A., & Kingo, K. (2015). Quality of life and emotional state in chronic skin disease. *Acta Dermato-Venereologica*, *95*, 312–316. doi:10.2340/00015555-1920.

Rapee, R. M., & Heimberg, R. G., (1997). A cognitive behavioral model of anxiety in social phobia. *Behaviour Research and Therapy*, *35*, 741–756. doi:10.1016/S0005-7967(97)00022-3

Reiss, S., & McNally, R. J. (1985). Expectancy model of fear. In S. Reiss & R. R. Bootzin (Eds.), *Theoretical issues in behavior therapy* (pp. 107-121). New York: Academic Press.

Richards, H. L., Fortune, D. G., Weidmann, A., Sweeney, S. K., & Griffiths, C. E. (2004). Detection of psychological distress in patients with psoriasis: Low consensus between dermatologist and patient. *British Journal of Dermatology*, *151*, 1227-1233. doi:10.1111/j.1365-2133.2004.06221.x

Ritzert, T. R., Forsyth, J. P., Sheppard, S. C., Boswell, J. F., Berghoff, C. R., & Eifert, G. H. (2016). Evaluating the effectiveness of ACT for anxiety disorders in a self-help context: outcomes from a randomized wait-list controlled trial. *Behavior Therapy, 47*, 444-459. doi:10.1016/j.beth.2016.03.001

Rumsey, N. (2002). Body image and congenital conditions with visible differences, in T. Cash & T. Pruzinsky (Eds.), *Body image: A handbook of theory, research and practice* (pp. 226–233). New York, NY: Guilford Press

Rumsey, N., & Harcourt, D. (2004). Body image and disfigurement: Issues and interventions. *Body image*, 1, 83-97. doi:10.1016/S1740-1445(03)00005-6

Segal, Z. V., Williams, J. M. G., & Teasdale, J. D. (2018). *Mindfulness-based cognitive therapy for depression: A new approach to preventing relapse* (3rd Ed.). New York: Guilford Press.

Schofield, J., Grindlay, D., & Williams, H. (2009). *Skin conditions in the UK: A health care needs assessment.* Centre of Evidence-Based Dermatology, University of Nottingham, UK.

Schulz, K. F., Altman, D. G., & Moher, D. (2010). CONSORT 2010 statement: Updated guidelines for reporting parallel group randomised trials. *The British Medical Journal*, *340*, 698-702. doi:10.1136/bmj.c332

Thompson A. R. (2012). Skin conditions. In T. F. Cash (Eds.). *Encyclopedia of body image and human appearance* (pp. 738–744). San Diego, California: Academic Press.

Thompson, A. R. (2014). Treatment challenges: Getting psychodermatology into the clinic. *Dermatological Nursing*, *13*, 26-31.

Thompson, A. R., Clarke, S. A., Newell. R, Gawkrodger, G., & The Appearance Research Collaboration (2010). Vitiligo linked to stigmatisation in British South Asian women: A qualitative study of the experiences of living with vitiligo. *British Journal of Dermatology*, *163*, 481-6. doi:10.1111/j.1365-2133.2010.09828.x

Thompson, A. R., & Kent, G. (2001). Adjusting to disfigurement: Processes involved in dealing with being visibly different. *Clinical Psychology Review*, *21*, 663-682. doi:10.1016/S0272-7358(00)00056-8

Thompson, A. R., Kent, G., & Smith, J. A. (2002). Living with vitiligo: Dealing with difference. *British Journal of Health Psychology*, *7*, 213-25. doi:10.1348/135910702169457

Trompetter, H. R., Bohlmeijer, E. T., Veehof, M. M., & Schreurs, K. M. G. (2015). Internet-based guided self-help intervention for chronic pain based on acceptance and commitment therapy: A randomized controlled trial. *Journal of Behavioral Medicine, 38*, 66-80. doi:10.1007/s10865-014-9579-0

Vickers, A. J. (2005). Parametric versus non-parametric statistics in the analysis of randomized trials with non-normally distributed data. *BMC Medical Research Methodology*, *5*, 35. doi:10.1186/1471-2288-5-35

Walser, R. D. & Hayes, S. C. (2006). Acceptance and commitment therapy in the

    treatment of posttraumatic stress disorder. In V. M. Follette & J. I. Ruzek (Eds.),

    Cognitive Behavioral Therapies Trauma (pp. 146-172). New York: Guilford

    Press.

Wicksell, R. K., Olsson, G. L., & Hayes, S. C. (2010). Psychological flexibility as a

    mediator of improvement in acceptance and commitment therapy for patients

    with chronic pain following whiplash. *European Journal of Pain*, *14*, 1059-e1-

    1059.e11. doi:10.1016/j.ejpain.2010.05.001

Wolgast, M. (2014). What does the Acceptance and Action Questionnaire (AAQ-II)

    really measure? *Behavior Therapy*, *45*, 831-839. doi:10.1016/j.beth.2014.07.002

Zahra, D., Qureshi, A., Henley, W., Taylor, R., Quinn, C., Pooler, J., ... & Byng, R.

    (2014). The work and social adjustment scale: reliability, sensitivity and value.

    International Journal of Psychiatry in Clinical Practice, *18*, 131-138.

    doi:10.3109/13651501.2014.894072

Appendices

Appendix A – Ethical approval letter

The University Of Sheffield.

Luke Powell
Registration number: 150123727
Psychology
Programme: Doctorate of Clinical Psychology

Dear Luke

PROJECT TITLE: Effectiveness of acceptance-based self-help for individuals with visible difference and social anxiety: a randomised controlled trial.
APPLICATION: Reference Number 012266

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 12/02/2017 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 012266 (dated 08/02/2017).
- Participant information sheet 1026229 version 1 (22/12/2016).
- Participant consent form 1026230 version 1 (22/12/2016).

If during the course of the project you need to deviate significantly from the above-approved documentation please inform me since written approval will be required.

Yours sincerely

Thomas Webb
Ethics Administrator
Psychology

Appendix B – Comprehensive assessment of Acceptance and Commitment

Therapy processes (CompACT)

[Ommitted due to copyright]

Appendix C – Brief Fear of Negative Evaluation scale -II (BFNE-II)

[Ommitted due to copyright]

Appendix D – Work and Social Adjustment Scale (WSAS)

[Ommitted due to copyright]

Appendix E – Clinical Outcomes in Routine Evaluation-10 (CORE-10)

[Ommitted due to copyright]

Surviving
to
Thriving

ACT self-help for living well with a visible difference in appearance

Luke Powell, Andrew Thompson & Nicolas Wilkinson

In society, you do not have to look far to find appearance is viewed as important. Some newspapers and magazines have entire sections focused on what people look like and what they are wearing. Many adverts continue to use people they believe to be stereotypically attractive. Social media is crowded with edited images of people's appearance. We are encouraged to pay a great deal of attention to our appearance, yet it is only one part of what makes us who we are, and when deciding on our friendships and relationships, is it really the most important thing to us?

In a society where the portrayal of 'beauty' is narrowly and unrealistically defined, it is understandable we may worry about our appearance, and this worry can impact on what we do in our day-to-day lives.

The aim of this booklet is to help people with a visible difference in their appearance* to be able to build confidence and overcome the unhelpful challenges posed by narrow definitions of 'beauty'. This booklet utilises modern psychological techniques to help identify what is important to you and to develop strategies to build self-confidence.

We hope you find it useful and we value any feedback you give us.

*The term visible difference is used in this booklet. There have been many terms used over time to describe differences in appearance as a result of an injury, health condition or birth condition. We use "visible difference" as it is generally regarded as more socially neutral than other terms which have been used.

Written by Luke Powell, Trainee Clinical Psychologist, with support from;
Andrew Thompson, Reader in Clinical Psychology and Nicolas Wilkinson,
Consultant Clinical Psychologist.

Address for correspondence:
Dr A. R. Thompson
Department of Psychology
University of Sheffield
Cathedral Court, 1 Vicar Lane, Sheffield S1 2LT

Surviving to Thriving

Introduction

This booklet aims to promote thriving/ getting the most from life, in people living with a "visible difference". Such conditions include: burns, scarring, skin and hair conditions and conditions present from birth. It is estimated 1.3 million people have a visible difference in their appearance. Of those individuals, approximately 540,000 identify with a facial visible difference. These figures do not include the approximate 2% people who have hair conditions, such as Alopecia.

Whether the visible difference is present from birth or acquired later in life, a visible difference may affect a person's confidence and self-esteem. Though many people may not notice or comment on somebody's appearance, unfortunately there are some who may make judgements, say hurtful things, some people may stare and some may ask personal questions. This can trigger a range of emotions from understandable annoyance, to anxiety, and low mood.

When we experience unwanted emotions, such as worry about our appearance, these emotions can impact on and determine our behaviour. For example, worrying about how others view us, can lead avoidance of situations, such as going out with friends, visiting shops or going to work. Avoiding situations may be experienced as a way of coping, but it does not make the worry go away and it stops us from building our confidence and self-esteem. Furthermore, worries can stop us doing the things in life which we enjoy and are meaningful and important to us.

It is important to say there are also many people with visible difference who are confident within social situations and have developed ways of coping with reactions of other people. In this booklet we will consider some strategies which may help both in difficult situations, and in general.

It may take some time to go through this booklet, completing the exercises as you go. **Please see the suggested timetable which recommends how you might make the best use of this booklet**. In addition to this booklet, there are some audio downloads which are designed to go with the booklet and may help you to practice some of the skills (not all of these feature in the booklet). You will find a QR barcode and a website address (link) next to each audio exercise; these can be scanned using mobile apps and will take you directly to the audio. There is also a video featuring Catrin Pugh, who describes her experience of going from 'surviving' to 'thriving' after experiencing significant burn injuries.

All the audio exercises and the video can be found on this YouTube channel:
http://bit.ly/surviving_to_thriving

ACT

This booklet is based upon Acceptance and Commitment Therapy, or "ACT" for short. ACT has been proven to help people experiencing a range of difficulties, including anxiety and long-term health conditions (e.g. chronic pain). ACT's key message is to reduce struggling with the parts of life you can't control and to focus on the aspects of life which are important to you. ACT also focuses on "being in the world" which simply means to focus on being present in the here-and-now. This is because we can often get caught up in our thoughts and we may play our worries over again and again, in doing so we can miss what is happening in the here and now.

The ACT approach is one where we seek to take actions to improve our quality of life. In ACT, we do things because they are important or meaningful to us, rather than doing (or not doing) things to escape unwanted thoughts and feelings.

This booklet follows this order:

This booklet aims to help individuals with visible difference improve in confidence. Though we hope everybody will find this booklet useful, it may not be for everyone. If you find you become distressed or feel you need to talk to somebody, you may wish to stop reading this booklet and contact your healthcare practitioner/ doctor. Other places for advice can be found at the end of this booklet.

This suggested timetable is meant as a guide. You are welcome to go through the booklet and accompanying written and audio exercises as you wish. Please aim to complete the booklet within four weeks as we will be asking you for feedback at that point.

As you go through the booklet, we recommend practicing some of the mindfulness and thought techniques for at least 10 minutes every day (practice diary available on page 26).

