THE PSYCHOLOGICAL IMPLICATIONS OF WRITING ONLINE: THE EXPERIENCE OF BLOGGING ABOUT VISIBLE AND CHRONIC SKIN CONDITIONS

VOLUME I

by

SELINA KAUR TOUR

A THESIS SUBMITTED TO THE UNIVERSITY OF BIRMINGHAM FOR THE DEGREE OF DOCTOR OF CLINICAL PSYCHOLOGY

Department of Clinical Psychology
School of Psychology
The University of Birmingham
June 2018

OVERVIEW

Volume I

Volume I consists of three chapters. The first chapter is a meta-analysis of the internal consistency of the Dermatology Life Quality Index (the most used dermatology quality of life measure). Chapter two is an empirical paper exploring the experiences of people with visible skin conditions writing online. The third chapter contains the public dissemination document.

Volume II

Volume II contains four clinical practice reports (CPRs) and a fifth abstract of a verbally presented CPR. The names and identifying details have been anonymised across the reports. The first CPR formulates the difficulties of Jane, an inpatient detained under the section 37/41 of the Mental Health Act (1983), from a cognitive behavioural and psychodynamic perspective. The second report describes a service evaluation assessing how well the cognitive and learning needs of females within a medium secure unit are met.

The third report details the experiences of Thomas, a young person with a diagnosis of Autism Spectrum disorder (ASD) and his difficulties with anxiety within a Child and Family Service. It describes a single case design and outlines assessment, formulation, intervention and evaluation. The fourth report describes the assessment, formulation, intervention and evaluation of John, a young male with learning disability, ASD and motivational difficulties. This was from a systemic perspective. The fifth CPR presented as an abstract briefly outlines the case of Kyle, a young person living within a residential home where assessment, formulation, intervention and evaluation are described and an indirect intervention was carried out.

ACKNOWLEDGMENTS

I would like to give thanks to all of the staff for their dedicated help and support throughout the course of my degree. In particular, I would like to thank my research supervisors – Dr Christopher Jones, Dr Michael Larkin, Dr Ruth Howard and Dr Andrew Thompson – for their ongoing support.

I would also like to thank my friends and family for their encouragement, patience and support throughout this time. In particular, my partner Hardeep, my siblings Ravina, Sharon and David and the 2015 cohort who have been alongside me throughout this journey.

VOLUME I

TABLE OF CONTENTS

CHAPTER ONE: LITERATURE REVIEW A META-ANALYSIS OF THE DERMATOLOGY LIFE QUALITY INDEX: INTERNAL CONSISTENCY

CHAPTER TWO: WRITING ONLINE: THE EXPERIENCE OF BLOGGING ABOUT VISIBLE AND CHRONIC SKIN CONDITIONS

CHAPTER THREE: PUBLIC DISSEMINATION DOCUMENT

LIST OF TABLES IN VOLUME I

Chapter One

Chapter Two

LIST OF FIGURES IN VOLUME I

Chapter One

Chapter Two

Chapter Three

LIST OF APPENDICES IN VOLUME I

Chapter Two

VOLUME II

TABLE OF CONTENTS

CLINICAL PRACTICE REPORT 1

CLINICAL PRACTICE REPORT 2

CLINICAL PRACTICE REPORT 3

CLINICAL PRACTICE REPORT 4

CLINICAL PRACTICE REPORT 5

LIST OF TABLES IN VOLUME II

LIST OF FIGURES IN VOLUME II

LIST OF APPENDICES IN VOLUME II

CHAPTER ONE: LITERATURE REVIEW- A META-ANALYSIS OF THE DERMATOLOGY LIFE QUALITY INDEX: INTERNAL CONSISTENCY

Abstract

Background: The Dermatology Life Quality Index (DLQI) is the mostly widely used quality of life instrument in dermatology. Health-related quality of life (HRQoL) instruments capture the subjective physical, social and mental wellbeing of patients; this can be helpful within dermatology as many conditions can negatively impact on HRQoL. For a measure to be useful within practice, it should be reliable and measure the target characteristics consistently so we can ascertain that it is measuring what we intend. However, no review to date has quantified the DLQI's reliability. Meta-analysis can synthesise findings across studies to provide an overall estimate of the reliability of a measure.

Objectives: This review aimed to quantify the internal consistency of the DLQI through meta-analysis.

Method: Five databases were searched for studies reporting internal consistency of the DLQI. Studies were screened against inclusion and exclusion criteria and relevant data extracted. A random effects model calculated the overall effect size and further analyses were conducted to better understand the variation across studies.

Findings: The meta-analytic effect from combining internal consistency across studies was 0.85 (CI 0.83, 0.86) and the predictive interval estimating where future literature will fall ranged between 0.74 and 0.91. Further analyses were unable to account for the variation found across studies.

Conclusions: The review suggests the DLQI has a high level of internal consistency which falls above the expected level for use in clinical practice; however, the review was unable to identify the source of the variation between studies. Future research exploring the sources of variation and a review looking at the DLQI's stability over time would support a more robust awareness of its overall reliability as a measure.

Introduction

Health-Related Quality of Life in Dermatology

Health-related quality of life (HRQoL) describes how a patient functions in everyday life as a result of their health status and subsequent treatment (Anker et al., 2014; Hays, Anderson, & Revicki, 1993; Wilson & Cleary, 1995). It captures physical, mental and social wellbeing from the patient's subjective experience (Hays et al., 1993; Wilson & Cleary, 1995).

Dermatological conditions[1] can often lead to a decrease in HRQoL regardless of symptom severity (Aghaei, Moradi, & Ardekani, 2009; Alavi, Anooshirvani, Kim, Coutts, & Sibbald, 2014; Sampogna, Tabolli, & Abeni, 2013). For example, non-life threatening conditions such as vitiligo can have a profound impact on quality of life (Sangma, Nath, & Bhagabati, 2015). Beyond the symptoms of the condition itself such as itching, having a skin condition can impact on social relationships, ability to engage with leisure activities, work and sleep (Borimnejad, Parsa Yekta, Nikbakht-Nasrabadi, & Firooz, 2006; Dufour, Emtestam, & Jemec, 2014; Heelan et al., 2015; Hong, Koo, & Koo, 2008). In addition, the impact on quality of life is comparable with other long term disorders.

---

[1] Dermatological conditions are those which fall under the dermatology branch of medicine, which is defined as the study of skin. This branch can include conditions which affect the skin, scalp, hair and nails. This DLQI research often uses the word 'skin' when thinking about quality of life, though conditions such as alopecia which affect the hair would also be defined as dermatological and fall within this area.

For example, psoriasis has been found to have a similar impact on HRQoL as cancer and heart diseases (Møller, Erntoft, Vinding, & Jemec, 2015).

Measuring quality of life in physical health settings can be helpful as the prevalence of mental health is often underestimated in physical health settings (Prince et al., 2007). In dermatological conditions, quality of life can be a better predictor of mental health problems than clinical severity (Picardi, Abeni, Melchi, Puddu, & Pasquini, 2000). For example, it has been found to be a mediating factor for anxiety and depression in rosacea (Böhm, Schwanitz, Stock Gissendanner, Schmid-Ott, & Schulz, 2014). Therefore, its measurement can support the understanding of difficulties beyond symptoms.

Assessing HRQoL in this way has become more widely recognised as forming an integral part of patient care delivery and influencing health policy decisions (Anker et al., 2014; Guyatt,1993; Hays, 1993). HRQoL measures are used across clinical trials and in routine clinical practice to assess effectiveness of intervention and to evaluate quality of care (Anker et al., 2014; Wilson & Cleary, 1995).

The Dermatology Life Quality Index

One HRQoL measure for dermatological conditions is the Dermatology Life Quality Index (DLQI). This is a simple questionnaire designed to measure the impact of skin disease in routine clinical practice (Finlay, 1997; Finlay & Khan, 1994). One hundred and twenty individuals representing over 32 dermatology conditions were interviewed in the development of the DLQI which resulted in the formation of a 10-item questionnaire. This evaluates the impact of skin disease on different aspects of daily living including symptoms and feelings, daily activities, leisure, work, school, personal relationships and treatment (Finlay & Khan, 1994; Lewis & Finlay, 2004). Each question on the DLQI has four potential answers: 0 (not at all), 1 (a little), 2 (a lot), 3 (very much), with some questions also having a 'not relevant' option. The total score is the sum of scores across the 10 questions, with a higher score indicating a greater impact of skin disease on the individual's quality of life (Finlay & Khan, 1994). The DLQI is designed to measure the impact over the preceding week and can be found in Appendix A.

Since its development, the DLQI has become the most widely used dermatology-specific HRQoL measure and has been translated into over 55 languages (Twiss, Meads, Preston, Crawford, & McKenna, 2012). The measure has been used across at least 36 different skin diseases including psoriasis (Aghaei et al., 2009; Atalay et al., 2017; Gniadecki et al., 2012), eczema (Badia, Mascaro, & Lozano, 1999; Georgieva, 2017; Van Coevorden, Van Sonderen, Bouma, & Coenraads, 2006), vitiligo (Borimnejad et al., 2006; Silverberg & Silverberg, 2013), viral warts (Mabel Qi He & Hazel Hwee Boon, 2016) and alopecia (Al-Mutairi & Eldin, 2011; Finlay, 2004). It is often used alongside a disorder-specific patient rated outcome measure to measure treatment effect across clinical trials and within routine practice. The DLQI is also used within the

NICE guidance to assess whether an individual is suitable for the systemic biological therapy pathway in psoriasis (Twiss et al., 2012) highlighting its influence in policy decisions.

It is clear that HRQoL has, and continues to have, a substantial impact upon the measurement of treatment outcome and has influenced the development of national and international treatment guidelines. In order to be effective and useful for their intended purpose, HRQoL measures need to be valid and reliable (Guyatt et al., 1993; Hays et al., 1993). Since the DLQI is the most common dermatology-specific HRQoL measure and can influence treatment and policy, good validity and reliability is essential.

Reliability

The reliability of an instrument is its ability to measure the target characteristics or construct consistently (LoBiondo-Wood & Haber, 2014). When measuring HRQoL, we have to use a ‘proxy indicator’ in the form of a self-report questionnaire as QoL cannot be directly observed (DeVellis, 2006). Therefore, what we measure is not HRQoL itself but the effect it has on an instrument we create to measure its indirect effects (DeVellis, 2006).

According to Classical Test Theory, the observed scores captured by such a measure are comprised of two components; a true score and random error (Hays et al., 1993). A true score is concerned with the measurement of the target attitude, attribute or behaviour (LoBiondo-Wood & Haber, 2014); error relates to all of the other factors that could influence the rating of that item, which are assumed to be random (DeVellis, 2006). The proportion of true score relative to random error is an index of the accuracy of measurement and is captured through reliability coefficients. Reliability coefficients fall between 0 and 1 and indicate the association between the true score, observed score and random error (LoBiondo-Wood & Haber, 2014). The closer the reliability coefficient falls to 1, the more reliable the measure is said to be in measuring the target attribute (LoBiondo-Wood & Haber, 2014). The more error that exists (and the lower the coefficient), the less useful the observed scores are for interpretation and clinical use as they do not reflect the behaviour of interest (Henson, 2001). Acceptable reliability estimates for clinical trials are 0.70 or above (Hays et al., 1993; LoBiondo-Wood & Haber, 2014).

Two indices of measurement accuracy are commonly used; the stability coefficient and internal consistency coefficient. Stability coefficients are usually calculated from the test retest correlation coefficient, with or without correction of a change in absolute level of performance. Test-retest reliability assesses how stable responses are from one participant over time by comparing two or more scores completed by the same individual (Hays et al., 1993; Litwin, 1995). Variability within an individual's responses over time is used to estimate the random error in test-retest evaluations (Hays et al., 1993).

Internal consistency coefficients are an index of the degree to which all items within a scale measure the same construct or attribute (Henson, 2001). Internal consistency coefficients can be calculated in a number of ways (e.g., the average inter-item correlation, the intraclass correlation, split half correlations), however, most of the literature reporting on the psychometric properties of a measure tends to report Cronbach's alpha coefficient (Cronbach, 1951). The alpha coefficient is based on two factors – the number of items in a measure and the correlation between items (DeVellis, 2006). Reliability increases as the intercorrelations among test items increase. As intercorrelations among test items are maximal when all items measure the same latent construct, the alpha coefficient is known as an estimate of internal consistency. However, it would be incorrect to interpret alpha as an index of unidimensionality[2], as high alpha coefficients can be observed in scales with a known multidimensional latent structure (Streiner, 2003).

Reliability coefficients provide an important contribution to test interpretation, principally in the calculation of confidence intervals. A confidence interval is the range of values, within a specified confidence, around an observed score that a respondent's true score is likely to lie. Given the interpretation of stability coefficients and internal consistency coefficients, it is unsurprising that stability coefficients tend to be used to calculate confidence intervals for change

---

[2] Dimensionality refers to the number of latent constructs that might account for a measure's observed covariance matrix. Unidimensionality would, therefore, suggest that a scale measures a single latent dimension.

over time and internal consistency coefficients may be preferred for the estimation of measurement accuracy (i.e., the confidence internal of the true score) when a measure is used at a single point in time.

The reliability of the DLQI

The DLQI has been validated in several research studies, across cultures and conditions. A previous review of the DLQI provided a summary of articles published on the DLQI from 1994-2004 which provided data on its internal consistency, repeatability, sensitivity to change, comparison to other measures and use across disorders (Finlay & Lewis, 2004). This initial review indicated high internal consistency (ranging from 0.67-0.92) where one study fell below the 0.70 threshold and good test-retest reliability. This review provided a summary of the articles for the reader to access.

No review has yet provided a more detailed numerical description of the psychometric properties of the DLQI. Meta-analysis synthesises quantitative findings from across studies and supports the integration of the existing research (Rodriguez & Maeda, 2006). For the DLQI, this allows for the reliability estimates found across studies to be combined in one review to give readers an overall understanding of its psychometric properties. Since reliability can be affected by sample characteristics, modifications to the measure and testing procedures (Streiner, 2003), meta-analysis can support the comparison of variation in the reliability of the DLQI (Rodriguez & Maeda, 2006). This is particularly relevant for the DLQI as it is used across conditions and has been modified through translation. Meta-analysis can support clinicians to make judgment on whether the measure is best suited for their intended purpose.

Objectives

This meta-analysis therefore aims to investigate the reliability of the DLQI, more specifically the internal consistency.

Methods

Search Strategy

A literature search was conducted in July 2017. In line with the initial review published on the DLQI (Basra, Fenech, Gatt, Salek, & Finlay, 2008a), the following electronic databases were searched: Medline, EMBASE, psycINFO, PubMed and CINAHL. The searches were liberal in line with Glass's meta-analysis procedure (Rodriguez & Maeda, 2006). The previous review was also checked for additional references. The following search was used to find studies measuring the internal consistency of the DLQI:

{"DLQI" OR "Dermatology Life Quality Index"}
AND
{alpha OR reliability OR "internal consistency"}

Eligibility Criteria

The initial search produced 875 papers. These were screened for eligibility using inclusion and exclusion criteria as outlined in Table 1. The results of the search and the application of the inclusions and exclusion criteria are reported in Figure 1.

Table 1*: Eligibility Criteria for Inclusion within Review*

Inclusion Criteria	Exclusion criteria
Paper published in the English language between 1994 and July 2017	Review articles, conference papers, protocols, appraisal and critique papers
Study sample taken from a population representing dermatology conditions which are routinely seen in dermatology clinics	
Use of the Dermatology Life Quality Index or a modified DLQI in the form of an approved modification by the originating author	The use of other Dermatology Life Quality indexes such as the Family Dermatology Life Quality Index or modified DLQI where wording/ context has changed
Statistical reporting of the overall internal consistency of the DLQI for the study sample (for example, in the form of Cronbach's alpha)	Reliability estimates reported from previous studies

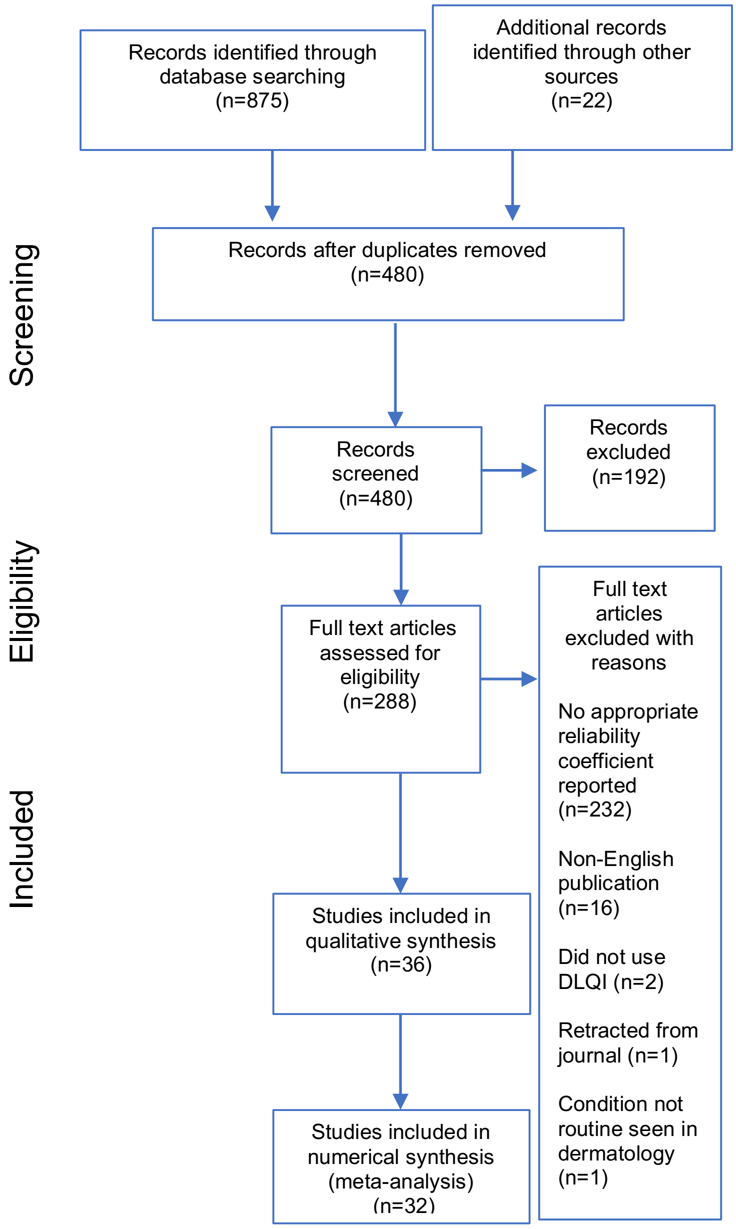


Figure 1: Flow diagram of the literature search, screening and application of inclusion and exclusion criteria

Data Extraction

One reviewer completed the literature search and assessed the papers against eligibility criteria. All conditions present within studies were sent to a dermatologist to assess their inclusion as a dermatological condition. This excluded a study which focused on burns, which was reported as not being a condition presenting in dermatology clinics. The appropriate data was then extracted from the eligible articles including descriptive detail (e.g. author, clinical setting, sample size, version of DLQI used, type of study) and data required for the synthesis (reliability coefficient, number of items, modifications made to DLQI). For papers in which multiple internal consistency estimates were reported for multiple samples, studies were split into parts A and B for data extraction. To check consistency of data extraction (Kitchenham, 2004), four of the included papers were selected at random and data from these papers was extracted by a second person. No difference between data extractors was observed.

Synthesis of results

Using the "Metafor" package from the R programming language (Viechtbauer, 2010), Cronbach’s alphas were initially aggregated. This is usually referred to as a 'reliability generalisation’ where the variation in score reliability across different studies is examined (Henson, 2001; Vacha-Haase, 1998). Data required for this includes the alpha coefficient, the number of items in the measure and the sample size. This data was extracted from the studies during the data collection process. When aggregating the estimates, it is possible to use either the raw alpha value or transformed values (Bonett, 2002; Bonett, 2010; Hakstian & Whalen, 1976). Transforming alpha is often recommended as it allows for better normal distribution as the inverse log linearises the coefficients. Therefore, transformed alpha values (using the transformation described by Bonett, 2010) were used for the calculation of the meta-analyses but, in order to aid interpretability, the figures and tables in this review were back-transformed into raw alpha values where possible.

A fixed effects or random effects model can be used to calculate the meta-analytic effect. A fixed-effects model assumes that every study will share the same effect size with the same accuracy and error (Brockwell & Gordon, 2001). For example, it may be assumed that an experiment within a lab will achieve the same results every time it is conducted. The random effects model on the other hand does not assume that the means across studies are equal, but that studies will vary in their estimated true effect sizes and there will be distribution (Borenstein, Hedges, Higgins, & Rothstein, 2010; Brockwell & Gordon, 2001). Since the studies assessing the reliability of the DLQI were conducted by independent researchers, across different samples in different settings and required self-report, a random effects model was used. This was deemed most appropriate as there are uncontrolled factors within the research compared to experimental trials with high internal control. The random effects model assumes that the response is a random variate.

Testing for Heterogeneity

Since meta-analysis aims to aggregate effect sizes across studies, the consistency of the effects is of key importance (Higgins, Thompson, Deeks, & Altman, 2003). Differences between studies such as the use of different research designs, study populations and variation in the administration of measures can all potentially lead to differences seen in the estimate of alpha (Higgins & Thompson, 2002). A test of heterogeneity assesses whether the effects observed are consistent across studies or whether the level of variance is greater than what might expect by known methodological factors (Higgins et al., 2003; Higgins & Thompson, 2002). If heterogeneity is high, then it is likely that uncontrolled methodological factors may be biasing the estimation of the alpha coefficient and the meta-analytic summary may be biased. If this is the case then emphasis will be placed upon the identification of key sources of variation within the meta-analytic summary.

Heterogeneity may be assessed using a number of indices (e.g., tau, tau^2, Q and chi squared) however, Higgins I^2 (Higgins, 2003) has a number of advantages. Firstly, I^2 is easily interpreted. It ranges from 0-100%, and quantifies the degree of variation due to heterogeneity across studies in a meta-analysis. This is advantageous over Cochran's Q which does not describe the extent of the heterogeneity but only its presence or absence (Huedo-Medina, Sánchez-Meca, Marín-Martínez, & Botella, 2006). Secondly, the value of I^2 is not dependent upon the number of studies in meta-analysis and can, therefore, be directly compared between different meta-analyses and different outcomes (Higgins et al., 2003).

Higgins (2003) suggests that I^2 values of 25%, 50%, and 75% suggest low, moderate, and high heterogeneity. When heterogeneity is deemed unacceptable, further analysis can be undertaken to identify the sources of variance not attributable to random effects in the estimation of the alpha coefficient. Given the differences in study design, clinical population, country of origin, etc., the higher value of 75% was chosen as a cut-off for unacceptable or problematic heterogeneity.

Assessing Methodological Variation

A quality effects model was also calculated. The quality effects model weights user defined variables (such as methodological quality) against studies with a greater risk of bias. Methodological variation was assessed by using the random effects model but weighted by the quality index for each study. A quality index was calculated using a quality framework. This allows for studies to be weighted against risk of bias. Bias can be introduced by a number of factors including differences in research design and the standards implemented in methodology. Though the random effects model accounts for a distribution of true effect sizes, it does not account for poor study quality within the conclusions drawn which may make them invalid (Doi & Thalib, 2008). Consequently, the quality effects model estimates the meta-analytical effect as if all of the studies had been of high methodological quality, accounting for the risk of bias more robustly.

Identifying Influential Studies

To assess whether any specific studies were highly influential to the observed meta-analytic combined effect, each study was removed in turn from the overall meta-analytic effect. If the removal of a study leads to a substantial change to the meta-analytic effect (i.e. if it falls outside of the 95% CI of the overall meta-analytic effect), that study can be said to have a disproportionate effect upon the meta-analysis. This ‘leave one out’ method helps to distinguish influential studies.

Assessing Publication Bias

Publication bias refers to the bias found in published literature. This is said to arise from statistical significance being a predominant driver in publishing findings (Duval & Tweedie, 2000; Easterbrook, Berlin, Gopalan, & Matthews, 1991) both from the perspective of researchers and editors. This results in a bias in what is published and what research is not. Since meta-analysis combines results across individual published studies, results may be unrepresentative (even when all published studies are accounted for) due to the lack of inclusion of the unpublished data (Duval & Tweedie, 2000).

To overcome this, the Trim and Fill funnel plot is often used in meta-analysis to detect publication bias (Duval & Tweedie, 2000). A funnel plot is a scatter graph which captures individual studies and their effect sizes. This usually means the largest samples with the most precise effect sizes are at the top of the plot and smaller studies with less precision are at the base (Duval & Tweedie, 2000; Peters, Sutton, Jones, Abrams, & Rushton, 2007). Without bias, the plot should be an inverted and symmetrical funnel shape. The Trim and Full funnel plot corrects for publication bias by ‘trimming’ away asymmetrical outliers, estimating the true centre of the plot and replacing the ‘trimmed’ studies and their mirrored equivalents (Duval & Tweedie, 2000).

A more quantitative and less subjective method is Rosenthal’s ‘fail safe N’ method (Duval & Tweedie, 2000; Rosenthal, 1979) . This offers a measure of the risk posed by the sampling bias (Orwin, 1983). Since unpublished studies are likely to be non-significant or showing small effect sizes, the fail-safe method calculates the number of studies needed to make the result nonsignificant (we used the assumption that effect size would be 0 for unpublished studies) (Orwin, 1983). In this way, if the number of studies needed to make the results nonsignificant is high, there would be less concern compared to if only a few were needed to nullify the effect.

Additional analyses

Analysis of Moderator variables

To assess whether there was a difference in meta-analytic effect dependent on differences in research design (e.g. difference in sample, setting, version of DLQI, methodological bias), meta-analysis estimates were conducted individually for different subgroups.

