Psychosocial Self Help for Disfigurement

Thesis submitted for the degree of Doctorate in Clinical Psychology

Clinical Psychology Unit, Department of Psychology, University of Sheffield

Zina Muftin, BSc (Hons)

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DECLARATION

This thesis is submitted for the degree of Doctorate in Clinical Psychology at the University of Sheffield. It has not been submitted for any other qualification or to any other institution.

The results, discussions and conclusions presented herein are identical to those in the printed version. This electronic version has been edited solely to ensure conformance with copyright of the self-help materials. The excisions are noted in the text. The final, awarded and examined version is available for consultation via the University Library.

STRUCTURE AND WORD COUNT

Both the literature review and empirical report have been prepared in accordance with guidelines for authors submitting articles to the British Journal of Clinical Psychology (BJCP). Writing style, figure and table formatting conform to the guidance set out by the Publication Manual of the American Psychological Society (sixth edition).

Literature Review:	
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Including references	**7,970**

Research Report:	
Excluding references	**8,765**
Including references	**10,075**

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Thesis Abstract

This thesis examines the utility of self-help for individuals with disfigurements. While variations in adjustment exist, research has also identified high levels of psychosocial distress, particularly relating to social anxiety and fear of negative evaluations. Psychological interventions have the potential to improve psychosocial functioning. However, owing to the stigma of disfigurements and gaps in services, psychological interventions are scarce. There is scope for self-help to meet the gaps in services. The first section is a systematic review of self-help for disfigurements. The aims were to identify and appraise what is currently known about self-help and explore outcomes and user perspectives in its use. Nine studies with varied methodology met the inclusion criteria. Randomised controlled trials are scarce but demonstrate tentative support for self-help interventions to lower psychosocial distress, particularly in reducing anxiety. Self-help is also actively sought with satisfaction for the medium. Recommendations for future research and clinical implications are discussed. To meet the gaps identified by the review, a randomised controlled feasibility trial was conducted with a psoriasis sample utilising compassion-focused self-help. The study aimed to address questions about recruitment, attrition, acceptability and effectiveness. The primary outcome of interest was external shame. Both self-help interventions significantly lowered external shame with small effects observed ($d = .20$). The interventions had high acceptability but attrition was high at 30%.

Abstract Word Count: 218

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To my father, I thank you for sharing with me your passion for learning and for your boundless love and support, I know we've made Mum proud. Thank you to Hala, Zane, Eyad and my friends for providing encouragement and laughter. Last but certainly not least, a special thank you to Alex for his kindness, nurture and excellent coffee making skills.

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[1] Appendix E has been removed to protect copyright

Section One: LITERATURE REVIEW

A Systematic Review of Self-help for Disfigurement: Outcomes and User Perspectives

Abstract

Background: Individuals with disfigurements have been found to experience high levels of psychological and social distress. Self-help has been found to be effective for mood disorders and is widely used in the NHS. However, little is known about its use and effectiveness with disfigured populations.

Objectives: The present review sought to identify what is currently available in the way of self-help interventions for people with disfigurements. Specifically, the aims were to identify what has been tested, with a view of furthering understanding of what is known about effectiveness and acceptability.

Method: A systematic search and appraisal protocol was developed, which enabled identification of studies and extraction of data relevant to the review. Clinical trials were included if the primary method of delivery was through variants of self-help. Qualitative and non-RCT studies were included if they investigated user perspectives.

Results: Nine papers met the inclusion criteria. Studies varied in quality and target populations. There is tentative support for improved outcomes particularly in reducing anxiety. Self-help is actively sought by people with disfigurements, with potential for lay-led organisations to support access of resources. To date there has been little development or evaluation of such interventions.

Conclusions: Self-help has the potential to improve psychosocial functioning in individuals living with disfigurements. Further research is required with improved methodology to develop specific interventions and to adequately demonstrate the effectiveness and acceptability self-help.

Abstract Word Count: 227

A Systematic Review of Self-help for Disfigurement: Outcomes and User Perspectives

This review aims to systematically identify and critically evaluate studies that have investigated psychosocial self-help interventions for adults with disfigurement. It is estimated that 1.1 million individual in the UK are living with a disfigurement or visible difference (Rumsey, Paraskeva, & Harcourt, 2011). Harris (1997) describes three causes of disfigurement: congenital disfigurements manifested at birth (e.g. cleft-lip/palate), traumatic experiences resulting in burns or scarring, and dermatological conditions like acne or psoriasis. Disfigurements can also be caused indirectly through treatments, for example head and neck surgery and through chemotherapy or amputation. For the purpose of the review the term disfigurement will be used to capture the conditions and presentations highlighted above. Research in this field has highlighted the physical, cultural and psychosocial processes involved in adjustment (Thompson & Kent, 2001).

As social beings we are very concerned with how we are perceived by others, which has great implications for people who are marked out as being visibly different. A number of theoretical models have guided and informed research on disfigurement. Goffman's (1963) work on stigma has been highly influential as has Scambler and Hopkins's (1986) distinction between 'felt' and 'enacted' stigma. The former relates to expectations of rejection while the latter is concerned with actual stigmatisation and rejection from others. These concepts have been developed and tested to further understand concealment and avoidant coping mechanisms. Body shame is also thought to be an important construct (Kent & Thompson, 2002). The literature makes a distinction between internal shame (e.g. negative self-evaluations) and external shame (e.g. fears of evaluation by others). Newell (1999) developed a model emphasising fear-avoidance with emphasis on its phobic nature. Finally, research has also explored the role of the self-concept (Moss & Carr, 2004). Crucially, the higher the value placed on appearance (its salience) and the extent to which the person negatively evaluates themselves (valance) will impact on their adjustment. The Appearance Research Collaboration (Rumsey et al., 2010) has developed a conceptual framework to integrate the models cited to further support research.

Studies, including those exploring personal accounts have not shown a demonstrable relationship between the size, severity or visibility of disfigurements and psychosocial wellbeing (Rumsey & Harcourt, 2004; Thompson & Kent, 2001). While variations in adjustment exist, studies have reported higher levels of psychological distress within this population. Several studies have found raised levels of anxiety and depression, fears of negative evaluation and difficulties with social functioning (Carr, Harris, & James, 2000; Kent & Keohane, 2001; Rumsey, Clarke, White, Wyn-Williams, & Garlick, 2004; Thompson, Kent, & Smith, 2002). Despite this evidence, it has been recognised that psychosocial care is not routinely available (Bessell & Moss, 2007).

Psychological Interventions

Bessell and Moss (2007) reviewed the effectiveness of psychosocial interventions for people with visible differences with 12 papers included. The interventions included self-help, individual and group-based Cognitive Behaviour Therapy (CBT), social skills training and group-based person-centred therapy. The review concluded that none of the papers adequately demonstrated the clinical effectiveness of the interventions. The authors reported that the studies were of limited methodological quality. The issues raised related to under-powered analyses and limitations in randomisation procedures. Whilst the Bessell and Moss (2007) review identified the majority of studies investigating effectiveness of interventions within visible difference, it did not include all the relevant self-help orientated research. The review also overlooked studies exploring user-perspectives in relation to the acceptability and usability of interventions.

The evidence for self-help for emotional disorders such as anxiety and depression is extensive, well evaluated and found to be effective with moderate to large effect sizes reported. These self-help interventions include written manuals or computerised programmes (Hirai & Clum, 2006; van Boeijen et al., 2005). The use of varied media such as audio and video alongside written material has been found to improve outcomes (Gould & Clum, 1993). The work of Newell and Marks (2000) found empirical support for similarities between facially disfigured individuals and social phobics on fear-avoidance. It would be reasonable to hypothesise that people with disfigurements who are impacted by social anxiety may benefit from similar self-help interventions.

To date, self-help interventions aimed at reducing distress associated with disfigurement have not been reviewed. Self-help approaches are widely used in the National Health Service (NHS) and have the potential to reach large numbers of individuals with unmet needs. For individuals with disfigurement it would allow access to expertise without the stigma of attending mental health clinics. The present review sought to identify and appraise studies investigating the forms of self-help currently available to people with disfigurement. Secondly to evaluate studies that have tested interventions, with a view to advance understanding of what is known about effectiveness and acceptability to users.

Method

The review retrieved papers published in peer reviewed journals. In order to examine outcomes, randomised controlled trials (RCT) were included. As the secondary aim was also to examine user experience of self-help, studies utilising other quantitative and qualitative designs were also included. Participants were adults, aged 16 years and over with a disfigurement. The review excluded studies that primarily recruited individuals with cancer, unless the self-help study specifically investigated appearance-related distress. The review also excluded studies within eating disorders and body dysmorphic disorder, to distinguish from research and models that examine body image distortion or dissatisfaction with "normal" appearance.

For the purpose of the review, self-help was defined as any intervention where the sole approach is presented through written (bibliotherapy) or other viewed or spoken material (audio, video, computer-based), and where there is minimal (e.g. instruction only) or no direct therapist contact. The review included studies that investigated self-help available in the public domain, for example use of resources through lay-led organisations. A review protocol was developed outlining the design and procedure for the systematic review.

Search Strategy

In line with the review protocol, each abstract was read and reviewed against the inclusion criteria. Full text articles were sought for papers meeting the criteria or when reviewing suitability via abstract alone was insufficient. A record of excluded papers was maintained. Once all the articles were obtained data were extracted and entered into a data extraction table (Table 2). In order to aid comparison, Table 2 presents the extracted studies by study type, first presenting RCT studies and followed by non-RCT studies. Studies were retrieved through systematic literature searches between

November and December 2011 and repeated in June 2012. The following databases were utilised: Cinahl, Cochrane library, Medline, Psychinfo, and Web of Knowledge. Citation and ancestry searches were also performed and key journals such as *Dermatological Nursing* and *Body Image* were hand searched. In addition, key authors were contacted and asked for articles in press. Figure 1 demonstrates the outcome of the search.

Searches were conducted with combinations of each intervention term along with population search terms. These included: intervention terms; ‘bibliotherapy’, ‘online intervention’, ‘online support’, ‘psychosocial intervention’/ ‘treatment’, ‘psychological treatment’, ‘self-help’. Population terms; ‘abnormal appearance’, ‘acne’, ‘altered appearance’, ‘alopecia’, ‘burns’, ‘dermatology’, ‘disfigurement’, ‘psoriasis’, ‘scars’, ‘visible difference’, ‘vitiligo’.

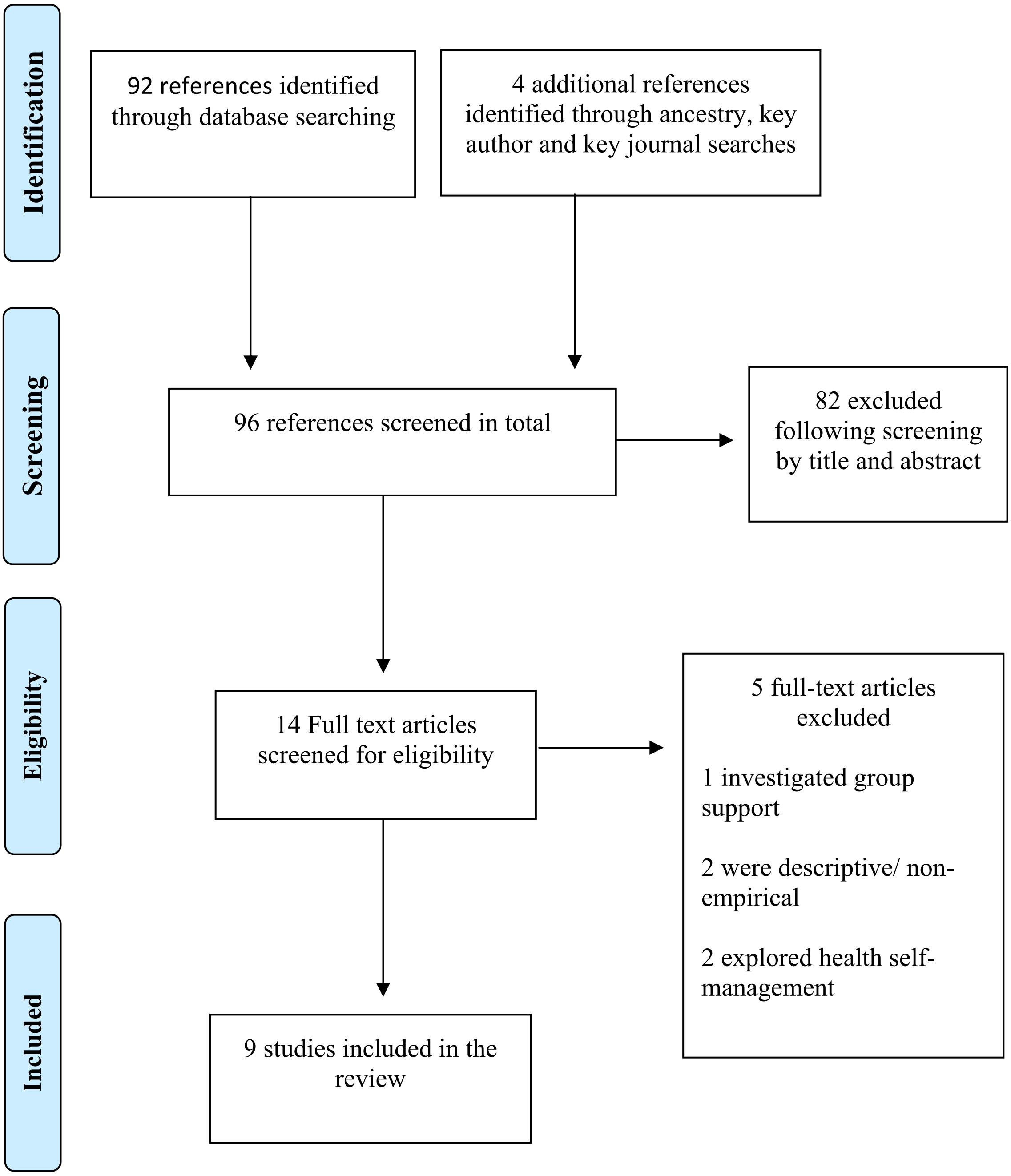

Figure 1. PRISMA diagram demonstrating the search strategy. Adapted from Moher et al., (2009).

Study quality

Quality assessment checklists were adapted from the critical appraisal skills programme (CASP; Public Health Resource Unit, 2006) and the criteria set out by Downs and Black (1998). These sources were adapted for RCT and non-RCT quantitative studies retrieved by the search (see Appendix B.1 & B.2). Qualitative studies were appraised through the qualitative framework set out by CASP (Public Health Research Unit, 2006; see Appendix B.3). Each paper was rated on each item on the appropriate checklist and awarded a total quality score. Based on this score, the study was categorised as being either ‘poor’, ‘limited’, ‘good’ or ‘excellent’ in quality. This system was adapted from the Bessell and Moss (2007) review of psychosocial interventions for visible differences. Table 1 demonstrates the ranking system for the different types of studies, including for non-RCT papers and qualitative studies. Reliability checks were carried out for 20% of the papers by an independent peer. There were no discrepancies found in the quality ratings.

Table. 1

Quality Assessment Ranking System

Study type	Study Quality			
	Poor	Limited	Good	Excellent
RCT & Quasi-experimental	<9	10-14	15-19	20-23
Non-RCT Quantitative	<5	6-8	9-11	12-13
Qualitative Studies	<5	5-6	7-8	9-10

Table 2.

Summary of identified studies investigating self-help in disfigurement

Author and year	Aims	Study type	Setting	Population & *N*	Outcome Measures	Quality rating
Jackson (2006)	Compared mindfulness-based stress reduction with waiting list control	Pilot RCT	Clinical	Psoriasis: Mindfulness *n*=9 Waiting list control *n*=10	Psoriasis Area & Severity Index Hospital Anxiety & Depression Scale Penn State Worry Questionnaire	Limited (11)
Kabat-Zinn et al. (1998)	Compared mindfulness-based stress reduction with standard care; phototherapy	RCT	Clinical	Psoriasis: Mindfulness: *n*=19 Standard care: *n*=18	Skin severity (idiosyncratic) State Trait Anxiety- Inventory Symptom Checklist-90	Good (18)
Kelly, Zuroff and Shapira (2008)	Compared two compassion-focused self-help interventions with control	RCT	Community	Acne: Self-soothing: *n*=23 Attack resisting: *n*=26 Waiting list: *n*=24	Depressive Experience Questionnaire Beck Depression Inventory Experiences of shame scale SKINDEX	Good (17)
McGarvey et al. (2010)	Compared computer programme for alopecia with standard care; ward-based resource room	RCT	Clinical	Cancer: Computer programme: *n*=25 Standard care: *n*=20	Brief Symptom Inventory Global Severity Index Importance of Hair Q The Brief Cope	Good (17)

Table2. (*Continued*)

Author and year	Aims	Study type	Setting	Population & *N*	Outcome Measures	Quality rating
Newell and Clark (2000)	Compared CBT self-help with waiting list control	RCT	Clinical	Facially disfigured patients: CBT Condition *n*=34 Waiting list *n*=36	Fear Questionnaire Social adjustment General Health Questionnaire Hospital Anxiety & Depression Scale	Good (15)
Vedhara et al. (2007)	Compared Emotional Disclosure task with non-specific writing exercise	RCT	Clinical and Community	Psoriasis: Emotional disclosure: *n*=31 Standard control: *n*=28	Psoriasis Area & Severity Index Dermatology Life Quality Index Profile of mood states Hospital Anxiety & Depression Scale	Limited (13)
Bessell, Clarke, Harcourt, Moss, and Rumsey (2010)	Examined user perspectives in development of online psychosocial interventions	Qualitative	Clinical and community	Individuals with visible differences and expert clinicians: Study 1: *n*=18 Study 2: *n*=28	Employed semi-structured interviews	Good (8)
Clarke (2001)	Provided an account of the use of Changing Faces self-help booklet series	Cross-sectional	Community	People with visible differences *n*=70	None utilised	Poor (2)
Idriss, Kvedar and Watson (2009)	Investigated characteristics and experiences of users of online psoriasis groups	Cross-sectional	Community	Psoriasis users of online forums *n*=260	Questionnaire developed for study Dermatology Life Quality Index	Limited (7)

Results

Overall, nine studies met the inclusion criteria. The review findings are structured in three sections. The first section examines the effectiveness of self-help treatments designed to address distress relating to appearance concerns. Section two examines self-help treatments that have investigated stress reduction and wider psychosocial change. The final section reviews studies that have investigated user experiences in the use and development of self-help treatments.

Self-help for Appearance Related Distress

Three RCT studies investigated the effectiveness of self-help interventions designed to lower psychosocial distress associated with appearance concerns (Kelly, Zuroff, & Shapira, 2008; McGarvey et al., 2010; Newell & Clarke, 2000). These studies were conducted with samples from different disfigured populations and recruited from both clinical and community settings.

The Kelly et al. (2009) study investigated interventions designed to improve depressive symptoms in participants with acne. Secondary outcomes of interest included levels of shame and skin complaints. Recruitment was via local online classifieds and newspapers. Participants were predominantly from a student population (87%). The interventions were based on Gilbert and Irons (2004) Compassionate Mind Training. Participants were randomly assigned to one of three groups: the self-soothing condition (*n*=23); the attack-resisting condition (*n*=26) and no-treatment control (*n*=24). Participants in the intervention conditions learnt about the self-help intervention at a desktop computer. They were instructed to train in daily imagery-based self-talk and writing exercises over a two week intervention period.

The study had clear aims and employed an appropriate RCT design to test the study hypotheses. The study randomly allocated participants to conditions, but did not make the randomisation procedure explicit. However, baseline comparisons between treatment groups did not reveal differences on the outcomes of interest. As acne largely affects young people, the sample was arguably representative of the wider acne population, showing good external validity. Pre-intervention, the means revealed that the sample was moderate to severely depressed.

Overall, the analysis was appropriate and the outcomes were presented in sufficient detail. Both intervention conditions significantly reduced shame and skin complaints in comparison with the controls. However, only the attack-resisting condition significantly reduced depression. Multiple regression analysis revealed that the attack-resisting condition was effective at lowering depression for the self-critics. Both treatment groups were found to be equally compliant in the way that they used the techniques. The lack of a reported power analysis did not help determine whether the sample size was adequate to detect an effect. Taking the methodological points into consideration, the study was overall appraised as producing "good" evidence for imagery-based self-talk in lowering acne sufferers' shame and in partially lowering level of depression.

In contrast, Newell and Clarke (2000) conducted an RCT evaluating an intervention based on cognitive behavioural principles. The authors developed a self-help booklet accessed by mail for individuals with facial disfigurements. The interventions paid particular attention to the role of social avoidance. The study recruited 106 participants (18 males and 88 females) from dermatology outpatient departments, plastic surgery and local media. Participants were randomly allocated to either the booklet condition or waiting list control. The study employed valid and reliable outcomes that measured global functioning and specific markers such as agoraphobia, social phobia, social leisure in addition to depression. Measures were completed at baseline and three months following the distribution of the booklet. The randomisation procedure was not made explicit but the groups were comparable at baseline on the outcomes of interest.

Data were available for 34 participants allocated to self-help and for 36 control participants. The paper reported statistically significant but modest gains for the social leisure subscale and the anxiety and depression subscales. Attrition was high at 34% with no discussion of the potential reasons. However, comparisons between responders and non-responders found no significant differences on demographic and psychosocial outcomes at baseline. In addition, inclusion was set so low that participants with mild psychosocial difficulties were included. It is therefore questionable whether the outcomes could be generalised to individuals managing more severe difficulties.

As a less intensive form of self-help, the study demonstrated evidence that brief self-help based on cognitive behavioural principles has potential in supporting individuals with facial disfigurements to lower social anxiety. The study was appraised as being within the “good” quality category. The aims were clear and use of an RCT design was appropriate to the study objectives. The majority of study completers reported that the booklet was helpful and understandable.

The McGarvey et al. (2010) study recruited a clinical sample in an RCT investigating a computer-imaging program, ‘Help with Adjustment to Alopecia by Image Recovery’ (HAAIR). The programme was developed to support adjustment to chemotherapy induced alopecia. Through digital imaging the programme allows women to select images of themselves without hair and of themselves wearing different wigs. The study examined effects of the programme on hair loss distress, anxiety and depression, and identified coping styles. Measures were taken pre-chemotherapy (baseline), following hair-loss and at three months follow-up. The authors used a randomisation sequence to allocate participants either into the HAAIR programme (*n*=25) or to standardised care (SC; *n*=20). SC involved access to an existing alopecia-specific resource room at the Cancer Centre. An a priori sample size calculation showed that the sample size was below what was deemed sufficient but was nonetheless respectable.

The study was appraised as producing “good” evidence. As with the other studies exploring appearance outcomes, the study had clear objectives and utilised appropriate analyses that were sufficiently reported. Randomisation was successful with the groups comparable at baseline. The results indicated both groups showed a statistically significant decline in hair loss distress. At follow-up, loss of hair distress in the HAAIR condition continued to fall, while there was an increase in hair loss distress within SC. However, there were no significant interaction effects between time and treatment on the psychological measures. Avoidant coping scores were found to positively correlate with distress associated with hair loss; participants with higher avoidance tended to have higher hair distress levels. User feedback showed that the programme was perceived to be useful and easy to use. The interactive nature of the programme was also well received.