Week one:

- Read parts 1 and 2
  (completing the written exercises and listening to the audio exercises as you go)
- Watch the lived experience video, featuring Catrin.
- Start working towards your value-based goals (from part 1)

Week two:

- Read through part 3 and the summary (do not revisit the video yet)
  (completing the written exercises and listening to the audio exercises as you go)
- Set yourself a couple of SMART goals (and try to complete them over the next week)

Week three:

- Revisit the booklet as necessary.
- Try to complete at least one exercise/practice every day, writing this in a practice diary of the exercises you have used
- Review progress of your SMART goals and consider ways to overcome barriers and if you managed to complete your goals, set new SMART goals.

Week four:

- Revisit the expert by experience video, as directed in the summary.
- Try expanding your mindful awareness to everyday life, no matter where you are.
- Review your progress working towards goals. Consider how you can keep moving in a "valued direction".
-

Some common experiences described by individuals who experience anxiety in relation to their experience include: difficulties in social situations, low self-esteem, a negative view of their body (or specific part of their body) and frequent worry. Some of these experiences may relate to negative reactions from other people. These unwanted experiences can stay in our minds and affect what we do and how we approach future situations.

Example: Ryan went out for a meal with a couple of friends and was called names by somebody he didn't know. When Ryan got home, he kept thinking about what had happened, which made him feel very upset. Although Ryan enjoys time with his friends, the next time he was asked if he would like to go out for a meal with them, he decided not to go in case name-calling happened again.

In the example above, Ryan chose to not go out with his friends, even though seeing friends was important to him. We are going to try and identify some of the things which are important to you. In picking up this booklet and reading these words, you have demonstrated one of your values is to get the most out of your life and not be controlled by challenging thoughts and feelings. As you go through this booklet, you will notice there is a focus upon "what is important to us" and our values and it is important to keep these in mind.

What is a value?

A value is a person's perspective on what is important in their life. A value is a quality, rather than an action and values can't be completed in the same way a goal or target might be. Values are generally what motivates us in day to day life and we can choose what we do based upon them. For example, some people may be very motivated by their families, or by their friends, their religion or by their career and these may be guided by values such as trust, responsibility, safety, spirituality, love, socialisation and kindness. Your values can be used to guide you in a meaningful direction in your life.
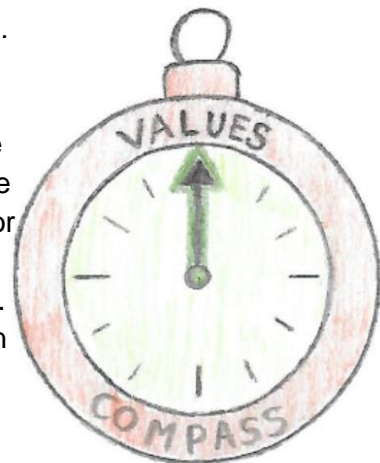
Some of the most commonly held values include:

- Acceptance /self-acceptance
- Adventure
- Appreciation
- Bravery
- Caring
- Connection
- Courage
- Creativity
- Curiosity
- Excitement
- Friendliness
- Fun

- Gratitude
- Hardworking
- Health
- Integrity
- Kindness
- Love
- Responsibility
- Self-care
- Skilfulness
- *There are many, many more…*

Please answer the following questions as they should be able to allow you to notice things which are important to you.

Written Exercise 1. Noticing what is important to me.

Think about people who are role models, or you have great admiration towards. What is it about these people, which makes them stand out to you? What qualities do they have?

e.g. I really admire the way my sister always stands up for what she believes in.

_____

_____

_____

_____

_____

What personal qualities would you like to develop or express?

_____

_____

_____

_____

When do you most feel like you are expressing who you are?

e.g. I feel most like myself when I am talking about something I am passionate

about

_____

_____

_____

If the things you did were guided 100% by what you really want to do, and not by difficult thoughts, feelings, other people etc. what would you be doing?

1 _____

2 _____

3 _____

4 _____

Looking back over your answers, take a moment to reflect upon and notice what your values may be.

It's likely that most of, if not all of, what you wrote was not about appearance. In Acceptance and Commitment Therapy, when we behave in a way that is guided by values, we call this "valued direction".

Looking over your answers to the above questions and reflecting upon your values, please use the space below to write down some thoughts about what your values are:

_____

_____

_____

_____

Thinking about these values, please write an action (or actions) you can do in the next week, which will help you feel more in tune with your values.

_____

_____

_____

_____

The struggle with thoughts and feelings

We, as humans, are complicated beings. No matter where we are, or what we're doing, we can experience a huge variety of thoughts, both related or unrelated to what is happening in that moment. These thoughts are often connected to passing feelings and you may be able to track them back to specific memories. Some thoughts and feelings may be pleasant, but some of them can be distressing. This part of the booklet focuses on living in the present moment. This is not easy to do, as we are often distracted by our inner world of thoughts and feelings. However, being able to be more present in the here and now is an important skill in helping us to get the most out of life. If we're stuck thinking over and over about past events, we can struggle to complete activities and find meaning in the things we do. Before we can try and change the impact of difficult thoughts and feelings, we have to become aware of what they are and when they arise.

Another useful reason to try and access the present moment is our minds do not like unresolved challenges. Unresolved thoughts and feelings can prevent us from doing what is meaningful to us and from noticing positivity. Imagine if you had been shopping and bought items from 10 shops. In 9 shops, your experience was good, your interactions were pleasant with the shopkeepers and you left those shops content. However, in the other shop, the shopkeeper tells you to wait whilst they finish chatting to a friend and then when they do serve you, they short-change you and insist they haven't done so. You would likely leave the shop feeling angry and hard done to. When you got home from your shopping, which part of the day would you be ruminating about? If somebody asked you about your day, what would you focus on? The chances are you would almost forget that 90% of your day went well and you would talk about your one bad experience over and above everything else. This is a natural way our minds work, but we can overcome this by training our brain to notice when our minds give power to negatives and instead focus on our values.

To think about how this booklet may help you, please listen to "*Getting all caught up*". This will provide only a brief introduction to the rest of the booklet and you may wish to re-visit this metaphor again when you are further through the booklet. This metaphor is also included in text below, and if you wish to see the metaphor, it is part of the lived experience video (*from 38:10 – 41:30*):

http://bit.ly/all_caught_up_s2t

Audio exercise 1. - Getting all caught up 🎧

For the purpose of this exercise, please find a large book or magazine, or piece of paper. You may also wish to find a quiet space so that you can listen uninterrupted. You will need to hold the object throughout the exercise.

Now that you have this object, imagine it represents some of the difficult thoughts, feelings and memories that you have been experiencing which relate to your appearance. Now hold the object up and bring it directly in front of your face, so you

can't see in front of you anymore. This is like being caught up with all of your difficult thoughts, feelings, memories.

What would it be like trying to have a conversation with somebody right now, while you're caught up with your thoughts and feelings? Would you be able to give somebody a hug, visit new places and look after yourself whilst you are gripping this object tight in front of you?

The answer is more than likely no, not at all. While you are caught up with these difficult internal experiences you can lose contact with the rest of the world, with others and with what you would really like to do.

Okay, so now whilst keeping both hands on the object and keeping it in line with your face, push the object as far away as you possibly can. Your arms should be straight from your shoulder past your elbow and to your hands. Try with all your might to get this object as far away from you as possible, really put all of your effort in to getting this object away from you. Keep doing so, but now notice as you do so, your arms might start to feel tired and heavy and in trying to make these difficult thoughts, feelings and memories away you have focused all your effort on this struggle. Though you can now see around you, you're looking right at the object and not at all noticing what is around you.

Keeping hold of the object, gently and slowly lower the object down on to your lap and let it rest there. Would it be easier to have a conversation with somebody now? Would you be more able to engage with what is around you? You've stopped struggling with your difficult thoughts, feelings and memories and you can now see what's going on around you. Notice however that they're still with you, but they are having less of an impact over you. You might not like them or want them to be there, but by stopping the struggle and not getting caught up with them, you can now focus on the other things around you. You might have tried loads of ways to get rid of these before – by distracting yourself, lying in bed, avoiding difficult situations, beating yourself up trying to understand why you feel this way, or some people may have tried drugs or lots of alcohol amongst the many other ways people try to get rid of difficult thoughts and feelings. Despite all this effort, though they may work for a little work, these thoughts and feelings still show up. So even though our instinct might be to fight away these difficult experiences and push away the object, this strategy doesn't have the effect you want.

This booklet is about using skills, such as mindfulness, to enable you to handle unwanted thoughts, feelings and memories in a way that reduces their influence and impact on you. The aim is to stop the struggle with these experiences so you can put all the energy you've used to try and get rid of these experiences in to doing the things which are important to you.

The "getting caught up" exercise suggests a new way of coping with our difficult thoughts and feelings. The idea is that bouncing between being "caught up" with our experiences, and then trying to avoid these inner experiences ultimately causes more distress. Understandably, we may not want to experience anything that makes us feel uncomfortable or gives us unwanted thoughts. However, is it important to recognise

these difficult thoughts and feelings are a normal part of the human experience and we all experience them.

Interestingly, there are times in our lives where we have been willing to experience unwanted thoughts and negative feelings; generally, this is because we are acting in a way which matches our values. For example, any tests, interviews, presentations or competitions you may have completed are likely to have made you feel anxious, but you were willing to experience this as achievement was important to you. Similarly, in the value of being healthy, people visit hospitals and places such as dentists where they may be exposed to discomfort and though they may not want the experience of discomfort, the value of being healthy comes first.

Finally, trying things for the first time, such as going on an aeroplane, or asking somebody out for a date can make us really anxious. However, by recognising the value in such activities, we are much more likely to engage in them, i.e. by asking someone on a date, we are much more likely to have a relationship, or by going on an aeroplane, we are better able to see places we've wanted to go. It allows us to make a choice between acting on our values or our fears (e.g. anxiety).

Our thoughts, feelings and memories can get in the way of us doing the things which are important to us. This is because as humans, we tend to want to avoid or fight anything which makes us feel uncomfortable, distressed, or we don't like. However, we generally find we can only push these difficult thoughts, feelings and memories away for a little while and we can sometimes get "stuck" trying to get rid of them. Instead of disappearing, our worrying, feelings of anxiety and painful memories can become the entire focus of our attention and then we ask ourselves why they won't go away. At this stage, it is useful for us to spend a moment to recognise the thoughts and feelings we can struggle with.