Results

Study selection

Of the thirty-six studies included, four studies were excluded from meta-analysis. Two studies did not report an overall, specific alpha coefficient for the full DLQI (Madarasingha, de Silva, & Satgurunathan, 2011; Silverberg & Silverberg, 2013) and the samples from which the estimate came from were unclear for two studies (Chuh & Chan, 2005; Van Beugen et al., 2015). Researchers were contacted for further details for inclusion; however, no further details were provided at the time of this review. This left 32 studies for the data synthesis. Five of the included studies reported two alpha coefficients for two distinct samples and therefore this data was separated for the meta synthesis. This gave a total of 37 datasets.

Study Characteristics

Table 2 describes the characteristics of each study. Excluded studies from the meta-analysis have been given an asterisk (*).

Table 2: *Characteristics of Included Studies*

Study	Year	Alpha	Items	N	Skin Disorder	Country	Sampling	Version of DLQI	Original vs Modified	Context of DLQI use
Abbas et al – A	2015	0.752	10	61	Pachyonychia Congenita	Multiple	Non-clinical sampling	DLQI	Original	Validation of another measure
Abbas et al – B	2015	0.877	12	61	Pachyonychia Congenita	Multiple	Non-clinical sampling	PCQoL	Modified	Validation of another measure
Aghaei et al	2009	0.79	10	125	Psoriasis	Iran	Clinical sampling	Persian	Original	Validation of another measure
Aghaei et al	2004	0.77	10	70	Vitiligo	Iran	Clinical sampling	Persian	Original	Validation of DLQI
An et al	2013	0.889	10	149	Neurodermatitis	China	Clinical sampling	Chinese	Original	Quality of life
An et al	2009	0.765	10	64	Lepromatous leprosy	China	Clinical sampling	Chinese	Original	Quality of life
Badia et al	1999	0.83	10	94	Eczema and Psoriasis	Spain	Clinical sampling	Spanish	Original	Validation of DLQI
Balkrishnan et al	2003	0.8	10	102	Melasma	USA	Clinical sampling	English	Original	Validation of another measure
Baranzoni at al	2007	0.787	10	22	All dermatological diseases	Italy	Clinical sampling	Italian	Original	Validation of DLQI
Chandrasena et al	2007	0.67	10	91	Filarial lymphedema	Sri Lanka	Clinical sampling	Modified English DLQI	Modified	Validation of DLQI
Chernyshov - A	2016	0.81	10	63	Atopic Dermatitis	Ukraine	Clinical sampling	Ukranian	Original	Quality of life

Study	Year	Alpha	Items	N	Skin Disorder	Country	Sampling	Version of DLQI	Original vs Modified	Context of DLQI use
Chernyshov – B	2016	0.86	10	63	Psoriasis	Ukraine	Clinical sampling	Ukranian	Original	Quality of life
Chuh and Chan *	2005	0.909	10	?	All Dermatological diseases and controls	China	Clinical sampling	Cantonese	Original	Quality of Life
He at al	2013	0.91	10	851	Psoriasis	China	Clinical sampling	Chinese	Original	Validation of DLQI
Henok and Davey	2008	0.9	10	148	Podoconiosis	Ethiopia	Clinical sampling	Amharic	Original	Validation of DLQI
Jin-Gang et al	2010	0.84	10	96	Scabies	China	Clinical sampling	Chinese	Original	Quality of life
Jobanputra	2000	0.83	12	607	All dermatological diseases	South Africa	Clinical sampling	English, Xhosa and Afrikaans - Two extra questions culture specific	Original	Quality of Life
Khoudri et al	2013	0.84	10	176	Psoriasis	Morocco	Clinical sampling	Arabic	Original	Quality of Life and Validation of the DLQI
Lennox and Leahy - A	2004	0.89	10	403	Urticaria	USA	Clinical sampling	English	Original	Validation of DLQI
Lennox and Leahy - B	2004	0.87	10	423	Urticaria	USA	Clinical sampling	English	Original	Validation of DLQI
Liu et al	2012	0.82	10	131	Urticaria	China	Clinical sampling	Chinese	Original	Quality of life

Study	Year	Alpha	Items	N	Skin Disorder	Country	Sampling	Version of DLQI	Original vs Modified	Context of DLQI use
Liu et al	2013	0.673	10	106	Pruitic Papular Eruption	China	Clinical sampling	Simplified Chinese Version	Original	Validation of DLQI
Lockhart et al	2013	0.93	10	58	Vulval Intraepithelial neoplasia (VIN)	UK	Clinical sampling	English	Original	Validation of another measure
Mabel et al	2016	0.87	15	218	Viral warts	Singapore	Clinical sampling	DLQI-VW	Modified	Quality of life
Madarasingha et al *	2011	-	10	200	All dermatological diseases	Sri Lanka	Clinical sampling	Sinhal	Original	Validation of DLQI
Mazzotti et al	2005	0.83	10	900	Psoriasis	Italy	Clinical sampling	Italian	Original	Validation of DLQI
McKenna et al	2003	0.88	10	148	Psoriasis	UK	Non-clinical sampling	English	Original	Validation of another measure
Mork et al	2002	0.9	10	230	Psoriasis	Norway	Clinical sampling	Norwegian	Original	Validation of DLQI
Ozturkcan et al	2006	0.87	10	79	All dermatological diseases	Turkey	Clinical sampling	Turkish	Original	Validation of DLQI
Pereira et al	2016	0.74	10	58	Skin Tumour	Portugal	Clinical sampling	Portuguese	Original	Quality of life
Qi et al	2014	0.887	10	698	Alopecia	China	Clinical sampling	Chinese	Original	Quality of life
Shikiar et al – A	2003	0.871	10	498	Psoriasis	USA and Canada	Clinical sampling	English	Original	Validation of multiple measures

Study	Year	Alpha	Items	N	Skin Disorder	Country	Sampling	Version of DLQI	Original vs Modified	Context of DLQI use
Shikiar et al - B	2003	0.869	10	597	Psoriasis	USA and Canada	Clinical sampling	English	Original	Validation of multiple measures
Shikiar et al – A	2005	0.87	10	403	Urticaria	USA and Canada	Clinical sampling	English	Original	Validation of DLQI
Shikiar et al – B	2005	0.84	10	423	Urticaria	USA and Canada	Clinical sampling	English	Original	Validation of DLQI
Shikiar et al	2006	0.89	10	147	Psoriasis	USA and Canada	Clinical sampling	English	Original	Validation of multiple measures
Silverberg and Silverberg *	2013	-	10	1525	Vitiligo and Dermatitis	USA	Clinical sampling	English	Original	Quality of Life
Takahashi et al	2006	0.83	10	197	Acne	Japan	Clinical sampling	Japanese	Original	Validation of DLQI
Thomas et al	2014	0.73	10	36	Lymphatic Filariasis	India	Clinical sampling	Malaya	Original	Comparison of measures
van Beugen et al *	2015	0.85	10	?	Psoriasis	Netherlands	Mixed Sampling	English (no statement around the Dutch version)	Original	Validation of another measure
Zachariae et al	2000	0.88	10	286	All dermatological diseases	Denmark	Clinical sampling	Danish	Original	Validation of DLQI

Risk of bias in individual studies

Table 3: *Assessment of risk of bias*

Domain	**Criteria**	**Low, unclear risk and high risk**	
1) Selection Bias	Are the study participants used representative of the target population for the measure? (e.g. would the sample be classed as a dermatological population or at least one group included be defined as dermatological)	🟩	Dermatology specific sample recruited
		🟧	A mixed sample where dermatology/ non-dermatology samples cannot be distinguished
		🟥	Only non-dermatology sample used
2) Performance bias	Were their restrictions or alterations to the standardised administration of the measure (e.g. was the DLQI completed with an investigator, were questions added changing the scoring of the measure i.e. skin specific and not general) Allowed: cultural and linguistic variation in questions to ensure appropriate responding	🟩	Standardised administration assumed
		🟧	Some minor adaptations such as support being given by an interviewer
		🟥	Major adaptation such as multiple questions added to DLQI and administered by an interviewer
3) Detection Bias	Was the measure shortened or were questions changed?	🟩	No reported changes made to measure
		🟧	Minor changes to measure such as changes to questions reported
		🟥	Questions removed from measure
4) Statistical Bias	Missing information or incomplete information relating to the internal consistency of the study's target population (e.g. unclear whether full sample was used for the estimate or missing data)	🟩	No data missing relevant to internal consistency
		🟧	Some data missing
		🟥	No information given around where internal consistency estimate has been calculated or a lot of missing information
5) Reporting Bias	Are the data related to the internal consistency that are reported selectively chosen by the author(s)? (e.g. based on a subsample data or reporting on part of measure only)	🟩	No data missed in reporting
		🟧	Some data missing from reporting information
		🟥	Important data missing from reporting information
6) Generalisability	Does the study allow for generalisation to the target population and fulfil the aims of the review?	🟩	Multiple skin disorders sampled
		🟧	One skin disorder sample
		🟥	Non-dermatology sample

A quality framework was developed to assess the risk of bias within studies (see Table 3). Higgins (2011) has strongly recommended that, rather than use “off-the-shelf” quality criteria, the assessment of risk of bias should be tailored to the methodological issues relating to a specific review. Therefore, the risk of bias framework was created for the specific needs of this review.

The risk of bias for each of these six dimensions is reported for each study in Table 4. Columned numbers are representative of the different biases labelled in Table 3. Following quality appraisal of all studies, an index of the risk of bias was calculated by summing an articles score across the six bias dimensions. This “quality index” was later used as a weighting factor in the “Quality Effects Model”.

Synthesis of results

Combining the studies through a random effects model gave a meta-analytic estimate of 0.85 (CI 0.83-0.86). This appeared to estimate high internal consistency for the DLQI. The predictive interval was also calculated. This is a prediction of where 95% of future literature is likely to fall. It was estimated at 0.74-0.91, emphasising the variation of studies around the true effect.

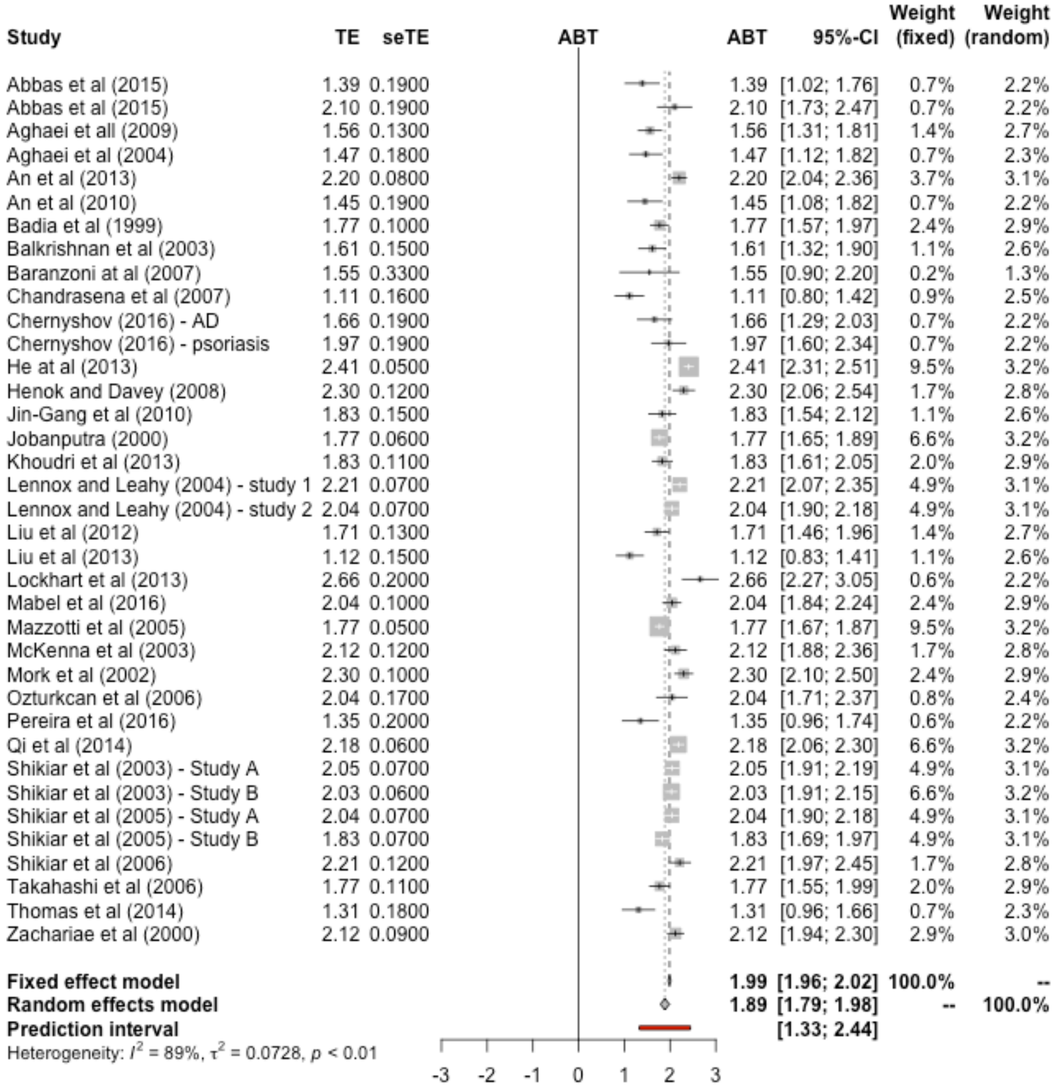
Testing Heterogeneity

A high level of heterogeneity was found within the data (Q=326.05, df 36, $p<0.0001$; $I^2 = 89\%$ [85.8%-91.4%]) as seen in Figure 2. At such a level of

Table 4: *Study level risk of bias*

Study	**1**	**2**	**3**	**4**	**5**	**6**	**Quality Index Score**
Abbas et al (2015)	🟩	🟥	🟩	🟩	🟩	🟧	70.8%
Aghaei et all (2009)	🟩	🟩	🟩	🟩	🟩	🟧	87.5%
Aghaei et al (2004)	🟩	🟩	🟩	🟩	🟩	🟧	87.5%
An et al (2013)	🟩	🟧	🟩	🟩	🟩	🟧	75.0%
An et al (2010)	🟩	🟧	🟩	🟩	🟩	🟧	75.0%
Badia et al (1999)	🟩	🟩	🟩	🟧	🟥	🟩	70.8%
Balkrishnan et al (2003)	🟩	🟩	🟩	🟩	🟩	🟧	87.5%
Baranzoni at al (2007)	🟩	🟩	🟩	🟩	🟩	🟩	100.0%
Chandrasena et al (2007)	🟩	🟧	🟩	🟩	🟩	🟧	75.0%
Chernyshov (2016)	🟩	🟩	🟩	🟧	🟩	🟧	64.3%
He at al (2013)	🟩	🟧	🟩	🟩	🟩	🟧	75.0%
Henok and Davey (2008)	🟩	🟧	🟩	🟩	🟩	🟧	75.0%
Jin-Gang et al (2010)	🟩	🟧	🟩	🟩	🟩	🟧	75.0%
Jobanputra (2000)	🟩	🟥	🟩	🟩	🟧	🟩	70.8%
Khoudri et al (2013)	🟩	🟧	🟩	🟩	🟩	🟧	75.0%
Lennox and Leahy (2004)	🟩	🟩	🟩	🟧	🟩	🟧	75.0%
Liu et al (2012)	🟩	🟩	🟩	🟩	🟩	🟧	87.5%
Liu et al (2013)	🟩	🟧	🟩	🟩	🟩	🟧	75.0%
Lockhart et al (2013)	🟩	🟩	🟩	🟩	🟩	🟧	87.5%
Mabel et al (2016)	🟩	🟥	🟧	🟩	🟩	🟧	58.3%
Mazzotti et al (2005)	🟩	🟩	🟩	🟩	🟩	🟧	87.5%
McKenna et al (2003)	🟩	🟩	🟩	🟩	🟩	🟧	87.5%
Mork et al (2002)	🟩	🟩	🟩	🟧	🟩	🟧	75.0%
Ozturkcan et al (2006)	🟩	🟩	🟩	🟧	🟩	🟩	87.5%
Pereira et al (2016)	🟩	🟩	🟩	🟧	🟩	🟧	75.0%
Qi et al (2014)	🟩	🟩	🟩	🟩	🟩	🟧	87.5%
Shikiar et al (2003)	🟩	🟩	🟩	🟧	🟩	🟧	75.0%
Shikiar et al (2005)	🟩	🟩	🟩	🟩	🟩	🟧	87.5%
Shikiar et al (2006)	🟩	🟩	🟩	🟩	🟩	🟧	87.5%
Takahashi et al (2006)	🟩	🟩	🟩	🟩	🟩	🟧	87.5%
Thomas et al (2014)	🟩	🟩	🟩	🟧	🟩	🟧	75.0%
Zachariae et al (2000)	🟩	🟩	🟩	🟩	🟩	🟩	100.0%

heterogeneity, the focus of the analysis was based on understanding the distribution of true effect sizes and carrying out subgroup analyses rather than computing significance testing of the combined effect size.



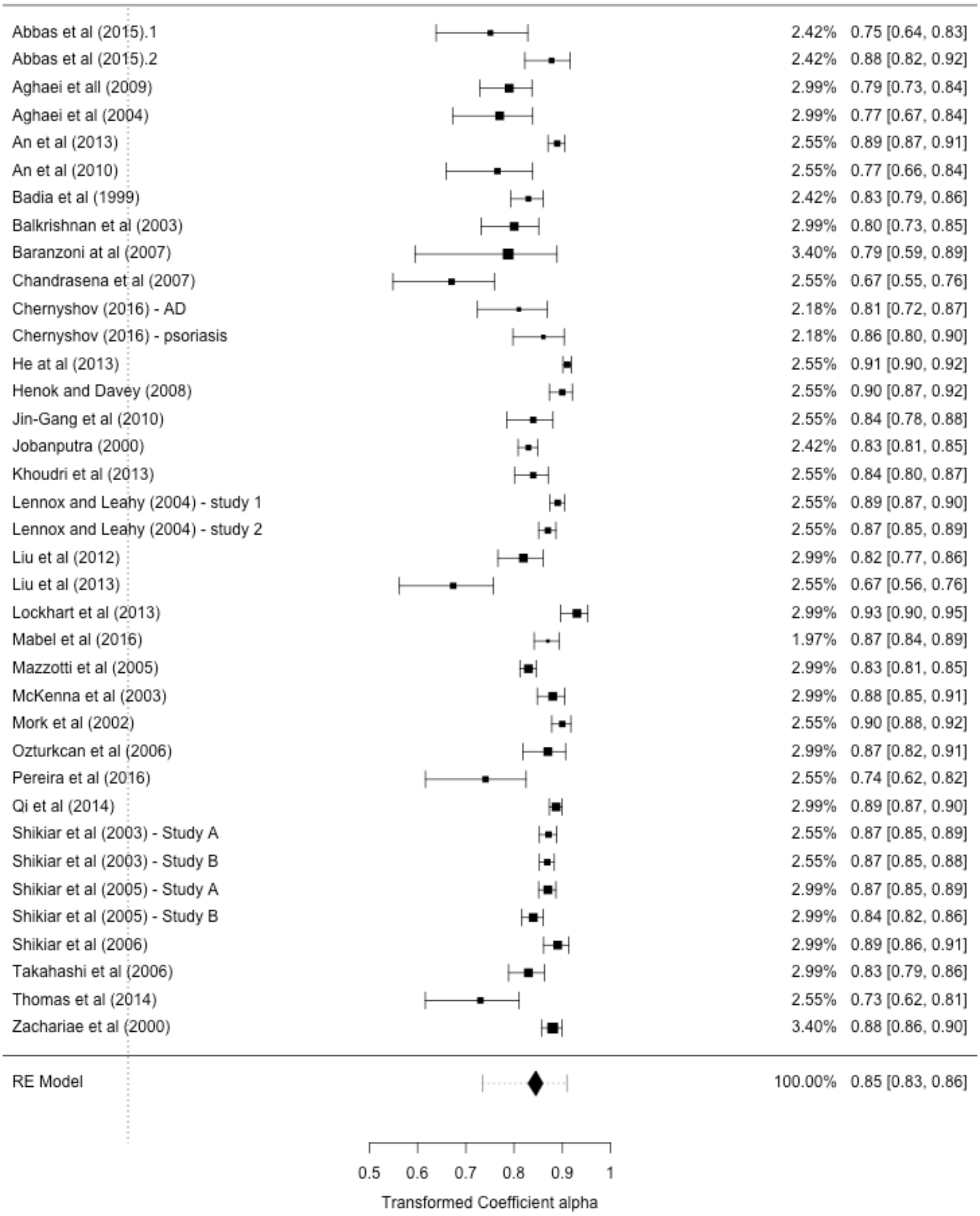
Study	TE	seTE	ABT	95%-CI	Weight (fixed)	Weight (random)
Abbas et al (2015)	1.39	0.1900	1.39	[1.02; 1.76]	0.7%	2.2%
Abbas et al (2015)	2.10	0.1900	2.10	[1.73; 2.47]	0.7%	2.2%
Aghaei et all (2009)	1.56	0.1300	1.56	[1.31; 1.81]	1.4%	2.7%
Aghaei et al (2004)	1.47	0.1800	1.47	[1.12; 1.82]	0.7%	2.3%
An et al (2013)	2.20	0.0800	2.20	[2.04; 2.36]	3.7%	3.1%
An et al (2010)	1.45	0.1900	1.45	[1.08; 1.82]	0.7%	2.2%
Badia et al (1999)	1.77	0.1000	1.77	[1.57; 1.97]	2.4%	2.9%
Balkrishnan et al (2003)	1.61	0.1500	1.61	[1.32; 1.90]	1.1%	2.6%
Baranzoni at al (2007)	1.55	0.3300	1.55	[0.90; 2.20]	0.2%	1.3%
Chandrasena et al (2007)	1.11	0.1600	1.11	[0.80; 1.42]	0.9%	2.5%
Chernyshov (2016) - AD	1.66	0.1900	1.66	[1.29; 2.03]	0.7%	2.2%
Chernyshov (2016) - psoriasis	1.97	0.1900	1.97	[1.60; 2.34]	0.7%	2.2%
He at al (2013)	2.41	0.0500	2.41	[2.31; 2.51]	9.5%	3.2%
Henok and Davey (2008)	2.30	0.1200	2.30	[2.06; 2.54]	1.7%	2.8%
Jin-Gang et al (2010)	1.83	0.1500	1.83	[1.54; 2.12]	1.1%	2.6%
Jobanputra (2000)	1.77	0.0600	1.77	[1.65; 1.89]	6.6%	3.2%
Khoudri et al (2013)	1.83	0.1100	1.83	[1.61; 2.05]	2.0%	2.9%
Lennox and Leahy (2004) - study 1	2.21	0.0700	2.21	[2.07; 2.35]	4.9%	3.1%
Lennox and Leahy (2004) - study 2	2.04	0.0700	2.04	[1.90; 2.18]	4.9%	3.1%
Liu et al (2012)	1.71	0.1300	1.71	[1.46; 1.96]	1.4%	2.7%
Liu et al (2013)	1.12	0.1500	1.12	[0.83; 1.41]	1.1%	2.6%
Lockhart et al (2013)	2.66	0.2000	2.66	[2.27; 3.05]	0.6%	2.2%
Mabel et al (2016)	2.04	0.1000	2.04	[1.84; 2.24]	2.4%	2.9%
Mazzotti et al (2005)	1.77	0.0500	1.77	[1.67; 1.87]	9.5%	3.2%
McKenna et al (2003)	2.12	0.1200	2.12	[1.88; 2.36]	1.7%	2.8%
Mork et al (2002)	2.30	0.1000	2.30	[2.10; 2.50]	2.4%	2.9%
Ozturkcan et al (2006)	2.04	0.1700	2.04	[1.71; 2.37]	0.8%	2.4%
Pereira et al (2016)	1.35	0.2000	1.35	[0.96; 1.74]	0.6%	2.2%
Qi et al (2014)	2.18	0.0600	2.18	[2.06; 2.30]	6.6%	3.2%
Shikiar et al (2003) - Study A	2.05	0.0700	2.05	[1.91; 2.19]	4.9%	3.1%
Shikiar et al (2003) - Study B	2.03	0.0600	2.03	[1.91; 2.15]	6.6%	3.2%
Shikiar et al (2005) - Study A	2.04	0.0700	2.04	[1.90; 2.18]	4.9%	3.1%
Shikiar et al (2005) - Study B	1.83	0.0700	1.83	[1.69; 1.97]	4.9%	3.1%
Shikiar et al (2006)	2.21	0.1200	2.21	[1.97; 2.45]	1.7%	2.8%
Takahashi et al (2006)	1.77	0.1100	1.77	[1.55; 1.99]	2.0%	2.9%
Thomas et al (2014)	1.31	0.1800	1.31	[0.96; 1.66]	0.7%	2.3%
Zachariae et al (2000)	2.12	0.0900	2.12	[1.94; 2.30]	2.9%	3.0%
Fixed effect model			**1.99**	**[1.96; 2.02]**	**100.0%**	**--**
Random effects model			**1.89**	**[1.79; 1.98]**	**--**	**100.0%**
Prediction interval				**[1.33; 2.44]**		

Heterogeneity: $I^2 = 89\%$, $\tau^2 = 0.0728$, $p < 0.01$

Figure 2: Forest Plot of the random effects model to calculate the meta-analytic effect and test for heterogeneity (using ABT transformed alpha values)

Methodological Variation

When weighting for methodological variation using the quality effects model (Figure 3), the meta-analytic effect was similar to the non-weighted estimate (0.85 [CI 0.83-0.86], p<0.001) and heterogeneity remained high (Q (df=36)= 326.05, p<0.0001; I^2 = 89%).