Contrary to the other studies within this area, an appropriate follow-up period was employed. However, as in the Newell and Clarke (2000) study, at pre-intervention 75% of the sample did not meet clinical levels of psychological distress. The sample as a whole also reported active coping styles. Both these factors meant that the findings could not be generalised to individuals with more severe problems and may have accounted for the lack of change between the before and after data on the psychological measures. The alopecia resource room used in SC may also have been an inappropriate control.

In conclusion, there is some evidence to suggest that self-help interventions specifically targeting appearance concerns can be of benefit to people with disfigurements. Two studies offered tentative support for improvements in levels of anxiety.

Self-help & Stress Reduction

The search identified self-help studies exploring stress reduction. These studies utilised outcomes that had some overlap (i.e. anxiety, depression, and quality of life) but were not exclusively focused on reducing appearance related distress. Three studies were identified, all conducted with psoriasis populations that were largely recruited from clinical settings. All three discussed the role of stress in exacerbating psoriasis. Two studies investigated mindfulness-based stress reduction (MBSR) delivered via audio-tape (Jackson, 2006; Kabat-Zinn et al., 1998). In contrast, Vedhara et al. (2007) investigated a brief emotional disclosure task.

Kabat-Zinn et al. (1998) compared psoriasis patients undergoing phototherapy treatments (PUVA and UVB) with patients assigned to phototherapy plus MBSR. The latter was delivered via audio-tape during phototherapy treatment. Phototherapy is typically employed when topical treatments have not been effective. The authors did not explicitly describe the randomisation procedure but noted that participants were randomly assigned either into MBSR conditions plus phototherapy (UVB, n =11; PUVA, n = 8) or to standard phototherapy (UVB, n = 10; PUVA, n = 8). An idiosyncratic measure was developed to assess skin status and psoriasis clearing rates measured by a non-blinded nurse specialist. To reduce bias a blinded Dermatologist assessed photographic evidence and provided skin status ratings.

The analysis revealed MBSR participants had reached skin clearing significantly more rapidly than participants in standard treatment. The effects were not significant for MBSR and UVB treated patients. The number of participants in MBSR and PUVA was very small (n=8). No differences were detected for standard phototherapy on the measures of psychopathology, which included a measure for trait anxiety. Nevertheless, a 35% reduction was found for the MBSR condition, but it was not a statistically significant change. The study employed intention-to-treat analysis and the data were presented with sufficient detail. Baseline characteristics between participants either in phototherapy alone or in the MBSR condition were comparable.

The study was appraised as having produced “good” evidence. An appropriate research design was utilised with clear presentation of procedures and outcome reporting. The study also took adequate steps to ensure blinding of assessors. There were methodological limitations worth consideration. The sample was arguably not representative of patients receiving care, as the majority are treated by a General Practitioner in primary care settings. This study was not sufficiently powered and there was no discussion of the acceptability of the intervention or adverse effects. However, the outcomes showed clear potential for audio-tape delivered MBSR to reduce the number of phototherapy treatments. Further research would be necessary to evaluate MBSR in a broader sample of psoriasis sufferers.

Jackson (2009) replicated the Kabat-Zinn et al. (1998) study through a pilot RCT. The intervention was delivered as a conventional eight week package instructing daily use. Outcomes of interest were taken at pre-intervention, four and eight weeks, measuring anxiety, worry, depression and psoriasis severity. In order to reduce bias, a blinded research nurse assessed psoriasis severity. The study recruited psoriasis patients from a UK dermatology department. Participants were randomised into a MBSR condition (*n*=9) or a waiting list control (*n*=10). The mean age was 45 years, with 58% males. Due to the small sample, the study utilised non-parametric methods to analyse the data. In comparison with controls, the MBSR group showed statistically significant improvements on anxiety. Although not significant, the MBSR group had more favourable outcomes on all but the depression measure at post-intervention. The intervention was rated as highly agreeable, with 87.5% reporting plans for continued use. In addition, 75% reported that MBSR had helped them to relax.

There were a number of confounding variables. At baseline, the control group had higher psoriasis severity. Secondly, a large proportion of the sample had previously received phototherapy treatment (89%) but there was no discussion of how much time had elapsed. The sample as a whole was also found to be in the non-clinical range on the measure for depression and anxiety, which in addition to the small sample may have contributed to the small effects reported. The study was therefore appraised as being of "limited" quality. However, similarly to other small *N* studies within this review, there is potential for MBSR to reduce psychological distress, particularly anxiety.

Vedhara et al. (2007) conducted an RCT investigating the effects of an emotional disclosure task on disease severity and quality of life in patients with psoriasis. The authors were interested in secondary outcomes relating to mood and anxiety. The study recruited 69 participants from community and clinical settings, with data analysed for 59. Participants were randomly allocated into the emotional disclosure group (*n*=31) or a standard control writing condition (*n*=28). The emotional disclosure intervention consisted of a 20 minute writing exercise inviting participants to write down their innermost thoughts and feelings about traumatic experiences, problems or conflicts. Control group participants were instructed to write a detailed account of their previous day. Both groups were instructed to carry out their respective task on four consecutive days. Measures were taken at baseline and repeated at two, eight and 12 weeks post-intervention.

Improvements in disease severity and quality of life were found for both groups with no difference in the magnitude of change. However, before and after means revealed very small differences in scores on the outcomes. The predictors of the change were found to be different for the groups. Disease severity at baseline and positive changes in mood predicted disease severity at follow-up in the emotional disclosure group. While for the control group, disease severity at baseline alone predicted severity at follow-up. The paper lacked a discussion of the potential implications of this finding.

The authors made attempts to reduce bias by blinding assessors of disease severity to group allocation. Furthermore, randomisation checks were carried out demonstrating the treatment and control were comparable. However, similarly to the Jackson (2006) study, outcomes at baseline indicated a sample with mild disease severity and psychological distress. The results may therefore have reflected a 'floor effect'. Future studies would benefit from recruiting patients with more severe clinical presentations. Further considerations must be given to the choice of control for emotional disclosure. It could be argued that the written exercise was not as neutral as was anticipated, and in itself may have elicited therapeutic benefits. Secondly, while content analysis revealed that the emotional disclosure group had significantly used more affective words, these may have related to 'traumatic experiences' that were unconnected to the skin condition. Taking into account the above methodological considerations, the study was appraised as having "limited" quality.

In conclusion, studies investigating self-help with the aim of reducing stress, found limited but promising outcomes for the use of self-help. However, these studies were found to vary in quality. As in RCTs with appearance-focused outcomes, the studies lacked stringent inclusion criteria, bringing into question the external validity of the studies. There were also issues raised by the specificity of the interventions.

The Development of Self-help and User Perspectives

Three studies were identified that explored service user (SU) perspectives in what is sought from self-help (Bessell, Clarke, Harcourt, Moss, & Rumsey; Clarke, 2001; Idriss, Kvedar, & Watson, 2009). The Bessell et al. (2010) paper was the only study that directly evaluated SU perspectives in the development of a self-help programme. The other two studies shed light on the use of web-based resources (online forums) and charity organisations. The absence of service provision for people with disfigurements has meant that the web has potential to become a powerful medium for accessing psychosocial support. It is therefore useful to investigate how these resources are used by SU.

In two qualitative studies, Bessell et al. (2010) investigated SU perspectives in the development of an eight week computer-based programme, FACE IT for individuals with visible differences. Study one aimed to identify what SU would find useful in psychosocial interventions. The researchers were also interested in gleaning the perceived positive and negative aspects of existing interventions. The themes were used to develop the programme FACE IT. Study two built on this study by evaluating the usability of the programme, aiming to remove programme errors and to ensure FACE IT meets the needs of its target audience.

Both studies employed semi-structured interviews with three SU groups: SU with prior experience of psychosocial interventions, SU with no prior experience and expert clinicians. Study one recruited 12 participants (six clinicians) while study two recruited 28 participants (14 clinicians). Study two participants were provided with a prototype version of FACE IT prior to taking part in semi-structured interviews. The paper was not explicit about the method of recruitment; however there was mention of an advert placed on support group websites. The interviews were analysed through content analysis. Coded data for the three participant groups were analysed separately with similarities and differences recorded.

A dominant theme related to the need to increase access to services and limits in the information available regarding useful interventions. The data also illustrated support for existing intervention packages as there was support for the social skills model and use of online interventions. The focus on addressing unhelpful self-perceptions and behaviours was supported, particularly in helping participants address self-perceptions in managing stigma from others. Social stigma was a dominant theme throughout the data.

Participants reported that the programme was easy to use but expressed the need for extra support within sections involving variants of exposure work. It was important for the programme to have a sense of realism with video exercises and true life stories. The inclusion of practical elements such as a social skills DVD, relaxation techniques and inclusion of quotes was thought to validate user experiences and support compliance with the programme. However, concerns were raised by clinicians and SU about difficulties in user motivation over an eight week period. Clinicians were also concerned that virtual support networks may encourage users to further isolate themselves. Satisfaction feedback was reported from seven experts and eight SU, a response rate of 54%. High to moderate satisfaction was expressed by 94%. The programme was also thought to have broad appeal to people with various visible differences, and especially useful for individuals who require minimal support.

The study set out very clear aims to incorporate user and clinician perspectives to develop a web-based psychosocial programme. The researchers applied appropriate qualitative methods and analysis to address the research aims. The recruitment strategy could have been made more explicit. It was not clear how participants were recruited and there was no discussion of how many individuals were approached or had declined. Themes were presented in sufficient detail with good use of extracts. In addition, the analysis underwent credibility checks. It would however have been useful for the authors to have been more explicit about the way contradicting responses were resolved. There was also limited discussion of the researcher-participant relationship. Evaluating the study through the qualitative appraisal tool placed the paper within the “good” quality category.

Clarke (2001) reported on lay-led organisations and the type of support sought by individuals accessing such organisations. Changing Faces supports people with facial disfigurements. The paper evaluated the manner in which Changing Faces was utilised in its first five years. The quality appraisal tool for non-RCT studies could not be appropriately used as the paper did not provide sufficient details of the methods employed to collect the data. The paper was therefore deemed to be “poor” in quality. However, it was included in the review as it provided some preliminary data from service-users that had accessed psychosocial resources through a prominent organisation supporting people with disfigurement.

Retrospective sampling of 1500 adults with a face disfigurement, provided data on the type of information sought when contacting the organisation. Over half sought advice and support for self-management approaches. The paper included an evaluation of a self-help booklet series accessed through Changing Faces. Data from 70 respondents was collected from routine 6 month follow-ups and through evaluation forms that accompanied the booklets, citing a 30% return rate. Over 80% reported the booklets were easy to understand; 73% found the booklets helpful and 69% reported that they were effective in stimulating the individual to use the suggested strategies. Feedback from health professionals and patients reported that they were unable to find self-management information elsewhere. The paper did not provide a description of the content of the booklets or the specifics of how the respondents were instructed to use the booklets.

Using an online, cross-sectional survey design, Idriss et al. (2009) investigated the characteristics, usage patterns and the perceived benefits of online support websites for psoriasis. Participants were recruited via UK and USA-based online forums. In total

260 respondents were included in the analysis. The mean age of participants was 40 years, with a predominantly female (60%) sample. A high proportion, at 74% reported themselves as having moderate-severe psoriasis.

The survey explored attitudes towards online communities and frequency of use. Respondents also completed a dermatology quality of life measure. Interestingly, 86% of respondents cited the internet as their main form of support, ahead of doctors and family members. Key factors associated with use of the internet included availability of resources and convenience. Respondents also reflected on the lack of embarrassment through greater anonymity provided by the forums. Finally, there was a sense that online support allowed a sense of control over the condition. Information seeking and sharing information was an important feature of online use. No association was observed between the reported level of online participation with self-reported improvements in psoriasis severity or health status. However, respondents with higher quality of life scores reported better health status and lower psoriasis severity.

The study was appraised as being “limited” in quality. Owing to the nature of cross-sectional survey designs, conclusions cannot be made about ‘improvements’ following use of online communities. The latter was acknowledged by the authors. There may have been unexplored confounding variables as the authors were only able to estimate a response rate for two of the five online forums. Finally, while the study collected useful demographic data, the authors did not have any specific predictors in mind, which limited the type of analyses conducted. Despite the methodological limitations, both the Clarke (2001) and Idriss et al. (2009) papers reported similar findings to the Bessell et al. (2010) studies, which were methodologically superior. All three papers recognised the potential for people with disfigurements to access forms of self-help resources over the internet.

Discussion

This review aimed to identify what is currently known about self-help within disfigurement, investigate its effectiveness, how it might be enhanced, and its acceptability to users. Research has demonstrated high levels of psychosocial distress within disfigured populations. There is therefore scope for psychological interventions to target these specific factors. Research has also recognised the gaps in service provision in addition to the stigma attached to presenting to services. It is therefore striking that this review identified a limited number of studies investigating self-help. This is particularly stark when considering the self-help literature for mood disorders.

Despite the limited number of studies, the studies that exist have applied RCT principles to investigate a number of therapeutic modalities. The interventions included: a cognitive-behavioural approach, imagery-based compassionate mind training, MBSR, emotional disclosure and exposure-based programme. The self-help was also delivered through various media: written material (bibliotherapy), computer programmes and multi-media formats (e.g. audio-tape). Only one approach, MBSR was investigated by more than one study. Due to the small number of studies and wide variation in therapeutic models, method of delivery, intervention period and settings, it was difficult to explore consistencies between trials or make firm conclusions about the more effective interventions.

In spite of this, a finding consistent across studies utilising anxiety measures, found anxiety to be the outcome that is the most positively impacted following the use of self-help. This lends support to theoretical models set out by Thompson and Kent (2001) and Rumsey et al. (2010) that have provided a framework for understanding adjustment processes in disfigurement. Anxiety and in particular social anxiety has been hypothesised to be an important predictor of distress. It is important for individuals to feel a sense of belonging, therefore being marked as different leaves the potential for rejection and elevates anxiety.

On the whole when comparing the self-help interventions with controls, there was a trend for self-help to show lower psychosocial distress as shown by changes on the validated measures. However the majority demonstrated either small changes in the before and after data or trends that were not supported statistically. The methodological strength of the six RCTs varied considerably from “limited” to “good”. The review identified the need for further RCTs to investigate self-help within this area. Crucially, future studies need to ensure high methodological quality to enable an evaluation of reported treatment effects.

User Perspectives

Self-help as a medium appeared to be acceptable, with users reporting satisfaction. This has been evidenced by studies that evaluated the use of self-help approaches. However, this was not systematically evaluated by all the RCT studies and rates of compliance were also not routinely available. Studies that explored user perspectives either evaluated viewpoints to aid the development of self-help interventions or to investigate how SU utilise self-help resources that are available in the public domain. These studies revealed that individuals with disfigurements are actively seeking psychosocial support. However, information regarding what is available and or how resources may be accessed was unsurprisingly, given the findings of this review, thought to be scarce.

The prominence of lay-led groups increasingly accessed via the web, was explored by two papers that were limited in quality. Nonetheless, they provided useful preliminary data exploring this growing medium of support. The Bessell et al. (2010) qualitative paper was methodologically superior but provided support for the findings of

Clarke's (2001) report evaluating use of Changing Faces booklet series. These papers in addition to the cross-sectional survey of users of psoriasis online forums (Idriss et al., 2009) placed particular emphasis on psycho-education, encouraging social support and skills development. The Bessell et al. (2010) paper is specifically valuable as it utilised research methods with SU prior to conducting an RCT. Research involving SU allows researchers and clinicians alike to consider the potential barriers to using psychosocial interventions and ways to maximise their benefit. These studies also highlighted stigma as a barrier for people with disfigurement. It was therefore understandable that users of online forums find this a useful medium to access support.

Clinical Implications

The review demonstrated that there is potential for brief self-help to offer people with disfigurements improved psychosocial wellbeing. The evidence-base for self-help within disfigured populations remains in its infancy. Despite this, it is promising that researchers have developed self-help from a wide range of therapeutic modalities. Crucially for clinicians, less frequently investigated models such as compassion-focused approaches are starting to be investigated alongside more widely used cognitive behavioural approaches. Furthermore, the studies that compared self-help with standard care found self-help to either result in more improved outcomes or to be comparable. This suggests that self-help may be a useful adjunct to standard care; this is particularly pertinent to individuals with skin conditions who are primarily supported in primary care. Self-help is also advantageous as it can be delivered at a low cost with minimal therapeutic support.

Researchers have advocated for the use of stepped care approaches in the development of intervention pathways (Rumsey et al., 2010; Thompson, 2009). The lowest step advocates signposting SU to support organisations such as Changing Faces.

The step above promotes the training of non-psychologists to provide low intensity guided support. Self-help has the added value of providing support remotely and encourages self-management. Finally, the rise of lay-led organisations such as charities or online forums potentially allows experts and clinicians to reach a wider audience with unmet needs. It would be useful for researchers and clinicians to make links with lay-led support groups to develop, evaluate and share resources.

Limitations and Future Directions

The research area would benefit from more RCTs with high methodological quality. Particular attention should be paid to participant characteristics and sample sizes. The majority of the included studies did not report how the sample size was determined or whether the analyses were sufficiently powered. In addition, most of the studies identified by the review that investigated a self-help intervention contained participants with mild presentations. It is conceivable that 'floor effects' contributed to the small changes in the pre and post data reported.

While there appeared to be satisfaction with the medium of self-help, it is unclear whether this form of psychosocial support would be acceptable to individuals with more severe psychosocial distress. Self-help is arguably more suited to individuals with milder forms of distress and for individuals requiring minimal support. It remains unclear what level of intervention would be suitable for whom. Future studies would therefore benefit from containing more stringent inclusion criteria, in order to support comparisons. Investigating the effectiveness of resources in the public domain (e.g. online forums or charity booklets) brings methodological challenges. However, there is a need for researchers to employ appropriate methodology to further investigate the effectiveness of such materials.

In relation to the choice of self-help interventions, future RCTs should give greater consideration to the theoretical framework that guides the intervention and the subsequent choice of outcome measures. For example, studies aiming to reduce disease severity as evidenced through psoriasis clearing, may have an impact on appearance-related distress that may be undetected if appropriate outcomes have not been employed. Evidence from a meta-analytic study investigating online self-help for health behaviour change, found theoretically informed interventions to be associated with increased effect sizes (Webb, Joseph, Yardley, & Michie, 2010).

One of the difficulties in reviewing this area is that individuals with disfigurements do not form a homogenous population. Interestingly, demographic and condition-specific factors have not been found to be the best predictors of adjustment. Instead psychosocial factors such as fear of negative evaluations, contentment with social support and the importance that an individual places on their appearance have been found to be key (Rumsey, Paraskeva, & Harcourt, 2011).

The review cannot comment on the ideal length of self-help interventions or the long-term benefits as only one study had an appropriate follow-up periods. Future trials would benefit from careful consideration of the comparator to ensure that it is distinct enough from the active intervention. Studies within the review all investigated standard self-help that was delivered with no additional therapist support. There is evidence to suggest that guided self-help leads to more improved outcomes (Hirai & Clum, 2006). Guidance with self-help was raised by SU and expert clinicians in the qualitative study. The respondents expressed that multi-media formats and practical elements within self-help interventions would encourage use and maintain compliance.

Finally, the Idriss et al. (2009) study of psoriasis users of online forums raised an interesting question about who uses such support. The respondents reported moderate to severe psoriasis severity. The study drew attention to statistics from the

National Psoriasis Foundation stating that the majority of psoriasis patients are mildly impacted, as measured by the amount of body coverage. It could be hypothesised that psoriasis severity may be associated with increased use of alternative support such as web-based resources. This is an interesting finding that requires further investigation as it may have consequences for the effectiveness of psychosocial interventions.

Conclusion

This review found tentative support for self-help interventions to lower psychosocial distress for people with disfigurements. Research within disfigurement covers a wide range of populations with both unique and overlapping needs. Despite the vast literature on appearance-related distress and the stigma of altered appearance, this appeared to be a subsidiary issue with only three studies aiming to reduce appearance-focused distress. However, while the effects were modest, the acceptability of the medium by its users was generally high. Self-help is actively sought by people with disfigurement. SU are however, unclear about ways to access information. There is therefore a need to develop effective and accessible psychosocial interventions, as demonstrated through studies exploring psychosocial adjustment and user feedback. Methodological limitations were identified, particularly relating to sampling and sample size. Future research could support our understanding by carrying out well designed studies that involve service users in the development of the self-help materials. This is particularly useful with the advent of the internet and the increase in lay-led online groups and charities.

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Section Two: RESEARCH REPORT

A Randomised Controlled Feasibility Trial of Online Compassion-focused Self-Help for Psoriasis

Abstract

Objectives. People with psoriasis experience psychological distress as a result of managing a visibly disfiguring condition. This study tested the feasibility of evaluating two self-help interventions based on Compassionate Mind Training (CMT). In particular, it aimed to test the feasibility of recruiting a psoriasis sample and investigating intervention acceptability and preliminary outcomes relating to shame, self-attack and dermatology specific quality of life. The study also focused on estimating sample size.

Methods. A parallel-group, randomised controlled feasibility trial was conducted with a community sample of 130 participants with psoriasis. Participants were randomly allocated to compassionate self-help (n =65) or mindfulness self-help (n =65) over a four week intervention period.

Results. The interventions were found to be acceptable with over 70% of study completers reported finding the materials helpful. A total of 92 participants completed the study with attrition at 30%. Both interventions showed modest yet statistically significant reductions in shame and quality of life. Assessment of shame showed a small pre-post effect size (d = .20), while quality of life showed small to moderate effect size (d = .40).

Conclusions. Brief self-help interventions based on CMT have the potential to alleviate specific psychosocial distress associated with stigma and shame in psoriasis and to improve quality of life. Reported effect size and retention issues raised questions about the feasibility of recruiting and retaining a sample large enough for a full scale RCT.

Abstract Word Count: 230

Psoriasis is an inflammatory, non-infectious skin condition that is characterised by red, scaly and at times painful lesions that may appear on any part of the body. There is no cure for the condition and treatment is focused on symptom management. Physical treatments can have unpleasant side-effects and can be time consuming, without necessarily leading to the desired clearing of lesions. Psoriasis is also highly visible to others and noticeably alters appearance (Leary, Rapp, Herbst, Exum, & Feldman, 1998).

Appearance Concerns & Stigma

Goffman's (1963) seminal work on 'stigma', describes how the visibility of a condition can mark one out as an object for negative reactions from others. Shame is described as an important aspect of stigma. More recently, Smart-Rickman and Leary (2009) posited a theoretical framework for understanding reactions to rejection, whereby stigmatisation threatens belongingness and leads to negative affect and socially avoidant behaviour. Researchers have also distinguished between 'enacted' and 'felt' stigma. The former is the result of expected negative evaluations and discrimination, while the latter relates to actual discriminatory attitudes and behaviours from others (Scrambler & Hopkins, 1986). A model of body shame has been developed, which combines evolutionary ideas relating to humans' innate need to belong, alongside experiences of social exclusion (Gilbert, 1997). The result is the development of specific cognitions related to appearance concerns (Thompson & Kent, 2001).

In psoriasis, perceived stigmatisation has been shown to be a better predictor of psychosocial distress than disease severity alone. The stigmatisation process has also been found to impede patients from engaging with psychological services (Richards, Fortune, Griffiths, & Main, 2001). The work of Vardy et al. (2002) demonstrated stigmatisation to mediate the impact of severity of psoriasis on quality of life.