Written exercise 2. Noticing difficult thoughts

Please use the space below to write some examples of difficult thoughts or relating to your appearance. These may relate to how you see yourself, or how you think others will see you.
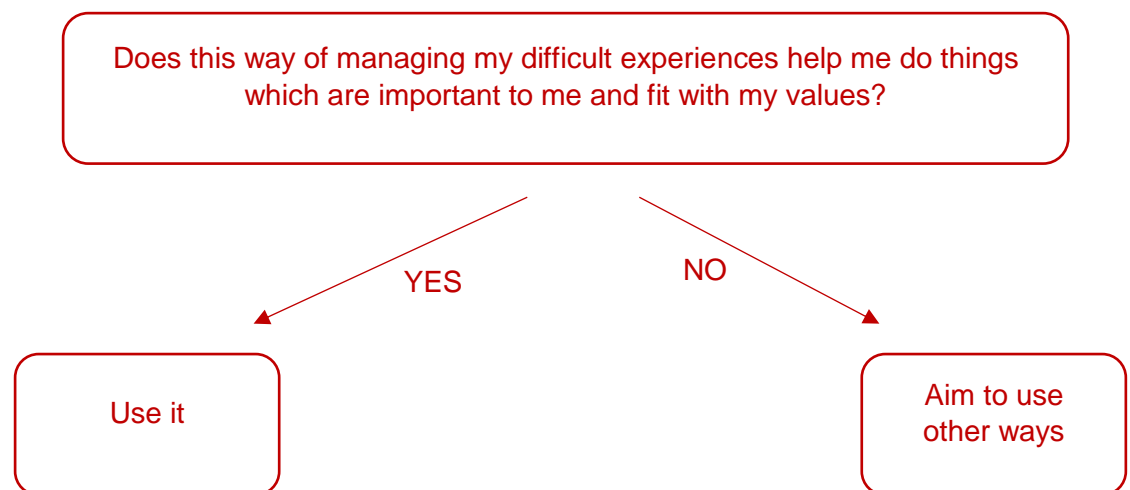
1. ………………………………………………………………………………………
……

2. ………………………………………………………………………………………
……

3. ………………………………………………………………………………………
……

4. ………………………………………………………………………………………
……

5. ………………………………………………………………………………………
……

It is also to think about how you have tried to manage these difficult thoughts and feelings relating to your appearance before now. Please tick the box if you have tried any of the following and please add other techniques you have used:

☐   I have tried really hard to try and get rid of any unwanted thoughts.

☐   I have talked to others to see if they could help how I feel.

☐   I have tried to distract myself in any way possible.

☐   I have tried to block out thoughts and feelings by drinking alcohol.

☐   I have avoided going out.

☐   I have tried to hide or cover up (e.g. using clothes, a hat, or my posture)

☐

☐

☐

It's quite likely you will have tried a range of methods to cope with difficult thoughts and feelings. Some of these methods might have been really useful and some might not have been. You may have tried some of these methods more than others and some methods might only work for a short while.

When we think about the ways we have tried to manage our difficult thoughts and feelings, we are not trying to find ways which are "bad" and ways which are "good". Instead it's best to think about whether the method is "*workable*". That is, does using this method get in the way of you doing something you would like to do. For example, if your one of your values is to 'have a good social life', avoiding situations would not be 'workable' as it would stop you acting in line with your value. If your method was to use 'skin camouflage', wear a wig or to use concealer, this may enable you to feel more confident to visit other people and this may be "workable" as it lets you do things you want to do. It's important to note, what is workable is different for every person and you will get to know what works for you. You may also have your own goals in relation to exposing your visible difference.

> Does this way of managing my difficult experiences help me do things which are important to me and fit with my values?

YES → Use it

NO → Aim to use other ways

It is a human desire to want to get rid of anything which makes us feel distressed, uncomfortable, anxious, unhappy and so on. Yet, all of these things are a part of the human experience and it is normal to feel each of these unwanted feelings in our lives. The desire to control our thoughts, feelings, urges and physical sensations can be problematic. Trying to not think a certain thought doesn't tend to make it go away for long and usually it comes back even stronger. Trying to control your thoughts and feelings is really tiring, it can be a bit like trying to hold an inflatable ball under water – no matter how much you try and push the ball down and keep it below the surface it is always trying to float to the surface and it's not possible to keep it under the surface for long.

Plus, we learn orders and patterns in words, if somebody were to say out loud "one, two, three…", it's quite likely your mind will automatically think "four", even if they don't say it. If somebody asked you to try really hard to not think about a bright orange polar
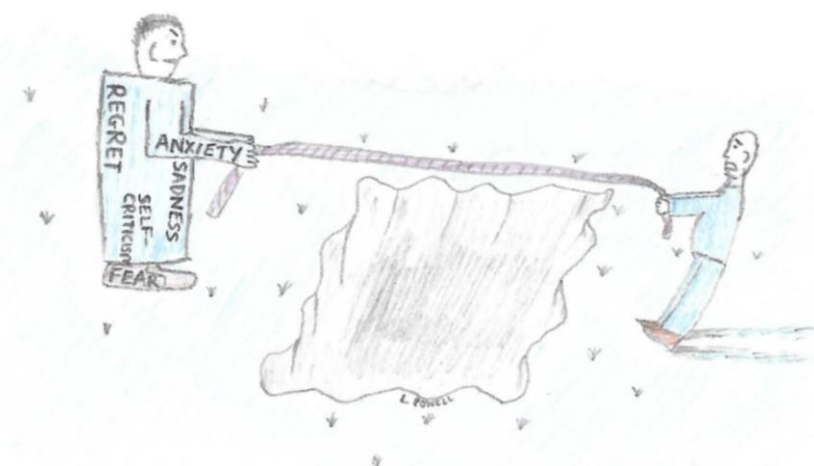
bear and to keep trying to not think about a bright orange polar bear, do you think you would be able to do it?

<u>Trying to control our thoughts is part of the problem, not the solution.</u>

Audio exercise 2. - Tug of War with our feelings

🎧

http://bit.ly/tug_of_war_s2t

Imagine you are in a tug of war with what seems to be a huge monster. This monster represents your difficult feelings; this could be anxiety, self-doubt, sadness etc. You have hold of one end of the rope and the monster has hold of the other end. Between you there's a gigantic, bottomless pit. You find you are pulling the rope as hard as you can, using up all your energy trying to pull this monster towards the pit as you want it to be gone forever.

However, you notice that the harder you pull, the harder the monster pulls back. You can't keep up this battle forever as it's so tiring and it seems no matter what, you can't make this monster fall down in to the pit, no matter how much you want it to.

So, we have to find another solution. Your mind is telling you to keep pulling, harder and harder, as it seems to be the obvious thing to do, but you're getting tired and the monster doesn't seem to tire at all. So what's the best thing to do now?

DROP THE ROPE!

When you drop the rope, the monster is still there. But notice by dropping the rope you've decided to stop the battle with your mind to try and control your thoughts and emotions. The monster doesn't disappear, but now you can put your attention and your energy into doing the things you really want to do.

So, there are some things which we may like to change, but we have no control over. One way we might cope with this is to be open to experiencing appearance-related anxiety (this isn't the same as liking it), and at the same time to focus our attention on

doing things which are important to us (for example, spending time with others). This is like the examples described earlier (e.g. going to the dentist). Control is part of the problem, it is not the solution. This doesn't mean we are giving up, instead it means we can stop getting caught up in our thoughts by stopping the struggle and "dropping the rope".

Written exercise 3. - Control

Please use the space below to write down some things which we can and cannot control. A couple of examples have already been included:

Things I can't control

Things I can control

The past

Bad news on TV

My hobbies

What I say
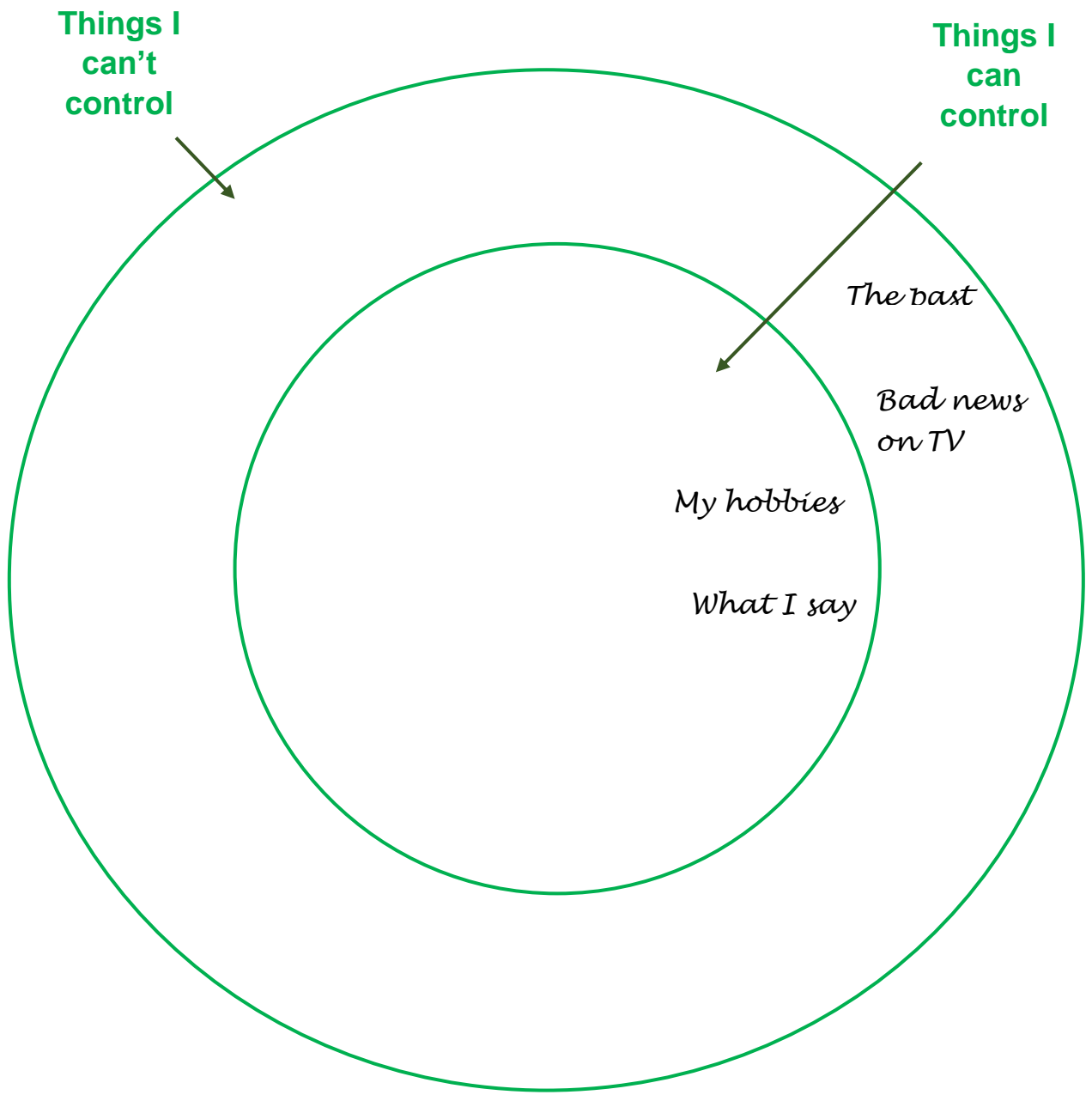
One good way of letting go of what we can't control and not getting caught up in the struggle is to become more focused on the here and now. We can develop this ability through using mindfulness.
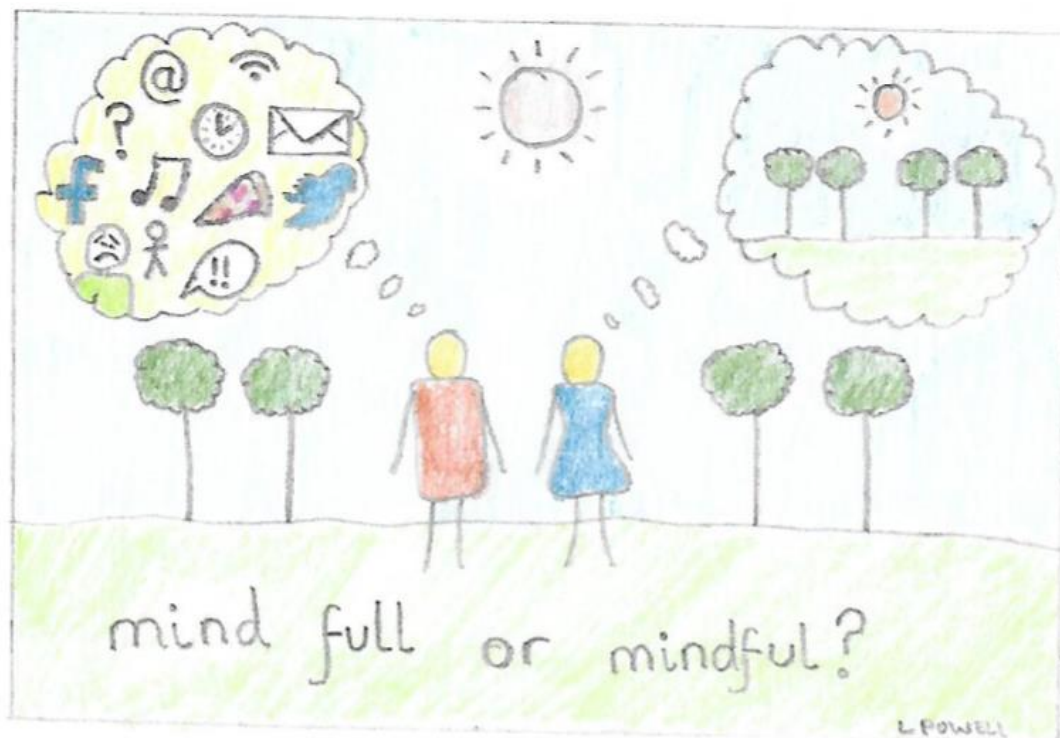
Mindfulness