Abbas et al (2015).1	2.42%	0.75 [0.64, 0.83]
Abbas et al (2015).2	2.42%	0.88 [0.82, 0.92]
Aghaei et all (2009)	2.99%	0.79 [0.73, 0.84]
Aghaei et al (2004)	2.99%	0.77 [0.67, 0.84]
An et al (2013)	2.55%	0.89 [0.87, 0.91]
An et al (2010)	2.55%	0.77 [0.66, 0.84]
Badia et al (1999)	2.42%	0.83 [0.79, 0.86]
Balkrishnan et al (2003)	2.99%	0.80 [0.73, 0.85]
Baranzoni at al (2007)	3.40%	0.79 [0.59, 0.89]
Chandrasena et al (2007)	2.55%	0.67 [0.55, 0.76]
Chernyshov (2016) - AD	2.18%	0.81 [0.72, 0.87]
Chernyshov (2016) - psoriasis	2.18%	0.86 [0.80, 0.90]
He at al (2013)	2.55%	0.91 [0.90, 0.92]
Henok and Davey (2008)	2.55%	0.90 [0.87, 0.92]
Jin-Gang et al (2010)	2.55%	0.84 [0.78, 0.88]
Jobanputra (2000)	2.42%	0.83 [0.81, 0.85]
Khoudri et al (2013)	2.55%	0.84 [0.80, 0.87]
Lennox and Leahy (2004) - study 1	2.55%	0.89 [0.87, 0.90]
Lennox and Leahy (2004) - study 2	2.55%	0.87 [0.85, 0.89]
Liu et al (2012)	2.99%	0.82 [0.77, 0.86]
Liu et al (2013)	2.55%	0.67 [0.56, 0.76]
Lockhart et al (2013)	2.99%	0.93 [0.90, 0.95]
Mabel et al (2016)	1.97%	0.87 [0.84, 0.89]
Mazzotti et al (2005)	2.99%	0.83 [0.81, 0.85]
McKenna et al (2003)	2.99%	0.88 [0.85, 0.91]
Mork et al (2002)	2.55%	0.90 [0.88, 0.92]
Ozturkcan et al (2006)	2.99%	0.87 [0.82, 0.91]
Pereira et al (2016)	2.55%	0.74 [0.62, 0.82]
Qi et al (2014)	2.99%	0.89 [0.87, 0.90]
Shikiar et al (2003) - Study A	2.55%	0.87 [0.85, 0.89]
Shikiar et al (2003) - Study B	2.55%	0.87 [0.85, 0.88]
Shikiar et al (2005) - Study A	2.99%	0.87 [0.85, 0.89]
Shikiar et al (2005) - Study B	2.99%	0.84 [0.82, 0.86]
Shikiar et al (2006)	2.99%	0.89 [0.86, 0.91]
Takahashi et al (2006)	2.99%	0.83 [0.79, 0.86]
Thomas et al (2014)	2.55%	0.73 [0.62, 0.81]
Zachariae et al (2000)	3.40%	0.88 [0.86, 0.90]
RE Model	100.00%	0.85 [0.83, 0.86]

Figure 3: Forest plot of the random effects model, weighted by quality index

Identifying Influential studies

The overall meta-analytic effect was estimated at 0.85. By removing each study in turn, there was no deviation greater than 0.02 from this estimate.

Therefore, we can conclude that no individual study was excessively influential effect on the overall meta-analytic effect.

Risk of Bias across studies -publication bias

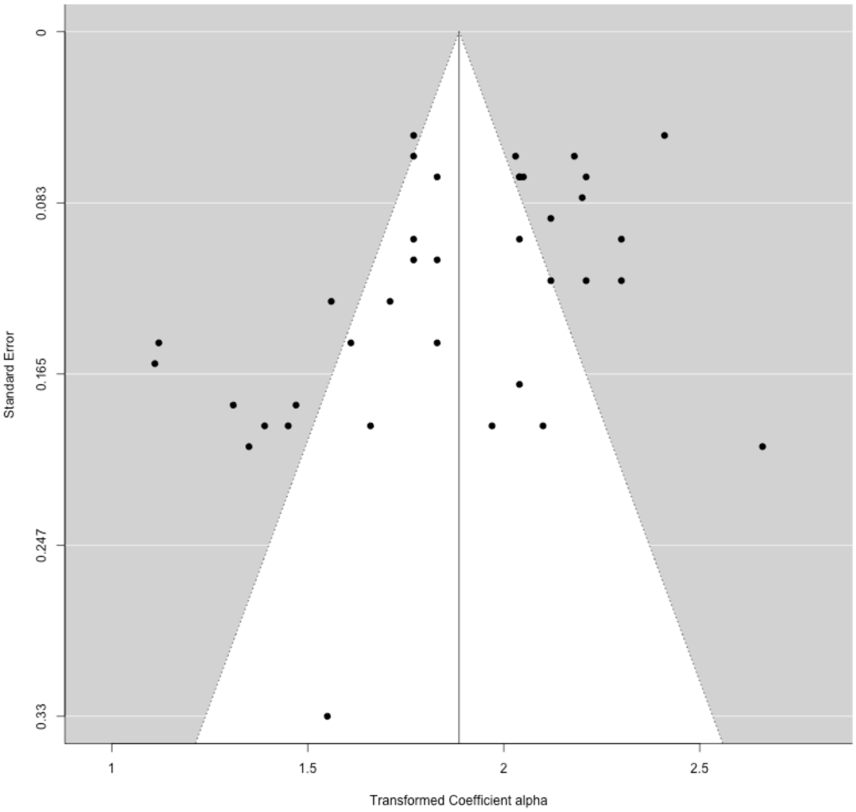


Figure 4: Trim and Fill Funnel Plot prior to correction

As can be seen in Figure 4, the observed studies are shown as dark circles. Studies with smaller samples tended to have smaller effect sizes. The uncorrected estimate of the effect size is 0.85 (CI 0.83, 0.86). Figure 5 shows the corrected funnel plot. The imputed studies are shown as empty circles, and the imputed estimate is 0.86 (95% CI 0.85, 0.88). The 'adjusted' point estimate suggests a greater effect size than the original analysis estimate. This therefore suggests that the true effect may be higher than initially expected. Using the

Rosenthal algorithm, 175158 unpublished null studies are required to reduce the effect to non-significance based on the 37 included studies. This leads us to believe the risk of publication bias is low within this meta-analysis.

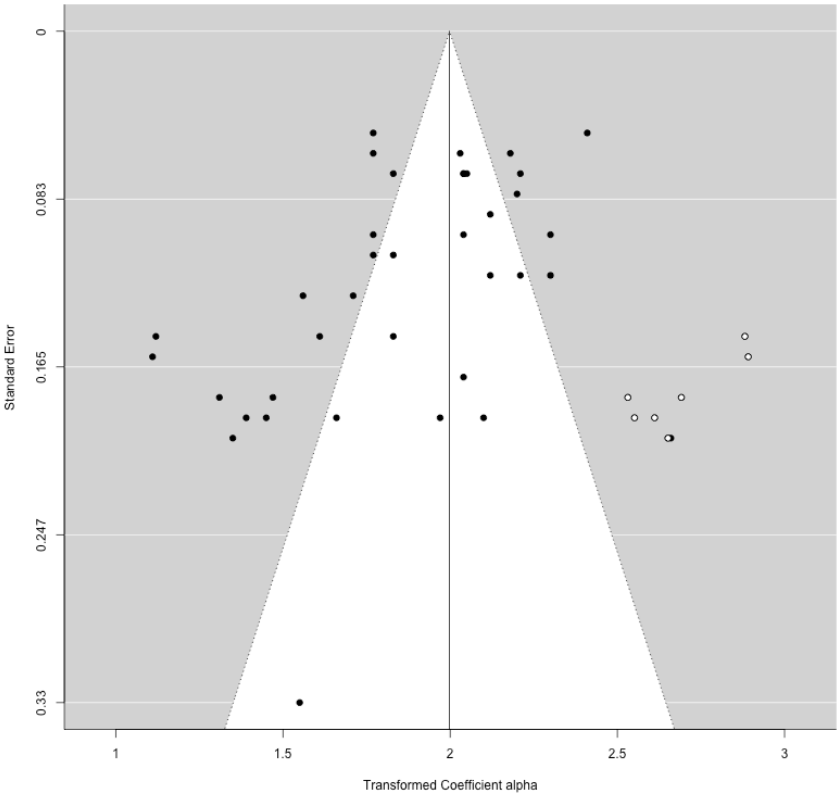


Figure 5: Trim and Fill Funnel Plot correcting for publication bias

Additional analyses

Moderator Variables

Table 5 and 6 report results from subgroup analysis. Selection bias was not included as there were no subgroups to compare. Subgroup differences based on quality and study characteristics showed no significant differences between groups. There was no significant reduction in heterogeneity. Therefore, the heterogeneity remained unexplained.

Table 5*: Subgroup analysis by quality*

Quality Variable	Level of Risk	Number of studies	Alpha value (Confidence Intervals)	Within Group heterogeneity (I^2)	Between group differences Q	df	P
Performance Bias	Low	25	0.85 (0.84, 0.87)	83.1%	0.81	2	0.67
	Unclear	8	0.83 (0.77, 0.88)	95.1%			
	High	4	0.84 (0.80, 0.88)	75.5%			
Detection Bias	Low	36	0.85 (0.83, 0.86)	89.3%	2.01	1	0.16
	Unclear	1	0.87 (0.84, 0.89)	–			
	High	–	–	–			
Statistical Bias	Low	26	0.85 (0.83, 0.86)	90.8%	0.43	1	0.51
	Unclear	11	0.86 (0.83, 0.87)	80.8%			
	High	–	–	–			
Reporting Bias	Low	35	0.85 (0.83, 0.86)	88.9%	2.84	2	0.24
	Unclear	1	0.83 (0.81, 0.85)	–			
	High	1	0.83 (0.79, 0.86)	–			
Generalisability	Low	5	0.85 (0.82, 0.87)	70.2%	0.01	1	0.99
	Unclear	32	0.85 (0.83, 0.86)	89.8%			
	High	–	–	–			

Table 6*: Subgroup analysis by study characteristics*

Group Variable	Subgroup	Number of studies	Alpha value (Confidence Intervals)	Within Group heterogeneity (I^2)	Between group differences		
					Q	df	P
Skin Disorder	Multiple	5	0.85 (0.82, 0.87)	70.2%	5.07	3	0.17
	Psoriasis	10	0.87 (0.84, 0.89)	91.8%			
	Urticaria	5	0.86 (0.84, 0.88)	80.5%			
	Other	17	0.83 (0.79, 0.86)	90%			
Language	English	14	0.86 (0.84, 0.88)	83.6%	3	2	0.22
	Chinese	7	0.85 (0.80, 0.88)	94.2%			
	Other	16	0.84 (0.81, 0.86)	80.5%			
Original or modified (item changes)	Original	33	0.85 (0.84, 0.87)	88.6%	0.64	1	0.42
	Modified	4	0.83 (0.76, 0.88)	88.9%			
Purpose of Study	Validation of DLQI	21	0.85 (0.83 0.87)	91.2%	0.22	2	0.89
	Quality of Life	10	0.84 (0.81, 0.87)	84.1%			
	Validation of another measure	6	0.85 (0.79, 0.89)	86.3%			

Discussion

Summary of Evidence

This meta-analysis aimed to quantify the internal consistency of the DLQI – the most used dermatology HRQoL measure. Thirty-six studies were identified from the literature search, 32 of which were suitable for meta-analysis. Four studies did not report internal consistency clearly enough to be included within the analysis. The literature search also highlighted 232 studies using the DLQI but not reporting reliability data. The meta-analysis suggests that the internal consistency of the DLQI is generally high (0.85, CI 0.83, 0.86). The previous review reported internal consistencies between 0.67-0.92 (Basra, Fenech, Gatt, Salek, & Finlay, 2008b). The current review is the first to quantify the internal consistency of the DLQI across published studies and has highlighted internal reliability of the DLQI across the broad range of samples it covers (different countries, disorders, versions of DLQI).

Compared to this meta-analytic effect, there is considerable, unexplained heterogeneity around the true effect within the literature (0.74 – 0.91). Though the meta-analytic effect and predictive interval suggests the measure falls above the recommended reliability for use in clinical practice across samples (Hays et al., 1993), the current review was unable to identify the source of the variation. Therefore, even though it seems a reasonable summary of the literature, until we have understood where this variation comes from, a more cautious approach may be to use the alpha coefficient for the sample researchers are using the DLQI for, as outlined in Table 6.

Reporting Reliability

One study did not report the total alpha coefficient (Madarasingha et al., 2011); the subscale estimates (0.56, 0.74, 0.69, 0.44) suggest it would have been low, however without a total score it could not be included. Attempts were made to contact the researchers where reporting was not clear to include the data within the meta-analysis to no effect. This highlights the potential impact of reporting bias on this meta-analysis. This is particularly important as one study validated a translated DLQI. Consequently, this version of the DLQI may not be internally reliable when used in future studies. Future researchers using this measure would therefore need to calculate the internal consistency for their sample to assess internal consistency.

Henson (2001) suggests that researchers should calculate and report reliability for their own sample when using a measure as standard practice, rather than report reliability from previous studies. This makes sense as reliability is a measure of the test scores obtained from a sample rather than the reliability of the measure itself (Henson, 2001). Therefore, it is likely to vary somewhat between samples. For the DLQI, most studies published which implemented the measure did not report their internal constancy estimates in line with findings from previous researchers concerning low reporting of reliability (Henson, 2001; Vacha-Haase, 1998). The Task Force on Statistical Inference have suggested that researchers report reliability data even when the study is not psychometric in nature (Wilkinson, 1999). Since reliability within the sample can impact on interpretation of the effect sizes, this information provides transparency for readers when interpreting treatment effect (Henson, 2001). Since the DLQI is predominantly used across clinical trials of treatment effect in the published literature, knowing whether the measure is internally reliable when interpreting effects on HRQoL is critical. This meta-analysis does provide a high aggregated alpha for internal consistency but draws attention to the fact that this does not mean that there is no heterogeneity between samples.

Limitations

This meta-analysis focused on the internal consistency of the DLQI. When thinking about reliability, stability of a measure over time is also important. Though we can assume that the items on the DLQI are inter-correlated, we are unable to draw conclusions on the reliability of the DLQI over time. Since the DLQI is used as a measure of treatment effect, it would be beneficial to identify whether it has good test-retest reliability across studies. A sister review will consequently be conducted to further quantify the reliability of the DLQI to complement the current review.

Regarding methodology, one researcher completed the literature search and identified studies against inclusion/ exclusion. This may have led to error in the sifting process. Inter-researcher consistency would have strengthened this process through a parallel sifting process (Kitchenham, 2004). Cross-checking of data extraction did occur and was a practical solution for this research. Nevertheless, inter-research consistency would have been most appropriate. Studies reported in a non-English language were also excluded due to resources needed to translate and an updated review would benefit from their inclusion.

The search for internal consistency did not include terms for different types of internal consistency measurements such as KR-20. Therefore, studies reporting internal consistency in different ways may have been missed. One study reported the internal consistency as the range of inter-item correlation (Finlay & Khan, 1994). However, this could not be transformed into an alpha coefficient to be included within the analysis. Future reviews would benefit from ensuring any non-alpha reliability estimates are searched for more specifically and if possible, transformed and included.

Clinical Implications

When thinking about the impact of this meta-analysis on clinical practice, the predictive internal and meta-analytic effect fall above the suggested threshold (0.70) advised for instruments to be used in practice (Hays et al., 1993; LoBiondo-Wood & Haber, 2014). Therefore, this review suggests that the DLQI is suitable to measure HRQoL of dermatological conditions in practice. However, it is unable to provide implications for the DLQI's ability to be used as an outcome measure.

Conclusions

In summary, this meta-analysis is the first to quantify the internal consistency of the DLQI and has identified some important recommendations for researchers making use of the DLQI in the future. In line with previous recommendations, reporting of internal consistency across studies using the DLQI is recommended to assess its reliability for individual samples and allow for more effective interpretation of treatment effect. Since heterogeneity exists, it is recommended that this occurs across studies regardless of study objectives. Future research on explaining the heterogeneity within internal consistency estimates would also be beneficial to enhance the current review and better make sense of the variation across studies. The reporting of the DLQI across treatment studies could also support this. Finally, a review of the test-retest reliability can also further shape our understanding of the repeatability of the DLQI over time and will be conducted by the current researchers to enhance the current findings. It is hoped that this will support researchers and clinicians using the DLQI to understand its reliability and utility more confidently.

The current review brings together research conducted on the internal consistency of the DLQI to date and provides evidence of its high internal consistency. It is hoped that this alongside the gaps identified within the published literature (e.g. reporting of alpha within interventions studies, heterogeneity) can support effective use of the DLQI.

References

Abbas, M., Schwartz, M. E., Smith, F. J., McLean, W. H., & Hull, P. R. (2015). PCQoL: A Quality of Life Assessment Measure for Pachyonychia Congenita. *Journal of Cutaneous Medicine & Surgery, 19*(1), 57-65. doi:https://dx.doi.org/10.2310/7750.2014.14017

Aghaei, S., Moradi, A., & Ardekani, G. (2009). Impact of psoriasis on quality of life in Iran. *Indian Journal of Dermatology, Venereology and Leprology, 75*(2), 220.

Aghaei, S., Sodaifi, M., Jafari, P., Mazharinia, N., & Finlay, A. Y. (2004). DLQI scores in vitiligo: reliability and validity of the Persian version. *BMC Dermatology, 4*, 8. doi:https://dx.doi.org/10.1186/1471-5945-4-8

Al-Mutairi, N., & Eldin, O. N. (2011). Clinical profile and impact on quality of life: Seven years experience with patients of alopecia areata. *Indian Journal of Dermatology, Venereology & Leprology, 77*(4), 489-493.

Alavi, A., Anooshirvani, N., Kim, W. B., Coutts, P., & Sibbald, R. G. (2014). Quality-of-Life Impairment in Patients with Hidradenitis Suppurativa: A Canadian Study. *American Journal of Clinical Dermatology, 16*(1), 61-65.

An, J. G., Liu, Y. T., Xiao, S. X., Wang, J. M., Geng, S. M., & Dong, Y. Y. (2013). Quality of life of patients with neurodermatitis. *International Journal of Medical Sciences, 10*(5), 593-598. doi:https://dx.doi.org/10.7150/ijms.5624

An, J. G., Ma, J. H., Xiao, S. X., Xiao, S. B., & Yang, F. (2010). Quality of life in patients with lepromatous leprosy in China. *Journal of the European Academy of Dermatology & Venereology, 24*(7), 827-832. doi:https://dx.doi.org/10.1111/j.1468-3083.2009.03534.x

Anker, S. D., Agewall, S., Borggrefe, M., Calvert, M., Jaime Caro, J., Cowie, M. R., . . . Kirchhof, P. (2014). The importance of patient-reported outcomes: a call for their comprehensive integration in cardiovascular clinical trials. *European Heart Journal, 35*(30), 2001-2009. doi:10.1093/eurheartj/ehu205

Atalay, S., van den Reek, J. M. P. A., van Vugt, L. J., Otero, M. E., van de Kerkhof, P. C. M., den Broeder, A. A., . . . de Jong, E. M. G. J. (2017). Tight controlled dose reduction of biologics in psoriasis patients with low disease activity: a randomized pragmatic non-inferiority trial. *BMC Dermatology, 17*, 1-7. doi:10.1186/s12895-017-0057-6

Badia, X., Mascaro, J. M., & Lozano, R. (1999). Measuring health-related quality of life in patients with mild to moderate eczema and psoriasis: clinical validity, reliability and sensitivity to change of the DLQI. The Cavide Research Group. *British Journal of Dermatology, 141*(4), 698-702. doi:https://dx.doi.org/10.1046/j.1365-2133.1999.03112.x

Baranzoni, N., Scalone, L., Mantovani, L. G., De Portu, S., Monzini, M. S., & Giannetti, A. (2007). Validation of the Italian version of the Dermatology Life Quality Index. *Giornale Italiano di Dermatologia e Venereologia, 142*(3), 209-214.

Basra, M. K., Fenech, R., Gatt, R. M., Salek, M. S., & Finlay, A. Y. (2008a). The Dermatology Life Quality Index 1994-2007: a comprehensive review of validation data and clinical results. *British Journal of Dermatology, 159*(5), 997-1035. doi:10.1111/j.1365-2133.2008.08832.x

Basra, M. K., Fenech, R., Gatt, R. M., Salek, M. S., & Finlay, A. Y. (2008b). The Dermatology Life Quality Index 1994-2007: a comprehensive review of validation data and clinical results. *British Journal of Dermatology, 159*(5), 997-1035.

Böhm, D., Schwanitz, P., Stock Gissendanner, S., Schmid-Ott, G., & Schulz, W. (2014). Symptom severity and psychological sequelae in rosacea: Results of a survey. *Psychology, Health & Medicine, 19*(5), 586-591. doi:10.1080/13548506.2013.841968

Bonett, D. G. (2002). Sample Size Requirements for Testing and Estimating Coefficient Alpha. *Journal of Educational and Behavioral Statistics, 27*(4), 335-340. doi:10.3102/10769986027004335

Bonett, D. G. (2010). Varying coefficient meta-analytic methods for alpha reliability. *Psychol Methods, 15*(4), 368-385. doi:10.1037/a0020142

Borenstein, M., Hedges, L. V., Higgins, J. P. T., & Rothstein, H. R. (2010). A basic introduction to fixed-effect and random-effects models for meta-analysis. *Research Synthesis Methods, 1*(2), 97-111. doi:10.1002/jrsm.12

Borimnejad, L., Parsa Yekta, Z., Nikbakht-Nasrabadi, A., & Firooz, A. (2006). Quality of life with vitiligo: comparison of male and female muslim patients in Iran. *Gender Medicine, 3*(2), 124-130.

Brockwell, S. E., & Gordon, I. R. (2001). A comparison of statistical methods for meta-analysis. *Statistics in medicine, 20*(6), 825-840. doi:10.1002/sim.650

Chandrasena, T. G., Premaratna, R., Muthugala, M. A., Pathmeswaran, A., & de Silva, N. R. (2007). Modified Dermatology Life Quality Index as a measure of quality of life in patients with filarial lymphoedema. *Trans R Soc Trop Med Hyg, 101*(3), 245-249. doi:10.1016/j.trstmh.2006.08.012

Chernyshov, P. V. (2016). Health-related quality of life in adult atopic dermatitis and psoriatic patients matched by disease severity. *Giornale Italiano di Dermatologia e Venereologia, 151*(1), 37-43.

Chuh, A. A. T., & Chan, H. H. L. (2005). Effect on quality of life in patients with pityriasis rosea: Is it associated with rash severity? *International Journal of Dermatology, 44*(5), 372-377. doi:http://dx.doi.org/10.1111/j.1365-4632.2005.02007.x

Cronbach, L. J. (1951). Coefficient alpha and the internal structure of tests. *psychometrika, 16*(3), 297-334.

DeVellis, R. F. (2006). Classical Test Theory. *Medical Care, 44*(11), S50-S59.

Doi, S. A., & Thalib, L. (2008). A quality-effects model for meta-analysis. *Epidemiology, 19*(1), 94-100.

Dufour, D. N., Emtestam, L., & Jemec, G. B. (2014). Hidradenitis suppurativa: a common and burdensome, yet under-recognised, inflammatory skin disease. *Postgraduate Medical Journal, 90*(1062), 216-221. doi:10.1136/postgradmedj-2013-131994

Duval, S., & Tweedie, R. (2000). Trim and Fill: A Simple Funnel-Plot–Based Method of Testing and Adjusting for Publication Bias in Meta-Analysis. *Biometrics, 56*(2), 455-463. doi:10.1111/j.0006-341X.2000.00455.x

Easterbrook, P. J., Berlin, J. A., Gopalan, R., & Matthews, D. R. (1991). Publication bias in clinical research. *Lancet, 337*(8746), 867-872.

Finlay, A. Y. (1997). Quality of life measurement in dermatology: a practical guide. *British Journal of Dermatology, 136*(3), 305-314.

Finlay, A. Y., & Khan, G. K. (1994). Dermatology Life Quality Index (DLQI)--a simple practical measure for routine clinical use. *Clinical & Experimental Dermatology, 19*(3), 210-216.

Georgieva, F. G. (2017). Hand eczema and its impact on wellbeing and quality of life of patients. *Journal of IMAB - Annual Proceeding (Scientific Papers), 23*(1), 1490-1494. doi:http://dx.doi.org/10.5272/jimab.2017231.1490

Gniadecki, R., Robertson, D., Molta, C. T., Freundlich, B., Pedersen, R., Li, W., . . . Zbrozek, A. S. (2012). Self-reported health outcomes in patients with psoriasis and psoriatic arthritis randomized to two etanercept regimens. *Journal of the European Academy of Dermatology & Venereology, 26*(11), 1436-1443. doi:10.1111/j.1468-3083.2011.04308.x

Guyatt, G. H., Feeny, D. H., & Patrick, D. L. (1993). MEasuring health-related quality of life. *Annals of Internal Medicine, 118*(8), 622-629. doi:10.7326/0003-4819-118-8-199304150-00009

Hakstian, A. R., & Whalen, T. E. (1976). A k-sample significance test for independent alpha coefficients. *psychometrika, 41*(2), 219-231. doi:10.1007/bf02291840

Hays, R. D., Anderson, R., & Revicki, D. (1993). Psychometric Considerations in Evaluating Health-Related Quality of Life Measures. *Quality of Life Research, 2*(6), 441-449.

He, Z., Lu, C., Basra, M. K., Ou, A., Yan, Y., & Li, L. (2013). Psychometric properties of the Chinese version of Dermatology Life Quality Index (DLQI) in 851 Chinese patients with psoriasis. *Journal of the European Academy of Dermatology & Venereology, 27*(1), 109-115. doi:https://dx.doi.org/10.1111/j.1468-3083.2011.04371.x

Heelan, K., Hitzig, S. L., Knowles, S., Drucker, A. M., Mittmann, N., Walsh, S., & Shear, N. H. (2015). Loss of work productivity and quality of life in patients with autoimmune bullous dermatoses. *Journal of Cutaneous Medicine and Surgery, 19*(6), 546-554. doi:http://dx.doi.org/10.1177/1203475415582317

Henok, L., & Davey, G. (2008). Validation of the Dermatology Life Quality Index among patients with podoconiosis in southern Ethiopia. *British Journal of Dermatology, 159*(4), 903-906. doi:https://dx.doi.org/10.1111/j.1365-2133.2008.08773.x

Henson, R. K. (2001). Understanding internal consistency reliability estimates: A conceptual primer on coefficient alpha. *Measurement and evaluation in counseling and development, 34*(3), 177.