Stigmatisation processes also support an understanding of the avoidant coping strategies commonly used by people living with a visible difference (Thompson & Kent, 2001).

As a result of the stigmatising nature of psoriasis, it is unsurprising that studies have found high levels of psychological distress. While there is individual variation, psoriasis has been linked with an increased risk of depression (Akey, Pekcanlar, Bozdag, Altintas, & Karaman, 2002) and anxiety (Fortune, Richards, & Griffiths, 2005). Anxiety particularly has a social focus with patients reporting a fear of negative evaluation from others (Leary, Rapp, Herbst, Exum, & Feldman, 1998). In addition, avoidant coping strategies have been found to be highly prevalent (Strangier, Ehlers, & Gieler, 2003). The Appearance Research Collaboration (Rumsey et al., 2010) has integrated research evidence and the vast number of theories influencing researchers, into a conceptual framework that pays attention to the multifaceted factors affecting adjustment. The final report emphasises the need for effective psychological interventions to support the development of a healthier sense of self that is not dependent on appearance and that also supports the management of negative reactions.

Psychological Interventions

The National Institute for Clinical Excellence is currently finalising guidelines for the management of psoriasis (NICE, 2012). The guidance recognises the potential stigmatising social impact of living with the condition. It also highlights the levels of psychological distress and the need for psychological interventions. However, treatments are largely biomedical with a focus on restoring skin and normalising appearance. The guidance acknowledges that there have been relatively few studies investigating psychological interventions. There is limited evidence for educational self-management programmes. These programmes aim to encourage people with long-term conditions to take a more active part in condition management.

Psychological approaches in this area arguably need to focus upon supporting individuals to manage the reactions of others and on developing psychological acceptance of their appearance and condition (Thompson & Kent, 2001). Within the literature for visible difference, Bessell and Moss (2007) conducted a systematic review of the effectiveness of psychosocial interventions. This review included twelve papers with interventions delivered via self-help, individual and group CBT, group based person-centred therapy, social skills training and support group interventions. The authors concluded that while the techniques used are important, the studies conducted were overall low in quality and therefore could not adequately evaluate the effectiveness of psychosocial interventions. Studies conducted with psoriasis populations have found evidence to support cognitive behavioural therapy (CBT) delivered via individual and group formats (Fortune et al., 2002; Kleve, Rumsey, Wyn-Williams, & White, 2002; Zachariae, Oster, Bjerring, & Kragballe 1996). However, access to services and to trained therapists remains limited.

Self-help

One way to meet the gap in services is to develop and evaluate the effectiveness of self-help interventions. Thompson (2009) presented a model of stepped psychosocial care for skin conditions. The lower, less intensive steps promote the delivery of self-help and support groups for all patients. The majority of psoriasis patients are treated in primary care services. Self-help has the potential to reach a wider client base and offers cost-effective interventions (Bower & Gilbody, 2005). Large effect sizes have been reported for self-help in treating anxiety disorders (Hirai & Clum, 2006). However, few studies have investigated the effectiveness of self-help for conditions that affect appearance or for skin conditions.

There is evidence that psoriasis patients can benefit from mindfulness-based stress reduction (Kabat-Zinn et al., 1998). Patients assigned to mindfulness-based stress reduction reported improvements in their physical condition, more rapidly than participants assigned to treatment as usual. However changes on measures of psychological wellbeing were not statistically significant. Jackson (2006) replicated the Kabat-Zinn et al. (1998) study and found mindfulness-based stress reduction to significantly reduce anxiety. These studies show potential for the clinical use of self-help to support adjustment to psoriasis. Future studies would benefit from improved study quality and sufficiently powered randomised controlled trials (RCT) that pay close attention to the relevant psychological outcomes.

Given the literature's emphasis on felt stigma, there appears to be a dearth of psychosocial approaches that aim to directly work with the shaming and stigmatising reality of living with a visibly disfiguring condition. CBT addresses ‘unhelpful’ thought patterns and their impact on mood and behaviour. However, managing enacted stigma through challenging unhelpful patterns of thought may only offer limited comfort. There is evidence suggesting that individuals high in self-criticism find it challenging to feel reassured by cognitive tasks and behavioural experiments, as used in standard CBT (Lee, 2005).

Compassionate Mind Training

There has been a trend in Western Psychology to integrate Buddhist constructs within psychotherapeutic approaches. The most prominent has been mindfulness-based interventions (Vøllestad, Nielsen, & Nielsen, 2012). Compassionate Mind Training (CMT) was designed to teach individuals high in shame and self-criticism to be self-soothing (Gilbert & Procter, 2006). The approach is rooted in evolutionary and neuro-psychological models, with an emphasis on affect regulation. There is evidence suggesting compassionate meditation that develops feelings of loving kindness alters brain circuitry (Lutz, Brefczynski-Lewis, Johnstone, & Davidson, 2008). A key therapeutic tool in CMT involves working with the individual’s mental imagery with a view to altering negative images such as that of the inner bully. This approach is relevant to people with psoriasis. Living with a disfiguring condition leaves the person acutely aware of how they may exist in the minds of other people. Shame extends beyond embarrassment and impacts on a person’s sense of worth and their subsequent social behaviour (Gilbert, Pehl, & Allan, 1994).

There is currently only one study that has investigated the impact of compassion-focused approaches with a visibly different population. Kelly, Zuroff and Shapira (2009) randomised individuals with acne to either self-soothing condition; attack-resisting condition or waiting list control. The interventions used imagery-based self-talk and letter writing. The two week intervention lowered shame and skin complaints in the self-soothing arm of the study. While the attack-resisting intervention lowered depression, shame and skin complaints. The interventions contained a number of ‘active’ ingredients; it was therefore unclear which aspects of the programme were the most effective. There was also no measure of the acceptability of the intervention and absence of measures that directly tapped into people’s abilities to self-soothe or resist self-attacks.

The Present Study

Guidelines for the treatment of psoriasis (NICE, 2012) acknowledge the psychological impact of the condition. However, treatment is largely focused on biomedical approaches aiming to restore or normalise appearance, through camouflage as an example. The present study sought to develop self-help interventions based on CMT that aim to support psychological acceptance of the condition with outcomes focused on external shame, which is the extent to which individuals are preoccupied with perceived negative beliefs from others.

The literature within disfigurement suggests that shame-proneness is an important predictor of distress (Jobling, 1976), and is associated with stigmatisation (Kent & Thompson, 2002). The study explored external shame as the primary outcome and outcomes associated with external shame, namely self-criticism. The latter will specifically explore any reductions in criticism focused on self-hatred but also changes in the ability to reassure and support oneself. Finally, the study is interested in the impact of the self-help interventions on quality of life (QoL) specific to living with a skin condition. The two self-help interventions developed for the trial were components of CMT. The first, compassionate self-help is designed to strengthen compassionate qualities. Mindfulness self-help will focus on cultivating a soothing-breathing rhythm.

The first stage of the study developed the interventions containing both written and audio components. The second stage investigated the feasibility of recruiting and engaging a community-based psoriasis sample with the interventions, delivered remotely over the internet and accessed over a four week period. The study aimed to estimate sample size to inform future studies that are powered accordingly. Thirdly, the study evaluated the acceptability of the interventions and investigated follow-up rates and adherence to the intervention protocol. Fourthly, the study sought preliminary outcome data on the psychological effects following use of the interventions, with particular focus on shame, self-attack and quality of life. Finally, the study considered methodological implications in order to consider the viability of a full-scale RCT to investigate the effectiveness of compassion-focused self-help with a psoriasis sample. It was hypothesised that self-help will reduce shame and self-hate, improve self-reassuring abilities and lower the impact of psoriasis on QoL.

Method

Design

The study was a parallel-group randomised controlled feasibility trial evaluating the acceptability, use and effectiveness of self-help interventions accessed via email, by a community psoriasis sample. An independent samples repeated measures design was employed in which participants were randomly assigned to treatment condition. The study contained two independent variables; one between-subjects variable with two levels, treatment condition (compassionate self-help vs. mindfulness self-help) and one within-subjects variable with two levels (pre-intervention, time one; post-intervention, time two). The dependent variables were shame, forms of self-criticism; self-hate and self-reassurance, and dermatology specific QoL.

The two interventions drew on Gilbert's (2010) compassion-focused therapy. Group A were provided with an intervention that aimed to develop a compassionate stance towards the self through a compassionate self-imagery technique. Group B received an intervention that focused on mindfulness, with a soothing-breathing technique.

Power

The existing evidence base offers effect sizes for self-help compared with therapist directed interventions. As the current study contained two self-help interventions there was insufficient evidence to calculate the sample size. One of the study aims was to estimate the sample size for compassion-focused self-help within psoriasis, which will determine the feasibility of future well powered studies. Given that the current self-help interventions are components of a single therapy, small effect sizes were expected. The study therefore aimed to recruit as many participants as possible within the limited time frame.

Participants

The current study was conducted between September 2011 and April 2012. An advert (see Appendix C) was placed in three web-based psoriasis organisations; The Psoriasis Association, Psoriasis Help Organisation and Living with Psoriatic Arthritis and the University of Sheffield mailing list. The study sought adults over 16 years who self-reported a diagnosis by a General Practitioner or Dermatologist. The inclusion criteria also included self-reported emotional distress (e.g. experiences of low mood, low self-esteem and anxiety). Participants were excluded if they were actively engaging in another psychological treatment or if they had done so 6 months prior to being invited to participate in the study. Individuals prescribed psychotropic medication were not excluded.

Participant Characteristics

A total of 170 individuals made contact seeking further information, with 28 declining to participate. Of 142 participants who provided consent and completed the eligibility questions, 12 did not meet the eligibility criteria. The final sample was made up of 130 participants (87 females, 43 males). The sample's ethnic background was predominantly "White" (85%). Individuals from minority ethnic backgrounds are underrepresented in research conducted with psoriasis populations with 15% being a respectable proportion. On trial entry 57% were aged between 36-65 years and 43% were aged between 16-35 years. A high proportion of the sample had college or higher university or post-graduation qualifications (86%). The majority of study completers were recruited from the Psoriasis Association (80%), followed by the University of Sheffield volunteer email list (16%), Psoriasis Help Organisation forum (3%) and Psoriatic Arthritis forum (1%). Self-reported psoriasis severity was collected on a 0-9 scale (0 not severe, 9 very severe); 79% of the sample reported a severity rating between 5 and 9 on trial entry.

Measures

The study's key outcome variable was external shame. This was measured by the Other as Shamer Scale (OAS; Allan, Gilbert, & Goss, 1994). This scale measures negative beliefs that individuals hold about how other people perceive them. The scale consists of 18 items rated on a five-point scale (0 = Never, to 4 = Almost always). Respondents reflect on statements such as 'I think that other people look down on me' or 'other people look at my faults'. The scale has high internal consistency with a Cronbach's alpha of 0.92 (see Appendix D.1).

The Forms of Self-criticising, Attacking and Self-reassuring Scale (FSCRS) was utilised to measure participants' critical and reassuring self-evaluative responses. The scale was developed by Gilbert, Clarke, Hempel, Miles, and Irons (2004). The scale contains 22 items that make up three components; inadequate self, hated-self and reassured-self. The current study was particularly interested in 'hated self'; focusing on a sense of disgust and anger with the self and reassured-self; focusing on how self-reassuring or supportive individuals are to themselves when things go wrong in their life. The responses are given on a 5-point Likert scale (0 = not at all like me, to 4 = extremely like me). The Cronbach alpha value for hated-self and reassured-self was respectively 0.86 (see Appendix D.2).

The Dermatology Life Quality Index (DLQI; Finley & Khan, 1994) is a widely used measure of quality of life within dermatology research. It was chosen as a measure of the extent to which the dermatological condition, in this case psoriasis, impacts on global areas of functioning. These areas include symptoms, daily activity, leisure, work and education, personal relationships and impact of physical treatment. The responses are on a 4-point likert scale (3= very much, to 0 not at all/ not relevant). The Cronbach alpha value was 0.78-0.79. The test re-test reliability score was consistent and high (0.99). Published bandings of scores indicate a score between 0-1=no effect on patients life, 2-5=small effect, 6-10=moderate effect, 11-20= very large effect and 21-30=extremely large effect (see Appendix D.3).

Following the end of the intervention period, participants also completed a self-help evaluation measure (see Appendix D.4). This explored compliance with the intervention and its acceptability and usefulness. As the study was entirely web-based, an online survey programme, 'Smart Survey' (smartsurvey.co.uk) was used for data collection. This programme was encrypted and password protected, with access restricted to the lead researcher. Unique identifying numbers (11001, 11002 etc...) were used to track participants through the study alongside email addresses supplied.

Intervention Development

Development of the self-help interventions involved a number of stages. Firstly, the materials were written by the lead researcher and Dr Andrew Thompson, which were subsequently sent to an expert clinician, Professor Paul Gilbert. Service user feedback on the usability of the draft interventions was also sought from the Psoriasis Association (UK) board of trustees. Feedback on terminology, particularly of the word 'shame' led to revisions to place emphasis on positive adjustment. Overall, the Psoriasis Association reported that the materials were understandable and appeared useful although there was concern that the delivery might be perceived as impersonal. Consequently access to guided audio instruction was introduced as a way to make the interventions less impersonal and more accessible. Once this process was finalised the lead researcher, recorded the audio techniques and converted them into MP3 files.

The final self-help interventions each comprised written materials (see Appendix E.1 and E.2[2]) and an audio MP3. The written materials followed a four step format. Step 1 introduced the rationale to either developing a skill in compassionate self-soothing (Group A) or to developing a skill in mindfulness soothing breathing (Group B). Step 2 for both groups explored ways to prepare for practise and overcome barriers such as a ‘wondering mind’ or time constraints. Step 3 contained a script for the respective techniques: Group A self-help contained a technique to develop compassionate self-imagery, while Group B self-help contained a technique to develop mindful soothing-breathing. The accompanying MP3s contained the respective technique. Finally, step 4 invited both groups to put together a plan to practise.

The goal planner used in step 4 was based on implementation intention theory. Implementation intentions are specific plans of action, which specify exactly where and how to act in future situations (Gollwitzer & Schaal, 1998). In a meta-analysis of 94 studies, implementation intentions had a medium-to-large effect on achievement of intended goals (Gollwitzer & Sheeran, 2006). A study investigating self-help augmented through implementation intentions, showed enhanced self-help to be more effective than standard self-help (Varley, Webb, & Sheeran, 2011). An implementation intention was therefore embedded within both self-help interventions to enhance use of materials.

Procedure

Following email requests for further study information from potential participants, the researcher sent an individualised hyperlink to the survey (See Appendix F). This contained the study information sheets, consent form and time one (T1) measures. Participants were not able to access the rest of the link unless they

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[2] Appendix E has been removed to protect copyright

completed the consent page, which followed the information sheets. The survey had in-built eligibility screening, with ineligible participants receiving a clear statement informing them of this and guiding them to contact their G.P. should they require further support. Eligible participants went on to access the demographic questionnaire and T1 measures.

A randomisation schedule with two conditions was developed and held by an independent statistical consultant. On receiving confirmation of an eligible participant, the researcher alerted the randomiser who then allocated to a group. Following allocation, the researcher sent a standard email informing the participant of the self-help instructions, study length and follow-up protocol. The email included the respective self-help intervention as an attachment. The email asked participants to read the self-help written material fully before accessing the MP3 technique, participants were also encouraged to use the materials as often as they could.

At time two (T2; four weeks later) participants were sent a follow up email with a second hyperlink to the survey website to complete the end of intervention measures, this included an evaluation questionnaire. If necessary, participants were prompted twice by email to complete the T2 survey. Overall, each survey took 10-15 minutes to navigate and complete. The surveys were designed to be easy to read with straightforward navigation, largely using single button responses. The flow chart presented in Figure 1 reports the participant flow through the study from enrolment through to analysis.

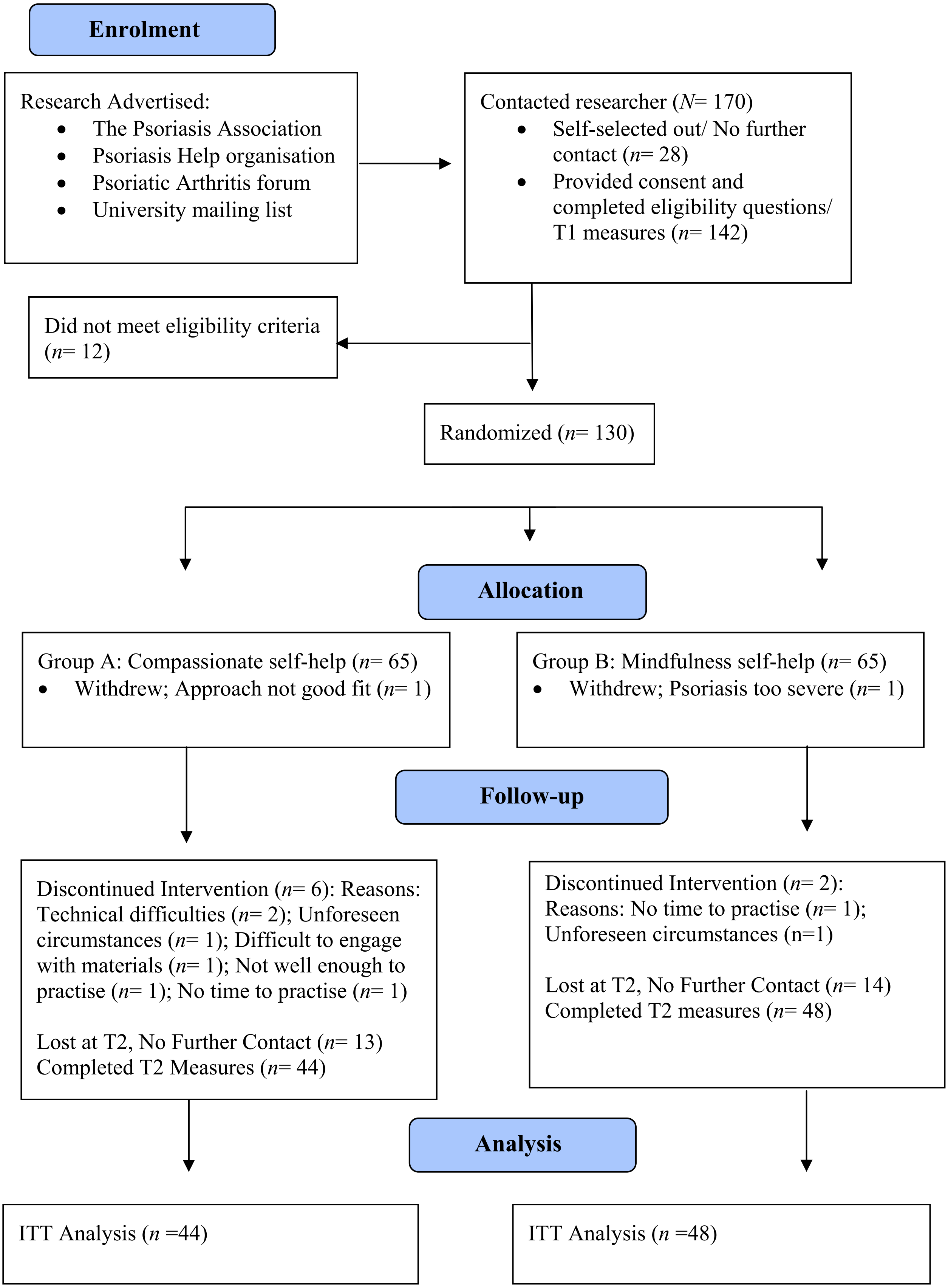

Figure 1. CONSORT diagram of participant flow through the key stages of the study.

Adapted from Schulz, Altman, & Moher (2010).

Ethical Considerations

Ethical review was undertaken by The Department of Psychology, University of Sheffield Ethics Committee (see Appendix A.1 – A.3). Participation with the study was voluntary with rights to withdrawal being clear. The information sheet detailed advantages and disadvantages of participation and provided a named contact for queries. Participants were also provided with advice relating to any distress caused either by survey completion or through use of the interventions. Adverse incident and complaint forms were also available on request as was the copy of results following the end of the study. Independent data monitoring was provided by the Chair of Department of Psychology Ethics Sub-Committee. This study adhered to the University's clinical trials guidelines. Three months after the study went 'live' an initial progress report was submitted. There were no direct untoward effects reported by this point or at the end of the trial. The study's design, conduct and analyses were guided by the CONSORT Statement (Schulz, Altman, & Moher, 2010).

Data Analysis

The data underwent intention to treat (ITT) analysis using the last observation carried forward method ($N = 130$) followed by completer analysis ($N = 92$). The data were analysed through the following distinct stages using SPSS (version 19). The alpha level was set at .05 for all statistical tests.

Assumptions Testing

Data were screened for normality and linearity using visual inspection of boxplots, histograms and normal probability plots (Normal Q-Q plots). As the study did not have a large sample (200+) the Shapiro-Wilk test of normality was used to further assess normality. These combined methods helped determine whether parametric testing was appropriate.

Screening for "Caseness"

The data were screened for the proportion of the sample with clinical levels of distress as measured by the DLQI. Higher scores on the OAS indicate higher levels of external shame. Higher scores on 'hated-self' indicate higher disgust and anger with the self. Higher scores on reassured-self indicate increased ability to reassure/support the self.

Randomisation and Representativeness checks

Randomisation checks were carried out using the Chi-square test for categorical demographical variables and an Independent Samples t-test for the one continuous demographic variable (psoriasis severity). To investigate the success of randomisation of the continuous variables (as measured by OAS, FSCRS and the DLQI), a Multivariate Analysis of Variance (MANOVA) was performed. A comparison of study completers and non-completers on T1 measures was conducted through a MANOVA.

Descriptive Statistics

Descriptive statistics were computed for participants that completed both T1 and T2 measures. The means and standard deviations for participants allocated to compassion self-help and mindfulness self-help were computed.

Areas of gain on DLQI

The DLQI has items relating to six areas of functioning: symptoms and feelings, daily activity, leisure, work and school, personal relationships and treatment. Pre and post scores for each participant were recorded for each of the sub-headings. Scores were subsequently screened for the direction of the scores at T2 relative to T1, noting whether scores had improved, deteriorated or remained unchanged. These scores were converted into treatment group percentages to evaluate the areas on the DLQI that showed the most gain following the introduction of the interventions.

Effects of interventions on shame, self-hate, self-reassuring and QoL

A two-way mixed Analysis of Variance (ANOVA); 2-between (group: compassionate self-help versus mindfulness self-help) by 2-within (time: T1 versus T2) was conducted for each measure to explore main effects for treatment group and time. This test allowed for exploration of interaction effects between group and time. Non-parametric tests- the Wilcoxon Signed-rank test and Mann-Whitney U tests -were conducted for data violating normality assumptions.

Effect size

Pre-post effect sizes were calculated using $\text{Mean}_{\text{start}} - \text{Mean}_{\text{end}}/\text{SD}_{\text{start}}$ (Cavanagh et al., 2006) for both ITT ($N = 130$) and completer participants ($N = 92$).