One of the reasons we use mindfulness is because we tend to live our lives on 'automatic pilot' we go about our day to day lives and don't often stop to observe what is happening at that very moment in time. Quite often we can ruminate about the past, thinking about painful memories. We can also get caught up thinking about the future – this may be simple things such as "what shall I have for dinner" or it could be anxious thoughts such as "people will ignore me". Mindfulness simply means paying attention in a particular way where:

1. You pay attention on purpose
2. You focus on the present moment
3. You try to not make judgements

Mindfulness is one way we can take ourselves off 'automatic pilot' and slow down our tendencies for thinking, judging and doing lots of things at the same time. In mindfulness, the idea is you are an observer, rather than a judge – you are not trying to label your experience as good or bad, and you are not trying to change your experience, you are simply curious about your own experience.

Let's try a mindfulness exercise:

mind full or mindful?

Audio exercise 3. - Mindfulness of the breath

First, make sure you are in a relaxed and comfortable position. It is usually best for people to be seated on a chair or on the floor, using a cushion for support. Try and make your back upright, without making it feel tight. Allow your hands to rest wherever they feel most comfortable. Take a brief moment to just notice any areas of tension around your body and try to relax and rest. If you feel comfortable to do so, allow your eyes to close.

In this exercise, we're going to focus on breathing. Breathing is a good place to begin any mindfulness exercise because no matter where we are or what we're doing, we're always breathing. We can use our breath to 'anchor' our awareness. If our attention drifts off, we can always come back to focusing on our breath.

Although we're not going to try and change our breathing in this exercise, it can be really useful to begin with a big, deep breath. So, when you're ready take a big gasp of air… and then let it all out.

Now, not trying to change the way we are breathing, tune into your breath. Just notice the natural flow of breathing in and out. You don't need to try to change your breath. Pay attention to where you can feel your breath in your body. Can you feel your breath in your nostrils? Your throat? Do you notice your breath in your chest, abdomen or stomach? Just take a moment to observe where the breath happens.

Now allow yourself to notice the sensory qualities of the breath. Notice if there is a temperature to the air as it enters and leaves your body…

Your mind may wander and you might start having thoughts about a variety of things. When this happens, which it will – as it is part of being human, just notice that your mind has wandered. When this happens and our busy brain tries to go back to automatic pilot, return your attention to your breath.

Let's take our attention to the moment between breaths. Notice the small pause as one breath leaves your body and another takes its place… Now try and pay attention to the small pause when your body is filled with breath before you exhale…

For a few minutes we're going to focus our attention on inhaling and exhaling. If you are able, or feel comfortable to do so, place a hand across your abdomen, slightly above your belly button. You should be able to notice your hand moving as you breathe in and as you breathe out. Let's stay like this, just noticing our breath, for a few moments. From time to time, when your attention drifts, just acknowledge it has done so and return your attention to your breathing.

Now as this exercise comes to a close. Congratulate yourself for taking a moment to try and come off automatic pilot and doing your best to not allow yourself to get caught up in the thoughts of your busy brain and when you're ready, open your eyes.

Mindfulness is a practical way to notice our experience in any given moment – we can observe our breathing, our thoughts, feelings in our body, sights, sounds, smells and other things we wouldn't normally give our attention to. However, this is quite different to how our mind normally works as we quite often have 'busy brains' which can ruminate on the past and worry about the future – taking us away from what is happening in the present.

Mindfulness does not conflict with any beliefs or tradition, religious, cultural or scientific. It is simply a practical way to notice thoughts, physical sensations, sights, sounds, smells - anything we might not normally notice. The actual skills might be simple, but because it is so different to how our minds normally behave, it takes a lot of practice. As you take part in mindfulness exercises, you will find your mind will drift off elsewhere, this is a completely normal part of being human and will improve with practice. Half of mindfulness is to practice bringing your attention back to the present moment and notice where your attention had drifted off to.

A common mistake about mindfulness is to view it as a stereotypical meditative exercise whereby you have to sit cross-legged with your eyes closed. Now whilst it is true some mindful exercises take this manner, mindfulness is a skill which can be used at any time in any place. Over the next few weeks you can try a few of these quick mindfulness tasks:

- Listen to a piece of music and one by one focus on each separate sound (e.g. guitar, drums, vocals, piano etc.)
- Use your senses, name 5 things you can see, 4 things you can touch, 3 things you can hear, 2 things you can smell and 1 thing you can taste.
- Sip a drink slowly to really notice the temperature and flavour. Try and savour the moment.
- Try to spend three minutes doing nothing. Put everything down, really try to just notice any urges to do tasks like checking your phone, looking at a tv or quitting the task. Just notice where you are and what you have just been doing in the moment.
- Pause and look around you, look for qualities in objects around you (e.g. bright, new)
- There are a couple of additional audio exercises available on the YouTube channel, which are not referred to in this booklet (http://bit.ly/surviving_to_thriving)

ALLOW YOURSELF TO NOTICE THE NOW

FULL AWARENESS

Audio exercise 4. - Body Scan Mindfulness

This body scan exercise will take approximately 15 minutes. For this exercise, you may wish to lie down on your back or to remain seated in a chair, making sure you are warm and comfortable. We are going to begin this exercise by noticing our breath and we will expand our attention to the sensations in our body.

To begin with, making sure you are comfortable; take one big deep breath allowing the air to fill your lungs and one big exhale. If you feel comfortable to do so, allow your eyes to close. Now focus your attention upon your breathing, without trying to change it, just noticing as you inhale and exhale… We're going to keep our attention on our breath for the next few moments.

Now we're going to shift our attention to our body. We're going to gradually move our attention from the top of head down to the tips of our toes. Some people may find it useful to imagine a light moving down through their body as this exercise progresses.

So, starting with the top of your head, notice any sensations which are present. Pay attention to any tingling, numbness, tightness or relaxation. Expand your awareness to your forehead and temples, noticing any tension. You may be able to notice your pulse. Try to not judge sensations as "good" or "bad"; just being curious about your experience at this exact moment in time. If you find your mind judging parts of your body as areas you do not like, just notice these thoughts and bring your attention back to the physical sensations. Now notice the weight of your head as it rests upon your neck or on a pillow… One by one pay attention to any sensation in your eyes… your nose… your cheeks… your ears… your mouth… and your chin.

Moving down our body, now moving your awareness to your neck and shoulders, noticing the strong muscles in this part of your body, becoming aware of any tension and you may also notice the feeling of breath in your throat… It's perfectly natural for your mind to wander. Noticing when it has done so is awareness in itself. If your mind wanders do your best to bring your attention back to the part of your body you are focusing on.

Now move your awareness to where your arms and shoulders meet, continuing to notice any tension or discomfort. Gradually move your awareness down each of your arms through your elbows, wrists, hands and fingers, being curious about your experience in this present moment.

Turn your awareness now to your chest and notice the small rising and falling of your chest with each breath. Move your awareness around your chest, front and back of your ribs, sides and notice the sensations in your upper back as it rests against the chair, floor or bed. As you do you, notice any aches and pains and imagine bringing a sense of gentleness and kindness to these areas.

Move your awareness to your abdomen and stomach, paying attention to any sensations which are arising in the stomach, such as the feeling of 'butterflies'. Notice how sensations change with each breath. Redirect your attention and awareness to your lower back and central parts of your body, your pelvis, hip bones, sitting bones, groin and bottom. Noticing any sensations.

Bring your attention to your thighs, notice if they feel tense or relaxed. If your mind has wandered off to memories, worries, plans and other thoughts, return your attention to your body and to your thighs. Notice whether there are any sensations in this part of your body and whether the sensations are different in the front and back of your thighs.

Moving down the body, become aware of the position of your knees and try to bring a curious attention to the sensations which are present. Continue moving your awareness to reach your calf muscles in both legs, taking a moment to really notice this part of your body which may not usually have so much attention paid to it.

As we reach the lower part of our body, shift your awareness to your feet, noticing your ankles, heels, top of your feet, soles of your feet and your toes. Try to see if you can pay attention to just one toe at a time and whether you can tell your toes apart through any sensations you are experiencing. You are not judging your body, or evaluating your body in any way. You are just being curious about your body and the sensations in the present moment.

Finally, take a few deep breaths and aim to expand your focus to your whole body, noticing whatever is present, becoming aware of any feelings of relaxation, noticing tension and allowing the tension to slowly soften. As you try and become aware of your whole body, notice any judgments or thoughts that arise and see if you can give yourself some compassion for any discomfort or troubling thoughts. Imagine feeling your pulse through your body as you take a few more deep breaths to end this exercise and allow your eyes to open.

_____

In part one we thought about how it is really difficult to control our thoughts and feelings. We moved on to consider whether we could make choices based on what is important to us, rather than to try and get rid of difficult thoughts and feelings. In part two, we will think about how to reduce the impact of our difficult thoughts.

When you have tried mindfulness tasks so far, you may have noticed thoughts popping up and taking your attention away from the task. We are going to keep using mindfulness to improve our ability to not get caught up with our thoughts. However powerful or distressing a thought may be, we can recognise thoughts are just thoughts – a collection of words created by our brain. We may be tempted to see our thoughts as good and bad, right or wrong, but two good questions to ask ourselves are:

"Is this thought helpful to me?"

"Does this thought guide me to do the things which are important to me, or the opposite?"

The exercises in part two are for you to try out when you notice you are having a thought which is unhelpful and gets in the way of you doing the things which are important to you.