Higgins, J. P., Thompson, S. G., Deeks, J. J., & Altman, D. G. (2003). Measuring inconsistency in meta-analyses. *Bmj, 327*(7414), 557-560. doi:10.1136/bmj.327.7414.557

Higgins, J. P. T., & Thompson, S. G. (2002). Quantifying heterogeneity in a meta-analysis. *Statistics in medicine, 21*(11), 1539-1558. doi:10.1002/sim.1186

Hong, J., Koo, B., & Koo, J. (2008). The psychosocial and occupational impact of chronic skin disease. *Dermatologic Therapy, 21*(1), 54-59.

Huedo-Medina, T. B., Sánchez-Meca, J., Marín-Martínez, F., & Botella, J. (2006). Assessing heterogeneity in meta-analysis: Q statistic or I² index? *Psychological methods, 11*(2), 193.

Jin-gang, A., Sheng-xiang, X., Sheng-bin, X., Jun-min, W., Song-mei, G., Ying-ying, D., . . . Xiao-peng, W. (2010). Quality of life of patients with scabies. *Journal of the European Academy of Dermatology & Venereology, 24*(10), 1187-1191. doi:https://dx.doi.org/10.1111/j.1468-3083.2010.03618.x

Jobanputra, R., & Bachmann, M. (2000). The effect of skin diseases on quality of life in patients from different social and ethnic groups in Cape Town, South Africa. *International Journal of Dermatology, 39*(11), 826-831. doi:http://dx.doi.org/10.1046/j.1365-4362.2000.00073.x

Khoudri, I., Lamchahab, F. Z., Ismaili, N., Senouci, K., Hassam, B., & Abouqal, R. (2013). Measuring quality of life in patients with psoriasis using the Arabic version for Morocco of the Dermatology Life Quality Index. *International Journal of Dermatology, 52*(7), 795-802. doi:https://dx.doi.org/10.1111/j.1365-4632.2011.05450.x

Kitchenham, B. (2004). Procedures for performing systematic reviews. *Keele, UK, Keele University, 33*(2004), 1-26.

Lennox, R. D., & Leahy, M. J. (2004). Validation of the Dermatology Life Quality Index as an outcome measure for urticaria-related quality of life. *Annals of Allergy, Asthma, & Immunology, 93*(2), 142-146. doi:https://dx.doi.org/10.1016/S1081-1206(10)61466-4

Lewis, V., & Finlay, A. Y. (2004). *10 years experience of the Dermatology Life Quality Index (DLQI).* Paper presented at the Journal of Investigative Dermatology Symposium Proceedings.

Liu, J. B., Yao, M. Z., Si, A. L., Xiong, L. K., & Zhou, H. (2012). Life quality of Chinese patients with chronic urticaria as assessed by the dermatology life quality index. *Journal of the European Academy of Dermatology & Venereology, 26*(10), 1252-1257. doi:https://dx.doi.org/10.1111/j.1468-3083.2011.04277.x

Liu, Z., Xie, Z., Zhang, L., Jin, Y., Guo, H., Jiang, Z., . . . Yuan, J. (2013). Reliability and validity of dermatology life quality index: assessment of quality of life in human immunodeficiency virus/acquired immunodeficiency syndrome patients with pruritic papular eruption. *Journal of Traditional Chinese Medicine, 33*(5), 580-583.

Litwin, M. (1995). *How to Measure Survey Reliability and Validity* Retrieved from http://methods.sagepub.com/book/how-to-measure-survey-reliability-and-validity doi:10.4135/9781483348957

LoBiondo-Wood, G., & Haber, J. (2014). Reliability and validity. *G. LoBiondo-Wood & J. Haber. Nursing research. Methods and critical appraisal for evidencebased practice*, 289-309.

Lockhart, J., Gray, N. M., & Cruickshank, M. E. (2013). The development and evaluation of a questionnaire to assess the impact of vulval intraepithelial neoplasia: a questionnaire study. *BJOG: An International Journal of Obstetrics & Gynaecology, 120*(9), 1133-1142. doi:https://dx.doi.org/10.1111/1471-0528.12229

Mabel Qi He, L., & Hazel Hwee Boon, O. (2016). The Impact of Viral warts on the Quality of Life of Patients. *Dermatological Nursing, 15*(4), 44-48.

Madarasingha, N. P., de Silva, P., & Satgurunathan, K. (2011). Validation study of Sinhala version of the dermatology life quality index (DLQI). *Ceylon Medical Journal, 56*(1), 18-22.

Mazzotti, E., Barbaranelli, C., Picardi, A., Abeni, D., & Pasquini, P. (2005). Psychometric properties of the Dermatology Life Quality Index (DLQI) in 900 Italian patients with psoriasis. *Acta Dermato-Venereologica, 85*(5), 409-413. doi:https://dx.doi.org/10.1080/00015550510032832

McKenna, S. P., Cook, S. A., Whalley, D., Doward, L. C., Richards, H. L., Griffiths, C. E., & Van Assche, D. (2003). Development of the PSORIQoL, a psoriasis-specific measure of quality of life designed for use in clinical practice and trials. *British Journal of Dermatology, 149*(2), 323-331.

Møller, A. H., Erntoft, S., Vinding, G. R., & Jemec, G. B. (2015). A systematic literature review to compare quality of life in psoriasis with other chronic diseases using EQ-5D-derived utility values. *Patient related outcome measures, 6*, 167.

Mork, C., Wahl, A., & Moum, T. (2002). The Norwegian version of the dermatology life quality index: a study of validity and reliability in psoriatics. *Acta Dermato-Venereologica, 82*(5), 347-351.

Orwin, R. G. (1983). A fail-safe N for effect size in meta-analysis. *Journal of educational statistics, 8*(2), 157-159.

Ozturkcan, S., Ermertcan, A. T., Eser, E., & Sahin, M. T. (2006). Cross validation of the Turkish version of dermatology life quality index. *International Journal of Dermatology, 45*(11), 1300-1307. doi:https://dx.doi.org/10.1111/j.1365-4632.2006.02881.x

Pereira, M. G., Baia, V., & Machado, J. C. (2016). Coping and quality of life in patients with skin tumors in the follow-up stage: The mediating role of body image and psychological morbidity. *Journal of Psychosocial Oncology, 34*(5), 400-412. doi:10.1080/07347332.2016.1196807

Peters, J. L., Sutton, A. J., Jones, D. R., Abrams, K. R., & Rushton, L. (2007). Performance of the trim and fill method in the presence of publication bias and between-study heterogeneity. *Statistics in Medicine, 26*(25), 4544-4562. doi:10.1002/sim.2889

Picardi, A., Abeni, D., Melchi, C. F., Puddu, P., & Pasquini, P. (2000). Psychiatric morbidity in dermatological outpatients: an issue to be recognized. *British Journal of Dermatology, 143*(5), 983-991. doi:doi:10.1046/j.1365-2133.2000.03831.x

Prince, M., Patel, V., Saxena, S., Maj, M., Maselko, J., Phillips, M. R., & Rahman, A. (2007). No health without mental health. *The Lancet, 370*(9590), 859-877.

Qi, S., Xu, F., Sheng, Y., & Yang, Q. (2015). Assessing quality of life in Alopecia areata patients in China. *Psychology Health & Medicine, 20*(1), 97-102. doi:https://dx.doi.org/10.1080/13548506.2014.894641

Rodriguez, M. C., & Maeda, Y. (2006). Meta-analysis of coefficient alpha. *Psychological methods, 11*(3), 306.

Rosenthal, R. (1979). The file drawer problem and tolerance for null results. *Psychological bulletin, 86*(3), 638.

Sampogna, F., Tabolli, S., & Abeni, D. (2013). Impact of different skin conditions on quality of life. *Giornale Italiano di Dermatologia e Venereologia, 148*(3), 255-261.

Sangma, L. N., Nath, J., & Bhagabati, D. (2015). Quality of Life and Psychological Morbidity in Vitiligo Patients: A Study in a Teaching Hospital from North-East India. *Indian Journal of Dermatology, 60*(2), 142-146. doi:10.4103/0019-5154.152508

Shikiar, R., Bresnahan, B. W., Stone, S. P., Thompson, C., Koo, J., & Revicki, D. A. (2003). Validity and reliability of patient reported outcomes used in psoriasis: results from two randomized clinical trials. *Health & Quality of Life Outcomes, 1*, 53. doi:https://dx.doi.org/10.1186/1477-7525-1-53

Shikiar, R., Harding, G., Leahy, M., & Lennox, R. D. (2005). Minimal important difference (MID) of the Dermatology Life Quality Index (DLQI): results from patients with chronic idiopathic urticaria. *Health & Quality of Life Outcomes, 3*, 36. doi:10.1186/1477-7525-3-36

Shikiar, R., Willian, M. K., Okun, M. M., Thompson, C. S., & Revicki, D. A. (2006). The validity and responsiveness of three quality of life measures in the assessment of psoriasis patients: results of a phase II study. *Health & Quality of Life Outcomes, 4*, 71. doi:10.1186/1477-7525-4-71

Silverberg, J. I., & Silverberg, N. B. (2013). Association between vitiligo extent and distribution and quality-of-life impairment. *JAMA Dermatology, 149*(2), 159-164.

Streiner, D. L. (2003). Starting at the beginning: an introduction to coefficient alpha and internal consistency. *J Pers Assess, 80*(1), 99-103. doi:10.1207/s15327752jpa8001_18

Takahashi, N., Suzukamo, Y., Nakamura, M., Miyachi, Y., Green, J., Ohya, Y., . . . Fukuhara, S. (2006). Japanese version of the Dermatology Life Quality Index: Validity and reliability in patients with acne. *Health and Quality of Life Outcomes Vol 4 2006, ArtID 46, 4*.

Thomas, C., Narahari, S. R., Bose, K. S., Vivekananda, K., Nwe, S., West, D. P., . . . Kundu, R. V. (2014). Comparison of three quality of life instruments in lymphatic filariasis: DLQI, WHODAS 2.0, and LFSQQ. *PLoS Neglected Tropical Diseases [electronic resource], 8*(2), e2716. doi:https://dx.doi.org/10.1371/journal.pntd.0002716

Twiss, J., Meads, D. M., Preston, E. P., Crawford, S. R., & McKenna, S. P. (2012). Can we rely on the Dermatology Life Quality Index as a measure of the impact of psoriasis or atopic dermatitis? *Journal of Investigative Dermatology, 132*(1), 76-84.

Vacha-Haase, T. (1998). Reliability generalization: Exploring variance in measurement error affecting score reliability across studies. *Educational and Psychological Measurement, 58*(1), 6-20.

Van Beugen, S., Ograczyk, A., Ferwerda, M., Smit, J. V., Zeeuwen-Franssen, M. E. J., Kroft, E. B. M., . . . Evers, A. W. M. (2015). Body attention, ignorance and awareness scale: Assessing relevant concepts for physical and psychological functioning in psoriasis. *Acta Dermato-Venereologica, 95*(4), 444-450.

Van Coevorden, A. M., Van Sonderen, E., Bouma, J., & Coenraads, P. J. (2006). Assessment of severity of hand eczema: Discrepancies between patient- and physician-rated scores. *British Journal of Dermatology, 155*(6), 1217-1222. doi:http://dx.doi.org/10.1111/j.1365-2133.2006.07531.x

Viechtbauer, W. (2010). Conducting Meta-Analyses in R with the metafor Package. *2010, 36*(3), 48. doi:10.18637/jss.v036.i03

Wilkinson, L. (1999). Task Force on Statistical Inference, American Psychological Association, Science Directorate.(1999). Statistical methods in psychology journals: Guidelines and explanations. *American psychologist, 54*(8), 594-604.

Wilson, I. B., & Cleary, P. D. (1995). Linking clinical variables with health-related quality of life: a conceptual model of patient outcomes. *Jama, 273*(1), 59-65.

Zachariae, R., Zachariae, C., Ibsen, H., Mortensen, J. T., & Wulf, H. C. (2000). Dermatology life quality index: data from Danish inpatients and outpatients. *Acta Dermato-Venereologica, 80*(4), 272-276.

CHAPTER TWO: EMPIRICAL RESEARCH PAPER

WRITING ONLINE: THE EXPERIENCE OF BLOGGING ABOUT VISIBLE AND CHRONIC SKIN CONDITIONS

Abstract

Background: Chronic skin conditions such as psoriasis, acne and alopecia can greatly impact on quality of life similarly to conditions such as cancer, chronic pain and depression. Having a visibly different skin condition can lead individuals to feel further distressed by their disorders. There is currently a lack of available support for the ongoing emotional, psychosocial distress associated with such skin conditions. One way in which individuals with other long-term conditions are self-managing is through blogs – these are online journals where users can post and interact with one another. To date, no research has specifically explored how individuals with visible, chronic skin conditions use blogging for self-management.

Methods: This study used systematic online blog searching and a short online survey for recruitment, followed by email interviews. Interpretative phenomenological analysis was used to explore the impact of blogging about such conditions. In addition, template analysis of blog content was used to complement the interview data.

Findings: The initial uncertainty of conditions was often overwhelming, leading to distress, isolation and a focus on searching for treatments. Blogging provided a space to talk about experiences at a time when individuals felt defeated and allowed them to re-build and connect with others. Positive feedback received and positive affect gained from helping others appeared to be important factors in maintaining blogs. A need for social approval was also a factor, unique to the interview data and not found within the blog content.

Discussion: Blogging may provide individuals a way to self-mange the distress associated with chronic, visible skin conditions. There is a need to further understand how blogging could support the psychosocial distress associated with chronic, visible skin conditions.

Introduction

The impact of Living with Skin Conditions

Many skin conditions, such as atopic dermatitis, psoriasis, vitiligo, uticaria and hidradenitis suppurativa, can be characterised by their longstanding, incurable and waxing and waning nature (Hong, Koo, & Koo, 2008). Such dermatological conditions require continuing care (Newman & Vidler, 2006). Relationships, leisure activities, and work can all be affected by having chronic skin conditions (Borimnejad, Parsa Yekta, Nikbakh t-Nasrabadi, & Firooz, 2006; Heelan et al.; Hong et al., 2008) and the impact can be similar to other long term conditions (LTCs) such as heart disease, cancer, diabetes and depression (Hay et al., 2014; Møller, Erntoft, Vinding, & Jemec, 2015; Parna, Aluoja, & Kingo, 2015; Rapp, Feldman, Exum, Fleischer, & Reboussin, 1999).

The impact on quality of life of skin conditions is becoming more widely recognised (Dalgard et al., 2015; Hay et al., 2014; Parna et al., 2015). Skin conditions are known to be associated with higher levels of depression, anxiety and suicidal ideation than the general population (Dalgard et al., 2015; Senra & Wollenberg, 2014). They can also be associated with insomnia (Parna et al., 2015) and feelings of shame and anger which all lead to additional distress (Sampogna, Tabolli, & Abeni, 2012).

In addition, visible skin conditions (VSCs) can lead to further psychosocial distress (Dirschka et al., 2015; Thompson, Kent, & Smith, 2002). Having a VSC can lead to social stigma and individuals can feel further distressed by their disorders (Roman, 2016). For example, in Asian communities, having vitiligo can negatively impact on the ability to marry due to cultural connotations associated with the condition (Parsad et al., 2003; Thompson, Clarke, Newell, Gawkrodger, & Appearance Research, 2010). The facial redness seen in rosacea can also lead to prejudice and assumptions of negative personality traits such as being less trustworthy (Dirschka et al., 2015). Since individuals not only have to manage the symptoms but also the reaction of others to their condition (Dirschka et al., 2015; Teovska Mitrevska, Eleftheriadou, & Guarneri, 2012), it is not surprising that individuals experience psychological distress when faced with a VSC.

Unfortunately, patient and dermatologist agreement can often be low in assessing for depression and anxiety (Richards, Fortune, Weidmann, Sweeney, & Griffiths, 2004) and health professionals may not recognise or ask about psychological difficulties during consultation (Green, 2010; Nelson, Chew-Graham, Griffiths , & Cordingley, 2013). Since clinical severity is not always the best predictor of the psychological impact of the condition (Batchelor et al., 2016; Picardi, Abeni, Melchi, Puddu, & Pasquini, 2000), the emotional impact can often be missed when focusing on clinician rated measures of impact alone. Further assessment is often needed to support an awareness of these difficulties.

Current Service Provision

Despite the need, there is an acknowledged lack of available support for the ongoing emotional and psychosocial distress associated with having a skin condition such as psoriasis (Nash, McAteer, Schofield, Penzer, & Gilbert, 2015) and poor provision of psychodermatology services across the UK has limited specialist support available (All Party Parliamentary Group for Skin, 2013; Bewley, Affleck, & Bundy, 2012). A meta-analysis of psychological interventions for patients with skin conditions has highlighted the positive outcomes of differing levels of psychosocial intervention such as cognitive behavioural therapy (CBT), habit reversal and arousal reduction techniques (Lavda, Webb , & Thompson, 2012). A stepped care approach has been suggested which can support individuals presenting with differing levels of distress from low level support from dermatology nurses and dermatologists to more specialist involvement of psychology and psychiatry within dermatology settings (Bewley et al.,2012; Shah, 2017). Lower levels of support include medication management and signposting for the psychological impact, whereas higher levels include tailored interventions for the psychological impact. However, this is currently not implemented across dermatology services within the UK.

Online Avenues for Support

The lack of specialist service provision and resources within the wider National Health Service has led to the development of online self-help in both facilitated and unfacilitated formats including websites providing information and online therapies such as CBT which are controlled by health services, and peer to peer support groups and blogs led by users (Barak & Grohol, 2011). Patients can use the web to meet their own needs (Kamel Boulos & Wheeler, 2007), not solely relying on clinician-led treatment or opinion. In this way, patients are becoming more responsible for their own health in line with self-management initiatives (Newman & Vidler, 2006).

Cross-sectional research on unfacilitated online support has begun to explore how patients with LTCs use social media. For example, people have been found to write about their personal experiences, ask questions and receive direct feedback when discussing diabetes on Facebook forums (Greene, Choudhry, Kilabuk, & Shrank, 2011). This study was based on Facebook groups and this included engagement from family and carers of those with diabetes too. This study did not exclusively explore the use of groups by individual with LTCs. In another study, a survey was conducted exploring the use of online support groups by patients with psoriasis; it found that access to resources, ease of access, advice and lack of embarrassment when talking about personal issues were key factors in their use (Idriss, Kvedar, & Watson, 2009). However, this study was based on support groups which had administrators and therefore, was not entirely unmoderated. These studies were therefore not focused solely on the benefits of engaging with peer to peer led communities.

Studies have also begun to understand the use of blogs in self-management. Blogs are one way that individuals can share their experiences online. They are web-based journals which support individuals in expressing their emotional experiences and thoughts in a chronological format (Barak & Grohol, 2011; Ressler, Bradshaw, Gualtieri, & Chui, 2012). They allow non-experts to publish their experiences online (Kamel Boulos & Wheeler, 2007) and connect peer to peer without moderation. Cancer blogs have been found to include physical, psychosocial, and emotional problems in their content (Keim-Malpass et al., 2013). Individuals with chronic pain have been found to experience decreased isolation, be more able to make sense of their chronic pain and gain support through the challenges of their condition through blogs (Merolli, Gray, & Martin-Sanchez, 2014; Ressler et al., 2012). Blog may therefore provide peer-provided support which allows for affective support and validation (Barak & Grohol, 2011; Neal & McKenzie, 2011). This study did not recruit from the blogs themselves or define blogging, instead participants were recruited through support networks and social media for a convenience sample.

Benefits of Emotional Expression

Expressing emotional experiences through writing is associated with therapeutic benefits (Pennebaker, 1997) which may be a factor in the utility of blogs. Emotional expression in cancer can support positive adjustment and has been associated with less need for specialist psychological support in services (Stanton et al., 2002). Writing about any trauma is associated with positive health outcomes and reduced health appointments (Berry & Pennebaker, 1993; Frisina, Borod, & Lepore, 2004). Thus, blogging about health conditions and the experiences of writing online may be associated with similar benefits to emotional expression.

The rationale for the current research

Research has begun to capture the content of blogs, and to explore some aspects of the personal experience of writing and maintaining a blog, through surveys. However, little is understood about the personal benefits of blogging: why people individuals turn to blogging, how it impacts on how they make sense of their condition, or how they manage this through their blogging. A phenomenological approach focuses on how individuals make sense of their own experience and tries to capture the first-person account of an experience; this can therefore build an understanding of blogging as a self-management experience (Pietkiewicz & Smith, 2014). Since we are unaware of motivations for blogging or underlying processes, Interpretative Phenomenological Analysis (IPA) can provide an insight of an unknown phenomenon. This provides a more exploratory account of the personal experience of blogging.

In shifting to a self-management model of care which encourages the patient to play a significant role in their care (Coulter, Roberts, & Dixon, 2013), it is important to understand peer to peer communities such as blogs and how these relate to coping with conditions which negatively impact on quality of life. This can inform recommendations offered to patients with LTCs (Merolli et al., 2014). It can also build an understanding of peer to peer communities with no professional involvement as a resource to manage the psychosocial distress encountered by LTCs and VSCs more specifically. Since previous research has predominantly focused on content or survey responses, this study will provide a more in depth exploratory approach to understanding blogging within chronic VSCs by exploring personal experiences of blogging and content.

Aims

This research therefore aims to explore the personal experiences of blogging about a chronic skin condition which affects one's appearance. This study asks the following questions:

1) What is the experience of blogging about a visible, chronic skin condition?
    a. What role does blogging play in the adjustment and management of a chronic VSC?
    b. What are the perceived benefits and challenges of blogging?
    c. What are bloggers with chronic VSCs writing about?

Methodology

Study Design

A dual qualitative approach was used to gain an understanding of the blogging experiences of individuals with chronic VSCs. Following an initial survey to gather demographic information, email interviews and blog content were used to explore the experiences of blogging using two distinct, but compatible approaches (Interpretative Phenomenological Analysis and Template Analysis). Figure 6 captures the process of the data collection and analysis to demonstrate this more clearly. Interpretative Phenomenological Analysis (IPA) was the leading approach and template analysis of blog content was complementary to this approach. IPA's purpose of identifying the fundamental components of a phenomenon (in this case blogging in VSCs) can provide insight into blogging as a self-management experience (Pietkiewicz & Smith, 2014). Its "bottom-up" is appropriate when trying to understand a phenomenon which has not been researched before.

Study Population

Sampling strategy

Sampling is often based on the best way to give an in-depth analysis of the experience within IPA (Pietkiewicz & Smith, 2014). This allows us to understand the person's account in a meaningful way. When sampling more than one participant, a homogenous sample is also important as IPA focuses on within group similarities and differences to better understand a specific phenomenon in detail (Pietkiewicz & Smith, 2014). In this study, a purposive sample was chosen using inclusion and exclusion criteria to ensure the participants were all blogging about VSCs in a similar manner and were suitable for an IPA approach.

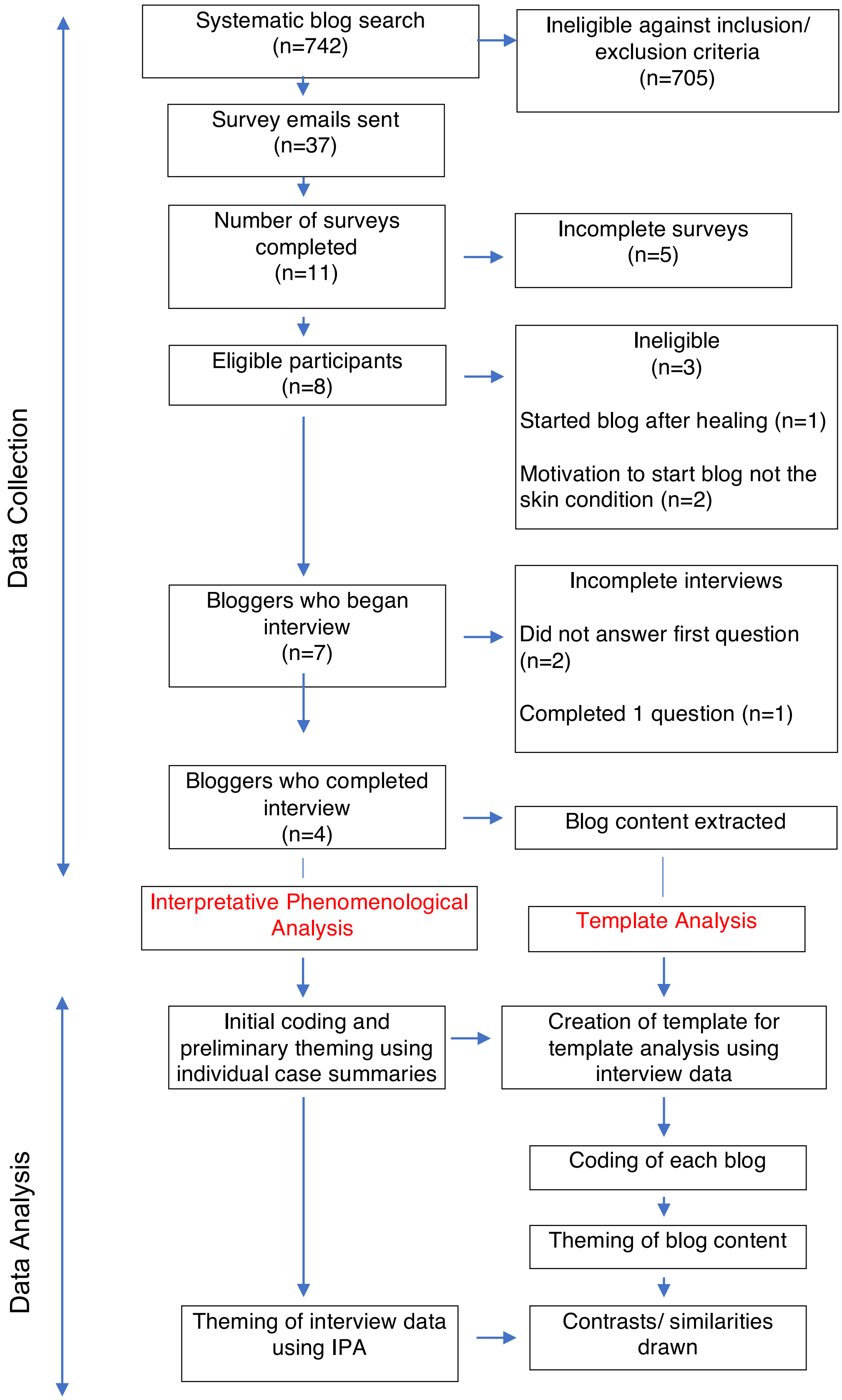


Figure 6. Sample recruitment and methodology

Inclusion Criteria:

- Has a VSC
- Writes about their individual experiences of a skin disorder online within a blog format such as WordPress or Blogger which has a page of blog posts in chronological order
- The primary reason for starting the blog is the VSC - this is likely to be identified on their ‘about’ page
- Has been blogging for at least six months
- Has uploaded a blog post within the past three months
- Writes their blog in the English language
- Has blogged at least ten times

Exclusion Criteria:

- Parents or carers who blog about experiences of caring for those with a VSC
- Primarily advertising products and not discussing personal experiences
- Writes about their VSC as a secondary topic to the blog content
- Has a form of cancer

Identification of Blogs

To recruit from the appropriate study population, I carried out a systematic blog search to identify blogs which were relevant to the aims of the study. Similar to literature searching, to find the most relevant blogs it was crucial to find blogs more objectively, rather than recruit through social media. I felt that the sample would be more biased through social media recruitment as it would be based on bloggers who utilise sites such as Twitter, Facebook and Instagram. This did not seem appropriate.