Evaluation of Acceptability & Usability of self-help

The evaluation questionnaire responses relating to different aspects of using the self-help materials will be converted to percentages. Chi-square tests were used to explore differences between treatment groups with the data transformed into two categories (Agree vs. Unsure/disagree).

Results

At T1, 130 participants were randomised into a group, however only 92 participants completed T2 measures. The attrition rate for this study was high at just under 30%.

Assumptions Testing

Inspection of histograms and boxplots supported normality for the OAS and the DLQI at T1. This was confirmed with insignificant results from the Shapiro-Wilk test (see Table 1). Histograms for the subscales of interest on the FSCRS, hated-self and reassured-self, indicated violation of the assumption of normality. This was confirmed with significant results from the Shapiro-Wilk test. Table 1 reveals the means, standard deviations, and significance values for the normality test for the standard measures at T1 (*N* = 130) and T2 (*N* = 92).

Table 1

Summary of Means, SD and Normality Testing for Continuous Variables at T1 and T2

Variable	Mean	SD	Shapiro-Wilk test	Associated p-value
OAS (T1)	29.88	13.04	.99	.322
DLQI (T1)	14.44	6.94	.98	.096
FSCRS				
Hated self (T1)	5.93	4.63	.94	.000*
Reassured self (T1)	15.14	6.33	.96	.001*
OAS (T2)	24.65	13.78	.97	.049*
DLQI (T2)	9.43	7.02	.89	.000*
FSCRS				
Hated self (T2)	4.83	4.85	.86	.000*
Reassure self (T2)	18.02	6.94	.98	.269

Note. * p < .05

The continuous scores at T2, except reassured-self violated normality testing (see Table 1). However, inspection of histograms revealed the OAS shame measure to have a reasonable normal distribution with one outlier. It is expected that following the introduction of an intervention, the clustering of scores would be positively skewed to the left (lower values). It was deemed legitimate to use parametric statistics to analyse the effect of the intervention for all of the dependent variables except FSCRS owing to violations at T1 and T2.

Screening for 'Caseness'

In developing the OAS, Goss et al. (1994) recruited 152 students (76% female), reported a mean of 20.0 and standard deviation of 10.1. In the present study the sample OAS mean on trial entry was 28.62 (*SD* = 13.71) indicating a level of shame higher than a general population of undergraduate students. On the DLQI, low scores demonstrate lower impact of the skin condition on QoL. At T1, 90% of study completers reported that psoriasis had a moderate to extremely large effect on their QoL (score of 6+).

Randomisation Checks

At T1, 130 participants were randomised into either the compassionate ($n = 65$) or mindfulness treatment group ($n = 65$). Assumptions testing revealed that the data conformed and was suitable for the analysis. A MANOVA was conducted to compare the treatment groups on the standard measures for: shame, hated-self, reassured-self and QoL. The MANOVA test was not significant, Pillai's Trace = .03, $F(4,125) = 0.81$, $p = .523$, $\eta_p^2 = .03$. This result indicates that the treatment groups were equally matched. However, conducting an Independent Samples T-test indicated that self-reported psoriasis severity was significantly higher for the compassion group ($M = 6.55$, $SD = 1.76$) than for the mindfulness group ($M = 5.91$, $SD = 1.95$); $t(128) = 1.98$, $p = 0.05$.

Further randomisation checks were carried out on categorical demographic variables using Chi-square tests. The percentage of participants that were prescribed anti-depressant medication was 10% in the mindfulness group and 4% in the compassion group. A Chi-square test indicated that the relationship between treatment condition and use anti-depressant medication was significant, χ^2 (1, N = 130) = 3.16, p = .042. Table 2 presents percentages of demographic characteristics of the sample at T1 with Chi-square test. This demonstrated no significant differences between the groups on the demographic variables.

Table 2

Demographic Characteristics by Treatment Groups at T1

Variable	Compassion (%)	Mindfulness (%)	Chi-square *p*
Gender			
Female	40 (31)	47 (36)	
Male	25 (19)	18 (14)	.192
Age			
16-25	14 (11)	6 (5)	
26-35	19 (15)	17 (13)	
36-45	18 (14)	17 (13)	
46-55	8 (6)	16 (12)	
56-66	6 (5)	9 (6)	.158
Ethnicity			
White	56 (43)	54 (42)	
Black, Asian & Mixed	9 (7)	11 (8)	.627
Education			
Secondary	9 (7)	9 (7)	
Higher college	19 (14)	18 (14)	
University/ Post-grad	37 (29)	38 (29)	.980
Accessing emotional support	57 (44)	54 (42)	.456
Co-morbid health condition	12 (9)	12 (9)	1.0
Co-morbid psychological	16 (12)	16 (12)	1.0
Psoriatic Arthritis	12 (9)	17 (13)	.292
Anti-depressant medication	5 (4)	13 (10)	.042

Note. Compassion, *n*=65; Mindfulness, *n*=65

Representativeness check

A representativeness check was conducted for each measure at T1 to compare participants that completed both waves of data collection; completers (*n* = 92) with participants who only completed T1 measures; non-completers (*n* = 38). A MANOVA performed to test differences between completers and non-completers on the outcomes of interest was not significant, Pillai's Trace = .06, $F(4,125) = 2.09$, $p = .086$, $\eta_p^2 = .06$. It can be concluded that study completers represented the population from which they were drawn.

Descriptive statistics

Table 3 presents the group means and standard deviations for the OAS, FSCRS; hated-self, reassured-self, and the DLQI at T1 and T2 (*N*= 92).

Table 3

Mean (SD) OAS, FSCRS and DLQI for Treatment Groups at T1 and T2

	Compassion group (*n*=44)		Mindfulness group (*n*=48)	
Measure	T1	T2	T1	T2
OAS	27.98 (13.46)	23.75 (12.85)	29.21 (14.5)	25.48 (14.67)
DLQI	13.73 (7.09)	8.93 (6.80)	13.79 (6.74)	9.90 (7.24)
FSCRS				
Hated Self	5.80 (4.69)	4.77 (4.80)	5.75 (4.97)	4.87 (4.50)
Reassure self	15.34 (7.06)	17.43 (7.29)	16.42 (6.53)	18.56 (6.64)

Note. OAS, Other as Shamer; FSCRS, Forms of Self-criticising, Attacking and Self-reassuring Scale; DLQI, Dermatology Life Quality Index.

Areas of Gain on QoL

DLQI items relating to symptoms and managing feelings showed most improvement in scores, which was followed by items relating to daily activity. Items relating to personal relationships, work and school and treatment of the skin condition showed overall lower improvement. Table 4 shows the direction of scores at T2 relative to T1 as converted into percentages for each treatment group.

Table 4

Percentage of gain and deterioration on sub-headings of the DLQI

	Compassion (*n* = 44)	Mindfulness (*n* = 48)
Symptoms and feelings		
Improved	70	56
Deteriorated	23	13
Unchanged	7	31
Daily activity		
Improved	59	54
Deteriorated	14	17
Unchanged	27	29
Leisure		
Improved	57	46
Deteriorated	7	17
Unchanged	36	37
Work and school		
Improved	41	42
Deteriorated	11	6
Unchanged	48	52
Personal relationships		
Improved	39	42
Deteriorated	9	20
Unchanged	52	38
Treatment		
Improved	36	29
Deteriorated	9	13
Unchanged	55	58

ITT Effects of Interventions on Shame

A two-way mixed ANOVA was conducted to assess the impact of the two treatment groups (compassion versus mindfulness) on participants' shame scores (measured by OAS), across two time points (T1 and T2). The effect of time was significant, Wilks' Lambda = .87, $F(1,128) = 19.65$, $p < .001$, $\eta_p^2 = .133$, with both groups showing reductions on level of shame from T1 ($M = 29.88$, $SD =13.04$) to T2 ($M = 27.07$, $SD = 13.49$). The main effect of group was not significant, $F(1,128) = .72$, $p = .398$, $\eta_p^2 = .006$, indicating no difference in the effectiveness of the two treatment groups in reducing shame. There was no significant interaction between group and time, Wilks' Lambda = 1.0, $F(1,128) = 19.65$, $p = .932$, $\eta_p^2 = .000$, indicating the rate of reduction in shame scores over time was the same for the two randomised groups.

ITT Effects of Interventions on Quality of Life

A two-way mixed ANOVA was conducted to assess the impact of the two treatment groups (compassion versus mindfulness) on participants' QoL scores as measured by the DLQI, across two time points (T1 and T2). The effect of time was significant, Wilks' Lambda = .76, $F(1,128) = 40.71$, $p < .001$, $\eta_p^2 = .241$. The DLQI scores reduced over time, which meant psoriasis was having a reduced impact on QoL (T1; $M = 14.44$, $SD = 6.94$ to T2, $M = 11.38$, $SD = 7.59$). The main effect of group was not significant, $F(1,128) = .03$, $p = .866$, $\eta_p^2 = .000$, indicating no difference in the effectiveness of the two treatment groups in improving QoL. There was no significant interaction between group and time, Wilks' Lambda = 1.0, $F(1,128) = .15$, $p = .701$, $\eta_p^2 = .001$, indicating the rate of improvement in QoL over time was the same for the two groups.

ITT Effects of Interventions on Hated-self and Reassured-self

T1 and T2 scores on the subscales of the FSCRS violated normality assumptions. The Wilcoxon Signed-rank test was conducted to investigate whether there was a significant change within the treatment groups between T1 and T2 on forms of self-criticism (hated-self subscale) and ability to reassure (reassured-self subscale). The results for the compassion group revealed a significant difference between T1 and T2 hated-self; T1 (*Mdn* = 6) to T2 (*Mdn* = 4), $Z = -2.21$, $p = .027$, as was the result for reassured-self; T1 (*Mdn* = 13) to T2 (*Mdn* = 16), $Z = -2.45$, $p = .014$. The Wilcoxon Signed-rank Test for the mindfulness group revealed a significant difference between T1 and T2 hated-self; T1 (*Mdn* = 5) to T2 (*Mdn* = 4), $Z = -2.01$, $p = .044$, as was the result for reassured-self; T1 (*Mdn* = 15) to T2 (*Mdn* = 17), $Z = -3.51$, $p < .001$. This suggests that both self-help interventions improved participants' ability to self-reassure and reduced self-hate.

Mann-Whitney U tests were conducted to examine group differences on forms of self-criticism as measured by the FSCRS. No significant differences were found between the treatment groups on scores for hated-self, $U = 2111.50$, $p = .996$. Similarly, no significant differences were found between the treatment groups on scores for reassured-self, $U = 1964$, $p = .489$. This does not support the hypothesis that compassionate self-help would be more effective than mindfulness self-help at reducing self-attack or strengthening self-reassuring capacities.

Completer Analysis

Repeating the analysis for study completers ($N = 92$) for the effects of the interventions on shame, self-attack and QoL, yielded the same outcomes as the ITT analysis. As in ITT, the only significant effects were for time. Both treatment groups showed statistically significant change from T1 to T2 on all measures of interest.

Effect Size

Pre-post effect sizes were calculated for both ITT (*N* = 130) and for completer participants (*N* = 92) and split by the respective treatment groups. Overall, small effect sizes were found on the main outcome of interest (shame), see Table 5. The effects were marginally larger for study completers on all outcomes. Overall, larger effects of change were observed on QoL for both treatments with small to medium effect sizes on the DLQI.

Table 5

Pre-post effect sizes for self-help groups by ITT and completer analysis

	Mean Intake	Mean End	Mean Difference	SD Intake	Cohen's *d*
Compassion ITT (*n* = 65)					
Shame	28.95	26.09	2.86	12.66	.23
DLQI	14.63	11.38	3.25	7.19	.45
Hated self	5.95	5.26	0.69	4.64	.15
Reassured self	14.78	16.20	1.42	6.57	.22
Mindfulness ITT (*n* = 65)					
Shame	30.80	28.05	2.75	13.45	.20
DLQI	14.25	11.37	2.88	6.73	.43
Hated self	5.91	5.26	0.65	4.66	.14
Reassure self	15.49	17.08	1.59	6.11	.26
Compassion Completer (*n* = 44)					
Shame	27.98	23.75	4.23	13.46	.31
DLQI	13.73	8.93	4.8	7.09	.68
Hated self	5.80	4.77	1.03	4.69	.22
Reassured self	15.34	17.43	2.09	7.06	.30
Mindfulness Completer (*n* = 48)					
Shame	29.21	25.48	3.73	14.05	.27
DLQI	13.79	9.90	3.89	6.74	.58
Hated self	5.75	4.87	0.88	4.97	.18
Reassure self	16.42	18.56	2.14	6.53	.33

Investigating User Feedback

Questionnaire feedback on the usefulness and usability of the self-help materials revealed similar group experiences. Table 6 reports feedback regarding acceptability of the materials. There was high agreement that the audio techniques were ‘easy to follow’: compassion, 86%; mindfulness 96%. The groups reported agreement that the treatment aims were clear, in particular that it was ‘understood’ how the respective technique would help manage difficult feelings: compassion, 76%; mindfulness, 79%.

Table 6

Group Percentages for Acceptability of Self-help Materials

	Written material understandable		Audio easily followed		Understand treatment aims	
	Group A	Group B	Group A	Group B	Group A	Group B
Strongly/Agree	98	94	86	96	76	79
Unsure	2	6	7	2	19	13
Strongly/Disagree	0	0	7	2	4	8

Note. Group A, Compassion (*n*=44); Group B, Mindfulness (*n*=48)

There was high agreement about the helpfulness of the information specific to the respective technique (Table 7), compassion, 74%; mindfulness, 88%. A Chi-square test indicated that the percentage that found information helpful did not differ by treatment condition, χ^2 (1, *N* = 92) = 1.92, *p* =.166. The goal planner was not perceived as an overwhelmingly useful tool; 45% of the compassion group and 54% of the mindfulness group were either unsure or disagreed that it was useful. The percentage of participants that reported that their goal planner helped them use the technique did not differ by treatment condition, χ^2 (1, *N* = 92) =.40, *p* =.526. Chi-square tests could not be conducted for the other variables as they each violated assumptions relating to minimum expected cell frequency'. Finally, the perceived usefulness of the audio exercise was at 62% for the compassion group and 60% for the mindfulness group.

Table 7

Group Percentages for Usefulness of Self-help Materials

	Technique information helpful		Audio exercise effective		Goal planner useful	
	Group A	Group B	Group A	Group B	Group A	Group B
Strongly/Agree	74	88	62	60	55	46
Unsure	19	13	29	25	36	29
Strongly/Disagree	7	0	2	4	9	25

Note. Group A, compassion (*n*=44); Group B, Mindfulness (*n*=48)

The evaluation questionnaire collected data on the pattern of use of the self-help materials. Converting the responses into percentages revealed wide variation in the way participants used the materials, both within and between the groups. Participants were more likely to have used the audio than read the materials; daily audio use was 52% and 63% for the compassion and mindfulness groups respectively, while reading the materials was at 21% and 24%. The most interesting finding was the high percentage of participants that did not use the goal planner: compassion, 26%; mindfulness, 42%. The goal planner was intended to enhance use of the materials, which did not appear to be successful within the current study.

Discussion

This feasibility study suggested that self-help interventions drawn from CMT have clinical relevance and are welcomed by a community psoriasis sample. The perceived usefulness and acceptability of the interventions were examined at T2 through an evaluation questionnaire. Data available for 70% of the randomised sample showed that between 60% and 80% found the materials helpful and effective; this was a similar finding for both treatment groups. The study completers also reported high acceptability of the presentation of the materials and the concepts specific to the techniques. Between 86% and 98% study completers reported the language and flow to be acceptable. The feedback was again similar for both groups. Data exploring the frequency of use saw wide variations. Overall the participants were more likely to use the audio than the written materials. This suggests that future development of simple self-help should utilise a range of methods of delivery.

The most startling finding was that both groups used the goal planner sporadically. Furthermore, approximately half the participants from each group reported that they were either unsure of the usefulness of the goal planner or did not find it useful at all. This is contrary to research that has found implementation intentions to promote compliance in a number of behavioural domains (Gollwitzer & Sheeran, 2006). The current study did not intend to empirically test the use of implementation intentions. The goal planner was embedded in the materials to enhance use of self-help for both groups. The use of implementation intentions in self-help is in its infancy with one study reporting effects (Varley et al., 2011) and requires further investigation.

Attrition & Sample Size Estimation

This study demonstrated a respectable rate of recruitment over a nine month period. However, attrition was high at just under 30%. Participants that withdrew (*n*=11) cited unforeseen circumstances, poor health, or difficulties with finding the time to practise. A further 27 participants were lost at follow-up. A comparison between study completers and non-completers did not reveal significant differences on the main outcomes of interest. The attrition rate was also similar to attrition reported by Newell and Clarke (2000) who investigated a cognitive-behavioural self-help leaflet with individuals with disfigurements. The current study builds on existing evidence within dermatology with a respectable randomisation of 130 participants. As a whole, outcomes research within dermatology and disfigurement tends to be limited to small *N* trials. However, to conduct a full scale RCT taking into account the small effect sizes reported in this study, a sample size of 200 would be required, with an additional 30% to allow for loss at follow-up ($N = 260$).

In the present study, qualitative feedback from study completers highlighted intervention-specific limitations that may have further influenced attrition. Firstly, the audio techniques were perhaps too short at just under 10 minutes to allow participants to settle into a routine. The feedback also alluded to the painful and itchy nature of psoriasis and psoriatic flare-ups, which was distracting to some participants when using the techniques. Furthermore, the self-help literature has shown guided self-help to be far superior to standard self-help (Hirai & Clum, 2006). Participants in the present study used self-help independently with no additional facilitative support. It is reasonable to hypothesise that the lack of guidance through the use of the self-help materials may have contributed to the modest before and after group means. Guided self-help was beyond the scope of the present study, which would have been preferable to support continued engagement with the materials and potentially help to problem solve any barriers faced by participants.

Psychosocial outcome research within disfigurement has not incorporated minimal therapist involvement. The exceptions are nurse-led educational programmes for psoriasis, which focus on the management of physical symptoms and treatment adherence. A qualitative account highlighted user preference for one-to-one contact with a practitioner alongside information provided within a wider range of delivery formats including written and audio-visual presentation (Ersser, Cowdell, Latter, & Healy, 2010).

The literature for CMT also raises factors that may have contributed to loss at follow-up. Two pilot studies found that individuals that are highly self-critical may fear becoming self-compassionate; self-compassion in itself may be experienced as a weakness and something to be resisted. The authors also argued that self-critics may find it difficult to call on soothing memories, further blocking use of the techniques (Gilbert & Irons, 2005; Gilbert & Procter, 2006). Feedback from compassionate self-help participants supported difficulties with “feeling compassionate”. The lack of a warm facilitator may have prevented participants from addressing some of these barriers.

As in other therapies, the therapeutic relationship plays a key role in CMT. Gilbert and Procter (2006) discussed the value of a therapist as an external provider of caring and safety, believed to be fundamental to the development of self-compassionate capacities. It could be that the absence of an empathic and warm therapist impeded the compassionate self-help group. Recent developments within self-help research are in favour of written self-help materials to incorporate “common factors” that are pertinent to the therapeutic relationship to improve outcomes (Richards, Richardson, & Barkham, 2010). This is clearly a fundamental issue for all therapies delivered through the medium of self-help to consider in the development of stand-alone treatments. Future studies would benefit from replicating the study to compare guided CMT with a standard control.

Preliminary Outcomes

This is the first study to investigate the effects of two self-help interventions drawn from CMT with a psoriasis population. It was predicted that the interventions would lower levels of shame and self-criticism. Secondly, that the self-help interventions would reduce the extent to which QoL is impacted by psoriasis. Following the end of the intervention period, both treatment conditions showed modest yet statistically significant improvements as shown by the before and after group means on the outcomes measured. These improvements suggested that brief self-help interventions based on CMT have the potential to reduce psychosocial distress and improve dermatology specific QoL domains in psoriasis.

CMT targets internal self-to-self relating. When patients are in self-attacking mode, the ability to internally generate a warm and supportive signal is diminished. CMT does not seek to alter negative self-evaluations. Instead CMT teaches individuals to attend to the negative emotions themselves. Within the current study, the compassionate self-help condition aimed to stimulate and further strengthen inner compassionate abilities through imagery practise. The mindfulness self-help condition aimed to develop a mindful soothing-breathing skill. Participants were invited to focus their attention with curiosity, kindness and non-judgement when dealing with self-attacking thoughts and desires.

The small effect sizes reported and the lack of an interaction effect between group and time may have been attributable to the self-help interventions being components of a single therapeutic modality. In CMT, mindful soothing-breathing is used as a way to prepare one's mind for practise. Gilbert (2010) has reflected that mindfulness allows for the ability to reflect on one's mental states and cultivate a calm mind. It could be argued that paying attention to the present moment, whilst letting go of preoccupations about the past or future can in itself cultivate soothing through a ‘quieter mind’. Future RCTs would have to carefully consider the appropriateness of a chosen comparator. As the study evaluated two interventions that were components of a single intervention, it is reasonable that small effects were detected. Future studies may wish to evaluate each component separately with an additional group that receives both compassionate and mindful techniques. However, the small effect sizes reported within this study suggest that this would not be viable owing to the large samples required.

Clinical Implications

An overwhelming majority of study email enquiries made reference to unmet psychological needs, showing that the face validity of the study was high. What was of interest was the low number of participants that had previously accessed psychological support. Of the 142 individuals that completed T1 measures, 12 did not meet eligibility, only one was ineligible because they had accessed a psychological intervention within the previous six months. Provision for psychological support within dermatological departments is limited. Research has also reported on the stigma attached to referral to mental health services (Fortune, Richards, Main, O’Sullivan, & Griffiths, 1998).Current guidelines for psoriasis, whilst recognising the psychological impact of the condition, have not readily recommended psychological support.

The current study has identified that brief self-help interventions based on CMT can have some benefit in reducing psychosocial distress. Analysis of the movement of participant scores on sub-headings of the DLQI showed the most improvement to be within symptoms and feelings (70% for compassion and 56% for mindfulness). Items relating to this heading include how itchy, sore, painful or stinging their skin has been and item for how embarrassed or self-conscious the person has been because of their skin. The latter gives support existing theoretical and empirical evidence for the role of social anxiety and stigma. It also provides preliminary support for the role of CMT in supporting adjustment in self to self relating.

It can also meet some of the barriers to accessing psychological support. As the majority of people with psoriasis are treated by their G.P., there is scope for a low intensity self-help intervention to reach a wide audience in the community. The self-help intervention trialled in this study may be adapted and used as part of routine care. This is in line with Thompson's (2009) stepped care model for the delivery of psychosocial interventions within dermatology. The model promotes access to self-help, for all patients at the lowest and least intrusive step. Further research may explore the role of specialist dermatology nursing support to enhance use of the self-help materials. This approach would offer a cost-effective and least intrusive access.

Finally, there is a paucity of research evaluating psychotherapy within psoriasis. Studies that exist have largely focused on CBT, which targets patterns of unhelpful beliefs and their impact on mood and behaviour. CMT shifts the focus away from the content of patient cognitions and instead aims to stimulate particular affect systems to target high-order emotions such as shame and self-criticism (Gilbert & Procter, 2006). This study builds on the evidence-base by offering preliminary evidence for elements of CMT to support patients with psoriasis to manage psychological distress.