In this next brief exercise, you will be encouraged to build more separation from your thoughts. This may feel like a difficult exercise as you will be asked to spend a little while thinking about a troubling thought, <u>but please stick with it and complete the whole exercise</u>.

Written exercise 4. Reducing the impact of difficult thoughts

Please write below a difficult thought which you experience, which relates to appearance:

_____

_____

Please spend the next 30 seconds repeating the above thought in your mind, or out loud if you wish, and pay attention to how it makes you feel and any urges or other thoughts it makes pop into your mind.

Now we're going to repeat the exercise above, but this time each time you say it add "I'm having the thought" to the beginning. Please write the thought which you used above below:

I'm having the thought

_____

_____

Please repeat this for the next 30 seconds in your mind, or out loud.

I notice I'm having the thought

_____

_____

Did you notice any difference from repeating the thought to repeating the thought with "I notice I'm having the thought" beforehand? This is one method of separating ourselves, or stepping back from a thought.

In this section, we will just notice our thoughts, rather than getting caught up with them. We will allow our thoughts to come and go rather than holding on to them. No thoughts or feelings are permanent, they all come and go like waves in the sea – the challenge is to ride the wave. Your thoughts are understandable and though we are trying to build separation to them, we are not trying to invalidate them or see them as wrong. Thoughts can make you suffer and it is important that we are kind and compassionate to ourselves and do not blame ourselves for our thoughts or feelings.

There are six main types of thoughts[1] for us to look out for, which can often be unhelpful. These are listed below with an example thought:

1. Rules about life, relationships etc.
   ("I can't go anywhere when I feel anxious or if I don't look good")
2. Reasons why change isn't possible or wanted.
   ("Nothing can change the way I look")
3. Unhelpful judgements.
   ("Other people won't want to be with me because of the way I look")
4. Ruminating on the past.
   ("It's not fair this happened, if my appearance wasn't changed everything be okay")
5. Focusing on the future.
   ("What if somebody points at me?")
6. Giving a negative all-encompassing self-description.
   ("I am ugly or I am disgusting")

Try to notice these thoughts, non-judgementally when they arise and be aware that these thoughts might want you to pay more attention to them than other thoughts. These types of thoughts come and go for everybody; we're not trying to control or remove the thought; we are just noticing it for exactly what it is – a thought.

---

[1] From R. Harris "ACT made simple".

The following audio exercise gives an example of how our minds are able to give 'power' to thoughts, so much so that the way we feel in our body and in our emotions can change.

http://bit.ly/our_tricky_brains_s2t

Audio exercise 5. - Our tricky brains

For the next couple of minutes we're going to use our mind to really explore the properties of an object. Please make sure you are comfortable and allow your eyes to close.

Now, using our minds, think about a lemon. Notice the bright colour, the texture on the outside and the shape of the lemon. Try and make a really clear image of this lemon in your mind. Now imagine bringing the lemon close to your nose and imagine whether you would be able to notice any scent from the lemon. Next, imagine using your hands to break the lemon apart, noticing the juice that spurts out from the lemon as you do so. Imagine taking another look at the lemon and really notice the differences in texture and the individual shapes from within the lemon. Now imagine bringing the lemon towards your mouth and taking a big bite out of the lemon. Imagine the sour taste you would likely experience.

It's quite likely that during that exercise you might have really been able to imagine all of the qualities of the lemon and you might have even noticed the smell and taste of a lemon and its juice whilst you were thinking about it. You may have even started to notice saliva building in your mouth or you have had had a pleasant or unpleasant feeling when you imagined biting in to the lemon.

What this shows us is, even without having a lemon by us, by buying in to thoughts about a lemon, we can create a consequential experience. Keeping this in mind, what may happen if you replaced the lemon with: negative judgements about yourself, imagined problems in the future or moments from the past you wish to change.

It's likely that if you gave any of these thoughts or images in your mind the same focus as you gave the lemon, you might start to feel stressed and you may also allow these thoughts to have an unhelpful impact on your life.

The key part to this exercise is that the lemon only ever existed in our minds – and our minds expanded our experience within our minds. A similar thing can happen when we experience unwanted thoughts, it's probably quite easy to bring to mind a thought we've had about ourselves that may have led to more unwanted thoughts, self-criticism and negative feelings. We can get really caught up on the words in our mind and when we do, these can get in the way of us doing the things we want most in life.

These words in our mind which we get caught up with are often associated with emotions and a tone of voice which can add to their 'power'. Listed below are a range of techniques we can use to try and reduce the impact of our thoughts by changing the way we experience the thought. You may find some more useful than others, and you are free to pick and choose which ones work for you. You may also think up your own techniques and create your own metaphors which are meaningful to you. Remember, we are not trying to avoid or get rid of thoughts; instead we are trying to reduce the influence thoughts have over us. These following methods rely on the principles that: 1) we give power and meaning to words and this can affect us and 2) by repeating the word, or saying it in a different way, the word or words can lose their power or meaning.

- Say the thought very slowly
- Repeat the thought quickly over and over
- Try saying the thought in a funny voice
- Thank your mind for giving you an interesting thought

Additionally, there are several metaphors which can be used to describe noticing our thoughts as they come and go, without getting caught up with them. We can see our thoughts as:

Clouds moving across the sky, cars moving down the road, suitcases on a conveyor belt or leaves on a stream. The following mindfulness exercise will help you observe your thoughts, whilst not getting "caught up" with them. We can notice our thoughts are just thoughts, passing strings of words in our mind which we don't need to react or respond to, we can just notice them as they come and go.

Audio exercise 6. - 'Leaves on a stream' mindfulness

Start by finding a comfortable position and allow your eyes to close, or if you prefer, focus your eyes on a spot in the room.

Take a couple of big deep breaths to begin with to relax the body and then allow yourself to breathe normally and naturally.

Now, focus your attention on your breath, noticing the air as you breathe in and as you breathe out… try your best to keep your attention on your breath for the next 30 seconds or so…

Try to imagine you're sitting by the side of a gently flowing stream. Looking at the stream, you notice there are many different types of leaves flowing past. Really use your imagination to build this image in your mind.

Now, for the next few minutes, take each thought as it pops into your mind and imagine placing that thought on a leaf, and let it float by. Try to do this with all thoughts; thoughts you like, thoughts you don't like and thoughts which don't bring out a feeling in you. No matter what the thought is, imagine placing it on to a leaf and allow it to float by.

If you notice your thoughts stop, just imagine the stream. Sooner or later your thoughts will pop up again. Allow the stream to flow at its own rate, you're not trying to make thoughts rush away or hang around. You're just allowing each thought to arrive and leave in their own time.

If your mind tells you something like "I can't do it", "I'm not doing this right", or even "this is rubbish", then stick with it, place these thoughts on to a leaf and let them float by.

If you notice a thought is sticking around, or it keeps coming back, allow it to do so. We are not trying to control our thoughts, we are just curiously noticing what comes up. Place the thought on a leaf, or leaves if it comes and goes and imagine placing it in the stream. Even if it is stuck, eventually it will flow downstream, as it is the nature of thoughts to come and go.

You may experience a difficult feeling, such as boredom or worry. Acknowledge this feeling, tell yourself what you are feeling by saying something like "Here's a worry feeling" and imagine placing it on a leaf and allowing it to flow away.

As with all mindfulness exercises, occasionally you will get caught up with a thought and you may lose track of this exercise. This is totally normal and part of the exercise. When this happens notice what thought or feeling took your attention and come back to this exercise, imagining placing that thought or feeling on to a leaf and letting it float on by.

We're going to keep doing this exercise for a few more minutes…

Slowly allow the picture of the leaves and the stream to fade, take a couple of deep breaths and take notice of the feelings in your body where it meets the chair or bed. Open your eyes, look around the room and allow your attention to come back to your surroundings.
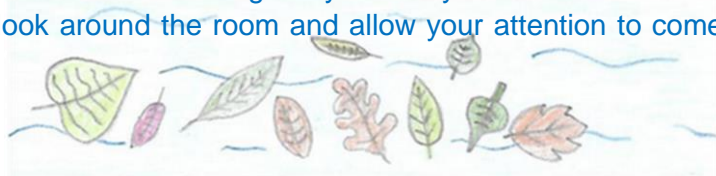
Noticing reason-giving

As stated above there are a few types of thoughts to look out for, as they may be unhelpful. I would like to pick up specifically on the 'reasoning' thought. Reason-giving is useful to think about in relation to why we don't always do things which we want to do. There are likely to be times when you have found yourself giving reasons such as "I'd really like to/ should…, but I don't …"?

Examples might be: "*I'd like to go on a date, <u>but</u> I'm not self-confident*" or
"*I should go for a walk in the countryside, <u>but</u> I feel worried what others might think of me*".

These thoughts are likely to influence the things we do and the way we feel. There is a simple way to reduce the influence of this type of thought and it has to do with the word "*but*". The issue with the word but is that increases our "stuck-ness", the use of the word 'but' contradicts the information put before it, so it creates a struggle between what we want to do and how we feel. It may be that both parts of the statement are true – you might want to go on a date and you might have low self-confidence. However, it is not true that these can't exist at the same time.

The way of reducing this stuck-ness and battle between our goals/ desires and our thoughts and feelings is to replace the word "but" with "and". Notice how the sentences now read
"*I'd like to go on a date, <u>and</u> I'm not self-confident*" and
"*I should go for a walk in the countryside, <u>and</u> I feel worried what others think of me*".

So now, instead of us being unable to act in a way we would like to, it is possible for us to do the things we want to do whilst experiencing difficult thoughts or feelings. We are open to the experience of our difficult thoughts and feelings, but we are able to get the most out of our life by doing the things which are important to us. The alternative, using "*but*", tells us both can't exist at the same time, so we either have to give up with the things we want to do in life, or get rid of our difficult thoughts and feelings.

By noticing when we use the word "*but*" we will be able to become more aware of the struggles our mind pulls us in to.

Practice

As you are making your way through this booklet, there are a variety of audio exercises and defusion exercises for you to use (these are listed at the end of the booklet). To get the most benefit from them, it is important to practice. Ideally, it is recommended that you practice for at least ten minutes each day. It may be best to begin practicing when you already feel content, and gradually use the exercises at times where you are experiencing difficult thoughts and feelings. A template for recording practice is on the next page. Within the template, there is space for you to record thoughts, feelings, the situation, practice(s) used and what you noticed/ any impact of the practice. You may not always want to complete the thoughts/feelings and situation boxes; however, it is best to always complete the other boxes. You may find you prefer certain exercises above others – this is fine, do what works best for you.

Day	Thoughts & Feelings	Situation	Practice(s) used…	What did I notice?
Example: Friday 4th	"I wish I could just do it" Fearful, nervous	Preparing for an interview	Mindfulness of thoughts (leaves on a stream) Defusion – "I notice I'm having the thought…"	I was very tense and needed to take a moment by myself. I was able to bring my attention back to doing my best at preparing.

Compassion

Another really important consideration is compassion. Compassion means having sensitivity to suffering with a commitment to try and relieve it. There are two parts to this definition, the first is becoming aware of distress, be it unpleasant thoughts, feelings, memories or physical sensations such as pain. The second part is doing your best to provide comfort to alleviate the distress.