Since there are no guidelines for how to systematically search blogs online at present, an online blog search platform and Google were used to sift through blogs. The first 60 hits of each included chronic skin condition (which had the potential to be visible) were assessed against inclusion and exclusion criteria. Chronic skin conditions were defined as those which are incurable and require ongoing management in line with the World Health Organisation definition (Pruitt, Canny, & Epping-Jordan, 2005). The British Skin Foundation's list of skin diseases was used to identify the appropriate skin conditions to search (British Skin Foundation, n.d.). The blogs were then assessed against inclusion and exclusion criteria. The identified websites were predominantly excluded due to not being a personal blog of living with a VSC. Of those blogs found on VSCs many had been inactive for a length of time or were written from a different perspective (i.e. carers or within the context of a different blog theme or advertising). This resulted in 37 suitable blogs.

Initial Survey

I contacted the writers of blogs which met the criteria for the study via email and directed them to an online survey. The survey included information about the study, a consent page and gathered initial demographic information, skin characteristics and blog information. The consent page and initial survey can be found in Appendices B and C. This survey helped to identify the reason that people started their blog, create a pen portrait of each blogger and ensure homogenous sampling. Two reminder emails were also sent.

Data Collection and Analysis

The following section provides an overview of the two methodologies used within the research design once appropriate blogs and bloggers were identified.

Exploring lived experiences

Data Collection

The most common data collection approach for IPA is one to one, in-depth semi-structured interviews. These are often face-to-face and have become the norm in qualitative research (Bowden & Galindo-Gonzalez, 2015), however, email interviews - though relatively new in qualitative research - can also offer a successful means of conducting interviews for IPA studies (Dunn, 2012; Meho, 2006). Email interviews involve multiple email exchanges between the interviewer and participant in an asynchronous manner (Meho, 2006). Email interviews can help overcome some of the challenges found with other interview methods such as reduced research cost, more flexibility and less time restraint, no transcription time and more safety in sharing difficult experiences (Bowden & Galindo-Gonzalez, 2015; Meho, 2006). Like other interview techniques, email interviews can also have their own set of difficulties. Firstly, they are limited to those who have access to the internet, however, since blogging is an online phenomenon, the study is already limited to a population which has internet access and therefore this does not impact on the sample recruited (Meho, 2006). Without the visual cues of a face-to-face interaction, social expressions, body language and other cues are not available in email interviews (Dunn, 2012). When considering the use of email interviews, the type of data that would be collected in relation to the research aim was considered.

Since the study population are an online population who communicate their experiences with peers asynchronously, the method of email interview fitted with their mode of communication and how they currently share their experiences. It therefore appeared to be an appropriate method of interview to use. Two bloggers who blog about their skin and represented the voice of the sampling group during research design, stated that email interviews would be more convenient, allow them to participate and suit their way of communicating.

Subsequently on completion of the initial survey, I invited eligible participants to take part in the email interview. The invitation email included brief information about the interview questions to be asked. The complete interview schedule can be found in Appendix D. I initiated the interview by asking an open-ended question, with prompts, and the participant then responded in their own time. An exchange of questions and answers then followed, at a pace determined by the participants' responses. The email interview was limited to me sending a maximum of 10 emails and had a time frame of 6 weeks.

Analysis

Since interviews were conducted across email, transcripts were created by copying the content of the email interview into a word document. An IPA framework was used flexibly to support the process of analysis (Pietkiewicz & Smith, 2014). IPA focuses on the researcher trying to understand the depths of meaning in the participants' personal stories and learning more about their world (Smith, Flowers, & Osborn, 1997). This involves the researcher reading the data repeatedly (Pietkiewicz & Smith, 2014; Smith, Jarman, & Osborn, 1999) and making notes of thoughts and reflections (Biggerstaff & Thompson, 2008; Pietkiewicz & Smith, 2014). Notes might include use of language, context and initial interpretations (Pietkiewicz & Smith, 2014). Notes are then used to develop themes, which are then clustered through their connections and similarities (Pietkiewicz & Smith, 2014).

Within this study, I read through each transcript multiple times and I noted any comments or thoughts on the transcript. This included any parts of the data which stood out to me, reflections on important elements and any initial interpretations. In addition, I noted whether anything surprised me within the data or wasn't as I had expected to find it as a blogger myself. On a clean transcript, I re-read each transcript and the data was coded the data line by line more thoroughly. Codes included the subject of concern, tone or feeling and language used. Each segment of data was also scrutinsed to capture the meaning of responses. For each participant, I created a case summary following this. The case summary clustered the codes through their associations, included the quotes of text for each code and a third column was used to add comments and interpretations of the data. For example, I added details about any contrasts within the participant's data, what the code might mean and how it related to other codes and clusters. The case summary helped to bring together notes, reflections and quotes in a more digestible format. Once individual case summaries were completed, I used flashcards to represent different codes and bring together codes across participants. These were themed through their connections and associations during supervision with the main research supervisor. Please see Appendices E-H for examples of the analysis process.

Exploring what bloggers are writing about

In order to explore what bloggers are *writing* about, template analysis was used. Template analysis is a type of thematic analysis which uses more of a top down hierarchical structure (Brooks et al., 2015). A template to code the data is created by analysing a part of the dataset and forming a structure of codes and themes; this template is then used to code the remaining dataset. The coding structure is further revised and adapted as more data is analysed if needed to capture the data more fully (Brooks et al., 2015). The number of revisions depends on what the researcher wants from the data and therefore revisions may end when it is felt that the core principles have been captured.

Data Collection

The first five blog posts and the most recent five were extracted for the purposes of analysis. Since many blogs have multiple blog posts, this method was a more practical way of capturing the journey compared to analysing all data available. The blogs chosen were written by the same participants who completed the email interviews.

Data Analysis

The coding structure – created initially from the preliminary clusters and objects of concern found within the IPA analysis – was refined through the coding of two blogs. Theory was not used to create the structure. Instead, I used the IPA data to create the structure to follow the more bottom up approach used in IPA and to maintain the exploratory aspect of the approach. This was also consistent with an *a priori* hypothesis that bloggers would be writing about (in their blogs) what they say they are writing about (in their interviews). Subsequent revisions of the template which were developed from analyses of the blogs themselves also allowed me to consider more implicit motives for writing. I then created case summaries for each blog using the finalised template structure (see extract in Appendix J). Codes across participants were then linked and themed through their connections with one another using flashcards. This thematic structure was then refined further during supervision.

The researchers

As the primary researcher, I am a trainee clinical psychologist who completed this research as part of a doctoral programme towards qualification. In addition, I have personal experience of living with a chronic and visible skin condition and blogging about it. My epistemological stance can be described as social constructionist whereby I believe that our realities are constructed within a social context. The research was co-supervised. The main supervisor is a qualitative researcher with an interest in understanding people’s experiences of psychological distress and the second a practicing clinical psychologist with a split academic post with an interest in understanding the process of adaptation to appearance-related conditions. Both supervisors have extensive experience of using qualitative methods, particularly IPA.

Ethical considerations

This study was approved by the research ethics committee at the University of Birmingham (Appendix K). Informed consent was gained through the initial survey which included information regarding right to withdraw and transparency around the research. It was highlighted that confidentiality of the personal blogs would not be possible since the blogs are found within the public domain. To maintain anonymity of the interviews within this paper, aliases are used for participants and blogs are labelled as 1,2,3,4. Data was held on the University of Birmingham's secure BEAR DataShare system which allows users to securely save and share files. It is password protected and allows for secure sharing with external parties (i.e. supervisors not based within the university) and provides secure remote access.

Quality and Reflexivity

Steps were taken to ensure the study was of good quality. Individuals blogging about their VSCs were contacted within the design of the research to assess which methodology would best suit the population (Treharne & Riggs, 2015). Two methodologies were also used to gain an understanding of whether the experiences of blogging are similar across contexts (i.e. talking about writing and writing itself).

Regular supervision with my research supervisors supported rigour within the research and the coherence of the analysis (e.g. auditing coding, case summaries and checking overarching themes, codes and quotes for coherence). In addition, a third supervisor (not involved with the design or data analysis) checked the quotes, subthemes and themes for coherence. This helped to evaluate the confirmability of the findings (Trevarne & Riggs, 2015). I also attended peer supervision for conducting qualitative analysis to support my ability in using the methods and gain feedback on my approach.

A field diary was kept during the process of the research. This allowed me to reflect within and between interviews, and have a space to think about my biases and assumptions. Due to my close connection to the research, it was even more important to consider what I brought to the research and the field diary helped me to consider the influence of these during data collection, analysis and interpretation. For example, during coding this helped to draw out some of the similarities and differences between my own blogging experiences and that of the participants. This also ensured the interpretations were grounded in the data and not my assumptions through an awareness of them (Campbell, 2013; Trevarne and Riggs, 2015). This helped for my beliefs and assumptions to be used to supplement the analysis rather than impede it. In addition, transparency of this within supervision and the empirical paper has provided a better understanding of the context within which my interpretations have been made (Campbell, 2013).

Findings

Participants

As outlined in Figure 6, four individuals participated in the research: two females and two males, all aged between 24 and 45. The following aliases are used within analysis: Laura, Tom, Debbie, Ian. Participants were based in three different countries (the UK, Canada and Australia) but all identified as White British. Body sites affected differed between participants. One participant's condition affected all body sites, two participants described their condition as affecting more than five sites which included the face and neck, and one described the condition as affecting hair only. The conditions had been present from between 2-5 years to over 10 years. One participant described their condition as being 'intermittent' compared to continuous. Three participants had physical co-morbid difficulties.

In terms of blogging, time blogging ranged between 2-10 years and blogging style for three participants was sporadic at times that they felt it was needed. For one participant, a blog post was written weekly. Reasons for blogging included wanting to support and inform others, raise awareness, let friends and family know, personal release and sharing good strategies with others.

Data for Analysis

The email interviews produced an average of 31 pages of data when double spaced and wide margined for analysis (range 18-46). The blog content analysis produced an average of 34 pages of analysis per blog (range 21-45).

Analysis Outline

Since multiple research studies have explored the experiences of living with a chronic and visible skin condition, this analysis predominantly focuses on the experiences of blogging about these conditions rather than on themes developed which have been described elsewhere. This allows for this research to focus on what it adds to the current research base in more depth. After an initial overview of the findings from the template analysis, I will present the findings within the content of the interview themes; similarities and differences from the template analysis will be drawn into this analysis.

An Overview of Blog Content Analysis

Six main themes were drawn out from the template analysis of the blogs. Figure 7 visually depicts the theming structure (with parallel boxes being two aspects of the same theme). The experiences of living with a chronic skin condition did not follow a linear pattern but individuals moved through the phases in their writing depending on the state of their skin. Participants continually shifted between being consumed by the condition and finding some unity between their sense of self and

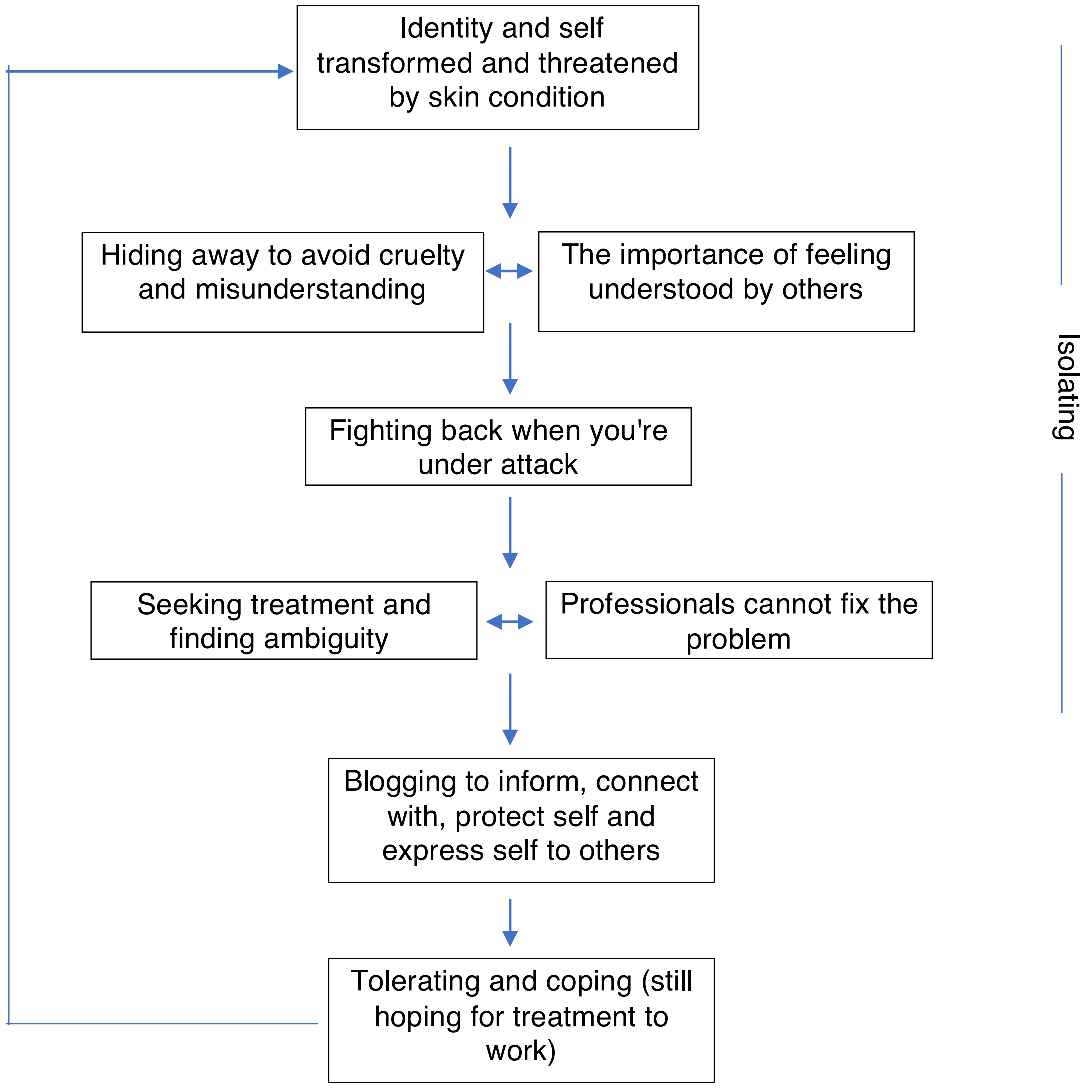


Figure 7. A visual depiction of the Template Analysis Theming structure

the condition which led to feelings of tolerance and coping. Individuals' writing shifted between the two, dependent on the threat presented by the condition. For example, if skin got worse, participants spoke more about social anxiety and focused more on finding a treatment. Blogging appeared to assist the participant in moving from overwhelmed by their condition to finding a place where it was no longer a threat. This did not reflect an acceptance but rather a tolerance of their condition.

Blogging as an experience

Five superordinate themes were developed from the IPA. Table 7 outlines these along with subthemes and contributions.

Table 7. *Themes identified for Blogging through IPA*

Superordinate Theme	**Subthemes**	**Contributing Participants**
Skin is an overwhelming threat to self	Skin appraisal and attempts to manage	Laura, Tom, Debbie, Ian
	Defeat and discontent	Laura, Tom, Debbie, Ian
Blogging for Self – Venting and Building	Having an outlet and processing	Laura, Tom, Debbie, Ian
	Being Built up	Laura, Tom, Debbie, Ian
Blogging for Others – Sharing and Informing	Being there for others	Laura, Tom, Debbie, Ian
	Complement but not a substitute for the rea world	Laura, Tom, Debbie, Ian
Trying out a way to engage with others	Safety in expression online	Laura, Tom, Debbie
	Social approval in blogging	Laura, Tom, Debbie, Ian
Blogging as a journey which ebbs and flows	When is the time to blog	Laura, Tom, Debbie, Ian
	Making the condition more tolerable	Laura, Tom, Debbie, Ian

Skin is an overwhelming threat to self

i) Skin Appraisal and Attempts to Manage

Participants began to appraise their symptoms as a threat to self when the symptoms moved from being insignificant to more threatening to their self-identity. Debbie, Ian and Tom described their symptoms gradually becoming worse over time which led to the condition becoming more of a health concern. The symptoms became harder to ignore when they experienced symptoms such as pain, itching and changes to their physical appearance. For Laura, she described never perceiving her condition as a threat until it was commented on socially:

> *"I remember being self-conscious about my facial hair as an adolescent, when it was simply blond, only noticeable when light shone through it. It may have been a bit longer than normal, or more profuse. I vividly remember a boy commenting rudely on it in school, around the age of thirteen or fourteen, and that's the first time I recall feeling like I should do something about it, even though I had been concerned about it for a while"*
>
> (Laura, L16)

Participants were no longer able to ignore the symptoms when they became more noticeable to themselves and others. Participants described feeling great uncertainty around what was happening, there was a sense of loss of their old self and there was a fixation on symptoms. This was also found within blog content:

> *"…two tiny little dots which I thought were just that – wee dots where hair didn't grow. Until they started to spread. Obviously like any other person who cared about their looks I was worried – in fact I was majorly freaked out if truth be told. Bordering on daily obsession! As The 'wee dots' graduated into 'big dots' I tried to remain calm – while simultaneously obsessively checking the reaction of people I bumped into and whether they thought I had some human form of mange!"*
>
> (Blog 1, L29)

Blog content reflected this description of the condition moving from being insignificance to more of a threat as worries about appearance heightened. Feelings of being attacked by their condition resonated within blogs with words such as "attack", "vengeance", "beating", "cruel" and "thorn" being used to describe the condition, further highlighting the feeling of threat the condition invoked. To manage this, participants considered their options and attempted to alter their situation with problem-focused strategies:

> *"I tried many other treatments that people recommended for example cranial osteopathic, acupuncture, diet changes. This was the point I decided to try*

> *the alternative medicine with western. I had also changed to my diet at this point. I avoided dairy, gluten and processed food. “*
>
> (Debbie, L54)

Strategies included seeking medical help, trying alternative therapies and skin checking. The use of multiple strategies reflected a sense of urgency in needing to manage the condition. Whilst Laura predominantly self-managed, Tom, Debbie and Ian described seeking support from professionals (both conventional and alternative) and wanting more of an understanding. The expectation and need for treatment to work outweighed cost for some of the participants. This was reflected within blog content:

> *“When she suggested steroids I was very apprehensive as I have become very clued up on the toxins and negative impacts that they can have. One of the main side effects is that it can affect your mood and you can put on weight, I thought to myself the last thing I want is to be not only a baldy but the size of an elephant too!! I have had a lot of people saying to me are you sure you should be taking steroids however, after seeing photo evidence of alopecia sufferers having this same treatment plan (light therapy and steroids) with a full head of hair back I cannot ignore this option.”*
>
> (Blog 3, L279)

This need for a cure or fix to their condition resonated as participants described repeated attempts to find something that worked. They became dissatisfied with healthcare professionals not knowing and wanted a treatment to work.

Alongside strategies focused on reducing the symptoms, self-presentation strategies were also used. These focus on maintaining self-esteem when faced with the reactions of others. Every participant described strategies they used to maintain a positive social image in the face of having a disease they perceived as distasteful:

"*The changing rooms were full of a group of girls in their early twenties all with beautiful long hair getting ready for a night out, I ran into the cubicle to get changed in embarrassment that someone would see and laugh at me with no hair"*

*(*Blog 3, L259)

"I held it all in for years, covering my skin, feeling ugly, not wanting anyone near me. I only started my blog five years ago so I think I bottled it all up for about 8 years or so"

(Tom, L187)

Participants described both their own feelings of disgust and their fears of being negatively judged by others. To compensate, attempts were made to hide the condition and its impact from others. There was a real anxiety around others knowing which was reflected in the fear they described experiencing when there was a chance that others might see their condition. Some family members knew about the condition such as parents and spouses but participants did not describe openly taking about the psychological impact of their condition. Rather the psychological distress appeared to be a hidden battle they were fighting.

ii) Defeat and Discontent

Participants experienced defeat and a loss of hope when they realised no treatment was working:

> "*That discouragement lasted for about four more years. I felt that no one could help me and nothing could fix this"*
>
> (Laura, L116)

> *"I was losing hope with the condition as no-one seemed to give me any answers that were helping. I was still a long way off accepting the condition"*
>
> (Debbie, L189)

There was an expectation of cure and participants described their feelings of defeat when this no longer seemed an option. This was hard for participants to face, though this was not reflected much in the blog content itself. The loss of control and restrictions imposed due to hiding the condition led to a real loss of self. Having no control led Laura and Tom to give up and they both described enduring the condition for some time. For Debbie it led to trying even more treatments and refusing to give up and for Ian, it led to the onset of depression.

In summary, the theme of ‘Skin is an overwhelming threat to self’ describes the experience of individuals trying to battle the external threat of their skin condition, the difficulties arising from coping with the changes personally and socially and the difficulty of not being able to control it. The overwhelm not only related to the symptoms of the condition and self-image but also the need to preserve a positive social image for others. Through this experience, there was a sense of isolation even when people knew about the condition.

Blogging for Self – Venting and Building

i) Having an outlet and processing

At a time when participants felt at a loss with their condition (or for Ian when he had just overcome a low period), participants described reaching a place where they could not continue in the same way:

> *"So I can guess the motivation to start writing was either tell people what I was going through or just stop living. As you can see I chose to live"*
>
> (Tom, L266)

> *"I knew it was interfering with things and causing some low moods and blue days. I wasn't content….I couldn't keep living life the way I was"*
>
> (Laura, L226)

After enduring the condition or searching for even more treatments for some time, Tom, Debbie and Laura reached a place where they felt they needed more. They described this in a way which highlighted how they had been holding in a lot of the overwhelm and trying to get by, but it had reached a place this was no longer effective. Blogs were described as a place they could release these strong emotions. All participants described the heaviness of their condition and their blog served as an outlet:

> *"I find that when I talk about it – it is usually weighing on my mind because I am sad…"*
>
> (Ian, L207*)*

Blogging also provided a means to gain perspective, normalise their experience, acknowledge the positives within their life and find strength in their ability to cope with the condition:

> *"If I write about the good things it reminds me how good my life is despite this condition. It reminds me what is worth fighting for"*
>
> (Tom, L426)

As they faced more losses with the continual difficulties that arise with chronic illness, the blogging space supported participants to keep hold of the positives and release the build-up of negative emotion. This appeared to serve the function of reducing low moods which resonated within participants' accounts when their conditions felt out of control. This was particularly important for three participants who had conditions which were more unpredictable. As the condition fluctuated between good and bad, the blog provided a way for them to emotionally process this. Their writing was described as a way to regulate their emotions and continue to adjust and incorporate their chronic condition into their identity. This also involved processing emotions around feeling unfeminine for Debbie and Laura. Though participants described a sense of tolerance rather than acceptance, the relationship to the condition changed over time and individuals described gaining a sense of control:

> *"I do feel that it has made me a stronger person and in many ways a very different person. I am by no means cured of my Alopecia but I am feeling more in control of it."*
>
> (Blog 3, L429)

In this way, the blog served as a vehicle to manage the psychological distress and uncertainty associated with their VSCs, processing the difficulties through writing.

ii) Being built up

Writing online allowed users to process their experiences through others. Though her main motivation for blogging was others, Laura described moving from a place of fearing the unknown and resigning to her ordeal, to being more determined to find something to manage and take back control:

> *"It felt emotionally uncomfortable to even think about my condition long enough to do research"*
>
> *"The more I wrote about the condition, and the more questions I got from readers, the more I noticed holes in my knowledge and it prompted me to do research."*
>
> (Laura, L131)

Through having an audience, Laura described how she gained newfound motivation and confidence to find solutions to manage her condition and advocate for herself in medical appointments which she had struggled with previously. Helping others appeared to build on Laura's self-efficacy. Through positive feedback and support from readers, there was also a sense of accomplishment for Ian, Debbie and Laura and validation for their experiences:

> *"It was much more rewarding then what I initially thought. I did not except the reception and the feeling I had from helping others was very rewarding"* (Debbie, L220)

Readers not only gave participants confidence in managing their condition, but also reinforced their blogging habit. Through helping others and gaining feedback, it built participants' sense of accomplishment and competency in something other than their condition. For Laura, blogging became a role she wanted to do well. She blogged with a more formal approach than the others by scheduling posts and blogging on a schedule. This appeared to build her confidence in being good at something regardless of her skin condition and provided another focus.