Limitations & Future Directions

The study has a number of methodological limitations that are worth further consideration. Recruiting and delivering the study over the internet, meant it was impossible to objectively verify a diagnosis of psoriasis. There was also a lack of an objective measure of psoriasis severity. However, research within visible difference supports the use of subjective severity ratings over objective measures, as the latter have not been found to be closely correlated with psoriasis severity (Ong et al., 2007).

It is also worth noting bias created by a self-selecting sample. The study may have only attracted individuals motivated to engage in the study due to higher levels of distress. Indeed, a high proportion scored above the threshold for clinical “caseness” on the DLQI. At T1, 90% reported psoriasis to have a moderate to extremely large impact on their quality of life. In addition, 79% of the sample reported high psoriasis severity ratings. The high levels of psychosocial distress raises the question of whether the brief self-help interventions were matched to the presenting levels of need. Furthermore, as the study sample was not drawn from a clinical population, it may limit the extent to which the outcomes may be generalised to a non-community population. The study can only draw meaningful conclusions about users of online support groups. The majority of the sample (80%) was recruited from the Psoriasis Association. These are individuals that are motivated to access resources through charities and online organisations. The sample as a whole was also highly educated. Further studies would benefit from replicating with a sample that includes a clinical sample.

There were also issues pertinent to the delivery and content of the self-help interventions. Due to study time constraints, the intervention period was only four weeks long with no additional follow-up period to measure longer-term effects. In addition, participants had to commence the intervention period immediately after providing consent. This may have contributed to participants dropping out of the study.

In addition, the study did not have the resources to conceal allocation or blind the researcher. Effort was made to reduce bias through independent randomisation and allocation. Furthermore, randomisation checks found no significant differences between the groups on the outcome variables or the demographic variables, with the exception of psoriasis severity, which was marginally higher for the compassion group.

To date, this is the only trial that has investigated shame in a psoriasis sample. The elevated levels of shame in the recruited sample lend support to models exploring the relationship between shame and disfigurement. The Appearance Research Collaboration (Rumsey et al., 2010) has emphasised the role of stigma, shame and social exclusion in adjustment to disfigurement. However, intake shame scores were not as severe as anticipated. It would be useful for further empirical research to establish the strength of the relationship between shame and psoriasis.

Conclusion

Given the limited evidence-base for psychological therapies for psoriasis, this study developed and evaluated the acceptability and effectiveness of two self-help interventions based on CMT. The study showed individuals with psoriasis to be willing to participate with compassion-focused online self-help. The interventions had high acceptability and were overwhelmingly perceived to be helpful. However, there was wide variation in the frequency and pattern of use. Attrition was also problematic, with the participation rate being at 70%. This alongside the small effect sizes reported, places the viability of conducting a full scale RCT in doubt given the numbers required to power the study accordingly (200+).

The present study did however provide evidence supporting brief self-help interventions based on CMT in lowering shame and self-attack. There were no significant differences between the two self-help interventions. Furthermore, despite recruiting a community sample, the level of distress as measured by dermatology QoL measure indicated a severely impacted sample. This builds on existing research which has investigated self-help with samples with mild psychosocial distress. While the preliminary data is encouraging, future studies would require a longer recruitment period and use of an appropriate intervention comparator.

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Section Three: APPENDICES

Appendix A

Appendix A.1 Ethics approval

University of Sheffield Mail - Fwd: Approval of your research proposal Page 1 of 1

The
University
Of
Sheffield.

Z Muftin <pcp09zm@sheffield.ac.uk>

Fwd: Approval of your research proposal

Andrew R Thompson <a.r.thompson@sheffield.ac.uk> 5 May 2011 12:49
To: Z Muftin <ZMuftin1@sheffield.ac.uk>, Helen McAteer <helen.mcateer@psoriasis-association.org.uk>, p.gilbert@derby.ac.uk

Dear Zina,

Good news we now have ethical approval to proceed - I only uploaded this a couple of days ago so its been reviewed extremely quickly!

There is still scope though to tweak the intervention but this is essentially very good news and I've copied Paul and Helen in to keep them updated.

Lets meet up after selection (next week).

BW

Andrew
---------- Forwarded message ----------
From: **research ethics application management system Psychology Research Ethics Application Management System** <no_reply@psychology>
Date: 4 May 2011 21:03
Subject: Approval of your research proposal
To: A.R.Thompson@sheffield.ac.uk

Your submission to the Department of Psychology Ethics Sub-Committee (DESC) entitled "A Randomised Controlled Trial Investigating the Effectiveness of Web-based Self-Help Compassion-focused Interventions for Psoriasis" has now been reviewed. The committee believed that your methods and procedures conformed to University and BPS Guidelines.

I am therefore pleased to inform you that the ethics of your research are approved. You may now commence the empirical work.

Yours sincerely,

Prof Paschal Sheeran

Chair, DESC

--

Dr. Andrew R Thompson
Reader in Clinical Psychology
Clinical Training Research Director
Clinical & Health Psychologist

Chartered with The British Psychological Society
Registered with The Health Professions Council
Clinical Psychology Unit
Department Of Psychology
University Of Sheffield
302 Western Bank
Sheffield

S10 2TN
+44(0)114 2226637
a.r.thompson@sheffield.ac.uk
http://www.shef.ac.uk/psychology/staff/academic/andrew-thompson.html

I work in Rotherham Foundation Trust on Wednesdays
New book on qualitative methods available:
http://eu.wiley.com/WileyCDA/WileyTitle/productCd-0470663707.html

https://mail.google.com/mail/u/0/h/1hg292k77ucex/?&v=pt&s=q&q=paschal+&msg=... 19/07/2012

Appendix A

Appendix A.2 First amendment-Psoriasis Health Organisation

University of Sheffield Mail - Fwd: Amendment to recruitment - A Randomised Contr... Page 1 of 2

Z Muftin <pcp09zm@sheffield.ac.uk>

Fwd: Amendment to recruitment - A Randomised Controlled Trial Investigating the Effectiveness of Web-based Self-Help Compassion-focused Interventions for Psoriasis (#200) - ethics application approved

Andrew R Thompson <a.r.thompson@sheffield.ac.uk> 1 September 2011 16:37
To: Z Muftin <ZMuftin1@sheffield.ac.uk>

---------- Forwarded message ----------
From: p.sheeran@sheffield.ac.uk <paschal.sheeran@googlemail.com>
Date: 1 September 2011 16:31
Subject: Re: Amendment to recruitment - A Randomised Controlled Trial Investigating the Effectiveness of Web-based Self-Help Compassion-focused Interventions for Psoriasis (#200) - ethics application approved
To: Andrew R Thompson <a.r.thompson@sheffield.ac.uk>

Dear Andrew,

The proposal involves a minor amendment - the inclusion of an additional self-help organisation - and does not alter the substance of the submission. As such, the amendment can be handled under Chair's Approval.

The ethics of the proposed changes are hereby approved.

Sincerely,

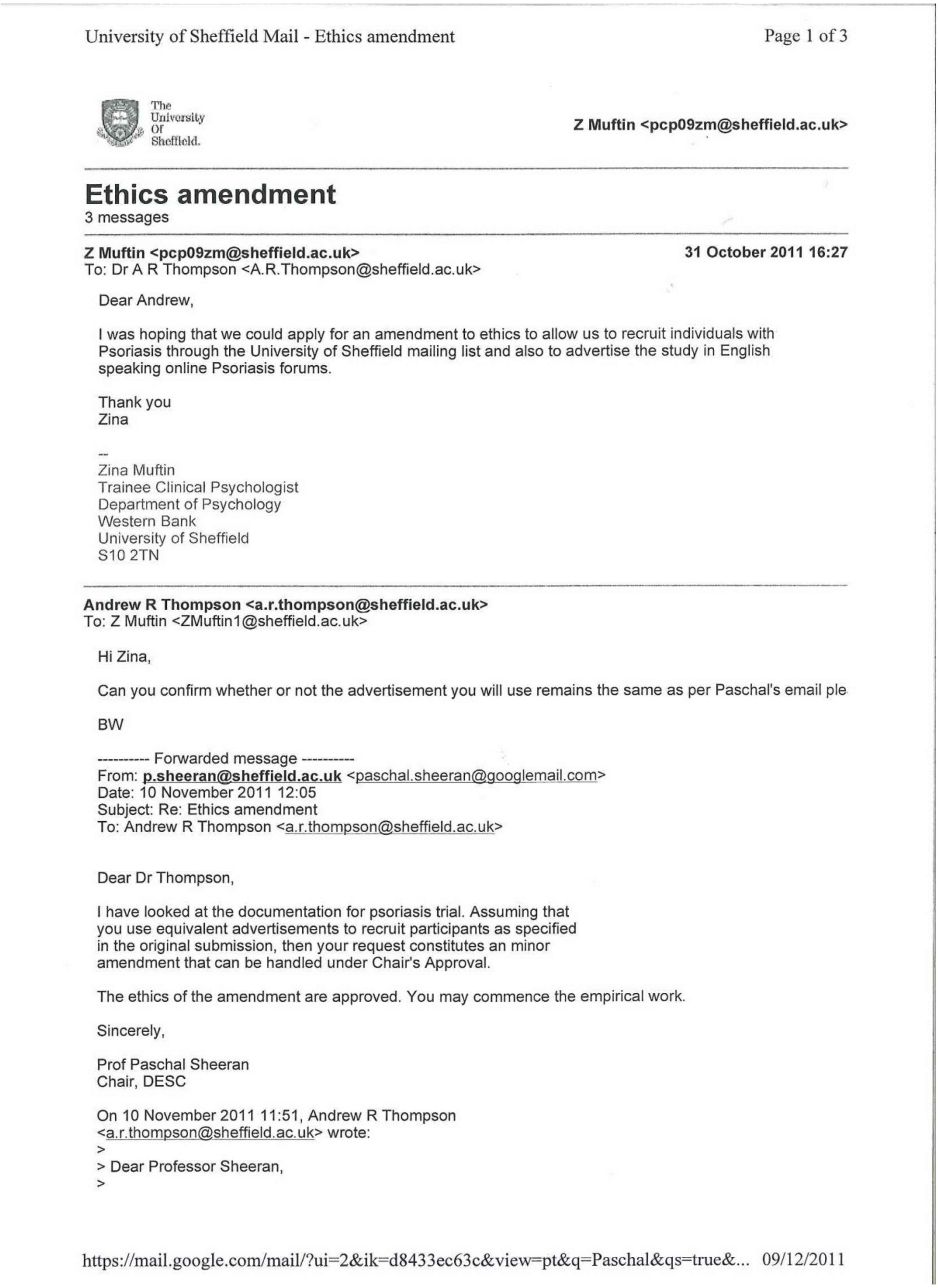
Prof Paschal Sheeran
Chair, DESC

On 1 September 2011 16:28, Andrew R Thompson
<a.r.thompson@sheffield.ac.uk> wrote:
>
>
> Dear Paschal,
>
> We'd like to seek an amendment to the above ethics application. This
> amendment simply is to extend recruitment out to another self help
> organisation - all methods of recruitment remain the same. The organisation
> is 'The Psoriasis Help Organisation' (PHO), they are a UK-based online group
> that offer support and advice for people with Psoriasis. We are already
> recruiting from The Psoriasis Association. PHO have an online forum where
> sufferers meet and upload different threads relating to the condition.
>
> We wish to recruit from this forum. As this is web-based it is likely that
> the participant characteristics will not be dissimilar to those already
> recruited.
>
> Do let me know if we need to upload another form.
>
> Best Wishes
>
> Andrew
>
>
> Dr. Andrew R Thompson
> Reader in Clinical Psychology
> Clinical Training Research Director
>
>
>
> Clinical Psychology Unit
> Department Of Psychology
> University Of Sheffield
> 302 Western Bank
> Sheffield
>
> S10 2TN
> +44(0)114 2226637
> a.r.thompson@sheffield.ac.uk
> http://www.shef.ac.uk/psychology/staff/academic/andrew-thompson.html
>
>
> I work in Rotherham Foundation Trust on Wednesdays
>
> New book on qualitative methods out now:

https://mail.google.com/mail/u/0/h/1hg292k77ucex/?&v=pt&s=q&q=paschal+&msg=... 19/07/2012

Appendix A

Appendix A.3 Second amendment-University voluntary list



The University Of Sheffield. **Z Muftin <pcp09zm@sheffield.ac.uk>**

Ethics amendment

3 messages

Z Muftin <pcp09zm@sheffield.ac.uk> **31 October 2011 16:27**
To: Dr A R Thompson <A.R.Thompson@sheffield.ac.uk>

Dear Andrew,

I was hoping that we could apply for an amendment to ethics to allow us to recruit individuals with Psoriasis through the University of Sheffield mailing list and also to advertise the study in English speaking online Psoriasis forums.

Thank you
Zina

--
Zina Muftin
Trainee Clinical Psychologist
Department of Psychology
Western Bank
University of Sheffield
S10 2TN

Andrew R Thompson <a.r.thompson@sheffield.ac.uk>
To: Z Muftin <ZMuftin1@sheffield.ac.uk>

Hi Zina,

Can you confirm whether or not the advertisement you will use remains the same as per Paschal's email ple

BW

---------- Forwarded message ----------
From: **p.sheeran@sheffield.ac.uk** <paschal.sheeran@googlemail.com>
Date: 10 November 2011 12:05
Subject: Re: Ethics amendment
To: Andrew R Thompson <a.r.thompson@sheffield.ac.uk>

Dear Dr Thompson,

I have looked at the documentation for psoriasis trial. Assuming that you use equivalent advertisements to recruit participants as specified in the original submission, then your request constitutes an minor amendment that can be handled under Chair's Approval.

The ethics of the amendment are approved. You may commence the empirical work.

Sincerely,

Prof Paschal Sheeran
Chair, DESC

On 10 November 2011 11:51, Andrew R Thompson
<a.r.thompson@sheffield.ac.uk> wrote:
>
> Dear Professor Sheeran,
>

Appendix B

Appendix B.1. Critical Appraisal for RCT & Quasi-Experimental Studies

Checklist item	**Response**	**Scoring**
Reporting		
1. Are the aims and objectives of the trial clearly described? *Did the trial address a clearly focused issue?*	Yes No	1 0
2. Are the characteristics of the participants included in the study made explicit? *Discussion of inclusion/exclusion*	Yes No	1 0
3. Are the main outcomes to be measured clearly described in the introduction or method section?	Yes No	1 0
4. Are the interventions of interest clearly described?	Yes No	1 0
5. Are the distributions of principal confounders in each group of subjects to be compared clearly described?	Yes No	1 0
6. Are the main findings of the study clearly described for the reader to be able to check the analyses and conclusions?	Yes No	1 0
7. Does the study provide estimates of the random variability in the data for the main outcomes? *The standard error, standard deviation or confidence intervals should be reported*	Yes No	1 0
8. Have actual probability values been reported (e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?	Yes No	1 0
9. Was there a discussion of any adverse events?	Yes No	1 0
External Validity		
10. Were the participants who were asked to take part representative from the entire population from which they were recruited? *The study must identify source population and describe how sample was selected (score 0 if unable to determine).*	Yes No	1 0
11. Were the subjects who were prepared to participate representative of the entire population from which they were recruited? *The proportion of those asked who agreed should be stated (score 0 if unable to determine).*	Yes No	1 0
Internal Validity- bias		
12. Was an attempt made to blind study subjects to the intervention they have received?	Yes No	1 0

13. Was an attempt made to blind those measuring the main outcomes of interest?	Yes No	1 0
14. Were the main outcome measures used accurate (valid and reliable)?	Yes No	1 0
15. Were the statistical tests used to assess the main outcomes appropriate?	Yes No	1 0
16. Was there a treatment effect? *Consider statistically significant effects and/ or clinical improvements*	Yes No	1 0
Internal validity- confounding		
17. Were study subjects randomised to intervention groups?	Yes No	1 0
18. Did the study employ intention to treat analysis?	Yes No	1 0
19. Were the intervention participants and/ or controls recruited over the same period of time? (Score 0 if unable to determine)	Yes No	1 0
20. Were the intervention and control participants comparable at baseline?	Yes No	1 0
21. Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%? (Score 0 if unable to determine)	Yes No	1 0
22. Were losses of participants to follow-up *the same across groups and were they compared? (if no loss score 1)*	Yes No	1 0
23. Was there a discussion of the acceptability of the intervention?	Yes No	1 0

Appendix B

Appendix B.2. Critical Appraisal Tool for Non-RCT Quantitative Studies

Checklist item		**Response**	**Scoring**
Reporting			
1.	Are the aims and objectives of the study clearly described?	Yes No	1 0
2.	Is the choice of study method appropriate?	Yes No	1 0
3.	Are the characteristics of the participants included in the study explicit?	Yes No	1 0
4.	Are the main outcomes to be measured clearly described in the introduction or method section?	Yes No	1 0
5.	Are the main findings of the study clearly described for the reader to be able to check the analyses and conclusions?	Yes No	1 0
6.	Have actual probability values been reported (e.g. 0.035 rather than <0.05) for the main outcomes except where the probability value is less than 0.001?	Yes No	1 0
7.	Were the conclusions justified based on the research findings	Yes No	1 0
External Validity			
8.	Were the participants who were asked to take part representative from the entire population from which they were recruited? *The study must identify source population and describe how sample was selected (score 0 if unable to determine).*	Yes No	1 0
9.	Were the subjects who were prepared to participate representative of the entire population from which they were recruited? *The proportion of those asked who agreed should be stated (score 0 if unable to determine).*	Yes No	1 0
Internal Validity- bias			
10.	Were the outcome measures used valid and reliable?	Yes No	1 0
11.	Were the statistical tests used to assess the main outcomes appropriate?	Yes No	1 0
Internal validity- confounding			
12.	Did the study have sufficient power to detect a clinically important effect where the probability value for a difference being due to chance is less than 5%? (score 0 if unable to determine)	Yes No	1 0
13.	Was there adequate adjustment for confounding factors in the analyses? *Should be answered no if known confounders were not taken into account or merely described but not analysed.*	Yes No	1 0

Appendix B

Appendix B.3. Critical Appraisal Tool for Qualitative Studies

Quality Criterion		**Response**	**Scoring**
1.	Were the aims clear? *Consider goals and relevance*	Yes No	1 0
2.	Was a qualitative method appropriate? *Did study seek to shed light on experience of participants?*	Yes No	1 0
3.	Did the research design address the research aims? *Was there clear rationale for research design?*	Yes No	1 0
4.	Was the recruitment strategy appropriate? *Explanation of how participants recruited/ discussion of drop-outs?*	Yes No	1 0
5.	Was the data collected in a way that addressed the research questions? *Was data collection method clear (e.g. focus group?) and justification of methods?*	Yes No	1 0
6.	Was there a discussion of researcher/participant relationship? *Did researcher examine own role and formulation of research questions?*	Yes No	1 0
7.	Were ethical issues considered? *Discussion of how research explained, impact on participants and how it was handled?*	Yes No	1 0
8.	Was the data analysis sufficiently rigorous? *Was there in-depth description of analysis and how data was selected?*	Yes No	1 0
9.	Were the findings clearly presented? *Were the findings balanced, undergone credibility checks (respondent validation/ multiple analysts) and related to research question?*	Yes No	1 0
10.	How valuable was the research? *Is there discussion of the contribution of research into existing knowledge?*	Yes No	1 0

Appendix C

Appendix C. Recruitment leaflet

Reducing feelings of stress and embarrassment associated with Psoriasis: Compassionate Visualisation and Mindful Relaxation Self-help trial (CVR-SH Study)

We would like to learn whether web-based self-help exercises in compassionate visualisation and relaxation can help people better manage emotional distress, particularly stress and embarrassment, associated with Psoriasis.

This project is sponsored by the University of Sheffield in collaboration with The Psoriasis Association and The Compassionate Mind Foundation[1]. If you would like to take part please email:

Zina Muftin on: Pcp09zm@sheffield.ac.uk

You will be sent a link with more information. If eligible, you will be able to access the self-help information and podcast online at your convenience. You will be asked to complete some questionnaires before and after using the self-help materials so we can explore whether the self-help is effective.

Thank you for your interest

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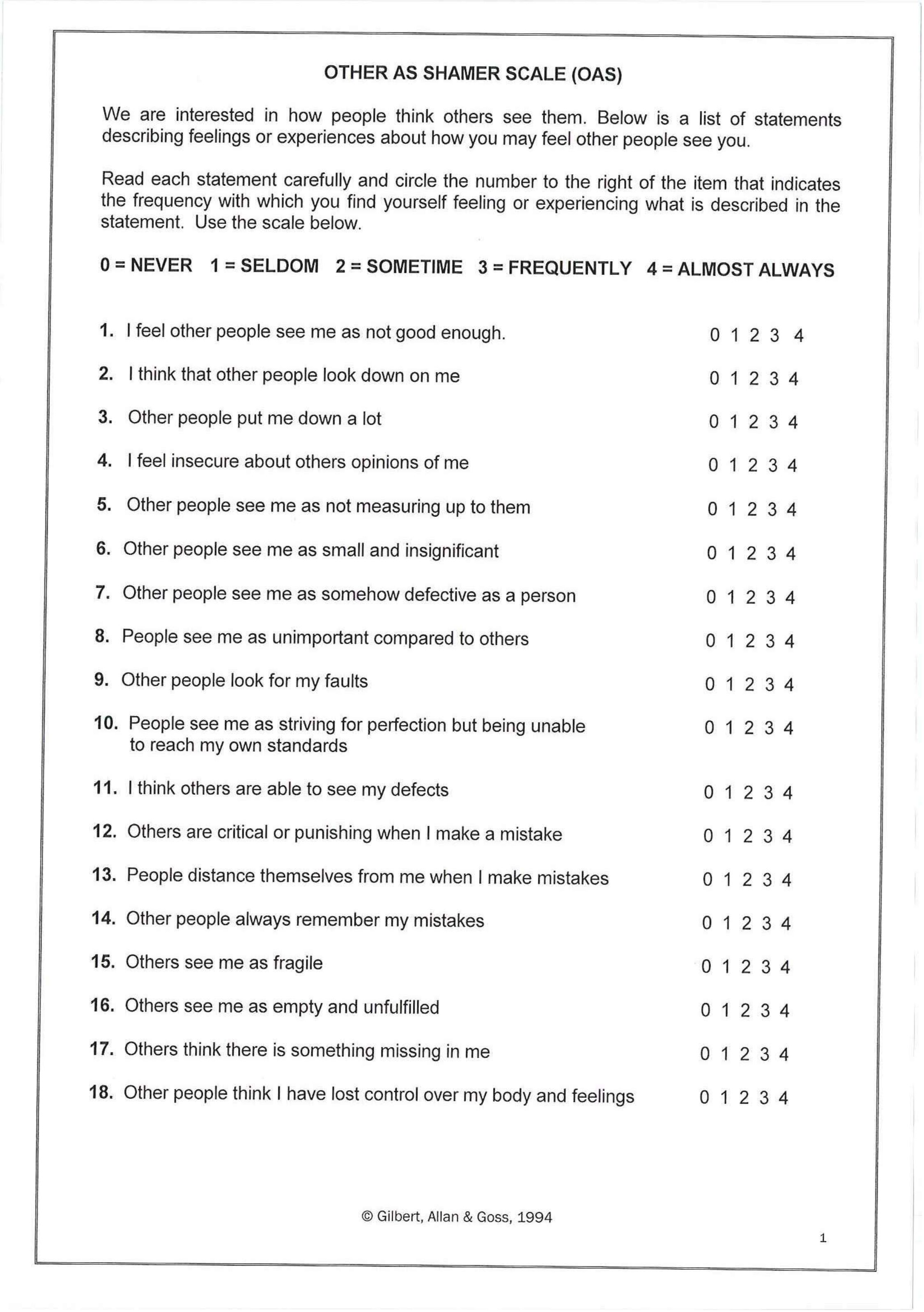
[1] This project is supervised by Dr. Andrew Thompson (a.r.thompson@sheffield.ac.uk and Professor Paul Gilbert.