Compassion can be given to others and to ourselves. We know that people generally find it much easier to be compassionate and kind towards other people than themselves, with people often 'getting on their own backs' and doing things such as focusing on their personal failures and perceived shortcomings, rather than their successes. Research has shown that being self-compassionate, acknowledging the difficulty you're experiencing and accepting this as part of life, gives us more motivation, than getting on our own backs by saying things to ourselves such as "I need to do better" or "I should do this" or "I'll never be any good". One simple method to try and build our compassion for ourselves is to notice when we're experiencing a moment of suffering and to imagine what we might say to a good friend if they were going through the same situation. Self-compassion is also a really useful skill to have for when things don't work out as planned. For example, if you had put lots of effort in to meeting a goal or a target, but for whatever reason you didn't quite achieve what you wanted to, it is good to appreciate we tried and to acknowledge things got in the way and that you will be able to have another go. Besides, some of the things which got in the way were likely to be out of our control. This is a more helpful way of thinking than to become self-critical, which can lead us to feel worse in mood and might make us want to avoid people, situations and not look after ourselves.

Now compassion has been introduced, let's complete another mindfulness exercise. This exercise is going to focus on body image and generating compassion for ourselves.

POSITIVE ACTS FAR OUTWEIGH NEGATIVES
(they just don't make the headlines)
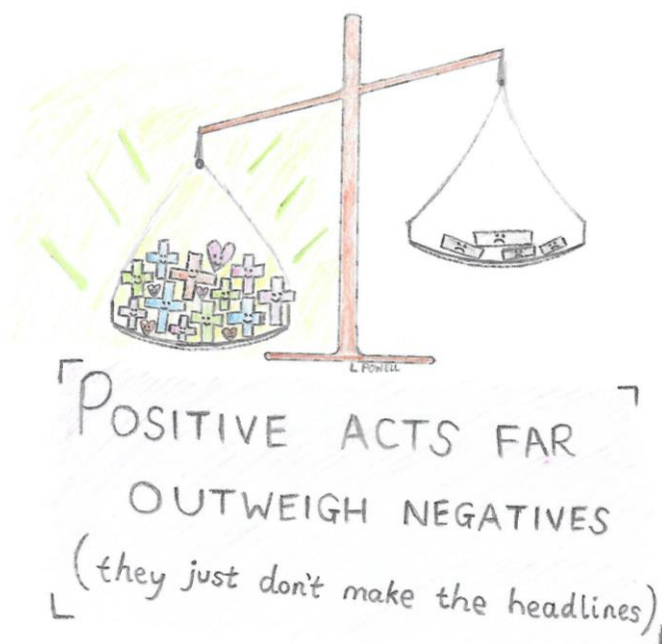
Audio exercise 7. - Body image and compassion mindfulness

Take a moment to make yourself comfortable, you may want to sit in a chair or lie down, whichever is most comfortable in this moment. Take a couple of deep breaths. Close your eyes, or focus on one spot in the room. This will help you to focus your attention on what is happening within you, rather than what is happening around you.

Notice how your body is feeling right now, in this present moment. We're going to briefly focus our attention through our body, scanning upwards from our toes. Notice your feet… your legs and knees, your waist. Moving upwards notice your stomach, back, chest and arms. Bring your attention to your shoulders, to your neck and to your face and up to the top of your head. Take a moment to notice your body, being curious about where is most tense and where is most relaxed.

You may notice how your body steadily relaxes, without any extra effort on your part. By taking this moment to rest, your body is likely to become more relaxed with each passing moment.

Let's start to think about body image. What does body image mean? Maybe body image is about your ideas about how your body relates to you, maybe it is about what your body looks like, or how your body might be. As we're thinking about body image, thoughts, feelings, ideas and maybe memories are likely to come up in our mind. Notice those thoughts, notice how you are feeling. Though these thoughts and feelings may not be pleasant or there may be a mixture of thoughts and feelings, don't try to change them. They are part of the human experience, it is okay to feel however you are feeling.

What might it be like to accept your body, as it is, right now in this moment? What might it be like to feel okay about your physical self? Spend a few moments imagining how this might feel.

Then bring in to mind a memory of when you felt accepting of your body, your whole body or even just part of yourself.

You might notice different parts of your body are easier for you to accept. Imagine if you could accept your physical self, rather than lots of separate parts.

We're going to move our attention now from these thoughts and feelings, though they may stick around. We're going to spend a few moments relaxing. Focusing now on your breath. Breathe in deeply and breathe out. Take a few good, calm and deep breaths.

As you are taking these deep breaths, expand your attention to your body once more and notice any areas of tension. Imagine as though you can bring the breath to those tense parts of the body, breathing in to bring relaxation and breathing out to remove tension.

I'm going to say some body image affirmations. Please listen carefully as I do so, you may wish to repeat what I say out loud, or just in your mind. Try to remain in this state of calm relaxation for these next few moments.

Really try to allow yourself to hear and experience each of these affirmations, even if it feels difficult to do so right now.

My experience is part of being human.

I am okay the way I am.

I can accept myself the way I am.

My body is acceptable the way it is.

My imperfections make me unique.

I accept my physical self.

I am fine just the way I am.

I am human and to be human is to be imperfect.

I accept my differences.

I do not have to judge my body.

I am okay just the way I am.

I can be kind to myself and accept myself.

Listening to those affirmations is likely to have brought up a range of feelings. Take notice of how you are feeling and what it was like to listen to those words. Be open and curious to your feelings, trying not to judge them as good or bad, but as part of the human experience.

Let's take a final few deep breaths. Breathing in to bring relaxation to the body and breathing out to relieve tension in the body… And when you're ready slowly bring your attention back in to the room.

SELF-COMPASSION ASKS US TO
TALK TO OURSELVES AS WE WOULD
TO A GOOD FRIEND

Part Three

Throughout the booklet so far, we have tried to become more open to our experience and willing to have difficult thoughts and feelings, whilst using techniques to limit the influence these difficult thoughts and feelings have on us. The purpose of this has been to reduce the constant struggle of wanting to completely rid ourselves of these difficult experiences, as this struggle is exhausting and doesn't work, as these experiences are part of being human. The struggle can also change the way we act - the things we do (or don't do). If we can successfully reduce how much we are paying attention to difficult aspects of our experience, we will be better able to choose what we do, based upon what is important to us. Furthermore, we will be better able to notice moments of positivity.

Part three is designed to build our thoughts about what is important to us and thinking about how we can use value-directed goals to help guide our choices, rather than our difficult thoughts and feelings.

The following questions are designed to build upon the value-related questions you answered in part one.

Written exercise 5. So, what is important to you?

There are many different parts of our lives, including health, relationships, spirituality, work and leisure. There are also many different things we value. The following questions should help you consider some of your values:

What in your life, brings you excitement, happiness and makes you feel proud?

_____

_____

_____

_____

_____

What motivates you, and helps you to get through the hard times in life?

_____

_____

_____

_____

_____

Imagine, just for a moment, that you can fast forward your life a few years to find all the people you care about are with you, in one place, to celebrate you – perhaps for a special birthday (or similar event). At this event, many of the people who are important in your life are going to be giving speeches… they will be talking about your relationships with them, your personality, character and what you stood for in life. What would you like them to say about you?

_____

_____

_____

_____

_____

Take a few moments to notice your answers to the questions above and look back at

your answers in part one. Try and see if you can pick out your core values and write

some of these below:

_____

_____

_____

_____

Keeping your values in mind, look at the nine areas below. Some of these may be important to you and others might not be. You might feel you are already satisfied in some of these areas, whereas you might feel there is more to be done for others. For each area consider whether it is important to you and if it is important, how satisfied you are with it.

	Is this important to me? (Extremely, moderately, a little, not at all)	Am I satisfied with this area? (Yes, Partly or No)
Work / Career		
Intimate Relationships		
Education / Learning		
Social life		
Health		
Family		
Spirituality		
Being part of the community / Environment		
Leisure		

The purpose of the above questions has been to make your values/ what is important to you really clear. This is essential as we have start to reduce the impact of our difficult thoughts and feelings. As, when we are less caught up with them, we can be guided by what is important to us, rather than to appease our difficult thoughts or feelings.

The following metaphor is used to describe this further:

http://bit.ly/passengers_bus_s2t

Audio exercise 8. - 'Passengers on the bus' metaphor

In this metaphor, suppose that you are the driver of a bus. This bus has several passengers. These passengers are your own thoughts, memories, feelings, physical sensations and other aspects of your experience. Some of the passengers appear to be really scary, and you don't really want them on your bus, in fact you don't want to see them at all. It's your bus and you're in charge of deciding where to go, these passengers are just along for the ride.

However, you notice the passengers become a disruptive and they start shouting at you, threatening and harassing you. They tell you they want to go somewhere else and not where you're going. The threat they have over you is that if you don't do what they say, these passengers are going to come right up to the front of the bus and get right up close next to you.

You don't want these passengers up close to you, so you make a deal - that if the passengers stay at the back of the bus and try and hide so you can't see them, you'll go exactly where they want you to go. After a while, you get fed up of going where they tell you to go, so you stop the bus and try and throw the unruly passengers off. However, now the bus isn't moving at all, you get caught up with these passengers, you're not getting anywhere and these passengers don't intend on leaving. No matter how hard you try, these passengers stay on the bus.

So, you go back to the deal you made before; you go where they want and they try and hide from your view. The problem with this deal is you do what they say in exchange for them getting out of your life. Eventually, you won't even need to hear the passengers to know which way they want you to turn, you might even be able to pretend they have no influence over you and you wanted to go in that direction anyway. When the passengers do turn up, it's with the added power of the deals you've made with them in the past.

However, notice how the power the passengers have over you is entirely based on this: if you don't do what they say, they're going to come up front and make you come face to face with them. That's the whole deal. Sure, they may look very frightening and as though they could do more. You as the driver, have total control of the bus. Though, by making this deal with the passengers to get more control, you actually give up control. If you stop the bus, you forfeit your control of the bus completely. Although your passengers may look scary and they might say unpleasant things, the passengers can't actually take control of the bus unless you let them. They will just be up at the front. The passengers can't make you do something against your will and as the driver, you choose where to go.

You have already given some thought to what your "passengers" might be – your difficult thoughts, feelings, memories etc. The key message throughout this booklet is to be able to notice your "passengers" whilst not getting caught up with them and do the things which are important to you (choosing the direction of the bus). We can use the skills learned earlier in this booklet to separate ourselves from our difficult thoughts and feelings and reduce their impact upon us.

138

life is like a
CAMERA

focus on what's important,
capture the good times,
develop from the negatives,
& if things don't work out...
just take another shot.

Goals

So you've been able to identify some of your values. Values are like a compass – they direct us in a direction which we wish to go in, but there is no final destination – we can't complete a value, just like we can never arrive at 'North'. However, we can set and achieve goals, which are like landmarks along our journey.

Now that we've considered being willing to experience some difficult thoughts and feelings and how to reduce the impact they have on us, we can use this opportunity to think about goals which would let us be directed by our values. Let us set a few goals – think about what you would like to change in your life – what would you like to do. You may want to look back at the values table to see which valued areas are 1) important to you and 2) you are not fully satisfied with this area of your life.

When planning goals, there are five (SMART) key things to keep in mind:

Specific: think about where and when you will try to achieve this goal and what or who will be involved. For example, "I will be more creative" is not specific, whereas "I will go to a painting class on Thursday afternoon" is.