Writing also supported the development of coping strategies. Participants described blogging as a way for them to build on their coping strategies through advice offered by readers, validation and through the processing of their own emotions. Blogging acted as a vehicle for change and appeared to help overcome the sense of defeat and isolation individuals experienced beforehand, though, how was not always as clear to define:

> *"My management strategies must have changed. This is a little blurry but suffice to say that before blogging I don't think I had any. [It] was clearly winning and I wasn't managing it at all"*
>
> (Tom, L529)

> *"But in all my wanderings, nothing has helped so much as hearing from other women struggling with the same things"*
>
> (Blog 2, L10)

Blogging was described as a sort of scaffold which helped participants to build themselves up emotionally after struggling to cope with the overwhelm of their VSC and led participants away from the feelings of defeat they felt initially.

In summary, 'blogging for self – venting and building' captures the varying ways in which the blogs served a function in both supporting participants to express themselves safely and building themselves back up after feeling so defeated by their condition. The theme captures how blogging personally benefited participants and offered them support. Their relationship with their condition changed and though acceptance wasn't a factor, the condition was no longer something participants were overwhelmed by.

Blogging for others – Sharing and Informing

i) *Being there for others*

There was a desire to offer what was missing in their skin journeys to others:

> *"I joined multiple forums and websites to try and help - googling mostly and finding sites where people were desperate and sad. What was missing was the happy stories or the sad stories with a positive slant - or the fact that there coudl be people who coped fine with alopecia. That is what I intended to do."*
>
> (Ian, L151)

Participants wrote about their progress, coping strategies and attempted to normalise the condition for their readers. They described having hopes to raise awareness and support an understanding and this was also reflected within blogs:

> *"As you may have realised after reading my first few blog posts, I decided to write this to help and support others and to bring attention to this crippling condition"*
>
> (Blog 3, L203)

This was a driving factor for starting the blogs for everyone except Tom:

> *"I sometimes get caught up in the noting that I'm doing this to help others and I know it sounds selfish but I'm not. I started this for me, for my own mental health"*
>
> (Tom, L434)

However even when participants described their motive as an outlet for themselves, all of the blogs affirmed a need to raise awareness and support others:

> "I hope this gives the reader an understanding of what Psoriasis does to a person's soul"
>
> (Blog 4, L12)

Being there for others meant that they could ensure others didn't experience the same frustrations they did. Participants described their role of blogging for others as being a source of social support, not selling miracle cures and sharing their genuine experience. It was important for them to share their journey with their condition for others. Participants talked about wanting to help others and about how writing for others also benefited them in return. Providing support meant participants could use their negative experiences in a meaningful way and participants described feeling good about the reception they received. However, it was also seen as an exhausting process at times as it meant supporting people who were often in a worse place emotionally than the writer. Blogging for others when you were doing well often meant it could become a draining process.

For Laura, blogging for others provided a conscious escape from her own problems:

> *"When I was writing to help others, I gained perspective and was distracted from my own problems, and they felt like much less of a burden"*
>
> (Laura, L263)

Blogging was described as a distraction and the focus moved away from the personal struggles with the condition. However, she also described wondering whether her blog meant she never really gained support herself as there was a focus on her being there for others. In this way, solely being there for others had the potential to prevent you asking for help or gaining it.

ii) Complement but not a substitute for the real world

It was clear that blogging did not replace a desire for interaction in the real world. Tom described blogging as an addition in the sense that it helped his friends and family to understand his experiences more:

> *"They will never admit to fully understanding exactly what I am living with. However, they do have a better understanding of why sometimes I want peace and quiet, why I am tired and they don't have to ask how I am all the time. I guess my blogging saves them time and questions"*
>
> (Tom, L581)

The blog therefore provided him with a safe way to express himself to those around him and to gain understanding. The blog supported Ian in connecting with others with the condition whom he then met in person and therefore helped him to grow his physical support network. In contrast, for Laura, though blogging supported her in being able to express herself and connecting with others similar, it was also something she described as a barrier for connecting with people in the real world:

> *"I was creating all this content and trying to manage my condition by myself, rather than reaching out to people in the real world. I have always been self-contained and don't like to involve others, so while blogging suited me well, I may have missed the opportunity to take the risk of relying on others. Now, in my 30's, I'm pretty set in my ways and I'm having challenges being vulnerable with people in the real world. I wonder if blogging played a part in reinforcing that inclination"*
>
> *(*Laura, L663)

Blogging did not appear to offer an alternative, but rather an addition to real world contact. Though participants described the benefits of connecting with others with their condition, the need for those around them to understand was always present. For Laura, blogging prevented her from engaging with people around her and she remained isolated. Tom, Ian and Debbie on the other hand described positive real world contact they experienced such as support from colleagues or family.

This theme captures both the benefits and pitfalls participants experienced from blogging for others. It was on the one hand a rewarding experience and being there for others supported individuals to use their experiences in a meaningful way. However, it also highlighted the ongoing need for the participants to be supported too and pitfalls when this doesn't occur. Though blogging provided social support in some ways it was not seen as a replacement for real world contact. Difficulties arose for Laura when the blogging did not change connection with people in the real world, outside of the blog itself.

Trying out a way to engage with others

i) Safety in expression online

Participants all described their social anxiety around people knowing. They feared receiving non-empathic or judgmental responses and being left feeling embarrassed, misunderstood and rejected (Kennedy-Moore & Watson, 2001). However, through avoiding negative responses, participants described how they became more withdrawn as their condition worsened and did not reach out for social support. The fear of negative reaction appeared to be less threatening to participants when writing online and offered a safe way to connect socially:

> *"It seemed less likely that I would be recognised amongst all that noise, but people who were looking for my content would hopefully find it."*
>
> *(*Laura, L247)

The anonymity the internet can provide created safety around sharing and was socially an easier way to express themselves. In addition, writing online supported Debbie to begin to connect with others but in a less intimidating way. Talking online provided an emotional distance when talking about a distressing condition compared to face to face interaction thereby increasing its safety as a communication tool:

> *"I did not want to meet mass groups of other sufferers but I did still want help…. Blogging for me helps bring together communities of other sufferers without having to interact if you don't want to."*
>
> (Debbie, L226)

Blogging was described as a medium through which you could engage when you wanted to, but weren't obliged to. This created safety and made it an easier way to engage with others. In contrast, Ian did not appear to be as isolated socially or feel more safety in talking online. His family had lived through his brother's experiences with a severe skin condition and this may have supported an understanding when his developed. It may be that connecting online provided additional support such as being able to make sense of the condition with others with the same diagnosis through sharing of similar experiences and what works (Colineau & Paris, 2010). In this way, online was not safer but provided an opportunity for additional connection.

Participants described feeling that no-one understood or could help. Friends were distant, professionals were matter of fact and family didn't always offer empathy as needed. Blogging provided a way for participants to voice their experiences and frustrations at the lack of social support and be understood without fear of retribution from the 'real' person. This supported expression without fear of being judged:

> *"Strangely though I find it easier with people I'm not so connected to such as interviews like this. For me it is easier to tell a stranger and I think the reason is that I am not worried too much about how they think of me after as I'm unlikely to see them again"*
>
> (Tom, L358)

In this way, blogging supported safe expression and created an emotional distant which made it easier. The detached nature of it appeared to be an appealing way to connect.

ii) Social approval in blogging

This subtheme was noticeably missing from blog content but appeared to be an integral part of writing online. In line with interpersonal theories of self-esteem, individuals were conscious of and keen on gaining social validation for their writing (MacDonald, Saltzman, & Leary, 2003). Though blogging provided an avenue where appearance wasn't important, there was often a caution to say the right thing:

> *"Though I am always wary not to be too negative as I don't think that is helpful. I am honest about the low times but don't want someone to be thoroughly depressed and leave my blog without some sort of hope"*
>
> (Ian, L210)

Tom often wrote raw pieces on his blog but Ian, Laura and Debbie tended to be more mindful of how their writing came across:

> *"It's when I can compose what I am feeling into the right words to help others and ensuring I get across the right messages I want to portray"*
>
> (Debbie, L260)

Though blogging rid of the appearance-related anxiety, the anxiety around saying the right thing was heightened within the interviews and participants described always being conscious of the reader:

> *"Even things that I wrote quickly I would edit to the best of my ability. I was always aware of the reader, and never wanted to make a mistake, whether it was grammar, spelling, or just appearing to be a black cloud"*
>
> (Laura, L510)

The need for social approval meant careful planning and sometimes this caused more anxiety around self-portrayal:

> *"I am learning I have an overdeveloped urge to protect myself, especially from embarrassment, so I think I was very aware of how I came across and never wanted to appear too self-indulgent or negative."*
>
> *(*Laura, L496)

Since blogging is not a face to face interaction, it appeared to heighten the need for social approval in the way participants came across to their readers instead. Humour was also something both Tom and Debbie were keen on including in their writing. Participants all described a need to be positive and there was always a conscious awareness of the person who may read the blog.

This theme captures the complexity of trying out a new way to engage with others. Blogging provided participants with a safe way to engage with others at a time when face to face social interaction felt challenging and provided a space for expression. However, blogging was not free from the need for social approval and instead carried its own set of anxieties. Participants were mindful of what they posted and it highlighted that though online communication may provide some safe distance, it still had a social dimension which was hard to ignore.

Blogging as an experience that ebbs and flows

i) When is the time to blog

Ian, Debbie and Tom described themselves as sporadic bloggers and they were open about their blog being there when there was a need:

> *"I see blogging as something I'll continue to use as long as my condition persists. I will tend to be less prolific when things are going well but do like sharing my status when it is bad as I would like people to see all sides of the story"*
>
> (Ian, L260)

As the skin condition became more threatening or flared, participants described using their blogs to manage the affect that came with it. On the reverse, there appeared to be less need when the condition no longer seemed to be causing distress. For Laura she described how blogging eventually became a barrier to moving forward as it brought her attention back to the condition:

> *"I had been blogging and answering emails consistently for over five years, and now I felt that I had moved through the process and was coming out the other side. I had done everything I reasonably could to reduce my hirsutism, and I didn't think it would get any better. I no longer had those powerful emotions I needed to let out. And I felt increasingly drained by the emails I received. I just felt ready for a life where I wasn't forcing myself to think about [it] every day, because it was no longer the overshadowing concern. The act of hiding body hair and acne felt like a normal part of my life now. [It] was no longer the thing that defined me. It had shrunk to a very small part of my life, and blogging was the only thing keeping it "big."*
>
> (Laura, L443)

Laura described reaching a place where she felt her condition was manageable and no longer a threat; she had appeared to adapt to living with the condition to a level acceptable for her and no longer paid as much attention to the symptoms. She had been absent from her blog and this reflected it no longer serving a purpose. When thinking about her blog use, she described it as a place she could escape from her problems. In this way, it appeared she no longer needed a distraction from her distress. Interestingly, her blog did not reflect this thinking in its entirety and being there for others and social approval maintained an online presence, though on a personal level the blog was no longer necessary.

ii) Making the condition more tolerable

Blogging supported participants to not feel so overwhelmed by their conditions. Participants described how it helped them to change perspectives, prevent mental health from deteriorating and offered space for processing. However, acceptance was not aimed for:

> *"Before I started blog I saw psoriasis as this big dark monster looming over my life and in a way that view hasn't really changed. Psoriasis has never been my friend and it never will be. Also unlike others who say they come to terms with it, I never have and refuse to do so. Mostly because I think if I do that then it has won. I perceive coming to terms with it as accepting it and I will never accept it, I want it gone. Actually, I guess it is still playing a treatment role for me"*
>
> (Tom, L513)

Though Tom didn't accept his condition, he described the benefits of expressing himself and gaining perspective through writing positively. In this way, blogging and peer validation supported the management of the affect raised by the unpredictable and defeating nature of their condition. It made it emotionally easier to bear, but it did not necessary lead to feelings of acceptance. Instead emotionally, participants were more contained through their writing.

Though participants described the positives of expressing themselves through their writing, it didn't make it any easier when the condition got worse:

> *"It was something that I had expected and prayed wouldn't come"*
>
> (Blog 1, L171)

A hope for improvement remained, and it meant every time the condition worsened, it was emotionally difficult. Participants used their blogs to make sense of the fluctuations but participants did not reach a place where the condition worsening was easy to tolerate. It was hard each time the condition 'attacked'. The blog appeared to support tolerance for the condition when it flared or got worse. Participants didn't revert back to their pre-blogging states and blogging therefore appeared to create a way to manage the affect that was once overwhelming. Ian, Debbie and Tom described it as therapeutic. For Laura, blogging also gave her focus and confidence to seek help and so it supported her beyond affect.

This theme captures the blog's role within participants' management of their chronic VSCs. Blogging wasn't always necessary but it appeared to play more of a role when the condition was becoming harder to manage. At times the condition was no longer a focus, the blog became less important. Participants described feeling more able to tolerate their condition through writing, but acceptance did not resonate with them. There was an underlying hope for something to work and this often meant the blog helped participants to manage when the conditions worsened by offering a therapeutic space and distraction.

Discussion

Connections to previous research

Living with a visible skin condition

Similar to previous research, living with a visible condition impacted on both the relationship with self and others (Thompson & Kent, 2001). Participants felt self-conscious about their condition, attempted to hide it and became isolated socially as they tried to come to terms with their condition (Hale et al., 2006; Johnston, Krasuska, Millings, Lavda, & Thompson, 2018; Thompson, Clarke, Newell, & Gawkrodger, 2010). The strategy of hiding the condition is a finding that has been found across studies. For example, using camouflage make up to hide the skin is common in vitiligo and rosacea (Johnston et al., 2018; Thompson et al., 2002; Whitton et al., 2015). These strategies can be helpful as they allow individuals to engage socially in a way which feels safe and 'correct' the condition to a certain extent. However, since individuals with chronic and visible skin conditions cannot entirely rid of their condition, problem-focused strategies can also be unhelpful as they are better suited to situations which can be changed (Allen & Leary, 2010). Within this study, participants felt a sense of defeat when they realised that their problem-focused strategies were not working. This is reflected within findings from a previous study on rosacea (Johnston et al., 2018). The current research therefore adds to the evidence around the difficulties that surround living with a chronic VSC, in particular the distress that can arise from the sole use of problem-focused strategies when facing a chronic condition.

This study differed to previous research in the sense that individuals turned to blogging as a way to manage the difficulties encountered from living with their condition and to overcome those feelings of defeat. In this way, blogging was a way to grieve for their losses and make sense of their emotions to support more adaptive adjustment (Allen & Leary, 2010; De Ridder, Geenen, Kuijer, & van Middendorp, 2008; Schulman-Green et al., 2012). The blog served as a way to support expression, to empower individuals to keep going and to offer connection with others. This appeared to compensate for the feelings of loss and isolation brought on by the condition and provided participants with a way to regulate their emotions (Allen & Leary, 2010; Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986; Glanz & Schwartz, 2008). Blogging therefore appeared to support individuals to change their thinking about their condition, in line with emotion-focused strategies. In this way, blogging served a similar function as psychological interventions such as CBT and emotional disclosure (Lavda et al., 2012) though blogging was a self-motivated practice.

Blogging as a form of communication

The current research is the first to explore the use of blogging when living with a chronic VSC. Nardi et al (2004) found five predominant motivations for blogging- documenting, providing commentary and opinion, expressing emotions, articulating ideas and maintaining community networks. Similarly, within this study, bloggers talked about their progress, shared their experiences, offered their thoughts/ advice, worked through their emotions and were able to voice themselves more confidently. Blogging therefore appeared to be used in similar ways to findings across different populations.

Blogging offered a safe space for expression with the choice around when to blog, what to include in posts and when to engage with others (Schmidt, 2007). It therefore supported individuals to begin to process their chronic conditions through a medium which personally felt safe at that time. Since there is a multitude of ways to communicate online, choosing to blog is likely to be a result of a desire for an asynchronous, controlled space for expression (Schmidt, 2007). Motivations for blogging may therefore generalise across groups.

Blogging about chronic illness

The experiences of blogging were similar to those of individuals with other LTCs. Blogging was helpful in allowing individuals to emotionally manage their condition and share information (Chung & Kim, 2008; Ressler, Bradshaw, Gualtieri, & Chui, 2012). In addition, the positive impact of blogging included refection, gaining perspective, having an outlet, gaining support and coping with the condition (Ressler et al., 2012; Sosnowy, 2013). Blogging also served as a coping strategy which was not always necessary when coping well (Ressler et al., 2012). Content was produced when individuals needed the space, further highlighting blogging as a functional, but optional, tool in positive adjustment which occurs across chronic conditions. This highlights similarities in blogging across chronic diseases and may relate to the similarities faced in impact across LTCs.

In contrast, the need for social approval in the context of writing online did not appear to be reflected in other blog studies for chronic illness. This may have been due to the use of survey and content analysis methods in previous studies. The use of interviews allowed for the personal benefits and challenges to be explored which was not possible in previous content-focused studies (Keim-Malpass et al., 2013; Ressler et al., 2012). In addition, there is a possibility this may relate to the visible aspect of conditions and the particular social difficulties this creates. This may be a finding which is unique to VSCs. However, more research would need to explore this phenomenon of social approval to understand this further.

Therapeutic writing

When thinking about expressive writing, participants appeared to process their emotions through writing about them. A study which compared emotional disclosure (ED) with neutral writing in psoriasis found that the ED group differed in mood rather than disease severity (Vedhara et al., 2007). A change in mood and perspective appeared to be more prominent in participants' descriptions than changes in symptoms. This suggests that blogging may provide an emotional support which can improve mood in a similar way to ED. This further reinforces the emotion-focused aspect of blogging as emotion-focused strategies focus on changing the thinking around a stressor when it cannot be changed (Glanz & Schwartz, 2008). In this way, blogging appeared to be a tool to support positive adjustment.

Blogging differs from writing on paper as it has an audience and the social element was key in what was posted within this study. Writing online allowed participants to redraft so they could compose their content in a way they wanted to (Manen & Adams, 2009). This differs from standard therapeutic writing as participants can edit and amend their writing. At times, the redrafting appeared to lead to social anxiety and a need to do it right, however, it was predominantly described as helpful in gaining perspective and maintaining positivity. Like rewriting narratives, it appeared to support regulation of emotions and sense-making (Manen & Adams, 2009). Writing for an audience may therefore differ in how it is therapeutic, but still provide positive benefits.

Personal Benefits of Helping others

Providing support to others can be a way to self-heal (Mead & MacNeil, 2006) and can be more beneficial than receiving help (Riessman, 1965). There was a strong focus on blogging for others, but many personal benefits of doing so were described. Helping others can improve the quality of life of the helper, enhance self-worth and increase feelings of competence (Liang, Krause, & Bennett, 2001; Lu & Argyle, 1992; Schwartz & Sendor, 1999). Blogging appeared to be something participants gained a sense of accomplishment from in a similar way to volunteers and peer supporters. This differs from standard therapeutic interventions due to the additional benefits from social connection.

Theoretical Implications

When thinking about blogging as a vehicle for change, it supported participants to start making positive change, re-define their lives with their skin condition, appreciate the positives and connect with others. Finding health within illness can be an important factor in continuing to live a meaningful life when faced with a chronic and incurable condition (Carel, 2016; Moch, 1998). The need for acceptance did not appear as important as finding a way to live through the condition. Participants appeared content with tolerating rather than accepting their condition. Measures of acceptance may therefore not correspond to an individual's adjustment.

The Shifting Perspectives Model of Chronic Illness describes how individuals oscillate between 'illness in the foreground' and 'wellness in the foreground' dependent on the severity of their symptoms (Paterson, 2001; Telford, Kralik, & Koch, 2006). This is particularly relevant for those conditions where skin can shift between being good and getting worse unpredictably such as psoriasis and alopecia (Rumsey, 2018). This model does not use the labels of acceptance and denial but instead appreciates the non-linear trajectory of living with a chronic illness (Paterson, 2001). This highlights that a focus on acceptance may not be as necessary as acknowledging that chronic illness can fluctuate as can the impact. Theoretically, it appears important to acknowledge the experience is not linear or contingent on acceptance. This also draws awareness to the fact that when an individual is seen to be coping well at one moment in time it does not guarantee they will maintain this.

Clinical Implications

The stepped model of care proposed for psychodermatology services does not explicitly report a need for both emotion and problem focused strategies (Bewley et al., 2012). Problem focused treatment is dominant at the initial stages of managing chronic skin conditions. Though signposting is also a recommendation and does include avenues of self-help. Since the current study and previous findings have indicated the negative affect that arises from trying to solely manage the symptoms of an incurable condition, it may be useful to support individuals or direct them to emotion-focused ways of coping prior to feelings of defeat arising. This may reduce the development of psychiatric co-morbidities often seen (Dalgard et al., 2015). Expressive writing reduced the need for cancer patients to access medical support (Stanton et al., 2002) and such emotion-focused support may also reduce medical visits for chronic skin conditions.

In addition, blogging supported patients to take control of their wellbeing, in line with a move towards empowerment within current healthcare (Corben & Rosen, 2005; Newman & Vidler, 2006). Participants used the blog at times when they needed support to move back towards a place of health (Moch, 1998; Paterson, 2001). Individuals found what worked for them (conventional and alternative methods) and processed their experiences through their writing. Above all, they appeared to be moving towards a place of self-management with three participants hardly talking about their contact with services. Consequently, there appears to be some value in a non-professional led way of self-managing via blogging which in turn may reduce demand on healthcare services.

The move towards patients being more empowered and responsible for their health can challenge professional-led clinical decision making (Newman & Vidler, 2006) and lead to the negative perception of non-compliance (Corben & Rosen, 2005). This may be why many intervention studies using online support groups often include health professionals (Eysenbach, Powell, Englesakis, Rizo, & Stern, 2004) whilst unfacilitated, non-moderated support forums are often questioned (Boyers, Quest, Karimkhani, Connett, & Dellavalle, 2014; Savas, Huang, Tuchayi, & Feldman, 2014). This perception maintains a narrative which promotes reliance on health professionals in managing LTCs. Since blogging appears to support positive adjustment, there may be some value in allowing patients to take a lead in their care and make use of unmoderated online networks. Exploration of how this fits into current care models needs to be further considered and whether it would be a suitable self-help option to direct patients towards. In particular, the social challenges of blogging may need to be considered.

Since blogs lie within the public domain, they also provide clinicians a direct insight into the impact of living with chronic conditions. For example, in this study it was apparent that acceptance was not a main factor in adjustment, but rather tolerating the condition was acceptable. Blogs also contained content around positive and negative contact with health professionals. Blogs therefore may provide an insight of lived experience for health professionals.

Limitations of this Research

With a small sample, further research is needed to understand this phenomenon in more depth across conditions and cultures. This is particularly important as there can be cross cultural differences in stigma and social perception (Thompson et al., 2010) and all participants identified themselves as White British. The sample for active bloggers within this area was relatively small and there may be value in exploring self-management through social media platforms such as Instagram where communities of individuals living with chronic skin disease photo journal more actively. Though photo journaling is a different type of blogging, it still allows for individuals to chronologically post, express themselves and connect with others. A larger sample may help us to understand whether emotional expression within an online community is a functional tool for adjustment across platforms.

In addition, the research would have benefitted from member checking to assess whether its findings fit with participants. Though the blog content was used, this would have allowed members of the population to be involved in the analysis and reporting of the research as well as the design.

Conclusions and Future Recommendations

This research has begun to explore the benefits of blogging about chronic, visible skin conditions and highlighted similarities and differences across studies of living with these conditions and other LTCs. This has helped to identify a similar pattern in coping and the distress individuals are faced with when realising treatment does not work. The study also brings our attention to a need for more emotion-focused strategies for individuals with chronic health conditions as sole use of problem focused strategies can lead to negative affect and distress. Theories and research of coping and positive adjustment appear to contrast with current treatment recommendations for chronic conditions. The recommendations do not appear to incorporate emotion-focused strategies at diagnosis, though the evidence highlights the need for them in conditions which cannot be cured.

To conclude, blogging is a multifaceted tool which helps individuals to process and adjust to their condition through a variety of mechanisms. The social aspect sets blogging apart from traditional therapeutic writing techniques but allows for the reduction of isolation. How blogging could fit into current practice will require further work around how we can safely incorporate unmoderated peer to peer strategies into care. This would support a move towards self-management and provide participants with a strategy they can implement when needed without financial demand on the health service.

Further research could help by drawing out the similarities across LTCs, comparing blogging through self-motivation versus blogging through treatment recommendation and gaining understanding of blogging on different platforms (such as photo journaling). This can further support us in understanding how blogging online supports the positive adjustment of individuals with chronic VSCs and LTCs more widely and can be translated into care practices.

References

Allen, A. B., & Leary, M. R. (2010). Self-Compassion, Stress, and Coping. *Social and personality psychology compass, 4*(2), 107-118. doi:10.1111/j.1751-9004.2009.00246.x

All Party Parliamentary Group for Skin. (2013). *The Psychological and Social Impact of Skin Diseases on People's Lives*. Retrieved from London:

Barak, A., & Grohol, J. M. (2011). Current and Future Trends in Internet-Supported Mental Health Interventions. *Journal of Technology in Human Services, 29*(3), 155-196. doi:10.1080/15228835.2011.616939

Batchelor, J. M., Tan, W., Tour, S., Yong, A., Montgomery, A. A., & Thomas, K. S. (2016). Validation of the Vitiligo Noticeability Scale: a patient-reported outcome measure of vitiligo treatment success. *British Journal of Dermatology, 174*(2), 386-394. doi:doi:10.1111/bjd.14208

Berry, D. S., & Pennebaker, J. W. (1993). Nonverbal and Verbal Emotional Expression and Health. *Psychotherapy and Psychosomatics, 59*(1), 11-19.