Appendix D

Appendix D.1. Other as Shamer Scale



OTHER AS SHAMER SCALE (OAS)

We are interested in how people think others see them. Below is a list of statements describing feelings or experiences about how you may feel other people see you.

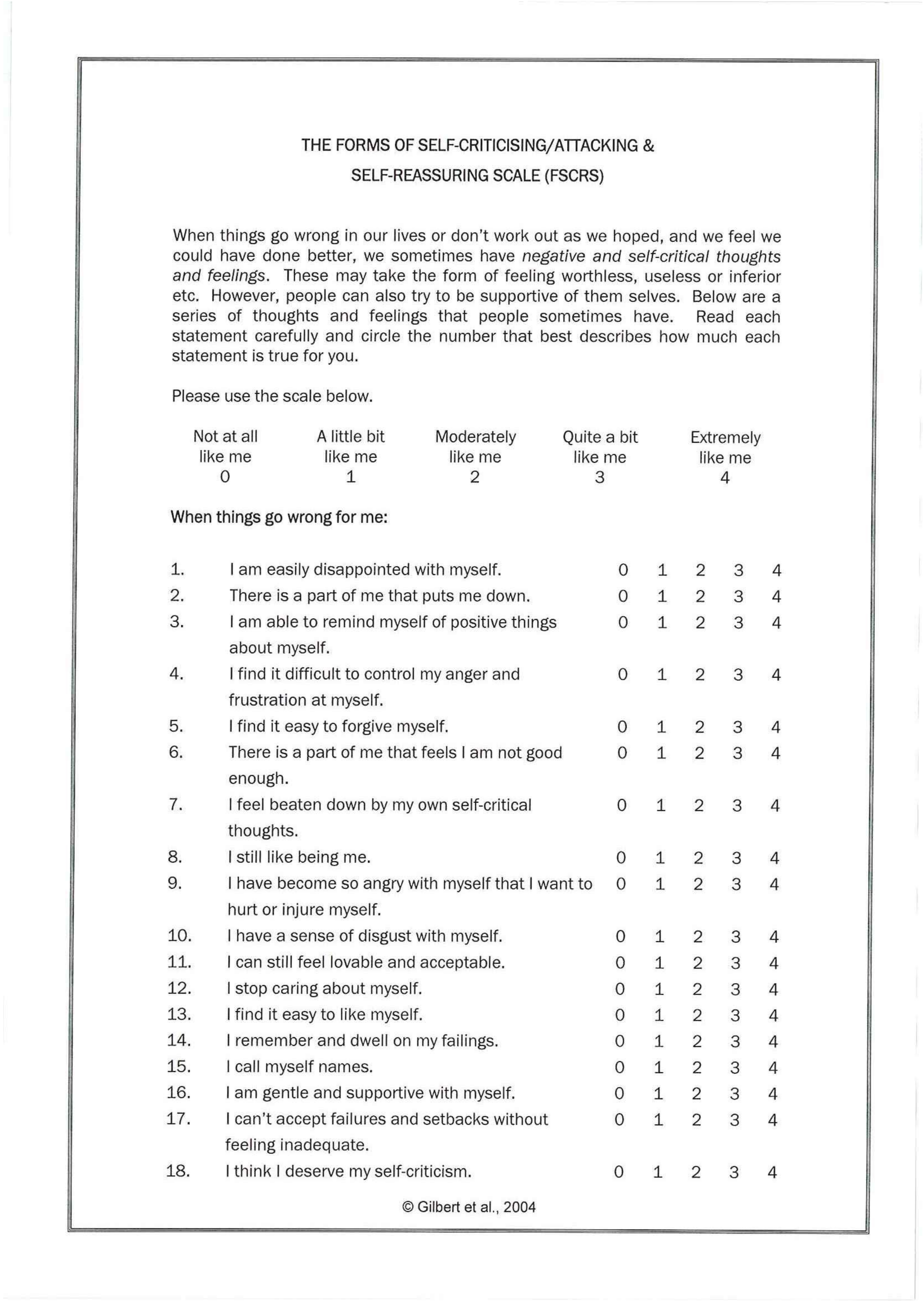
Read each statement carefully and circle the number to the right of the item that indicates the frequency with which you find yourself feeling or experiencing what is described in the statement. Use the scale below.

0 = NEVER 1 = SELDOM 2 = SOMETIME 3 = FREQUENTLY 4 = ALMOST ALWAYS

1. I feel other people see me as not good enough. 0 1 2 3 4
2. I think that other people look down on me 0 1 2 3 4
3. Other people put me down a lot 0 1 2 3 4
4. I feel insecure about others opinions of me 0 1 2 3 4
5. Other people see me as not measuring up to them 0 1 2 3 4
6. Other people see me as small and insignificant 0 1 2 3 4
7. Other people see me as somehow defective as a person 0 1 2 3 4
8. People see me as unimportant compared to others 0 1 2 3 4
9. Other people look for my faults 0 1 2 3 4
10. People see me as striving for perfection but being unable to reach my own standards 0 1 2 3 4
11. I think others are able to see my defects 0 1 2 3 4
12. Others are critical or punishing when I make a mistake 0 1 2 3 4
13. People distance themselves from me when I make mistakes 0 1 2 3 4
14. Other people always remember my mistakes 0 1 2 3 4
15. Others see me as fragile 0 1 2 3 4
16. Others see me as empty and unfulfilled 0 1 2 3 4
17. Others think there is something missing in me 0 1 2 3 4
18. Other people think I have lost control over my body and feelings 0 1 2 3 4

Appendix D

Appendix D.2. The Forms of Self-criticising/Attacking and Self-reassuring Scale



THE FORMS OF SELF-CRITICISING/ATTACKING & SELF-REASSURING SCALE (FSCRS)

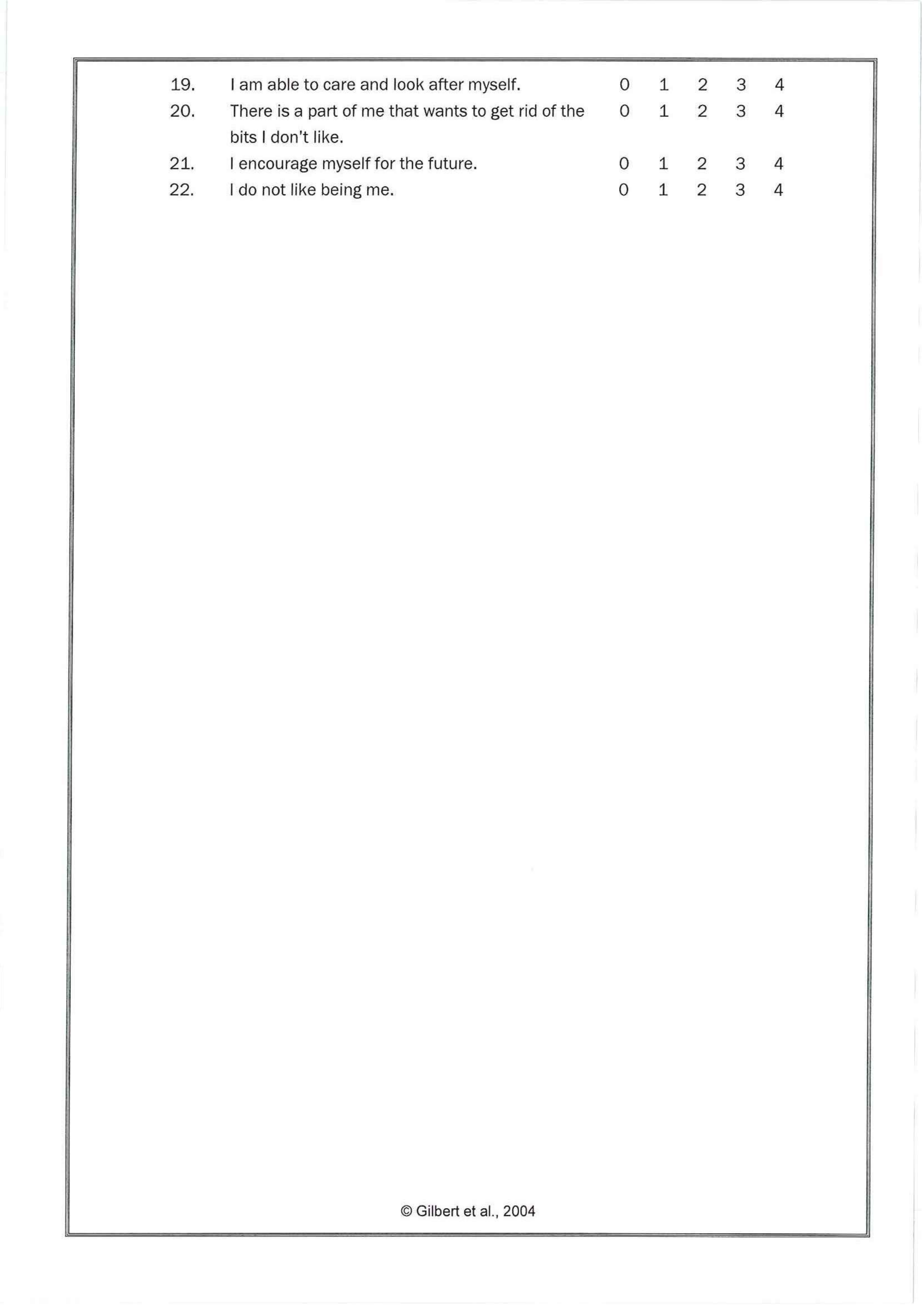
When things go wrong in our lives or don't work out as we hoped, and we feel we could have done better, we sometimes have *negative and self-critical thoughts and feelings*. These may take the form of feeling worthless, useless or inferior etc. However, people can also try to be supportive of them selves. Below are a series of thoughts and feelings that people sometimes have. Read each statement carefully and circle the number that best describes how much each statement is true for you.

Please use the scale below.

Not at all like me	A little bit like me	Moderately like me	Quite a bit like me	Extremely like me
0	1	2	3	4

When things go wrong for me:

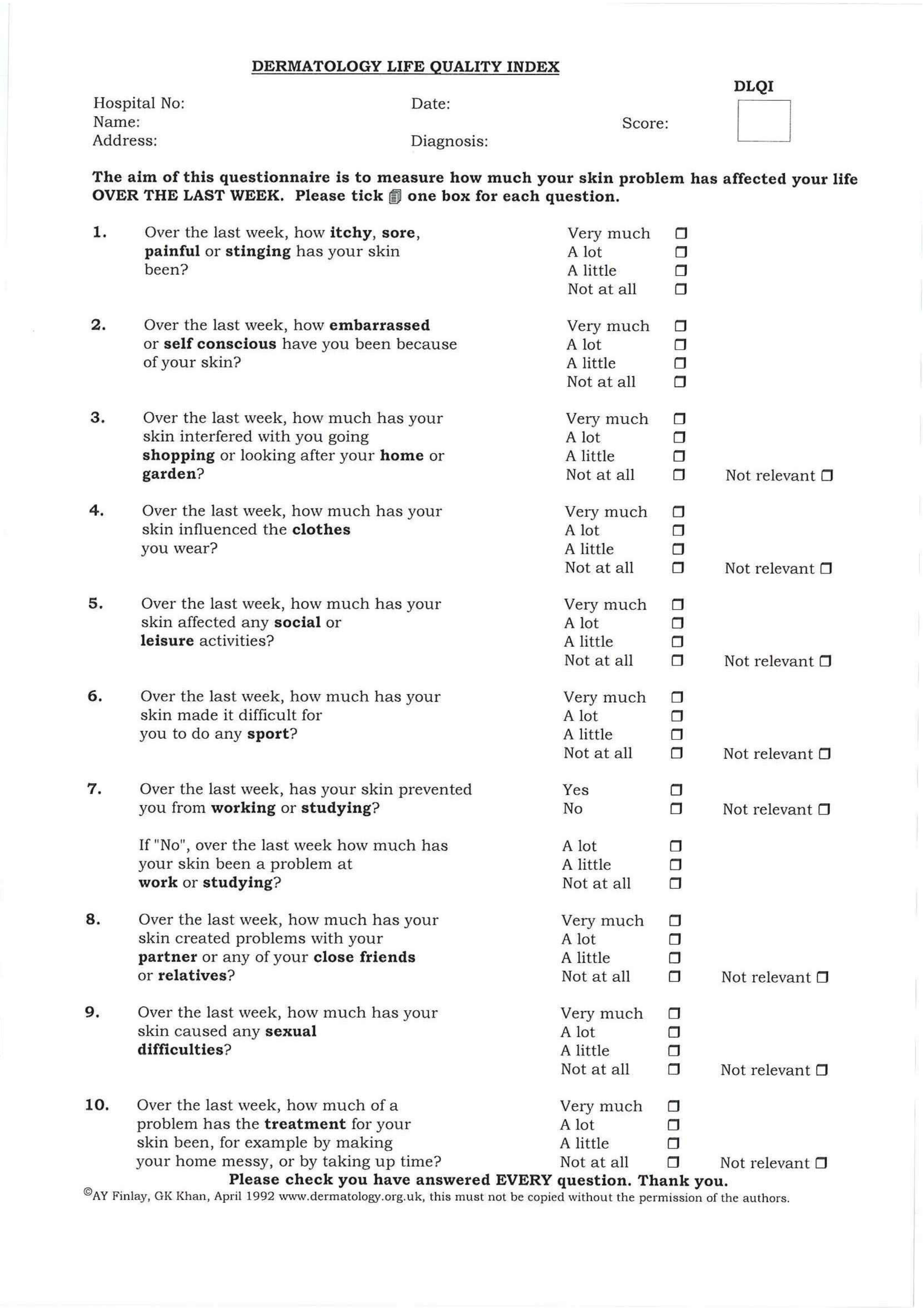
1.	I am easily disappointed with myself.	0	1	2	3	4
2.	There is a part of me that puts me down.	0	1	2	3	4
3.	I am able to remind myself of positive things about myself.	0	1	2	3	4
4.	I find it difficult to control my anger and frustration at myself.	0	1	2	3	4
5.	I find it easy to forgive myself.	0	1	2	3	4
6.	There is a part of me that feels I am not good enough.	0	1	2	3	4
7.	I feel beaten down by my own self-critical thoughts.	0	1	2	3	4
8.	I still like being me.	0	1	2	3	4
9.	I have become so angry with myself that I want to hurt or injure myself.	0	1	2	3	4
10.	I have a sense of disgust with myself.	0	1	2	3	4
11.	I can still feel lovable and acceptable.	0	1	2	3	4
12.	I stop caring about myself.	0	1	2	3	4
13.	I find it easy to like myself.	0	1	2	3	4
14.	I remember and dwell on my failings.	0	1	2	3	4
15.	I call myself names.	0	1	2	3	4
16.	I am gentle and supportive with myself.	0	1	2	3	4
17.	I can't accept failures and setbacks without feeling inadequate.	0	1	2	3	4
18.	I think I deserve my self-criticism.	0	1	2	3	4



19.	I am able to care and look after myself.	0	1	2	3	4
20.	There is a part of me that wants to get rid of the bits I don't like.	0	1	2	3	4
21.	I encourage myself for the future.	0	1	2	3	4
22.	I do not like being me.	0	1	2	3	4

Appendix D

Appendix D.3. Dermatology Life Quality Index



DERMATOLOGY LIFE QUALITY INDEX

DLQI

Hospital No: Date:
Name: Score: ☐
Address: Diagnosis:

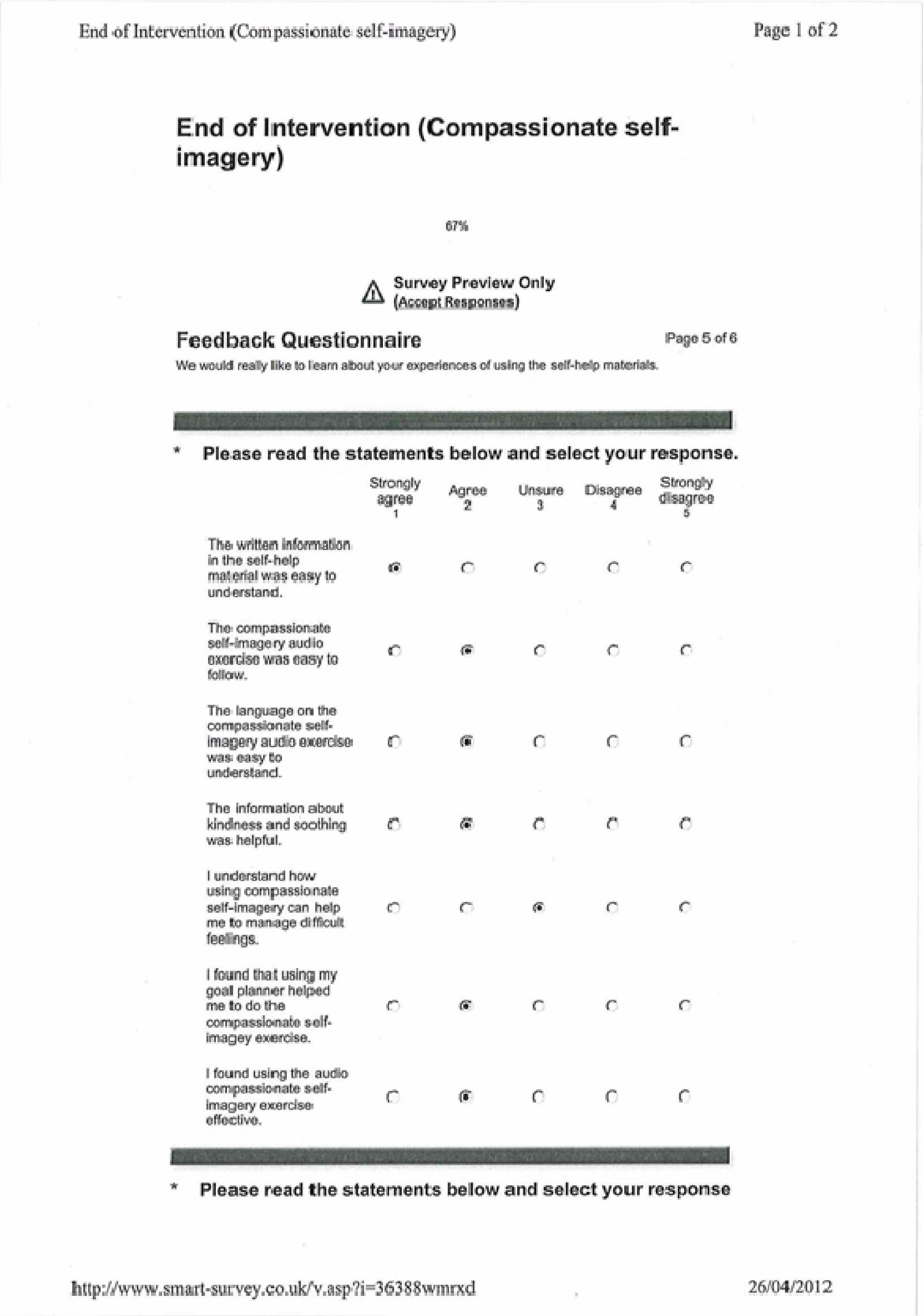
The aim of this questionnaire is to measure how much your skin problem has affected your life OVER THE LAST WEEK. Please tick ☑ one box for each question.

1.	Over the last week, how **itchy**, **sore**, **painful** or **stinging** has your skin been?	Very much A lot A little Not at all	☐ ☐ ☐ ☐	
2.	Over the last week, how **embarrassed** or **self conscious** have you been because of your skin?	Very much A lot A little Not at all	☐ ☐ ☐ ☐	
3.	Over the last week, how much has your skin interfered with you going **shopping** or looking after your **home** or **garden**?	Very much A lot A little Not at all	☐ ☐ ☐ ☐	Not relevant ☐
4.	Over the last week, how much has your skin influenced the **clothes** you wear?	Very much A lot A little Not at all	☐ ☐ ☐ ☐	Not relevant ☐
5.	Over the last week, how much has your skin affected any **social** or **leisure** activities?	Very much A lot A little Not at all	☐ ☐ ☐ ☐	Not relevant ☐
6.	Over the last week, how much has your skin made it difficult for you to do any **sport**?	Very much A lot A little Not at all	☐ ☐ ☐ ☐	Not relevant ☐
7.	Over the last week, has your skin prevented you from **working** or **studying**?	Yes No	☐ ☐	Not relevant ☐
	If "No", over the last week how much has your skin been a problem at **work** or **studying**?	A lot A little Not at all	☐ ☐ ☐	
8.	Over the last week, how much has your skin created problems with your **partner** or any of your **close friends** or **relatives**?	Very much A lot A little Not at all	☐ ☐ ☐ ☐	Not relevant ☐
9.	Over the last week, how much has your skin caused any **sexual difficulties**?	Very much A lot A little Not at all	☐ ☐ ☐ ☐	Not relevant ☐
10.	Over the last week, how much of a problem has the **treatment** for your skin been, for example by making your home messy, or by taking up time?	Very much A lot A little Not at all	☐ ☐ ☐ ☐	Not relevant ☐

Please check you have answered EVERY question. Thank you.