Meaningful: It must mean something to you and be guided by your values. It should not be following a rigid rule, trying to please others, or trying to avoid some pain. If it lacks a purpose, it is unlikely to have been guided by your values.

Achievable: The goal must be something you are able to do. You wouldn't teach somebody how to swim by throwing them in at the deep end. If necessary, use small achievable steps as you are more likely to experience success. For example: if you are afraid of being in public, the first step might be to walk in public for five minutes, or meet a friend for a drink for a short while. It's unlikely your first goal would be to do public speaking for an hour.

Realistic: Take into account your health, demands on your time, financial status and whether, if required, there are resources or people to help you achieve your goal.

Time-bound: Where possible, setting a day, date and time can be useful. Set yourself a time-frame to complete the goal.

Written exercise 6. SMART valued goals

Goal	Date to complete by:	Completed? ✓ or ✗
1		

2		
3		

If you are able to achieve a goal, please set a new goal. It is important to keep moving in a "valued direction".

Before you try and meet these goals, please continue to read this section, as we will now draw our attention to some barriers to our goals and tips which may help overcome them.

What gets in the way?

If these things are important to us and make us feel good about life, then why weren't we already doing them? The answer to this is there are barriers. Some barriers may be due to circumstances, such as not having the resources, skills or support required to complete a goal. Other barriers may be our own experience – our passengers on our bus. Barriers can quite often be our difficult thoughts which might tell us things such as "you're not normal", "people will think I'm contagious" or "if you try, other people will laugh at you".


Written exercise 7. Barriers

Please choose one of the goals from above and write down some of the barriers - the difficult thoughts, feelings and memories which may come up as we try and meet our goal:

_____

_____

_____

_____

_____

These barriers might show up (like passengers on our bus), and we might get caught up with them and try to get rid of them (throwing them off the bus). They might try and tell us we can't do something or to act in ways that will try and remove them, rather than expanding our enjoyment in life. We have already discussed some of the ways to overcome barriers. These include:

- Being open to experience difficult thoughts and feelings
- Noticing our thoughts are just thoughts
- Step back from our thoughts or feelings – just noticing, whilst not getting caught up
- Practicing mindfulness and focusing on the present moment
- Not judging yourself when you don't succeed
- Focusing on what is important to you, so you can get the most from life

Thinking back to the barriers you wrote down above. Should these barriers arise again when you try and complete your goal, how might you try to overcome these barriers (such as, what might you tell yourself):

_____

_____

_____

_____

SELF - CRITICISM

FEARFUL THOUGHTS

BAD MEMORIES

SELF - DOUBT
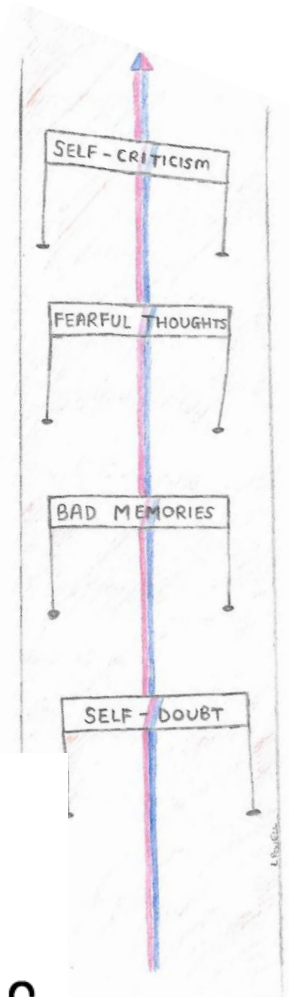
A JOURNEY OF A THOUSAND MILES BEGINS WITH A SINGLE STEP

Tips for meeting goals

In addition to making our goals specific, measurable, achievable, realistic and time-bound, here are some other tips which may be useful to help you meet your goal:

- Tell somebody who you trust what you are planning to do
- Include other people in your plans, as this makes more likely to be successful
- When you think a thought or a feeling or situation is likely to come up when trying to complete the goal, make a specific plan based on IF and THEN. For example, IF I am thinking I am not confident when asked about myself THEN I will express interest in the other person and focus questions on them.
- Be prepared to face my challenges and remind myself it is worth it and many challenges are hard to begin with.
- If you are finding it difficult, give yourself compassion and thank yourself for trying. (This is also valuable to remember if you are not successful).
- Remember each goal is just part of your journey, sometimes the route we take isn't the one we expected, there may be hurdles along the way and persistence is key.

Dealing with comments and reactions from others

Unfortunately, people with a visible difference in appearance may experience intrusive, negative or even rude reactions from other people. Generally, it may be better to give people the benefit of the doubt and assume that they are being curious, as this may prevent you from getting "caught up" and distressed by the experience.

Nevertheless, being asked something personal such as '*what happened to you?*' or '*what's that?*' can be upsetting and frustrating, so planning your responses can be really helpful. Planning responses may be "workable", as doing so, may give you more confidence should an unwanted situation arise. Dealing with comments in a confident way shows you're not worried by what's happening and the conversation will generally soon move on.

Changing faces and Alopecia UK both recommend four strategies: Distract, Explain, Reassure and Assert. Here are some examples of what you could say if asked about your appearance:

Things you could say to move the conversation on (distract):

"Oh, it's a long story, too long to go into now. I'll have to tell you another day"

"I'd rather not talk about it right now. What do you think to the news that… / I like your boots where are they from?"

You could give precise information (explain/ re-assure):

"It's just a condition I was born with"

"It's a scar from an operation/accident I had when I was little; I'm used to it now"

"It's a skin condition called X it is not contagious"

"I am okay, thanks for your concern"

Dealing with staring

Occasionally, looking over at somebody you have noticed staring, and smiling at them can stop their staring (people return your smile). If not, you could say something like:

"Can I help you?"

"Please stop staring at me, it makes me feel uncomfortable" (assert)

Practice saying these in a calm and curious way that will point out to the other person that you know they are looking. Aggressiveness is best avoided as it can escalate the situation, although understandably you might feel annoyed!

There are two important things we must remind ourselves of in such situations. Firstly, the other person's behaviour isn't typical of how everyone acts. This sort of behaviour would most likely be rude by anyone who'd observed what had happened. Secondly, as these situations arise due to our appearance, there may be an urge to get out of the situation or see it as being our own fault. It is absolutely not your fault, we may want to ask ourselves whose problem is it? It might also be useful to remind yourself why you are doing whatever you are doing at that time, knowing that it is you have just as much right as everybody else to be out with friends, at the shops etc.

In line with this booklet, we can try to distance ourselves from our difficult thoughts. If somebody is staring we don't have to respond to this, instead we can acknowledge and notice the uncomfortable thoughts and feelings which may arise out of the situation, and try to give these thoughts less power by focusing our attention on other aspects of our experience.

Another important point is to make sure you don't internalise something which is external. Put simply, you don't make somebody else's problem your own.

These negative experiences can make us feel as though visible difference is all we are. Visible difference does not define you, it is just one of thousands of aspects of you.
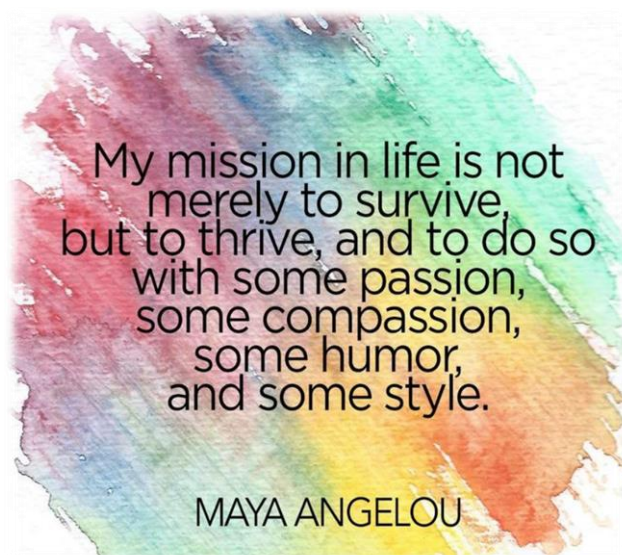

My mission in life is not merely to survive, but to thrive, and to do so with some passion, some compassion, some humor, and some style.

MAYA ANGELOU

Image from pinterest.com

Part 4 – Summary

This final part contains a summary and a list of relevant websites. The suggested timetable and a list of mindfulness and thought exercises are at the end of this booklet.

As we have almost reached the end of this booklet, it would be useful to look back upon the lived experience video you watched at the beginning (http://bit.ly/catrin_s2t) . This time, whilst you're watching the video listen out for content relating to:

- ❖ difficult thoughts and feelings which arise
- ❖ whether the focus was on difficulties in relation to appearance or achievements and values in life
- ❖ the size of the goals and the values guiding them
- ❖ how barriers were overcome

Summary

It can be really difficult to make changes in our life and to build self-esteem and develop confidence. It takes time to develop upon these parts of us; doing the things which are meaningful to us and not getting caught up in an internal struggle with our thoughts and feelings are really important. Self-compassion enables us to develop these further. The techniques in this booklet have been shown to be effective when practiced and they can make a difference.

Our internal experiences – difficult thoughts, emotions, physical sensations, memories etc. are a normal part of being human. We can sometimes get caught up with these experiences, but with compassion, and commitment to our values, we can move our attention and focus on what is important to us. We can use mindfulness to try and keep ourselves in the present moment and we can set ourselves goals which will help us to get the most from our lives. If we can prevent ourselves from getting caught up in a struggle with the things we cannot control, we allow ourselves the freedom to decide how we want to get the most from life – we move from surviving to thriving.

Congratulations for completing this booklet. Hopefully you have found this useful and you are able to keep practicing some, or all, of the techniques and using metaphors from this to improve your quality of life. You've shown real commitment to get through to the end.

We are very interested to know whether this booklet has been helpful and how it can be improved. We would greatly appreciate if you could complete the questionnaires you receive from us via e-mail, so we can continue in our aim to improve the wellbeing of individuals with a visible difference.

One final note is if you feel you need additional support, please speak a healthcare practitioner or contact a support group or charity, relevant to your appearance. Contact details for some of these support groups and charities are listed below.

Useful links (mostly UK based)

Katie Piper Foundation

UK-based charity offering support for people living with burns and trauma scarring, including 1:1 peer support.

Call: 020 7420 7813.

Email: info@katiepiperfoundation.org.uk
Website: www.katiepiperfoundation.org.uk/

Changing Faces

UK-based charity giving support and information to people with visible difference to the face, hands or body, and their families.

Call: 0845 4500 275 or 0207 391 9270.

Email: info@changingfaces.org.uk
Website: www.changingfaces.org.uk

Alopecia UK

Offering support and advice for individuals with Alopecia in the UK. Including support groups and an online forum.

Call: 07763293687 or 07983810490.

Email: info@alopecia.org.uk
Website: http://www.alopeciaonline.org.uk/

British Skin Foundation

Offering support for skin conditions and information including a list of charities where   people can access other support, including support groups.

Call: 0207 391 6341.
Website: http://www.britishskinfoundation.org.uk

British Association of Skin Camouflage (BASC)

BASC provides camouflage consultations within the NHS and private practice,

Email: info@skin-camouflage.net
Website: www.skin-camouflage.net

Dan's fund for Burns

Offering practical help to burn survivors in the UK.