Bewley, A., & Trust, L. (2012). Working party report on minimum standards for psychodermatology 2012.

Biggerstaff, D., & Thompson, A. R. (2008). Interpretative phenomenological analysis (IPA): A qualitative methodology of choice in healthcare research. *Qualitative research in psychology, 5*(3), 214-224.

Borimnejad, L., Parsa Yekta, Z., Nikbakht-Nasrabadi, A., & Firooz, A. (2006). Quality of life with vitiligo: comparison of male and female muslim patients in Iran. *Gender Medicine, 3*(2), 124-130.

Bowden, C., & Galindo-Gonzalez, S. (2015). Interviewing when you're not face-to-face: The use of email interviews in a phenomenological study. *International Journal of Doctoral Studies, 10*(12), 79-92.

Boyers, L. N., Quest, T., Karimkhani, C., Connett, J., & Dellavalle, R. P. (2014). Dermatology on YouTube. *Dermatology Online Journal, 20*(6).

British Skin Foundation. (n.d.). A to Z of Skin Diseases. Retrieved from http://www.britishskinfoundation.org.uk/SkinInformation/AtoZofSkinDisease.aspx

Brooks, J., McCluskey, S., Turley, E., & King, N. (2015). The Utility of Template Analysis in Qualitative Psychology Research. *Qualitative Research in Psychology, 12*(2), 202-222. doi:10.1080/14780887.2014.955224

Campbell, D. F., & Machado, A. A. (2013). Ensuring quality in qualitative inquiry: using key concepts as guidelines. *Motriz: Revista de Educação Física, 19*, 572-579.

Carel, H. (2016). *Illness: The cry of the flesh*: Routledge.

Chung, D. S., & Kim, S. (2008). Blogging activity among cancer patients and their companions: Uses, gratifications, and predictors of outcomes. *Journal of the Association for Information Science and Technology, 59*(2), 297-306.

Colineau, N., & Paris, C. (2010). Talking about your health to strangers: understanding the use of online social networks by patients. *New Review of Hypermedia and Multimedia, 16*(1-2), 141-160. doi:10.1080/13614568.2010.496131

Corben, S., & Rosen, R. (2005). Self-management for long-term conditions. *London: King's Fund*.

Coulter, A., Roberts, S., & Dixon, A. (2013). Delivering better services for people with long-term conditions. *Building the house of care. London: The King's Fund*, 1-28.

Dalgard, F. J., Gieler, U., Tomas-Aragones, L., Lien, L., Poot, F., Jemec, G. B. E., . . . Kupfer, J. (2015). The psychological burden of skin diseases: a cross-sectional multicenter study among dermatological out-patients in 13 European countries. *Journal of Investigative Dermatology, 135*(4), 984-991. doi:10.1038/jid.2014.530

De Ridder, D., Geenen, R., Kuijer, R., & van Middendorp, H. (2008). Psychological adjustment to chronic disease. *The Lancet, 372*(9634), 246-255.

Dirschka, T., Micali, G., Papadopoulos, L., Tan, J., Layton, A., & Moore, S. (2015). Perceptions on the Psychological Impact of Facial Erythema Associated with Rosacea: Results of International Survey. *Dermatology and Therapy, 5*(2), 117-127. doi:10.1007/s13555-015-0077-2

Dunn, K. (2012). A qualitative investigation into the online counselling relationship: To meet or not to meet, that is the question. *Counselling and Psychotherapy Research, 12*(4), 316-326.

Eysenbach, G., Powell, J., Englesakis, M., Rizo, C., & Stern, A. (2004). Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions. *Bmj, 328*(7449), 1166. doi:10.1136/bmj.328.7449.1166

Folkman, S., Lazarus, R. S., Dunkel-Schetter, C., DeLongis, A., & Gruen, R. J. (1986). Dynamics of a stressful encounter: cognitive appraisal, coping, and encounter outcomes. *J Pers Soc Psychol, 50*(5), 992-1003.

Frisina, P. G., Borod, J. C., & Lepore, S. J. (2004). A Meta-Analysis of the Effects of Written Emotional Disclosure on the Health Outcomes of Clinical Populations. *The Journal of Nervous and Mental Disease, 192*(9), 629-634. doi:10.1097/01.nmd.0000138317.30764.63

Glanz, K., & Schwartz, M. D. (2008). Stress, coping, and health behavior. *Health behavior and health education: Theory, research, and practice, 4*, 211-236.

Green, L. (2010). The effect of skin conditions on patients' quality of life. *Nursing Standard (through 2013), 25*(9), 48.

Greene, J. A., Choudhry, N. K., Kilabuk, E., & Shrank, W. H. (2011). Online Social Networking by Patients with Diabetes: A Qualitative Evaluation of Communication with Facebook. *Journal of General Internal Medicine, 26*(3), 287-292. doi:10.1007/s11606-010-1526-3

Hale, E., Treharne, G., Norton, Y., Lyons, A., Douglas, K., Erb, N., & Kitas, G. (2006). 'Concealing the Evidence': The Importance of Appearance Concerns for Patients with Systemic Lupus Erythematosus. *Lupus, 15*(8), 532-540. doi:10.1191/0961203306lu2310xx

Hay, R. J., Johns, N. E., Williams, H. C., Bolliger, I. W., Dellavalle, R. P., Margolis, D. J., . . . Wulf, S. K. (2014). The global burden of skin disease in 2010: an analysis of the prevalence and impact of skin conditions. *Journal of Investigative Dermatology, 134*(6), 1527-1534.

Heelan, K., Hitzig, S. L., Knowles, S., Drucker, A. M., Mittmann, N., Walsh, S., & Shear, N. H. Loss of Work Productivity and Quality of Life in Patients With Autoimmune Bullous Dermatoses. *Journal of Cutaneous Medicine & Surgery, 19*(6), 546-554.

Home, P., Mant, J., Diaz, J., & Turner, C. (2008). Guidelines: management of type 2 diabetes: summary of updated NICE guidance. *BMJ: British Medical Journal, 336*(7656), 1306.

Hong, J., Koo, B., & Koo, J. (2008). The psychosocial and occupational impact of chronic skin disease. *Dermatologic Therapy, 21*(1), 54-59.

Idriss, S. Z., Kvedar, J. C., & Watson, A. J. (2009). The role of online support communities: Benefits of expanded social networks to patients with psoriasis. *Archives of Dermatology, 145*(1), 46-51. doi:10.1001/archdermatol.2008.529

Johnston, S. A., Krasuska, M., Millings, A., Lavda, A. C., & Thompson, A. R. (2018). Experiences of rosacea and its treatment: an interpretative phenomenological analysis. *British Journal of Dermatology, 178*(1), 154-160. doi:10.1111/bjd.15780

Kamel Boulos, M. N., & Wheeler, S. (2007). The emerging Web 2.0 social software: an enabling suite of sociable technologies in health and health care education1. *Health Information & Libraries Journal, 24*(1), 2-23. doi:10.1111/j.1471-1842.2007.00701.x

Keim-Malpass, J., Baernholdt, M., Erickson, J. M., Ropka, M. E., Schroen, A. T., & Steeves, R. H. (2013). Blogging through cancer: Young women's persistent problems shared online. *Cancer nursing, 36*(2), 163-172.

Kennedy-Moore, E., & Watson, J. C. (2001). *Expressing emotion: Myths, realities, and therapeutic strategies*: Guilford Press.

King, N. (2012). Doing template analysis. *Qualitative organizational research: Core methods and current challenges, 426*.

Lavda, A. C., Webb , T. L., & Thompson, A. R. (2012). A meta-analysis of the effectiveness of psychological interventions for adults with skin conditions. *British Journal of Dermatology, 167*(5), 970-979. doi:doi:10.1111/j.1365-2133.2012.11183.x

Liang, J., Krause, N. M., & Bennett, J. M. (2001). Social exchange and well-being: Is giving better than receiving? *Psychology and aging, 16*(3), 511.

Lu, L., & Argyle, M. (1992). Receiving and giving support: Effects on relationships and well-being. *Counselling Psychology Quarterly, 5*(2), 123-133.

MacDonald, G., Saltzman, J. L., & Leary, M. R. (2003). Social approval and trait self-esteem. *Journal of Research in Personality, 37*(2), 23-40. doi:https://doi.org/10.1016/S0092-6566(02)00531-7

Manen, M. V., & Adams, C. (2009). The Phenomenology of Space in Writing Online. *Educational Philosophy and Theory, 41*(1), 10-21. doi:10.1111/j.1469-5812.2008.00480.x

Mead, S., & MacNeil, C. (2006). Peer support: What makes it unique. *International Journal of Psychosocial Rehabilitation, 10*(2), 29-37.

Meho, L. I. (2006). E-mail interviewing in qualitative research: A methodological discussion. *Journal of the Association for Information Science and Technology, 57*(10), 1284-1295.

Merolli, M., Gray, K., & Martin-Sanchez, F. (2014). Therapeutic affordances of social media: emergent themes from a global online survey of people with chronic pain. *J Med Internet Res, 16*(12), e284. doi:10.2196/jmir.3494

Messenger, A., McKillop, J., Farrant, P., McDonagh, A., & Sladden, M. (2012). British Association of Dermatologists' guidelines for the management of alopecia areata 2012. *British Journal of Dermatology, 166*(5), 916-926.

Moch, S. D. (1998). Health-within-illness: concept development through research and practice. *Journal of Advanced Nursing, 28*(2), 305-310.

Møller, A. H., Erntoft, S., Vinding, G. R., & Jemec, G. B. E. (2015). A systematic literature review to compare quality of life in psoriasis with other chronic diseases using EQ-5D-derived utility values. *Patient related outcome measures, 6*, 167-177. doi:10.2147/PROM.S81428

Nash, A. S., McAteer, H., Schofield, J., Penzer, R., & Gilbert, A. K. (2015). Psoriasis today: experiences of healthcare and impact on quality of life in a major UK cohort. *Prim Health Care Res Dev, 16*(4), 415-423. doi:10.1017/s1463423614000450

Neal, D. M., & McKenzie, P. J. (2011). Putting the pieces together: endometriosis blogs, cognitive authority, and collaborative information behavior. *Journal of the Medical Library Association : JMLA, 99*(2), 127-134. doi:10.3163/1536-5050.99.2.004

Nelson, P. A., Chew-Graham, C. A., Griffiths , C. E. M., & Cordingley, L. (2013). Recognition of need in health care consultations: a qualitative study of people with psoriasis. *British Journal of Dermatology, 168*(2), 354-361. doi:doi:10.1111/j.1365-2133.2012.11217.x

Newman, J., & Vidler, E. (2006). Discriminating Customers, Responsible Patients, Empowered Users: Consumerism and the Modernisation of Health Care. *Journal of Social Policy, 35*(2), 193-209. doi:10.1017/S0047279405009487

Parna, E., Aluoja, A., & Kingo, K. (2015). Quality of life and emotional state in chronic skin disease. *Acta Dermato-Venereologica, 95*(3), 312-316. doi:10.2340/00015555-1920

Parsad, D., Dogra, S., & Kanwar, A. J. (2003). Quality of life in patients with vitiligo. *Health Qual Life Outcomes, 1*, 58. doi:10.1186/1477-7525-1-58

Paterson, B. L. (2001). The Shifting Perspectives Model of Chronic Illness. *Journal of Nursing Scholarship, 33*(1), 21-26. doi:10.1111/j.1547-5069.2001.00021.x

Pennebaker, J. W. (1997). Writing About Emotional Experiences as a Therapeutic Process. *Psychological Science, 8*(3), 162-166. doi:10.1111/j.1467-9280.1997.tb00403.x

Picardi, A., Abeni, D., Melchi, C. F., Puddu, P., & Pasquini, P. (2000). Psychiatric morbidity in dermatological outpatients: an issue to be recognized. *British Journal of Dermatology, 143*(5), 983-991. doi:doi:10.1046/j.1365-2133.2000.03831.x

Pietkiewicz, I., & Smith, J. A. (2014). A practical guide to using interpretative phenomenological analysis in qualitative research psychology. *Psychological Journal, 20*(1), 7-14.

Pruitt, S., Canny, J., & Epping-Jordan, J. (2005). *Preparing a health care workforce for the 21st century: the challenge of chronic conditions*: World Health Organization.

Rapp, S. R., Feldman, S. R., Exum, M. L., Fleischer, A. B., & Reboussin, D. M. (1999). Psoriasis causes as much disability as other major medical diseases. *Journal of the American Academy of Dermatology, 41*(3), 401-407. doi:https://doi.org/10.1016/S0190-9622(99)70112-X

Ressler, P. K., Bradshaw, Y. S., Gualtieri, L., & Chui, K. K. H. (2012). Communicating the Experience of Chronic Pain and Illness Through Blogging. *Journal of Medical Internet Research, 14*(5), e143. doi:10.2196/jmir.2002

Roman, J. (2016). Beauty That Is More Than Skin Deep. *JAMA Dermatol, 152*(5), 562-563. doi:10.1001/jamadermatol.2015.4762

Richards, H. L., Fortune, D. G., Weidmann, A., Sweeney, S. K. T., & Griffiths, C. E. M. (2004). Detection of psychological distress in patients with psoriasis: low consensus between dermatologist and patient. *British Journal of Dermatology, 151*(6), 1227-1233. doi:doi:10.1111/j.1365-2133.2004.06221.x

Riessman, F. (1965). The" helper" therapy principle. *Social work*, 27-32.

Rumsey, N. (2018). Psychosocial adjustment to skin conditions resulting in visible difference (disfigurement): What do we know? Why don't we know more? How shall we move forward? *International Journal of Women's Dermatology, 4*(1), 2-7. doi:https://doi.org/10.1016/j.ijwd.2017.09.005

Samarasekera, E., Sawyer, L., Parnham, J., Smith, C. H., & Group, G. D. (2012). Assessment and management of psoriasis: summary of NICE guidance. *Bmj, 345*, e6712.

Sampogna, F., Tabolli, S., & Abeni, D. (2012). Living with psoriasis: prevalence of shame, anger, worry, and problems in daily activities and social life. *Acta Dermato-Venereologica, 92*(3), 299-303. doi:10.2340/00015555-1273

Savas, J. A., Huang, K. E., Tuchayi, S. M., & Feldman, S. R. (2014). Understanding the influence of social media in medicine: lesson learned from facebook. *Dermatology Online Journal, 20*(9).

Schmidt, J. (2007). Blogging practices: An analytical framework. *Journal of Computer-Mediated Communication, 12*(4), 1409-1427.

Schulman-Green, D., Jaser, S., Martin, F., Alonzo, A., Grey, M., McCorkle, R., . . . Whittemore, R. (2012). Processes of Self-Management in Chronic Illness. *Journal of Nursing Scholarship, 44*(2), 136-144. doi:10.1111/j.1547-5069.2012.01444.x

Schwartz, C. E., & Sendor, R. M. (1999). Helping others helps oneself: response shift effects in peer support. *Social Science & Medicine, 48*(11), 1563-1575. doi:https://doi.org/10.1016/S0277-9536(99)00049-0

Senra, M. S., & Wollenberg, A. (2014). Psychodermatological aspects of atopic dermatitis. *British Journal of Dermatology, 170*(s1), 38-43. doi:doi:10.1111/bjd.13084

Smith, J.A., Jarman, M., & Osborn, M. (1999). Doing interpretative phenomenological analysis. Dans M. Murray, & K. Chamberlain (Éds), Qualitative health psychology: theories and methods (pp. 218-240): London: Sage.

Smith, J. A., Flowers, P., & Osborn, M. (1997). Interpretative phenomenological analysis and the psychology of health and illness. *Material discourses of health and illness*, 68-91.

Sosnowy, C. (2013). *Blogging chronic illness and negotiating patient-hood: Online narratives of women with MS*: City University of New York.

Stanton, A. L., Danoff-Burg, S., Sworowski, L. A., Collins, C. A., Branstetter, A. D., Rodriguez-Hanley, A., . . . Austenfeld, J. L. (2002). Randomized, Controlled Trial of Written Emotional Expression and Benefit Finding in Breast Cancer Patients. *Journal of Clinical Oncology, 20*(20), 4160-4168. doi:10.1200/jco.2002.08.521

Telford, K., Kralik, D., & Koch, T. (2006). Acceptance and denial: implications for people adapting to chronic illness: literature review. *Journal of Advanced Nursing, 55*(4), 457-464. doi:10.1111/j.1365-2648.2006.03942.x

Teovska Mitrevska, N., Eleftheriadou, V., & Guarneri, F. (2012). Quality of life in vitiligo patients. *Dermatologic Therapy, 25 Suppl 1*, S28-31. doi:10.1111/dth.12007

Thompson, A., & Kent, G. (2001). Adjusting to disfigurement: processes involved in dealing with being visibly different. *Clinical Psychology Review, 21*(5), 663-682. doi:https://doi.org/10.1016/S0272-7358(00)00056-8

Thompson, A. R., Clarke, S. A., Newell, R. J., & Gawkrodger, D. J. (2010). Vitiligo linked to stigmatization in British South Asian women: a qualitative study of the experiences of living with vitiligo. *British Journal of Dermatology, 163*(3), 481-486. doi:10.1111/j.1365-2133.2010.09828.x

Thompson, A. R., Kent, G., & Smith, J. A. (2002). Living with vitiligo: dealing with difference. *Br J Health Psychol, 7*(Pt 2), 213-225. doi:10.1348/135910702169457

Vedhara, K., Morris, R. M., Booth, R., Horgan, M., Lawrence, M., & Birchall, N. (2007). Changes in mood predict disease activity and quality of life in patients with psoriasis following emotional disclosure. *Journal of Psychosomatic Research, 62*(6), 611-619. doi:https://doi.org/10.1016/j.jpsychores.2006.12.017

Whitton, M. E., Pinart, M., Batchelor, J., Leonardi-Bee, J., González, U., Jiyad, Z., . . . Ezzedine, K. (2015). Interventions for vitiligo. *Cochrane Database of Systematic Reviews,* (2). Retrieved from http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD003263.pub5/abstract doi:10.1002/14651858.CD003263.pub5

CHAPTER THREE: PUBLIC DISSEMINATION DOCUMENT

Overview

The following document summarises the literature review and empirical study completed as part of the award towards the Degree of Doctor of Clinical Psychology by Selina Kaur Tour at the University of Birmingham.

Literature Review

Introduction

The Dermatology Life Quality Index (DLQI) is the most commonly used quality of life measure within dermatology. Since it was developed, it has been translated into over 55 different languages and used to measure the impact of skin conditions in clinical practice and in clinical trials. Quality of life measures like the DLQI aim to capture physical, mental and social wellbeing from the patient's perspective. This is important in dermatology as skin conditions can impact on social relationships, ability to engage with leisure activities, work and sleep. Skin conditions like psoriasis can affect an individual similar to other long term conditions like cancer and heart disease.

When using a quality of life questionnaire like the DLQI, we want to ensure that it is reliable at measuring quality of life so we can be confident that it provides a good reflection of somebody's wellbeing. One way we can check whether it is reliable is by ensuring that the questions all relate to each other and are measuring the same thing – in this case quality of life. This is called internal consistency. This is one type of reliability and is calculated as a reliability coefficient. This is a value between 0 and 1, where the closer it falls to 1 the more reliable the measure is said to be.

A previous preview of the literature highlighted that the internal consistency of the DLQI ranged between 0.67 and 0.92. However, this review did not pool all the estimates together to quantify the overall reliability of the DLQI. It can be helpful to combine the data across the existing literature to better understand the DLQI's true reliability and help future researchers make an informed decision about whether the DLQI is fit for their intended purpose.

Aims

This review aimed to explore the internal consistency of the DLQI by pooling together all of the studies reporting internal consistency in a meta-analysis.

Method

One researcher searched 5 research databases online for studies that reported the internal consistency of the DLQI. Studies were screened against inclusion/ exclusion criteria to ensure they were appropriate. The relevant information was extracted from included studies such as sample size, the reliability coefficient, the skin condition participants had and the language of the DLQI. A random effects model was then used to calculate the overall effect size. Following this, the same model but weighted by the quality of each individual study was conducted. This calculated the effect as if every study was of the highest quality.

Further tests including testing for variation across the studies and assessing the presence of publication bias and highly influential studies. In addition, the meta-analytic effect was calculated for different subgroups (i.e. for different skin disorders, across languages).

Findings

The meta-analytic effect from combining internal consistency across studies was 0.85 (CI 0.83, 0.86). The predictive interval estimating where future literature will fall ranged between 0.74 and 0.91. The quality of studies did not change this effect. There was a high level of variation across studies and the analysis attempted to find the source of this variation. Publication bias did not appear to be an issue and no one study was disproportionately influencing the effect found. Subgroup analysis was unable to account for the variation found across studies.

Conclusions

The current review is the first to quantify the internal consistency of the DLQI and has identified some important recommendations for future research and clinicians. The review suggests the DLQI has a high level of internal consistency; however, the review was unable to identify the source of the variation between studies. Though it seems a reasonable summary of the literature, a more cautious approach may be more appropriate until we can better understand the source of variation. Clinicians are therefore recommended to use the alpha coefficient for their specific sample, as outlined in Table 6 (Volume I, Chapter One). Overall, the internal consistency falls above the expected level for use in clinical practice.

Future research exploring the sources of variation would be beneficial. In addition, a future review looking at the DLQI's stability over time would support a more robust awareness of its overall reliability as a measure of quality of life.

Empirical Study

Introduction

Chronic skin conditions such as psoriasis, atopic dermatitis and vitiligo can have a profound impact on quality of life, similar to conditions such as cancer, arthritis and depression. When conditions are visible, they can lead to further difficulties due to the need to manage symptoms and the reaction of others. There is a limited amount of support for the ongoing psychosocial distress related to having a visible and chronic skin condition and current guidance encourages self-management of long term conditions such as these. Therefore, it is important to explore the different resources available to individuals to support self-management.

The World Wide Web provides individuals with an array of ways to acquire knowledge and seek support. This can be both facilitated (such as self-help and clinician-moderated groups) and unfacilitated (such as peer to peer Facebook groups and web blogs). Cross sectional research into the use of unfacilitated avenues of support have highlight the potential benefits of connecting with others online when managing a long-term condition. Research into blogging – a web based personal journal - has found that individuals can gain validation and make sense of their conditions through connecting with others. To date, no research has looked at how individuals with visible and chronic conditions self-manage their skin conditions through blogging.

Aims

This research aimed to explore the experiences of blogging online about chronic and visible skin conditions.

Method

This study explored both the experiences of blogging and what bloggers were writing about. This involved a two-method approach using both Interpretative Phenomenological Analysis and Template Analysis. Figure 8 outlines the process

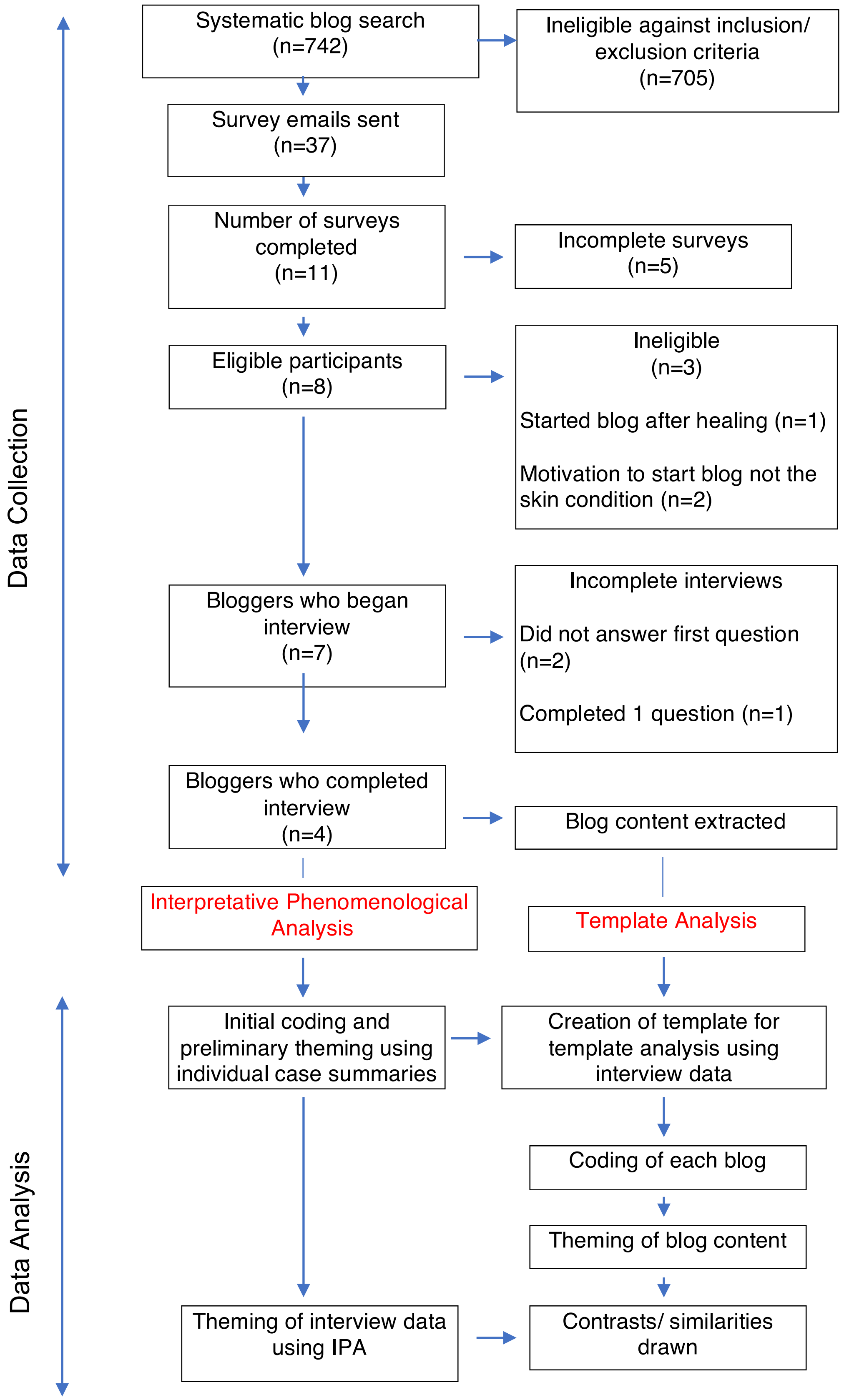


Figure 8. Sample recruitment and methodology

of the data collection and analysis. Blogs were systematically searched and bloggers were approached via email to take part in an online survey. The survey gathered initial information and informed consent. Potential participants were then invited to take part in an email interview. The blogs of those interviewed were then used for the purposes of template analysis. This involved the first five and last five blog posts being extracted for analysis. Data was coded and themed and the similarities and differences were considered. Coding was cross checked at random to ensure coherence from data to themes.