Appendix D

Appendix D.4. Sample End of Intervention Evaluation Questionnaire



End of Intervention (Compassionate self-imagery) Page 1 of 2

End of Intervention (Compassionate self-imagery)

67%

⚠ Survey Preview Only
(Accept Responses)

Feedback Questionnaire

Page 5 of 6

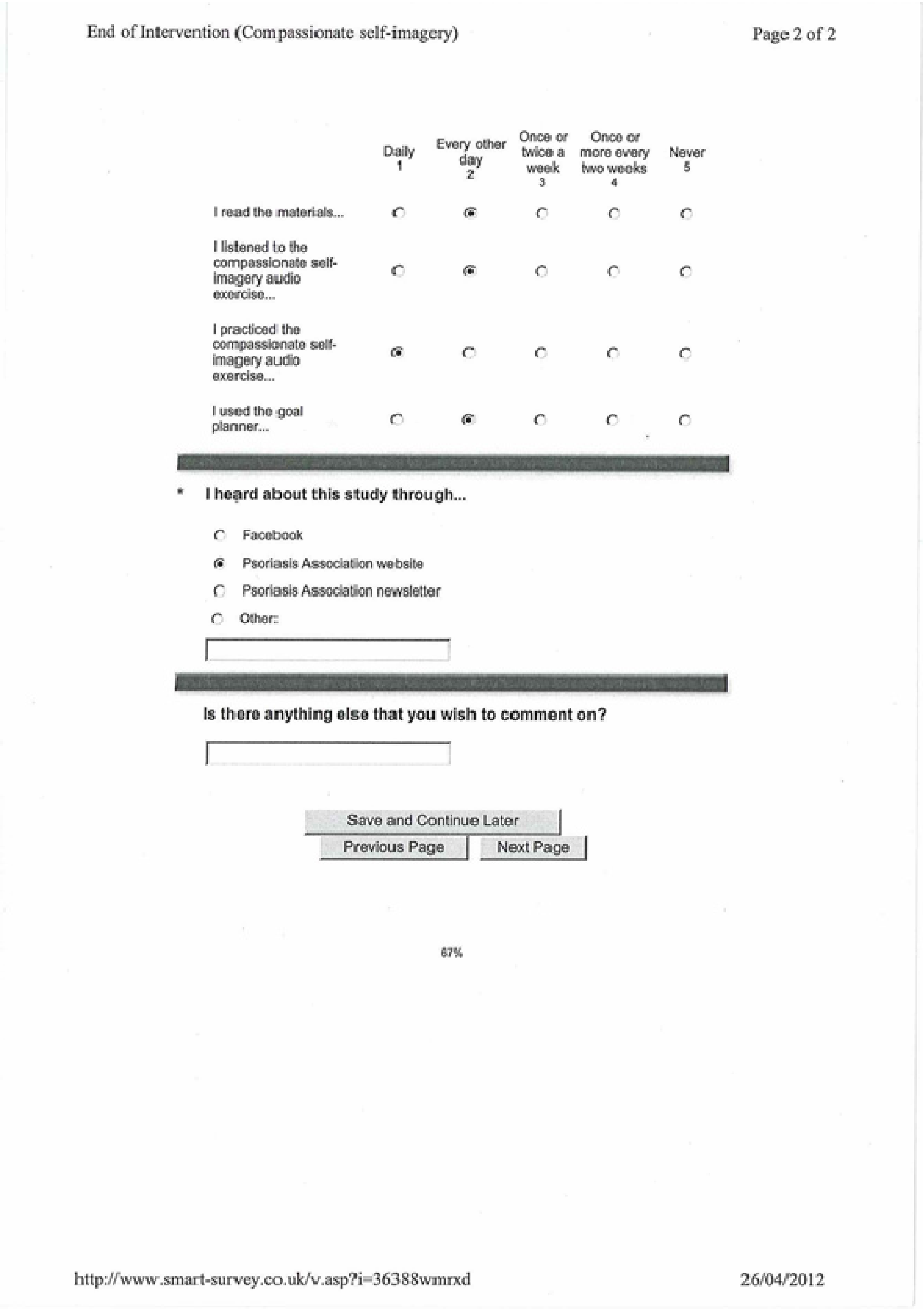
We would really like to learn about your experiences of using the self-help materials.

* **Please read the statements below and select your response.**

	Strongly agree 1	Agree 2	Unsure 3	Disagree 4	Strongly disagree 5
The written information in the self-help material was easy to understand.	●	○	○	○	○
The compassionate self-imagery audio exercise was easy to follow.	○	●	○	○	○
The language on the compassionate self-imagery audio exercise was easy to understand.	○	●	○	○	○
The information about kindness and soothing was helpful.	○	●	○	○	○
I understand how using compassionate self-imagery can help me to manage difficult feelings.	○	○	●	○	○
I found that using my goal planner helped me to do the compassionate self-imagey exercise.	○	●	○	○	○
I found using the audio compassionate self-imagery exercise effective.	○	●	○	○	○

* **Please read the statements below and select your response**

http://www.smart-survey.co.uk/v.asp?i=36388wmrxd 26/04/2012



End of Intervention (Compassionate self-imagery)

Page 2 of 2

	Daily 1	Every other day 2	Once or twice a week 3	Once or more every two weeks 4	Never 5
I read the materials...	○	●	○	○	○
I listened to the compassionate self-imagery audio exercise...	○	●	○	○	○
I practiced the compassionate self-imagery audio exercise...	●	○	○	○	○
I used the goal planner...	○	●	○	○	○

* **I heard about this study through...**

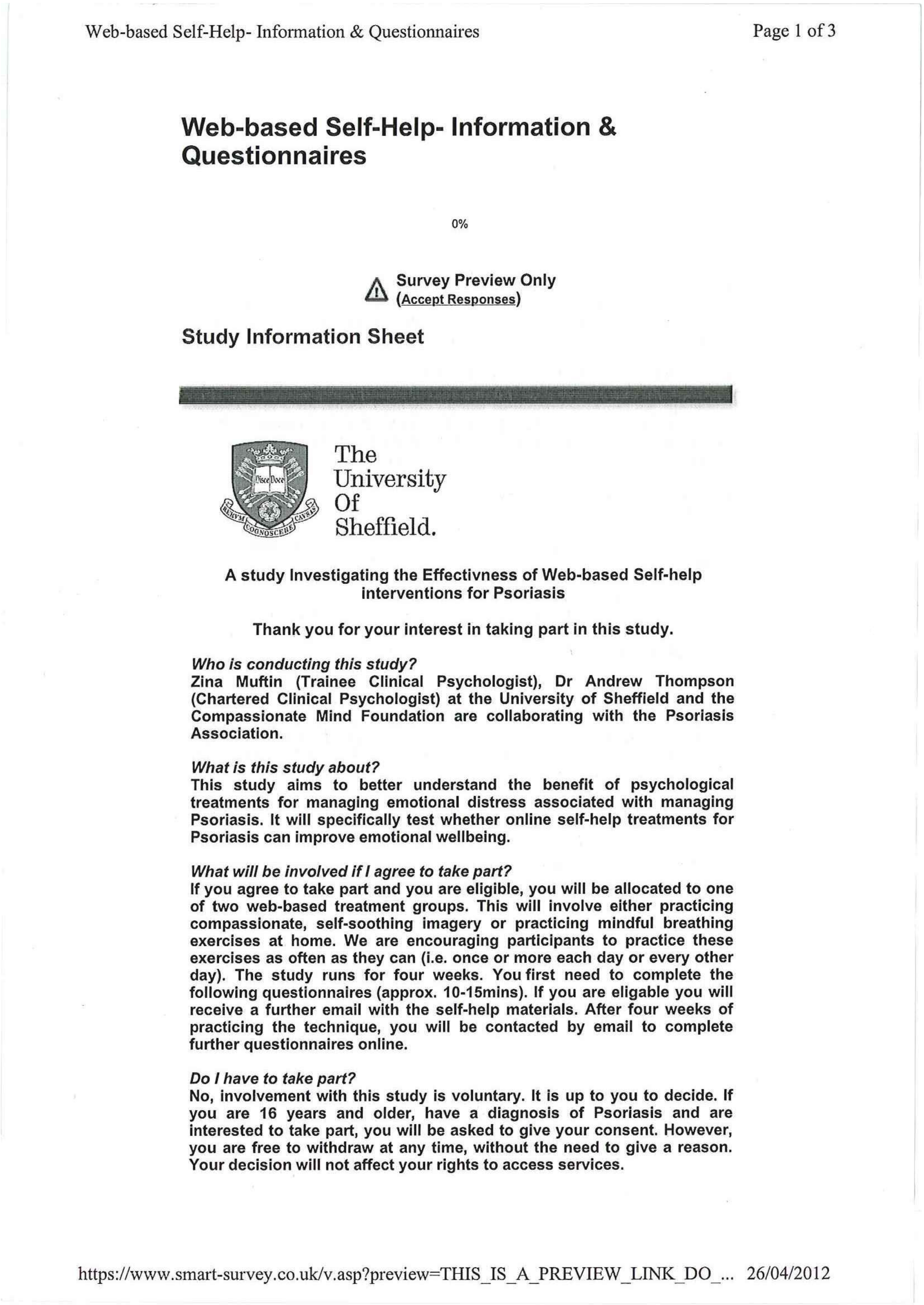
- ○ Facebook
- ● Psoriasis Association website
- ○ Psoriasis Association newsletter
- ○ Other:

Is there anything else that you wish to comment on?

http://www.smart-survey.co.uk/v.asp?i=36388wmrxd

26/04/2012

Appendix F. Participant Pack & Survey



Web-based Self-Help- Information & Questionnaires Page 1 of 3

Web-based Self-Help- Information & Questionnaires

0%

⚠ **Survey Preview Only**
(Accept Responses)

Study Information Sheet

The University Of Sheffield.

A study Investigating the Effectivness of Web-based Self-help interventions for Psoriasis

Thank you for your interest in taking part in this study.

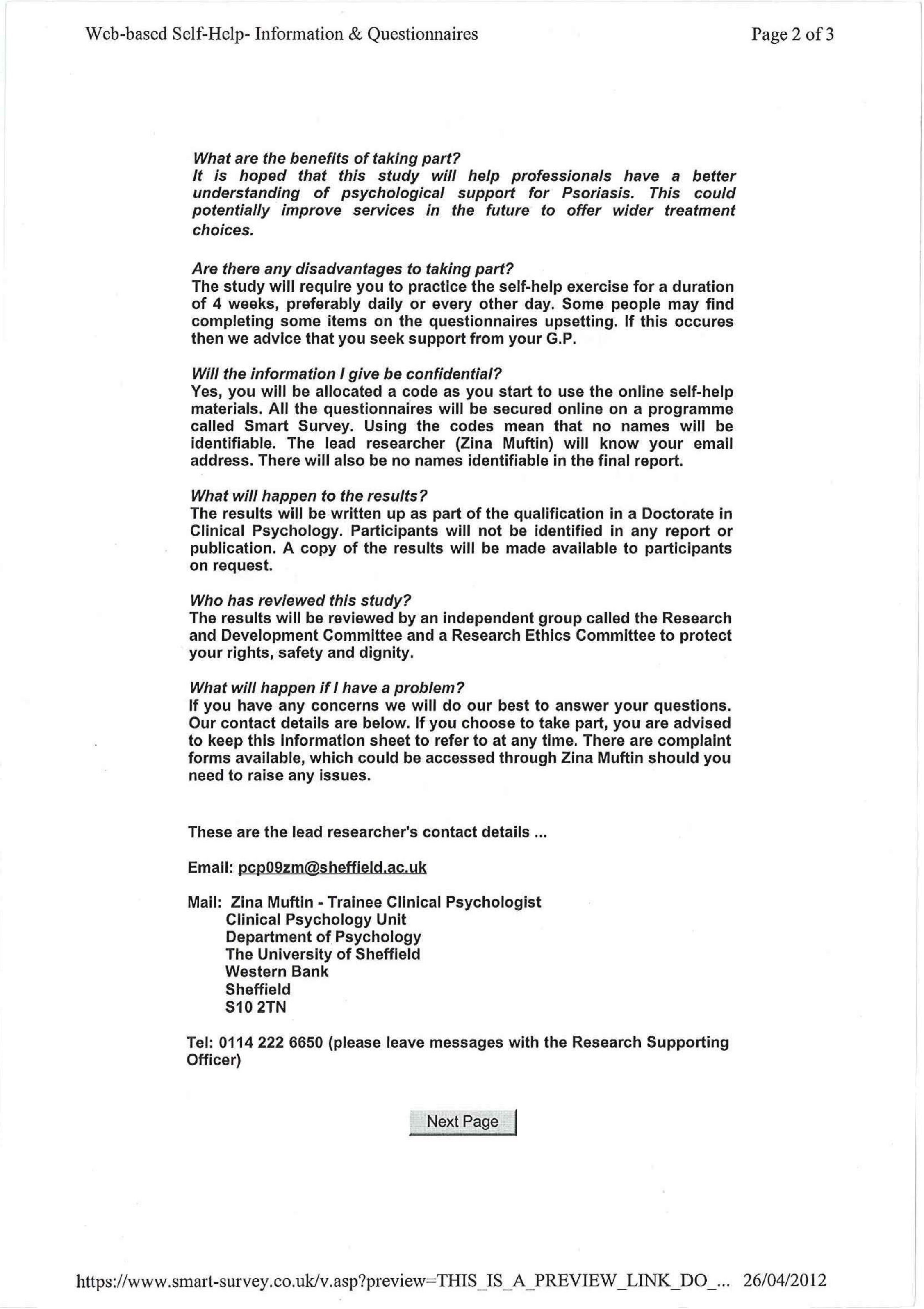
Who is conducting this study?
Zina Muftin (Trainee Clinical Psychologist), Dr Andrew Thompson (Chartered Clinical Psychologist) at the University of Sheffield and the Compassionate Mind Foundation are collaborating with the Psoriasis Association.

What is this study about?
This study aims to better understand the benefit of psychological treatments for managing emotional distress associated with managing Psoriasis. It will specifically test whether online self-help treatments for Psoriasis can improve emotional wellbeing.

What will be involved if I agree to take part?
If you agree to take part and you are eligible, you will be allocated to one of two web-based treatment groups. This will involve either practicing compassionate, self-soothing imagery or practicing mindful breathing exercises at home. We are encouraging participants to practice these exercises as often as they can (i.e. once or more each day or every other day). The study runs for four weeks. You first need to complete the following questionnaires (approx. 10-15mins). If you are eligable you will receive a further email with the self-help materials. After four weeks of practicing the technique, you will be contacted by email to complete further questionnaires online.

Do I have to take part?
No, involvement with this study is voluntary. It is up to you to decide. If you are 16 years and older, have a diagnosis of Psoriasis and are interested to take part, you will be asked to give your consent. However, you are free to withdraw at any time, without the need to give a reason. Your decision will not affect your rights to access services.

https://www.smart-survey.co.uk/v.asp?preview=THIS_IS_A_PREVIEW_LINK_DO_... 26/04/2012



What are the benefits of taking part?
It is hoped that this study will help professionals have a better understanding of psychological support for Psoriasis. This could potentially improve services in the future to offer wider treatment choices.

Are there any disadvantages to taking part?
The study will require you to practice the self-help exercise for a duration of 4 weeks, preferably daily or every other day. Some people may find completing some items on the questionnaires upsetting. If this occures then we advice that you seek support from your G.P.

Will the information I give be confidential?
Yes, you will be allocated a code as you start to use the online self-help materials. All the questionnaires will be secured online on a programme called Smart Survey. Using the codes mean that no names will be identifiable. The lead researcher (Zina Muftin) will know your email address. There will also be no names identifiable in the final report.

What will happen to the results?
The results will be written up as part of the qualification in a Doctorate in Clinical Psychology. Participants will not be identified in any report or publication. A copy of the results will be made available to participants on request.

Who has reviewed this study?
The results will be reviewed by an independent group called the Research and Development Committee and a Research Ethics Committee to protect your rights, safety and dignity.

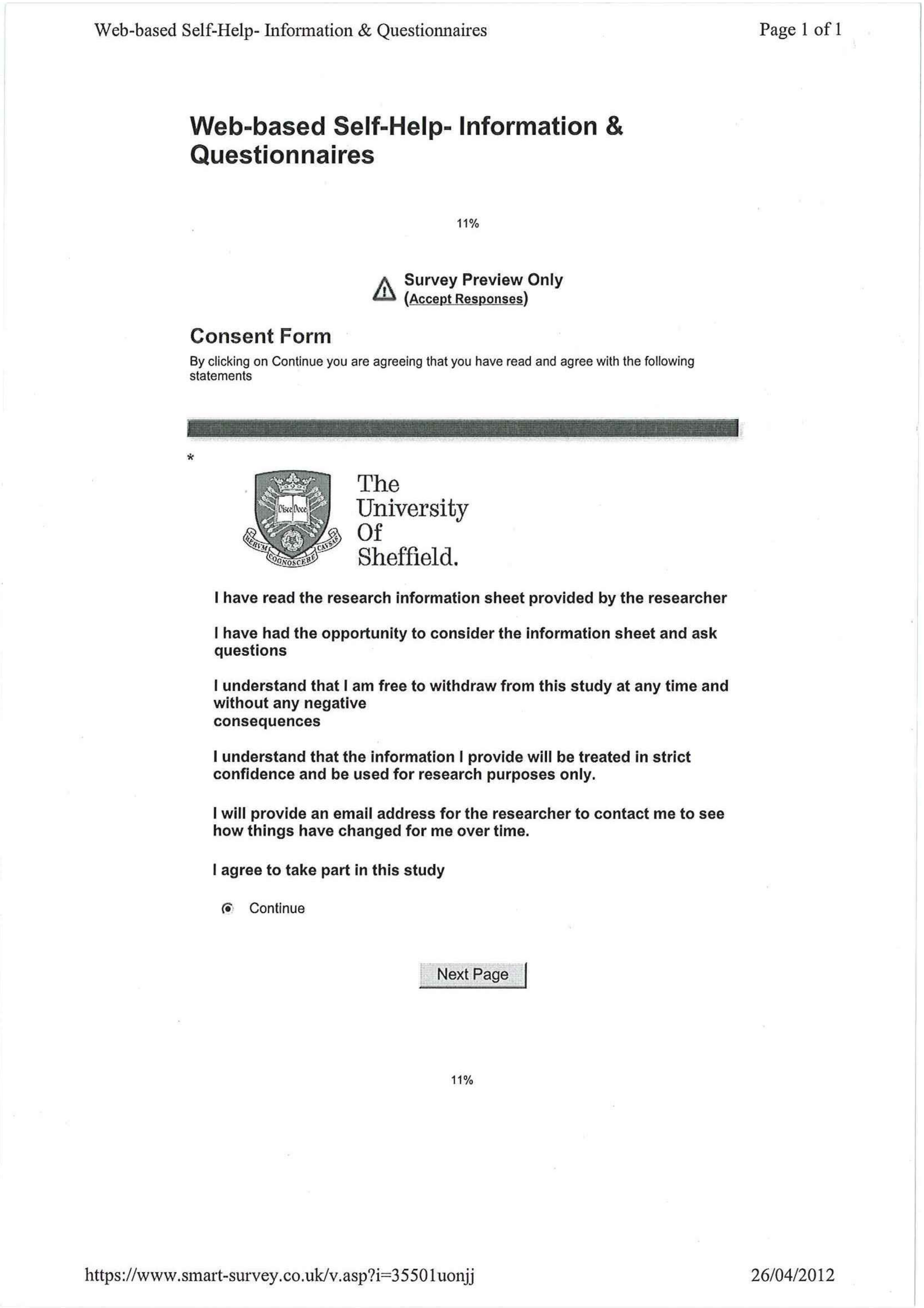
What will happen if I have a problem?
If you have any concerns we will do our best to answer your questions. Our contact details are below. If you choose to take part, you are advised to keep this information sheet to refer to at any time. There are complaint forms available, which could be accessed through Zina Muftin should you need to raise any issues.

These are the lead researcher's contact details ...

Email: pcp09zm@sheffield.ac.uk

Mail: Zina Muftin - Trainee Clinical Psychologist
Clinical Psychology Unit
Department of Psychology
The University of Sheffield
Western Bank
Sheffield
S10 2TN

Tel: 0114 222 6650 (please leave messages with the Research Supporting Officer)



Web-based Self-Help- Information & Questionnaires Page 1 of 1

Web-based Self-Help- Information & Questionnaires

11%

Survey Preview Only
(Accept Responses)

Consent Form

By clicking on Continue you are agreeing that you have read and agree with the following statements

*

The University Of Sheffield.

I have read the research information sheet provided by the researcher

I have had the opportunity to consider the information sheet and ask questions

I understand that I am free to withdraw from this study at any time and without any negative consequences

I understand that the information I provide will be treated in strict confidence and be used for research purposes only.

I will provide an email address for the researcher to contact me to see how things have changed for me over time.

I agree to take part in this study

● Continue

11%

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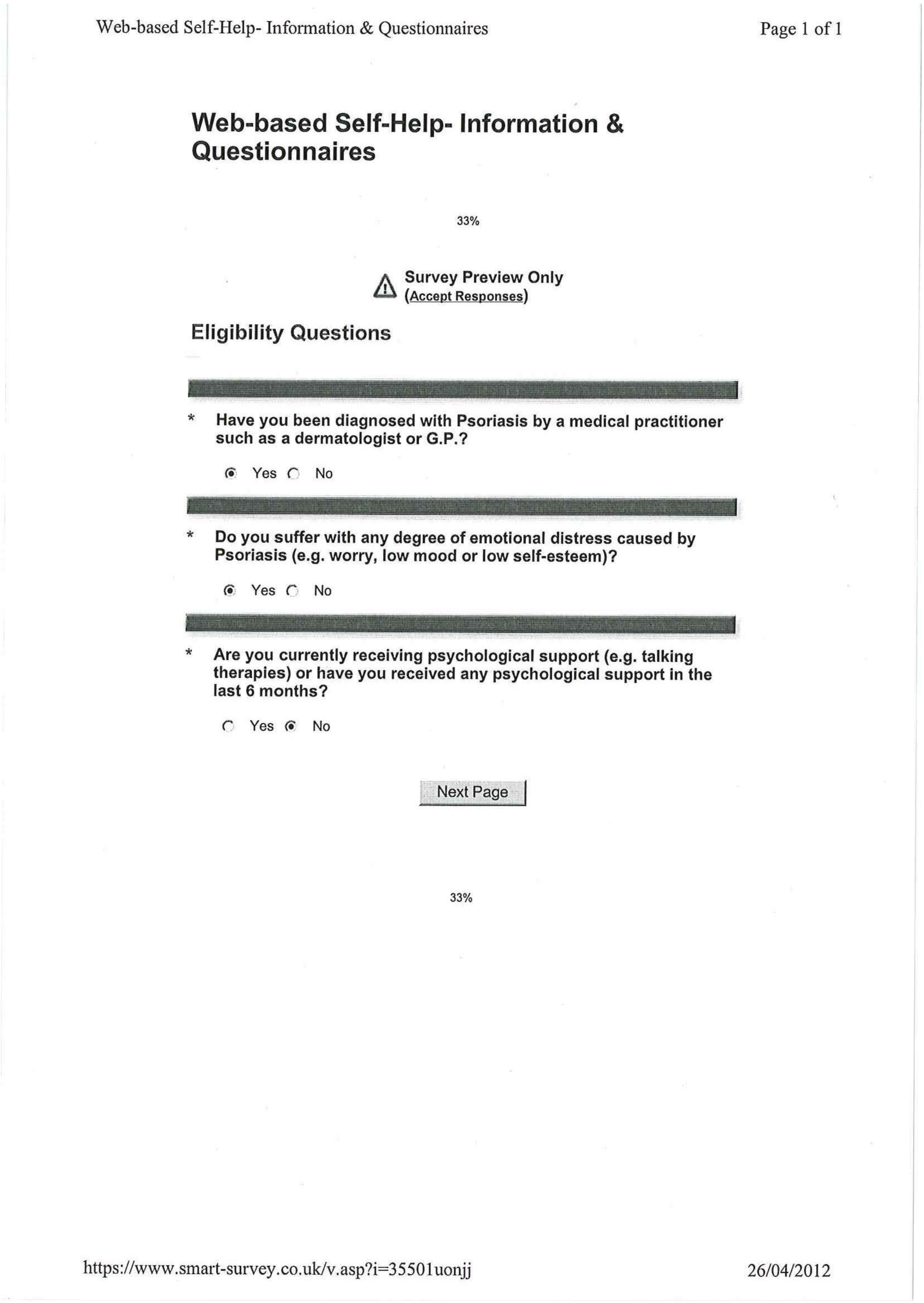