Website: http://www.dansfundforburns.org/

NHS self-help

A variety of *self-help* guides available to download: www.ntw.nhs.uk/pic/selfhelp

General advice on self-help therapy: http://www.nhs.uk/Conditions/stress-anxiety-depression/Pages/self-help-therapies.aspx

Get Self Help

This website offers self-help information including downloadable resources.

Website: www.getselfhelp.co.uk

Skin support website

This website contains some other self-help information and resources and is managed by The British Association of Dermatologists

Website: www.skinsupport.org.uk

National Alopecia Areata Foundation (US)

The National Alopecia Areata Foundation (NAAF) serves the community of people affected by alopecia areata that results in hairloss and emotional pain.

Website: https://www.naaf.org/

Australia Alopecia Areata Foundation (Australia)

The Australia Alopecia Areata Foundation was founded in 2010 with the purpose of improving the lives of people living with Alopecia Areata and their families.

Website: https://aaaf.org.au/

National Rosacea Society (US)

Support for individuals with rosacea.

Website: https://www.rosacea.org/

Ichthyosis Support Group

The ISG is committed to the ongoing provision of an infor network and support structure for sufferers and families a ichthyosis. **Website:** http://www.ichthyosis.org.uk/

<u>Crisis contacts</u>

Samaritans

Available 24 hours a day to provide confidential emotional support for people who are experiencing feelings of distress or despair.

Call: 08457 90 90 90

Website: www.samaritans.org

LifeLine Australia

Lifeline is a national charity providing all Australians experiencing a personal crisis with access to 24 hour crisis support and suicide prevention services.

Call: 1-300-13-11-14

Website: www.lifeline.org.au

Lifeline New Zealand

Lifeline's 24/7 helpline offers free, confidential support.

Call: 0800 543 354

Website: info@lifeline.org.nz

USA - National Hopeline Helpline

Help for people in crisis. Phone and webchat available.

Call: 1-800-784-2433

Website: https://hopeline.com/

Canada - Local helpline contacts available at http://suicideprevention.ca/need-help/

Mindfulness and thought exercises

Audio:

- o Mindfulness of the breath
- o Body scan mindfulness
- o Leaves on a stream
- o Body image and compassion mindfulness
- o Mindfulness of sounds
- o Mindfulness using mobile
- o Five senses mindfulness
- o Conveyor belt of thoughts

Other:

- o "I notice I'm having the thought…"
- o Listen to a piece of music and one by one focus on each separate sound (e.g. guitar, drums, vocals, piano etc.)
- o Use your senses, name 5 things you can see, 4 things you can touch, 3 things you can hear, 2 things you can smell and 1 thing you can taste.
- o Sip a drink slowly to really notice the temperature and flavour. Try and savour the moment.
- o Try to spend three minutes doing nothing. Put everything down, really try to just notice any urges to do tasks like checking your phone, looking at a tv or quitting the task. Just notice where you are and what you have just been doing in the moment.
- o Pause and look around you, look for qualities in objects around you (e.g. bright, new).
- o Changing "but" to "and".
- o Say the thought very slowly
- o Repeat the thought quickly over and over
- o Try saying the thought in a funny voice
- o Thank your mind for giving you an interesting thought
- o Treating yourself with compassion
- o Noticing when I'm "internalising" something external (caused by others)
- o Other (you may wish to access other compassion and mindfulness exercises available on the internet)

http://bit.ly/surviving_to_thriving

Additional Goals Sheet

When planning goals, there are five (SMART) key things to keep in mind:

Specific: think about where and when you will try to achieve this goal and what or who will be involved. For example, "I will be more creative" is not specific, whereas "I will go to a painting class on Thursday afternoon" is.

Meaningful: It must mean something to you and be guided by your values. It should not be following a rigid rule, trying to please others, or trying to avoid some pain. If it lacks a purpose, it is unlikely to have been guided by your values.

Achievable: The goal must be something you are able to do. You wouldn't teach somebody how to swim by throwing them in at the deep end. If necessary, use small achievable steps as you are more likely to experience success. For example: if you are afraid of being in public, the first step might be to walk in public for five minutes, or meet a friend for a drink for a short while. It's unlikely your first goal would be to do public speaking for an hour.

Realistic: Take into account your health, demands on your time, financial status and whether, if required, there are resources or people to help you achieve your goal.

Time-bound: Where possible, setting a day, date and time can be useful. Set yourself a time-frame to complete the goal.

Goal	Date to complete by:	Completed? ✓ or ✗
1		
2		
3		
4		

Appendix G – Information provided to charities and organisations with templates

Individuals with visible difference commonly experience appearance-related social worry. There are limited resources to help people with appearance-related distress, so internet-provided self-help interventions may be beneficial. An online self-help intervention based upon Acceptance and Commitment Therapy (ACT) has been developed.

What is the study about?

This study examines whether a self-help booklet based upon ACT is effective in improving social confidence in adults with a visible difference who experience appearance-related social worry.

Who is being invited to take part?

We are asking adults with a visible difference who experience appearance-related social worry to take part. To take part, you need to be fluent in the English language and not currently receiving psychological therapy.

What will participants be asked to do?

We will ask participants to complete some questionnaires on two occasions, four weeks apart. Participants will be randomly assigned to one of two groups. One group will receive the self-help booklet straight away and the other group will receive it in four weeks' time. Those receiving the intervention straight away, are asked to work through it in the four-week period.

By taking part in this study, participants also have a chance to win one of two £25 Amazon gift vouchers.

_____

Suggested social media posts:

Do you experience a loss of confidence in social situations due to a visible difference in appearance, such as a hair condition, skin condition or scarring? Take part in a new study being conducted by the University of Sheffield - http://bit.ly/actselfhelp

Do you experience a loss of confidence in social situations due to a visible difference in appearance? Take part in a new study being conducted by the University of Sheffield - http://bit.ly/actselfhelp

Take part in new research, examining a self-help booklet for people who experience social worry related to a visible difference in appearance - http://bit.ly/actselfhelp

Do you experience a loss of confidence in social situations due to a visible difference in appearance? Take part in a new study - http://bit.ly/actselfhelp

Appendix H – Full list of charities and social media who agreed to advertise the study

The following organisations and charities agreed to advertise the study: Changing Faces (UK), The Katie Piper Foundation (UK), Alopecia UK, the National Alopecia Areata Foundation (USA), Australia Alopecia Areata Foundation Inc., British Skin Foundation, mindandskin.com (UK), Ichtyosis Support Group (UK), Dan's Fund for Burns (UK), Lupus UK, Vitiligo Support and Awareness Foundation (VITSAF: Nigeria), Eczema Association of Australasia, the Psoriasis and Psoriatic Arthritis Alliance (PAPAA: UK), Vitiligo Research Foundation (USA), Birthmark Support Group (UK) and Bald Girls do Lunch inc. (USA).

The following social media groups agreed to advertise the study: Skin Disease Support (Eczema, Psoriasis, Vitiligo, Acne, Skin Cancer etc), Alopecia Areata, Rosacea (in English), Eczema Support Group, Psoriasis, Vitiligo UK, Overcoming Psoriasis, Vitiligo, and Burn Victim Survivors.

Appendix I – Study information provided to participants

Information about this research

You are being invited to take part in a research study. Before you decide on whether or not to take part, it is important for you to understand why the research is being carried out and what it will involve. Please take time to read the following information carefully. You can email the lead researcher (lpowell2@sheffield.ac.uk) if you would like more information or have any questions.

What is the purpose of this research?

We have created a self-help booklet for people with a visible difference (such as, but not limited to, a skin or hair condition, scarring) who experience appearance-related anxiety. The purpose of this study is to examine the effectiveness of the self-help booklet.

Why have I been chosen/ Can I take part?

You are invited to participate in this study if you are aged 18 or above and identify yourself as having a visible difference, which has led to you experiencing appearance-related anxiety - such as worries. We are recruiting people from a range of charities, online forums and social media. Unfortunately, if you are currently receiving psychotherapy, you will not be able to take part.

Do I have to take part?

No, participation in this research is completely voluntary. If you decide to take part, then you are free to withdraw from the study at any time, without giving a reason and without any negative consequences. You can do this by contacting the lead researcher, using the email address given above.

What happens if I decide to take part?

If you are eligible to take part, you will be asked to complete some brief questionnaires. Then, you will be randomly allocated to receive either the self-help

booklet immediately, or in four weeks' time. At the end of this four-week period, you will be asked to complete the questionnaires again. Those who were randomly allocated to the a four-week waitlist will then receive the self-help booklet. When you receive the booklet, we ask that you read and work through it in the following four weeks. The study will then be completed.

What are the possible benefits of taking part?

At the end of the four-week time period, after you have completed the questionnaires, you will be entered into a prize draw to receive one of two Amazon.co.uk vouchers worth £25. It is hoped the booklet may improve psychological wellbeing.

What are the possible risks of taking part?

For some people, completing questionnaires and working through the self-help booklet could raise concerns. The researchers are not able to provide any psychological support to participants, so we recommend that participants contact their GP for support if they are concerned about their psychological wellbeing.

Will participation be kept confidential?

Yes, the data you provide will be treated in strict confidence and will not be disclosed beyond the researchers directly involved in the study (see below).

You will be asked to provide your email address. We will use your e-mail address as your entry into the prize draw and this is how we will contact you if you are selected. Your e-mail is also used so we can contact you in four weeks to ask you to complete the

154

questions once more.

E-mail addresses will be stored securely and separated from any data which you provide. All data will be reported anonymously in any future publication of the results and it will not be possible to identify you in any reports on the findings.

What will happen to the results?

Your responses will be used to assess whether the self-help booklet was beneficial. The findings will be written up as part of the lead researcher's thesis for the Doctorate in Clinical Psychology at the University of Sheffield and we will seek to disseminate the findings through publication in academic journals. A copy of the findings of the research will be available upon request.

Who is organising this research?

This study is being run by Luke Powell, a Trainee Clinical Psychologist at the University of Sheffield. It is being supervised by Dr Andrew Thompson at the University of Sheffield and Dr Nic Wilkinson at Sheffield Health and Social Care NHS Foundation Trust.

Who approved this research?

This study has been approved by the Ethics Committee in the Department of Psychology at the University of Sheffield.

If you have any questions or concerns, please contact Dr Andrew Thompson (a.r.thompson@sheffield.ac.uk) in the first instance. If you feel your concern has not been addressed, please contact the University of Sheffield's Office of the Registrar and Secretary at 0114 222 1051.

Appendix J – Consent and eligibility questions

1. Do you experience a lack of confidence or social worries due to your 'visible difference' (in appearance)?

2. Are you fluent in the English language?

3. Are you currently receiving psychotherapy?

4. Are you aged 18 years or older?

(If eligible)

Thank you for your interest in taking part in this study.

By clicking the next link to begin the questions you are confirming:

- You have read the information about the study, you understand it, and you are happy to participate.

- You agree to being contacted in four weeks when we will ask you to complete some of the questions once more.

- You understand that your participation is voluntary and that you are free to exit the questionnaire at any time without giving any reason.

- You understand that you can ask to withdraw your data from the study by contacting the researcher.