Findings

The main themes identified through the interview analysis were: ‘Skin condition as an overwhelming threat to self’, ‘Blogging for self – Venting and Building’. ‘Blogging for others – sharing and informing’, ‘Trying out a way to engage with others’ and ‘Blogging as a journey which ebbs and flows’. Individuals reached a stage of feeling defeated by their skin condition and turned to blogging as both an outlet and way to connect with others. It supported social connection, expression and blogging was an experience which was contingent on the state of the skin condition. Template analysis mostly reflected the explicit motives for blogging; however, social presence online and the steps taken to come across well appeared to be unique to IPA. This hidden effort for social approval mirrored the hidden effort to hide the condition in face to face communication, highlighting that the same difficulties could be encountered online.

Conclusions

This research reflected previous studies looking at the experiences of living with a chronic and visible skin condition. Blogging was used as a way to overcome the feelings of defeat when treatment did not work and appeared to support participants in finding ways to manage through the uncertainty. Experiences of blogging reflected the findings found for writing online about other chronic conditions.

Though blogging is unmoderated and can challenge clinician-led interventions, it appears to provide individuals with a way to make sense of their condition and tolerate the uncertainty that arises from a chronic condition. Future research to consider how blogging and similar online platforms could be used to support individuals to feel more empowered and self-manage would support the move towards self-management within the current health service more effectively.

References

Basra, M. K. A., Fenech, R., Gatt, R. M., Salek, M. S., & Finlay, A. Y. (2008). The Dermatology Life Quality Index 1994-2007: A comprehensive review of validation data and clinical results. *British Journal of Dermatology, 159*(5), 997-1035. doi:http://dx.doi.org/10.1111/j.1365-2133.2008.08832.

Bewley, A., & Trust, L. (2012). Report on Minimum Standards for Psychodermatology services 2012.

Borimnejad, L., Parsa Yekta, Z., Nikbakht-Nasrabadi, A., & Firooz, A. (2006). Quality of life with vitiligo: comparison of male and female muslim patients in Iran. *Gender Medicine, 3*(2), 124-130.

Chung, D. S., & Kim, S. (2008). Blogging activity among cancer patients and their companions: Uses, gratifications, and predictors of outcomes. *Journal of the Association for Information Science and Technology, 59*(2), 297-306.

Finlay, A. Y., & Khan, G. K. (1994). Dermatology Life Quality Index (DLQI)--a simple practical measure for routine clinical use. *Clinical & Experimental Dermatology, 19*(3), 210-216.

Greene, J. A., Choudhry, N. K., Kilabuk, E., & Shrank, W. H. (2011). Online Social Networking by Patients with Diabetes: A Qualitative Evaluation of Communication with Facebook. *Journal of General Internal Medicine, 26*(3), 287-292. doi:10.1007/s11606-010-1526-3

Heelan, K., Hitzig, S. L., Knowles, S., Drucker, A. M., Mittmann, N., Walsh, S., & Shear, N. H. Loss of Work Productivity and Quality of Life in Patients With Autoimmune Bullous Dermatoses. *Journal of Cutaneous Medicine & Surgery, 19*(6), 546-554.

Henson, R. K. (2001). Understanding internal consistency reliability estimates: A conceptual primer on coefficient alpha. *Measurement and evaluation in counseling and development, 34*(3), 177.

Higgins, J. P., Altman, D. G., Gøtzsche, P. C., Jüni, P., Moher, D., Oxman, A. D., . . . Sterne, J. A. (2011). The Cochrane Collaboration’s tool for assessing risk of bias in randomised trials. *Bmj, 343*, d5928.

Higgins, J. P. T., & Thompson, S. G. (2002). Quantifying heterogeneity in a meta-analysis. *Statistics in medicine, 21*(11), 1539-1558. doi:10.1002/sim.1186

Johnston, S. A., Krasuska, M., Millings, A., Lavda, A. C., & Thompson, A. R. (2018). Experiences of rosacea and its treatment: an interpretative phenomenological analysis. *British Journal of Dermatology, 178*(1), 154-160. doi:10.1111/bjd.15780

King, N. (2012). Doing template analysis. *Qualitative organizational research: Core methods and current challenges*, *426*.

Smith, J. A., Flowers, P., & Osborn, M. (1997). Interpretative phenomenological analysis and the psychology of health and illness. *Material discourses of health and illness*, 68-91.

APPENDIX B
CONSENT FORM WITHIN THE ONLINE SURVEY

Participant Identification Number: (Please provide the number given within the invitation email)

CONSENT FORM

The psychosocial implications of writing online: the experience of blogging about chronic visible skin conditions

Researchers: Selina Tour, Dr Ruth Howard, Dr Michael Larkin and Dr Andrew R Thompson

Please place your initials in each box

1. I confirm that I have understood the information sheet dated 28/02/2017 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time during the research interview process, without giving any reason ☐

3. I understand that following the research interview I will have a two-week period for reflection. The researcher will then contact me at which point I may withdraw my interview entirely or in part, without giving any reason ☐

4. I understand that the data collected during this study will be looked at by the researcher and relevant others at the University of Birmingham and University of Sheffield in the UK to ensure that the analysis is a fair and ☐

reasonable representation of the data. This is likely to be the researchers outlined above.

5. I understand that direct quotes may be published in any write-up of the data, and used for training purposes. My name will not be attributed to any such quotes if I take part in the interviews and I understand that I will not be identifiable by my comments. ☐

6. I understand that direct quotes may be published from my blog, and used for training purposes. My name or blog address will not be attributed to such quotes; however, I understand that the blog content cannot be anonymous as it is available within the public domain. I understand that all attempts will be made so my interview will not be attributable to my blog content. ☐

....

Name of participant Date

APPENDIX C
INITIAL SURVEY

Consent Form (see Appendix B)

Demographic questions

1. Preferred name
2. Age
3. Gender
4. Ethnicity
5. City, Country
6. Education Level

Questions in regards to skin

1. What skin condition do you have?
2. Which body sites are affected?
3. How long have you had the condition?
    - Extra comment section here to say whether this has been constant or intermittent
4. Any other health conditions

Dermatology Quality of Life Index

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	A lot	✕

	your skin been a problem at	A little	×
	work or **studying**?	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.

Questions related to blog

1. When did you first begin to blog?
2. Why did you begin your blog?
3. Do you mainly blog about your skin?
4. How frequently do you blog?

APPENDIX D
INTERVIEW QUESTIONS

Can you tell me about your skin experiences before you began blogging?

Prompts: What can you remember about when you initially began to get symptoms? Did your skin symptoms change over time? How did it feel in your body? How did you interpret your skin condition? What was going on in your mind then?

Can you tell me about what happened when you began to seek help?

What kind of treatments did you think were appropriate? What did you think should be done to overcome your skin condition? What kind of support did you find helpful/ unhelpful?

Can you tell me about how you came to begin blogging?

Prompts: What was going on with your skin at that time? How were you managing at that time? How did you start blogging?

Can you tell me a bit more about your writing?

Prompts: When do you write? What do you write about? What have you learned? What has been challenging?

How would you describe the role played by blogging in living with your skin condition?

What is similar/ different about how you thought/perceived your skin condition prior to blogging? Have your management strategies changed or stayed the same? What would you say blogging is about? What role does blogging play for you? How has blogging impacted on your support networks?

APPENDIX E
EXAMPLE EXTRACT OF INITIAL READ THROUGH AND NOTES FOR IPA

Mental support

More towards looking for cure?

I started to look for help but all I found was miracle cures, no real support to help me, certainly not with the mental issues. I became even more of a recluse, has little self confidence and became extremely anxious and paranoid. I didn't o to anyone for help I think in part because I felt let down but mostly because I was not thinking straight. I gave in to psoriasis at this point and it took hold for many years. I felt embarrassed and that no one understood.

emotional impact
- social
|
feeling let down.

Skin taking over
|
Succumbing defeated.

Alone.

I did find the Psoriasis Association and got some information about the decease to understand it more. Partly this made me more depressed as I found out for sure there was no cure, that the treatments were hit and miss. I was more confused and more angry with the second flare up as well, especially as it came with such

cure

Skin - attacking? aggressive?

vengeance, quicker than the first time, clear skin to covered in about a week or two I seem to remember.

My GP at the start was the biggest help, He questioned what I had been told by the consultant, whether I had the condition explained properly. He referred me without a second thought and gave me topical steroids to keep me going. I was a mess by the time I saw a consultant, they gave me light treatment again and that's all I cared about. The appointments are a haze now as I wasn't really listening, didn't want to listen. All I wanted was to be better. This time they explained it better, especially the nursing staff during the light treatment who took time to actually sit me down and talk through the condition. Although everyone kept asking how I was, nothing was actually done about my mental state. I do think I became

information
listening
understanding

emotional
toll
- out of
control?

'Blur'
Getting rid
of it.

emotional
- no support
no action

APPENDIX F
EXAMPLE EXTRACT OF LINE BY LINE CODING FOR IPA

initial symptoms → less noticeable

feeling self-conscious of condition being noticeable

an adolescent, when it was simply blond, only noticeable

when light shone through it. It may have been a bit

Initial symptoms
- aware but not debilitating.

longer than normal, or more profuse. I vividly remember

Being judged / negative comment

a boy commenting rudely on it in school, around the age

social disapproval
not something easily forgotten
- cannot forget

of thirteen or fourteen, and that's the first time I recall

Negative Social perception
a driver to do something about skin
↓
social motivation

feeling like I should do something about it, even though I

A need to do something

own concern
vs
social concern

had been concerned about it for a while. After that, I

own concern not overwhelming, social too much.

began trimming it with nail scissors. - Needing to hide it / make it less noticeable
- Fear of being judged again

symptoms getting worse over time

I can't remember exactly when I noticed the hair getting

condition more consuming

coarser and darker, but by the time I was sixteen I was

plucking my chin and the sides of my face every day, and

treatment becoming longer
- taking more time

it was showing up on my breasts and stomach and

thighs. I remember being worried that something was

Not knowing: worrying what is happening.

wrong, but I wasn't willing to go to the doctor to find out. I

not wanting to know

was afraid it was something really bad, but I couldn't

- Fear of it being the worst thing possible
life-threatening?

Easier to be in denial?

imagine what. This was in the early 2000's, when the internet was not the established resource it is today, and even if it had been, I'm not sure I would have had the courage to do an online search about unusual body hair.

Fear of finding out more (what's wrong)
- not wanting to acknowledge it as a problem then it would become real.

Denial?
Not wanting to accept something being wrong
- not wanting to acknowledge it

It would have been like admitting to a stranger that I had it.

seeking social validation

My mom didn't appear to be concerned, and told me positive things like how it would probably disappear when puberty was over. I hoped, rather than believed, that was true.

→ being given reassurance

→ reassurance not resonating
- not enough to make it feel better

needing hope it will go away

forced/needed to but reluctant → desperate?

Seeking help
- condition overwhelming
- needing something.

I don't remember what finally compelled me to agree to see the doctor. I think I just couldn't keep up with tweezing anymore. There was so much hair on my face alone that I had to move on to cream bleach every morning. I was afraid to wear shirts that might ride up and show my hairy stomach or back, or swimsuits

(Not wanting to though)

condition/treatment overwhelming
-can't cope

Symptoms getting worse

overwhelming/out of control

Condition overwhelming becoming all consuming

-Treating becoming more intense
-time consuming

Fear of people seeing skin condition
- it being noticed.

3

APPENDIX G
EXTRACT EXAMPLE OF AN INDIVIDUAL CASE SUMMARY FOR IPA

Cluster	Quotes	Comments on Quotes/ Clusters
Social		
Being understood and validated	L13 “she was an incredible listener” L106- “I sat with her and chatted in her living room.” L117 – “Emotionally I was suffering at the time but then getting all the lovely messages and comments gave me a real boost and I felt much stronger about dealing with it.” L205 – “The feedback from it has been very rewarding. “ L220 – “It was much more rewarding then what I initially thought. I did not except the reception and the feeling I had from helping others was very rewarding”	Being validated, heard, able to express feelings about condition, appreciation for having some listen
Reluctance to share / let people in Easier to share with strangers	L201 – “Also the support I get from friends and even more so random people from blogging really helps.” L114 – “I started writing it without knowing if I would actually publish it.”	

Cluster	Quotes	Comments on Quotes/ Clusters
People seeing the condition Social acceptance - Apprehension about people knowing – fear of being judged Reluctance to share – safe with closer people? – fear of judgment Choosing when/how to connect with others	L131 – “I did tell people I saw and it was pretty obvious by that stage. I had large patches on the top of my head” L134 – “. I was mainly wearing headscarves. I was not consciously going out to social events and seeing people as I was not emotionally stable to do so” L137 – “I mainly kept my emotions and worries to my husband and family.” L112 – “I still hadn’t spoken to lots of friends about this” L173 – “The challenges was initially getting started with the blog and launching it. I was very apprehensive about people knowing about my condition and how it would be perceived.” L260 - It’s when I can compose what I am feeling into the right words to help others and ensuring I get across the right messages I want to portray. L224 – “Blogging for me helps bring together communities of other sufferers without having a interact if you don’t want to.”	Reluctance to let people in but what when you can SEE the condition? Avoiding interaction – fear of judgement? Socially isolated? Bottling up, fear? Contrast to opening up to lady selling the wigs – comfort in strangers? What will other people say? Who defines this? Fear that people cannot handle the reality? Can she? Why cannot the bad be shared? Needing to portray a certain image

APPENDIX H
EXAMPLES OF PARTICIPANT QUOTES FOR SUBTHEMES FOR IPA

Being Built up

Laura: "it felt good to finally be doing something about it. Like I had some control."

Tom: "My management strategies must have changed. This is a little blurry but suffice to say that before blogging I don't think I had any. Psoriasis was clearly winning and I wasn't managing it at all"

Debbie: "Emotionally I was suffering at the time but then getting all the lovely messages and comments gave me a real boost and I felt much stronger about dealing with it."

Ian: "It has been helpful knowing I have an unofficial support network and that there are multiple people out there in the same position as me"

Social approval in Blogging

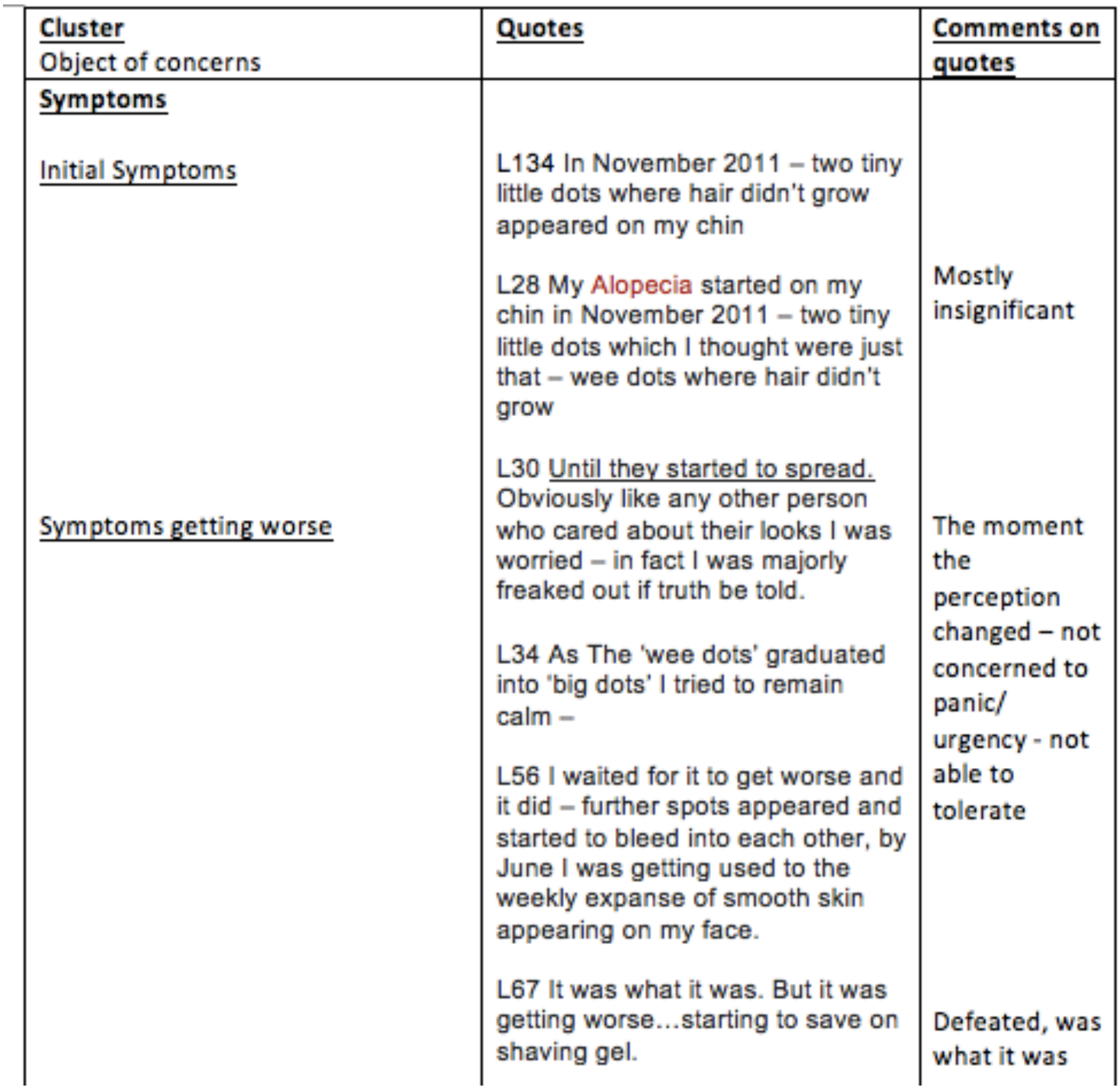
Debbie: "The main aim and hope from my blog is to get my experience across, for instance any feelings, treatments experience etc in a light heart but honest way"

Ian: "Though I am always wary not to be too negative as I don't think that is helpful. I am honest about the low times but don't want someone to be thoroughly depressed and leave my blog without some sort of hope"

Tom: "The only other challenge is when I don't feel great, thinking what to write and how to turn it into a positive. The only way I can deal with that is to write a depressing piece"

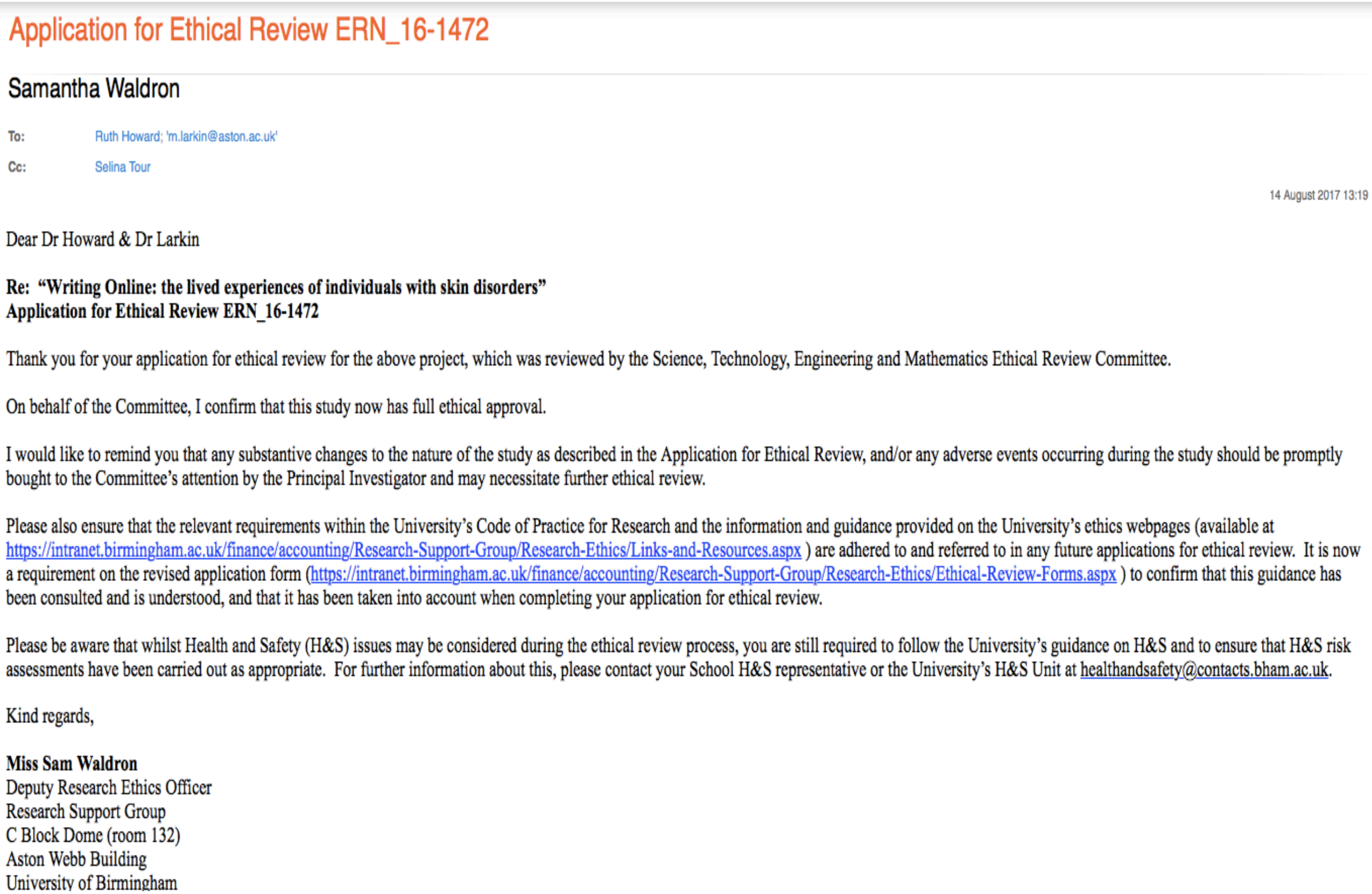
Laura: "There was often temptation to just rant and rail at the unfairness of life, the judgmental nature of others, or the unrealistic ideals from media. I didn't want to treat my blog like a diary of unedited word-vomit. I was always conscious about it possibly being of use to others. I wanted them to come away from it feeling better."

APPENDIX J
EXTRACT FROM TEMPLATE USED FOR TEMPLATE ANALYSIS



Cluster Object of concerns	**Quotes**	**Comments on quotes**
Symptoms		
Initial Symptoms	L134 In November 2011 – two tiny little dots where hair didn't grow appeared on my chin L28 My Alopecia started on my chin in November 2011 – two tiny little dots which I thought were just that – wee dots where hair didn't grow	Mostly insignificant
Symptoms getting worse	L30 Until they started to spread. Obviously like any other person who cared about their looks I was worried – in fact I was majorly freaked out if truth be told. L34 As The 'wee dots' graduated into 'big dots' I tried to remain calm – L56 I waited for it to get worse and it did – further spots appeared and started to bleed into each other, by June I was getting used to the weekly expanse of smooth skin appearing on my face.	The moment the perception changed – not concerned to panic/ urgency - not able to tolerate
	L67 It was what it was. But it was getting worse…starting to save on shaving gel.	Defeated, was what it was

APPENDIX K
CONFIRMATION OF ETHICS APPROVAL



Application for Ethical Review ERN_16-1472

Samantha Waldron

To: Ruth Howard; 'm.larkin@aston.ac.uk'
Cc: Selina Tour

14 August 2017 13:19

Dear Dr Howard & Dr Larkin

Re: "Writing Online: the lived experiences of individuals with skin disorders"
Application for Ethical Review ERN_16-1472

Thank you for your application for ethical review for the above project, which was reviewed by the Science, Technology, Engineering and Mathematics Ethical Review Committee.

On behalf of the Committee, I confirm that this study now has full ethical approval.

I would like to remind you that any substantive changes to the nature of the study as described in the Application for Ethical Review, and/or any adverse events occurring during the study should be promptly bought to the Committee's attention by the Principal Investigator and may necessitate further ethical review.

Please also ensure that the relevant requirements within the University's Code of Practice for Research and the information and guidance provided on the University's ethics webpages (available at https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Links-and-Resources.aspx) are adhered to and referred to in any future applications for ethical review. It is now a requirement on the revised application form (https://intranet.birmingham.ac.uk/finance/accounting/Research-Support-Group/Research-Ethics/Ethical-Review-Forms.aspx) to confirm that this guidance has been consulted and is understood, and that it has been taken into account when completing your application for ethical review.

Please be aware that whilst Health and Safety (H&S) issues may be considered during the ethical review process, you are still required to follow the University's guidance on H&S and to ensure that H&S risk assessments have been carried out as appropriate. For further information about this, please contact your School H&S representative or the University's H&S Unit at healthandsafety@contacts.bham.ac.uk.

Kind regards,

Miss Sam Waldron
Deputy Research Ethics Officer
Research Support Group
C Block Dome (room 132)
Aston Webb Building
University of Birmingham