Web-based Self-Help- Information & Questionnaires Page 1 of 1

Web-based Self-Help- Information & Questionnaires

33%

⚠ **Survey Preview Only**
(Accept Responses)

Eligibility Questions

* **Have you been diagnosed with Psoriasis by a medical practitioner such as a dermatologist or G.P.?**

● Yes ○ No

* **Do you suffer with any degree of emotional distress caused by Psoriasis (e.g. worry, low mood or low self-esteem)?**

● Yes ○ No

* **Are you currently receiving psychological support (e.g. talking therapies) or have you received any psychological support in the last 6 months?**

○ Yes ● No

33%

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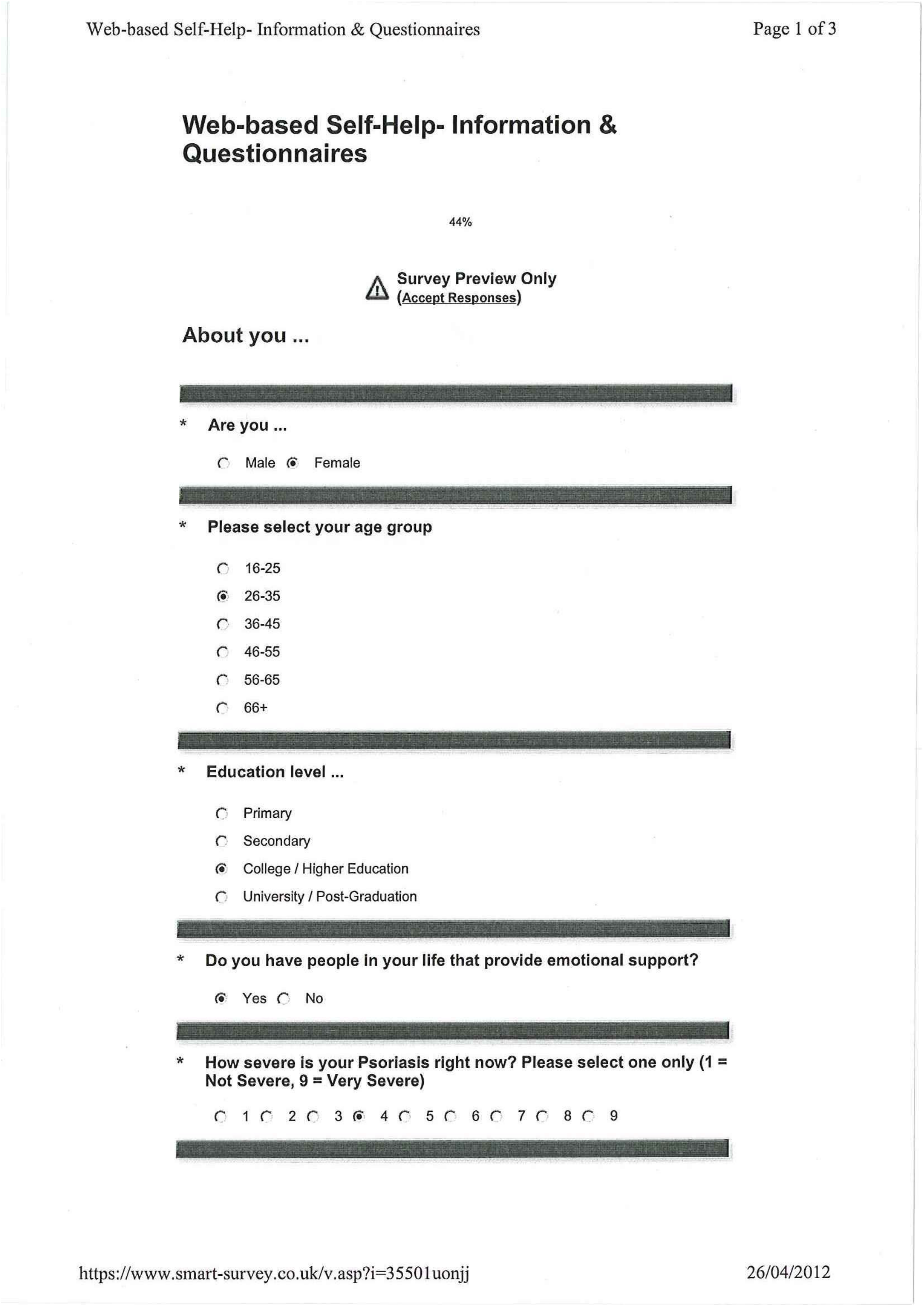

Web-based Self-Help- Information & Questionnaires Page 1 of 3

Web-based Self-Help- Information & Questionnaires

44%

⚠ **Survey Preview Only**
(Accept Responses)

About you ...

* **Are you ...**

○ Male ● Female

* **Please select your age group**

○ 16-25
● 26-35
○ 36-45
○ 46-55
○ 56-65
○ 66+

* **Education level ...**

○ Primary
○ Secondary
● College / Higher Education
○ University / Post-Graduation

* **Do you have people in your life that provide emotional support?**

● Yes ○ No

* **How severe is your Psoriasis right now? Please select one only (1 = Not Severe, 9 = Very Severe)**

○ 1 ○ 2 ○ 3 ● 4 ○ 5 ○ 6 ○ 7 ○ 8 ○ 9

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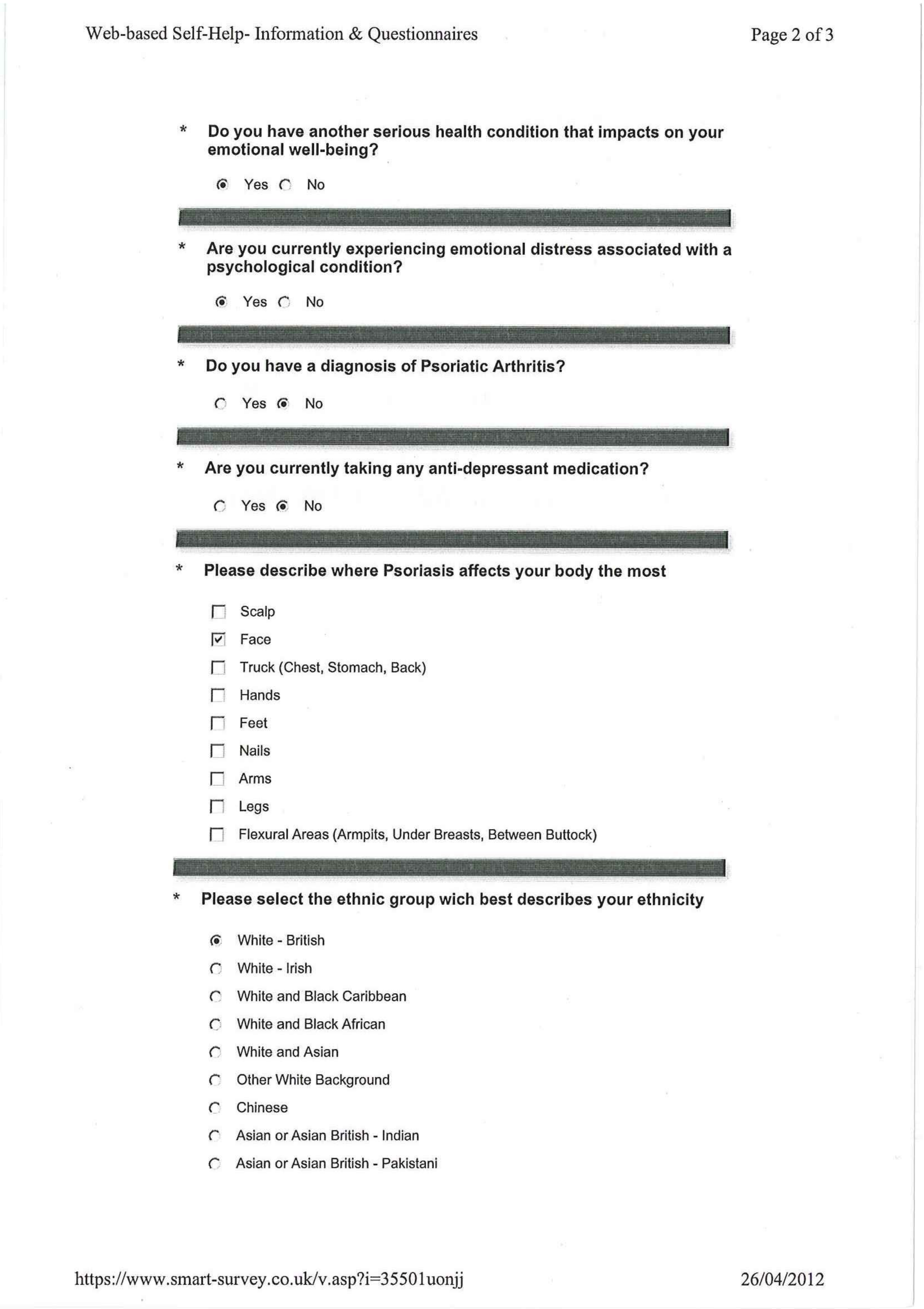

Web-based Self-Help- Information & Questionnaires Page 2 of 3

* **Do you have another serious health condition that impacts on your emotional well-being?**

● Yes ○ No

* **Are you currently experiencing emotional distress associated with a psychological condition?**

● Yes ○ No

* **Do you have a diagnosis of Psoriatic Arthritis?**

○ Yes ● No

* **Are you currently taking any anti-depressant medication?**

○ Yes ● No

* **Please describe where Psoriasis affects your body the most**

- ☐ Scalp
- ☑ Face
- ☐ Truck (Chest, Stomach, Back)
- ☐ Hands
- ☐ Feet
- ☐ Nails
- ☐ Arms
- ☐ Legs
- ☐ Flexural Areas (Armpits, Under Breasts, Between Buttock)

* **Please select the ethnic group wich best describes your ethnicity**

- ● White - British
- ○ White - Irish
- ○ White and Black Caribbean
- ○ White and Black African
- ○ White and Asian
- ○ Other White Background
- ○ Chinese
- ○ Asian or Asian British - Indian
- ○ Asian or Asian British - Pakistani

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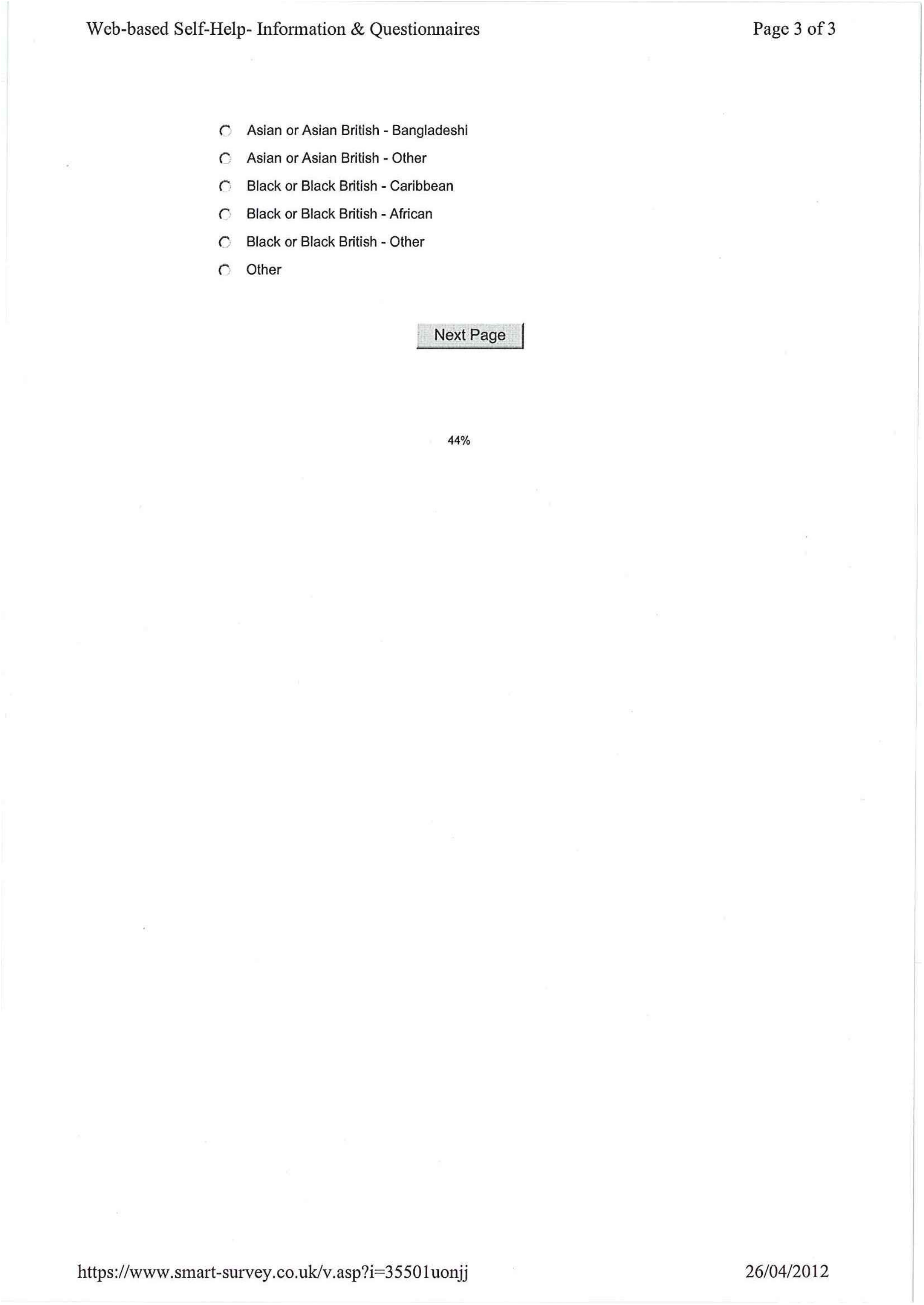

Web-based Self-Help- Information & Questionnaires

Page 3 of 3

- ○ Asian or Asian British - Bangladeshi
- ○ Asian or Asian British - Other
- ○ Black or Black British - Caribbean
- ○ Black or Black British - African
- ○ Black or Black British - Other
- ○ Other

44%

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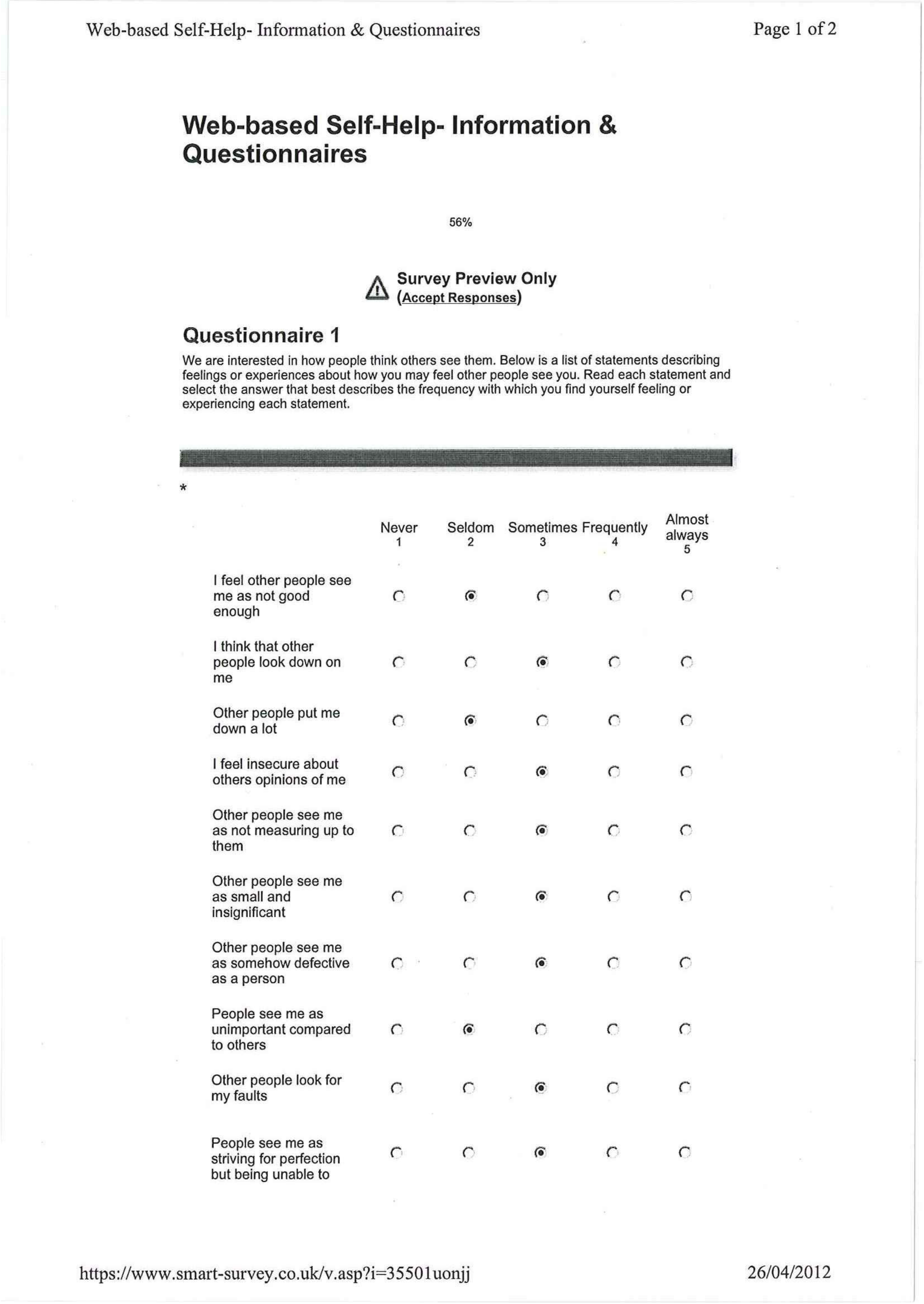


Web-based Self-Help- Information & Questionnaires Page 1 of 2

Web-based Self-Help- Information & Questionnaires

56%

Survey Preview Only
(Accept Responses)

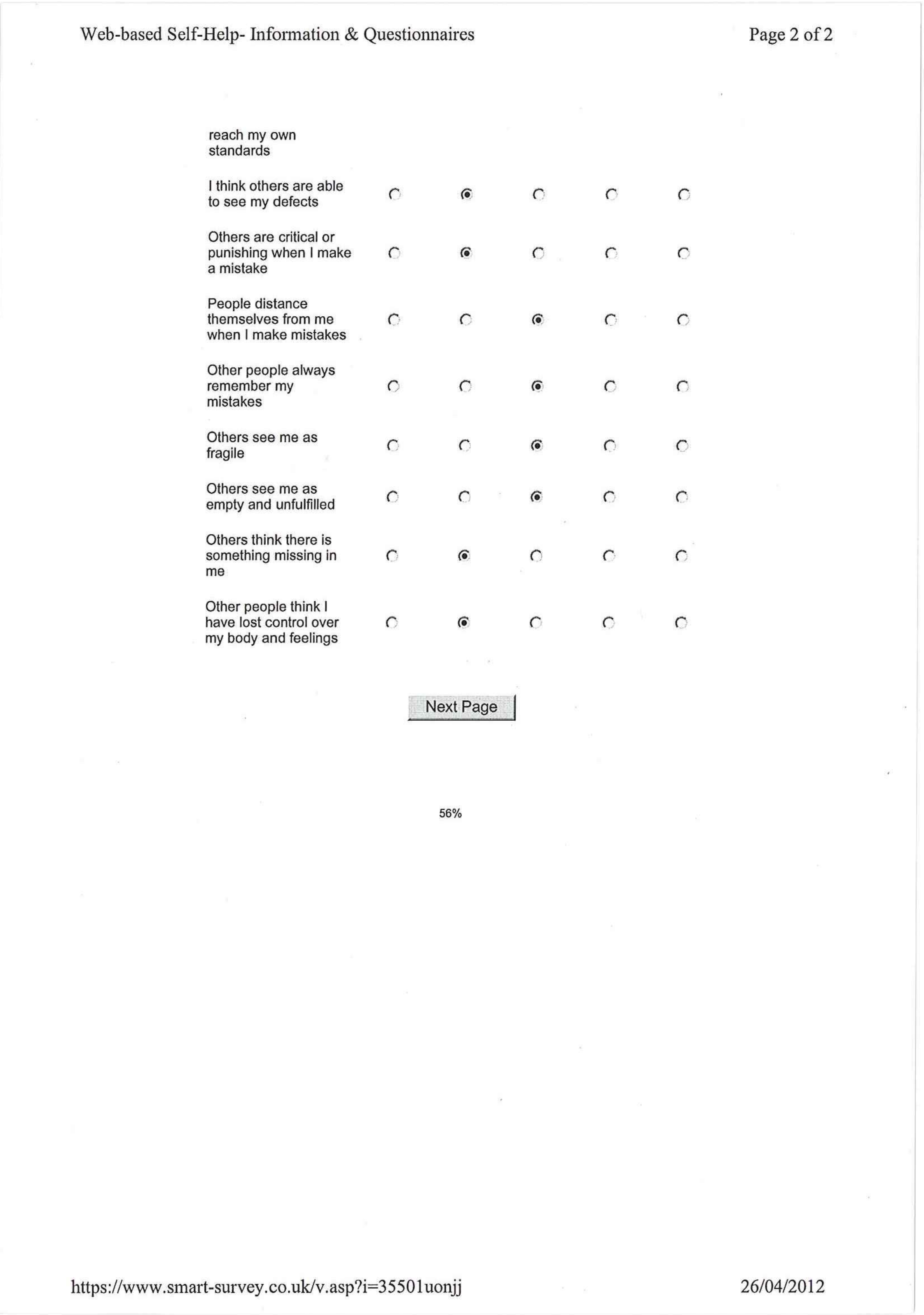
Questionnaire 1

We are interested in how people think others see them. Below is a list of statements describing feelings or experiences about how you may feel other people see you. Read each statement and select the answer that best describes the frequency with which you find yourself feeling or experiencing each statement.

*

	Never 1	Seldom 2	Sometimes 3	Frequently 4	Almost always 5
I feel other people see me as not good enough	○	●	○	○	○
I think that other people look down on me	○	○	●	○	○
Other people put me down a lot	○	●	○	○	○
I feel insecure about others opinions of me	○	○	●	○	○
Other people see me as not measuring up to them	○	○	●	○	○
Other people see me as small and insignificant	○	○	●	○	○
Other people see me as somehow defective as a person	○	○	●	○	○
People see me as unimportant compared to others	○	●	○	○	○
Other people look for my faults	○	○	●	○	○
People see me as striving for perfection but being unable to	○	○	●	○	○

https://www.smart-survey.co.uk/v.asp?i=35501uonjj 26/04/2012



Web-based Self-Help- Information & Questionnaires

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reach my own standards					
I think others are able to see my defects	○	●	○	○	○
Others are critical or punishing when I make a mistake	○	●	○	○	○
People distance themselves from me when I make mistakes	○	○	●	○	○
Other people always remember my mistakes	○	○	●	○	○
Others see me as fragile	○	○	●	○	○
Others see me as empty and unfulfilled	○	○	●	○	○
Others think there is something missing in me	○	●	○	○	○
Other people think I have lost control over my body and feelings	○	●	○	○	○

56%

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